EVEN HA-EZER 1:5

Choosing Our Children's Genes: The Use of Preimplantation Genetic Diagnosis

This responsum was approved by the CJLS on May 28, 2008 by a vote of ten in favor, two opposed and four abstaining (10-2-4). ***Members voting in favor****: Rabbis Pamela Barmash, Elliot Dorff, Myron Fenster, Reuven Hammer, Adam Kligfeld, Alan Lucas, Aaron Mackler, Daniel Nevins, Jay Stein, and David Wise.* ***Members voting against:*** *Rabbis Jerome Epstein and Avram Reisner.* ***Members abstaining:*** *Rabbis Kassel Abelson, Robert Fine, David Hoffman, and Loel Weiss.*

She'eilah—Is it permissible for Jewish parents to employ an increasingly common technology known as Preimplantation Genetic Diagnosis (PGD), which allows parents to select the genetic make-up of a potential child?
If so, under what circumstances? May parents use PGD to ensure that their child is free from known genetic disease? May parents use PGD to have a child with a genetic make-up less susceptible to cancer or other disease than a child conceived naturally would likely be? May parents use PGD to select the sex of their child? May parents use PGD to select for genes correlated to particular behavioral or personality traits? May parents use PGD to select for certain physical traits? May parents use PGD to ensure that their child will be a suitable stem-cell or bone marrow donor for an older sibling in need of a matching donor for survival? What limitations and restrictions does Jewish tradition place on the use of this technology?

Teshuvah—The desire to have healthy and happy children is the most basic parental instinct. A parent's moral obligation to care for the child extends before the moment of birth back to the point of conception. The Talmud itself offers pregnant women advice on how to improve the well-being of their offspring, such as eating parsley in order to have handsome children, drinking wine in order to bear healthy children, or eating coriander to have especially plump children.[1] We stand on the cusp of a new era today because an explosion of genetic knowledge in recent years has provided us the ability to pursue certain health and wellness advantages even before pregnancy has begun. Technology called Preimplantation Genetic Diagnosis (PGD) allows parents to screen the DNA of embryos fertilized *in vitro* and to implant only those embryos that match the parents' desired genetic make-up. This may include selecting only embryos guaranteed not to have a particular genetic disease, only embryos of one particular gender, or eventually even only embryos with a predisposition for certain traits such as height, eye-color, or enhanced memory.

I am not interested in making an argument about which uses of PGD should be legal or illegal in terms of civil law. While I will argue that a majority of PGD's potential applications

[1] כתובות ס ע"ב-סא ע"א

stand opposed to core Jewish values, I fear that the interference of civil authorities in the health and reproductive decisions of individuals might lead to far greater harms than the misuse of PGD technology ever could. Disagreeing with someone's choice does not constitute sufficient reason to legally prohibit the individual's making that choice. The case against PGD in society should be made by persuasion, not legislation.

The Technology

PGD is only possible when a woman is undergoing *in vitro* fertilization (IVF) treatment. While generally considered safe, IVF carries with it a much greater risk to the mother's health than natural conception, including a significantly increased chance of life-threatening ectopitc pregnancy or adnexal torsion.[2,3,4] Some studies have also suggested an increased risk of ovarian cancer for women who undergo IVF treatment, especially if they do not achieve pregnancy.[5]

As part of IVF, between 5 and 20 ova are harvested from the mother during a laproscopy procedure. Those eggs are then fertilized in a laboratory by sperm collected from the father or donor. The resultant embryos are allowed to grow for about 3 days. Typically, 5-10 embryos survive and are available for implantation into the woman. The eggs that are not fertilized or do not develop into growing embryos disintegrate in the laboratory. In America, 2-4 healthy embryos are usually implanted during one round of IVF and the others are frozen for use in future rounds should the first effort fail. About 30% of IVF cycles lead to pregnancy and about 83% of those pregnancies end in a live birth. The American Society for Reproductive Medicine estimated the average cost of IVF at $12,400 per cycle, over $36,000 per live birth in 2006.[6]

Before 1990, the choice of which embryos to implant in the woman during any given round of IVF was mostly random, determined only by rough measures of which embryos were more robust and thus more likely to implant successfully. In most cases today, the choice still is random. However, during the 1990's, several techniques were developed that allowed scientists

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[2] Heather Clayton, Laura Schieve, Herbet Peterson, *et al.*, "Ectopic Pregnancy Risk With Assisted Reproductive Technology Procedures," *Obstetrics & Gynecology* 107:3 (March, 2006): 595-604.
[3] Evangelos Papanikolaou, Christina Pozzobon, Efstratios Kolibianakis, et. al., "Incidence and Prediction of Ovarian Hyperstimulation Syndrome in Women Undergoing Gonadotropin-releasing Hormone Antagonist in vitro fertilization Cycles," *Fertility and Sterility* 85:1 (January, 2006): 112-20.
[4] H. Gorkemli, Matthieu Camus, Koen Clasen, Adnexal Torsion After Gonadotrophin Ovulation Induction for IVF or ICSI and Its Conservative Treatment. *Archives of Gynecology and Obstetrics* 267:1 (November, 2002): 4-6.
[5] Louise Brinton, Emmet Lamb, Kamran Moghissi, *et al.*, Ovarian Cancer Risk After the Use of Ovulation-Stimulating Drugs. *Obstetrics & Gynecology* 103:6 (June, 2004):1194-1203.
[6] American Society for Reproductive Medicine website: http://www.asrm.org.

to remove one cell from a three-day-old embryo in order to screen its genetic makeup. There is no evidence that the removal of this one cell for screening impedes its development; however, some recent data suggests that cell removal may affect the embryo's chances for successful implantation, at least in older women.[7] The rate of damage to the embryo during the process of removing the cell currently stands at 0.9%.[8] This technology, PGD, allows a couple to decide which fertilized embryos to implant for pregnancy based on the genetic information found.[9] At present, a couple can screen the embryos for a number of single-gene diseases and implant only those free from the diseases tested. A couple can determine the sex of their embryos and elect to implant only those that are either male or female. Soon, testing may be possible to select embryos at a lesser risk for particular cancers, diabetes, or cardio-vascular disease. Selection for non-disease genes may also be possible in the future allowing parents to implant embryos more likely to be taller, have a certain skin tone, a particular hair color, or a greater chance of one sexual orientation than another. PGD can cost an additional $10,000-$18,000 per IVF cycle. It is almost 100% accurate for sex selection and approximately 90% accurate for determining the presence or absence of a particular gene.[10] PGD is not currently the standard of care for typical IVF procedures, but it is used when the parents' genetic history puts the child at increased risk of a genetic disease or to screen out embryos with chromosomal abnormalities in older women when IVF has failed repeatedly in the past.

While some of the halakhic issues overlap, it is important to distinguish PGD from prenatal diagnostic testing (PND) and genetic engineering. PND describes the technologies available to test a live fetus for a range of genetic markers. Because it happens after pregnancy has begun, should disconcerting genetic information come to light, the parents' only options are to proceed with the pregnancy or to abort the fetus. The core ethical question PND raises is: what genetic information warrants such concern that it becomes preferable to terminate the pregnancy than carry the fetus to term? PGD, alternatively, is a test done in the laboratory prior to implanting the embryo into the uterus. The question PGD raises is not "should we abort this

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[7] Sebastiaan Mastenbroek, Moniek Twisk, Jannie van Echten-Arends, et al., "In Vitro Fertilization with Preimplantation Genetic Screening," *New England Journal of Medicine* 357:1 (July 5, 2007):9-17.

[8] Laura Shahine, Aaron Caughey, "Preimplantation Genetic Diagnosis: The Earliest Form of Prenatal Diagnosis," *Gynecologic and Obstetric Investigation* 60:1 (July, 2005): 39-46.

[9] A full scan of the embryo's genome is not possible now and is unlikely to be in the near future. At present, physicians regularly look at 4-6 specific genes per instance. Technology is currently under development that would permit the scanning of 200-300 genes per instance. A regularly updated list of genetic conditions possible to select for or against can be found at http://www.reproductivegenetics.com/single_gene.html

[10] Anver Kuliev, Yury Verlinsky, "Preimplantation Genetic Diagnosis: Technological Advances to Improve Accuracy and Range of Applications," *Reproductive Biomedicine Online* 16:4 (Apr. 2008): 532-538.

fetus that has already begun developing?" but rather "which of these several embryos should we implant in the hopes that it will become a developing fetus?"

PGD differs from genetic engineering because it does not involve the manipulation of any genetic material. When I write that PGD may one day allow parents to "select for height," I mean simply that, of the embryos fertilized in the laboratory, scientists may be able to determine which has a genetic makeup with the greatest likelihood of being taller than the others. PGD cannot help two short people have a child any taller than they would have been able to create naturally. Genetic engineering to repair mutations, fix disease genes, and even insert synthetic genes is in development and carries its own distinct set of halakhic concerns. However, PGD does not involve changing an embryo's DNA; it is simply a process to scan the genetic material of an embryo *in vitro* before it is implanted and allowed to develop into a fetus *in utero*.

Underlying Values

We often assume that technology is value-neutral and, depending on how human beings employ it, that technology may serve either good or evil purposes. However, the technology a society creates reflects the values of that society. The scientists who have made PGD possible devoted their attention to this work because they believed that many people might benefit from, or at least pay for, their results. They did so at the expense of other research, such as finding treatments for the diseases the PGD can select against. The technology we create, in turn, reinforces the values that it reflects, entrenching those values deeper into our society. For this reason, prior to my halakhic analysis, I will explore the different values that underlie PGD technology and assess whether those values are consistent with the core teachings of Jewish tradition.

Beneficence

Parents employing PGD, no doubt, want to provide their children with the best possible chance at a healthy and happy life. The Torah commands "Do not stand idly by the blood of your neighbor," "Love your neighbor as yourself," and "You shall restore the lost property to him."[11] In different contexts, each of these verses has been understood as the biblical basis for a mandate compelling individual Jews to actively work towards the health and well-being of others. Any Jew who has the ability to help someone avoid illness and fails to do so stands in violation of this precept. Parents who do not aggressively ensure the health of their children are

[11] Leviticus 19:16, Leviticus 19:18 and Deuteronomy 22:2.

especially culpable. There is no question that from the moment of birth onward, any medical intervention which might prevent or delay disease is morally obligatory unless that intervention itself could cause harm. A parent who failed to provide basic antibiotics, for example, to a child with cystic fibrosis would rightly be viewed as negligent. At first glance, the principle of beneficence here suggests that a parent should (or, at least, may) use PGD technology to have a child free from genetic disease.

However, the beneficence claim with respect to PGD differs significantly from the incontrovertible moral obligation of a parent to seek medical care to treat a child's illness. With basic medical intervention, the care provider is attempting to improve the health of the recipient. That is, a child with cystic fibrosis is likely to live longer and with less suffering while taking antibiotics than without taking them. Even when using PGD to avoid disease, one is not *improving* the child's health. Rather, one is consigning the embryo with the disease gene to disintegrate in a laboratory and selecting an entirely different embryo for implantation in the mother's uterus with the hope of future life. The embryo with the gene for cystic fibrosis is not made any healthier; it is simply never provided the opportunity to grow into life. PGD does not heal; it helps us decide which potential life will begin and which will not. Arguing strongly that we have an obligation to heal the sick does not necessarily imply that we have an obligation (or even permission) to actively intervene with the intention of preventing sick people from coming into existence.

Reproductive Freedom

A second value related to PGD is reproductive freedom. Secular ethicists who defend the expanded use of PGD consistently affirm the basic right of individuals to have full autonomy in making decisions about if, when, and how to reproduce. This principle acknowledges that individuals are in the best position to make appropriate reproductive choices for themselves and that outside interference from courts and legislatures could cause more overall harm than the problematic reproductive choices that some individuals will make.

In the current political climate, it is impossible to hear a term such as "reproductive freedom" without conjuring the contemporary debate surrounding abortion; such associations unfortunately cause some to conflate the issues raised by PGD with abortion, leading to a distorted view of the key concerns. It is also important to remember that the past century has witnessed some of the most egregious violations of individual reproductive freedom in history including Nazi-era eugenics programs, forced conception through rape as a means of ethnic cleansing by Serbians, and the involuntary sterilization efforts that persisted in America through

the 1970's.[12] These lessons from our recent past remind us that any future effort to abridge reproductive freedom must proceed with extreme caution.

Jewish tradition, however, has always placed some limits on an individual's reproductive freedom. While a couple may have some latitude to control when exactly they have children, the biblical command to "be fruitful and multiply," as traditionally interpreted, demands that Jews must attempt to have children in all but the most rare of circumstances. Once a pregnancy has begun, the threshold to terminate that pregnancy under Jewish law is relatively high.[13] In short, the process of reproduction in Judaism is seen as a three-way partnership between mother, father and God. The individual's own wishes about how and when to reproduce are important but not always paramount. With respect to PGD, this suggests that a parent's desire to have a child of a certain genetic makeup may be restricted if fulfilling that wish interferes with other core Jewish values.

Coping with Uncertainty

The random process by which genes are passed on to the next generation through reproduction is a necessary precondition for human evolution and our ability to adapt to new environments. That genetic lottery, however, also introduces an immense element of uncertainty into the one aspect of life that we most want to control—the fate, happiness, health and well-being of our children. Much of the appeal that genetic innovation holds for lay observers is the hope that we may be able to control that which has always felt uncontrollable—that we may reduce our vulnerability to chance and uncertainty. We fantasize about living in a world that is less chaotic. Acknowledging the true degree to which we are vulnerable to chance and uncertainty is one of greatest challenges that Judaism demands we face.

On the one hand, Jewish tradition has always encouraged us to explore science and technology in order to provide people with every possibility for a full and healthy life. On the other hand, Jewish tradition warns us consistently against fooling ourselves into believing that we have more control over the vast domain of God's creation than we really do. The thrust of dozens of rabbinic narratives and teachings can be summarized in the simple Yiddish saying: *der mensch trakht un Gott lahkht*—man plans and God laughs.

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[12] Philip Reilly, *The Surgical Solution: A History of Involuntary Sterilization in the United States* (Baltimore: Johns Hopkins University Press, 1991).

[13] For a more nuanced discussion of the situations when abortion is permitted in Jewish law, see Elliot Dorff, *Matters of Life and Death* (Philadelphia: The Jewish Publication Society, 1998), pp. 128-133; Avraham Steinberg, *Encyclopedia of Jewish Medical Ethics*, Vol. 1, trans. Fred Rosner (New York: Feldheim Publishers, 1998), pp. 1-29; Daniel Schiff, *Abortion in Judaism* (Cambridge: Cambridge University Press, 2002).

While scientists are constantly finding more and more links between one's genetic makeup and disease, behavioral tendencies and personality traits, scientists are, at a similarly rapid pace, learning more about how a specific genotype does not guarantee a specific phenotype. In lay terms, the presence or absence of any one characteristic is not determined by genetic makeup alone. The muscle cells, the nerve cells and the blood cells in one's body all have the same DNA. The reason these cells are so different from each other is because, in each, different genes are "switched on" or "switched off." This process, sometimes, allows the same gene to express itself in one way for some people and in another way for other people. Environmental stimuli as well as biological factors such as a gene's particular location on a chromosome or the complicated interaction between the proteins created by unrelated genes all play a role in determining how a single gene will express itself in a particular organism. Our understanding of this process at present is extremely limited. We are attracted to the simplicity and certainty of imagining that the presence of a specific gene will generate a particular trait. This fantasy of genetic determinism may lead people to be positively inclined towards the expanded use of PGD. We must be careful to avoid the hubris of fooling ourselves into believing that a few blunt interventions with human hands can realistically lead to genuine improvements in divine creation.

The rabbis of the Talmud imagine a conversation between the biblical king Hezekiah and his court prophet, Isaiah. When this conversation takes place, Hezekiah is still childless. Isaiah rebukes him for refraining from his obligation to "be fruitful and multiply." Hezekiah responds that he has elected not to have children because he has received a divine prophecy that his future sons will turn evil and bring great suffering upon the Jewish people. Isaiah retorts with the simple yet profound question, בהדי כבשי דרחמנא למה לך—Why do you concern yourself with the hidden things of the Merciful One?[14] In its context, Isaiah seems to be suggesting that no matter how certain we are of our knowledge or how accurate we imagine our predictive powers to be, as mortals, we have access to only the most limited understanding of how the universe works. Attempting to "improve" divine creation by substituting our judgment for God's is destined to be a fruitless effort. Isaiah's admonition comes in the context of Hezekiah making predictions based on a phenomenon as authoritative as רוח הקודש—divine prophecy; yet it still is not appropriate behavior. Our ability to predict outcomes from knowledge of a few genetic markers is geometrically less reliable.

PGD may appeal to some because it appears to offer a "quick-fix" solution. Instead of directing our energy towards the difficult task of acknowledging and learning to cope with the

[14] ברכות י ע"א

uncertainty of the cosmos, we can use technology to control that uncertainty. While Jewish tradition has always encouraged the pursuit of science for the betterment of humankind, it has also consistently cautioned us against overestimating our capacity to predict and determine future outcomes. It is a core Jewish insight that one's talents and strengths do not come about solely through his or her own doing but rather they represent the product of a covenantal relationship with the divine. By treating potential life as raw material, available to satisfy our needs and desires, we risk turning the sacred into a commodity. We must remain vigilant not to lose the humility to acknowledge that God's creation is not open to whatever purposes we contrive.

Coping with Difference and Disability

Another motivating force behind the use of PGD may be our fear of those who are different or disabled. What parent would choose a short, pudgy and knotty-haired child when given the option to have a tall child with a nose just the right size? A parent using PGD wants what is best for the child. Often, what seems best is what seems normative. We prefer a child who is not too ugly, not too short, and not too lazy. Our instinctive emotional reaction to disability is even stronger. Imagine, upon the birth of your child, what it might feel like for a doctor to say, "Eight fingers. Eight toes." Even though we know many deaf people have fulfilling and rewarding lives, most hearing parents would likely do anything possible to prevent deafness in their children.

When the genetic lottery provides us with a child who has certain traits outside of the normal range, our tradition demands that we look past the sum total of constituent parts and learn to love the child because he or she is created in God's image. Upon seeing someone who is different, traditional Jews bless God as משנה הבריות—"the one who makes creatures different." The difficult yet rewarding process of learning to accept these differences elicits the awesome power to care for and connect with others. Developing ways to help people who are made vulnerable because of their differences constitutes one of the greatest moral and spiritual achievements a human being can reach in life. Using technology to "enhance" away these differences may reduce our capacity to regard human beings as more than a simple collection of traits and behaviors—as beings created in the divine image.

As Jews, we suffered under a Nazi regime that could not tolerate difference. The Nazi eugenics program represented a coercive effort to eliminate certain undesirable differences and disabilities from society. The moral logic behind that program set the philosophical foundation for the Final Solution. Among all peoples, our recent history should make us especially

sensitive to any technology that might collude with human beings' tendency to fear and hate difference.

Consequences of PGD Technology

Because PGD is so new, we have at present little empirical data to judge its effect either on the children selected or on the broader society. Any discussion of the technology's possible consequences will remain purely speculative. Those inclined in favor of its expanded use will likely emphasize its beneficial effects; those inclined against will, of course, call attention to the possible harms. Neither claim will be possible to verify. However, the more widespread a technology's presence in our society, the more we tend to focus on its benefits and downplay its negative consequences. Were pesticides not yet in use or were our society not developed around the burning of fossil fuels, the harms that we now understand these technologies pose would likely warrant our severely restricting their use. However, since a more full understanding of their dangers has come to light only after we have grown accustomed to them, rational regulation of these technologies is difficult. For this reason, it is essential to imagine what consequences might follow from the use of PGD before it becomes so widespread that we forfeit our ability to reduce the possible harms, all the while acknowledging that such an effort remains entirely speculative.

The Child

Proponents of the technology argue that the child born following PGD has a higher probability of a better quality of life. The Australian ethicist Julian Savulescu even goes so far as to claim that it is "morally required" for parents to use safe technology in order to select against both disease and non-disease genes that would have a significant impact on a child's well-being.[15] Even though the information available to us may be limited and imperfect, it is irrational, Savulescu argues, not to use every means possible to have a child with the greatest chance of the best life.

The extremely limited usefulness of the genetic information we have to tell us about the future life of the child, alone, should be enough to counter this argument. In the process of selecting against a gene loosely related to an undesirable behavioral trait, we might unwittingly implant an embryo with a gene that greatly increases the child's future risk of cancer, cardio-vascular disease or an even more serious condition. However, the more concerning aspect of

[15] Julian Savulescu, "Procreative Beneficence: Why We Should Select the Best Children," *Bioethics* 19:1 (Oct. 2001): 12-28.

Savulescu's argument is that it relies on a speculative quality of life assessment. That is, with limited information, one needs to guess in advance which embryo might produce a child with the best possible quality of life. Jewish tradition strongly warns us to avoid making decisions based on what an outside observer perceives to be the relative quality of another person's life. In the context of comparing the relative worth of different people's lives, the Talmud challenges,

מאי חזית דדמא דידך סומק טפי? דילמא דמא דההוא גברא סומק טפי!

"Do you think that your blood is redder than his? Perhaps his is redder than yours!"[16] This rabbinic teaching reminds us that simple gauges such as age, physical health, apparent happiness, and worldly success tell us nothing about a person's spirit or being. In the end, because we cannot determine which life is of more value than another, the only possible consequence is that we must treat all lives as having equal merit. Applying this principle to the use of PGD, selecting for or against a handful of particular attributes fails to improve the quality of life for the child selected. All one does in selecting is to exhibit the false hubris of imagining that we can predict the value of a life from a smattering of partially understood genetic indicators.

At most, I have so far argued that there is little or no benefit to the child selected from using PGD. It is equally important, however, to question if the child born might actually face harm because of the selection. One possible harm to the child is that by selecting for or against certain genes, parents reduce the level of autonomy that the child can later express. Overbearing parents could make decisions using PGD which would point the child towards a particular future, as a musician or an athlete for example, and thus greatly limit the child's freedom to determine his or her own destiny.

The counter-argument responds that parents make thousands of choices that play a role in determining their children's future. It is likely that the choice to send a child to a school with a reputable music program and a minimal athletics department will influence the child's future far more significantly than selecting for a particular gene with a slightly increased correlation to musical ability. If our goal is to prevent overbearing parents from harmfully imposing their own desires on their children, prohibiting genetic selection through PGD will prove extremely ineffective.

Nevertheless, PGD might signal to the child born that the traits selected are so important to the parents that he or she is worthy of the parents' love only to the degree that those traits are present. The child might come to perceive him-or-herself as a collection of component parts that are the property of the parents. If one of these "parts" does not meet the

[16] פסחים כה ע"ב

parents' wishes, the child might be rejected. We run the risk of the child feeling like a commodity—worthy of love only insofar as he or she manifests the traits that the parents desire.

Of course, this possible undesirable outcome is purely speculative. Some parents may have a strong wish for musical children but love their non-musical child just as much. The parents' process of overcoming the disconnect between their wish prior to conception and the ultimate reality may even strengthen their eventual bond with their child. Effective counseling of parents using PGD may work to limit the potential harms even further. While the reality of harmful psychological consequences to the child is not certain, the mere possibility of such harm obligates us to approach PGD with extreme caution. In the absence of empirical data at present, we cannot say that one outcome is any more likely than another; however, it is my judgment that the magnitude of possible harms to the child born of PGD outweighs the possible benefits in a majority of instances.

Society

So far we have focused our discussion of PGD's possible consequences on the parents who will use the technology and the children born from it. We must also consider how the use of PGD might affect others in society who do not use the technology. One significant fear is that expanded use of PGD will greatly widen the gap between those with the means to access the technology and those without. The random nature of which genes are passed onto the next generation through natural reproduction currently ensures that those with all the social advantages do not necessarily have all the genetic advantages as well. As that randomness is replaced by choice—a choice that only those who can afford the expensive technology have—we should expect an increase in disparity between top and bottom. Genetic disease, shortness, and poor memory could exist only in the domain of the poor. It would become more and more difficult for those who are disadvantaged to overcome their disadvantages. The social stratification already in place could grow increasingly rigid. This consequence is not a necessary one. Governments, for example, could tax the use of PGD technology in such a way that, as more people use it, more money becomes available to provide access to others who cannot afford it on their own. It is possible that, as the technology grows more widespread, it will become cheaper and accessible to more and more people.

Some of the most vocal opposition to PGD comes from those who are disabled and their advocates. Even if it is not conscious or intentional, a parent who elects not to implant an embryo carrying a gene linked to a particular disability exhibits behavior potentially implying that it is preferable not to live at all than to live with that disability. Some people alive with that

disability may find this deeply offensive or personally hurtful. Rabbi Elliot Dorff suggests that the classical distinction between להתחילה and בדעבד provides a useful vocabulary through which to respond that while one may wish to avoid certain disabilities in advance, he or she may still fully respect and love those who are born with such disabilities after the fact.

Some disability rights advocates make the further claim that the use of PGD to select against certain disabilities might lead to greater discrimination against people living with those disabilities.[17] As the technology becomes more widespread, fewer and fewer people will be born with diseases such as Down's Syndrome and sickle cell anemia, for example. The argument continues that this will reduce the level of public awareness and consequently reduce the level of public resources available for research, treatment and the support of people with these diseases. Because PGD technology is accessible only to those with great financial resources, in the next generation, those born with these diseases will disproportionately come from poor and disadvantaged families. This will make effective political organization of people with a particular disease or disability increasingly difficult and undermine already limited social support. Critics respond that this chain of events is not the consequence of PGD *per se* but rather that of a profoundly imbalanced healthcare system. Instead of restricting the use PGD to avoid these problems, one should work to ensure greater justice in the healthcare system.

Another argument arising from sources in the disability rights community is harder to dismiss. We generally view genetic disease and disability as both unpredictable and unavoidable. Ethicist Lynn Gillam notes that as technology that allows us to avoid giving birth to children with certain diseases and disabilities becomes available, the birth of a child with a disability increasingly may be viewed as a matter of choice. A parent who declines to use PGD in order to avoid the birth of a child with a disease may be viewed as acting irresponsibly.[18] This shift in perception may prompt governments to reduce services available to these parents on the rationale that they should not expect society to pay for the consequences of their "reckless" behavior. We may begin to perceive those living with disease or disability as "accidents that should never have happened." Fearing these negative consequences, parents otherwise uninterested in employing PGD may feel social coercion to undergo the medical risk

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[17] See, for example, Nils Holtug, "Altering Humans--The Case For and Against Human Gene Therapy," *Cambridge Quarterly of Healthcare Ethics,* 6:2 (April, 1997): 157-174; Alec Buchanan, "Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion," *Social Philosophy and Policy* 13:2 (Summer, 1996):18-45; Harry Houghton, "Does Prenatal Diagnosis Discriminate Against the Disabled?" in John McKie, ed., *Ethical Issues in Prenatal Diagnosis and Termination of Pregnancy.* (Melbourne: Center for Human Bioethics at Monash University, 1994), pp. 97-102.

[18] Lynn Gillam, "Prenatal Diagnosis and Discrimination Against the Disabled," *Journal of Medical Ethics* 25:2 (April 1999): 163-171.

of the procedure and to take on the great financial burden of PGD—money that could provide much greater benefit to the child if used in other ways.

The exact consequences of PGD on social equality are impossible to determine in advance. As our tradition demands that we strive to use technology in order to improve society, we should proceed with extreme caution when approaching a technology that does not heal but rather prevents certain lives from entering into existence. At the same time, I am reluctant to make the possible harm of increased social stratification central to my argument for an extremely restricted use of PGD. Emphasizing the harm which might follow from unequal access suggests that, were we able to provide universal access, the technology would be acceptable. I believe strongly that the possible deleterious consequences to social equity alone might prove significant enough to warrant strong moral objections to the use of PGD in most situations. Nevertheless, based on the values underlying the technology and its possible effects on the families that employ it, even greater harm may ensue if access to PGD were ever to become widespread.

Specific Applications

Disease Prevention

Currently, PGD can be used by couples known to be at high-risk of producing a child with a serious genetic disease that can cause death or extreme suffering. For example, parents who are genetic carriers for such diseases as cystic fibrosis, Tay-Sachs or sickle-cell anemia may elect to forgo natural childbirth and conceive *in vitro.* They would then implant only embryos known not to have the single-gene mutation through PGD screening. While the attempt to prevent disease is certainly noble, the Jewish basis on which to permit it cannot be a simple claim of improving the child's health. As I noted above, the embryo with the disease gene is not healed using PGD; rather, it is simply denied the chance to later develop into a fetus. The embryo will remain frozen indefinitely or eventually disintegrate in a laboratory. Consequently, it is impossible to argue that the embryo is made better-off through the technology.

Within Jewish law then, the most solid argument in favor of using PGD to select against serious genetic diseases is that PGD, in this case, represents an act benefiting the mother and other family members--not the child. Rabbi Israel Zilberstein asserts that while the technology may not heal the child, the parents' health and overall well-being might be improved through the use of PGD. Without it, they may suffer "mental anguish in fear of giving birth to a sick

child, pressure which can drive a mother mad."[19] One is not then making a quality of life determination that a sick child does not deserve to live; one is simply acknowledging a truth for many people that it is emotionally difficult to carry and raise a child with a severe disease or disability. The possibility of avoiding that suffering and bringing a healthy child into the world instead is consistent with the Jewish principle of favoring the physical health and emotional well-being of those who are currently alive over that of potential life.

For a woman who is able to conceive naturally and who would not otherwise undergo IVF treatment, the risk/benefit calculus must first consider the benefit of avoiding a child with a disease against the additional medical risk to the woman of IVF treatment. The concern here is one of self-endangerment or engaging in potentially self-injurious behavior— להכניס עצמו בספק סכנה. A passage in the Talmud Yerushalmi recounts Reish Lakish's valiant effort to rescue Rabbi Ami from captors.

> רבי איסי איתציד בספסופה אמר רבי יונתן יכרך המת בסדינו אמ' רבי שמעון בן לקיש עד דאנא קטיל ואנא מיתקטיל אנא איזיל ומשיזיב ליה בחיילא אזל ופייסון ויהבוניה ליה
>
> Rabbi [Ami] was being held by murderous robbers. Rabbi Yonatan said, "Let the deceased wrap himself in shrouds" [that is, nothing more can be done for him]. Then Rabbi Shimon ben Lakish said, "Either I will kill them or they will kill me, but I will try to rescue him by force." He went and appeased the robbers and they surrendered [Rabbi Ami] to him.

Reish Lakish's comment has been understood by many to suggest that there are times when it is obligatory for an individual to endanger his own well-being in order to save the life of another.[20] However, in light of some seemingly contradictory passages in the Babylonian Talmud, the scope of this obligation is severely restricted when applied in halakhic rulings.[21] It is understood by Yoseif Caro and subsequent *poskim* to exist only in situations when the risk to oneself is doubtful whereas the risk to the other is definite, for example, when one person will drown without help and the rescuer may save him with little risk of drowning himself. Caro writes, ונראה שהטעם מפני שהלה ודאי והוא ספק–"it seems that the reason [for the requirement to endanger oneself on behalf of another in this case] is because the [risk to the other] is certain and the risk to [the rescuer] is uncertain."[22] Rabbi Ovadiah Yoseif elucidates the implication of Caro's ruling: when the danger to the other person is not definite, there is no obligation for one

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[19]Personal correspondence to Dr. Richard Grazi as cited in Richard Grazi and Joel Wolowelsky, "Preimplantation Sex Selection and Genetic Screening in Contemporary Jewish Law and Ethics," *Journal of Assisted Reproduction and Genetics* 9:4 (August, 1992): 318-322.

[20] See, for example, בית יוסף ח"מ תכו and שו"ת חוות יאיר סי' קסד.

[21] See, for example, שבט מיהודה חלק א סי' ט and יד אליהו סי' מג.

[22] בית יוסף ח"מ תכו; see also כסף משנה, הל' רוצח א:יד.

to endanger his or her own well-being in order to save the other.[23] In fact, basing himself on a statement of Rabbi David ibn Zimra, Yoseif goes on to argue that not only is there no obligation to act but that one proves himself to be a "pious fool"—חסיד שוטה—when he endangers his own well-being or risks his life in situations when the one ostensibly benefiting from the act might not benefit at all due to the uncertainty of the danger.[24]

In his *Sefer Ha-Mitzvot*, Maimonides limits the obligation to save another to situations when יהיה לנו יכולת להצילו—we have to capacity to help him.[25] Commenting on this qualification and attempting to resolve any possible contradiction with the Yerushalmi source cited above, Rabbi Hayim Heller, like Yoseif, understands the obligation to endanger oneself as limited to situations when it is definite that the act will bring benefit. With respect to the example of a drowning man, Heller understands the mitzvah as applying only שברור לו שיטבע בנהר אם לא יחוש לעזרתו—"when it is certain to him that [the other] will drown in the river if he does not come to his aid."[26] Using the same language as ibn Zimra and Yoseif, Heller goes ever further to suggest that one who endangers himself by taking on a major risk when the likelihood of benefit to the other is questionable acts as a "pious fool"—חסיד שוטה. That is, when it is doubtful if one can help or not, yet attempting to help necessitates that one endanger himself, he should refrain. Similarly, Rabbi Yechiel Heller rules

> אם גם בהכניסו עצמו לספק סכנה עדיין הצלת חבירו מסופקת, א"כ ספק וספק הוא שמא לא יועיל מעשיו...[ו]לא עדיפה ספק הצלת חבירו מספק סכנת הבא להצילו

"If one enters into possible danger [by acting] while it is uncertain if the act will save the other, this is a case of 'uncertain' and 'uncertain' for [the rescuer's] act may not succeed…the risk to the one in danger should not take precedence over the risk to the rescuer."[27] The consensus conclusion of all these sources is that *one must be confident that acting will lead to a benefit in order to justify endangering oneself.*

Two variables emerge from the above discussion that must be considered 1) the level of risk to the actor and 2) the certainty of the danger to the other if no action is taken. With respect to the former, the actual level of medical risk that IVF treatment poses will vary from person to person and cannot easily be quantified. Though death is rare, it can occur, most commonly as a result of ectopic pregnancy which may be over 30 times as likely using IVF when compared to

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[23] עובדיה יוסף, תשובה: בהיתר השתלת כליה. דיני ישראל ז:כה-מג, תשל"ו

[24] *ibid*, citing שו"ת הרדב"ז חלק ג סי' תרכה

[25] ספר המצות, לא תעשה רצז.

[26] משה בן מימון, ספר המצות, מאת חיים העליר, מוסד הרב קוק, ירושלים, עמ' 175, ה' 11

[27] עמודי אור צו'

natural conception.[28] As mentioned above, even more likely are a number of major negative health outcomes short of immediate death. In all cases, IVF brings a much greater risk to the mother's health than natural conception. At present, it is reasonable that a particular woman might accept this level of additional medical risk upon herself concluding that it is preferable when compared to the even greater risk to her well-being of bearing a seriously ill child. It is also reasonable that another woman may decide differently. Consequently, Jewish tradition cannot be interpreted to mandate that a woman use PGD technology in order to avoid the conception of a seriously ill child. In fact, every effort must be made to remove coercive pressure on the mother causing her to feel as if she would be "a bad parent" or a "negligent mother" were she to decide against PGD. Such pressure might force her to accept a level of risk to her own health beyond that with which she is comfortable.

The second consideration is the certainty of the danger to the other should one elect not to intervene. This will vary significantly from case to case depending on the specific genetic condition screened. A helpful parallel can be found in live organ donation which is one area where many rabbinic authorities across all movements are comfortable permitting an individual to accept more than minimal risk in order to benefit someone else.[29] Should the patient not receive a transplant, his or her health will remain greatly compromised, eventually resulting in premature death. The permissive rulings state explicitly that were the risk to the patient neither so grave nor so certain, the donor might not be allowed to take on the medical risk of donating an organ. Many autosomal recessive diseases and major chromosomal abnormalities can be considered halakhically analogous to live solid organ donation. In both cases, physicians can predict with high-confidence that disease will result in the absence of intervention. In cases where such diseases are fatal or severely debilitating and untreatable, we can say that the potential life with the undesirable genetic makeup is in definite—ודאי—danger and there is permission for a woman to endanger herself in order to prevent such harm. In cases where the disease may be treatable or if we cannot predict with confidence whether the disease will manifest at all, the danger of not acting to the potential life is uncertain—ספק. As we saw above, there is rabbinic permission to endanger oneself in cases when the harm to the other is certain—ודאי; however, that permission dissipates as the likelihood of the threatened harm becoming an actual harm diminishes. Where we cannot confidently say that a particular genetic

[28] Ectopic pregnancy may occur in 2-11% of all pregnancies following *in vitro* fertilization depending on the medical condition of the mother and the specific techniques used. Heather Clayton, Laura Schieve, Herbet Peterson, et al., *op cit.*

[29] See, for example, Joseph Prouser, "Hesed or Hiyuv?," The Committee on Jewish Law and Standards of the Conservative Movement, YD 336:1995; אגרות משה י"ד חלק ב סי' קעד(ד); ציץ אליעזר חלק ה סי' מה וחלק י סי' כה; יחווה דעת חלק ג סי' פד ; and CCAR Responsum no. 5763.2, "Live Organ Donation."

characteristic will cause definite harm, the halakhic case to permit the self-endangerment of the mother in order to avoid the possibility is weak.

In cases where the additional medical risk of IVF treatment is halakhically permissible in order to avoid bearing a child with a serious disease, another halakhic consideration arises as *in vitro* fertilization necessitates the creation and eventual destruction—even if only passively—of embryos that would not have existed through natural conception. In Jewish tradition, few voices argue that an unimplanted embryo has the legal status of a fetus *in utero*.[30] Even if this analogy held, Rabbi Elliot Dorff argues that the embryo would surely be no more than מיא בעלמא —mere water—the status of a fetus before the fortieth day of gestation.[31] Because the embryo exists outside the womb and implantation is necessary for birth to be possible, the argument follows that the embryos may passively be allowed to disintegrate in certain situations where benefit is likely.[32] Other rabbis argue for a more restrictive position, namely that the laws of השחתת זרע—wasted seed—should apply, making the destruction of embryos permissible only when necessary for reproduction or life-saving purposes.[33] Though I believe that applying the laws of השחתת זרע to unimplanted embryos constitutes an unnecessary expansion of a stringency intended for an altogether different purpose, I do assert strongly we must still appreciate that embryos have the potential to become life and thus deserve some degree of special care and protection from unnecessary destruction. In the words of Rabbi Dorff, "In our own day, when we understand that the fertilized egg cell has all the DNA that will ultimately produce a human being, we must clearly have respect for human embryos and even for human gametes alone (sperm and eggs), for they are the building blocks of human procreation."[34]

For couples able to conceive naturally, employing PGD technology through *in-vitro* fertilization entails the creation of embryos not necessary to produce a child. The embryos produced but found not to have the desired genetic makeup have no chance of ever being implanted. They could, however, be used for scientific research. It might seem at first that this

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[30] Two of the few sources that equate the unimplanted embryo with the fetus *in utero* are Ya'akov Weiner, "The halakhic status of an embryo in-vivo and in-vitro," in *Ye Shall Surely Heal* (Jerusalem: Jerusalem Center for Research – Medicine and Halakhah, 1995), pp. 121-134 and David Novak, *The Sanctity of Human Life* (Washington, DC: Georgetown University Press, 2007), pp. 1-73.

[31] Elliot Dorff, "Stem Cell Research. The Committee on Jewish Law and Standards of the Conservative Movement," YD 336:2002, pg. 10, citing יבמות סט ע"ב.

[32] Substantively similar arguments to that of Rabbi Dorff's are also made by authorities in both the Orthodox and Reform movements. See, for example, מרדכי אליהו, השמדת ביציות ודילול עוברים, תחומין, כרך יא (1991); עמ' 272-273 the statement of the Union of Orthodox Jewish Congregations of America at www.ou.org/publicstatements/2005/n//.html and CCAR Responsum no. 5761.7 entitled, "Human Stem Cell Research."

[33] See, for example, Rabbi Shmuel Wosner as cited in אברהם פריעדלאנדער, ספר חסדי אברהם, החולה בהלכה, ברוקלין (1999) עמ' 312-317

[34] Elliot Dorff , 2002, *op. cit.*

concern about the creation of extra embryos would be absent when couples already intend to use IVF treatment because they are unable to conceive naturally. With every case of IVF, a determination of which particular embryos to implant among the total created is made. Without PGD, that determination is made randomly by hand of the scientist or based on a rough visual assessment of which embryos might be the most likely to implant successfully. Using PGD, that decision is made with the help of extremely limited but potentially relevant genetic information. With the exception of the approximately 1% of embryos damaged in the attempt to remove a cell for genetic screening, no additional embryos need to be destroyed to use PGD if the mother is already undergoing IVF treatment for infertility. PGD's effect on the embryos in this situation is thus minimal, though not wholly insignificant.

However, as PGD technology expands beyond screening for single-gene mutations or gender towards more complex trait selection, the distinction between women already undergoing IVF treatment for infertility and those employing IVF solely for the purpose of PGD diminishes. The probability of finding an embryo with a particularly desirable genetic makeup increases as more embryos are available for screening. Consequently, an increasing number of PGD cases entail the creation of additional embryos beyond the minimum necessary for the successful treatment of infertility. This practice also raises the medical risk to the woman as the ovaries must be stimulated beyond the minimum level necessary for the treatment of infertility. The key halakhic distinctions then between woman able to conceive naturally and women already employing IVF for the treatment of infertility become irrelevant as the procedure in both instances entails increased medical risk and the creation of additional of embryos. Consequently, the halakhic conclusions of this responsum, like those of all the halakhic arguments I have read on the subject to date, apply equally to women already planning to undergo IVF for the treatment of infertility and those using it exclusively in order to select embryos.

Rabbi Moshe Feinstein, who permits standard IVF and the consequent destruction of embryos to treat infertility, states emphatically that no room for leniency exists regarding the destruction of gametes when the parents' motive is simply to prevent the birth of a child with a disease.

ולהולד הא יותר טוב לו שנולד משלא נולד כלל דהא הנולדים באין לעוה"ב...ולכן אף שיש מזה צער גדול להאב ולהאם וטרחא גדולה אין להתיר

"For the child [at risk of disease], it is better to be born [even with the disease] than not to be born at all because those who are born will attain *Olam Ha-ba*—The World to Come. Therefore, even though this may cause great pain and significant burden to the father and the

mother, [the destruction of gametes as part of a process to prevent disease] is not permissible."[35,36] Rabbi Shlomo Zalman Auerbach, on the other hand, permits the destruction of gametes and even embryos as long as the intention remains to produce a healthy child.

הרי בדיקה אין דינה כבטלה הואיל וזה לצורך רפואה כדי שיוכל לקיים פו"ר

"[The destruction of embryos following genetic] screening is not considered wanton destruction since it is for the purpose of healing in order to be able to fulfill the mitzvah of 'be fruitful and multiply.'"[37]

Adding nuance to these broad positions, Rabbi Aaron Mackler notes that many modern halakhic authorities permit aborting a fetus with a severe genetic disease or deformity. If the disease screened for using PGD is so severe that, were the fetus to carry that disease the parents would abort, then certainly "selective non-transfer of an early *in vitro* embryo would be preferable to abortion of a more fully developed fetus *in utero*."[38] Rabbi Shlomo Daichovsky implies a similar argument when he writes, הייתי מעדיף ביצוע בדיקות-אבחנתיות בעובר טרום השרשה מאשר בעובר מושרש--"I would prefer the genetic screening of embryos prior to implantation than after implantation."[39]

The destruction of embryos should never be considered a light matter but nor should it be confused with the taking of life. Prior to implantation, embryos created *in vitro* and stored in a laboratory cannot correctly be said to be on a trajectory towards becoming life. For those of us willing to tolerate the limited destruction of embryos for the sake of the non-specific future benefits that might someday come from embryonic stem-cell research, it follows that we should be at least equally willing to tolerate the creation of extra embryos for the purpose of allowing a specific couple to bear a healthy child when there is a reasonable risk that they might not otherwise. In the final analysis, the creation and likely destruction of embryos as part of PGD is not a sufficient concern to prohibit the technology on halakhic grounds. It should, however, heighten our caution as we consider employing this technology in an increasing number of cases to select for or against a wider range of traits. The benefits of each particular use of PGD need to be weighed against the harm which follows from the active creation of embryos which will

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[35] אגרות משה ע"ה חלק א סי' סב

[36] Feinstein's argument is reiterated and expanded upon by his son-in-law, Rabbi Moshe Tendler, in *The Tendler Lectures, First Sydney Conference of Jewish Bioethics (August 11-19, 1987),* Nosson Shulman, ed., (Sydney: Fellowship of Jewish Doctors of North South Wales, 1987), pp. 7-17.

[37] As cited in נשמת אברהם א"ה א' ה

[38] Aaron Mackler, "In Vitro Fertilization," in Kass Abelson and David Fine, eds., *Responsa: 1991-2000, The Committee on Jewish Law and Standards of the Conservative Movement*, (New York: The Rabbinical Assembly, 2002), pp. 510-525.

[39] שלמה דיכובסקי, ברירה תרם עובר ומעמדו של קדם-עובר, אסיא ע"ז-ע"ח, כרך כ', א-ב, טבת תשס"ו, עמ' 73-75

have no opportunity to develop into life. The emphasis that Jewish tradition places on the sacred value of potential life suggests that many situations may not overcome this threshold.

Following Rabbi Mackler's claim that a significant benefit of PGD is that it helps to avoid the selective abortion of fetuses after pre-natal testing, the standard as to when PGD would be permissible to select against embryos with serious disease markers should be set no higher than the level that we currently permit abortion in Jewish law for fetal indications alone. Our conclusion above that Jewish law is reluctant to permit self-endangering behavior when one cannot say with confidence that there will be a real benefit directs us not to set the standard much lower either. Consequently, PGD should be permitted only to select against chromosomal abnormalities and genetic mutations which cause diseases that a) the fetus will very likely manifest should it be carried to term[40] b) are fatal or associated with a severely debilitating condition[41] and c) have no effective therapies at present. Some examples include Tay-Sachs Disease, Cystic Fibrosis, Fragile X Syndrome and Spinal Muscular Atrophy.

For only a fraction of diseases with genetic links will a particular genetic make-up accurately predict that the disease will manifest. For the vast majority of diseases that humans face, including cancer, diabetes, and cardio-vascular disease, certain genetic make-ups may correlate to a somewhat higher or lower risk of the disease, but they will not reliably predict the presence or absence of disease. Even with information about an embryo's genotype as it pertains to the disease, a physician cannot say with any confidence that one embryo will manifest the disease or that another will not.

For example, researchers have discovered that female embryos carrying mutations in the BRCA1 or 2 genes may hold a 40-60% risk of eventually developing breast cancer whereas embryos without these mutations would have only about a 12% risk.[42] If we are willing to

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[40] I have not attempted to define the initial criterion more precisely than "very likely." This is a conscious effort acknowledging the fact that genetic penetrance—the likelihood that a given gene will result in disease—represents a spectrum. Complete certainty does not exist in practice. Selecting a round number such as 90% or 95% likelihood of disease presentation is *ab initio* arbitrary. My use of terms such as "very likely" and "high likelihood" is intended to include only the relatively few genetic conditions with high penetrance—those in which we expect the gene to express itself regardless of environmental or other factors.

[41] With respect to the second criterion, I encourage readers to adopt a broad reading that includes not only diseases with measurable physical discomfort such as those listed but also conditions that prevent emotional intimacy such as some forms of major mental retardation so profound that the individual would lack the capacity for self-awareness and to recognize significant people in his or her life even when relatively free from physical pain.

[42] Antonis Antoniou, Paul Pharoah, Steven Narod, et al., "Average Risk of Breast and Ovarian Cancer Associated with BRCA1 or BRCA2 Mutations Detected in Case Series Unselected for Family History: A Combine Analysis of 22 Studies," *American Journal of Human Genetics* 72:5 (May, 2003): 1117-1130; Jaya M. Satagopan, Kenneth Offit, William Foulkes, et al., "The Lifetime Risk of Breast Cancer Among Ashkenazi Jewish Carriers of BRCA1 and BRCA2 Mutations," *Cancer, Epidemology, Biomarkers and Prevention* 10:5 (May, 2001): 467-473; Jeffery Struewing, Patricia Hartge, Sholom Wacholder, et al., "The Risk of Cancer Associated

permit the use of PGD to select against embryos with the serious and near-certain diseases I discussed above, a similar logic could be used to argue for selecting against embryos with the BRCA1&2 mutations or similar genetic-markers that put that embryo's future health in greater apparent jeopardy than another embryo without the mutation. Why should we draw the line at Tay-Sachs and not use PGD technology also to prevent giving birth to children with an increased risk of cancer?

The need for a distinction follows from the fact that our ability to predict long-term health outcomes from a few basic genetic markers is so limited as to be almost negligible. PGD technology at present allows us to look at only a few of the almost fifty thousand genes in the human genome. We understand the function of only a small subset of all human genes. Our understanding is further complicated by variable expressivity--environmental factors and other phenomena that impact an organism's phenotype in currently unpredictable ways. We tend to focus our attention on the small number of genetic outcomes we can predict and ignore the vast gaps in our current understanding.

All embryos will have some genetic advantages and some genetic disadvantages. While current technology may allow us to foresee one particular disadvantage—the BRCA 1 mutation, for instance—it cannot provide us with enough information to make any reliable predictions about the relative long-term health outcome of one embryo as compared to another. Both the embryo with the BRCA 1 mutation and the embryo without are equally likely to carry a genetic makeup conducive to major diseases that strike earlier than breast cancer or a genetic makeup conducive to extraordinary longevity. No data exists suggesting that one is more likely to live a longer, healthier or more meaningful life than the other. Further, our knowledge is so limited at present that, in an effort to select for an embryo with a reduced risk of breast cancer, for example, we may unwittingly be selecting an embryo at a greatly increased risk of stroke, Alzheimer's disease, mental illness or all three. An active intervention with such potentially deleterious consequences can only be justified if the condition we seek to avoid is unquestionably worse than the conditions we may play an active role in bringing about.

Drafting a comprehensive list of specific diseases for which PGD would be "in" or "out" according to Jewish law would be imprudent. Any such list will necessarily change as therapies and predictive technologies develop. However, the standard should be set so that the disease screened for and its effects must be so horrible that no matter what possible genetic disadvantages the alternate embryo selected may carry, their impact cannot reasonably be

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with Specific Mutations of BRCA1 and BRCA2 Among Ashkenazi Jews," *New England Journal of Medicine* 336:20 (May, 1997): 1401-1408.

understood as worse than the disease avoided. This brings us, then, to the same criteria I set above—high likelihood of disease presentation, fatality or debilitating condition, and the absence of effective treatment. Using PGD to select embryos with lesser likelihoods of complex major disease such as cancer, cardio-vascular disease and diabetes should not be considered halakhically permissible as a rule. However, individual cases should be discussed with a rabbi who, in addition to providing pastoral support, should also factor preventing extreme mental anguish on the part of the parents into any final decision.

Many religious Jews are initially uncomfortable with this standard and prefer a more intuitive distinction between permitting genetic selection for reasons of health and forbidding selection for non-health related reasons. Such a distinction though would be impossible in practice. Most observers would agree that under such criteria, genes related to cardio-vascular functioning would fall squarely in the category of "health-related" whereas genes for height would be "non-health related." However, disease represents a social product with variable contours whose factors include environmental conditions, economic dynamics and personal behavior in addition to genotype. The advocate to permit selection for reasons of health and to forbid it for non-health reasons will need to explain why he or she is not committed to selection based on behavioral predispositions, sexual orientation, height and a wide range of other factors that may correlate to increased life expectancy and better overall health outcomes to an even greater degree than a particular gene linked a slight increased risk of one particular disease. Further, any effort to distinguish between disease genes and genes that affect other characteristics greatly overestimate our knowledge of genetics at present and falsely assumes that a simple isomorphic relationship exists between one gene and one trait. Each gene codes for one protein, but that protein, in combination with others, may affect a great number of human characteristics, some health related and some not. Scientists are far from understanding this complex web of relationships. New discoveries consistently show that predicting which characteristics will manifest based on genotype is a much more tenuous effort than initially imagined.

Others may incline towards a broader use of PGD technology on the grounds that Jewish tradition has always favored disease prevention over treatment after the fact. Certainly, the initial premise of this argument is correct. As just one example, Maimonides dedicates an entire chapter of the *Mishneh Torah* to issues of health, consistently emphasizing the value of prevention over treatment.[43] However, this argument accepts the fallacy that PGD is a curative intervention and confuses PGD technology with gene therapy. When genetic technology that

[43] משנה תורה, דעות פרק ד'

allows a simple medical intervention *in vitro* to forestall disease later in life becomes available, the argument that prevention is preferable to treatment will likely serve as the basis for a permissive ruling. Unfortunately, such technology does not exist in clinical practice at present. As I have argued above, PGD does not prevent a disease from manifesting in a human being who would have suffered from the disease otherwise. Rather, it allows the embryo with the disease gene to be destroyed and implants instead an embryo with an altogether different genetic makeup. Judaism favors prevention because helping an individual to avoid a disease constitutes a significant benefit to that person's health and well-being. PGD offers no such benefit. No embryo's later life is improved by employing this technology. The technology simply selects one embryo to have a chance to develop into a fetus instead of another.

Treatment of a Sibling

An especially controversial use of PGD technology is to select only embryos that will develop into children who can serve as stem-cell, tissue or solid organ donors for an older sibling with a serious disease. There are several fatal disorders for which the most effective treatment, in some cases the only treatment, is the transplantation of bone marrow or blood cells.[44] The success of the transplant often depends primarily on how well the donor's human leukocyte antigen (HLA) types match that of the recipient. While umbilical cord blood banks and expanded bone marrow registries have greatly increased the possibility of finding a fairly compatible HLA match among unrelated-donors, sibling donation remains the treatment of choice for the foreseeable future.[45] For one of the relevant disorders, Fanconi anemia, studies have shown that 18-33% of stem cell recipients survive long-term following transplantation from an unrelated donor whereas over 75% survive long-term following donation from a sibling.[46]

Current demographic data in Western countries suggest that in about 15% of cases, a child with one of these disorders will already have an HLA-matched sibling who can serve as a

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[44] Anna Benito, Miguel Diaz, Marta Gonzalez-Vicent, *et al*., "Hematopoietic Stem Cell Transplantation Using Umbilical Cord Blood Progenitors: Review of Current Clinical Results," *Bone Marrow Transplantation* 33:7 (April, 2004): 675-690.

[45] Jean-Marie Tiercy, M. Bujan-Lose, Bernard Chapuis, *et al*., "Bone Marrow Transplantation with Unrelated Donors: What is the Probability of Identifying an HLA-A/B/Cw/DRB1/B3/DQB1-matched Donor?," *Bone Marrow Transplantation* 26:4 (August, 2000): 437-441.

[46] John Wagner, Margaret Davies and Arleen Auerbach, "Hematopietic Cell Transplantation in the Treatment of Fanconi Anemia" in E. Donnall Thomas, Karl Blume, Stephen Forman, eds., *Hematopoietic Cell Transplantation*. (Malden, MA: Blackwell Science, 1999), pp. 1483-1506.

donor.[47] For the remaining 85% of cases, parents may consider intentionally conceiving another child in order to create a matching donor. Using natural reproduction, the chances of the ensuing child being HLA identical to the sibling is one in four. The fetus's HLA type can be checked prior to birth. One study followed the conception of 32 children conceived naturally with the express purpose of creating a sibling donor. Two healthy pregnancies in the cohort were terminated when it was determined that the fetus was HLA-mismatched to the sibling.[48] The use of PGD to select and implant only embryos that are matched would eliminate the abortion of fetuses who will not be able to serve as donors while increasing the chances of producing a HLA-matched sibling. Though we have no solid data at present, it is reasonable to assume that this will lead to increased survival rates for many children with serious diseases.

In benefiting the older sibling, however, we must ask if we are exploiting or otherwise harming the child conceived in order to serve as a donor. First we must consider the possible physical risks. For many disorders, the hematopoietic stem cells necessary for transplantation can be harvested from the umbilical cord blood of the PGD-selected, HLA-matched sibling. The cord blood could be discarded otherwise, and collecting these cells poses no risk whatsoever to the child. However, the initial cord blood donation might fail, or the disease may recur after transplant. The next step then is a bone marrow transplant—a far more invasive procedure with some risk to the donor, especially while the donor is a neonate. Several bone marrow transplants may be required, and additional tissue may need to be harvested from the donor. It is possible that the toxicity of the chemotherapy, irradiation or immunosuppressant drugs used to treat the sick child could cause the failure of the kidneys or liver. The HLA-matched donor-sibling would then become the most likely candidate to serve as a solid organ donor. In using PGD for the purpose of creating a savior sibling, we run the risk of turning a child into a tissue and organ factory.

There may also be psychological consequences to the donor child. He or she might feel that the parents' love is conditional on continued consent to donate. The standard imbalances of sibling dynamics might be magnified exponentially once it is clearly understood that the child was not created for his or her "own sake" but rather for the benefit of the sibling. Alternatively, the donor child might find increased self-esteem knowing that he or she is "a hero" who saved someone else's life. Even if the initial reason for conceiving the child is to

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[47] G. Pennings, R. Schots and I. Liebaers, "Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling," *Human Reproduction* 17:3 (March, 2002): 534-538.

[48] Arleen Auerbach, "Umbilical Cord Transplants for Genetic Disease: Diagnostic and Ethical Issues in Fetal Studies," *Blood Cells* 20:2-3 (1994): 303-309.

serve as a stem-cell match, there is no reason to believe that the parents will not love the child. We must be careful not to presume that a parent's initial intention for having a child will determine that parent's attitude towards the child once born. There are, of course, far worse reasons to conceive a child. The extent to which parents in this situation are going in order to save the older sibling may even provide some evidence that they are especially concerned and committed parents overall.

Intuitively, many feel that it might be acceptable to use PGD to produce an HLA-matched sibling if the parents were already planning to have another child, but the thought of creating a child expressly for the purpose of becoming a donor makes the child vulnerable to a degree of exploitation beyond that which we can tolerate. However, turning this standard into practice is virtually impossible because people make reproductive choices for dozens of confluent reasons that are impossible to isolate. People's motives also shift over time. Parents with little interest in another child, for example, might find that their feelings change dramatically the first time they hear the fetal heartbeat or see an ultrasound image of the fetus.

While there is no obligation on the parents to employ PGD technology in order to save an older sibling, sufficient halakhic grounds do not exist to prohibit it either when transplantation from a related-donor constitutes the only effective treatment. Of course, the parents may only select for the desired HLA-match and select against other genetic diseases for which PGD is permissible. The legitimate use of PGD for one purpose does not provide individuals with full permission to employ the technology in an unrestricted manner. In order to limit any possible exploitation of the child born through PGD, no deliberate increase of the medical risk to the child for the benefit of the sibling can be justified. Consequently, the implanting of extra embryos to the mother's uterus, prolonging efforts to achieve vaginal delivery thereby increasing the amount of quality cord blood available for transplant, rapid umbilical cord clamping, the raising of the newborn above the mother's abdomen to increase placental blood volume following delivery, and all similar actions which reduce blood flow to the newborn for the sole purpose of increasing the volume of cord blood would be prohibited.[49] Additionally, an independent physician uninvolved in the treatment of the older sibling would need to serve as an advocate for the donor sibling to ensure that no harvesting procedure puts the child at any significant health risk before the child is able to consent for him-or-herself. Further, parents pursuing this option would need to commit to extensive psychological support

[49] Susan Wolf, Jeffrey Kahn and John Wagner, "Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits," *Journal of Law, Medicine & Ethics* 31:3 (September, 2003): 327-339.

and family therapy in order to ensure that they are able to rear the donor child with love and free from exploitation.

Trait selection

We have so far discussed uses of PGD technology that relate to disease and the treatment of disease. Genes, however, influence far more than our health. As our understanding of the human genome increases, PGD could be used in the future to select for any number of traits including height, shade of skin color, a propensity towards altruistic behavior or sexual orientation. Our extended discussion of the issues thus far should make clear that the use of PGD for trait selection runs counter to several core Jewish values. Even when the parents' intention is solely to benefit their child, the increased risk to the mother's health, the unnecessary destruction of embryos, danger to the child and the possible harms to others in society make trait selection unacceptable for religious Jews.

Nachmanides reminds us that physicians are granted license to perform invasive procedures only when their intention is to heal. He writes,

האי רשות רשות דמצוה הוא דמצוה לרפאות ובכלל פקו"נ הוא

"The permission [for doctors to practice medicine] is permission to perform a mitzvah, the mitzvah to heal, and it is considered in the category of preserving life."[50] Rabbi Moshe Feinstein builds on this argument asserting that a medical act which has no possibility of healing constitutes סותר גזירת המלך–"interfering with a divine decree."[51] As soon as permission is granted for PGD to screen against certain genetic diseases for the benefit of the intended-child's health however, one can argue convincingly that the line between traits affecting health and those that do not is impossible to draw. For example, the advantages that may follow in our society from increased height or from being straight could potentially affect someone's overall health and well-being far more than the presence or absence of one specific genetic disease. This argument cannot be dismissed. The response must be to direct our resources and attention towards creating a more just healthcare system and minimizing the disadvantages that arbitrary traits confer on those who manifest them. Pursuing a more expansive use of PGD will only calcify the injustices present in our current system and draw resources away from projects with a far greater likelihood of producing true benefit.

Sex Selection

[50] תורת האדם, שער המיחוש, ענין הסכנה
[51] אגרות משה א"ח חלק ג' סי' צ

At present, PGD is the most effective, though not the only, screening technology available to implant embryos of only one sex. While selecting for sex is not a health-related criterion and as such has much in common ethically with the uses of PGD for trait selection discussed above, the halakhic issues differ slightly. Jewish tradition interprets פרו ורבו –the commandment to "be fruitful and multiply"—as meaning that a couple must attempt to have at least one boy and one girl. The Talmud and other rabbinic sources provide numerous suggestions for how to influence a child's gender.[52] For this reason, some have suggested that room for leniency may exist in Jewish law to permit sex selection in order to fulfill פרו ורבו.[53] A permissive halakhic ruling might be especially likely when IVF is already in use to treat infertility and thus no increased risk to the mother's health or additional destruction of embryos is necessary for sex selection.[54]

Most rabbis who have written responsa to this point have rejected the above arguments with respect to sex selection solely for the purpose of fulfilling פרו ורבו, arguing that the obligation to bear a child of each gender compels parents only to pursue natural methods of reproduction.[55] Rabbi Shlomo Zalman Auerbach, who inclined towards permitting the use of PGD to select against some diseases in very limited circumstances, forbade the use of any technology that destroys gametes or embryos in order to select for sex even in situations where אשתו מצטערת הרבה מזה שאין להם עוד בנים—"the wife is so distraught by [having many girls and no boys] that the couple will refrain from having future children [unless they select for sex]."[56]

One Israeli couple, however, received halakhic permission on the grounds of שלום בית–family harmony—to select for a girl in order to avoid the shame that they feared would follow from a male son born to them but not recognized as a *cohein* like his father because infertility problems required the couple to use donor sperm.[57] While the parents' intentions were no doubt virtuous given their communal context, this use of the technology extends far beyond the extremely narrow range in which sex selection can be viewed as compatible with the many Jewish values that incline against employing PGD for this purpose. Though this particular case

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[52] For a comprehensive treatment of rabbinic efforts to influence a child's sex, see Fred Rosner, *Biomedical Ethics and Jewish Law* (Hoboken, NJ: Ktav Publishing, 2001), pp. 165-173.

[53] See, for example, Joseph Schenker, "Gender Selection: Cultural and Religious Perspectives," *Journal of Assisted Reproduction and Genetics* 19:9 (September, 2002): 400-410.

[54] See, for example, Richard Grazi and Joel Wolowelsky, "Genetic Screening and Preimplantation Sex Selection in Halakhah," *Le'ela* 36 (Summer, 1993); and Joshua Flug, "A boy or a girl? The ethics of Preconception Sex Selection," *Journal of Halakhah and Contemporary Society* 48 (Fall 2004): 5-27.

[55] See, for example, the responsa of Yigal Shafran and Yitzhak Zilberman as summarized in Richard Grazi and Joel Wolowelsky (1993). One counterargument permitting sex-selection in some very limited and extreme circumstances can be found in אברהם שטינברג, בחירת מן העובר, אסיא ע"ז-ע"ח, כרך כ', א-ב, טבת תשס"ו, עמ' 76-89.

[56] As cited in נשמת אברהם א"ה א' ה.

[57] ת. תרובמן וה. שדמי, תקדים בישראל: בחירה מראש של מן התינוק, הארץ, אוקטובר 18, 2002

involved selecting a female child, given the significant gender imbalances in classical Jewish tradition, it is not unrealistic to imagine that the expanded use of sex-selection technology among traditional Jews would strongly favor selecting male children. If widespread, this would then introduce a number of concerns about possible social instability and the potential for the increased exploitation of women in a society where gender ratios are skewed.

Some diseases, though, are sex-linked. That is, the genes causing the disorder appear exclusively on the X-chromosome and, therefore, express themselves only in male offspring. For example, many kinds of hemophilia, Duchenne muscular dystrophy, Lesch-Nyhan syndrome, and some forms of severe mental retardation are absent in females. A couple known to be at a high genetic risk for a disease of this category would find the same halakhic permission to use PGD for sex selection as another couple at risk of a non-sex related disorder. Because PGD is currently a more effective technique to guarantee desired results than other sex-selection technologies, it would be permissible to use it in order to avoid bearing a child with a debilitating disease that meets the criteria outlined above under "Disease Prevention." Another technique to select for sex sorts the sperm prior to fertilization, allowing only sperm with the chromosome makeup for the desired gender to fertilize the ovum. As soon as this technique reaches accuracy rates comparable to PGD, it should be preferred by couples concerned with Jewish tradition because it avoids the need to create and destroy or freeze extra embryos—those of the undesired gender.

Disability

While we have discussed using PGD to prevent disease, another potential use of PGD is to select *for* a child with what most people view as a disability or impairment. Most such examples in the literature cite cases of deaf parents who wish to have a deaf child or people with achondroplasia—a growth disorder whereby adults reach an average height of about four feet—who wish to have a child who will grow at a proportional rate relative to the height of his or her parents. The intention in these situations is certainly not to harm the child. The parents wish to help the child integrate into the culture of the parents or, in the case of a growth disorder, to have the experience of physically looking up to his or her parents during formative years. These uses of PGD technology follow from a radical rethinking of how disability should be understood in our culture—one that may ultimately reduce discrimination and help those with impairments live even more rewarding lives. From the perspective of the parents pursing this use of PGD then, the presence of these genetic conditions constitutes a benefit to their child—not a harm. Whether or not outside observers share this assessment is irrelevant. Just as I have

argued above that it is ethically problematic to use PGD in an effort to produce children with other kinds of genetic benefits such as height or memory, according to the parents' own logic, it would similarly be inappropriate to use PGD to produce children with the "benefit" of deafness or achondroplasia.

Final Thoughts

When considering the expanded use of PGD technology, we must be wary that we do not fool ourselves into imagining that human beings have a great capacity to avoid harm than we really do. I return to the question Isaiah asks in the Talmud, בהדי כבשי דרחמנא למה לך—Why do you concern yourself with the hidden things of the Merciful One? By failing to acknowledge our narrow perspective on the cosmos, we risk misdirecting our attention towards false efforts to control that which is uncontrollable. Instead of using our knowledge and experience to face our own vulnerability as mortals, many uses of PGD technology may enable a vain effort to deny that vulnerability. In most cases, our limited resources are much better spent learning how to treat disease and supporting those who are disadvantaged in our society. While preimplantation genetic diagnosis may provide benefits to some individuals, the potential harms to society and to the children born from PGD that could follow from its expanded use demand severe halakhic restrictions on the technology.

P'sak Halakhah

-A couple at an increased genetic risk of bearing a child with a genetic or chromosomal disorder may employ PGD when all the following criteria are met:
a) the child will very likely manifest the disease should it be carried to term
b) the disease is fatal or associated with a severely debilitating condition
c) the disease has no effective therapies at present.

-PGD may also be used in certain circumstances to produce a child who will make a suitable stem-cell or bone marrow donor for an older sibling with a fatal disease as long as a rigorous set of safeguards is followed in an effort to avoid the deliberate increase of medical risk to the child for the benefit of the sibling. Such safeguards include prohibiting the implanting of extra embryos to the mother's uterus, prolonging efforts to achieve vaginal delivery thereby increasing the amount of quality cord blood available for transplant, rapid umbilical cord clamping, the raising of the newborn above the mother's abdomen to increase placental blood volume following delivery, and all similar actions which reduce blood flow to the newborn for the sole purpose of increasing the volume of cord blood. Further, an independent physician uninvolved in the treatment of the older sibling must serve as an advocate for the donor sibling and parents pursuing this option must commit to extensive psychological support and family therapy.

-PGD with the intention of bearing a child with a lowered disease risk (e. g., a child without BRCA1&2 mutations) does not, as a rule, fall within the bounds of the permission granted by

this teshuvah. However, in extreme circumstances when the mental anguish of the parents is overwhelming and cannot be relieved through non-directive genetic counseling, individual rabbis may factor in the benefit of preventing the parents' mental anguish when making individual decisions.

-PGD for other purposes such as to select the sex of a child or to choose other traits is not permitted.