

Assisted Reproduction in the Conception of Babies with Disabilities

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Section Headings

- A. Improving Our Children
- B. An Unexpected Turn
- C. Do We Really Want the Best for Our Children?
- D. The New Reproductive Technologies
- E. In Vitro Fertilization to Avoid Disease
- F. What Is a Disability?
- G. Choosing Not to Choose
- H. Is There a Prohibition of Choosing a Disabled Child Once IVF Is Being Performed?
- I. Where Is the Line?
- J. Halachic and Hashkafic Justifications for Avoiding Disabilities
- K. Choosing Infertility over Possible Disability
- L. A Last Dilemma: Infertility versus Disability
- M. The Conundrum of Non-Existence
- N. Limitations on the Ability to Choose

A. Improving Our Children

The first modern step toward influencing the creation of children with desirable traits was the field of eugenics, which proposed that the human species could be improved if those individuals with “desirable” traits were encouraged (or permitted to the exclusion of others with less desirable traits) to reproduce. In the first third of the 20th century, eugenics programs were robustly pursued throughout the world, including the United States.¹ After the Second World War, most of the world lost interest in eugenics, but eugenics groups still exist to this day. Nevertheless, eugenics has always been a rather hit-or-miss prospect, unable to accurately predict or control the outcome of childbearing.

¹ For a discussion of the checkered history of eugenics, see Richard A. Soloway, “The ‘Perfect Contraceptive’: Eugenics and Birth Control Research in Britain and America in the Interwar Years,” *Journal of Contemporary History* 30 (1995): 637–664. See also the classic work by Mark A. Haller, *Eugenics: Hereditarian Attitudes in American Thought* (New Brunswick, NJ: Rutgers University Press, 1965).

With the advent of in vitro fertilization (IVF) and preimplantation genetic diagnosis (PGD), the ability to choose the genetic characteristics of a baby became a reality. Not even the genetic qualities of the parents were a barrier to choosing “good” genes for a child, exemplified by the development of “genius” sperm banks such as the *Repository for Germinal Choice*, colloquially known as the Nobel Prize sperm bank. Further advances in genetics currently in development may allow parents to genetically engineer their children and select any genetic traits that they wish from a genetic menu.

The idea of designer babies has raised a myriad of ethical questions. While most people probably accept the use of genetic engineering to correct genetic defects that cause incapacitating or deadly diseases, many people draw the line at choosing more peripheral characteristics, such as eye or hair color. Nevertheless, while it is likely that the more obvious cases will garner a consensus (such as favoring repairing the gene for Tay-Sachs and eschewing manipulating genes for minor cosmetic issues), there are traits which will remain contentious. Where will the ability to select for athletic ability or intelligence fit into an equation that balances valid medical advances with frivolous manipulation of our genomes? Even before society has come to terms with the basic question of which traits are legitimate to actively pursue, a new and unexpected issue has arisen.

B. An Unexpected Turn

Until recently, discussions about what parents desire for their children, whether in the area of education or genetics, assumed that parents wanted the “best” for their children. For instance, it has long been axiomatic that parents pray that their children will be healthy. Secondly, parents hope for desirable physical and personality traits and go to great lengths to obtain both. But what if objective observers would find the trait considered “desirable” by the parents to be clearly undesirable to the child – particularly, what if parents did not want “healthy” children?

In late 2006, the on-line edition of the medical journal *Fertility and Sterility* published the results of a survey of United States fertility clinics. As part of the study’s inquiry into the practice of pre-implantation genetic diagnosis, labs were asked whether they had provided help to families seeking to select an embryo for the presence of a disability:

Genetic tests for more than 1,000 conditions are now available – including deadly childhood illnesses, milder conditions such as hereditary deafness, and risk of adult-onset cancers. Virtually any genetic test could be used in PGD and there is no consensus on what diseases or conditions warrant the use of PGD. . . . Some prospective parents have sought PGD to select an embryo *for* the presence of a particular disease

or disability, such as deafness, in order that the child would share that characteristic with the parents. Three percent of IVF-PGD clinics report having provided PGD to couples who seek to use PGD in this manner.²

The publication of the survey caused a small media sensation, as demonstrated by an Associated Press article describing the journal findings:

The power to create “perfect” designer babies looms over the world of prenatal testing. But what if doctors started doing the opposite? Creating made-to-order babies with genetic defects would seem to be an ethical minefield, but to some parents with disabilities – say, deafness or dwarfism – it just means making babies like them. And a recent survey of U.S. clinics that offer embryo screening suggests it’s already happening. Three percent, or four clinics surveyed, said they have provided the costly, complicated procedure to help families create children with a disability. . . . But the survey also has led to a debate about the definition of “normal” and inspires a glimpse into deaf and dwarf cultures where many people do not consider themselves disabled.³

Despite the shocked reaction of many observers, there was not universal condemnation of this practice. As media accounts reported, some people with inherited disabilities, particularly dwarves, have publicly questioned why they should not be permitted purposefully to create offspring like themselves. They question the criteria used to decide what is “best” for a child and argued that other considerations, such as the child fitting into the family and increased parental convenience in raising the child, should also play a role.

In a recent essay in the *Hastings Center Report* entitled “The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making,” the authors discuss the difficulty of distinguishing the needs of a disabled child from the convenience of their parents. The essay deals with the case of a nine year old girl with static encephalopathy, whose parents subjected her to “growth-attenuated” treatment when she was six years

2 Susannah Baruch, David Kaufman, and Kathy L. Hudson, “Genetic Testing of Embryos: Practices and Perspectives of U.S. IVF Clinics,” *Fertility and Sterility*, forthcoming, corrected proof available online 19 September 2006

(<http://www.sciencedirect.com/science/article/B6T6K-4KXNW0J-1/2/784fb872b1cac374e7e726a773aaadb7>).

3 The AP story by Lindsey Tanner, originally posted on December 21, 2006, was utilized by multiple news outlets, including MSNBC (<http://www.msnbc.msn.com/id/16299656>, “‘Designer’ Babies With Made-To-Order Defects?”); CNN

(<http://www.cnn.com/2007/HEALTH/parenting/01/18/designerd.disability.ap/index.html>. “Idea Of ‘Designer’ Babies With Defective Genes Stirs Ethics Questions.”), and *USA TODAY* (http://www.usatoday.com/tech/science/genetics/2006-12-21-designer-disability_x.htm. “Some Ponder ‘Designer’ Babies With Mom Or Dad’s Defective Genes.”).

old.⁴ In an act later widely condemned by advocates for the disabled as demonstrating fundamental disregard for the dignity of a helpless child, Seattle Children's Hospital, with the consent of its ethics committee,

devised what [it] called the "Ashley Treatment," which included high-dose estrogen therapy to stunt Ashley's growth, the removal of her uterus via hysterectomy to prevent menstrual discomfort, and the removal of her breast buds to limit the growth of her breasts. . . .

According to her parents, keeping Ashley small – at around 75 pounds and four feet, five inches tall – means that Ashley can be moved considerably more often, held in their arms, be taken "on trips more frequently," "have more exposure to activities and social gatherings," and "continue to fit in and be bathed in a standard-size bathtub." All this serves Ashley's health and well being, so the parents argue, "the increase in Ashley's movement results in better circulation, GI functioning (including digestion, passing gas), stretching, and motion of her joints," which means that Ashley will be less prone to infections.

Undoubtedly, the parents are right that Ashley will benefit in the manner they have proposed if they can do all these things for her. The claim about the value of small size in a particular social circumstance is certainly not unique. Dwarves have given the same argument as a justification for preferring to have short children. They have argued that parenting dwarves is desirable for them because of their own size and because they have made modifications to their homes and their surroundings to take into account their short stature.⁵

While acknowledging the possible benefits that might accrue to Ashley, the authors point out that the parents may well have had other motives besides the exclusive benefit of their daughter, not least of which would be their own convenience. However, equating the cases of Ashley's parents with dwarf couples who desire to raise dwarf children obscures an important distinction. Regardless of how one balances the issues, there is an inherent and very important distinction between the case of Ashley and the deliberate creation of a child with a disability similar to its parents. Namely, Ashley will always be dependent on her parents, while a normal stature child born to dwarves is only dependent for the early portion of its life. While Ashley's parents arguably are not depriving their daughter of any future opportunities, the parents who choose to create a child who is deaf or a dwarf most certainly are.

4 S. Matthew Liao, Julian Savulescu, and Mark Sheehan, "The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making," *Hastings Center Report*, March–April 2007, pp. 16–17. As explained by the authors, static encephalopathy is a "severe brain impairment that leaves her unable to walk, talk, eat, sit up, or roll over. According to her doctors, Ashley has reached, and will remain at, the developmental level of a three-month-old." After pressure from a disabilities rights group, Seattle Children's Hospital administrators admitted that they had violated state law by failing to consult a judge before removing Ashley's uterus.

5 Ibid.

C. Do We Really Want the Best for Our Children?

But is it a given that parents must always do what is best for their children? We do not expect parents *always* to take the course that maximizes opportunities and benefits for their children. Most parents who undergo assisted reproduction for infertility purposes are content with a “normal” child and do not attempt to improve upon the randomly produced outcome, perhaps seeking only to steer clear of avoidable diseases. The challenging question is when does a given genetic or congenital trait cross the line from being a “normal variant” to being “abnormal?” Is “normal” in the eye of the beholder, or is there an objective standard that can be applied to questions of assisted reproduction to evaluate such situations? Additionally, there may be differences between choosing to create a disabled child, passively allowing the creation of such a child, and choosing not to influence what type of child is born. The most difficult question arises when the choice is between using assisted reproduction (when halachically permitted) to create a disabled child and remaining childless.

A key component in formulating an authentic Jewish approach to these questions must take into account parental motivations. Despite halachic support for procreation utilizing assisted reproduction, it is apparent from the Torah and everyday experience that it is often the emotional desire for children that primarily motivates married couples to utilize reproductive technologies, not only the mitzva of procreation.⁶ As we shall see, were a couple unable to have children by any unassisted method, most *poskim* allow (but do not require) IVF and consider the offspring to have a status similar to a child conceived via normal means.⁷ The fact many *poskim* permit assisted reproduction when not required demonstrates that there is a compassionate halachic approach to infertility which recognizes parenthood as the fulfillment of a legitimate strong emotional need. If this is so, were there to be no means of preventing the creation of a child with a significant disability, there might be no compelling reason to forbid implantation of pre-embryos with genetic abnormalities that will lead to even significant potential disability, if the pregnancy is expected to lead to a viable child.

On the other hand, one might still question whether it is appropriate to create a child who will suffer if halacha does not require the procedure

6 The account of Rachel’s infertility in Genesis 30:1 describes the jealousy and lack of fulfillment experienced by Rachel due to her lack of children. She demands of Jacob: “Give me children! If not, let me die!” (A. Kaplan, *Living Torah*, Brooklyn, NY: Maznaim Publishing Corp., 1981), or alternatively, “Give me children, for if not, I am dead!”

7 Responsa Yabia Omer 8, Even HaEzer 21; Rabbi Avigdor Nebenzahl, “Notes on the Examination of the Pre-embryo,” “הפרייה במבחנה-הערות” *Assia* vol. 5 (Jerusalem, Israel, Schlesinger Institute, 1986), pp. 92–93.

that will cause the conception in the first place. Those *poskim* who permit IVF with PGD for the prevention of severe genetic abnormalities are merely allowing a couple who is not infertile to avoid conceiving naturally in order to fulfill the mitzva of procreation without the risk of a severe genetic defect.⁸ Were the couple to be unable to have a child naturally, it is possible that the *poskim* would rule that *shev v'al taaseh adif*, that “it is better not to act (and create a disabled child)” than to do the non-required procedure of performing IVF and PGD and thereby creating a disabled child. We will evaluate the halachic factors involved in assisted reproduction and the Jewish approach to disability to aid in determining which approach is correct.

To begin, we must recognize that most parents are satisfied with having average offspring. Presumably, they are content with children of average intelligence, athletic ability and eyesight because they themselves tend to be near the center of the bell curve. Simply put, “normal” parents just want “normal” children like themselves. Presumably, the current consensus against designing babies to be “artificially” smarter, faster, and having better eyesight is because these are not traits that we possess, and we therefore do not place sufficient value on them to outweigh our fear of eugenics.

But if society does not place the genetic perfection of its children as the highest ideal, why should it object to those people who want to choose offspring that share their own limitations or disabilities? As one woman with dwarfism commented in a public interview, “You cannot tell me that I cannot have a child who’s going to look like me. . . . It’s just unbelievably presumptuous and they’re playing G-d.”⁹

D. The New Reproductive Technologies

In reality, the ideal in Judaism *is* for us to “play G-d.” We are instructed to emulate Hashem in all of our activities, including the ability to make distinctions.¹⁰ In the *havdala* service performed at the end of the Sabbath and festivals, we praise Hashem for distinguishing: between Holy and mundane, between light and dark, between the Jews and the other nations, and between the Sabbath and the weekdays. The Torah itself (Deuteronomy 30:15–19) clearly commands us to distinguish between good and evil and to choose the good. It is the ability to make distinctions

8 Rabbi Yitzchak Zilberstein, “The Evaluation of the Pre-embryo Before Implantation for Prevention of Defective Embryos and Gender Determination,” *ברירת עוברים להשתלה למניעת ולדות* פגומים ולקביעת מין היילוד – שו"ת" 51–52, Iyar 5752 (1992), pp. 54–58.

9 AP story discussed in note 3.

10 *Sota* 14a interprets the biblical command “You should walk after Hashem, your G-d” (Deuteronomy 13:5) as an edict to emulate the actions of Hashem, including: clothing the naked, visiting the sick, comforting the mourner, burying the dead, etc.

between difficult cases that makes us humans in the image of Hashem. Judaism not only finds it reasonable to make fine distinctions, it demands that we utilize that ability to untangle complex ethical questions.

Just such nuanced distinctions are necessary for correct evaluation of the multiple scenarios that the new reproductive technologies present. While Judaism enthusiastically embraces any technology that helps to further the mandate of healing the sick, all medical interventions must take into account Jewish values and be performed within the confines of halachic constraints. As Dr. Richard Grazi, director of the Division of Reproductive Endocrinology and Infertility Healing at Maimonides Medical Center and noted expert on the Jewish approach to infertility, writes, “Most people can quote the biblical injunction to “be fruitful and multiply” (Genesis 1:28). However, it is important to understand that this is not a command to be actualized at all cost.”¹¹ Sometimes we must demur when the ethical costs of assisted reproduction outweigh the benefits. Additionally, there are societal concerns to be taken into account. As Rabbi Prof. Avraham Steinberg, author of the *Encyclopedia of Jewish Medical Ethics* asserts, “Obviously society should not be involved in intimate and private decisions of couples, but when they come to the society for help and for [assistance with] expenses it seems to me legitimate for society to make limiting decisions.”¹²

Despite differing rulings as to the practical permissibility of IVF, there is no intrinsic halachic objection to in vitro fertilization or genetic engineering procedures for treatment of infertility.¹³ Judaism has no

11 Richard V. Grazi, M.D., *Overcoming Infertility: A Guide for Jewish Couples* (New Milford, CT: Toby Press, 2005), p. 412.

12 Rabbi Prof. Steinberg refers to the reality that in many countries, the state has taken an interest in helping to defray the costs of reproductive technologies for infertile couples. In some parts of the United States, health insurance companies are mandated by law to include infertility treatment among covered benefits. Personal communication with Rabbi Professor Avraham Steinberg, February 7, 2007.

13 Those *poskim* forbidding IVF fall into two main categories: Some authorities object to IVF due to considerations unrelated to the actual procedure itself. Others, such as Rabbi Eliezer Yehuda Waldenberg (*Responsa Tzitz Eliezer* 15:45; “הפרייה במבחנה דיון רפואי והלכתי” *Assia*, vol. 5, (Jerusalem, Israel, Schlesinger Institute, 1986, pp. 84–92) and Rabbi Moshe Sternbach (*BiShevilei HaRefua* 8:29–36), object to IVF due to concerns involving emission of seed in vain, the fact that it is usually not performed for male infertility, their opinion that paternity is not established through IVF, and the fear of the introduction of sperm or eggs from someone other than the married couple. However, these objections do not concern IVF conceptually but represent barriers that would prevent one from reaching the point where these *poskim* would permit IVF. Authorities such as Rabbi Ovadia Yosef (*Responsa Yabia Omer* 8, Even HaEzer 21), Rabbi Avigdor Nebenzahl (“Notes on the Examination of the Pre-embryo,” “הפרייה במבחנה-הערוות” *Assia* vol. 5, 1986, pp. 92–93), and Rabbi Yosef Sholom Elyashiv (cited in Prof. Avraham S. Avraham, *Nishmat Avraham* (second expanded edition), vol. 3, *Even HaEzer*, p. 27) all permit IVF from husband to wife if done under appropriate supervision, but only if there is no other alternative. Rabbi Prof. Avraham Steinberg points out that in

philosophical objection to the use of technology for constructive purposes. As a rule, Judaism does not invoke objections such as tampering with nature in areas of scientific endeavor unless the *application* of the technology has ethical shortcomings. For those who would argue that only G-d should decide who will have children, the Jewish answer is that G-d certainly does decide who will conceive, but what is the basis for asserting that allowing man to perfect in vitro fertilization is not one of the ways that He utilizes to provide couples with a family?¹⁴

Nevertheless, the *poskim* have enunciated the rule that all technology, including assisted reproduction, must be used within certain ethical parameters. IVF is almost never appropriate except for a married couple, using only the couple's egg and sperm.¹⁵ With respect to choosing the characteristics of offspring, the same issues apply. The use of reproductive technologies is permitted so long as they do not contravene any other mitzvot.

For example, Rabbi Shlomo Zalman Auerbach rules that artificial insemination is permitted even if a couple already has fulfilled the mitzva of procreation with a boy and girl. However, Rabbi Auerbach explains that they may not choose the sex of the baby by separating out the sperm containing the X or Y chromosome since they will be actively destroying the unused remainder. This is true even if by making such a selection, an additional mitzva will be observed, such as a childless couple choosing a boy so that there might be a *pidyon haben* (redemption of the firstborn son). On the other hand, if the mother is a carrier of an X-linked disease, Rabbi Auerbach permits artificial insemination with female sex selection if the couple so desires.¹⁶ The issue of discretionary gender selection once IVF is being performed for a valid indication is a more complex question.¹⁷

Responsa Tzitz Eliezer 3:27, Rabbi Waldenberg considers the act of artificial insemination to be “an abomination and an ugly act which leads to undermining the family structure.” *Encyclopedia of Jewish Medical Ethics* (Jerusalem, Israel: Feldheim, 2003), s.v. “Artificial Insemination,” p. 64.

14 See “Judaism and Modern Technology,”

http://www.aish.com/societyWork/sciencenature/Judaism_and_Modern_Technology.asp.

Editor's note: See also Prof. Nachum Rakover, "שיבוט גנטי – תחרות במעשה ה'?" elsewhere in this book.

15 Grazi, *Overcoming Infertility*, pp. 415–421.

16 Prof. Avraham S. Avraham, *Nishmat Avraham* (English) (Brooklyn, NY: Mesorah Publications, 2004), vol. 3, pp. 4–5.

17 J. Flug, “A Boy or a Girl? The Ethics of Preconception Gender Selection,” *Journal of Halacha and Contemporary Society* 48 (2004), p. 527.

E. In Vitro Fertilization to Avoid Disease

Conventionally, preimplantation genetic diagnosis involves taking a cell from the 8 cell stage of an in vitro fertilized pre-embryo and testing it for specific genetic defects. Only pre-embryos free of genetic disease are implanted in the uterus of the woman. Prof. Avraham Avraham, author of *Nishmat Avraham*, has reported that in principle, both Rabbi Yosef Sholom Elyashiv and Rabbi Yehoshua Neuwirth have granted permission for PGD to be performed for couples where both partners are carriers of a defective recessive genetic trait or have a child that has such a genetic abnormality.¹⁸

In particular, according to Rabbi Prof. Avraham Steinberg, Rabbi Elyashiv has permitted PGD and destruction of affected zygotes to prevent cases of Fragile-X and even in a case of a woman with neurofibromatosis who only had skin lesions.¹⁹ Rabbi Dovid Feinstein has taken a similar view as to the permissibility of discarding “extra” pre-embryos.²⁰ We see that preimplantation genetic diagnosis is accepted by rabbinic authorities when used to prevent serious diseases in offspring.

It is important to understand that in vitro fertilization and preimplantation genetic diagnosis are permitted to further the goals of procreation for those who are infertile and desire children or to prevent disease in children. No such permission exists merely to allow the parents to choose particular traits for their child. This is because artificial insemination and in vitro fertilization involve potential Torah prohibitions that are only waived for the sake of allowing infertile couples to conceive or to avoid serious illness in the children.²¹

The capability of a couple to have unaffected children naturally (and therefore the absence of a halachically sanctioned purpose for IVF) is certainly a sufficient reason to disallow the use of the new reproductive technologies to create ill children or to *a priori* create disabled children. It is less obvious whether the same logic is sufficient to bar the deliberate creation of disabled children as part of an already existing IVF cycle, particularly when the parents argue that what appears to be a disadvantage to outsiders is actually beneficial within a family where the parents are disabled.

18 Prof. Avraham S Avraham, *Nishmat Avraham* (English), vol. 3, p. 320.

19 Personal communication with Rabbi Prof. Steinberg, July 9, 2000.

20 Personal communication with Rabbi Sholom Kamenetsky, January 13, 2000. See also Rabbi Yitzchak Zilberstein, “שו”ת – מין היילוד ולקביעת מין היילוד – שו”ת”, *Assia* 51–52, Iyar 5752 (1992), pp. 54-58.

21 The issue of sperm retrieval is the primary halachic concern.

F. What Is a Disability?

The issue revolves around which traits are considered to be disabilities and which traits are considered to be variations of “normal” (or more aptly, “typical”). There is a line beyond which normative halacha would consider a trait to be a disability worthy of avoidance while considering another undesirable trait which is less “severe” to be insignificant.

The question of defining a disability is a sensitive one, but it need not be. The term disability is a descriptive term, not a value judgment. In the most literal sense, one who lacks the ability “to perform some or all of the tasks of daily life” or a “medically diagnosed condition that makes it difficult to engage in the activities of daily life” is the dictionary definition of disability.²² One may have other wonderful traits and coping mechanisms that make up for the disability, but that does not remove the obstacles inherent in the disability.

Some disabilities are relative, such as height. The Americans with Disabilities Act (ADA) recognizes that in a world built for those five to six feet tall, being of very short stature is a disability.²³ That is why the law particularly includes dwarfism. “Little People of America,” a nonprofit organization that provides support and information to people of short stature and their families, recognizes this reality:

Certainly a number of short-statured people could be considered disabled as a result of conditions, mainly orthopedic, related to their type of dwarfism. In addition, access issues and problems exist even for healthy LPs. Consider, for example, the simple fact that most achondroplastic adults cannot reach an automated teller machine. Dwarfism is a recognized condition under the Americans with Disabilities Act.²⁴

Other disabilities are more objective, such as blindness or deafness, both of which are also included in the ADA. If no one else could hear, being deaf would not be a disability. But in a world where others can hear, being deaf is a disability. At least in the workplace, society attempts to help level the playing field by enacting laws such as the Americans with Disabilities Act. While many people with disabilities are able to overcome their limitations, many still need significant extra help.

²² *Encarta Dictionary*.

²³ As per the Americans with Disabilities Act, “An individual is considered to have a ‘disability’ if s/he has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment.” <http://www.jan.wvu.edu/links/ADAq&a.html>.

²⁴ http://www.lpaonline.org/resources_faq.html.

G. Choosing Not to Choose

While it is clear that Jewish law does not sanction the usage of assisted reproduction to deliberately create children with preventable disabilities, such a desire is unlikely to become a common scenario. The ability to perform PGD raises a far more complex problem. Take, for example, the case of married dwarves who wish to have viable children. The most common type of dwarfism is achondroplasia, a condition that usually allows for a normal life expectancy and normal intelligence. The main features of the condition are disproportionate short stature and a high frequency of orthopedic abnormalities, which may cause medical problems such as spinal stenosis and hydrocephalus. The inheritance of two genes for achondroplasia (homozygous achondroplasia) is a lethal condition. If a child inherits one gene for the condition, he will be a dwarf. Therefore, if two dwarves with heterozygous achondroplasia marry, there is a 25% chance of having a child with a lethal condition, a 50% chance of having a child who is a dwarf, and a 25% chance of having a child of normal stature. Obviously, dwarf parents would like to avoid having children with a lethal condition, so IVF with PGD is an excellent (and halachically sanctioned) option. However, once the pre-embryos homozygous for achondroplasia are removed, which pre-embryos should be implanted – the dwarves or the normal stature ones? That is, once a dwarf couple is doing IVF and PGD for the permitted purpose of avoiding the lethal disease, a decision must be made regarding which of the remaining pre-embryos to implant.

This question is well framed by the response of “Little People of America” (LPA) to an inquiry as to whether it has a policy on choosing a dwarf child as part of the IVF procedure. The well reasoned response by LPA’s medical resource director, a genetic counselor, speaks to the more difficult set of questions that can arise during IVF:

LPA has no policy on PGD. But I guarantee you that the position statement would be that dwarf parents be able to implant whichever embryos looked best suited for implantation, regardless of whether they are heterozygous for dwarfism or unaffected. I know of no parents who would make a choice involving termination or not using an embryo so as to only have a dwarf child. They just don’t want to be told that their only option is an average-stature child. . . . We just want the opportunity to not have the double dominant. The issue is that some doctors involved in PGD want to tell us that we can’t have children like ourselves. Even when using technology, we would like that option to continue to be possible, not guaranteed.²⁵

²⁵ Personal correspondence with Ericka Okenfuss, M.S., January 25, 2007. The text of the question was “Does the LPA have a policy regarding the use or selection of embryos for in vitro fertilization that carry the genetic predisposition for dwarfism? That is, do you support the choice of selecting only embryos that are dwarfs for parents who are dwarves?”

It is clear that the major *poskim* permit IVF and PGD only in order to avoid having a child with a disease or abnormality, and it is very unlikely that any *posek* would permit these procedures in order to specifically create a child with a disability. But once IVF/PGD is being performed for infertility or to legitimately prevent lethal disease (such as homozygous achondroplasia) or severe disability, must we actively prevent the implantation of other pre-embryos with less severe disabilities, such as dwarfism or deafness?

H. Is There a Prohibition of Choosing a Disabled Child Once IVF Is Being Performed?

When the question posed is choosing between implanting a pre-embryo with a lethal disease or one with a normal genotype, the decision is straightforward: we opt for the healthy child. In reality, this simple dichotomy is not always the case. If the condition that is discovered by PGD is not life-threatening, but only significantly limiting, the prospective parents, who may be disabled themselves, are faced with the question of whether to implant an embryo with a disabling genetic disorder. Do the would-be parents have any moral responsibility to their yet unborn children that might compel them to avoid implanting the affected pre-embryos?

Rabbi Dovid Cohen argues that the parents do indeed have such an obligation.²⁶ He postulates that the prohibition of causing pain to another Jew includes a not yet conceived fetus. Just as one may not take an action that will cause “*tzaar*” to another person, one may not perform an action that will *create* a child who will suffer.²⁷ He uses this concept to forbid a single woman from becoming impregnated by IVF via a donor since this would necessarily create a “fatherless” child, who will be emotionally pained and embarrassed by the circumstances of his birth.²⁸

The novel approach of Rabbi Cohen does not imply a lesser value to the life of a disabled child. Judaism approaches the birth of a child as a blessing and every life is valuable and treasured. Jewish law does not have the secular legal concept of wrongful life, which is accepted in many legal systems around the world.²⁹ While Judaism recognizes no such right

²⁶ Personal communication with Rabbi Kamenetsky, May 28, 2007.

²⁷ Leviticus 25:17. An additional source for this idea might be the famous rule of "ואזהבת לרעהך" "כמוך" (Leviticus 19:18) which prohibits any form of abuse, not only verbal. In addition, see *Sefer Chasidim* 44, which elaborates on this issue.

²⁸ It is not the mere lack of a father that is problematic, but the process of creating a child in such a way that the child is stigmatized.

²⁹ This legal concept posits that a child who is born handicapped due to a genetic defect that should have been detected by his mother's doctor may be allowed to sue for damages, claiming that he would have been better off not being born in the first place.

on the part of the child, it does posit an obligation on the part of the responsible party to choose wisely for the not yet implanted pre-embryo.

There is a general Jewish legal ethic that from the perspective of the parent, there is a preference, or possibly an obligation, not to take an action that will likely create a child that is disabled. This is clear from the Talmudic dictum that specifically advises against any marriage that will likely create genetically inherited diseases in offspring. The Talmud (*Yevamot* 64b) states that “. . . a man should not marry a woman from a family of epileptics or from a family of lepers.”³⁰ The presumption is that in either case, by marrying into such a family, he would endanger the health of his prospective offspring.³¹ In practice, halacha applies this rule to any hereditary or contagious disease.³² Elsewhere in the Talmud, we see that there is concern for purposefully creating children that are significantly different from the average in physical appearance, including the admonition that “a very (abnormally) tall man should not marry a very tall woman lest their offspring be abnormally tall. A dwarf should not marry a dwarf, lest their offspring be a dwarf of the smallest size.”³³

These Talmudic principles are applied by contemporary *poskim* to carriers of genetic defects. Rabbi Moshe Feinstein, universally considered among the greatest 20th-century experts in Jewish law, favored testing young men and women for Tay-Sachs disease when they reach marriageable age.³⁴ Carriers are then discouraged from marrying each other and thereby avoid the possibility of producing offspring with the deadly disease.

Similarly, while the Talmud and some later halachic authorities considered it praiseworthy to marry one’s niece (i.e., a sister’s daughter), contemporary halachic authorities rule that one should not marry close

30 The same restriction applies to a woman marrying into such a family. See *Sefer Chazon Ish, Yoreh Dea* 154:2.

31 Because his wife might bear offspring who will be epileptics or lepers. Some *poskim* have forbidden such an act. See *Responsa Chatam Sofer*, cited in *Otzar HaPoskim, Even HaEzer* 2:43; *Sefer Chazon Ish, Nashim* 134 in glosses to 64b; *Yam Shel Shlom, Yevamot* 33). However, Rabbi Shmuel Kamenetsky, head of the Talmudical Yeshiva of Philadelphia, told me that the Talmud’s admonition is merely advisory.

32 Rabbi Prof. Avraham Steinberg, *Encyclopedia of Jewish Medical Ethics*, s.v. “Preventative Medicine,” p. 834, in the name of *Responsa Pri HaSadeh* 2:26, and *Responsa Chatam Sofer, Yoreh Dea* 137.

33 *Bechorot* 45b. The Talmud applies the same admonition to albinos’ marrying each other. These matches are discouraged, not because the marriage of the couple is any problem, but because they would be required to have children to fulfill their mitzva of procreation and might bear children who share their unusual or undesirable traits. Interestingly, in the case of dwarves, the Talmud may have been warning about the one-in-four chance of an achondroplastic couple’s having a gestation incompatible with life (homozygous achondroplasia).

34 *Responsa Igrot Moshe, Even HaEzer* 4:10.

relatives for fear of hereditary abnormalities in the subsequent children.³⁵ Referencing contemporary halachic authorities,³⁶ Rabbi Prof. Avraham Steinberg explains that the endangerment of one's offspring is subsumed in the binding Jewish legal axiom that rules that "regarding danger to life, [we] are more stringent than [regarding] ritual regulations, and one should avoid such danger."³⁷

It is crucial to stress that Judaism demands respect for every person, regardless of their physical attributes or disabilities. However, it is clear from the Talmud and later Rabbinic writings that Jewish law demands that we not voluntarily compromise our children's health and well-being for our own agendas.

I. Where Is the Line?

Nevertheless, determining which traits qualify as sufficiently limiting to merit active avoidance requires thought. While some traits may be relatively desirable (good visual acuity) or undesirable (male pattern baldness), they are not taken into account in choosing pre-embryos for implantation. Such traits are not considered important enough to warrant having a role in implantation decision-making.

Even when IVF and PGD are being performed for a particular indication, such as avoidance of Tay-Sachs disease, we do not give the parents a print out of the genetic code of each pre-embryo and ask the parents if we should implant the ones that are taller, or smarter, or more athletic, nor do we usually ask which sex child the parents would like.³⁸ But some genetic traits are more ethically vexing. All things being equal, does the pre-embryo Tay-Sachs carrier state play a role in choosing which

35 Support for such marriages is found in *Yevamot* 62b; *Mishneh Torah, Issurei Bia* 2:14; Rama, *Shulchan Aruch, Even HaEzer* 2:6. As early as the 12th century, Rabbi Yehuda HaChasid, author of *Sefer Chasidim* (477), stated that one should not do so. Several later authorities, such as Rabbi Yechezkel Landau (*Noda BiYehuda, Even HaEzer* 79) and Rabbi Ovadia Yosef (*Yabia Omer*, vol. 2, *Even HaEzer* 7:8–11), concurred.

36 *Responsa Be'er Moshe*, 6:159–160; Rabbi Shlomo Zalman Auerbach, cited in *Nishmat Avraham* (second extended edition) vol. 3, *Even HaEzer* 2:1:3; *Responsa Tzitz Eliezer*, vol. 15:44.

37 Rabbi Prof. A. Steinberg, "Preventative Medicine," p. 834.

38 "Certainly, the use of PGD solely for the purpose of sex selection, while eminently feasible scientifically, would be considered a frivolous use of IVF and prohibited by most *poskim*." Grazi, *Overcoming Infertility*, p. 352. Note that this does not imply that the Torah objects to utilizing methods that do not interfere with normal marital relations in order to produce a gender-specific child. The Talmud suggests various ways of producing boys or girls if a couple desires, but all fall within normal activities of life, including recommended foods, timing (*Berachot* 60a, *Nidda* 25b), and positioning of the bed (*Berachot* 5b). Nevertheless, some *poskim* have permitted gender selection if PGD is being performed for another valid reason.

pre-embryo to implant? Should the parents deliberately choose the homozygous normals, even if they are not of the highest grade from an implantation standpoint, to avoid issues of Tay-Sachs disease in future generations?³⁹ Alternatively, perhaps the parents should choose not to take into account which pre-embryos are heterozygous for Tay-Sachs (since children with the Tay-Sachs trait would be normal), but only take into account which pre-embryos have the best chance of creating a viable pregnancy. The latter course is more likely to yield a successful pregnancy, a concern particularly important to an otherwise infertile couple. In practice, the carrier status of a pre-embryo would not be considered significant enough by Jewish law to merit being excluded from implantation.⁴⁰

The genetic counselor from Little People of America argues that dwarf couples should be permitted to do the same thing as Tay-Sachs carrier couples: not to choose the pre-embryos that will be dwarves, but rather not to choose at all beyond removing the lethal homozygous pre-embryos. They merely want the pre-embryos to be graded based on likely viability of the pregnancy and they will accept whichever child results, whether dwarf or normal stature. Their objection is to being told that they *have* to choose the normal stature child over a dwarf child, regardless of the likely outcome of the pregnancy (a choice that a Tay-Sachs carrier couple may also find problematic if being required to choose the homozygous unaffected pre-embryos would reduce the chances of a successful pregnancy). Many dwarves do not consider dwarfism to be sufficiently problematic to bar implantation of a pre-embryo, just as the general populace does not consider poor eyesight, poor hearing, mildly decreased height, etc. as valid criteria for not implanting a pre-embryo. Is there a halachic imperative to choose the typical child over the non-fatally disabled child when performing PGD?

J. Halachic and Hashkafic Justifications for Avoiding Disabilities

The issue is not relative value of life. From the point of view of Torah hashkafa, one child is no more valuable than another.⁴¹ The real issue is whether the Torah requires that a parent attempt to make the life of his child as trouble free as possible.

The beginning of the book of Samuel describes the angst of Chana, who had been childless for many years. One year while visiting the

39 “During subsequent days [after fertilization] the embryos are inspected and graded according to the number of cell divisions that have occurred and the morphology of the cells within each embryo.” Grazi, *Overcoming Infertility*, p. 337.

40 Personal communication with Rabbi Sholom Kamenetsky, June 7, 2007.

41 *Sanhedrin* 74a , *Pesachim* 25b.

Tabernacle during a festival, she formulated a heartfelt prayer requesting of G-d that she be blessed with a child.⁴² In her prayer (I Samuel 1:11), Chana requests “*zera anashim*,” literally translated as “seed of men.” The Talmud (*Berachot* 31b) entertains four possible interpretations of this phrase, the last one being that Chana requested a child who would be typical:

And the Rabbis say: “male offspring” means a child who is “absorbed” among other people. When Rav Dimi came [from Israel], he explained [that Chana meant]: neither tall nor short, thin nor fat, pale nor ruddy, brilliant nor foolish.

Rashi there explains that Chana did not wish her son to be out of the ordinary so as not to “provoke amazement in the eyes of those around him.” There is an unequivocal message that parents should desire that their children “fit in” with the rest of society and should not have to feel the pain of being “different.”

The “*shehecheyanu*” blessing is recited upon reaching any religiously significant milestone that brings joy. In his glosses to the *Shulchan Aruch’s* discussion of *shehecheyanu* (*Orach Chaim* 225:2), Rabbi Moshe Isserles adds that there is a special blessing to be recited at the time of a son’s bar mitzva. The text of the blessing is: “Blessed is He Who has relieved me of the punishment associated with this one.” This might appear to be an unusual way to display joy, but according to Rabbi Meir Levush (cited in *Magen Avraham*, *ibid.* 5), the reason for the blessing is to signify the father’s relief that he will no longer be responsible for causing punishment and suffering to his son by his own misdeeds, “for until now, the son was punished for the transgressions of the father.”

We see from the prayer of Chana and the *beracha* recited at the time of bar mitzva that the appropriate emotion for the parent is to wish normalcy on his child and to loathe being the source of their child’s suffering. Certainly to choose a disability for the child is unthinkable, but even to choose not to prevent a disability in a child which will cause suffering or hardship is also not the Torah approach. It is the height of selfishness to desire a disabled child for one’s own benefit. As King Solomon teaches (Proverbs 3:17), “*d’racheha darchei noam* – the ways of the Torah are pleasantness,” and “it is not *darchei noam*, it is not a pleasant way, to have your child suffer” from a preventable, disabling genetic condition.⁴³

42 The Talmud (*Berachot* 31b) learns many laws of prayer from Chana’s entreaty.

43 Rabbi Mordechai I. Willig, “Jewish Gene: Genetic Screening and the Prevention of Diseases,” Yeshiva University Medical Ethics Society lecture, March 28, 2006 (available at http://www.yutorah.org/showShiur.cfm/714313/Rabbi_Mordechai_I._Willig/Jewish_Gene:_Genetic_Screening_and_the_Prevention_of_Diseases). Rabbi Willig invoked *d’racheha darchei noam* to explain why it is inappropriate not to do genetic testing before marriage to prevent

So if all pre-embryos in a given IVF cycle have an equal chance of producing a successful pregnancy, the proper approach would be to choose those pre-embryos that would produce a child that would not have preventable significant suffering.⁴⁴

K. Choosing Infertility over Possible Disability

Sometimes the choice is not so easy. Potentially, it may not be possible to have a child and avoid a high likelihood or certainty of the child having a significant disability. Deliberately sterile marriage is not permitted in Jewish law. Before the advent of the new reproductive technologies such as IVF with PGD, couples were still required to fulfill the mitzva of procreation, even when there was a high risk of a sick or disabled child.

This principle is illustrated by the Talmud (*Berachot* 10a) with respect to an event recorded in II Kings 20:1 and Isaiah 38:1. King Hezekiah became deathly ill and the prophet Isaiah came to visit him, warning him that he would soon die and lose his place in the World to Come:

[Hezekiah] said to [Isaiah]: What is the reason for all this? [Isaiah] said to him: It is because you did not engage in [the mitzva of] procreation. [Hezekiah] said to him: That was because I saw with *ruach hakodesh* (Divine inspiration) that immoral children would come forth from me! [Isaiah] said to him: What concern are the hidden things of Hashem to you? What you are commanded to do [by Hashem], you are required to do; and what is good before Hashem, He will do!

While King Hezekiah had believed it better to remain celibate than to bring evil children into the world, the Talmud teaches that the deliberate refusal to have children, even if the offspring will inevitably be limited or even immoral, as punishable by premature death and the loss of a place in the next world. Obviously, one who is unable to have children is exempt from the mitzva of procreation.⁴⁵ In fact, one is not required or expected to utilize extraordinary measures, such as IVF, to produce children.⁴⁶

Tay-Sachs babies, but his point is equally valid for preventing any avoidable genetic abnormality.

Editor's note: See editor's note on Rabbi Asher Weiss, *שמעתי ושמעתי*, "בענין גזירת שהירת סממנים ולקחת ושמעתי" elsewhere in this book, as to the halachic use of this source throughout the Oral Torah.

44 Ruling of Rabbi Dovid Cohen as per personal communication with Rabbi Sholom Kamentsky, May 28, 2007.

45 *Minchat Chinuch, mitzva* 1, s.v. "V'tumtum."

46 "I heard from Hagaon Rabbi Shlomo Zalman Auerbach, *z"tl*, that there is no obligation whatsoever for an infertile couple to engage in IVF in order to fulfill the mitzva of *p'ru ur'vu*." Prof. Avraham S Avraham, *Nishmat Avraham* (second expanded edition), vol. 3, *Even HaEzer*, p. 27. See also Rabbi Yitzchok Breitowitz, "The Preembryo in Halacha,"

<http://www.jlaw.com/Articles/preemb.html>: "On one hand, the obligations of *p'ru ur'vu* and *lashevet* have never been understood as compelling resort to any type of surgical procedure to achieve procreation. At the same time, most *poskim* do consider the offspring produced from

Nevertheless, one is still required to attempt all natural means at one's disposal to marry and have children, even if the children might be born with disabilities.

One might therefore infer that disability is not an important criterion in Jewish "family planning" when the parents have a known genetic defect. This would be a misinterpretation of the Jewish approach to childbearing. The juxtaposition of two responsa of Rabbi Moshe Feinstein illustrates the dual nature of the obligation to procreate: the obligation to marry and have children on the one hand and the expectation that parents try to avoid genetic defects in their offspring on the other.

In 1973, a few years after the introduction of Tay-Sachs carrier screening programs, Rabbi Feinstein was asked if one should test for Tay-Sachs carrier status before marriage. He wrote (*Responsa Igrot Moshe, Even HaEzer IV:10*):

I have been asked my opinion regarding several questions: (1) Is it proper for a boy or girl to endeavor to find out their carrier status? (2) If it is desirable, should the test be done during youth or only once one reaches the age of marriage? (3) Should the testing be done publicly or privately?

I looked into these questions and my humble opinion is that even though only a small minority of children are born with this disease, and it is appropriate to apply the verse "You must act wholeheartedly with the Lord your G-d" (Deuteronomy 18:13) and as Rashi explains it, "walk with Him wholeheartedly and anticipate His support, and do not delve into the future"; nevertheless, since this information can be discovered so easily, it is possible to say that if one does not test himself, it is as if he is closing his eyes to seeing that which it is possible to [easily] see. And since that if, G-d forbid, this were to happen (to have a Tay-Sachs baby), it would cause tremendous suffering for the parents of the child, it is appropriate for one who is ready to get married to test himself. And thus it is proper to publicize the test in newspapers and through other avenues that would inform the public that there is a test like this.

Rabbi Feinstein supported utilizing technology to proactively avoid creating children with severe genetic defects. His only implied reservation is whether the infrequency of Tay-Sachs carrier status (and therefore the rarity of children afflicted with Tay-Sachs) merits active intervention such as genetic screening to prevent the birth of Tay-Sachs babies.

IVF as having a familial bond to the biological parents." Additionally, Rabbi Breitowitz points out that the woman is not required to undergo IVF: "Insofar as *ona* and *lashevet* are concerned, these obligations do not require consent to an IVF procedure, nor would [they] require her to complete the procedure once begun." However, in discussing general halachic issues involved in IVF, Rabbi Prof. Steinberg states that in light of the reasons to permit IVF, "it seems clear that one is allowed, and perhaps even obligated, to use whatever procedures are necessary and allowable to effect procreation." *Encyclopedia of Jewish Medical Ethics*, s.v. "In-Vitro Fertilization," p. 576.

However, when asked what the case would be if the trait was dominant and therefore the possibility of severely affected offspring could not be prevented, Rabbi Feinstein was definitive that the obligation of procreation is paramount.⁴⁷ In dealing with case of an unmarried 25-year-old man with a severe case of Marfan syndrome,⁴⁸ Rabbi Feinstein wrote (*Responsa Igrot Moshe, Choshen Mishpat II:73b*):

If he marries a normal woman, half their children may be expected to inherit the disease. Is he forbidden to marry a woman who can bear children, or, on the contrary, is he obligated to fulfill the obligation of procreation?

It is, in my opinion, obvious that if he can find a woman who knows his condition and is willing to marry him (because he must inform her before marriage so that the marriage ceremony not be under false pretences, [which would annul the marriage] and, regardless of this, it is prohibited to commit fraud in marriage to the same extent as in business, and maybe even more so), he is permitted and obligated to marry her to fulfill the mitzva of procreation. Behold, it is possible that he will have healthy children, and he should pray to G-d to grant him upright and healthy children. It is possible that all his children will be healthy, since [the statistic that] half the children are afflicted represents only a probability and therefore this does not represent [praying for] a miracle.

And even if some of his children will have the disease, he will still fulfill his obligation, since they [are viable children who] can fulfill the obligation of inhabiting the world. . . .⁴⁹

Rabbi Feinstein concludes by stating that “Only if all fertile women refuse him, then it is beyond his control, and he is exempt from the obligation of procreation. [In such a case,] he should then marry a sterile woman because of the obligation to marry.”

47 The responsum was written before in vitro fertilization and pre-implantation genetic diagnosis were developed. Additionally, Rabbi Feinstein rejected the possibility of performing an abortion for a genetic defect, ruling that abortion is in the category of murder. See *Responsa Igrot Moshe, Choshen Mishpat II:69b*.

48 Marfan syndrome is a dominantly inherited disorder that can cause severe abnormalities of the aorta, eyes, and connective tissues. The questioner was a student with severe symptoms of the disease and had already undergone heart surgery and was blind in one eye. It is important to note that the severity of disease in the offspring may vary.

49 In *Crossroads: Halacha and the Modern World*, vol 2 (Alon Shvut, Israel: Zomet Institute, 1988), p. 61, an English-language version of what appears to be the same responsum adds two points. After the line explaining that half of the offspring would be expected to inherit the disease, the responsum points out: “The disease does not cause mental impairment or early death. The children may require heart surgery, which itself poses a certain measure of risk. Physicians recommend that one afflicted with this disease not have children so as not to pass on the genetic disorder.” After posing the question of whether the questioner is required to marry, the responsum continues: “the disease is not especially severe, and he is capable of bearing children, half of whom will be totally healthy, and half, although afflicted, will be able to study Torah and fulfill the commandments of G-d. It is said that President Lincoln was afflicted with this disease and it is carried by his descendants to this day: nonetheless, he was able to achieve great things.”

It is apparent from the approach of Rabbi Feinstein that while prevention of abnormalities is desired and expected if possible, it does not trump the obligation of procreation.⁵⁰ It would follow from the two rulings of Rabbi Feinstein that one should avoid marrying a spouse where the union has a high probability of producing children with significant genetic abnormalities (such as two Tay-Sachs carriers or the Talmud's advice against two dwarves marrying at a time when there was no way to avoid the outcome of dwarf or lethally affected children).

However, if avoidance of defects is not possible within the realm of normal behavior, so long as the marriage will produce viable offspring, procreation is required. For this reason, there is no obligation on the part of two married dwarves to avoid having children naturally even if the probability is that 75% of the children will be dwarves or non-viable.

The rulings of Rabbi Feinstein apply to natural, unaided procreation, where the avoidance of the possible creation of a disabled child is not possible. But if the couple does choose to utilize IVF with PGD (an endeavor into which they are not required to enter), then the scenario changes. The ability to avoid children with a lethal homozygous genome and the ability to choose children unaffected by dwarfism are now within their control. In such a case, the preponderance of halachic evidence would indicate that if there is a choice, the couple should choose to implant the unaffected pre-embryos if they will likely lead to a viable pregnancy. This analysis fits well with Rabbi Cohen's *psak*, which would bar the deliberate creation of a disabled child by IVF but allow married couples who run the risk of having disabled children to reproduce naturally.

While one may argue that such a choice is not absolutely required,⁵¹ the reasoning of Rabbi Dovid Cohen might necessitate agreeing to choose the unaffected pre-embryo as a prerequisite for performing IVF in the first place. All *poskim* would agree that the sole reason why IVF is permitted, considering the halachic barriers, is to fulfill some part of the mitzva of procreation. However, all would also agree that one may not utilize the optional process of IVF if by doing so one transgresses some other prohibition. The logic is similar to that of Rabbi

⁵⁰ Rabbi Shlomo Zalman Auerbach questioned "whether one who has a hereditary disease from which his children will suffer all their lives, or one who has hemophilia which will be passed on to his male offspring, is permitted to marry a woman who is unable to have children." He wrote to Prof. Avraham that "it is clear to the *Igrot Moshe* that such a person is obligated to keep the *mitzva* [of procreation]; however, in my opinion, this ruling requires further study." Prof. Avraham S Avraham, *Nishmat Avraham* (English), vol. 3, p. 3.

⁵¹ Personal communication with Rabbi Shmuel Kamenetsky, January 31, 2007. The *piskei halacha* in the final version of this article were confirmed with Rav Dovid Cohen on October 29, 2007.

Moshe Feinstein, who forbids a *kohen* from becoming a doctor if it requires touching or being in an enclosure with a corpse.⁵² Rabbi Cohen argues that there is no permission to undertake the optional act of IVF if by doing so one intends to transgress the prohibition of causing pain to a fellow Jew. If the choice is between infertility or *a priori* knowledge that the use of assisted reproduction will result in the definite creation of a disabled child, Rabbi Cohen rules that one must remain childless.

L. A Last Dilemma: Infertility versus Disability

However, in almost every case, the knowledge that all available pre-embryos will result in disabled children does not arise until *after* the IVF procedure has commenced and the halachic barriers have been surmounted. Even if one accepts the logic of Rabbi Cohen that one may not utilize IVF for the purpose of creating a disabled child from the outset, once the IVF process is initiated, it is not necessarily the case that if all available pre-embryos will grow into disabled children, that one may not implant any of them. Perhaps at that point, the pre-embryos are treated similarly to the potential offspring of natural conception. The choice whether to implant in such a case would likely depend on the particular condition, the spectrum of disabilities that it might cause, and the probability that the child would develop severe manifestations of the condition. Rabbi Cohen applies his ruling even in this case, barring implantation of a pre-embryo that will develop into a disabled child. Nevertheless, the degree of disability required to bar implantation remains a subjective one, even for Rabbi Cohen.

In every case, the choice whether to implant a potentially disabled embryo is an emotional one. The already born individual with a particular genetically-based disability sees the choice not to implant a pre-embryo with the same genetic defect in favor of a “normal” pre-embryo as questioning the value of his own existence, an existence which the disabled individual rightfully considers of infinite value. He may approach the issue as if the decision to implant the “normal” pre-embryo implies that those doing the implanting have judged that it would have been better had the living disabled person never have been born. The already existing person approaches the implications of PGD from a personal “after the fact” perspective, possibly feeling that a decision not to implant a pre-embryo with the same defect that he possess is a rejection of his personal worth.

⁵² *Responsa Igrot Moshe, Yoreh Dea* III:155. Because there is no *mitzva* to become a doctor, despite the *mitzvos* one may perform once he has become a physician, Rabbi Feinstein forbids one to transgress any biblical prohibitions in order to attend medical school.

The third party performing IVF-PGD, however, sees the decision as a choice between alternatives and should opt for the one that will likely create the best outcome, that being a child without a disability. He or she is choosing between two not yet extant humans and is determining which one should become a tangible human being. The parents undergoing IVF enter the decision-making process from an *a priori* perspective, grappling with the issue of which pre-embryos to implant.

But, when the only currently extant pre-embryos will have a severe disability, the choice is to implant or attempt another round of IVF which may not be feasible. While recognizing that the decision not to implant may appear to some to make the bold statement that it is intrinsically better not to have people with certain disabilities, we must recognize that this simply is not the case. The world is better for having all of the people that Hashem has chosen to create, but the Torah-observant Jew recognizes that the corpus of Jewish law and tradition would suggest that a parent not create a child who will suffer if it can be avoided.

M. The Conundrum of Non-Existence

There is a fundamental existential question underlying the whole discussion of choosing a disability as part of an IVF procedure, whether directly by opting to implant an affected embryo or indirectly by not preventing the implantation of an affected embryo. If only two options are available, is it better to be born with a disability or to have never been born if one will be affected by a severe disability? While it may seem that we cannot have the perspective necessary to answer such a question, the concept underlying this difficulty was the basis of a debate between the great *Tannaim*. The Talmud (*Eiruv* 13b) reports:

For two and a half years, the School of Shammai and the School of Hillel debated. These said, "It is better for man not to have been created than to have been created"; and these said, "It is better for man to have been created than not to have been created." They voted and concluded that it would have been better for man not to have been created, but now that he has been created, let him investigate his deeds.

This cryptic passage lies at the heart of the question of whether parents should create children with disabilities. The Talmud teaches that one must accept life as it is. For each individual, his life is of the utmost value and must be cherished, regardless of what obstacles lay before him. It lies within the soul of each person to make the most of their gifts and their lives. Some people with no apparent limitations make nothing of their life. Others, with apparently insurmountable obstacles achieve great things.⁵³

53 Helen Keller, who was both blind and deaf, is a prime example.

However, it is an inescapable truth that some obstacles are not a *priori* welcome. The conundrum is that were an individual never to have been created, he could not contemplate whether it would be better to have been created. A person necessarily lacks a point of reference from which to make the determination of whether it is better to have been created, since the alternative cannot be conceptualized. However, while the Talmudic discussion takes place between men who have already been created, because the decision to create them was made by G-d, the unavoidable conclusion is that from G-d's perspective, it *must* have been better to have created man than not.

The Talmud's conclusion that it would have been better for man not to have been created is from the perspective of an already created being. From our viewpoint, given the trials and tribulations of life, it may appear to us that it would have been better never to have been put in this world. But since we are here, we must make the best of it, and must strive for greatness, because that is what G-d, the ultimate arbiter of value, has decreed.

But, when the decision to create a person is not a result of the biblical mandate to procreate, but is the optional decision of a couple to create a child where known disabilities will ensue, we cannot necessarily claim that it is better to be created than not. The Torah has commanded us to avoid causing avoidable pain to others and the reality that Hashem chooses to create children with disabilities does not absolve us of our own Torah obligations. The acceptance of life as Hashem creates it does not justify purposeful creation of humans with severe disabilities except when mandated by the Torah.

Rabbi Cohen argues that when there is a high likelihood of disability arising as part of the IVF procedure, the parents must utilize PGD to ensure the implantation of an unaffected embryo. For a couple who have a high likelihood of producing a disabled child by normal conception, Rabbi Cohen recommends utilizing IVF with PGD to forestall that possibility. Of course, no technology can eliminate the risk of producing a disabled child, but Rabbi Cohen believes that one is required to do one's best to avoid such an outcome.

So when we apply our "conundrum of non-existence" to pre-implantation diagnosis, we see that the roles change. We must now perform the role of G-d as He has instructed us through the Torah. We must take the best interests of the would-be child into account and decide under which conditions the potential child should not be born and duly avoid creating such a child. Just as G-d's decision is necessarily made as a third party, so must our decision be made the same way, since there is no way to consult with the yet unformed child. Some of these conditions

are accepted as self-evident, such as Tay-Sachs disease. Regarding some conditions, there will likely be no consensus.

The only objective criteria that we can and must demand is that the decision be based on what is best for the potential child and not what is best for the prospective parents. Self-interest and ego on the part of the parents must not be used as a criterion in making such a crucial life and death decision. If we apply this rule with intellectual honesty, a consensus is much more likely to be obtained.

N. Limitations on the Ability to Choose

Despite the Torah-based mandate to actively pursue normalcy for our children, the ability to prevent a disabled child from entering the world is limited by our personal Torah obligations. The commandment to procreate supersedes many other decision-making factors involved in PGD. That is, our ability to evaluate whether it would be better for a child not to be born only comes into play if we pursue technological assistance to fulfill the mitzva of procreation. Otherwise, the decision is not in our hands.

It is important that we not devalue any person based on their outward characteristics. However, Judaism requires that we make an effort to bring normality to our children. In our attempt to grant respect to everyone, we must avoid harming others. It is not disrespectful to recognize the equality of those born with limitations, yet recognize that it would be better not to be limited. Using in vitro fertilization to deliberately create children with disabilities is a fundamental misuse of modern reproductive technologies and an abuse of the Torah mandate to manipulate the world for the good of mankind.

To specifically choose to have a deaf, dwarf, or otherwise disabled child is to purposefully create unnecessary serious obstacles for the child. While many disabled people overcome their limitations and pursue lives virtually indistinguishable from their neighbors, it is seldom without great effort.

The Mishna (*Pirkei Avot* 5:26) teaches that the gain in life is proportional to the pain. However, the Torah also teaches that one may not deliberately make life more difficult for himself⁵⁴ or another by placing

⁵⁴ "ויהי רצון... שתרגילנו בתורתך, ודבקנו במצותיך, ואל תביאנו לא לידי " (And may it be Your will... that You accustom us to study Your Torah and attach us to Your commandments. Do not bring us into the power of error, transgression, and sin, or into the power of challenge, or into the power of scorn. Let not the evil inclination dominate us).

See also *Bava Batra* 57b, which condemns one who "deliberately exposes himself to a situation in which he might be tempted to sin," and *Sanhedrin* 107a, which states that "R'

a physical or emotional stumbling block before someone who is challenged in a given area.⁵⁵ Despite the natural desire of a parent to have children that resemble themselves, no person has the right to place serious obstacles before their children in order to satisfy their own self-interest. While we respect all people equally, whether healthy or ill, we must not lose sight of the Torah's mandate to heal. So too, while we value and love all children equally, we must not lose sight of our ultimate goal of removing all possible physical and emotional limitations from our children and we must not give up on our desire to make the lives of our children the best that they can be.

While the particular applications of the new reproductive technologies, particularly PGD, will require specific rulings from great *poskim*, taking into account the multiple discussions in from the Tanach to the present, it would seem that the Torah commands that we proactively attempt to create children who will not have severe handicaps. Having a child through the new reproductive technologies is not a religious duty and the preponderance of halachic sources seem to indicate that one should not pursue such technology at the expense of creating a child who will suffer.

When all is said and done, if we wish to have the "best" children possible, nothing has really changed. We must rely upon the same factors as our ancestors – choosing the right mate, good parenting skills, and a heavy dose of *siyata diShmaya* (Divine help).⁵⁶

Yehuda said in the name of Rav: A person should never bring himself to a test (ed. note: a situation in which he will be tempted to sin), for David, king of Israel, brought himself to a test and he stumbled." See also *Avoda Zara* 17a–b which makes an exception for the select few who continuously study Torah.

55 Derived from Leviticus 19:14.

56 See *Nidda* 70b-71a which explains that if a man wishes to have children, in addition to marrying a woman who is spiritually appropriate for him, he must pray for Divine help. As the Talmud teaches, ". . .one without the other is not enough."