Fundamental problems and solutions concerning genetic testing (first part)

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When in 1989 a European Parliament's resolution banned all genetic research external to the womb because of the related dangers of selection that continue to be in force, a new tendency was quickly emerging.[1] This tendency now suggests that it is only a matter of time and a question of indication or intention before human genetic selection will become commonplace. The need for clarification is indicated by such breaks in continuity, and concerted action is indispensable at all levels.

In the normative debate on genetic testing and prenatal diagnostic technologies, at least two levels of discourse can be discerned. One level concerns socio-ethical issues, such as social attitudes towards the unborn or disabled persons, the role of the scientific community, and the economic structures that condition research and therapy. A second level concerns micro-ethical issues, for instance questions regarding the individual's rights to health and life, the relation between testing and the risks involved for the individual, rights regarding information

[1] Cf. Strobel E.: *Gentherapie beim Menschen. Empfehlungen der European Medical Research Councils*, Fortschritte der Medizin, Volume 107, Issue 4, 10 Febuary 1989, page 56. (Translation of the title: *Gene therapy in the human. Recommendations of the European Medical Research Councils*).

Also cf. Beneken J.E.: *Medical research in the European community*, Journal of Medical Engineering and Technology, Volume 13, Issue 1-2, Jan-Apr 1989, pages 2-4.

and autonomy, and the role of the physicians involved. This second level is the concern of the present article.

1. Embryo status, research and legislation

1.1. Is the human embryo a person with rights?

Research and legislation treat the embryo according to the concept they have of it. They might consider it as a person with human rights, or as a non-person without them. There might also be ambiguity both in concept and in practice. For instance, the criteria proposed by the Steering Committee on Bioethics of the Council of Europe, in Articles 16 and 17, seems to be incoherent with what it proposes in Article 18 where it paves the way for experimentation on live embryos.[2]

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[2] Cf. Council of Europe, Steering Committee on Bioethics (CDBI): *Draft Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Bioethics Convention and Explanatory Report*, Strasbourg, France: Council of Europe, Directorate of Legal Affairs, July 1994, Chapter 5, Articles 16 to 18.

Article 16 (Protection of persons undergoing research): Research on a person may only be undertaken if all the following conditions are met: i) there is no alternative of comparable effectiveness to research on humans, ii) the risks which may be incurred by that person are not disproportionate to the potential benefits of the research, iii) the research project has been approved by the competent body after independent examination of its scientific merit, including assessment of the importance of the aim of the research, and multidisciplinary review of its ethical acceptability, iv) the persons undergoing research have been informed of their rights and the safeguards prescribed by law for their protection, v) the necessary consent as provided for under Article 5 has been given expressly, specifically and is documented. Such consent may be freely withdrawn at any time.

Article 17. (Protection of persons not able to consent to research):

1. Research on a person without the capacity to consent as stipulated in Article 5 may be undertaken only if all the following conditions are met: i) the conditions laid down in Article 16, sub-paragraphs (i) to (iv), are fulfilled; ii) the results of the research have the potential to produce direct benefit to his or her health; iii) research of comparable effectiveness cannot be carried out on individuals capable of giving consent; iv) the necessary authorization provided for under Article 6 has been given specifically and in writing, and v) the person concerned does not object.

2. Exceptionally and under the protective conditions prescribed by law, where the research has not the potential to produce results of direct benefit to the health of the person concerned, such research may be authorized subject to the conditions laid down in paragraph 1, sub-paragraphs (i), (iii), (iv) and (v) above, and to the following additional conditions: a) the research has the aim of contributing, through significant improvement in the scientific understanding of the individual's condition, disease or disorder, to the ultimate attainment of results capable of conferring benefit to the person concerned or to other persons in the same age category or afflicted with the same disease or disorder or having the same condition; b) the research entails only minimal risk and minimal burden for the individual concerned.

Article 18. (Research on embryos in vitro):

According to the Jean Michaud's Explanation, approved by the Steering Committee and the Committee of Ministers, "it was acknowledged that it was a generally accepted principle that human dignity and the identity of the human being had to be respected as soon as life began."[3] This seems to contradict the fact that the Council suggests permitting the law to allow research on embryos *in vitro*, for it is difficult to perceive how an embryo that is being used for research purposes can be adequately protected, given that the embryos used in *in vitro* research are later discarded. The question also arises concerning where these particular embryos come from; it seems that they might have to be produced for the purpose. Yet, Article 18, 2 prohibits such production. Such incoherence in the document is quite unfortunate.

Moreover, the embryo is obviously not able to consent to research, and, therefore, it must be decided whether or not to implement the criteria concerning proxy consent given in Article 17 which is applied to persons. What is at stake is the individual protection of the embryo who undergoes research and its corresponding status, whether or not it is a person. The question is, must its health and life be guaranteed, and must there be direct benefit for it from the potential results of the research as in the case of a human person, and, likewise, must the risk be proportionate to the potential benefit?

Many consider that here also scientific research should have autonomy, and need not necessarily be guided by an imposing moral criteria. Some would consider that enforcing any moral criteria would be a grave hindrance to scientific development, rather than an incen-

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1. Where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo.

2. The creation of human embryos for research purposes is prohibited.

[3] Michaud J.: *Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Amplification of Biology and Medicine*, Directorate of Legal Affairs (for the Council of Europe), Strasbourg, May 1997, number 19, the explanation of Article 1.

This Explanatory Report to the Convention on human rights and biomedicine was drawn up under the responsibility of the Secretary General of the Council of Europe, on the basis of a draft prepared, at the request of the Steering Committee on Bioethics (CDBI), by Mr. Jean Michaud (France), Chairman of the CDBI. It takes into account the discussions held in the CDBI and its Working Group entrusted with the drafting of the Convention and the remarks and proposals made by Delegations. The Committee of Ministers authorized the publication of this Explanatory Report on 17 December 1996. The Explanatory Report is not an authoritative interpretation of the Convention. Nevertheless, it covers the main issues of the preparatory work and provides information to clarify the object and purpose of the Convention and to better understand the scope of its provisions.

tive towards a progress that respects human dignity and maintains it as its inherent and principal fundament.

Embryo status is frequently considered in relation to the mother. Judicial intervention in pregnancy and birth – the use of legislation and court decisions to control a pregnant woman's behavior in situations where a fetus is thought to be at risk – provides another example of how embryo status can raise new issues for society. Along with the technological developments, new diagnostic capacities with regard to the fetus have the potential for both positive and negative consequences. On the positive side, society has become increasingly aware of the effects of tobacco, alcohol, drug abuse and nutrition on the health of the fetus during pregnancy. The ability to analyze the fetus with the aid of genetic diagnosis can allow better management of the pregnancy when this is necessary; the information gained may allow fetuses with certain anomalies to be treated at birth and, although in rarer cases, prenatal treatment could lead to the birth of a healthy child.

Because of these new capacities, there has also been an increasing tendency to view the fetus as a patient separate from the pregnant woman, and as having interests which may conflict with hers. In extreme cases, this perception of the relationship between a woman and her fetus as separate can lead to efforts to force compliance by the pregnant woman to act in the interests of this separate patient. However, even if the woman and her child are considered as two separate human beings, the woman as mother is most often considered as responsible for her child and with the corresponding duty to care for the infant, nurture it adequately and ensure its integral welfare in so far as this is possible. It is difficult to see any solid foundation for this if the embryo were really not considered a person.

Whether or not there be judicial intervention would depend on what concept the law has of the embryo. If it were considered as a person, the woman who is judged to be endangering the fetus she is carrying by drug abuse or alcohol or by refusing medical treatment believed necessary for fetal health, might be liable for prosecution; a woman could inclusively be ordered to refrain from specific activities, or to undergo intrusive medical procedures, including caesarian sections, if this were considered necessary for the health of the fetus. If, on the other hand, the law did not consider the fetus as a person, then no prosecution would be necessary and practices such as abortion or experimentation on live embryos would not represent any legal matter.

There are significant legal, ethical and practical problems with judicial intervention as a response. It might violate the pregnant woman's human and constitutional rights, it might infringe on her personal autonomy or that of the fetus, and, equally significant, it might be ineffective, or even produce the opposite effect to that which is intended.

It is generally accepted that all individuals have the right to make personal decisions, and to have their bodily integrity respected. These rights are not mere legal technicalities; they represent some of the most deeply held values in any society and form the basis for fundamental human rights. In this light, is compelling a pregnant woman to conform to certain standards of behavior, or requiring her to undergo surgery or other invasive procedures, an unacceptable violation of her individual rights? On the contrary, is the creation of pseudo-necessities by some sectors of the pharmacological industry, and for mere economic reasons, justifiable? Does a woman have the right to undergo the invasive methods inherent to many genetic tests that imply a risk for her fetus when there are no indications that suggest the necessity to do so?

If society imposes a legal obligation upon a woman to care for her fetus – even if it were possible to legislate a caring and nurturing relationship – the potential for curtailing women's choices and behavior is great. The kinds of substances and activities that could pose a danger to the fetus are many, varied, and increasing: cigarettes, alcohol, drugs (both legal and illegal), environmental pollutants, strenuous exercise, saunas, inadequate nutrition, etc. As medical research leads to a better understanding of how the fetus is affected and by what, the list is becoming longer. Where should the line be drawn? Some argue that every woman's management of her pregnancy could be potentially subject to challenge and scrutiny.

It is of particular concern that the threat of judicial intervention could have significant negative effects on fetal and maternal health. If women knew that they could be confined against their will, forced to submit to medical treatment, or charged with criminal offences, some might well avoid seeking medical care, and, unfortunately, those might be the ones who most need it; women who are dependent on drugs or alcohol, for example. As a result, health problems would escape detection and treatment, which would be precisely the opposite effect sought by those who would use judicial means to intervene. If physicians are perceived to be potentially coercive instead of caregivers, some women might begin to withhold information or stop seeking

prenatal care, with detrimental consequences for their health and that of the fetus.

In an attempt to avoid an ethical gridlock on human embryo research that subsequently led to the blockage of funding, the Human Embryo Research Panel was created to recommend guidelines for such funding of research on embryos.[4] It met six times from February to September 1994, when the final report was issued.[5]

The results were far from adequate from a personalist point of view.[6] The panel classified potential research involving *ex utero* human embryos into one of three categories: research acceptable for federal funding, research warranting additional review, and research unacceptable for federal funding.[7] No serious effort was made to determine whether or nor it is morally correct to experiment on live embryos. The problem concerning the status of the human embryo was completely ignored, hardly on account of a lack of scientific knowledge, more likely on account of a premeditated utilitarian omission.[8]

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[4] Cf. United States. Human Embryo Research Panel: *Proceedings of the Meeting of the Human Embryo Research Panel, Bethesda, MD, 27 Sep 1994: Review of panel's scientific findings; Review of panel's public policy conclusions and recommendations; Ethical considerations in preimplantation human embryo research; Sources of gametes and embryos for research; Principles and guidelines for preimplantation human embryo research and categories of preimplantation human embryo research*, The Panel, Bethesda MD, 27 September 1994.

[5] Cf. Annas G.J.- Caplan A.- Elias S.: *The politics of human-embryo research-avoiding ethical gridlock*, New England Journal of Medicine, Volume 334, Issue 20, 16 May 1996, pages 1329-1332.

[6] Cf. Green, R.M.: *Report of the Human Embryo Research Panel*, Kennedy Institute of Ethics Journal, Volume 5, Issue 1, March 1995, pages 83-84.

Also cf.: *The Human Embryo Research Panel: lessons for public ethics*, Cambridge Quarterly of Healthcare Ethics, Volume 4, Issue 4, Fall 1995, pages 502-515.

Also cf. Marwick C.: *NIH panel finds embryo research justifiable, recommends support*, JAMA, Volume 272, Issue 17, 2 November 1994, pages 1311-1312. Also cf. Gershon D.: *US panel firms up views on embryo research*, Nature, Volume 370, Issue 6484, 7 Jul 1994, page 8.

[7] By majority vote, the 11 researchers and 8 non-researchers on the panel (a total of 10 men and 9 women) concluded that research on methods of improving the chances of pregnancy – fertilization; egg activation, maturation, and freezing; genetic diagnosis before implantation; and the development of embryonic stem cells – was acceptable for federal funding. Research on the cloning and use of oocytes without their transfer to the uterus for gestation was considered to warrant additional review. Unacceptable research included the cloning and use of oocytes followed by transfer, and cross-species fertilization.

[8] The panel offered specific guidelines for the review and conduct of federally funded research. The guidelines stipulated that there be a qualified researcher and a valid research design promising major scientific or clinical benefit; that the research goals not be accomplishable with animals or gametes; that the number of embryos required for the research be kept to the minimum necessary to ensure valid results; that informed consent be

The composition of panels such as this one has been widely criticized. For example, an earlier NIH panel on the use of fetal tissue for transplantation research was criticized by right-to-life groups for including too few members with explicit right-to-life views. Others have said that the Human Embryo Research Panel and earlier panels had too many scientists as members. Feminists have also complained that past embryo-research panels, such as the Ethics Advisory Board, were made up almost exclusively of men and had a tendency to view embryos and fetuses... as a man's sperm personified (making them) appear to be real to these men in a way women are not. The Human Embryo Research Panel was balanced according to sex, but nonetheless there may have been insufficient attention to the vast differences involved in supplying sperm as compared with ova.

The surprising fact is that while many dedicate time to arguing whether, for a question of equilibrium and rights, more men or women should be on the panel, or whether more scientists etc., the principal issue is forgotten, omitted or simply ignored: namely, the question concerning the status of the human embryo, whether it is or not a human person, and, as such, whether it has the fundamental and inalienable right to life and health.

In some countries, for example in the United Kingdom, the creation of embryos is allowed for the sake of scientific progress.[9] The need for a moral argument is most vividly demonstrated by the question of whether or not to allow embryos to be created solely for research. A recommendation in favor of this idea was publicly rejected by President Clinton in December 1994 and probably eroded whatever public support the report might otherwise have received at the time. As subsequent congressional action has clearly indicated, anyone who recommends federal funding for research on embryos has the burden of persuasion, at least at the moment.

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obtained from gamete donors; that no gametes or embryos be purchased or sold for use in research; that the research protocol be reviewed by an institutional review board; that gamete donors be selected equitably; and that no research be conducted on embryos more than 14 days after fertilization.

[9] This is not surprising, especially when one examines the Human Embryo Research Panel's description of a human embryo. In fact it described the human embryo as significantly smaller than the period at the end of this sentence; words that suggest that we should judge an embryo's value by its size, given that it is after all just a speck or a dot.

1.2. Personal dignity and the human embryo

It is clear that an ethical framework must be applied to the question of judicial intervention. This framework could comprise commitment to an ethic of care which seeks to prevent conflict before it arises, and to guiding principles which include: respect for all human life from the moment of conception, autonomy, equality, respect for human life, protection of the vulnerable, appropriate use of resources, non-commercialization of reproduction, accountability, and balancing individual and collective interests. Such an ethical framework predisposes to viewing judicial intervention with considerable reservation. As we can learn from history, the potential for harm is evident, and the results potentially devastating.

Regardless of whether a fetus is a "person" with "rights," it is clear to most people – except perhaps for some like Engelhardt, or at least as much as can be deducted from some of his affirmations – that the interests of the fetus are worthy of protection.[10] What transpires before birth can seriously affect the health and well-being of the child who is eventually born. Society, therefore, should have an interest in promoting the prenatal health and well-being of the fetus and of the woman carrying it. No coherent society can willfully accept harm to a fetus. Precisely for this reason judicial intervention in pregnancy and birth should be examined carefully before deciding whether it is a course that should be followed.

What must be decided is whether the dangers posed by allowing judicial intervention outweigh the benefits that it might yield. After all, if society is really concerned about questions like child abuse, it should also be concerned about the abuse of a child before birth, and it should count upon legal resources to ensure that no such abuse ever takes place. If child education is subject to liability, this surely makes pregnancy a condition subject to liability also. Precisely because there can be abuses on both sides, cautious legislation and judicial intervention are necessary.

In evaluating judicial intervention, above all regarding genetic testing and diagnosis, major concern should be in line with the ethic of care; the goal of genetic testing and diagnosis should be the protection of the life and health of every embryo, while fostering relationships

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[10] Cf. Engelhardt H.T.: *The Foundations of Bioethics*, Oxford University Press, second edition, New York 1996, page 144: "One must remember that the level of obligations one has to a fetus, *ceteris paribus* in general secular morality, is the same as one would have to an animal with a similar level of sensory motor integration and perception."

that respect human dignity and that protect it from all harm. The best possible prenatal health should be ensured along with the maximum degree of well-being for both the pregnant woman and the fetus.

Legislation regarding genetics cannot remain indifferent with respect to these problems. By its very nature legislation is called to define the fundamental rights of the person and to configure the instruments to be used to defend and promote them. It is the duty of jurisprudence to defend the genetic identity of every human being, embryo, child or adult, in every stage of life. The necessity for such legislation is all the more true with regard to those lives which are more fragile and helpless in the midst of an increasing and powerful technological growth, namely embryos, infants, the mentally retarded, the elderly, and comatose persons.

The defense and the integrity of the human embryo is the duty of every citizen – and especially of the mother – called to respect the gift of life, and it is the duty of the juridical order to supervise the members of society in the respect of this gift in which resides the primary and fundamental value and the condition of possibility of every human association.[11]

For these reasons the embryo ought to be recognized by the laws of the nations as a subject with rights. If not, humanity endangers itself. When it defends the embryo, society recognizes in this small vulnerable being that which each and every person is at the beginning of his or her existence. When society guarantees respect for its weakest members, it satisfies the fundamental need for justice and solidarity which unites the entire human family.[12]

The health and well-being of a fetus can better be achieved by examining the reasons for the behavior that is putting a fetus at risk, and seeking solutions to address them. In doing so, it should be possible to prevent a situation developing where child welfare, medical, or other authorities might consider judicial intervention necessary.

Clearly, the majority of women act in a manner they believe to be in the best interests of their fetus. This implies that the best way to

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[11] Cf. John Paul II: *Scienza medica e diritto a difesa dell'integrità della persona*, All'Unione Giuristi cattolici, Insegnamenti di Giovanni Paolo II, Libreria Editrice Vaticana, Volume 10, Issue 3, 5 December 1987, number 2.

[12] Cf. John Paul II: *Utilizzare l'embrione come puro oggetto di sperimentazione significa attentare alla dignità della persona e del genere umano*, Udienza al Gruppo di lavoro sul genoma umano promosso dalla Pontificia Accademia delle Scienze, Insegnamenti di Giovanni Paolo II, Libreria Editrice Vaticana, Volume 16, Issue 2, 20 November 1993, number 8.

promote prenatal health is to provide the integral information and support necessary to enable pregnant women to make healthy, informed choices for the well-being of themselves and their fetuses, and informing them, in non-coercive, non-judgmental ways, about the implications of their decisions.

Extending care to the fetus by giving the pregnant woman the support she needs provides the best hope for enhancing the health and well-being of both. Society as a whole cannot ignore, however, what happens when this positive environment breaks down, as it does in some cases. No moral argument can be persuasive for conducting any type of research on live human embryos, less still if they are "made" specifically for that purpose.

Equally unacceptable is every form of experimentation that damages the fetuses integrity, unless it is an extreme attempt to save it from sure death,[13] since an embryo has moral standing not only because it is the result of procreative activity, but above all on account of what it ontologically is from the moment of conception onwards: a human being, a person with inalienable rights. Given that scientific research must be orientated towards a respect of the dignity of the human person and the sustenance of human life, scientific validation according to the particular laws of each discipline is not sufficient. Therefore, any scientific action – such as the genetic intervention on embryos – must also be positively qualified from the ethical point of view, that is to say, for the good and perfection of the human person as an individual and at community level.[14] The strong public reaction to the ongoing embryo scandal at the University of California at Irvine, for example, occurred not only because embryos were made the objects of medical research, but also because they were used to create babies without either the consent of the ova providers or disclosure of information about the origins of the children to the parents now raising them. People have a direct interest in the status and fate of every embryo formed from their gametes, because such embryos carry their genes and are their children. Besides that, it is their duty to have such

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[13] Cf. John Paul II: *Il progresso scientifico non può prescindere dalla dignità del trascendente destino dell'uomo*, Ai partecipanti al convegno del «Movimento per la vita», Insegnamenti di Giovanni Paolo II, Libreria Editrice Vaticana, Volume 5, Issue 3, 3 Dicembre 1982, number 3.

[14] Cf. John Paul II: *Non possiamo nascondere il pericolo che la scienza subisca la tentazione del potere demiurgico, dell'interesse economico e delle ideologie utilitariste*, Udienza: Ai membri della Pontificia Accademia per la Vita riuniti in Assemblea Generale, 20 Novembre 1995, in La Traccia, Number 11, 1995, number 3.

an interest. Similarly, society has a direct interest in that embryo, since society has a concern in how its members procreate and how families are created. The smallest member, and the condition of possibility of every society, is the human embryo. If society insists on harming or killing its fundamental cell, if it cannot or will not protect the human embryo, then it cannot expect to protect itself; to eliminate its condition of possibility of existence is to eliminate itself.

It must therefore be firmly asserted, that embryo's moral status derives from what it ontologically is in reality and not only from a property or from a cluster of properties – such as the genetic information – it possesses, or from the interests that potential parents and society bring to procreation and reproduction. The moral criterion of genetic research is the human person who is physical as well as spiritual. Therefore, anything that offends the human dignity of embryos – such as their creation for genetic research, or using them in a way that hinders their integral growth – is immoral.

This does not mean that scientific research in genetics is condemned to ignorance, but rather it is an invitation to scientists to use their ingenuity in a way that can also protect the individual embryo, thus rendering their services not only useful but also moral and in favor of the human community, which is the goal of scientific genetic research in the first place.[15] To create embryos for research, or to sell them, or to use them in toxicity testing, not only puts women at risk as sources of ova for projects that provide them no benefit, but it also cheapens the act of procreation by converting embryos into mere objects, commodities that can be purchased at will, as if from a supermarket, used or deprived of life and thrown out like an empty beer bottle.

2. Doubts concerning preimplantory and prenatal diagnosis

During the past two decades genetic testing has rapidly become part of everyday life; prenatal screening for fetal defects has become a standard part of nearly every pregnant woman's medical care in first world countries. Tests conducted during the first half of pregnancy are

[15] Cf. John Paul II: *Utilizzare l'embrione come puro oggetto di sperimentazione significa attentare alla dignità della persona e del genere umano*, Udienza al Gruppo di lavoro sul genoma umano promosso dalla Pontificia Accademia delle Scienze, Insegnamenti di Giovanni Paolo II, Libreria Editrice Vaticana, Volume 16, Issue 2, 20 November 1993, number 7.

designed to detect a wide range of genetic and other disorders, and evidence shows that frequently this is designed in order to give women the option of obtaining abortions if defects are diagnosed. Some people have heralded this development as a breakthrough in the age-old war against disease.

Others regard it as more than that: a tool to improve society. Modern birth control methods, the argument goes, brought us quantity control; the addition of prenatal testing offers an even more efficient system of quality regulation. For the first time in history, parents are able to "customize," albeit in limited ways, the kinds of children they bring into the world. Procreation seems to become a supermarket-type activity. If you don't like the product, just leave it on the shelf and choose something else. With the development of IVF and genetic testing one will probably be able to acquire the type of fetus according to subjective desires, "ad hoc" as regards eyes, race, color, IQ, sex, height and weight etc.

2.1. Preimplantory genetic diagnosis

With regard to the ethical issues involved in preimplantory genetic diagnosis (PID), some of these issues are specific for PID, while others concern prenatal diagnostic technologies as a group. The introduction and further development of PID is closely linked to preclinical research with human "pre-embryos." The ethics of such research is very controversial. A more general question is whether there are any convincing moral arguments for having a PID rather than a regular prenatal diagnosis. Gender selection for social reasons – the major example of selection for non-medical reasons – is highly debatable. Such selection could, according to some of its proponents, take place without destroying "pre-embryos" of the undesired sex by donating them to infertile couples, and thus contribute to a "gender distribution." One may wonder, however, whether such donations would only add to the large numbers of frozen surplus "pre-embryos" already waiting for adoptive parents. Another case, still hypothetical, that needs to be scrutinized is PID for dysgenic purposes. An example could be a deaf couple, fertile or infertile, preferring to have a deaf child. PID, aimed at a selective transfer of deaf "pre-embryos," is another case for non-directive counseling, but some consider that this constitutes a perversion of reproductive medicine.

PID faces yet another problem when the "pre-embryos" are identified as carrying an autosomal recessive or an X-linked recessive dis-

order. The question is what would be the transfer-policy with regard to these healthy carriers. The major reason to not transfer healthy carriers, would be to prevent difficult reproductive decisions for the prospective children who would have a higher risk of having a handicapped child. In order to develop a sound transfer-policy, it would then be necessary to draw a distinction between "pre-embryos" carrying autosomal recessive disorders on the one hand and (female) "pre-embryos" carrying X-linked recessive disorders on the other hand. Indeed, the genetic risks for the second generation will be much greater in the latter case; approximately 50% of the future boys will get the disease. So once again the specter of selective abortion appears.

Then there is another question regarding whose "pre-embryo" is it anyway; some might claim that it belongs to the woman who donated the ovum, while others assert that it belongs to the sperm donor, or to the ovum or sperm bank, or to the clinic or laboratory involved in the process, or to those who paid for the process, or to the state. It all seems to depend on what interests are at stake.

In preimplantory genetic diagnosis, a number of relevant moral problems of IVF are in close association with the reproductive context: the problem of prevention coupled with the problem of cause; individual socio-psychological factors; homologous and heterologous areas of application; border cases in the desire to have a child. What remains uncontroversial is that psychological factors play a fundamental role and that – to cite an example – the increase in relative subfertility can be conditioned by postponing the desire for children. The internal contradictions of the persons involved must also be taken into consideration, no less so than an exaggerated desire for children without a trace of ambivalent feelings or thoughts.

The term "pre-embryo" is more an invention than an empirical fact and has been coined by some groups of scientists to smoothen the controversy on the manipulation of human embryos and so enable human embryo experimentation. Yet even though most of the theories concerning the moral status of the "pre-embryo" leave some room for "pre-embryo research," some difficult questions remain.

The ethical debate should not be restricted to the issue of the moral status of the "pre-embryo," but should also address the interests of the women donating eggs or "pre-embryos" for research purposes. With regard to the moral evaluation of "pre-embryo research" aimed at developing and perfecting PID, a preliminary question is, of course, whether PID as such is acceptable.

Therefore, is PID intrinsically wrong? At least three direct non-consequentialist objections can be found in the literature. A first objection to PID runs that the intended selection is intrinsically wrong because it does not respect the sanctity of human embryonic life, given that isolating a blastomere involves the creation of a duplicate embryo and its resulting disposal. This objection does not apply to pre-conceptional diagnosis of the unfertilized egg.

A second objection reads: PID is eugenics. In evaluating this objection, one must realize that the term "eugenics" is being employed in different ways. Some definitions focus on aims and/or means, others on effects. The various sorts of eugenics need to be distinguished from a moral point of view. Some geneticists seem to promote PID as a potentially effective strategy for greatly reducing or even eliminating Huntington disease (and other late-onset autosomal dominant disorders) from the population. Such population-eugenic perspective clashes with the primary goal of (most of the Western) reproductive counseling, i.e. to promote free, informed reproductive decision-making.

A third direct objection to post-conceptional PID concerns the preparatory biopsy: isolating a blastomere involves the creation of a duplicate "pre-embryo," which is later destroyed during the diagnostic procedures. Some argue, that even if it were proven that PID necessarily involves the creation of a duplicate "pre-embryo" one could still justify this technique, considering the relatively "low" moral status of a "pre-embryo," and the "pros" of PID in comparison with a selective abortion. In other words, it would be more acceptable to kill a "pre-embryo" than an embryo. According to what we have previously asserted, this is immoral. The argument is clearly contradictory and points to the gravity of a sophism that seeks to scientifically justify the scientifically unjustifiable (which is analogical to the contradiction of a moral justification of that which is immoral).

In comparing the ethics of PID on the one hand and the ethics of regular prenatal diagnosis on the other hand, one can discern between a "fetalist" and a feminist perspective. The fetalist perspective focuses on possible differences concerning the moral status of "pre-embryos" in comparison with embryos or fetuses, while a feminist perspective focuses primarily on the impact of different technologies on the autonomy of the women involved. PID would supposedly give the physician greater control over what is in the ordinary course of events a process controlled by women; the physician would also presumably use his medical expertise in deciding which "pre-embryos" to transfer.

From a feminist perspective, one could argue that given an adverse prognosis from the biopsy, the choice, whether to have the embryo replaced or not, must lie with the potential mother. In view of the physician's own responsibility to prevent serious harm to the prospective child, however, a partial shift with regard to the locus of decision-making would be inevitable. At the same time, nevertheless, this shift would require complex moral solutions regarding what standards should be used in making these decisions and how to operate in the context of uncertainty with regard to the prognosis of an affected "pre-embryo." It is difficult to see how physicians would cross the boundary between a legitimate concern for the well-being of the prospective child on the one hand and a "preventive perfectionism" on the other hand. In any case, once again the problem of the little or no respect for human life – the "pre-embryo" – emerges.

Here also one of the central questions is whether there is a fundamental moral distinction between the research uses of surplus "pre-embryos" on the one hand and the generation of "pre-embryos" for research purposes on the other hand. In the praxis, such a distinction is without foundation. Moreover, PID is still experimental, and can only be offered in the context of a clinical trial. Although there is at present no indication that congenital anomalies are increased in pregnancies resulting from PID, a systematic anomaly assessment, including pediatric follow up, is nonetheless necessary.

It is of utmost importance that couples understand the pros and cons of PID in comparison with regular prenatal diagnosis. It is likewise important that they be aware of the fact that IVF procedures run on the same sophisms as those above stated; namely, they always imply selection, manipulation and the disposal of surplus embryos, and, in any case, it is of particular relevance that the "take home baby rate" after IVF is, according to the most optimistic calculations, less than 15%.[16] Although the use of intracytoplasmic sperm injection (ICSI)[17]

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[16] Cf. Anonymous: *FIVNAT 1996 report. French National Register on In Vitro Fertilisation*, Contraception, Fertilité, Sexualité, Volume 25, Issue 7-8, July-August 1997, pages 499-502.

Also cf. Anonymous: *Report from the Alberta Heritage Foundation for Medical Research. In vitro fertilization and embryo transfer as a treatment for infertility*, International Journal of Technology Assessment in Health Care, Fall 1997, Volume 13, Issue 4, pages 631-632.

[17] Intracytoplasmic sperm injection: A single sperm is injected into the egg's cytoplasm. The mature egg is held with a specialized holding pipette. A very delicate, sharp and hollow needle is used to immobilize and pick up a single sperm. This needle is then carefully inserted into the cytoplasm of the egg. The sperm is injected into the cytoplasm and

instead of regular IVF may result in a higher fertilization rate, this strategy also requires close scrutiny, not only from the moral point of view, but also in view of the possible long-term health risks for ICSI-children.

A consequentialist objection to PID concerns the misuse of this technique for trivial reasons. Although controversial medical applications include PID of late-onset diseases – like Huntington's disease and some hereditary forms of cancer, susceptibility genes which predispose for multifactorial disorders, and treatable disorders like phenylketonuria – many PID of late-onset diseases are symptomatic of a questionable striving at genetic perfectionism, that is to say, the putative right of only "perfect" babies.

Finally, PID should be placed in the perspective of current and future alternative methods of prenatal diagnosis. Other new methods are particularly relevant for the comparative analysis, for example, the analysis of fetal cells in maternal blood, in which there is no risk of inducing a miscarriage, and which may be used very early in pregnancy.

2.2. Prenatal genetic diagnosis

Prenatal diagnosis may be a routine procedure, but it raises a number of controversial issues. While the women who avail themselves of the tests are usually worried about their children's health, the political, legal, and medical communities have their own reasons for encouraging large-scale screening for fetal defects. Unknown to most prospective parents, scientists are still debating the safety of the most widely offered screening tests. The ethical issues raised by prenatal screening are even touchier.[18] Prenatal testing promises to eradicate illness in a completely new way. In so doing, it is imperceptibly altering the very concept of disease in first world countries. It is changing society's fundamental attitudes toward parenting, toward sickness, and toward social responsibility. It is even influencing women's notions of childbirth, medicine, and motherhood.

The most common form of prenatal testing, is ultrasound imaging, which is frequently used as an aid in genetic methods of diagnosis. Women deemed at "high risk" for giving birth to a child with

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the needle carefully removed. The eggs are checked the next morning for evidence of effective fertilization.

[18] Cf. Kristol E.: *Perfect Picture: The Politics of Prenatal Testing*, First Things, April 1993, number 32, pages 17-24.

chromosomal abnormalities are also habitually offered amniocentesis usually between the sixteenth and twentieth weeks of pregnancy. Women may also opt for the somewhat riskier procedure of chorionic villus sampling between the tenth and twelfth weeks, or earlier, or other methods such as the multiple marker screening, or the analysis of fetal cells in maternal blood which is without the risks of invasive methods.[19]

More experimental and high-risk diagnostic procedures include fetal skin sampling, and fetoscopy. And – as we have previously observed and which had long been considered the cutting edge of prenatal screening – the testing of embryos before implantation (PID) is slowly becoming a reality. Even the most common forms of prenatal testing are open to dispute. The point here is that despite the "matter-of-fact" manner in which physicians offer the tests to their patients, their safety has never been scientifically established.

Ultrasound, for example, is presented as a thoroughly uncontroversial procedure. However, it is still being contested within medical literature. A classic example of a "creeping technology" -similar to that of X-rays – ultrasound in pregnancy has scarcely been subjected to a large-scale randomized controlled trial to assess either its safety or usefulness.[20]

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[19] Cf. Roberts C.J.- Hibbard B.M.- Elder G.H.- Evans K.T.- Laurence K.M.- Roberts A.- Woodhead J.S.- Robertson I.B.- Hoole M.: *The efficacy of a serum screening service for neural-tube defects: the South Wales experience*, Lancet, Volume 1, Issue 8337, 11 June 1983, pages 1315-1318.Also cf. Olajide F.- Kitau M.J.- Chard T.: *Maternal serum AFP levels in the first trimester of pregnancy*, European Journal of Obstetrics, Gynecology, and Reproductive Biology, Volume 30, Issue 2, Febuary 1989, pages 123-128.

Also cf. Kristol E.: *Perfect Picture: The Politics of Prenatal Testing*, First Things, April 1993, number 32, pages 17-24.

[20] Cf. Jensh R..-, Lewin P.A.- Poczobutt M.T.- Goldberg B.B.- Oler J.- Brent R.L. *The effects of prenatal ultrasound exposure on postnatal growth and acquisition of reflexes*, Radiation Research, Volume 140, Issue 2, November 1994, pages 284-293.

Also cf. Owen P.: *Routine ultrasound scanning in pregnancy. Apgar scores are poor predictors of outcome*, British Medical Journal, Volume 307, Issue 6903, 28 August 1993, pages 559-560.

Also cf. Bucher H.C.- Schmidt J.G.: *Does routine ultrasound scanning improve outcome in pregnancy? Meta-analysis of various outcome measures*, British Medical Journal, Volume 307, Issue 6895, 3 July 1993, pages 13-17.

Also cf. Konje J.C.- de Chazal R.- Taylor D.J.: *Routine ultrasound scanning in pregnancy. The benefits are clinical ... and psychological*, British Medical Journal, Volume 307, Issue 6903, 28 August 1993, page 559.

Amniocentesis and CVS do pose known dangers,[21] and a physician is supposed to discuss these with the patient at the time the tests are offered and have her sign an informed-consent form.

The use of AFP tests has a peculiarly non-medical history. It has been noted that in order to detect enough cases of open spina bifida and anencephaly the tests would necessarily have a high false-positive rate – about fifty false positives for every true positive.[22] To offset the inaccuracy of AFP tests, the American College of Obstetricians and Gynecologists (ACOG) developed a rigorous protocol for obstetricians. If AFP levels are unusually high, for instance, doctors are urged to repeat the test. If the second test also comes back positive, they are to do an ultrasound to determine the reason for the elevated AFP level (such as multiple pregnancy or inaccurate assessment of fetal age). If that is inconclusive, they are to advance to amniocentesis. If that is abnormal, they are to perform a high-resolution ultrasound. With each subsequent test, there is an increased chance that any number of anomalies, slight or severe, may be detected.[23] What is implicit here is that a patient who follows her doctor's suggestion to undergo testing for neural-tube defects might find herself, a few weeks down the line, being counseled to contemplate an abortion for a variety of lesser disorders for which she had no original intention of seek a test.

As prenatal screening becomes increasingly routine, disability ceases to be viewed as a random misfortune. But even if a woman had all the reproductive options in the world – whether to conceive, whether to undergo diagnostic testing, whether to treat the fetus, or whether to abort for a particular condition- she could still not be guaranteed a healthy child.

Another question that stems from this is when children are born with disabilities or suffer injuries in childhood, would parents steeped in a culture of screening regard them with resentment? The effect of

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[21] Cf. Heckerling P.S.- Verp M.S.- Albert N.: *Prenatal testing for limb reduction defects. How patients' views affect their choice of CVS*, Journal of Reproductive Medicine, Volume 42, Issue 2, Febuary 1997, pages 114-120.

Also cf. Drazancic A.- Skrablin S.- Latin V.- Fuduric I.- Kuvacic I.- Tadic V.- Corusic A.: *Ishod trudnoce nakon rane amniocenteze*, Jugoslavenska Ginekologija I Perinatologija, Volume 31, Issue 3-4, May-Aug 1991, pages 55-60. (The title translated to English is "Pregnancy outcome after early amniocentesis").

[22] Cf. Milunsky A.- Alpert E.: *Prenatal diagnosis of neural tube defects. II. Analysis of false positive and false negative alpha-fetoprotein results*, Obstetrics and Gynecology, Volume 48, Issue 1, July 1976, pages 6-12.

[23] Cf. Ibid., pages 6-12.

this culture is that conditionality, rather than acceptance and generosity, is built into parental love from the start.

Disability advocates and feminists interested in the social impact of reproductive policies often criticize society's growing role in developing and enforcing quality-of-life standards. Even some feminists who are resolutely pro-choice have trouble with abortion for defect. As Ruth Hubbard explains, one thing is to abort when a woman does not want to be pregnant and quite another when she wants a baby, but decides to abort this particular fetus she is carrying with the hope of coming up with a "better" one next time.[24] The specter of abortion appears all too frequently as the final solution.

Besides, other types of results, such as the psychosocial sequelae and emotional stress, are recurrently hidden from the public.[25] Therefore, there is apparently a poisonous effect of the double standard that governs prenatal screening. Physicians and policymakers assume that abortion for sex selection is tantamount to a declaration that females are of much less social value than are males. Society is not willing to make such a statement, which would have profound implications for how women are viewed in society, and also for how women view themselves. Yet, in many societies there are no restrictions on the patient's autonomy to abort for any disability whatsoever. This indicates the low value that our society places upon those with genetic disorders and handicaps. It appears that some moral lines are drawn for social, but none for genetic termination of pregnancy.[26]

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[24] Cf. Hubbard R.- Wald E.: *Exploding the Gene Myth*, Beacon Press, Boston 1997, page 30.

[25] Cf. Kristol E.: *Perfect Picture: The Politics of Prenatal Testing*, First Things, April 1993, number 32, pages 17-24. The author shows that while a second trimester termination of pregnancy for fetal abnormality may physically be relatively safe for the mother, it remains an emotionally traumatic, major life event for both father and mother. Yet the researchers who arrive at this conclusion do not reassess prenatal screening in light of their findings. Instead, they simply criticize the "post-termination care" the couples receive, and urge that those who abort under such circumstances receive more counseling: Grief cannot be prevented, they say, but may be shortened if couples are given the right tools, in the form of skilled preparatory counseling, to come to terms with it.

[26] Cf. Ibid. The President's Commission on genetic screening bears this out; while endorsing testing for disorders and defects, the commission roundly condemns sex selection on the grounds that it is incompatible with the attitude of virtually unconditional acceptance that developmental psychologists have found to be essential to successful parenting. For the good of all children, it is suggested that society's efforts should go into promoting the acceptance of each individual -with his or her particular strengths and weaknesses- rather than reinforcing the negative attitudes that lead to rejection.

Governments and the public health sector have considerable interest in being able to point to reductions in disease, and morbidity and mortality rates are considered as key expressions of a region's standard of living. When most people hear of "reducing illness," they usually think of providing greater access to health care or developing new treatments for disease. Public health experts, however, frequently boast of reducing illness by means of prenatal diagnosis and abortion. The highly influential 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research asserted that genetic screening and counseling may be used to contribute to the public health goals of reducing the incidence and impact of inherited disorders.[27]

Policy makers and medical experts are under pressure not only to achieve noticeable improvements in health but also to reduce soaring health care costs. Widespread prenatal screening followed by abortion for fetal defects would accomplish both of these objectives. The motivation to reduce costs also helps explain the long-standing emphasis on preventing the birth of children with Down's syndrome. The discovery that Down's syndrome could also be detected by the AFP blood test, considered safe enough to be given to all pregnant women, was therefore regarded as a major breakthrough, and there has been no shortage of arguments to eliminate the ill or the disabled before they become a financial burden to society.[28] Medical cost-benefit analyses are startlingly cold-blooded. The market is littered with studies that feature graphs comparing the costs to society of a disabled child with the expense of testing and abortion; articles debate the appropriate discount rate that should be used in calculating the lifetime costs to the state of caring for a disabled individual.

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[27] Cf. Anonymous: *Summary from "Splicing life": a report on the social and ethical issues of genetic engineering with human beings. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research*, Recombinant DNA Technical Bulletin, Volume 6, Issue 1, Mar 1983, pages 10-12.

Also cf. Hansen H.: *Brief reports decline of Down's syndrome after abortion reform in New York State*, American Journal of Mental Deficiency, Volume 83, Issue 2, September 1978, pages 185-188.

[28] Cf. Farrant W: *Stress after amniocentesis for high serum alpha-fetoprotein concentrations*, British Medical Journal, Volume 281, Issue 6237, 9 August 1980, page 452.

In a survey of British obstetricians in the late 1970s, researcher Wendy Farrant discovered that two-thirds of the respondents rated savings in costs to society of caring for people with disabilities as an important benefit of a national screening program for neural-tube defects; 13 percent agreed that the state should not be expected to pay for the specialized care of a child with a severe handicap in cases where the parents had declined the offer of prenatal diagnosis of the handicap.

As prenatal screening becomes increasingly widespread and sophisticated, physicians, policymakers, and the courts are more often making judgments about what kind of life is worth living and what kinds of disabilities are too costly to society. Already, parents who undergo prenatal testing are finding that answering life-and-death questions is more difficult than they had imagined. How "normal" does a baby have to be to continue the pregnancy? Which is worse, a severe physical or a slight mental handicap? Should one abort if there is a 30 percent chance that a genetic disease will be transmitted? Is it worth giving birth to a child who will die at the age of forty? Thirty? Twenty?

There is also the daunting problem posed by the detection of late-onset disorders, such as Huntington's disease, that do not manifest themselves until adulthood. If parents know the awful secret that their child probably will not live past a certain age, how will this knowledge affect their relationship with the child? Will they find themselves keeping an emotional distance to protect themselves from future pain? Will they, consciously or unconsciously, skimp on ways they invest in their child, whether in education or in encouragement of talents, hobbies, and other skills?

The decisions raised by prenatal testing are without doubt the stuff of moral philosophy and theology. But they put real-life parents into inhumane situations. Moreover, they coarsen our very notions of what is involved in being a parent and what it means to be a responsible member of society. Through the gradual introduction of new forms of technology and testing, the medical establishment and the public health sector have been developing subtle quality-of-life standards and not-so-subtle ways of discouraging the birth of those who do not measure up. Testing for birth defects has crept into the life of millions of women of childbearing age, whether they avail of it or not. It is not too strong to say that childbearing has, in a profound sense, been transformed. This transformation is not the province of one interest group or another: it is not exclusively a medical issue, a legal issue, an economic issue, or a women's issue. Like many revolutions in medicine and technology, prenatal testing took on a life of its own before its implications could be fully assessed. Like many revolutions, its social consequences are proving to be both far-reaching and long-lived.

When a prenatal diagnosis of the genetic sort is carried out, and especially where there is risk involved, it is deontologically and ethically prescribed that there be fundamented reasons for such an examination to take place. In technical terms, these reasons are called "indi-

cations." The principle of totality may also be invoked. Whether there are indications or not should be ascertained in the genetic counseling which precedes the intervention.[29]

Regarding the overall ethical judgment of the praxis of prenatal diagnosis it is interesting to note that from the same experience 28.5 percent of those who originally apply for the test, decline it after having been informed.[30] In fact many requests are due either to superficial or inadequate information concerning the necessity of the test, or to the ethical conviction of the woman in not wanting to take into account the eventuality of abortion as a successive hypothesis to the examination, permitting her, on the other hand, to carry through her pregnancy without anxiety.

If there is no real founded necessity for an intervention it would be humanly foolish, economically an unnecessary expense, and morally illicit, above all when the risk factor is very real, as in the case of amniocentesis, placentocentesis or chorionic villus sampling. The simple request or curiosity of the patient is not a sufficient reason to justify this type of intervention; to proceed in this case would be sign of an insufficient ethical and deontological responsibility.

A point to underline is how is it that perfectly healthy women may find themselves having a series of medical tests, some of which pose distinct risks to themselves or their children? The typical pregnant woman would be disturbed to realize that a good deal of the testing that goes on is motivated by factors that, at best, are only remotely related to her well-being or the health of her child.[31]

Crucial to all the discussions, reports, and studies supporting prenatal testing is the assumption that women will have abortions if fetal defects are detected. Very often this is thought of as being a fundamental "right," something that is good, for the benefit of the woman and her family. As John Paul II observes in "Evangelium Vitae," crime paradoxically assumes the guise of a "right" and is legitimized by the State; and worst of all, these criminal acts are perpetrated

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[29] Cf. Serra A.: *La diagnosi prenatale di malattie genetiche. Esperienze, prospettive e problemi*, Il progresso medico, Volume 15, 1981, pages 1-18.

[30] Cf. Sgreccia E.: *Manuale di Bioetica, I. Fondamenti ed Etica Biomedica*, Vita e Pensiero, 2nd edition, Milan 1996, page 283.

[31] Cf. Kristol E.: *Perfect Picture: The Politics of Prenatal Testing*, First Things, April 1993, number 32, pages 17-24.

within that which should be the very "sanctuary of life," namely, the family.[32]

Moreover, the hard truth is that there are still very few conditions that can be treated *in utero*. Hospitals will occasionally do fetal blood transfusions or perform surgery for urinary tract obstruction, and drug therapy is useful for treating some metabolic diseases. Experimental research in the area of gene therapy, the replacement or correction of a defective gene in the fetus, would open up the possibility of new forms of prenatal treatment. For the foreseeable future, however, the chief purpose of prenatal diagnosis is seemingly to give parents the opportunity to abort a fetus diagnosed with a disorder. It is telling that research in the area of prenatal diagnosis is overwhelmingly concentrated on finding ways to diagnose conditions in the first few months of pregnancy, when abortion is a simpler and safer procedure, even though information about the fetus is much richer later on.

Yet the "A" word is almost never mentioned in literature concerning genetic testing. When allusion to the subject is unavoidable, it is glossed over with an extraordinary amount of euphemism. This is the case even in medical journals, where doctors are addressing one another rather than pregnant patients. Physicians refer to "screening and its sequelae." Pregnancies are "terminated," "selected" or "interrupted." Parents who receive news of a fetal disorder are urged to "choose a reproductive option," to "decide the disposition of their pregnancy," or simply to "intervene." In discussing abortion procedures, physicians refer to "permanent asystole" or "mechanical disruption of the fetus" rather than fetal death. The word "amniocentesis" often serves as a stand-in for testing-plus-abortion; one genetics textbook states that if all mothers of thirty-five years and over had amniocentesis then this would reduce the incidence of chromosomal disease by 30 percent; many British physicians, for example, take recourse in acronyms, referring simply to "TOP," that is to say, the termination of pregnancy.[33]

Realities must be called by their true name. Eugenic abortion can never be "therapeutic" abortion, no matter how a certain mentality names it in an attempt to legitimize it and hide the crude reality. Legalized eugenic abortion will always be a license to kill the most vul-

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[32] John Paul II: *Evangelium Vitae*, Acta Apostolicae Sedis, Libreria Editrice Vaticana, Città del Vaticano, 2 May 1995, number 11.

[33] Cf. Kristol E.: *Perfect Picture: The Politics of Prenatal Testing*, First Things, April 1993, number 32, pages 17-24.

nerable human persons of any society on account of some defect or sickness.[34] In fact, no abortion can ever be "therapeutic."

Much of the coyness can be explained by political expediency. A technical bulletin on screening issued by ACOG, a group that presumably would rather be identified with babies than abortion, never mentions the "A" word, but recommends that supportive or therapeutic services appropriate to the decision should be made available.[35] The report of the 1983 President's Commission on genetic screening is, for obvious political reasons, a masterpiece of doublespeak. When the report discusses screening for Tay-Sachs disease, abortion is nowhere mentioned but is everywhere between the lines. According to the report, prenatal testing of the fetus has provided carrier couples with an option that did not exist previously; in the past, couples who had a child with Tay-Sachs disease often found the 25 percent risk of having another affected child to be unacceptable, and decided therefore not to have any more children; so prenatal screening for Tay-Sachs has meant the continuation of countless pregnancies and the conception of hundreds of infants who would otherwise not have been born.[36] The Commission also refers to the inevitable tension between the public health goals of reducing the incidence and impact of inherited disorders, and the special place accorded to the right of individuals to obtain and use screening information as their personal values dictate, whether or not their decisions result in a reduction in genetic disease. The only occasions where the Commission report actually uses the term "abortion" is when it wishes to capitalize on its pejorative sense. In its discussion concerning sex selection, for example, the report straight forwardly condemns the use of prenatal diagnosis to abort a fetus of the unwanted sex.

Such paraphrasing, ambiguity and double talk is deceiving to many people, willfully lacking in clarity, a hiding of the real truth and agenda of the Commission, and, therefore, contrary to the principle of informed consent, and immoral. Prejudices and discriminations be-

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[34] Cf. John Paul II: *Evangelium Vitae*, Acta Apostolicae Sedis, Libreria Editrice Vaticana, Città del Vaticano, 2 May 1995, number 14.

[35] Cf. Anonymous: *ACOG educational bulletin. Maternal serum screening*. Number 228, September 1996 (replaces no.154, April 1991). Committee on Educational Bulletins of the American College of Obstetricians and Gynecologists, International Journal of Gynaecology and Obstetrics, Volume 55, Issue 3 , Dec 1996, pages 299-308: It is suggested that patients receiving positive results from a definitive test should have access to adequate counseling, including the availability of support groups and pediatric surgeons.

[36] Cf. Kristol E.: *Perfect Picture: The Politics of Prenatal Testing*, First Things, April 1993, Number 32, pages 17-24.

cause of genetic defects should not be tolerated because all human life, including that of a fetus, is sacred and inviolable; it is an indivisible good and all have the duty to take care of it.[37]

Moreover, screening for defects may at times be a way of saying: "These are my standards. If you meet these standards of acceptability, then you are mine and I will love and accept you totally, after you pass this test." Many pediatrics experts agree that screening may have a destructive effect on the parent-child relationship, noting that testing raises parents' expectations of their children, rather than encouraging parents to recognize the uniqueness of each child.

Disability groups and feminist supporters rightly fear that when physicians encourage the abortion of fetuses with diseases or disabilities, they are fostering intolerance of the less-than-perfect people who are already born. Church authorities, following this same logic, courageously speak out against those who deny the most elementary health care, and even supplying nourishment, to children born with serious deficiencies or illness.[38]

Even more disconcerting are the proposals which seek to legitimate the so called "right" of abortion, and even infanticide, a crude return to barbaric means from which many societies have yet to be emancipated. In his Encyclical "Evangelium Vitae" John Paul II refutes the logic that legitimates the negation of basic cures and therapies, and even the feeding of children born with handicaps or diseases.[39]

Anecdotal evidence gives cause for concern: in one study of seventy-three parents-to-be undergoing prenatal screening, 30 percent said they thought screening might encourage negative attitudes toward the disabled; half thought that mothers of disabled children would be blamed for their failure to undergo screening or have abortions.[40] It just goes to show where the social pressure lies, and how little free and truly informed consent is really respected.

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[37] Cf. John Paul II: *Evangelium Vitae*, Acta Apostolicae Sedis, Libreria Editrice Vaticana, Città del Vaticano, 2 May 1995, number 87.

[38] Cf. Ibid., number 14.

[39] Cf. Ibid., number 14.

[40] Cf. Kristol E.: *Perfect Picture: The Politics of Prenatal Testing*, First Things, April 1993, Number 32, pages 17-24.

Sommario: *L'articolo si suddivide in due parti. Nella prima, viene affrontata la questione dell'embrione, della sua ricerca e legislazione: vengono affermati con forza la dignità personale dell'embione umano e, di conseguenza, i suoi diritti umani. Dopo avere affrontato il tema della dignità personale dell'embrione umano, nella seconda parte l'autore prende in considerazione la validità morale sia della diagnosi genetica prima dell'annidamento, sia della diagnosi genetica prenatale.*

Parole chiave: Statuto dell'embrione, diagnosi genetica prima dell'annidamento, diagnosi genetica prenatale, test genetico

Key words: Embryo status, genetic testing, preimplantory genetic diagnosis, prenatal genetic diagnosis