

Prenatal Genetic Testing and Disability

By Dr. Kathy McReynolds

The Genetic Revolution

The Genetic Revolution began in 1953 when James Watson and Francis Crick discovered the structure of the DNA molecule. Their work was foundational for the next major step in the revolution: *The Human Genome Project*. On June 26, 2000, Dr. Francis S. Collins, director of the National Human Genome Research Institute, and Dr. J. Craig Venter, president of Celera Genomics, announced at a press conference held in Washington, D.C., that they had successfully completed the first rough draft of the entire human genome. President Clinton praised their work and stated that, “Without a doubt, this is the most important, most wondrous map ever produced by humankind.”¹

The Human Genome Project was originally intended to be a 15-year effort to map the entire human genome. But the map was completed several months ahead of schedule, probably due to the sometimes heated competition that came from Celera Genomics. In the end, however, the two rivals made peace, but decided to remain independent. As it stands now, both sides view this monumental event as a shared success.

Understanding the genes that make up the human genome is expected to revolutionize medicine in several ways. Researchers hope to target dysfunctional genes and to eventually prevent and cure diseases such as colon and breast cancer, cystic fibrosis, and diabetes. Many years have passed since President Clinton asserted that this new knowledge will provide us with the immense power to heal. With confidence at the time, scientists touted that they could virtually eliminate inherited disease. Their hope was pinned on gene therapy, a technique which aims to cure genetic disease by replacing disease-causing genes in certain cells in the body. However, gene therapy has proven time and again to be a disappointment. No breakthroughs yet, and they probably won’t happen any time soon.

Researchers also expect they will eventually be able to develop diagnostics and treatments tailored to individual patients. There is good reason to believe that this goal is more realistic. While attention was diverted to all the hype surrounding gene therapy, this “micro” genetic revolution was slowly taking place. Many call this revolution *genomic medicine*. According to Edward McCabe, co-director of the UCLA Center of Society and Genetics, “This really is the future. Genomic medicine will be predictive, preventive and personalized.”² One example of this trend can be seen with the new heart disease drug, BiDil, which is marketed exclusively to African-Americans who seem to be genetically disposed to respond to it.³ The hope, however, is that in the future, doctors will be able to predict a person’s risk for diseases which involve multiple genes such as Alzheimer’s and diabetes.

But this powerful knowledge is not without significant risks. Many people have concerns about how their individual genetic information will be used and who will have access to it. Many fear the possibility of discrimination if their insurance company or employer were to gain access to their medical records and

discover the results of a genetic test that revealed a predisposition to a particular disease. Indeed, long before the announcement of the completion of the first rough draft of the human genome in June 2000, there was some evidence supporting the fact that these are legitimate concerns.

In 1990, The American Council of Life Insurance formed a committee to explore the issues related to genetic test information and insurance. Their primary task was to develop policy guidelines to ensure that genetic information is kept confidential in order to prevent discrimination based on genetic information.⁴ As of 1998, laws have been established in more than half of the states to prohibit health insurance companies from discriminating based on genetic test information.⁵

The primary federal law prohibiting discrimination in employment on the basis of health status is the Americans with Disabilities Act, which was established in 1990.⁶ In 1995, the Equal Employment Opportunity Commission (EEOC) issued an interpretation regarding the applicability of the ADA to genetic discrimination. The EEOC argued that an employer who discriminated against an individual based on genetic information regarded that individual as having a disability. Therefore, these individuals are covered by the ADA.⁷ However, people with disabilities are still subject to discrimination, not the least of which is the unborn.

Prenatal Genetic Testing

It is safe to say that few disciplines in medicine have been more impacted by the genetic revolution and the possibility of genetic discrimination than reproduction. Prenatal genetic tests are widely used to diagnose such diseases as fragile X, cystic fibrosis, and Down syndrome. The list of prenatal genetic tests is growing, and many people are beginning to wonder why certain tests for conditions such as deafness, breast cancer and colon cancer are not automatically offered to them. This raises a question concerning who gets to choose what prenatal tests are offered: The prospective parents? The professionals? The government? One thing is for certain: parents, professionals, and indeed society in general needs to be much more educated on the meaning of genetic findings or else the consequences could be substantial.

One reason for alarm is that the possibility of genetic discrimination for any number of traits is rising. Scientists, for example, have recently identified minute changes in some DNA which may account for some differences in skin color and disease resistance in some races. As news of some of these findings seep into the everyday conversation of the public, the message seems to be that racial difference may be more than skin deep. As these discussions become more commonplace on internet blogs and in the classroom, it is clear that people are beginning to question whether other traits such as intelligence or morality can be attributed to DNA.

For instance, Amy Harmon reports that a blogger in Manhattan described a study that supposedly linked high IQ to certain pieces of DNA. According to the blogger, an online genetic database showed that these specific DNA snippets were found more often in Europeans and Asia than in Africans. The blogger then asserted that just the existence of genetic differences between the races means that the “egalitarian theory is proven false.” Of course, he left out the fact that the link between IQ and those DNA snippets is unsubstantiated, and that other DNA snippets attributed to high IQ are more common in Africans, and that many other factors such as environment play an enormous role in intelligence.⁸ Needless to say, it would not be difficult to discredit this blogger’s empty assertions. Nevertheless, once these ideas infiltrate the mainstream public ethos, the social damage is done.

Samuel Richards, a professor at Pennsylvania State University, discovered this truth when a recent class assignment backfired on him. He asked his students to participate in genetic ancestry tests in order to prove that racial categories are arbitrary at best. But the opposite position was taken by many of his students. Richards tells of a white student who was told that she was nine percent West African, who then participated in a Kwanzaa celebration. This same student claimed that she would never attend an Asian cultural gathering because her DNA did not match.

The possibility of racial discrimination based on genetics has enormous implications for prenatal testing. Do we as a society then discourage certain races from procreating because they may not be as intelligent and therefore not as useful as other races? What will happen to the notion of equal opportunity for all? What will become of those with certain genetic disorders such as Down syndrome? If our society cannot tolerate slight *differences* in DNA between races, to what degree can we expect it to tolerate those with genetic *disorders*?

The Disability Rights Critique of Prenatal Genetic Testing

Before we discuss a disability rights critique of prenatal genetic testing, it is appropriate to say something about the movement itself. The last several decades have seen the growing influence of the *disability culture* which has led to a disability rights movement. Those with disabilities have increasingly grown wary of an American culture which idolizes beauty, youth, optimum functioning abilities, and intelligence. They are wary of media which emphasizes physical beauty and strength with little attention paid to those who might not meet such lofty standards.

People with disabilities and disability advocates are also highly critical of a medical system which seems to be prejudiced against them by not providing adequate resources for them to function on their own. They also sense a social pressure to exercise their right to forego any kind of life sustaining treatment so that others who are younger and more productive can have access to scarce medical resources. These issues taken together, along with other important medical considerations that affect people with disabilities, have led to the development of a *disability rights critique* of various issues in medicine.

According to Erik Parens and Adrienne Asch, the disability rights critique of prenatal genetic testing involves three fundamental points: 1) Prenatal genetic testing undermines the notion that the *meaning* of disability is socially constructed; 2) Prenatal genetic testing is usually coupled with a misunderstanding of what a disability might mean for a child and family; 3) Prenatal genetic testing indicates a parent's unwillingness to accept an "imperfect" child.⁹

It is safe to say that prenatal testing does indeed portray a certain negative social mindset toward disability in American culture. What is most problematic about this issue is not the diagnosis itself, but the fact that the diagnosis of a genetic abnormality leads to the termination of the pregnancy. Amy Harmon, for example, reports that about 90 percent of pregnant women who are given a Down syndrome diagnosis choose to have an abortion.¹⁰ This is a staggering statistic. Until this year, only women 35 years of age or older were routinely screened for the extra chromosome 21. Now, with the new recommendation from the American College of Obstetricians and Gynecologists, physicians have begun to offer screening for Down syndrome to women of all ages.

This recommendation not only gives evidence of a negative social mindset, but it also reveals an enormous misunderstanding concerning what a disability might mean for a child and a family. In fact, parents of Down syndrome children, convinced of the lack of understanding, are coming together in order to provide a better appreciation of what it means to raise these special children. Their goal is to be a positive voice in a medical arena which is often overwhelmed by negative medical statistics and physicians who believe it is their duty to describe the difficulties associated with raising a child with a disability.

In some cases, the use of prenatal genetic testing may indicate a parent's unwillingness to have a child with disabilities. But, there are just as many situations where parents who have a history of certain genetic disorders might want to know if their unborn child has acquired any of them. This is so they may be prepared to care for their child. Again, the problem is not with the genetic test per se, but with the possible termination of a pregnancy based on the genetic information. Oftentimes, justification of the termination of a pregnancy is based on the moral status of the unborn child—that he or she is not a person, but only a *potential* person. This is not a view that can be justified biblically. From a biblical viewpoint, there is no such thing as a human non-person.

Besides the preceding three claims, Parens and Asch offer what they call the expressivist argument. The expressivist argument states that prenatal testing sends a message to people with disabilities that their lives are not worth living. As Asch puts it, “a single trait stands in for the whole, the trait obliterates the whole with no need to find out about the rest.”¹¹ It is a reductionist view of the human person, one in which people with disabilities often fall victim. It is important now to give further consideration to the arguments for and against prenatal testing.

Arguments For and Against Prenatal Testing

An analysis of the arguments for and against prenatal testing will begin by examining first those which oppose it followed by those which support it. This in turn will give a clear picture of the complex array of issues involved in these technologies.¹²

Opposed to prenatal testing: Genetics and eugenics have the same goals: the elimination of “lives not worth living.”

Supportive of prenatal testing: This claim is akin to saying that all geneticists are Nazis, and that is an unwarranted characterization of most geneticists. While eugenics is exceedingly difficult to define, there is one blaring difference between 20th century eugenics and prenatal testing today. In the 1930s up until 1945, decisions were a matter of state policy. Today, it is up to the individual to decide.

Oppose: Legally, a woman has a right to choice concerning her pregnancy. This is not the main issue in this present context. The fundamental issue under consideration here is the choice a woman can make concerning what kind of child to be pregnant with. It is unethical to make a choice concerning a pregnancy based solely on the characteristics of the child.

Support: The issues cannot be separated in this way. Suppose a single woman gets pregnant. If she finds out that the unborn child has a disability, she might decide to terminate because she is not in a position to care for a child with a disability. She might have limited resources and limited access to other aid. But, she may be able to care for a “healthy” child who will not require such demanding care.

Oppose: That is a point to consider. There is no question that personal autonomy and free choice are crucial in any medical setting. However, practically speaking, it is questionable whether a woman who finds herself in such a situation is really making a *free* choice. Four reasons for this view can be put forth: 1) Women often are not fully informed. They are rarely given the full picture clinically concerning a particular disability and the implications for quality of life; they also are not properly informed about the possible psychological impact of ending a pregnancy; 2) Physicians tend to be biased against people with disabilities. For the most part, they do not understand disability and, therefore, they see it as something to be avoided rather than embraced. The general consensus among physicians is that screening is a good and responsible thing to do; 3) There is the notion that because a test is available, it is good to have that test done. There is rarely time for a woman to think through the implications of a particular test; 4) Society in general is pressuring women to have as many tests as possible because it is her duty to do so. In light of these four reasons, it seems that choice is very limited.

Support: Granted, society ought to make sure that women are fully informed on the wide range of issues related to prenatal testing and that they have adequate access to care for children born with disabilities. Apart from these issues, a woman both ethically and legally still has the right to terminate a pregnancy based on impairment.

Oppose: There is nothing ethical about such a decision. To terminate a pregnancy based on impairment is to make a judgment that people with disabilities do not have lives worth living.

Support: This is not the only reason that can be given for terminating a pregnancy. There are at least four valid reasons why a woman might choose to avoid the birth of a disabled child: 1) She does not think disabled people should exist; 2) Society should not be burdened with the disabled. These are eugenic reasons which seem *prima facie* unjust; 3) Disability involves suffering, and we should not knowingly bring people into the world to suffer; 4) Parents and siblings of disabled children are burdened with their daily care routine and thus suffer unduly. If we can avoid this situation, we are duty-bound to do so.

Oppose: The first two reasons are just plain oppressive. The last two are not really about the people with disabilities at all; they are much more about the way society views impairment. We need to remove social factors that cause suffering, rather than removing those who suffer with disabilities.

Support: The fact of the matter is that people with certain kinds of disabilities suffer horribly and then die a miserable death. Are we not morally obligated to do all we can to prevent this kind of unjust suffering, even if it means in some cases to not allow the sufferer to be born?

Oppose: We can never eliminate suffering completely. It is a fact of life. We are to do all we can to relieve suffering by having the proper treatments and support in place to help. But, an ethical line is crossed when elimination of suffering means doing away with the sufferer. If we do this, where do we draw the line? A person might “suffer” because he/she is short. Shall we prevent him/her from being born because society has deemed shortness to be problematic?

Support: Ronald Dworkin is opposed to the notion of “fetal interests” and believes that abortion is not immoral. Nevertheless, it should not be taken lightly. It is the ending of a life. Therefore, it should be chosen only when the alternative would be much worse for the parents or the child.

Oppose: If this is taken to the logical conclusion, many of us might not be here right now.

Support: This is an emotional appeal, and, therefore, illogical and irrational.

Oppose: The fact remains that prenatal testing can prevent some disabled people from being born.

Support: There is an assumption that a fetus is a person. Fetuses are not persons, but a collection of cells. Therefore, a disabled *person* is not prevented from being born.

Oppose: There is an assumption in the medical community that the definition of personhood is settled—that personhood has to do with the ability to value one’s existence and to contribute to society. However, there are good reasons to believe that personhood has much more to do with essence than function. The idea that one can be a human being and not a human person is a purely modern invention. It still remains that terminating a pregnancy simply because of disability is a judgment that disabled people ought not to live.

Support: What about the notion of wrongful birth. The time will come when some people with disabilities will find it unethical to have been forced to be born. Those who insist that all life is valuable may find their greatest challenge coming from those with disabilities.

Oppose: It is a dangerous thing to entrust the definition of what is ultimately good to finite beings. We do not owe our existence to ourselves; therefore, we are not at liberty to end our existence. The point of this discussion is that prenatal testing ought to be regulated. Women should be fully informed about a wide range of issues concerning disabilities. The fact of the matter is that people with disabilities have much to offer to society, and they also have a right to life, liberty and the pursuit of happiness.

Support: Granted, women ought to be better informed on these complex issues. Since there are no federal laws regulating the use of prenatal testing, medical institutions must take extra measures to assure this level of information. Under the present circumstances, however, we should rethink whether prenatal testing should be offered to the whole population. It seems that screening is often used on the basis of cost-benefit calculations about avoiding the birth of disabled people. In this way, genetics appears not to be much different than eugenics.

A Theological Critique of the Arguments

In Western medicine, there are very few bioethical principles which take precedence over autonomy. There has to be a very good reason to override someone's decision concerning treatment or non-treatment. A physician has a strong ethical duty to make sure a patient is fully informed about his/her condition and treatment, and he/she is bound not to discuss a person's case with anyone other than the patient. If a person is clearly a threat to his/herself or others, this may provide just cause to override patient autonomy without consent. Otherwise, to override someone's autonomy is to violate his/her very being. Therefore, the concept must not be taken lightly.

This contemporary view of autonomy can in the modern era be traced back to Kant. Immanuel Kant communicated four important ideas concerning autonomy which he understood to be based on human reason alone: 1) Ethics is not a matter of consequences but of duty; 2) A right act has a maxim that is universalizable; 3) A right act always treats other humans as ends-in-themselves, never as mere means; 4) People are only free when they act rationally.

Scripture teaches that human beings are created in God's image and have been endowed by their Creator with the ability to reason and make choices.¹³ This is what sets us apart from other creatures. Now, this is not to say that God's image is based on mere function such that if a person loses the capacity to reason or make choices that he/she is no longer to be considered in his image. Reason and will are properties of the human soul, an aspect of the essence of God's image which is stamped upon the human soul as an image is stamped upon a coin. That stamp makes it what it is and it cannot be lost. God's image imprinted on the soul may not function properly in those with certain cognitive disabilities; nevertheless, human beings who suffer in this way are still persons. If God's image remained intact in the entire human race after the Fall, it certainly cannot be lost in an individual regardless of the severity of the disability.

With the Fall came the knowledge of good and evil (Gen. 3). Thus, in a fallen world, it stands to reason that if a human person can use the will for good, he/she can also use it for evil. With regard to prenatal genetic testing itself, it is not necessarily wrong from a biblical viewpoint to seek out and gain knowledge concerning the genetic makeup of an unborn child. A good reason to seek this information is if there is a possibility of inheriting a particular condition, the parents can be more prepared for the birth of their affected child. In fact, there are many spiritual and moral benefits associated with the pursuit of wisdom and knowledge, especially in this context (Prov. 2 & 3).

However, this information often leads to the termination of a child affected with a disability. *From a theological standpoint, it is never morally justifiable to terminate any pregnancy on the basis of information gleaned from prenatal testing.* There are at least two biblical reasons to justify this position: 1) All human life is sacred in that every human being bears God's image; 2) It is an abuse of God's good gift

of free will. First, as was mentioned earlier, every human being is a human person who bears the image of their Creator. This image is not based on human function, but on essence, and therefore it can never be lost or diminished no matter how disabled a person might be. Hence, to terminate any pregnancy is to discard a human person who is valuable simply because he/she exists.

Augustine argues that all things are good insofar as they exist, especially human persons. Simply to exist is to be good. But what are we to say of an unborn child with disabilities? Is it good if he/she exists? Yes. It is God who made all persons, even those affected with disabilities. He made them just as they are (Ex. 4:11). But, why did he make them like this? The Scripture is clear that the “secret things belong to the Lord our God, but the things revealed belong to us and to our children forever, that we may follow all the words of this law (Dt. 29:29). And what has been revealed is that we are not to relieve suffering by getting rid of the sufferer! This is to do evil. But, what is evil? Where does evil come from? The Bible locates evil impulses in the fallen human will (Gen. 3; 4:6).

In an attempt to elucidate the biblical teachings on the problem of evil and suffering Augustine says that evil in a human being arises not from some evil principle embodied in his/her nature, but from the will’s free determination to turn from higher things to lower, from eternal to temporal; to bind itself to things which, though good in themselves, lack the worth and dignity proper to itself. Thus evil is to be found in a human being’s free choice to pervert and corrupt his/her own will by turning aside from that good which is proper to it; that is, the ultimate good which is God.

Every good is from God. Evil stems from the will’s free choice to depart from its true vocation. This departure constitutes the very nature of corruption and imperfection. Hence evil is to be explained not as the creation of an incompetent God, not as the handiwork of some evil principle, but as a result of the abuse of one of God’s good gifts, free will—an abuse which is to be attributed not to the Giver, but to those to whom it has been given. But what happens when the vast majority of people in a society turn from higher things to lower things, from transcendent to temporal things, and then reject the idea that such a process is actually taking place?

For one thing, such a society forsakes the idea that the will is corrupted, at least in some metaphysical sense. Second, such a society claims absolute freedom. This is certainly the condition of American society, especially with regard to individual autonomy. According to many secular bioethicists, the human will is sovereign. As long as a patient is fully “informed,” his/her wishes should be granted. This is the main criterion for any medical treatment. From a biblical standpoint, however, we understand that we are finite creatures who do not owe our existence to ourselves. We also acknowledge that human beings are born sinful; the mind and the will are not free from the obscurity of sin. By implication, the decision-making process can become clouded by selfish motives.

In light of this, we must ensure that women are given the full picture clinically concerning a particular disability and the implications for quality of life. They must be informed about the possible psychological impact of ending a pregnancy. The Christian community must expose the physician’s bias against people with disabilities. They must be shown that it is an abuse of a good gift (free will) to tell their patients that it is “good and responsible” to have every test done. It is the nature of human beings to have a continuing desire to know, but women are rarely given the time to think through the implications of a particular test. Finally, society in general must be reformed. It must stop pressuring women to have as many tests as possible by implying that it is her duty to do so.

References

- Augustine, *The City of God Against the Pagans*, ed. by R.W. Dyson, (Cambridge: Cambridge University Press, 1998).
- Parens, Erik & Adrienne Asch, eds., *Prenatal Testing and Disability Rights* (Washington, D.C.: Georgetown University Press, 2000).
- Swinton, John & Brian Brock, eds., *Theology, Disability and the New Genetics* (London: T & T Clark, 2007).

Notes

1. Bill Clinton, "White House Remarks on Decoding the Genome," *New York Times*, 27 June 2000, 8(D).
2. Edward McCabe, "A Doctor for the Future," *New York Times Magazine*, 6 November 2005, 70.
3. Amy Harmon, "In DNA Era, New Worries About Prejudice," *New York Times*, 11 November 2007, 1.
4. The American Council of Life Insurance Subcommittee, *Genetic Test Information and Insurance: Confidentiality Concerns and Recommendations* (Washington D.C.: The American Council of Life Insurance, 1990).
5. See, for example, B.A. Trolin, ed., *Mapping Public Policy for Genetic Technologies: A Legislator's Guide* (Denver: National Conference of State Legislatures, 1998).
6. Americans with Disabilities Act, 42 U.S.C., 12101–12213 (1990).
7. See, 2 EEOC Compliance Manual (CCH), 902–45 (March 14, 1995), reprinted in Daily Labor Report (March 16, 1995), E-1, E-23 (citing definition of disability); and M.A. Rothstein, "Genetic Discrimination in Employment and the Americans with Disabilities Act," *Houston Law Review*, 29 (1992): 23–84.
8. *Ibid.*, *New York Times*, 24.
9. Erik Parens and Adrienne Asch, *Prenatal Testing and Disability Rights* (Washington D.C.: Georgetown University Press, 2000).
10. Amy Harmon, "Prenatal Test Puts Down Syndrome in Hard Focus," *New York Times*, 9 May 2007, 1.
11. Parens and Asch, 13.
12. Many of the arguments and the format for this section were drawn from Tom Shakespeare's work entitled, "Arguing about Genetics and Disability," which he contributed to *Theology, Disability and the New Genetics* (London: T & T Clark, 2007).
13. See for instance, freedom as a mental faculty: Ge. 4:6–10; Dt. 5:29; 1 Ki. 20:42; Isa. 1:18–20; 43:26; Jer. 36:3, 7; Jn. 7:17. Our reasoning capacities: Ex. 4:11; 20:5–11, Isa. 5: 3–4; Hos. 4:1; Mic. 6:2. Natural understanding: Da. 4:36; Ac. 17:2; 18:4, 19; 24:25; 1 Co. 10:15; 1 Pet. 3:15.

About the Author

Dr. Kathy McReynolds is the former Director of Academic Studies for Joni and Friends. Kathy has a B.A. in Christian Education from Biola University, a M.A. in Systematic Theology from Talbot School of Theology and a Ph.D. in Ethics from the University of Southern California. She has taught in the Biblical Studies Department at Biola University and served on ethics committees for hospitals and universities. Kathy has received numerous prestigious awards, including the Leading Health Care Professional of the World by the International Biographical Center in 2009.