ABSTRACT

Editing Humanity: A Disability Centered Approach to Human Gene Editing

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Since the development of CRISPR technology, the reality of editing the human genome seems closer than ever. With this technology comes a plethora of ethical questions about the boundaries that should be imposed on this gene editing ability and the impact of this technology on disability communities. To begin to address these ethical questions, it is important to start with an understanding of disability by examining current models of disability, including the medical, social, and theological models of disability. Furthermore, an examination of the application of these disability models to eugenics, physician assisted suicide, and selective abortion can help predict and guide responses to human gene editing. Since this technology was first developed, scientists have been at the forefront in discussing its ethical application. However, this prioritization of scientists has led to ethical horror stories, such as Dr. He Jiankui's experimentation on human embryos to create the first CRISPR edited children. To best proceed in the exploration of human gene editing, people with disabilities must first be seen as humans intentionally created by a loving God and as valued members of society. Their perspective on human gene editing must be prioritized, or permanent genetic changes that most impact them will be made without their permission.

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EDITING HUMANITY: A DISABILTY CENTERED APPROACH TO HUMAN GENE EDITING

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CHAPTER ONE

The Starting Point: The Medical and Social Models of Disability

Introduction

The understanding of disability from the contemporary Western perspective has developed from a long, and often discouraging, history. In modern Western culture, people with disabilities have been kept on the margins of society, often seen by others as less than human. Yet progress has been made, and continues to be made, in many areas of disability. Scientists better understand the pathophysiology of specific disabilities, advocates have worked to create a society in which those with disabilities are more fully included, and, most importantly, many Christians come to see those with disabilities as friends and brothers and sisters in Christ. These perspectives on disability shape how we address difficult ethical questions about creating and using technologies that impact the birth or treatment of people with disabilities. Likewise, our view of disability will continue to evolve in light of the rapid development of human gene editing. We have reached a point in history when how both scientists and regular people view those with disabilities will soon be shaped by the technology we have, and how we apply that technology to disability is a monumental decision.

Before exploring how human gene editing may impact how disability is viewed and addressed, it is important to understand various perspectives that shape our current understanding of disability. One way in which to view disability is through the lens of three intertwined models: the medical model, the social model, and the theological

model. Each of these three models shape different narratives of history to convey their perspective on disability. The medical model relies on a perspective of the history of disability in which those with disabilities were treated horrendously in the past often on account of the dominant belief of a spiritual cause of disability. According to this model, treatment of those with disabilities significantly improved when a biological cause of disability was discovered. The social model, in contrast, presents the narrative that those with disabilities have long been prevented from telling their own story of disability and their stories have instead been overshadowed by the disability story of professionals, such as those in the medical field. The social model seeks to restore the voice of people with disabilities and allow them to shape their own narrative of disability. Finally, the theological model of disability tells the story of people with disabilities as intrinsically valued as children of God without needing to prove their worth or value to society. In this chapter I will argue that the medical and social models both believe themselves to be a humanitarian view of disability, yet both fall short of this claim because they fail to understand the intrinsic value of human beings. While an understanding of all three models is necessary to critically approach to the future of disability, the theological model provides the truest humanitarian perspective.

The Medical Model of Disability

The medical model of disability focuses on a narrative of disability as having been viewed as a form of spiritual punishment until it was rescued from this vicious perspective when an understanding of disability as a biological ailment developed. The medical model understanding of disability is exemplified by the definition of disability by

the Center for Disease Control: "A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)."[1] In this definition, the problem clearly lies with the individual, and not with society. Disability is thus something that needs to be fixed, and modern science has provided this solution for people with disabilities. This model is supported by a selective historical narrative that creates a persuasive argument. It is certainly true that people with disabilities were treated in cruel ways before the advent of modern science. However, if one focuses on other stories a wide variety of narratives can take form that may contradict the one created by the medical model. From the perspective of the medical model of disability, medicine stepped in to protect those with disabilities in the past by restoring reason, and it can be argued that medicine will be the "cure" to disability in the future.

The treatment of people with disabilities under the medical model is often contrasted with the treatment of those with disabilities in the Middle Ages [*c.* 500 to 1453]. During the Middle Ages, disability was often attributed to supernatural causes, or demonology.[2] This belief in demonic causes of disability led to the exploration of spiritual treatments, such as exorcism. While some spiritual cures for disability were physically benign, such as having a patient sing Masses over a concoction of tea with

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[1]"Impairments, Activity Limitations, and Participation Restrictions," *Center for Disease Control*. September 16, 2020. https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html#:~:text=A%20disability%20is%20any%20condition,around%20them%20(participation%20restrictions)

[2]David Lawrence Braddock and Susan Parish, *An Institutional History of Disability* (Thousand Oaks, CA: Sage Publications, 2001), 17-18.

various herbal ingredients before drinking it,[3] more extreme cures, such as witch hunting, were dangerous and often lethal. Even those that created no physical harm still reinforced the idea that disability was a problem to be solved and created social, emotional, and spiritual isolation. Furthermore, this persecution of so-called witches, who included at least some people with mental disabilities, was at times headed by The Catholic Church.[4] The Church's involvement in the persecution of witches clearly presents religion as a cause of suffering for those with disabilities. It should be noted that at the same time that some were persecuting witches, others, including religious leaders, were advocating for humane treatment and charity towards those with certain disabilities (especially since those with disabilities during the Middle Ages were often impoverished, and many organizations and individuals existed to help those in poverty, if not specifically those with disabilities).[5]

In the "darkness" of the horrid treatment of people with disabilities during the Middle Ages, the medical model offers the development of the Scientific Method during the Renaissance as the hero of the disability story. During the Renaissance, disability began to be seen as a biological ailment instead of a spiritual punishment. This view arose alongside the development of etiology and classification of different kinds of disability. Once disability had been classified, specific treatments for different conditions could be explored.[6] Of course, many of these medical treatments could still be viewed as

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[3]Braddock and Parish, *An Institutional History*, 18.

[4]Protestant persecution of witches was common in colonial New England, but Catholic persecution of witches was more common during the Middle Ages.

[5]Braddock and Parish, *An Institutional History*, 18-19.

more harmful than helpful from our modern perspective. For example, the "tranquilizing chair" designed by Benjamin Rush in the early 1800s was designed to help calm panicked patients and return them to normal function, yet the confining nature of the chair may have done more to cause panic than to resolve it. Rush, often considered the "father of American Psychiatry," believed he practiced moral treatment of individuals with disabilities, but in reality, few today would consider his "tranquilizing chair" moral.[7] Nevertheless, such treatments were an important step on the journey towards the more ethical and effective medical treatments of disability we have today.

The story presented by the medical model presents a more-or-less straightforward narrative of medicine protecting those with disabilities, but a more nuanced perspective can be gained by tracing the development of institutions for people with disabilities. The development of institutions had a two-fold motivation: medical and religious.[8] Those inspired by the Enlightenment wanted to disassociate disability and divine or supernatural explanations and find natural explanations for the cause of disability. It was believed that if natural reasons could explain disability, then human intervention could ameliorate, or even cure, disability. Yet others advocated for the development of institutions out of a religious motivation that was especially prevalent following the Second Great Awakening. These people were motivated by their Christian beliefs to work to improve the lives of those in poverty and those with disabilities (which were—and are—often

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[6]Braddock and Parish, *An Institutional History*, 21-22.

[7]*Brainwaves*, season 1, episode 3, "Madness," directed by Richard Denton, written by Jonathan Miller. Aired October 20, 1991. Brook Productions.

[8]Steven Noll, *Institutions for People with Disabilities in North America* (Oxford, UK: The Oxford Handbook of Disability History, 2018), 3.

overlapping categories). The motivation for founding institutions for people with disabilities was well-intended from both the medical and theological perspective, but its implementation left much to be desired. There were certainly some well-run institutions that genuinely helped people with disabilities, but a series of problems led to unhealthy living conditions for residents of most institutions. First of all, most institutes quickly became overcrowded. It was believed that there would be a cycle of admission, treatment, and release of patients with a high cure rate, but it was soon discovered that curing patients was far from simple. Funding depended on high capacity, however, which led to overcrowded institutions and high expenditure on resources that could not cure disability. When it was eventually understood that cure rates at these institutions were much lower than what had been hoped, funding was then decreased, which meant even less resources for patients. In desperation, many institutes turned to patient labor to make up for their lack of funding, which did little to help the patients.[9] Although institutions were founded from both a medical and theological perspective from a desire to help those with disabilities, they did much more damage than they had ever intended.

The medical model presumes that effective medical treatments and management plans for people with disabilities have greatly improved the lives of people with disabilities. A better scientific understanding has allowed us to more fully comprehend what causes disability. This knowledge has opened up opportunities to reduce the suffering of people with certain disabilities and increase their levels of comfort. Furthermore, by diminishing suffering, those with disabilities are allowed more

[9]Noll, *Institutions for People with Disabilities in North America,* 6-7.

opportunities to live a "fuller" life with less limitations on their capabilities.[10] A greater understanding of disability also has personal implications for the patients besides improved medical treatment and management of disabilities: patients can easily find information to better understand the biological cause of their own disabilities. The ability to attribute a specific, scientific cause to a condition can remove the guilt often associated with understanding disability to be a spiritual punishment. The medical model of disability has removed the association between personal or moral failures as the cause of disability, restoring a sense of pride and dignity to many patients. Furthermore, parents of children with disabilities often carry a great burden of guilt and believe they may have been responsible for their child's disability. This guilt has even been at times encouraged by society and the medical field itself, such as when mothers of children with autism, deemed "refrigerator mothers," were scientifically condemned for causing their child's autism through accusations of cold, emotionless interactions with their infants.[11] Parents can find relief in understanding the genetic causes of some disabilities and recognizing that their child does not have a disability because of their actions. The medical model can offer reassurance, answers, and sometimes comfort to many patients with disabilities and their families.

Despite the benefits of the medical model of disability, it has also been challenged for presenting disability as a personal problem to be fixed. When a significant characteristic of a person, such as that person's disability, is constantly presented in a

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[10]Hans S. Reinders, *The Future of the Disabled in Liberal Society* (Notre Dame, IN: University of Notre Dame Press, 2000), xi.

[11]Patty Douglas, *Refrigerator Mothers* (Bradford, ON: Journal of the Motherhood Initiative), 1.

negative light, a person can be made to feel dehumanized. The medical model sees many disabilities as personal, medical traits that are outside of an expected range of function. Seeing disability within such cold, scientific parameters is not a wholistic view of disability or people with disabilities, despite its medical value. This perspective focuses on the individual's impairment as the source of disability and largely disregards the ways society shapes what it means to have a disability. Moreover, when disability is seen as nothing but a value outside of an accepted range, there is a danger that the individual's understanding of their own disability will be dismissed if it does not align with the medical view of disability.

Furthermore, the medical model makes the assumption that suffering is to be unquestionably avoided. Disability scholar Christopher Newell argues that we should question this assumption: "I have come to realize not only that brokenness is important, but also that I really have something to offer humanity: that is, to reflect on the projects of bioethics and theology, a reflection that comes from an experience of the very attributes of disability that are feared by the people carrying out such projects, including myself".[12] Newell goes on to argue that while his physical suffering on account of his disability should not be minimized, his greatest source of suffering comes from how his relationships have suffered through others' lack of understanding.[13] It should be noted that Newell's argument still places emphasis on the value he has gained from suffering in having something to contribute to the conversation of disability. While this gain should

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[12]Christopher Newell, *On the Importance of Suffering: The Paradoxes of Disability* (Grand Rapids, MI: Wm. B. Eerdmans Publishing Co., 2010), 174.

[13]Newell, *On the Importance of Suffering*, 175.

not be discredited, it focuses primarily on the extrinsic value of his disability and not his intrinsic value as a person with or without a disability (these concerns will be discussed in greater detail in Chapter 4). Nevertheless, the suffering of people with disabilities, while difficult, should not be seen as utterly pointless or without redemption. The perspectives of people with disability on their specific form of suffering should not be disregarded or minimalized, but the virtues they may have gained from this experience should be appreciated. The medical model makes many reasonable conclusions about how medical developments have improved the lives of people with disabilities, but many of the unstated assumptions of the model, such as the understanding of suffering as something to be avoided at very high costs, should be carefully evaluated.

The medical model sees people with disabilities as a problem to be treated and solved, and the obvious end of this perspective is the prevention or remediation of disability, in whatever form that may take.[14] However, the proposal of prevention as a solution to disability raises concerning questions about how we view those who have disabilities that cannot be prevented. As Daniel Wikler writes, "It takes considerable rhetorical agility to urge the public to support screening programs so as to prevent the conception of handicapped [sic] individuals while at the same time insisting that full respect be paid to such developmentally disabled adults as are already among us."[15] It should certainly be noted that screening purposes have impacts besides just the prevention of the birth of children with disabilities through selective abortion. Such programs can help get infants on life-saving medications as soon as they are born and

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[14]Reinders, *The Future of the Disabled in Liberal Society,* x.

[15]Daniel Wikler, *Paternalism and the Mildly Retarded* (Hoboken, NJ: Wiley, 1979), 377-392.

help best prepare parents to the reality of caring for a child with disabilities, with all its ups and downs. However, screening technology is primarily used and was created for the purpose of prevention of disability, as is supported by the medical model when its argument for the "treatment" of disability is taken to its logical conclusion. While the social model, discussed in the next section, makes progress on the path towards addressing this concern, it is the theological model that best addresses this problem.

The Social Model of Disability

The social model of disability presents itself as restoring the voice of those with disabilities which has often been overshadowed by professionals and others without personal experience of disability. The social model often places the "blame" of disability onto society instead of focusing on the individual's impairment (the physical or genetic cause of their disability).[16] While the medical model sees a disability as lying outside of the range of what is considered normal, the social model argues that the socially constructed "range of normal function" is arbitrary and that disability should not be measured by such a metric. Instead, society has marginalized those with disabilities through its architecture, education and professional systems, and widespread, false assumptions about and fear of disability that has created an environment wherein those with disabilities are not welcome. Were the stories of those with disabilities to be more widely shared and accepted, the narrative around disability might change such that the societal creation of disability would start to be eliminated.

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[16]Hans S. Reinders, *Receiving the Gift of Friendship* (Grand Rapids, MI: Wm. B. Eerdmans Publishing Co., 2008), *59*.

Although the social perspective on disability became prominent in the early 1990s, it had been argued long before then. In 1957, Helen Keller stated that, "Not blindness, but the attitude of the seeing to the blind is the hardest burden to bear."[17] Later, Peter Berger and Thomas Luckmann proposed the idea of the "social construction" of reality in their 1967 sociological treatise on the social nature of knowledge. They presented the argument that people create concepts of each other's actions and these concepts evolve to take on meaning, but do not inherently having the meaning they are assigned.[18] Berger and Luckmann's treatise would lay the foundation for the social model's argument that disability is an idea created by people and not inherently an abnormality of the individual.[19] In 1980, the World Health Organization distinguished between impairment, disability, and handicap in an attempt to acknowledge the role of society in the creation of disability, marking a wider acceptance of the ideas of the social model in society. At the same time as these landmark changes, organizations were beginning to be formed by friends and family of people with disabilities to advocate for and create more opportunities and space in society for those with disabilities. These organizations, such as the National Association for Retarded Children,[20] especially fought for institutional change through the creation of schools with the capacity to educate children with different disabilities. However, there soon arose concerns that these organizations were created *for* people with disabilities but not *with* or *by* people with

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[17]Braddock and Parish, *An Institutional History*, 44.

[18]Peter Berger and Thomas Luckman, *The Social Construction of Reality* (London, UK: Penguin Books, 1966), 1.

[19]Braddock and Parish, *An Institutional History*, 44.

[20]Now called The Arc. Formed in 1950, and still an active organization today.

disabilities. In response to this concern, more organizations were created by people with disabilities to advocate for themselves, such as the World Federation of the Deaf and the International Federation of the Blind.[21]

The push for the creation for a more accommodating society for those with disabilities continued to increase, leading to the passage of the American Disabilities Act (ADA) in 1990. The ADA was a government response to, and acknowledgement of, the long history of discrimination and isolation faced by those with disabilities and made progress on the path towards reconciling those mistakes. This act made discrimination towards people with disabilities illegal in areas of employment, public services, public accommodations, and telecommunications.[22] The ADA required employers to provide reasonable accommodations to employees with disabilities, as enforced by the U.S. Equal Employment Opportunity Commission; required public entities to make programs, services, and facilities accessible to people with disabilities (such as making ramps available in public buildings); directed businesses to make "reasonable modifications" to serve people with disabilities; and required communication companies to design systems that allowed those with hearing or speech disabilities to better comprehend and communicate through technology. Legislation such as the ADA and others that pushed for disability reform were successful in part through the work of disability rights activists, who primarily follow the social model of disability.[23] Few would argue that legislation

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[21]Braddock and Parish, *An Institutional History*, 44-45.

[22]"An Overview of the Americans With Disabilities Act", *ADA National Network*. 2017. https://adata.org/factsheet/ADA-overview

[23]Braddock and Parish, *An Institutional History*, 50-51.

such as the ADA was not a step in the right direction for the disability community, but it can be contended that while the ADA changed the structure of society it did not do enough to change the perspectives of those who still feared disability. There is still much work to be done before those with disabilities are accepted, and not just accommodated, in society.

The social model, much like the medical model, believes itself to be the humanitarian response to disability that fully recognizes and addresses those with disabilities as human. It addresses may of the shortcomings of the medical model by differentiating between impairment and disability, making space for people with disabilities to discuss their own ideas of their suffering and exclusion, and seeing people with disabilities as more than just a problem to be solved. This restoration of the voice of people with disabilities has helped shape the language of disability as well. People with disabilities can emphasize their humanity before their disability by using person first language (e.g., “a person with autism”). Alternatively, many people with disabilities choose to proudly claim their disability (e.g., “autistic person”) and see the disability term not as something to shy away from but as a declaration of who they are and a proud statement of their disability. While different people with disabilities may choose to communicate their status as a person with a disability in different ways, the social model supports both terms and encourages those with disabilities to express themselves as they deem fit.

Certainly, the social model has made progress in many areas where the medical model failed, but it falls short in creating a truly humanitarian perspective of disability on account of its affirmation of a hierarchy of disability. With a strong emphasis on the

ability to "tell one's own story" and advocate for oneself, the social model indicates that the capacities of will and reason are important values for all people.[24] While this prioritization of intellectual capabilities may be applicable to some people with disabilities, it excludes many with profound intellectual disabilities. In doing so, a "hierarchy of disability" is created in which those with the capacity to reason and articulate their experience with disability are more highly valued than those without this capacity. Reinders argues that the social model itself dismisses the question of what it means to be human as insulting, but even if it refuses to answer the question directly it has answered it in the value it places on self-advocacy.[25] Since the development of the social model, its faults in often failing to address profound intellectual disability have been more thoroughly addressed (such as by the development of the 'friendship model of disability' as an extension of the social model, as will be discussed in Chapter 4). However, I will argue in the coming chapters that the theological model provides more satisfying answers to the questions raised by profound intellectual disability. Listening to people with disabilities who are able to convey their own perspective on disability is certainly valuable and offers more than listening only to professionals without disabilities. However, the social model cannot be the ultimate humanitarian perspective on disability while it excludes those with severe intellectual disabilities.

Furthermore, since the social model defines disability as an imposition of society that prevents people from being fully accepted into that society, it can be argued that all people are "disabled" in some sense since all have limitations imposed on them by

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[24]Reinders, *Receiving the Gift of Friendship*, 59-62.

[25]Reinders, *Receiving the Gift of Friendship*, 59-62.

society. These limitations are easily seen by the long history of prejudice based on race, ethnicity, gender, sexual orientation, and many other characteristics that continues to be prevalent in American society today. Although discrimination based on these characteristics is an imposition by society that limits these groups of people, race, ethnicity, gender, and sexual orientation are not disabilities. Were these classifications to be understood as such, some people with disabilities may feel as though their disability was minimized.[26] As Andrew Solomon writes:

> It is tempting, in the end, to say that there is no such thing as a disability. Equally, one may admit that almost everything is a disability. There are as many arguments for correcting everything as there are for correcting nothing. Perhaps it would be most accurate to say that "disability" and "culture" are really a matter of degree. Being deaf is a disability and a culture in modern America; so is being gay; so is being female; so even increasingly is being a straight white male. So is being a paraplegic, or having Down Syndrome.[27]

Extending the definition of disability to the extent that everyone is disabled simply perpetuates the marginalization of people with impairments and does nothing to restore a sense of humanity to people with disabilities. If every societal disadvantage is a disability, the stories of people with disabilities are easily dismissed since everyone has a similar story. Recognizing society's part in the creation of disability is a significant step in presenting a humanitarian view of disability but stops short of fully accomplishing this goal. To truly value those with disabilities and recognize their existence as beloved human beings, the value of all humans, both those with disabilities and those without, must be intrinsic and not dependent on the actions of a human individual.

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[26]Reinders, *Receiving the Gift of Friendship*, 59-62.

[27]Andrew Solomon, "Deaf is Beautiful", (New York, NY: New York Times Magazine, 1994).

Conclusion

The medical model of disability argues that (1) people with disabilities were treated cruelly on account of disability being attributed to superstitious and religious causes until a pathophysiological understanding of disability developed; (2) medicine has provided great relief for those with disabilities by allowing them to live fuller lives with less suffering; and (3) medicine has alleviated the burden of guilt often carried by the loved ones of people with disabilities. However, more nuanced historical understandings of disability present a more complicated story of disability in which it was not medicine alone that improved the lives of people with disabilities. The medical model presents suffering solely as something to be avoided, but some people with disabilities have argued that they have gained much from their suffering and would not have chosen to live without it. The medical model has its purpose, but it does not convey a sense of value of people with disabilities.

The social model of disability argues that (1) disability is a social construct and the blame for disability should lie with how society treats individuals with disability, not the individuals themselves; (2) the story of disability should be told primarily by those with disabilities; and (3) advocacy is needed to change society's perception of disability such that those with disability are more accepted in society. The social model lays the foundation for much of the theological and friendship models of disability, which will be discussed at length in Chapter 4. However, on its own the social model does not go far enough in defending the humanity of people with disabilities because it creates a hierarchy of disability.

The medical and social models of disability, when applied to the consideration of the future of those with disabilities in the context of human gene editing, provide starkly different solutions. In the following chapter, the argument for using genetic and other medical technology for the treatment and eradication of disability will be presented. This argument is an extension of the medical model as presented in this chapter. Chapter 3 will discuss the development of gene editing technology up to the current point of human gene editing with CRISPR, as well as how the ethical implications of these technologies have been and are being addressed. Through this story of this technological development, both the medical and social models of disability will be apparent. Finally, in Chapter 4 the ideas of the social and medical models of disability presented in this chapter will be contrasted with the theological model's approach to disability.

CHAPTER TWO

The Medical Model: Past and Present Strategies to Eliminate Disability

Introduction

In the first chapter, both the history of the medical model of disability and its present understanding were presented. The medical model arose during the Renaissance to present disability as a biological condition, as opposed to a spiritual or moral punishment. It views itself as a humane perspective on disability and looks to eliminate the suffering caused by disability. In this chapter, the application of the medical model in context of human gene editing will be presented.

First, a brief history of the eugenics movement of 1870-1950 will be examined. The eugenics movement can be seen as an expression of the medical model of disability, albeit an extreme expression of this model. It sought to use scientific technology, as well as other means, to eliminate those deemed to be less valuable. People with disabilities were viewed by the eugenics movement as an unhealthy detriment to society, and a variety of attempts were made to eliminate the presence of people with disabilities and the transmission of their "faulty" genes. The eugenics movement is often associated with Nazi doctrine, and rightfully so, but the presence of the eugenics movement in the United States is often too easily overlooked.

Secondly, the use of physician assisted suicide as a more modern "solution" to disability will be analyzed. Physician assisted suicide, along with prenatal screening, may

be viewed by some as the 'new eugenics.' While there are many distinctions between the eugenics of the nineteenth and twentieth centuries and the 'new eugenics' of modern times, at its core it aims for an ideal picture of the human which often means diminishing the presence of people with disabilities. The argument in favor of physician assisted suicide will be presented alongside the story of Brittney Maynard, followed by a rebuttal by Kay Toombs.

The second part of this new eugenics, prenatal screening with the intent of abortion, will be presented as another example of how the medical model of disability plays out in modern times. Many countries have a medical culture that encourages parents to receive prenatal screening and presents the option of terminating a pregnancy should a congenital disability be found. Encouraging the termination of fetuses with disabilities demonstrates a value judgement of the lives of people with disabilities as less worth living than the lives of people without disabilities. This judgement can be incredibly hurtful for people with disabilities. Arguments in favor of terminating a fetus with a disability will be presented, followed by a rebuttal applying the expressivist objection to selective abortion of fetuses.

Finally, this chapter will conclude by looking to how the medical model of disability may be applied to the future in using human gene editing technology to decrease the birth of people with disabilities. An introduction of this topic will be presented in Chapter 2, but Chapter 3 will more fully discuss this subject. While human gene editing has long been dreamed of by some, we have reached the point of technical development where this technology may not be too far away from becoming a daily reality. Therefore, it is important to consider both the events and ethical considerations

that have led up to this point in time before this technology is implemented on humans. In this chapter I will argue that the application of the medical model of disability has done great damage through the old eugenics movement and continues to do damage in the new eugenics movement; it's application through human gene editing in the future should thus be cautiously considered.

The Eugenics Movement

Modern genetic developments will always lie in the "shadow of eugenics."[1] This caution is well-founded, as the eugenics movement of the 1870-1950s committed unspeakable horrors in its pursuit to "purify" the gene pool of various populations. The eugenics movement believed the source of societal unrest to be in genes of certain individuals who were "programmed" to be a detriment to society (as defined by a select group of people). In order to eliminate social unrest, eugenicists believed the transmission of such defective genes must be prevented—with little regard to the morality of the means used to prevent the transmission of these genes.

The beginnings of the eugenics movement in modern times can be traced back to Francis Galton, the cousin of Charles Darwin.[2] Galton noticed that intelligence seems to run in certain families and soon connected virtues and vices with heritable traits. He coined the term "eugenics" and defined it as "the science of improving stock—not only by judicious mating, but whatever tends to give the more suitable races or strains of blood

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[1]Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler, *From Chance to Choice* (Cambridge: Cambridge University Press, 2000), 9.

[2]Buchanan, Brock, Daniels, and Wikler, *From Chance to Choice*, 30.

a better chance of prevailing over the less suitable than they otherwise would have had."[3] Eugenics was differentiated into two strains: positive eugenics and negative eugenics. Positive eugenics looked to reinforce perceived virtues by encouraging "better" families to have more children. Negative eugenics, on the other hand, attempted to decrease perceived vices by discouraging "lesser" families from having children. While some eugenicists supported only one of these forms of eugenics, many supported both. Many eugenicists saw civilization and medical developments as obstacles that prevented natural selection from following its appropriate course. Because those who may have otherwise died from their various medical "weaknesses" were saved by medicine, they were allowed to pass down their faults to future generations to create a less healthy society.

The ideas presented by Francis Galton were quickly embraced, both by scientists pursuing eugenic research and by individuals as a popular movement. The interest of lay people was encouraged by the publication of *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness* by Henry Herbert Goddard in 1912.[4] The "Kallikak" family, a pseudonym for the family of study, means "beauty" (from the Greek, Kallos) and "bad" (from the Greek, Kakos), because it focuses on the union between a "good" family with a "bad" one, and warns of the results of such a union. Martin Kallikak Sr. reportedly fathered an illegitimate son, Martin Kallikak Jr., with a "feeble-minded" woman. Their son was also deemed "feeble-minded" and it was concluded that this was a trait he inherited from his mother. Martin Kallikak Sr. then married a Quaker woman and

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[3]Buchanan, Brock, Daniels, and Wikler, *From Chance to Choice*, 30.

[4]Amy Samson, "Henry Herbert Goddard publishes *The Kallikak Family*: A Study in the Hereditary of Feeble-Mindedness," *Eugenics Archive.* March 15, 2014. https://eugenicsarchive.ca/discover/connections/53246c10132156674b00025e

produced a family of "better stock" with his second relationship. From the contrast between these two families, Goddard concluded that both "feeble-mindedness" and virtues could be passed down in families.[5] His conclusion supported both positive and negative eugenics in encouraging the propagation of "virtuous" families while shaming the propagation of "feeble-minded" families. It was later found, unsurprisingly, that many of the extended family of Martin Kallikak Jr. presented by Goddard had been fabricated[5], but this family history had already been embraced as convincing evidence by many who supported the eugenics movement.

The popularity of the eugenics movement led to legislation that favored discrimination against those considered to be "feeble-minded." From 1910 to 1930, involuntary sterilization of people with disabilities was permitted in the United States. Tens of thousands of people in the United States, and hundreds of thousands in Germany, were forced to undergo inhumane sterilization procedures. The eugenics movement was also used to target immigrants, who were often portrayed as "lesser" families who would "weaken" the breeding pool. This racist belief was used to push for laws prohibiting interracial marriage. It should be noted that not all people supported these discriminatory initiatives—the Catholic Church notably remained opposed to eugenics, as they are opposed to many technologies that limit reproduction.[6] Yet there was enough support that a lot of eugenic-supported legislation was passed, and much damage was done to people with disabilities.

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[5]Samson, "Henry Herbert Goddard publishes *The Kallikak Family*."

[6]Braddock and Parish, *An Institutional History*, 38-42.

While the United States' faults in eugenic practices should not be overlooked, those of Germany and the Nazi Party in the mid 1900s were more extensive. The Nazi Party pursued "racial hygiene" through medical leadership of eugenics. Eugenics was a central tenet of Nazi doctrine which grew out of the racist, anti-Semitic views that saw the Nordic race as superior above all others. Eugenics in the Nazi regime unfolded through sterilization, euthanasia of the "unfit", and the Holocaust, where both Jews and people of disabilities were targeted. Fields such as biology, anthropology, and medicine taught and encouraged eugenics in the curriculum. While the Nazis were unprecedented on the scale to which they encouraged eugenics, they did not come up with their eugenics system alone. Many of their ideas came from regulations seen in California, and many eugenicists in the United States supported the eugenics work in Germany prior to World War II. Unsurprisingly, eugenics fell out of favor after the horrors of the Holocaust and other Nazi eugenic practices were revealed after the defeat of Germany.[7] But unrepairable damage had already been done, and more may be done if the horrors of eugenics are too easily forgotten.

During this eugenics movement, it is clear that people with disabilities were judged only for what they could contribute to society and were thought of as lacking in virtue. Following the medical model of disability, disability was seen as a problem of the individual, and a problem that needed to be stopped. People with disabilities were kept at the margins of society where others did not have to feel uncomfortable in their presence. Worse, they were killed, sterilized, and experimented on with little ethical recourse.

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[7]Braddock and Parish, *An Institutional History*, 40-42.

When people with disabilities are seen only their condition, and not as people, it is much easier to justify such inhumane treatment. While most today would strongly disagree with the actions of the eugenics movement, this same understanding of people with disabilities as an inconvenience and detriment to society has allowed us to develop new technologies, such as physician assisted suicide and selective abortion, through the new eugenics movement of our time.

The New Eugenics Movement: Physician Assisted Suicide

Physician assisted suicide (PAS) is another way to address disability (specifically disability at the end of life), but much like eugenics, it presents disability as a problem to be solved. While PAS is ostensibly about how one chooses to die and not directly concerned with disability, many people make this decision in order to avoid disability at the end of life. This end-of-life disability would lead to a loss of autonomy and a need for the care of others—the same conditions of many people with disabilities. PAS it has been upheld by many as a way to restore dignity to those with disabilities and is supported by some (but not most) individuals with disabilities themselves. While PAS may not share the sordid history of eugenics, implicit within the practice is the idea that the value of a human being lies in both their autonomy and what they are able to provide to society and not intrinsically in their being.

The story of Brittney Maynard is often upheld as a paradigm for PAS as a peaceful, dignified alternative to an otherwise unimaginably difficult death (or natural death). Brittney Maynard was diagnosed with Glioblastoma multiforme (a form a brain cancer) in 2014 at the age of 29. She was given an estimated six months to live after this

unexpected diagnosis. As her symptoms began to worsen, Maynard decided that she wanted to choose how and when to end her life, instead of waiting to die what would likely be a painful death. At the time, she and her husband lived in San Francisco, California, where PAS was not legal. The couple decided to move to Oregon where it was legal so that she could go through with her plan. She spent the last few months of her life traveling and spending time with her husband, parents, and friends, before choosing to end her life on November 1, 2014. Her experience and death inspired the Brittney Maynard Fund through the pro-PAS organization, Compassion and Choices. [8] This organization works to make PAS legal in all states. Both Maynard and Compassion and Choices support the "death with dignity" movement and present the argument that PAS is a humane option to reduce suffering and restore autonomy in an unimaginable situation.

Kay Toombs, an author and disability scholar in Waco, Texas, argues strongly against PAS from the perspective of a woman with multiple sclerosis. On examining the story of Brittney Maynard, Toombs points out that Maynard's story was carefully selected to sway public opinion. Maynard's death was presented as a decision between two particular outcomes: a peaceful, quiet death of Maynard's choosing surrounded by loved ones, or a horrific, painful experience over which she would have no control. Yet this portrayal of these two exclusive alternatives ignores the reality that each diagnosis is different and that no one could really know how terrible Maynard's natural death would have been. Toombs goes on to argue that media presentation of cases such as Maynard's ignore the details (such as not discussing or downplaying the option of palliative care)

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[8] "Brittney Maynard," *Compassion and Choices.* https://www.compassionandchoices.org/stories/brittany-maynard/

and create an emotional argument using an example that does not represent the majority of patients who decide to use PAS. This allows more morally ambiguous usage of PAS to be legalized along with cases like that of Maynard without drawing much attention to such ambiguous cases to the public eye.[9] In concluding her discussion of Maynard, Toombs writes, "In the end she killed herself to maintain her autonomy, thus effectively ending her autonomy forever."[10] Maynard's case was a very sympathetic one, which is not necessarily representative of all cases in which PAS is pursued. In a difficult situation, Maynard ultimately prioritized autonomy and dignity. Certainly this choice is understandable to some extent, but the value of a compassionate community were not as prevalent in Maynard's choice as they could have been.

Toombs points to a variety of reasons that one may choose to receive assisted suicide, but focuses on loss of autonomy, burden on loved ones, and an emphasis on "doing" over "being" as the three primary concerns. In addressing these three concerns, she sees the problem lying in part in the values of Western culture, which is often over-focused on the individual. Because of these cultural values, a loss of control through a disability or disease can cause great suffering for those who prioritize the value of autonomy. Assisted suicide thus provides a way to regain control—ultimate control over one's own life. The perspective of individual over community may also lead some to believe that the burden they would create for their loved ones is too great, even if they themselves would not believe the disability or disease of a loved one to be a burden on

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[9]S. Kay Toombs, *How Then Should We Die?: Two Opposing Responses to the Challenges of Suffering and Death* (Elm Mott, TX: Colloquium Press, 2010), 41.

[10]Toombs, *How Then Should We Die?*, 46.

themselves. This perspective fails to see oneself as deserving of love and care, which transitions to the third problem Toombs cites: a concern over "doing" more than "being". Because disability and disease often lead to a diminished ability to perform actions one once found value and meaning in, some may believe that because of this loss they have nothing to contribute and therefore have no meaning. Since they can no longer provide for their loved ones in the same way they may once have done, they may come to believe that they are not deserving of the care and provision of that loved one without an equal exchange of goods and services. Throughout these three problems as well as many more which Toombs addresses, there is a common theme of misplaced understanding of the value of people. To combat this problem, Toombs presents an argument for the values gained from living in community and actively practices this prioritization in her own life.

Toombs presents a community that cares for all individuals indiscriminate of ability or talent—which she deems "a culture of healing"—as the best alternative to assisted suicide. Toombs herself has found one such community in Homestead Heritage in Waco, Texas: a nondenominational Christian community with its roots in the Anabaptist tradition. She writes of this community:

> The focus is on honoring and serving one another as the expression of the love of God. The values and practices that spring from this foundational ethic necessarily affirm human dignity in all circumstances and provide a nurturing context in which it is possible for individuals to retain personal integrity and worth in the face of pain, suffering, and the inevitable uncertainties and vulnerabilities experienced in serious illness, aging, and dying.[11]

While Toombs recognizes that her community is unique and that such communities cannot be the answer for all people with disabilities or who may be considering assisted

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[11]Toombs, *How Then Should We Die?*, 87-88.

suicide, she believes that the values of this community are transferable across many contexts. These values include self-sacrificial love, relationships over individualism, and "being" instead of "doing". Toombs believes that self-sacrificial love, such as that displayed by Christ, is the foundation of her diverse community. It is a care and love that transcends one's individual desires and prioritizes the other over the self. With this foundation, care giving is not a burden but the foundation of community and something to be valued. Toombs also argues that our pursuit of autonomy inhibits our relationships with God and neighbor, which are ultimately more satisfying and meaningful. Finally, Toombs argues that as a result of being made in the image of God, all being have intrinsic value that is not dependent on their works. When we can embrace that value instead of measuring people by what they accomplish, we retain value even through loss of ability.[12]

The New Eugenics Movement: Selective Abortion

While both eugenics and PAS have been and continue to be prominent in the strategy to eliminate disability, the technique currently most debated and most common is that of selective abortion of disabled fetuses. Some bioethicists, such as the authors of *From Chance to Choice*, present favorable arguments for the "prevention of genetically transmissible harms"[13] on the grounds that elimination of "preventable" disability is better for society as a whole. Others argue for the intrinsic value of fetuses with disabilities and believe that selective abortion against these fetuses should be prevented.

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[12]Toombs, *How Then Should We Die?*, 87-104.

[13]Buchanan, Brock, Daniels, and Wikler, *From Chance to Choice*, 205.

Ultimately, much as with the arguments surrounding eugenics and PAS, the debate on selective abortion revolves around the question of the value of disability. This section will directly address the arguments both in support of and against selective abortion and will briefly discuss the value of disability, but a full discussion of the value of disability will be presented in the Chapter 4.

Oftentimes, arguments in favor of the selective abortion of fetuses with disabilities focus on maintaining all reproductive rights. These rights include the choice of "whether to procreate, with whom, and by what means; when to procreate; how many children to have; what kind of children to have; and whether to have biologically related children."[14] This argument allows for a simultaneous rejection of eugenics and its forced sterilization of those with disabilities, while at the same time encouraging a system that will lead to a decrease in people with disabilities. This is because, much as with the argument for PAS, the primary value in this decision is autonomy. Those who support unrestricted reproductive rights believe that parents should be able to choose if they want to have a child with disabilities. They argue that it would be unjust to impose the care of a child with disabilities on parents (and especially the mother, who is often the primary care-giver of children with disabilities) who are not in a position—whether financially, emotionally, or otherwise—to care for such a child.[15] Overall, the argument for reproductive freedom allows women to choose to carry a fetus with a disability to term or not.

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[14]Buchanan, Brock, Daniels, and Wikler, *From Chance to Choice*, 209-210.

[15]Buchanan, Brock, Daniels, and Wikler, *From Chance to Choice*, 221-222.

A second argument in support of selective abortion goes a step further in limiting reproductive freedom such that fetuses that are detected to have unfavorable genetic variants *should be* aborted. This argument claims to prioritize the good of society as a whole and assumes that disability is a universally unwanted trait. It is believed that the elimination of genetic disability through the selective abortion of fetuses with such traits reduces the burden on society to care for such individuals as well as the suffering of such individuals. It is assumed by this argument that to have a genetic disability is to suffer, or at least have a less meaningful life. While the United States does not currently support mandated selective abortion, other countries, such as Iceland, have encouraged this practice through fetal screenings and abortion with a strong recommendation of termination. Iceland has all but eliminated Down Syndrome—a genetic disability that usually happens through random mutations in fertilization and is not passed down through families. Because of the random genetic mutation that causes Down Syndrome and lack of a cure, the only way to eliminate its presence from a country is through selective abortion. Iceland has very close to a 100% termination rate with only one or two children born with Down Syndrome each year nationally. Other European countries have similarly high rates, with Denmark at 98%, United Kingdom at 90%, and France at 77%. The United States is also not all that far behind, with a 67% termination rate. While it is not mandated, genetic screening is highly encouraged for pregnant woman in countries like Iceland and Denmark with the goal of detecting abnormal fetuses. Advocates for the elimination of Down Syndrome in these countries have argued that termination of fetuses

with Down Syndrome decreases suffering for both the parents and the child, and thus is the morally correct decision.[16]

While there are a plethora of rational arguments for the selective termination of fetuses with disabilities, many still argue that such selective abortion is immoral, and not too far from eugenics. For example, the "expressivist objection" is the argument that "prenatal testing and selective termination practices are objectionable as they express disvalue not only of the foetus being tested, but also of disabled people [sic] as a whole, by focusing exclusively on the disabling trait."[17] Instead of focusing on the disability of a fetus as a medical problem, the experiences of those with a specific condition or who have children with that condition should be prioritized. The impetus for selective abortion is a cultural perspective that prioritizes the people who can produce, or do more, than others and views suffering as something to be strictly avoided (with the assumption that disability must be a form a suffering). This is often the perspective that many parents have when considering the termination of a fetus with congenital disabilities. However, by sharing the stories of people with disabilities with parents faced with the possibility of having a child with a disability, a new perspective can be gained of the value of people with disabilities and the joy they often bring to those around them, even with the suffering they may endure.

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[16]Julian Quinones and Arijeta Lajka, "'What Kind of Society Do You Want to Live in?': Inside the Country where Down Syndrome is Disappearing," *Columbia Broadcasting System*. August 14, 2017. https://www.cbsnews.com/news/down-syndrome-iceland/

[17]Felicity Kate Boardman, "The Expressivist Objection to Prenatal Testing: the Experiences of Families Living with Genetic Disease," *Social Science Medicine*. April, 2014. https://pubmed.ncbi.nlm.nih.gov/24602967/

While the status of the personhood of a fetus is a hotly debated topic, the selective abortion of fetuses with disabilities is as much a commentary on views of disability as it is on the use of abortion. While this form of discrimination against people with disabilities is not as extreme of the murder and sterilization of people with disabilities seen in the negative eugenics movement, it implies many of the same perspectives of people with disabilities. To combat this disability discrimination, it is important to promote communities that actively invite in people with disabilities and intentionally make opportunities to learn from their experiences. If disability is seen primarily as a medical condition that causes suffering and burdens others, it will continue to be rejected. However, those who spend time with people with disabilities often come to see their value, and the motivation to eliminate disability through drastic measures becomes much more questionable.

Conclusion

People with disabilities have repeatedly been subjected to drastic measures to decrease their presence in society. While eugenics is now recognized by most in Western society as a horrible mistake of the past, new forms of discrimination against people with disabilities, such as PAS and selective abortion, have developed. As we continue to develop new technologies, such as the CRISPR technology that may allow us to strategically edit the human genome, we should learn from how similar technologies that limit the presence of people with disabilities have impacted this population. This constant drive to avoid the presence disability can be demoralizing to many people with disabilities, and frustrating to those who have found value and purpose in their

disabilities. The development of human gene editing and the ethical considerations that have already taken place concerning this technology will be the topic of the following chapter. The understanding of technologies used to decrease the presence of people with disabilities (as presented in this and the following chapter) will inform the topic of the final chapter: a proposed solution for how to proceed with these technological developments in a way that prioritizes the value of people with disabilities.

CHAPTER THREE

The Road to Human Gene Editing

Introduction

In the first chapter, three different perspectives on disability were presented: the medical model, the social model, and the theological model. The previous chapter examined how the medical model has been applied in the past through the eugenics movement, physician assisted suicide, and prenatal screening with the intent of abortion. In some instances, such as with the eugenics movement, practices that are largely working against people with disability were implemented before their immorality was recognized and their practice largely prohibited. On the other hand, practices such as physician assisted suicide and prenatal screening with the intent of abortion continue to be promoted. While it is possible (although quite unlikely) that these practices may one day be rejected much as eugenics has been, their current implementation will impact how we view developing technologies with a potentially even greater impact on people with disabilities, such as human gene editing technology. In this chapter, the recent development of genetic technologies will be presented, and their potential application as it applies to disability will be discussed.

First, a brief history describing the explosion of knowledge in the field of genetics over the last 70 years will be presented. The basis of genetic inheritance has been understood since Gregor Mendel's work with pea plants was rediscovered in 1900. However, it was not until the structure of the deoxyribonucleic acid (DNA) double helix

was elucidated by Rosalind Franklin, Maurice Wilkins, James Watson, and Francis Crick in 1953 that the recent growth of genetics knowledge occurred. Soon the enzymes that control the replication of DNA were discovered and manipulated, giving us the ability to create recombinant DNA from two different species. This discovery led to some of the first ethical conversations about gene editing at the Asilomar Conference. Following this significant discovery, the Human Genome Project of the 1990's resulted in a 99.9% accurate human genome sequence, taking us one step closer to genetic technologies that had been dreamed of for decades. While this information will undoubtedly do a great deal of good and improve the lives of many people, it will also bring us into morally ambiguous territory.

Second, a basic introduction to the genetics underlying the CRISPR project will be given. To understand this more complex genetics technology, it will be important to understand the basics of genetics as well as how our genetic code carries information that shapes so much of our lives. Our genetic code is the "blueprint" from which proteins are made, which are the central actors in our bodies. When the genetic "blueprint" code that describes how to make a certain protein is mutated, that protein may be produced (or not produced) in such a way that it is unable to serve its function. These mutations are the basis for genetic diseases, and they can be targeted by CRISPR-Cas9 technologies to give us the ability to edit the human genome to decrease the presence of disability.

Third, current developments on the path to human gene editing will be explored. The research of Dr. Jennifer Doudna, the scientist who first discovered CRISPR technology while researching the defense systems of bacteria, will be presented. While Doudna quickly understood the ethical implications of her discovery and took action to

create a space for deep consideration of this tool, other researchers have not been so cautious. After considering the discovery of this gene editing technology, its current use in altering the human genome will be discussed. Dr. He, a scientist from China, has already used this technology on a set of twins in an attempt to make them less susceptible to HIV. Following this experiment, Dr. He was given a three-year prison sentence, giving the first attempt at human gene editing an ominous start.

The last half of this chapter will address some of the potential ethical concerns that may come to light should CRISPR-Cas9 technology be widely used. CRISPR has the potential to improve human lives through its use in crops to fight food insecurity, its use in animals to create human organs, and, to some extent, its use in humans to treat disease. However, it also brings up many ethical questions in its use to treat genetic disability. With the potential to edit embryos before a child is born, the assumption that disability is a problem to be solved may be perpetuated. While the potential problems that arise from CRISPR gene editing will be discussed in this chapter, the final chapter of this thesis will be devoted to discussing potential solutions by considering how society could better view people with disabilities and proceed more cautiously in the realm of human gene editing. In this chapter, I will argue that the impact of gene editing technology on people with disabilities has not been a priority, which sets a dangerous precedent for careful consideration of the current CRISPR gene editing technologies.

How We Got to CRISPR: A Brief History of Recent Genetic Discoveries and Their Ethical Concerns

While our understanding of genetics has grown exponentially in the last seven decades, the beginning of our understanding of genetics is often attributed to Gregor Mendel. Mendel was a monk in what is now the Czech Republic in the nineteenth century. In the 1850s, he bred thousands of pea plants and recorded his observations of seven different traits in an attempt to understand how these traits are passed down from generation to generation. Through this process, he discovered the basis of what would become known as "dominant" and "recessive" alleles, which forms the basis of genetic inheritance. While Mendel completed his pea plant research in the 1860s, his work was not widely recognized until many years after his death.[1] In 1900, Hugo DeVries, Carl Correns, and Erich von Tschermak each individually came upon the work of Mendel while conducting their own research into the basis of inheritance, brining it back into the scientific realm.[2] Today, Mendel's work is understood as part of the foundation of genetics and is the root from which we have made innumerable discoveries about the inherence of genetic conditions.

While Mendel's discovery set the foundation for genetic inheritance, the more recent discovery of the structure of the DNA double helix was another significant step in bringing us closer to editing genetic traits. Rosalind Franklin, James Watson, and Francis Crick were responsible for this remarkable discovery. Watson and Crick pioneered the

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[1]Roy Caldwell, "Discrete Genes are Inherited: Gregor Mendel," *University of California Museum of Paleontology.* 2021. https://evolution.berkeley.edu/evolibrary/article/0_0_0/history_13

[2]"1900: Rediscovery of Mendel's Work," *National Human Genome Research Institute*. April 22, 2013. https://www.genome.gov/25520238/online-education-kit-1900-rediscovery-of-mendels-work#:~:text=Three%20botanists%20%2D%20Hugo%20DeVries%2C%20Carl,inheritance%20in%20the%20scientific%20world

"double helix" model of DNA by using the X-ray diffraction images taken by Rosalind Franklin[3] (without her knowledge or permission).[4] Much like Mendel, Franklin died without being recognized for her contribution to this significant discovery.[5] With the structure of DNA understood, significant research could now be done on the physical means by which the genetic information contained within DNA is passed on from generation to generation in biological organisms.

Throughout the 1960s, many of the small proteins, called enzymes, that allow for the duplication of DNA strands (a process called transcription) that are passed down to replicating cells (through mitosis) and future generations (through procreation) were also discovered. It was during this period that "restriction enzymes"—enzymes that are able to selectively cut at a specific point on a DNA sequence—were first discovered. The discovery of restriction enzymes was one of the first indications that DNA could be selectively modified and is part of the foundation for our modern gene editing technology in CRISPR. In the 1970s, recombinant DNA—DNA from two distinct sources (one source being introduced artificially), such as individuals from different species, that can be naturally replicated within an organism—was first created in a laboratory by Paul Berg[6]. The creation of recombinant DNA was not only monumental in setting the foundation for CRISPR gene editing, but it also began to raise serious ethical questions

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[3]"History of Genetic Engineering and the Rise of Genomic Editing Tools," *Synthego.* 2021. https://www.synthego.com/learn/genome-engineering-history

[4]Ilona Miko and Lorrie LeJeune, "Rosalind Franklin: A Crucial Contribution," *Essentials of Genetics.* January 17, 2014. https://www.nature.com/scitable/topicpage/rosalind-franklin-a-crucial-contribution-6538012/

[5]Miko and LeJeune, "Rosalind Franklin: A Crucial Contribution."

[6]"History of Genetic Engineering and the Rise of Genomic Editing Tools."

about the future of human gene editing. To address these questions, Berg himself called a moratorium on gene editing research in 1974.

Since human gene engineering was first seen to be a realistic possibility, ethical considerations have been raised. Although ethical concerns about the progress of science have often been raised by the public (especially after the development of the atomic bomb), the concern over human gene editing was first raised within the scientific community. The National Academy of Sciences and the National Institute of Medicine looked to Paul Berg to lead the discussion of human gene editing ethics. In July of 1974, Berg assembled a committee of other human gene editing scientists and drafted a letter proposing a moratorium on genetic engineering experiments, writing that research on plasmids (recombinant DNA) should be "voluntarily deferred…until the potential hazards of…recombinant DNA molecules have been better evaluated or until adequate methods are developed for preventing their spread."[7] This moratorium was kept in place until the Asilomar Conference in February of 1975. During this conference, "the self-imposed pause in research [was lifted] and replaced with controls for broad categories of work, deemed to pose minimal, low, moderate and high risks…Certain experiments posed such serious risks that they should not be done with presently available containment facilities."[8] The Asilomar Conference was successful at creating boundaries on especially risky procedures (such as those that could result in the creation of a new

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[7]Paul Berg, "Potential Biohazards of Recombinant DNA Molecules," *Proceedings of the National Academy of Sciences of the United States of America,* (Science, 1974).

[8]Nicolas Rasmussen, "DNA Technology: 'Moratorium' on Use and Asilomar Conference," *John Wiley & Sons, Ltd.* January 27, 2015. https://onlinelibrary.wiley.com/doi/full/10.1002/9780470015902.a0005613.pub2

virus that could infect humans), but the conference has received a good deal of criticism, and for good reason.

The Asilomar Conference, on its surface, may have appeared to a be a careful and wise consideration of the impact of recombinant DNA research and other recent genetic developments, but in many ways it failed address the depth of the problem. While regulations for the research on gene editing were established during the Asilomar Conference, there was little discussion of the wider social or ethical implications of human gene editing research. The attendees of the Asilomar Conference were scientists personally involved with research in recombinant DNA.[9] While their concern for the ethical implications of their research may certainly have been legitimate, they were also motivated to implement regulations that would allow them to continue pursuing their research. Indeed, the conference and self-imposed regulations to their research gave them an opportunity to attempt to create their own regulations before government regulations on their research were imposed on them. Finally, the lack of other voices—and especially those of people with disabilities—created only a narrow image of the implications of their research. While at this point in time the implications of recombinant DNA technology on people with disabilities may not have been as clear as the implications of CRISPR technology, this possibility may have been considered had more qualified persons—besides just those involved in the scientific research—been invited to the conference. Had ethicists, medical historians, or experts in other fields been invited to

[9]Rasmussen, "DNA Technology."

this conference, these possibilities may have been foreseen and discussed. As a precedent for current conversations of CRISPR research, there is reason for concern.

From the 1970s to the 1990s, more genetic discoveries, many relying on recombinant DNA technology, were made that brought us closer and closer to the reality of human gene editing. However, it was not until 2003 that a crucial piece of this puzzle—the human genome itself—was finally put together. The Human Genome Project was a publicly funded project with the goal of determining the linear sequence of the 3 billion base pairs that constitute the human genome as well as the specific genes that are encoded in this 3 billion base pair sequence. It was initiated in 1990 with a 15-year timeline and reached this goal early, finishing in 2003.[10] From its inception, the Human Genome Project welcomed collaborators on a global scale, and ultimately included the contributions of scientists from 18 different countries. Furthermore, it released the human genome sequence publicly within 24 hours of its completion. There were efforts made towards significant collaboration and transparency, and the significance this project was clearly recognized in these attempts at open global communication.[11] However, despite its beginning with lofty goals of public cooperation, the private sector of biotechnology quickly got involved and grew to have more control over the applications and progress of the Human Genome Project.[12]

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[10]Heidi Chial, "DNA Sequencing Technologies Key to the Human Genome Project," *Nature*. 2008. https://www.nature.com/scitable/topicpage/dna-sequencing-technologies-key-to-the-human-828/

[11]Heidi Chial, "DNA Sequencing Technologies Key to the Human Genome Project."

[12]Charles J. Epstein, "Some Ethical Implications of the Human Genome Project," *Genetics in Medicine*. May 2000. https://www.nature.com/articles/gim2000245.pdf?origin=ppub

The Human Genome Project itself brought up many concerns, such as whose genes would be sequenced and how representative of humanity these genes would be. However, the implications for using the information about the human genome to diagnose genetic conditions and potentially edit the human genome directly impacted the disability community. First, the information provided by the Human Genome Project allowed for the pre-symptomatic diagnosis of late-onset conditions, such as Huntington's Disease and breast cancer. Such information raised concerns over privacy of information that might result in genetic discrimination in the form of increased insurance rates or unwanted information for other family members; correct interpretation of test results and risk (especially in the case of cancer) when information is limited; and the lack of treatment or preventative measures to combat a life-changing diagnosis. Secondly, the information provided by the Human Genome Project may be applied to analyze the genetic influence of personality traits, such as intelligence, or physical features.[13] While the genetics of personality is much more complicated than the results of the Human Genome Project can explain, as our understanding of the human genome grows it is possible that we may reach a time when we discover a connection between genes and personality traits. This knowledge could easily be applied in a discriminatory way and minimize the impact of environment and free will in shaping the personalities of individuals. Knowing information about genetic conditions, susceptibility to genetic conditions, and the influence of genetics on personality all come with their own ethical concerns (which are currently being played out in clinical settings). However, this thesis is most concerned with the third ethical concern raised by the information gained from

[13]Epstein, "Some Ethical Implications of the Human Genome Project."

the Human Genome Project: the possibility of editing the human genome so as to change the outcome of genetic influences. The information provided by the Human Genome Project, combined with recent developments of the CRISPR project (the subject of the next section) has taken us significantly closer to making this scientific fiction a reality.

The Development of CRISPR

In 2012, the possibilities for genetic engineering blew up when Jennifer Doudna, Emmanuelle Charpentier, and their teams discovered the CRISPR-Cas9 bacterial immune system.[14] Doudna began researching the CRISPR genes in 2005, although at the time they were only know for the advantage that they gave to bacteria in fighting off viruses. However, once Doudna and her team had elucidated the CRISPR mechanism, they began to realize its potential application for gene editing. By 2012, they had successfully developed the technology to find and snip out a specific gene in a strand of DNA, further opening the realm of possibility for CRISPR gene editing.[15]

CRISPR, or Clustered Regularly Interspaced Short Palindromic Repeats, is the repetition of gene sequences found in the DNA of some bacteria. Cas (CRISRP associated proteins), the protein that enables CRISPR technology, was first found to have the ability to make specified cuts in fragments of DNA. Bacteria contain this protein in order to defend themselves against viruses, who attack the bacteria by entering their own

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[14]"History of Genetic Engineering and the Rise of Genomic Editing Tools."

[15]Sally Ride Science, "Nobel Prize Winner Jennifer Doudna: How a Curious Girl from Hawaii became a Science Superstar," *University of California San Diego*. October 7, 2020. https://sallyridescience.ucsd.edu/how-a-curious-girl-from-hawaii-became-a-science-superstar/#:~:text=She%20started%20investigating%20unusual%20repeating,how%20CRISPR%20does%20its%20job

DNA (or RNA) in an attempt to get the bacteria to read its genetic code and produce the proteins necessary for reproduction of the virus. Bacteria can defend themselves by recognizing this invading DNA and then using the Cas protein to insert the viral DNA into their own CRISPR region. The CRISPR region keeps the viral DNA from taking over the bacteria's cellular machinery while also creating a "databank" of invading viral DNA to protect itself against similar viruses in the future. Another Cas protein, Cas9, can then transcribe this viral DNA into an RNA molecule, providing a small record that it can use to find matching viral DNA that may have invaded the host. Once it has found a match to its RNA molecule, the Cas 9 protein can bind to that matching viral DNA and destroy it by making cuts in its DNA sequence (that match where the RNA molecule tell it to cut).

How does a bacterial viral protection system give us the potential to edit human DNA? Doudna and her team soon discovered that this Cas protein also provided the opportunity to insert new strands of DNA into the cuts it makes. The Cas9 protein can be isolated and given "guide RNA," which is an RNA fragment designed by humans to match a specific DNA sequence that is being targeted.[16] Once Cas9 cuts this specific DNA sequence, there are two options to repair the gene. First, the cell may undergo a process called "nonhomologous end joining" in which the jagged ends are trimmed and the cell adds new base pairs to the gene. This process often deactivates the gene because it adds extra information that disrupts the cell's ability to make proteins from this gene. This process only works to fix the gene (make it a functioning, protein producing gene)

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[16]Jennifer A. Doudna and Samuel H. Sternberg, *A Crack in Creation*: *Gene Editing and the Unthinkable Power to Control Evolution* (Boston: Houghton Mifflin Harcourt, 2017), 81.

about 1% of the time.[17] The second option, "homologous recombination," provides a second piece of DNA that matches the two broken ends of DNA from the Cas9 cut and works as a template to repair the DNA sequence to create a DNA fragment matching the provided DNA. If this second piece of DNA fragment contains a functional gene between the ends matching the broken gene fragment, this function gene will be copied into the broken gene, allowing for new genes to be inserted. In this way, a broken gene can be cut by Cas9 such that non-functional genes are removed, and then repaired by inserting a functional gene using a template provided by scientists.[18]

When Doudna first began to realize the implications of her work on human gene engineering, she also understood the serious ethical implications of these possibilities and took steps to encourage international ethical discussion about gene editing technology.[19] After Doudna's paper describing the CRISPR technology and its potential impacts was published in *Science*, it soon became a topic of interest not only for scientists, but also for the public once it was discussed in mainstream media. Very soon after its discovery, CRISPR was used to modify food products and animals, being tested on monkeys with the hope of beginning human testing soon after. Doudna, along with countless others, saw these developments with concern. While she welcomed the prospect of somatic (body cell) changes that CRISPR could bring—especially in blood diseases, which were the simplest target—she had significantly more apprehension about germline edits.

> [CRISPR] technology can be used not just to treat diseases in living humans but also to prevent diseases in future humans. The CRISPR technology is

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[17]Doudna and Sternberg, *A Crack in Creation*, 26.

[18]Doudna and Sternberg, *A Crack in Creation*, 105.

[19]Doudna and Sternberg, *A Crack in Creation,* xviii.

> so simple and efficient that scientists could exploit it to modify the human germline—the stream of genetic information connecting one generation to the next. And, have no doubt, this technology will—someday, somewhere—be used to change the genome of our own species in ways that are heritable, forever altering the genetic composition of humankind.[20]

Germline changes, performed on human embryos, are ethically concerning for many reasons. First, the person who is the direct recipient of such editing has no opportunity to consent for herself—only the consent of the parents is possible. Second, these changes not only modify the individual who receives them, but also all of that person's descendants when they pass down that edited genetic code to future generations. In other words, we could be choosing to genetically shape future generations in the context of the values we have now without knowing how they may one day feel about these changes—and with no way to reverse them. Third, germline changes could be made to edit not only diseases, but also superficial characteristics, such as eye or hair color.

In an effort to get ahead of the concerns Doudna saw in potential germline editing, she began considering past and current gene editing development. Genetic selection is already being used through preimplantation genetic diagnosis before in-vitro fertilization. Embryos for implantation into a woman's uterus are first examined for any potential genetic mutations (especially if there is a familial risk for a specific condition), thus eliminating the possibility of a specific congenital disability. CRISPR technology would simply allow for embryos to be edited for what was desired, instead of chosen for the qualities deemed favorable that they already possessed. Therefore, it could be argued that editing through CRISPR technology was just another step on the path of selecting

[20]Doudna and Sternberg, *A Crack in Creation,* xvi.

favorable genetic traits in humans that had already begun. However, this argument seems much too simple to address the potential consequences of human gene editing.

When CRISPR technology became more and more accessible with little formal regulation, Doudna grew concerned and began organizing ethical conversations about this technology. She primarily looked to the model of Paul Berg and the Asilomar Conference, discussed earlier in this chapter, for guidance. She saw his decision to halt his research progress in recombinant DNA and call for the Asilomar Conference as a wise and cautious choice, but she recognized that scientists were making decisions that others members of the public should have been involved in (and were not). Nevertheless, she saw the Asilomar Conference as a positive way to address scientific concerns and did not see this conference as a way for scientists to maintain control of scientific decisions within their field, as some critics of the Asilomar Conference have pointed out.

Doudna began the process of discussing the ethical implications of her research by calling a small one-day forum—called the Innovative Genomics Institute Forum on Bioethics—and inviting other scientists, including Paul Berg and other attendees of the Asilomar Conference. During this Forum, the scientists narrowed their focus to the implications the CRISPR project had on germline editing. They ultimately decided to publish and "academic op-ed" in the scientific journal *Science*, with the expectation that this would catch the attention of both other scientists and the wider public. In this paper, titled "A Prudent Path Forward for Genomic Engineering and Germline Gene Modification," the attendees of the conference made four recommendations. First, they encouraged experts in the field to create forums to engage the public. Second, they called on researchers to continue using CRISPR when working on cultured human cells and

nonhuman animal models. Third, they recommended an international conference in which the perspectives of a wide variety of people—including scientists, bioethicists, religious leaders, disability-rights activists, and government officials, to name a few—could be heard. Finally, following the example of the Asilomar Conference, they recommended a pause on using CRISPR to make changes to the human germline.[21]

This first forum was the beginning of many national and international conferences that Doudna would be a part of in the years to come. Certainly, she has been proactive in taking steps to openly address the ethical concerns her research has raised and include many others in the discussion. Nevertheless, it seems possible that in these ethical conversations she has run into the same problem faced by Paul Berg and those of the Asilomar Conference: she has opened the discussion of the ethics of human gene editing by questioning *how* and *when* the process of germline editing will begin, and not *if* it should begin. Furthermore, by putting the work of scientists at the center of these discussions, she is continuing the path in which scientists maintain a good amount of control over the ethical decisions their research brings up.

By beginning ethical conversations with the assumption of the inevitability of germline editing, those who create the genetic technology are once again prioritized over those who are most affected by this technology—mainly, people with disabilities. Although Doudna has clearly taken many precautions by calling for a pause on using human germline editing and organizing international conferences, she still sees scientists as the primary actors addressing this situation. People with disabilities are guests at the

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[21]Doudna and Sternberg, *A Crack in Creation,* 210-211.

table, but scientists (and to a lesser extent bioethicists) are the hosts. While many of these scientists may have the best interest of people with disabilities and others impacted by this technology in mind, they are also biased in wanting to continue their work on this project. With such a bias in mind, they should not be the primary overseers of germline editing discussions.

To better prioritize the people who would be most affected, the primary role of scientists regarding CRISPR ethics should be as teachers. To the best of their ability, they should provide the information they know about CRISPR and how it could be used to edit the human genome and allow ethical decisions to be made by others. This is not to say that their opinions on the ethics should be completely disregarded, but simply that they should not be the dominant voices in the conversation. Instead, people with disabilities and those who care for people with disabilities should be prioritized, and their arguments and experiences heavily considered by bioethicists. Then, people with disabilities, bioethicists, scientists, and politicians should work together to create appropriate regulations on the use of gene editing technology (and especially germline editing). If those who are motivated to continue their research are the primary drivers of ethical conversations, their bias may unduly influence them to consider how they can create minimal regulations, instead of prioritizing the wellbeing of those their research will impact.

CRISPR and Humans: Current Developments

Despite the warnings of Doudna and many others, in 2016 Dr. He Jiankui of China began a research project that would result in the live birth of two twin girls who had received CRISPR editing as embryos. Dr. He would ultimately end up serving a three-year prison sentence for this experiment, setting an unsettling precedent for the first CRISPR edited embryos.[22] The paper he wrote was rejected for publication by a number of companies, but MIT Technology Review has published some of the excerpts from the paper they were sent.[23] Doudna and many others have attempted to regulate the use of CRISPR, but it is clear that now that this technology is available and easily accessible, it will be very difficult to control how others choose to use it. This lack of regulation can often result in a lack of ethical consideration and the exclusion of people with disabilities.

Not only was jumping to human embryo gene editing with CRISPR deeply troubling, but Dr. He also made many unethical decisions in the process of conducting this research. First, the parents of the children that received the CRISPR gene editing were offered up to $42,000 worth of coverage for IVF treatment and pregnancy expenses, but with the threat that they would have to repay this money if they dropped out of the research project.[24] The father who was chosen for the experiment was HIV positive, and

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[22]Andrew Joseph, "CRISPR Babies Scientist Sentenced to 3 Years in Prison," *Scientific American*. December 30, 2019. https://www.scientificamerican.com/article/crispr-babies-scientist-sentenced-to-3-years-in-prison/#:~:text=A%20Chinese%20court%20on%20Monday,%2C%E2%80%9D%20Chinese%20state%20media%20reported

[23]Antonio Regalado, "China's CRISPR Babies: Read Exclusive Excerpts from the Unseen Original Research," *MIT Technology Review*. December 3, 2019. https://www.technologyreview.com/2019/12/03/131752/chinas-crispr-babies-read-exclusive-excerpts-he-jiankui-paper/

the couple may not have been able to afford IVF and avoid passing on HIV from the father to their children without the help of the experiment.[25] Secondly, the health ministry of Guangdong found that He forged his ethics-review documents,[26] and the only ethics review mentioned in his paper was done after the birth of the twins when it was much too late to intervene.[27]

Even the editing of the gene itself, the CCR5 gene, seemed to have been a poor target for gene editing. While this gene is known to encode a protein necessary for HIV to infect cells, it has also been associated with protection of cells against other infections, like the West Nile virus. Mutations induced in the CCR5 gene have been shown to provide HIV resistance, but the specific mutation induced by He has never been found in another human. No testing was done on animals besides humans before this mutation was induced, and since it is a new mutation it is possible that it will not even provide HIV resistance (assuming the CRISPR editing worked) or it might cause other problems that have not been considered.[28]

Finally, many other scientists were listed as authors or credited as consultants by He who have since denied or minimized their contributions. Many of those who were

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[24]David Cyranoski, "The CRISPR-Baby Scandal: What's next for Human Gene-Editing," *Nature*. February 26, 2019. https://www.nature.com/articles/d41586-019-00673-1

[25]It should be noted that the edited genes of themselves were not what prevented the children from getting HIV. Instead, they were protected from getting their father's HIV through sperm washing, a common procedure. The edited genes were intended to protect them from contracting HIV in the future.

[26]Cyranoski, "The CRISPR-Baby Scandal."

[27]Regalado, "China's CRISPR Babies."

[28]Regalado, "China's CRISPR Babies."

credited with authorship have stated that they did not give permission to have their names listed or claimed that they encouraged Dr. He not to continue with his research.[29] However, none of the scientists who were aware of the experiment Dr. He was preforming were concerned enough to alert the proper authorities or take any further action to prevent his research from continuing. Even if their claims are true and these scientists were not as involved with the research as Dr. He seemed to indicate they were, they are still complicit in their silence.

Many scientists want to use CRISPR technologies to help patients and cure disease while following ethical guidelines. However, it is clear that there are also scientists who will abuse this technology and treat patients as little more than objects for their scientific manipulation. Furthermore, other scientists may not conduct ethically questionable CRISPR research themselves but may be content to watch the scientific progress unfold without voicing any concern. Ethical guidelines for the use of CRISPR technology on the human germline must be set and enforced, and soon. However, if the precedents that have been set in making ethical decisions with genetic technology are followed, there is much cause for concern. While there have certainly been some steps in the right direction, much more consideration of people with disabilities—the people who would primarily be impacted by human genetic editing—needs to take place, and a more empathetic view of the value of people with disabilities needs to be more widely understood before any application of CRISPR technology to edit the human genome.

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[29]Cyranoski, "The CRISPR-Baby Scandal."

Conclusion

CRISPR technologies have opened up a new realm of possibilities in human gene editing, but the ethical considerations that have taken place in the past have not set a strong precedent for current ethical discussions of these technologies. Both the Asilomar Conference and Doudna's Innovative Genomics Institute Forum on Bioethics took small steps in the right direction to pause the research being done and consider ethical boundaries for that research. Doudna has since taken a further step to open up the conversation around ethics to others, including people with disabilities and bioethicists. The progress that has been made in addressing these ethical concerns should be applauded, but these ethics conversations are still being conducted primarily by scientists who are not experts in ethics and are mostly not disabled. As they will not be the most impacted by these technologies and do not have the background in ethics to properly consider the implications of these technologies, they should not be the primary decision makers on how this technology is used. The first trial to use CRISPR technology on human embryos that grew to be children was a disaster and should serve as a warning of what can happen if scientists are left to create their own ethical boundaries. Now that a foundation of different perspectives on disabilities has been established (Chapter 1); current and past procedures to decrease the presence of people with disabilities have been investigated (Chapter 2); and the scientific discoveries and ethical conversations around those discoveries have been analyzed (Chapter 3), the final chapter will argue that the theological model of disability provides the best foundation to proceed with ethical considerations of human gene editing.

CHAPTER FOUR

The Foundation: The Theological Model of Disability and its Application

Introduction

In the first chapter of this paper, two different models of disability—the social model and the medical model—were presented. In this chapter, we shall turn to a third model of disability: the theological model of disability. The principles of the medical and social models of disability have largely been applied when dealing with problems concerning people with disabilities in the past and leading up to the present, as discussed in Chapters 2 and 3. However, these models fail to fully represent the value of people with disabilities and, if used for consideration with CRISPR human gene editing ethics, are more likely to lead to discriminatory policies. The theological model of disability, translated into secular terms as the friendship model of disability, will provide the best perspective for considering people with disabilities in the discussion of human gene editing and will allow for mindful regulations to be made.

The theological model of disability views people with disabilities as having much to offer and receive through the gift of friendship and through what they can share of their experience with those in their communities. People with disabilities are not viewed as people suffering from a genetic mutation or the effects of an accident, but as intentionally designed humans from a loving, perfect, creator God. In many ways, they represent what it means to live a Christian life and can teach those of us obsessed with our schedules and other worldly concerns a great deal about patience and love. This

model can be interpreted into a secular model—the friendship model—to convey many of these important concepts to a secular culture, even if there is inevitably some meaning lost in translation.

After developing a fundamental basis for understanding people with disabilities, the concerns of human gene editing will be considered and a plan for appropriately proceeding with this research will be proposed. When the insight of people with disabilities, their advocates, and bioethicists are prioritized, the opinions of those who will be most impacted by this technology will be appropriately considered. It will be argued that while somatic germline editing is similar to other medical treatments in the autonomy it provides to those who choose to undergo it, germline editing should face much more stringent regulations. While it is likely that germline editing will one day become much more accepted, there must be a great deal of caution in the precedents we set now, at the beginning of this development.

As with many of the other complicated bioethical issues discussed in previous two chapters, a simple solution that pleases all parties is unlikely, if not impossible. However, by prioritizing the people who would be most impacted by this technology, and specifically by focusing on the opinions of individual communities of disability (such as the Down Syndrome community and the Deaf community), we can accommodate the people who most need to be prioritized. It is unlikely that this technology will give us the capability to eliminate all disability, but it may drastically decrease the number of people born with congenital conditions. In a reality in which people with disabilities would be even less common than they are now, it is more important than ever that we work to

create a more accepting society for people with disabilities and acknowledge their inherent value.

The Theological Model of Disability

Arguably the most common response to people with disabilities is one of fear or pity—a response seen in large part in the medical model of disability. People with disabilities, and especially those with profound disabilities, are seen as people in need of support and charity. While the social model of disability works to change this perspective of people with disabilities and advocates for the opportunity of people with disabilities to shape their own narratives, the theological model of disability goes a step farther by arguing for the inherent value of people with disabilities. People with disabilities are seen not as the pitiful result of an unfortunate accident or genetic mutation, but as intentional creations of a loving Father.

Those who view people with disabilities through the medical model of disability can quickly come to see people with profound disabilities as child-like, or perhaps even "animal-like", perceiving the world solely through their senses.[1] In the medical model of disability, there is a one-way interaction between the medical professional and the person with a disability in which the person with a disability is solely the recipient of help and support while the medical professional gives this support. On first glance, this relationship may seem understandable. A person with a profound disability may have limited self-awareness, not have plans or goals for the future, have limited or no ability to

[1]Hans S. Reinders, *Watch the Lilies of the Field: Theological Reflections on Profound Disability and Time* (Grand Rapids, MI: Wm. B. Eerdmans Publishing Co., 2010), 154.

produce or comprehend language, and have little concept of time outside of the present.[2] It may seem as though they would be able to provide very little to others within these limitations. However, Hans Reinders and other theologians and disability advocates have argued that those with disabilities do if fact have much to offer, and not just receive, in their gifts of friendship and they ways in which allow us to see the world through a new, and often better, lens.

The theological model of disability, as intended here, refers to a specific understanding of people with disabilities as made by a loving creator God and as having great value in society through the gifts they can give to others. For its purposes here, this model is used to consider people with profound disabilities, although its principles can be extended to all people with disabilities (and in some respects all people in general). It should be noted that the theology here is a Christian theology. While it is the argument of this section that a Christian theology provides a loving perspective towards people with disabilities, it is acknowledged that this has often not been the case. People with disabilities have frequently been excluded from conversations around theology as well as by the Christian church.[3] These failures, however, are the result of human sinfulness, and not because of Biblical understandings of disability.

The theological model of disability is rooted in a fundamental understanding of a loving God who has created all humans (and other beings) with intention in God's image. According to the theological model of disability, people with disabilities are not an

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[2]Reinders, *Watch the Lilies of the Field*, 154.

[3]John Swinton, "Who is the God We Worship? Theologies of Disability; Challenges and New Possibilities," (Walter de Gruyter, 2011), 274-275.

abnormality or an exception to what it means to be "made in the image of God." When this assumption of abnormality is made, they can be perceived as a consequence of sin that needs to be fixed through healing and prayer. Such a perspective can lead to marginalization, and this has been the case in many Christian and non-Christian communities.[4] However, we should understand the "image of God" as a reflection of all of humanity—including people with disabilities—and not simply as a more perfect version of people without disabilities. When this perspective is assumed, people with disabilities are drawn into the Christian community as valued members with much to give to the community.

The theological model of disability has much in common with the social model of disability, and it has taken many of the ideas of the social model and evaluated them theologically.[5] Specifically, it has adapted the idea that the "fault" of disability lies with societal systems that exclude people with disabilities, as opposed to a personal tragedy that the person with a disability must bear. There is a distinct difference, however, between the theological model and the social model in the values they cherish. The social model supports autonomy, freedom, rights, and choices as the highest values to be achieved. People with disabilities achieve equality by sharing their stories and fighting to be recognized. In this sense, the social model of disability lends itself to a social justice movement of disability. However, the same values of autonomy and freedom that are prioritized by the social model of disability also allow for others to stand against people with disabilities or work to eliminate their presence. This includes the freedom that

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[4]Swinton, "Who is the God We Worship?", 276-278.

[5]Swinton, "Who is the God We Worship?", 278-279.

parents would have to choose not to have a child with a disability through selective screening or, soon, genetic engineering. Furthermore, it portrays people with disabilities as a burden to be cared for which impinges on the autonomy of others, providing another reason to work to decrease the prevalence of people with disabilities.[6]

The theological model of disability, however, prioritizes different values: community, friendship, and love. In this context, people—*all* people—possess inherent value given to them by a perfectly loving God. This love is grown in community with others, much like the community Kay Toombs describes as necessary for providing the support that allows people to live through great pain and not choose to pursue physician assisted suicide (Chapter 2). Reinders writes:

> The benefits bestowed by love and friendships are consequential rather than conditional, which explains why human life that is constituted by these relationships is appropriately experienced as a gift. A society that accepts responsibility for dependent others such as the mentally disabled will do so because there are sufficient people who accept [this] account as true.[7]

These gifts of love and friendship are given freely, to all people, no matter their accomplishments. They are not dependent on any other qualities. This was the example given to us in Christ's death on the cross, and it is the calling of a Christian to follow this example. When this life is lived well, a community can develop in which the gifts of all people are received as a communal blessing, and especially the gifts given by people with disabilities.

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[6]Swinton, "Who is the God We Worship?", 293-294.

[7]Hans S. Reinders, *The Future of the Disabled in Liberal Society* (Notre Dame, IN: University of Notre Dame Press, 2000), 17.

People with disabilities have much to offer, but two of the primary gifts are the gift of friendship and the gift of what this friendship can teach others about the nature of God and God's relationship with us. When non-disabled people first begin to interact with people with profound disabilities, the experience is often uncomfortable: people with profound disabilities often fail to meet the expectations non-disabled people have for other people. Communication can be difficult and frustrating for the non-disabled person, and impatience is a common response. However, when this friendship is pursued, a great deal of beauty can grow from it. People with profound disabilities often do not perceive time in the same way others do. They may not have a concept of past or present, and likely do not feel the urge to constantly fill their time with events and things to keep them busy. People without disabilities, however, often are unable to prioritize rest or see time as a gift, but instead see time as a limited commodity to be used to fulfill their goals. Friendships with people with disability can teach those who receive the gifts of this friendship the value of accepting time as a gift from God[8], and in receiving this gift learn to appreciate time spent with others and not just time spent pursuing one's own goals.

This gift of a friendship that can teach others to appropriately value time and learn patience is just one example of the gifts that people with profound disabilities have to give. People with disabilities serve a divine purpose, and as such have much to contribute to the community of Christ. They are to be valued and loved, not eliminated. When people with disabilities are seen for their true value, we can truly begin to have conversations about how gene editing technology should be used.

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[8]Reinders, *Watch the Lilies of the Field*, 156-157.

The Friendship Model of Disability: A Secular Translation

In reality, a theological model of disability will not be accepted by everyone considering the ethical implications of gene editing (and especially not by those who are not considering the ethical implications but pursuing this technology anyway). Therefore, there needs to be some kind of translation of the ideas of the theological model of disability into a secular language. The concept of translating theological beliefs into a secular morality is not new in bioethics and is a topic of much debate. Tristram Englehardt, a prominent bioethicist, argues that there is no way to effectively translate theological ideas into a secular ethics and the best that can be done is to agree upon a relatively weak "common morality" that most people can agree to.[9] However, other bioethicists are more hopeful, such as Lisa Cahill. Cahill argues that we can use the tool of narrative to convey ethical ideas of a specific theological traditions. Through narrative, we can create a common space for discussions of these ideas that may better persuade others.[10] Therefore, Cahill believes there is a way to communicate beliefs and values of theological ethics to the wider secular community without completely diluting the rich contents of a tradition. The value of narrative in conveying the theological model of disability will be discussed in the conclusion.

The basis of the theological model of disability is an understanding of the inherent value of all people because of their creation in the image of a perfect, loving God. Clearly, this foundation will not be accepted by most people with a secular understanding

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[9]H. Tristram Englehardt, *The Foundations of Bioethics* (New York: Oxford University Press, 1996), 5.

[10]Lisa Cahill, "Theology's Role in Public Bioethics," in *Handbook of Bioethics and Religion*, Lisa Cahill and David E. Guinn (Oxford Scholarship Online, 2006), 37-43.

of disability. However, while the creation of a common morality may necessarily be a diluted understanding of the value of people with disabilities, as Englehardt argues, there is still some hope in conveying the value of people with disabilities through the secular "friendship model" of disability. Many within the secular Western society have noticed the business of our modern lives and have sought opportunities for rest. Because a rejection of busy schedules with no breaks is becoming recognized as something to be desired in our modern society, some may be more open to the lessons that can be taught about rest by people with profound disabilities. This desire for rest creates an opportunity to emphasize what can be gained from friendship with people with disabilities, which is the secular foundation of the friendship model of disability.

This friendship model of disability can be seen as a branch from the social model of disability (as can the theological model of disability, although to a lesser extent). It also advocates for the voices of people with disabilities to be heard, although there is more emphasis on personal relationships with people with disabilities. Often, people with disabilities are kept in separate programing, such as in schools, than people without disabilities. However, both the friendship and theological models of disability would advocate for integrated programing in which people with disabilities (and especially people with profound disabilities) are seen as accepted members of society. However, it is important to acknowledge that people with disabilities often do need extra support and integrated programs should not come at the cost of this support.

Were people with disabilities to be seen as valuable by a greater majority of the population[11] and not just Christians (which, sadly, is not currently a reality either), a loving conversation about the potential of human gene editing could occur. However, the common morality that we currently share is by necessity shallow and prioritizes autonomy. When autonomy is seen as a primary value, everyone must advocate primarily for their own interests—which is deeply problematic for those who do not have the capacity to do so. When the desires of the individual are understood as more meaningful than the good of a community, it is hard to imagine a reality in which human gene editing is not pursued—and eventually pursued with little or no limitations.

A Practical Exploration of Human Gene Editing: How Then Should We Proceed?

With an understanding of the basis of the theological and friendship models of disability, the application of these values can now be considered in the context of human gene editing. However, even with these models (and primarily the theological model of disability) as a foundational outlook, there will still be much debate as to the best way to address the complicated ethical questions brought by the possibility of human gene editing. Certainly, the theological model (and even the friendship model) could be used to argue for a moratorium of human gene editing as a completely unethical practice. While this is unlikely to happen, there is some precedent in the negative response to eugenics: while in the past people with disabilities (and others) who had already been born were killed because of their disabilities, such negative eugenics is now seen as horrific and is

[11]This thesis primarily deals with the Western view of disability, although a global understanding of the value of people with disabilities is also hoped for.

rejected by most people in Western societies. However, because of the nuance of human gene editing, it seems more likely that the ethical considerations will follow the path of physician assisted suicide and abortion: a slow progression of less and less restraint as ethical barriers are torn down. Yet, there is still hope for a middle path between these two fates in which firm guidelines—created primarily by people with disabilities—are set for this technology and strictly followed. This is the argument that will be supported in this section.

First of all, it is important to differentiate between somatic and germline human editing. Somatic human editing can take place with the consent of the individual or their parent/guardian (with careful consideration that such a treatment is in the best interest of the recipient) and in many ways is similar to treatments that already exist, such as chemotherapy or dialysis. In fact, the first trial of somatic human editing with CRISPR has already occurred. A young woman named Jannelle Stephenson agreed to undergo the first trial to use CRISPR technologies to treat her sickle cell disease. Sickle cell disease is a genetic condition in which the patient has "sickle shaped" instead of round red blood cells, which can lead to clumping and life-threatening blood clots, as well as difficulty breathing (these sickle shaped red blood cells cannot transport the oxygen the body needs as well as round red blood cells can). In this treatment, some of her hematopoietic stem cells (a type of cell in the bone marrow that produces red blood cells) were removed from her body, edited with CRISPR technology to produce round red blood cells, and put back into her body. Because these cells come directly from the patient and go back to the patient, her body is less likely to reject the treatment (which often happens with organ donations, for example). This treatment occurred almost four years ago at the time of

writing, and so far there is no indication that the treatment failed or caused deleterious side effects.[12] While there may be other ethical considerations to take into account with somatic germline editing, those will not be the focus of this paper. Somatic human editing—as currently being used—is a life-saving treatment similar to many other treatments for genetic and non-genetic conditions. It poses a much smaller threat to the perceived value of people with disabilities than does germline editing.

Germline human editing, as described in Chapter 3, should be approached with much more hesitancy. Jennifer Doudna's decision to call for a pause in human germline editing with CRISPR was an appropriate first step (even if it was not respected by all scientists), and a good example of the role scientists have in this ethical conversation. Decisions about human gene editing should in no way be rushed, as the changes made through germline editing may be passed down through generations and shape a specific family and, on a larger scale, potentially the human race. Furthermore, during this break from human gene editing, specific regulations should be established on the limits of human gene editing. This is not a decision that should be left up to individual parents to make for their children. The temptation to create "designer CRISPR babies" without oversight is problematic for a wide variety of reasons including, but not limited to, an unhealthy understanding of what it means to be human, discrimination in the use of this technology for only specific (likely wealthy) individuals, unexpected health (and social) consequences of this action, and many more. While creating designer babies is certainly a long way away from the current development of CRISPR technologies, using this

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[12]Francis Collins, "A CRISPR Approach to Treating Sickle Cell," *National Institute of Health.* April 2, 2019. https://directorsblog.nih.gov/2019/04/02/a-crispr-approach-to-treating-sickle-cell/

technology to edit specific traits in embryos is a much nearer reality (and indeed has already been done by Dr. He).

In many ways, this technology is already at play with the use of selective abortion and in-vitro fertilization (IVF) to select for children with or without specific traits. Parents who undergo this procedure are given the choice not to have a child with a disability. With the current technology, however, embryos that are not implanted must be discarded or indefinitely frozen in some way, which creates more ethical dilemmas. While the use of selective abortion or IVF only allow for the selection or rejection of existing traits in a child, CRISPR would provide the opportunity to selectively add, modify, or remove specific traits. This choice to not have a child with a specific condition places a value judgement on that condition and is not supported by the theological or friendship models of disability, which emphasize the inherent values of all human beings. It is already clear that some parents will make the choice to select against children with specific traits and should not be given free reign to make whatever modifications they may desire.

While the primary decision to edit the human germline should not be left to parents, it should also not primarily be the role of scientists. As discussed in Chapter 3, scientists have a bias towards continuing the progress of their research and often spend more time in a culture driven by the idea of making progress than a culture that reflects on the good of that progress. Instead, the primary policy advocates should be people with disabilities, those who know well and care for people with disabilities, and bioethicists. Scientists certainly have a role in this process in explaining the information they gather to those who should be the primary decision makers. Scientists who work closely with

patients with disabilities, such as palliative care workers and genetic counselors, may also be able to share their experiences and take on an advocacy role. However, the scientists who were personally involved in CRISPR research should primarily take on a teaching role, instead of advocating for policies that would allow a continuation of their research. Those most impacted by this technology should be the loudest voices in the discussion of its potential uses, not those biased by the desire to continue working on developing that technology.

By making the primary decision makers for human gene editing technology people with disabilities, their caretakers and supporters, and bioethicists, there is a greater chance these ethical discussions can start in the right place. However, in order to truly see a change that supports people with disabilities, there needs to be a cultural change in how people with disabilities are viewed. Most people who advocate for people with disabilities are either disabled themselves, have a relative who is disabled, or were fortunate (or intentional) in befriending people with disabilities. However, because disability is something many people fear (people with disabilities can be an uncomfortable reminder of one's temporarily abledness), people with disabilities are often kept at the margins of society. In order for there to be space for the friendship or theological model to work, this must change. People with disabilities must be given a more visible place in society, instead of being isolated. They must be intentionally drawn into community. This may be done through advocacy of integrated education programs, efforts to make buildings and other infrastructure more accessible to people with disabilities, and many more steps. When there are more opportunities to befriend people with disabilities, an understanding of their inherent value—whether through the

theological or friendship model—can be gained. When people with disabilities are seen as valuable members of their communities, the emphasis on eliminating congenital disability in children may have a chance to fade.

Although encouraging visibility and greater inclusion of people with disabilities could lead to a complete rejection of human gene editing, this is an unlikely reality. Given our past tendencies to use the newest developed technologies with limited ethical limits (at least in the realm of medical ethics), it seems almost certain that this technology will be implemented. Should this be the case, people with disabilities should still be the primary consultants for *how* this technology is used, and within what disability communities. "Disability" is an incredibly wide-reaching category with innumerable conditions. Some disability communities, such as the Deaf community, can feel very strongly about rejecting cochlear implants and other technologies that would eliminate their disability. It is likely that they would be opposed, at least to some extent and by some members within this community, to the idea of using CRISPR technology to eliminate deafness. On the other hand, people with Alzheimer's, those who support them, and those with a genetic risk for developing this condition may be more likely to accept germline editing that would decrease the genetic risk for this condition. Conversations about the use of gene editing technology, if it is indeed unstoppable, should listen to the unique disability communities within the greater disability communities as well. While deafness and Alzheimer's may be on the edges of a larger spectrum, there will likely be a great variety of reactions to human gene editing within specific disability communities.

Even were germline gene editing to be heavily implemented in society, this technology would not eliminate disability. Disabilities, including profound disabilities

caused by brain injuries, can occur after birth (non-congenital disabilities). However, if we create a society in which disability is seen solely as something to be eliminated as much as possible, people with disabilities will become less common, less visible, and less accepted. Those who have (rare) congenital disabilities or become disabled later in life will likely become even more rejected by society than they are now, as their conditions become less and less common.

Secular society at large (even those who follow the friendship model of disability), is unlikely to advocate against human gene editing to decrease the incidence of disability. Autonomy will likely be seen as a priority value above community, and even if some non-Christian parents would not choose to select against a child with a disability themselves, they may not oppose others who would make this choice. Christians, on the other hand, have a greater calling to care for people with disabilities through the theological model of disability. While Christians should be loving and empathetic towards those who may choose to use medical technology to select against people with disabilities, they themselves should not make this choice (using any kind of medical technology). Were the Christian community to set such a role model, a loving community accepting of people with disabilities might be created (although this would take a lot more work from where most Christian communities are now). This community and its love could set a beautiful model to others, drawing them in to both Christianity and the love of people with disabilities in Christianity. This is the goal of the theological model of disability.

CONCLUSION

At its center, the theological model of disability is about forming friendships with people with disabilities, recognizing them as brothers and sisters in Christ who are made in the image of God, and learning from the gifts of friendship they share. This model is lived out in the lives of many, but there are few better examples than that seen in Henri Nouwen's *Adam: God's Beloved*.[13] Nouwen tells the story of his time in the L'Arche Daybreak community and his friendship with Adam, a man with profound disabilities who, for Nouwen, was an image of the living Christ. When Nouwen first arrived at Daybreak and began caring for Adam, he describes his significant fear of hurting his friend, discomfort in caring for his personal needs, and impatience when he is a rush to get to his day. Yet as Nouwen spends more time with Adam, their friendship grows. He takes time to see Adam's radiant inner light. He comes to see that because Adam lacks the constant distractions Nouwen has put in his own life, he does not have to practice the spiritual disciplines to become empty before God—this spiritual gift is a part of who he is. He is able to be filled up with love and reflect that love to others. Nouwen writes: "God sent Adam as God sent Jesus, to be an instrument of grace, a source of healing, a cause of new joy. He was so whole, so peaceful, silent, breathing heavily, fidgeting with his fingers, and never aware of how special he was."[14] This is the theological model of

[13]Henri J.M. Nouwen, *Adam: God's Beloved* (Maryknoll, NY: Orbis Books, 1997).

[14]Nouwen, *Adam: God's Beloved*, 81.

disability. This is what is hoped for, and what can save us from our quest for biological perfection.

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