Is Non-selection of Disabled and Diseased Embryos Using PGD Ethically Acceptable, Legally Permissible and Halachic?[1]

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Given the recent birth, in the UK, of the first embryo to be genetically screened and selected to ensure freedom from a breast cancer gene,[2] there may be renewed concern with the use of PGD for this purpose and the fear that future use of this technology could create designer children who possess desirable characteristics.[3] It is therefore prudent to consider both secular and Jewish ethics and legality of designer children. In common with other religions, Judaism has a long history of grappling with questions of central importance and so is a useful resource for the relatively new secular ethics.[4] As one of the classes of people directly affected by Holocaust eugenics, the viewpoint may present a unique rationale for either a permissive or non-permissive system. A recent Poland visit, standing outside Auschwitz medical experiment Block 10, was a reminder of Glover's statement that whatever the technology's use and theoretical basis, it must not provide justification for Nazi actions.[5] The Jewish and Israeli perspectives also serve as an example of idiosyncratic cultural and religious principles and laws that could either hinder international consensus or provide a solid baseline or list of exceptions to the rules, acting as a societal conscientious objection.[6] I have been privileged to complete a month-long program in Jewish Medical Ethics in the Schlesinger Institute, Shaare Zedek hospital, Jerusalem[7] but I am a scholar neither of *halacha* (Jewish law) nor Jewish history and tradition. I am a Jew, steeped in and responsive to the culture in which I participate.

Judaism has a long history of grappling with questions of central importanc

PGD is used to test for several diseases and disabling conditions before implantation by removing one to two cells from a six to ten cell embryo, created by *in vitro* fertilisation (IVF). Only embryos free of conditions' genes are implanted. Conditions for which this technique has been licensed and used by the Human Fertilisation and Embryology Authority (HFEA) of the United Kingdom include cystic fibrosis, breast cancer and Huntington's disease.[8]

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[1] Based on chapter four of dissertation submitted as part of the MA in Medical Ethics and Law at King's College, University of London

[2] Lister, S. et al. (10/01/09). Breast Cancer Gene that Blighted a Family is Wiped out at Birth. *TimesOnline,* accessed 19/01/09, http://www.timesonline.co.uk/tol/life_and_style/health/article5485224.ece

[3] Jones, D. (09/01/09). Immoral Advances: Is Science out of Control? *New Scientist,* http://www.newscientist.com/article/mg20126905.100, accessed 19/01/09

[4] Callahan, D. (1990). Religion and the Secularisation of Bioethics, *Hastings Center Report*, *20*, 2-4

[5] Glover, J. (2000). Humanity: A Moral History of the Twentieth Century. New Haven: Yale University Press, 406

[6] Gross, M. L. & Ravitsky, V. (2003). Israel: Bioethics in a Jewish-Democratic State. *Camb. Q. Healthc. Ethic., 12(3)*, 247-55

[7] http://www.medethics.org.il/siteeng/PagesEn.asp?cat_id=9&page_id=46, accessed 09/07/08

[8] HFEA. (2007). *Examples of Licensed PGD Conditions*, http://www.hfea.gov.uk/docs/PGD_list.pdf, accessed 08/07/08

The law pertaining to the use of PGD is contained within the Human Fertilisation and Embryology Act 1990, which has been criticised due to its lack of ethical foundations[9] and conceptual depth.[10] We will therefore analyse throughout the legal acceptability of PGD by considering the ethical issues arising.

abortion is seen by many to be ethically inferior to PGD in several ways. Judaism contains a spectrum of views about abortion

Abortion Alternative

One can consider the ethical and/or legal superiority of PGD to alternatives, i.e. abortion, under the foetal abnormality ground after 24 weeks[11] or social ground before 24 weeks.[12] The HFEA's sixth Code of Practice[13] equated PGD with prenatal diagnosis (PND).[14] However, abortion is seen by many to be ethically inferior to PGD in several ways.[15] Considering embryo status, PGD occurs at an earlier stage in development (under three days old) than abortion, used in certain circumstances, up to term.[16] Whatever the value attributed to embryos, PGD will always be more respectful. Additionally, by definition, the embryo has yet to be implanted. Legally and culturally many do not think of not-yet-implanted embryos as part of a pregnancy,[17] or deserving of an independent legal right to life.[18] PGD is also easier on women physically and emotionally. While this may be problematic in that the fewer the difficulties with PGD, the lower the barrier to its trivial use, one should also consider IVF demands before asserting this.[19]

Examining Jewish views will contribute a group's idiosyncratic approaches to PGD use and its implications for international consensus, using classical Jewish sources and in the light of the Holocaust.

Judaism contains a spectrum of views about abortion. Regarding embryo status, anything that cannot be seen with the naked eye lacks *halachic* significance.[20] Up until forty days, the foetus is considered *maya b'alma* (mere water).[21] Until the unborn baby's head emerges, if causing the mother harm, the foetus is considered a pursuer (*rodef*). The mother's life can be preserved through self defence even if resulting in foetal death.[22] However, if the threat is foetal abnormality, R. Feinstein prohibits abortion and rules that amniocentesis birth defect detection with the possibility of abortion is impermissible. Whilst most *poskim* concur, R. Waldenberg is a notable exception allowing first trimester abortion of a suffering-causing deformed foetus and termination of a lethally defected foetus until the end of the second trimester.

Legality

Given abortion's ethical issues, PGD may be preferable. Variations to licences are necessary before centres can carry out PGD for any disorder. If centres have the required staff and there is an established precedent for disorder testing, approval

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[9] McDonald, I., Fenton, R. A. & Dabell, F. (2007). Treatment Provisions: Proposals for Reform of the Human Fertilisation and Embryology Act 1990, *J. S. Wel. Fam. L., 29*, 293-305

[10] Brazier, M. (1999). Regulating the Reproduction Business, *Med. L. Rev., 7,* 167

[11] S1(1)(d), Abortion Act 1967

[12] S1(1)(a), Ibid

[13] HFEA. (2003). *Code of Practice, Sixth edition*, accessed 11/08/08 http://www.hfea.gov.uk/docs/Code_of_Practice_Sixth_Edition_-_final.pdf

[14] Paragraph 14.21

[15] Ram, N. (2006). Britain's New Preimplantation Tissue Typing Policy: An Ethical Defense, *J. Med. Ethics, 32*, 278-82

[16] Ibid

[17] E.g. Human Fertilisation and Embryology Act 1990, section 2(3); Human Genetics Commission (HGC). (2006). *Making Babies*, Paragraph 4.17

[18] Scott, R. (2006). Choosing Between Possible Lives: Legal and Ethical Issues in Preimplantation Genetic Diagnosis, *Ox. J. Legal Stud., 26(1),* 153-78

[19] Pennings, G., Schots, R. & Liebaers, I. (2002). Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling, *Hum. Reprod., 17(3),* 534-8

[20] Bleich, R. D. (1988). *Bioethical Dilemmas: A Jewish Perspective*. New York: KTAV, 216

[21] Yevamot 69b, Nidda 30a, Rashi Nidda 30a, in Epstein, I. (Ed.) (1952). *Babylonian Talmud*. London: Soncino

[22] Mishnah Ohalot 7:6 in Danby, A. (1933). *Mishnah,* English translation. Kaufman: London; Rambam, Hilchot Rotzeach, 1:9, in Hyamson, M. (Ed.). (1962). *Mishneh Torah*. Jersusalem: Boys Town Jerusalem Publishers

will be routine. More complex disorders must be individually considered by the licence committee. The HFEA's sixth Code of Practice,[23] based on a public consultation and Outcome Document,[24] stated that PGD can be used only where there is a significant risk of a serious condition,[25] a matter for discussion between the people seeking the treatment and the clinical team. Following the White Paper,[26] which proposed a change so that there were explicit embryo testing criteria,[27] 1ZA(1)(b) has been added into the latest Bill[28] (Schedule 2, after Paragraph 1). Licenses under Paragraph 1 cannot authorise embryo testing, except for specified purposes including establishing embryo gene, chromosome or mitochondrion abnormality presence to which there is a particular risk. Whilst there are no accompanying Explanatory Notes for Bill 120, those for Bill 70 explain that this could refer to PGD.[29] Subparagraph (2) limits the use of Paragraph 1 to situations where there is a significant risk of a serious condition.[30]

The social model suggests remedial options extend to changing society. We should therefore try and accommodate disabled individuals and not eliminate the condition

There are a number of criteria for appropriate PGD use listed under Guidance 12.3.3 in the seventh Code of Practice.[31] There has been much discussion over differing definitions of and perspectives on 'serious' and 'significant', with several views even amongst health professionals and scientists highlighting this area's subjectivity.[32]

Legal Analysis using Ethics

Should we allow PGD at all? This depends on disability definition. The World Health Organisation (WHO) originally defined disease in terms of aetiology and process,[33] into which disability was subsumed: diseases can cause impairments, in turn causing disabilities, in turn causing handicaps.[34] They have been attributed to function breakdown[35] assessed by the species-typical, measured by the biostatistical or factual norm.[36] However, this medical model doesn't account for *super*normal deviations, not necessarily classed as *dis*abling,[37] nor function *need* but expectation, availability and acceptability.[38]

An alternative social model proposes that it is 'the disadvantage or restriction caused by a contemporary social organization which takes no or little account of people who have impairments and thus excludes them from the mainstream of social activities'.[39] Whereas the medical model may suggest if a condition cannot be medically treated, it should be eliminated e.g. by PGD, the social model suggests remedial options extend to

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[23] Supra, note 13

[24] HFEA and HGC. (18/06/01). *Outcome of the Public Consultation on Preimplantation Genetic Diagnosis*, Recommendation 11

[25] Paragraph 14.22

[26] Department of Health. (2006). *Review of the Human Embryology and Fertilisation Act*

[27] Paragraph 2.42

[28] HFEA. (2007-8). *Bill 120,* accessed 11/08/08 http://www.publications.parliament.uk/pa/cm200708/cmbills/120/2008120.pdf

[29] Paragraph 51, HFEA. (2007-8). *Bill 70 Explanatory Notes,* http://www.publications.parliament.uk/pa/cm200708/cmbills/070/2008070.pdf, accessed 11/08/08

[30] Paragraph 53, Ibid

[31] HFEA. (2004). http://cop.hfea.gov.uk/cop/pdf/CodeOfPracticeVR_3.pdf, accessed 15/07/08

[32] Scott, R., et al. (2007). The Appropriate Extent of Pre-implantation Genetic Diagnosis: Health Professionals' and Scientists' Views on the Requirement for a 'Significant Risk of a Serious Genetic Condition', *Med. L. Rev., 15*, 320-56

[33] WHO. (1980). *International Classification of Diseases, Injuries and Causes of Death (ICIDH)*

[34] Nordenfelt, L. (1995). On Chronic Illness and Quality of Life: A Conceptual Framework, *Health Care Anal., 3,* 290-8

[35] Kitcher, P. Creating Perfect People, in: Burley, J. & Harris, J. (Eds.) (2004). *A Companion toGenethics*. Malden: Blackwell Publishing, 229

[36] Boorse, C. (1977). Health as a Theoretical Concept, *Phil. Sci., 44,* 542-73; Daniels, N. (1985). *Just Health Care*. New York: Cambridge University Press, 28

[37] Nordenfelt, L. (1995). *On the Nature of Health: An Action-Theoretic Approach*. New York: Springer-Verlag, 19

[38] Silvers, A. A Fatal Attraction to Normalizing: Treating Disabilities as Deviations from "Species-typical" Functioning, in: Parens, E. (Ed.). (1998). *Enhancing Human Traits*. Washington D.C.: Georgetown University Press, 95-123

[39] Union of Physically Impaired Against Segregation (UPIAS) in a article entitled *Fundamental Principles of Disability,* www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/fundamental%principles.pdf, accessed 08/07/08

changing society.[40] The blame and coping responsibility are removed from the individual onto the surrounding environment.[41] We should therefore try and accommodate disabled individuals and not eliminate the condition. While this may be the case for society-induced handicaps where one can provide e.g. access to wheelchair users, no amount of societal support and adjustment can cure pain, suffering and poor quality of life associated with some conditions,[42] e.g. Tay Sachs. Here, the medical model and PGD are most useful, supported by consequentialism.[43] PGD is particularly justified when doctors, due to limited medical resources, discontinue treatment for sufferers who develop infections.[44] If resources are not spent on discomfort reduction post-birth, it may be the most humane thing to spare them this pain initially. The HFEA[45] has licensed PGD for late-onset conditions e.g. Huntington's disease, susceptibility genes and carrier status detection. The suffering reduction rationale also extends to these condition types which while are not of immediate or definite effect, may cause much unnecessary distress through knowledge of and condition manifestation.[46]

Judaism's perspective include the sanctity of life[1] and belief in each person being made in God's image (betzelem Elohim)

On this basis, it seems ethically acceptable for PGD to be legal, but there is an expressivist objection. Allowing society to discard affected embryos expresses a negative opinion towards existing people with those conditions who live good quality lives.[47] However, this suggests that the person and the disability are one and the same, refuted by many.[48] Either people are equated with or separate from their disability. Alternative definitions cannot be differentially used to suit the situation.[49] Also, while some people have a positive attitude towards disabled life, this may not and will not be shared by all, as demonstrated by the ongoing right-to-die debate.[50] While it could lead to decreased disability awareness and less research when non-selection results in fewer affected people,[51] if a conscious effort was made and maintained to continue education and research alongside PGD, this would not be a strong argument. There is an important role for organisations such as the Equality and Human Rights Commission[52] and development of, for example, dolls with disabilities,[53] which could raise awareness[54] or merely emphasise differences, in an unappealing way.[55] As an idea it does have potential if alternative models were manufactured.

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[40] Scully, J. L. (2004). What is a Disease? *E. M. B. O. Rpts., 5(7),* 650-3.

[41] Oliver, M. (1990). *The Politics of Disablement*. London: Macmillan, chapter 2, 23

[42] Shakespeare, T. (2002). The Social Model of Disability: An Outdated Ideology? *Res. Soc. Sci. Disabil, 2,* 9-28

[43] Savulescu, J. (2006). Bioethics: Utilitarianism, *Encyclopedia of Life Sciences*. London: John Wiley & Sons, 1

[44] Savill, R. (01/07/08). Mother Launches 'Right-to-Life' Legal Battle Against Hospital to Save Six-Year-Old Daughter, *The Telegraph*, www.telegraph.co.uk/news/2229487/Mother-launches-'right-to-life'-legal-battle-against-hospital-to-save-six-year-old-daughter.html, accessed 08/07/08

[45] Supra, note 8

[46] Robertson, J. A. (2003). Extending Preimplantation Genetic Diagnosis: Medical and Non-Medical Uses, *J. Med. Ethics, 29*, 213-6

[47] Shakespeare, T. (1998/9). Eugenics? Slipping Down the Slope, *Splice of Life, 5*, as cited in Boyle, J. B. & Savulescu, J. (2001). Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person, *B. M. J., 323*, 1240-3

[48] E.g. Folkins, J. (1992). American Speech-Language-Hearing Association's Resource on Person-First Language - The Language Used to Describe Individuals With Disabilities, *ASHA Publications Board*, http://www.asha.org/about/publications/journal-abstracts/submissions/person_first.htm, accessed 09/07/08

[49] Baily, M. A. Why I had Amniocentesis, in: Parens, E. & Asch, A. (Eds.) (2000). *Prenatal Testing and Disability Rights.* Georgetown University Press: Washington, 64

[50] Knox, R. (2003). Preimplantation Genetic Diagnosis: Disease Control or Child Objectification? *St. Louis U. Pub. L. Rev., 22,* 434-53.

[51] Popovsky, M. (2007). Jewish Perspectives on the Use of Preimplantation Genetic Diagnosis*, J. Law Med. Ethics, 35(4),* 699-711

[52] http://www.equalityhumanrights.com/en/Pages/default.aspx, accessed 29/07/08

[53] Fisher, L. (07/07/08). Parents' Fury at 'Down's Syndrome Dolls' Designed to Help Children Deal with Disability, *Daily Mail*, http://www.dailymail.co.uk/femail/article-1032600/Parents-fury-Downs-Syndrome-dolls-designed-help-children-deal-disability.html, accessed 09/07/08

[54] Campas, M. Ibid.

[55] Moorcroft, E. Ibid.

Useful principles to understand Judaism's perspective include the sanctity of life[56] and belief in each person being made in God's image (*betzelem Eloh-im)*.[57] Each person has intrinsic spiritual value no matter their abilities or lack thereof. There is even a blessing that to say upon seeing a deformed person.[58] Many laws concern *gemilut khasadim* (acts of lovingkindness)[59] and *tzedakah* (charity):[60] being compassionate to the needy.[61] The *Talmud* questions: 'Do you think your blood is redder than his? Perhaps his is redder than yours',[62] which serves to remind how judgments are made on externalities, lacking knowledge of individuals' true value. However, the disabled are excluded from the performance of several *mitzvot*[63] due to lack of required functionality. This could be seen as sparing the individual from unreasonable requirements, or withholding the spiritual status gained through their performance. In terms of PGD, individuals who already exist would still be given much care and assistance in Jewish communities, despite non-selection. PGD itself could be seen as a positive intervention, a kindness towards parents who need help producing healthy children[64] and enabling embryos to develop who could reach their maximum *halachic* potential.[65]

most poskim ***agree that IVF results in biological paternity and fulfils the procreation command***

Is using IVF for selecting embryos and not infertility a just resource allocation? IVF and PGD financial costs are justified by the alternative costs of continued support throughout a disabled child's life. For couples who have already experienced the heartache of fatal condition child loss, leaving their child's health to chance is not a consideration. Whilst not biologically infertile, they may feel that not having another child is the only PGD alternative, i.e. elective infertility with similar childlessness results.

In Judaism the need to undergo IVF for PGD can be problematic, disrupting normal sexual relations between the couple,[66] risking the mother's health and possible implantation when *niddah* (laws of family purity, avoiding sexual contact and procreation during men-struation and for seven further days).[67] Some[68] say IVF does not fulfil the command of *pru urvu* (be fertile and increase*)*.[69] However, most *poskim*[70] agree that IVF results in biological paternity[71] and fulfils the procreation command, a *mitzvah* so important that Israel offers free IVF.[72] Judaism sees value in potential life, extending to not wasting sperm (*Zera Levatala)*[73] which could occur in IVF. Most argue that this does not apply if sperm is being used at least in part to

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[56] A recurring principle in Jewish sources. E.g. Bereshit, 9:6, Berlin, A. & Brettler, M. Z. (Eds.). (1990). *Jewish Study Bible*. New York: Oxford University Press

[57] Bereshit 1:26-27, Ibid

[58] 'Blessed are You…who varies the forms of His creatures', Sacks, J. (2006). *The Authorised Daily Prayer Book of the United Hebrew Congregations of the Commonwealth*. Singers: London, 752; Brakhot 58b, supra, note 21

[59] E.g. Nedarim, 39b, supra, note 21; Rambam, Hilchot Avelot 14:1, supra, note 22

[60] E.g. Devarim 24:19-21, supra, note 56

[61] E.g. *A v Special Educational Needs and Disability Tribunal*, [2004] E.L.R. 293

[62] Pesakhim 25b, supra, note 21

[63] Outlined in Marx, T. (1993). Thesis: *Halacha and Handicap: Jewish Law and Ethics on Disability.* Jerusalem: Marx, T.

[64] Halperin, M. (1996). Lecture: *In-Vitro Fertilization (IVF), Insemination and Egg Donation*. Copenhagen, Denmark: International Congress on Medicine, Ethics and Jewish Law. Halperin M., In-vitro fertilization, insemination and egg donation, in: *JME Book* II: 162-171 (2006)

[65] Perhaps there is room for accommodating limited capabilities by reconceptualising command fulfilment, see Jeffay, N. (15/04/05). Making Their Day*, Jewish Chronicle*, 39; some of the greatest leaders, e.g. Moses, have had disabilities: Sh'mot 4:10-11, supra, note 56

[66] Shafran, Y. B. (1991). *Responsum to Richard Grazi*. Jerusalem: Department of Halacha and Medicine of the Jerusalem Religious Council, 20

[67] Forbidden in Shvadron, M. S (1961). *Teshuvot Maharsham , 3*, 268. Grosman: Jerusalem; Permitted in Feinstein, M. (1959). *Responsa Iggrot Moshe, Even HaEzer, 2*, 18. New York: Moriyah

[68] Waldenberg, E. (1944-82). *Tzitz Eliezer, 15*, 45. Jerusalem: Self-published

[69] Bereshit 1:28, supra, note 56

[70] Auerbach, S. Z. in: Breitowitz, Y. The Pre-Embryo in Halacha, *Jlaw,* http://jlaw.com/Articles/preemb.html, accessed 12/08/08

[71] Steinberg, A. (1982). Artificial Insemination in the Light of Halacha, *Sefer Assia, 1,* 128-141. Jerusalem: Schlesinger Institute

[72] Kolirin, L. (17/08/07). Israel's Birth Pains, *Jewish Chronicle,* 13

[73] Bereshit 38:9-10, Rashi Bereshit 38:7, supra, note 56; Rambam, Hilchot Issurei Biah 21:18, supra, note 22; Niddah 13a, 13b, supra, note 21

create offspring in an infertile couple.[74] Although with PGD the couple is generally fertile, where intent is to spare physical hazard, it is permitted.[75] What about discarding affected embryos? Whilst allowing IVF, Feinstein[76] prohibits embryo discarding in this situation. However, Auerbach allows it because producing healthy children is intended[77] as do Eliyashuv,[78] Zilberstein[79] and Lichtenstein[80] through consideration of parental anguish. The Committee on Medical Ethics of the Federation of Jewish Philanthropies of New York concluded that as the embryo was in a test tube environment in which viability is unattainable, it lacks humanhood and can be discarded.[81]

> ***legislation could ensure no parent is compelled to use this technology***

One could question the place of humans to intervene and dominate in what is considered God's world. However there is the belief that humans should do so, using world resources to continue God's creation (*tikun olam*: healing the world).[82] This is one way to be in God's image (seeing as God is considered non-corporeal). Therefore physicians are allowed to practice and heal.[83] However, a medical act that has no chance of healing violates the Jewish decree against tampering with God's creation.[84] PGD does not heal, it just selects one embryo over another, so this is a possible basis for Jewish prohibition. There seems to be a lack of *halachic* consensus within this area. Many authorities are yet to come to a conclusive ruling,[85] however, consideration of the individual issues could be informative for general secular discussion.

PGD highlights the issue of consumerism versus viewing children as gifts to love unconditionally, again dependent on whether one sees the person *as* their disability or a person *with* a disability. Using PGD *can* be seen as a consumerist choice, *or* as a desire for pain and suffering prevention for potential offspring manifested through parental reproductive choice. What right do the parents have to decide their child's health or existence? The post-natal test[86] can be of use: whatever is acceptable to do to an existing child is acceptable pre-birth. Parents do decide to withhold life-saving treatment from debilitated children.[87] If this is an acceptable action towards an existing child then it should be similarly acceptable at the embryonic stage.[88] Section 13(5) of the Act could be used as legal justification for using PGD to eliminate disability.

Once one legislatively allows choice, it is difficult to ensure motivations. However, if parents are concerned by lack of unconditional caring ability, perhaps those children should not be brought into the world by them anyway. Whilst there are fears that we will create a society where parents only accept those children with pre-birth selected characteristics, genetic counsellors can explain a number of facts. Only tested-for conditions can be ruled out, and even then, without one hundred percent certainty, congenital birth defects can still occur,[89] and parents should be

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[74] Yosef, O. in: Jakobovits, Y. (2005). Assisted Reproduction Through the Prism of Jewish Law, *Jewish Action, 65*, 3-4

[75] de Trani, I. in: Gourgey, R. (12/09/05). *Designer Babies: A Halachic Viewpoint*. Rimon Conference: London School of Jewish Studies

[76] Feinstein, supra, note 67, *1*, 62

[77] Auerbach, S. Z. in: Avraham, S. A. (1992). *Nishmat Avraham, 1*, 5. Jerusalem: Schlesinger Institute

[78] Eliyashuv, Y. S. in: Eisenberg, D. (2005). The Ethics of Genetic Screening, http://www.aish.com/societyWork/society/The_Ethics_of_Genetic_Screening.asp, accessed 14/07/08

[79] Zilberstein, Y. (1991). Selecting a Fetus for Implantation: Avoidance of Birth Defects and Determining Sex [Response to Richard V. Grazi, 1991]. *Noam, 8*, 47-8

[80] Lichtenstein, A. (1991). Abortion: A Halachic Perspective, *Tradition, 25(4),* 3-12

[81] Feldman, D. M. & Rosner, F. (1984). *Compendium on Medical Ethics*. New York: Federation of Jewish Philanthropies of New York, 28

[82] Bereshit 1:26, supra, note 56; Buber, S. (1925). *Midrash Shemuel*. Vilna: Romm, section 4

[83] Sh'mot, 21:18-9, Vayikra 19:16, Devarim 22:1,3, supra, note 56; Bava Kama 85a; Brakhot 60a; Sanhedrin 73a; supra, note 21 Shulkhan Arukh, Yoreh Deah, 336:1, in Steinberg, A. & Rosner, F. (2003) *Encyclopedia of Jewish Medical Ethics*. Jerusalem: Feldheim, 101

[84] Feinstein, supra, note 67, *3*, 90

[85] Rosner, F. (1998). Judaism, Genetic Screening and Genetic Therapy, *Mt. Sinai J. Med., 65,* 406-13

[86] Pennings, supra, note 21

[87] *Re T (A Minor) (Wardship: Medical Treatment),* [1997] 1 WLR 242

[88] Knox, supra, note 50

[89] Botkin, J. (1998). Ethical Issues and Practical Problems in Preimplantation Genetic Diagnosis, *J. Law Med. Ethics, 26*, 17-18

aware of and prepared for such eventualities.[90] Directed genetic counselling sessions could create a coercive atmosphere, but even just *providing* non-directive genetic counselling suggests that there is a choice that can and should be made, versus natural conception and pregnancy.[91] Whilst this is true, these decisions do not have to be taken. Parents could opt to let nature take its course. PGD does emphasise that disorders should not be blamed on individuals but rather on their genetic luck, but it is conceivable that social trends blaming parents for not availing themselves of offered PGD could develop.[92] Whilst fear and politics previously motivated eugenicists to aim to change trait possession, modern use of PGD is spurred by humanitarian concern, aimed at medical conditions.[93] However, in order to avoid eugenic associations with societal compulsion versus individual choice, legislation could ensure no parent is compelled to use this technology initially, nor be penalised by higher health insurance[94] for declining, especially as this could interfere with patient confidentiality by revealing preferably undisclosed paternity or disease inheritance.[95]

Judging case-by-case ensures the plight of individuals is considered rather than a one-size fits-all classification

Should 'serious', 'significant' and parent-doctor discussion remain the legal criteria? It is difficult to draw a non-arbitrary line between severe and non-severe, it being dependent on the circumstances and view point.[96] Therefore it seems ethically correct to legally leave decisions to a discussion using guideline criteria as a baseline.[97] Judging case-by-case ensures the plight of individuals is considered rather than a one-size fits-all classification,[98] avoids the sense of obligation of embryo non-selection if there is a list of conditions and pointless pregnancy continuance enforcement (with eugenic connotations) when abortion under the social ground could be used later on. Parents may indeed feel unable to cope with a severely disabled child who may have some quality of life, but never be independent, compromising their parenting ability. However, through genetic counseling the parents should have exposure to what living with disability entails, be reminded that all children can be burdensome, but just in different ways[99] and that a genetic test gives you a snapshot about one aspect of their child, not a complete picture.[100]

Given that PGD is legally permissible for some conditions, does this mean that if one only produces affected embryos, one is legally compelled not to implant them and to retry? Implantation can only cause embryo harm if life would not be worth living.[101] Following the White Paper prohibiting screening in disorders,[102] the latest Bill[103] proposes subsection (9) insertion in section 13 whereby one must not prefer embryos with a significant risk of serious condition development to those not known to have an abnormality.

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[90] Knox, supra, note 50

[91] Jennings, B. Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability. In Parens & Asch, supra, note 49, 131

[92] Ibid

[93] Gillott, J. (2001). Screening for Disability: A Eugenic Pursuit? *J. Med. Ethics, 27*, 21-23

[94] Knox, supra, note 50

[95] Hope, T. (2004). *Medical Ethics: A Very Short Introduction.* Oxford: Oxford University Press, 8

[96] Holm, S. Ethical Issues in Preimplantation Diagnosis, in Harris, J & Holm, S. (Eds.) (1998). *The Future of Human Reproduction: Ethics, Choice and Regulation.* Oxford: Clarendon Press, 176

[97] Whereas *foetal* destruction using abortion is based on 'substantial' conditions and needs a non-personally involved informed person's approval, Royal College of Obstetricians and Gynaecologists. (1996). *Termination of Pregnancy for Fetal Abnormalities*, Paragraph 3.2.1

[98] Glover, J. Eugenics: Some lessons from the Nazi experiments. In: Harris & Holm, supra, note 96, 55-65

[99] Vehmas, S. (2002). Parental Responsibility and the Morality of Selective Abortion, *Ethical Theor. Moral Pract., 5(4),* 463-84

[100] Baily, supra, note 49

[101] Savulescu, J. (2002). Deaf Lesbians, "Designer Disability" and the Future of Medicine. *B. M. J., 325*, 771-3

[102] Paragraph 2.43, supra, note 26

[103] Supra, note 28

While one may not be legally compelled to have PGD initially, once test information is obtained, one must use it to make a certain decision, which seems directive and restrictive given that it is the parents who will look after the child. It is also rules out consideration of it being the last child-bearing opportunity. While this may seem a justified restriction with Tay Sachs-type conditions, it may not for disorders with a quality of life. However if a clause was added to the effect of 'unless there was no other option' this would be a sufficient loop-hole to deliberately try to have disabled children, which we will examine next.

Deliberately Choosing Disability

Whilst PGD has not been used in the UK for this purpose, it is important to consider the ethics and legality as precaution and preparation, using deafness as an example. The American case of a deaf lesbian couple Sharon Duchesneau and Candy McCullough[104] who deliberately created a deaf child, using a deaf sperm donor, with five generations of deafness in his family prompts consideration of this issue.

by selecting a deaf child, one goes against nature's species-typical norm, restricts future choices and experiences of that child, contravening a child's right to an open future

From a social model, deafness is a difference entailing a high quality of life with societal adaptation. Deaf people argue that they have a rich cultural identity and sophisticated communication system, a mystery to those of the hearing world who lack their community experience. It is not parental selfishness to want to include their child in their community, a desire we all share, but an attempt to give them the best kind of life that they can. Prohibition of deaf embryo selection may express a non-acceptance attitude to already existing deaf people. One is not inducing deafness into a child, but selecting them to exist,[105] an argument used to distinguish between deaf embryo selection and deafening a hearing child, which should not be allowed.[106] Many argue that they would prefer a deaf life to non-existence. While deaf embryo selection results in a difference that other embryos would not have, it can be considered on par with all the socially accepted environmental differences parents establish and supports the notion of reproductive freedom. Few people would avail themselves of this technology and so it would not drastically change society.[107] Whilst allowing the use of PGD to select deaf embryos may be acceptable according to these arguments, fresh consideration would be needed for other conditions causing suffering.[108]

From a medical model deafness *is* a non-curable disadvantaging disability, as supported by those who have sued when they discovered that their child was deaf post-birth.[109] Thus, if there is a choice, healthy versus deaf embryos should be implanted. Biologically, we are created with ears for many functions. However, by selecting a deaf child, one goes against nature's species-typical norm, restricts future choices and experiences of that child, contravening a child's right to an open future.[110] Whilst Mill[111] was in support of liberty (reproductive freedom), this was only until one person's liberty infringed another's. One ensures communication and integration difficulty in the hearing world.

During a personal informal discussion with a cochlear implantee deafened by meningitis as a

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[104] Spriggs, M. (2002). Lesbian Couple Create a Child who is Deaf like Them. *J. Med. Ethics, 28*, 283-4

[105] Parfit, D. (1984). *Reasons and Persons.* Oxford: Oxford University Press, 359

[106] Häyry, M. (2004). There is a Difference Between Selecting a Deaf Embryo and Deafening a Hearing Child, *J. Med. Ethics, 30*, 510-12

[107] Savulescu, supra, note 101

[108] Buchanan et al, (2000). *From Chance to Choice*. Cambridge: Cambridge University Press, 156

[109] *Harriton v Stephens*. [2002] NSWSC 461

[110] Feinberg, J. The Child's Right to an Open Future, in Allen, W. & LaFolette, H. (Eds.). (1980). *Whose Child? Children's Rights, Parental Authority and State Power*. Totowa, New Jersey: Littlefield, 124-53.

[111] Mill, J. S. (1910). *On Liberty*, London: J. M. Bent & Sons, 20

toddler, they said that would be equally accepting if their child was deaf or not but they would never wish a disability upon their child. They had an impression of close-mindedness in the deaf world which considered them a traitor for using unnatural means to be part of the non-deaf world.[112] While deaf people argue that they are not being selfish, thinking deafness will be best for their child, they lack hearing world experience and understanding of their child's deprivation. Why not select hearing children and surround them with deaf culture resulting in the best of both worlds?[113] When there is the possibility of not bringing disabled people into the world needing extra allocation of finite resources for support, it would be prudent to take the opportunity to conserve resources and use them for existing people with disabilities. Therefore, while there is no harm to the embryo involved, there may be societal harm.[114] In terms of Judaism, discarding healthy embryos in this situation may not be justified. If, as we will argue, this technology should not be used in order to create designer children, than why should this use of it be allowed, when it is no less consumerist and is questionably beneficial?[115]

It appears ethically and legally acceptable to prefer the use PGD over abortion for conditions which would cause much suffering provided that it is accompanied by genetic counselling and societal education on disability

For this use of PGD, both sides have strong arguments, dependent on distinctive life experiences, hard to fully comprehend without experience,[116] akin to viewing a face-goblet optical illusion.[117] One could argue that while last resort defective embryo implantation should be permissible, this is morally distinguishable from deliberately setting out to find the deaf embryo. Current legality of deliberate deaf embryo selection is as outlined above for disability elimination and could be prohibited when considering section 13(5) of the 1990 Act. In the light of the ethical discussion above, it is difficult to ascertain what would be the best legal framework regulating this area. If individuals should judge for themselves what constitutes their child's best life, it becomes difficult to then draw a distinct legislative line between this and designer selection as discussed later. Whilst current law does not allow maximal reproductive freedom, it does stall the feared 'slippery slope' and is in keeping with much ethical thinking. The HFEA has come under much criticism for its lack of ethical foundation. This is one area in which the ethical reasons underpinning its prohibition could be made clearer.

Preconception Alternative

As Jewish and Israeli culture places much emphasis on an alternative to abortion and PGD, premarital screening, the Jewish and not the secular perspective will be considered. In *talmudic* times, it was forbidden to marry a woman from an epileptic or leper family lest the condition be transmitted in the future.[118] *Dor Yisharim* carries out screening, disclosing individuals' genetic compatibility by matching numbers representing their results. Though breaking three cardinal rules of screening (screening minors, result non-disclosure, directive)[119] it is effective in greatly reducing condition incidence. No other country has such a widespread programme. Perhaps no other country feels it can, given eugenic history. R. Feinstein[120] supported Tay Sachs testing if one is

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[112] Informal discussion with anonymous individual, 16/07/08

[113] Savulescu, supra, note 101

[114] Utilizing the transpersonal harm notion: Glover, J. (2006). *Choosing Children*. Oxford: Clarendon Press, 73-104

[115] A stance with which Judaism may agree, see Popovsky, supra, note 51

[116] Magee, B. & Milligan, M. (1995). *On Blindness*. Oxford: Oxford University Press, 14-59

[117] Koch, T. (2001). Disability and Difference: Balancing Social and Physical Constructions, *J. Med. Ethics, 27,* 370-6

[118] Yevamot 64b, supra, note 21, Rambam, Hilchot Issurei Biah 21:30, supra, note 22, Shulkhan Arukh Even HaEzer 2:7, in Sinclair, D. (2003). *Jewish Biomedical Law*. Oxford: Oxford University Press, 122

[119] Gessen, M. (08/07/08). Night Waves, *BBC Radio 3*, 21.45-22.30

[120] Feinstein, supra, note 67, *4, 10*

preparing to marry, suggesting test availability advertisement, but result non-disclosure and test discretion, i.e. not in mass groups. R. Bleich[121] concurs in encouraging screening, but argues the best time for screening is early adolescence and supports mass screening. Savulescu[122] lists predictive testing's many advantages including decreasing future risk uncertainty and increasing genetic condition societal openness. Criticisms including impaired marital prospects and discrimination apply only with result disclosure. Despite non-disclosure disadvantages, more widespread use of this could be encouraged.

Based on the discussion in this chapter, it appears ethically and legally acceptable to prefer the use PGD over abortion for conditions which would cause much suffering provided that it is accompanied by genetic counselling and societal education on disability. Although there is still a lack of Jewish consensus in this area halachically, Jewish opinions and rulings could still inform secular ethical and legal discussions and could emphasise the possible increased role of premarital screening alternatives when viable.

International Responsa Project

When a medical procedure raises ethical, moral, or halachic questions, advice from a reliable source is needed. The International Responsa Project provides this service to people all over the world who send their questions – some of general and theoretical, some specific and technical – via e-mail (irp@medethics.org.il), website (www.medethics.org.il), telephone, fax, and post. The questions are answered as quickly as possible by one of the rabbi-doctors at the Institute. The following are samples of recent questions and their answers. Please note that these are answers to specific questions and no general halachic conclusions should be drawn. A competent halachic authority should always be consulted.

Subject: Shiduchin & procreation with Klinefelter's Syndrome
Date: January 2009
Answered by: Rabbi Mordechai Halperin, M.D.

Shalom,

A boy with kleinfelter, lo aleinu, parents want to know what and what not is one allowed to check pre-marriage? Is freezing of sperm allowed in case there will be some use for the sperm later on?

Yours sincerely

If a young man is diagnosed as Klinefelter, and he has some sperm cells in his ejaculate, he is allowed to freeze the sperm cells for further use. In principle, he is also allowed to perform a sperm test for that purpose, but practically this should be done only after consulting with a prominent Rabbinic authority.

The late Rabbi Shlomo Zalman Auerbach told me that it is permitted to perform sperm test in order to find out if a man has a chance to have children, as it may effect his future decision with whom to marry.

For more references, please see ASSIA Book Vol. VII (Hebrew) pp. 273-303.

Continuation of IRP section on p. 59

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[121] Bleich, J.D. (1977). *Contemporary Halachic Problems*. New York: KTAV, 109-115.

[122] Savulescu, supra, note 101