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SCIENTIFIC CONTRIBUTION

Prenatal diagnosis as a tool and support for eugenics: myth or reality in contemporary French society?

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Abstract Today, French public debate and bioethics research reflect an ongoing controversy about eugenics. The field of reproductive medicine is often targeted as pre-implantation genetic diagnosis (PGD), prenatal diagnosis, and prenatal detection are accused of drifting towards eugenics or being driven by eugenics considerations. This article aims at understanding why the charge against eugenics came at the forefront of the ethical debate. Above all, it aims at showing that the charge against prenatal diagnosis is groundless. The point of view presented in this article has been elaborated jointly by a geneticist and a philosopher. Besides a survey of the medical, bioethical, philosophical and social sciences literature on the topic, the methodology is founded on a joint analysis of geneticist's various consults. Evidence from office visits demonstrated that prenatal diagnosis leads to case-by-case decisions. As we have suggested, this conclusion does not mean that prenatal diagnosis is devoid of ethical issues, and we have identified at least two. The first is related to the evaluation of a decision to abort. The second line of ethical questions arises from the fact that the claim for "normality" hardly hides normative and ambiguous views about disability. As a conclusion, ethical dilemmas keep being noticeable in the field of reproductive medicine and genetic counselling, but an enquiry about eugenic tendencies probably does not allow us to understand them in the proper way.

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Introduction: an ethical charge against a medical and social practice

Today, French public debate and bioethics research reflect an ongoing controversy about eugenics. Certain medical practices, particularly in the field of reproductive medicine, are accused of drifting towards eugenics or being driven by eugenics considerations. The targets of this criticism are pre-implantation genetic diagnosis, prenatal diagnosis, and prenatal detection. The word "eugenics" was coined by the British biologist Francis Galton (1822–1911). Interpreting Darwin's work, Francis Galton expressed concern about the "degeneration" of the human species, and suggested that the "unfit" be prohibited from having children. In the late nineteenth and early twentieth centuries, his thesis, applied to animal species, had become widespread. However, its significance then acquired a deep ambivalence: eugenics could be associated both with a concern for public health and hygiene or with the concept of racial or class miscegenation as the source of species degeneration. By the 1950s, eugenics thought was associated only with horrors like the mass sterilization implemented in various countries before World War II, on the one hand, and on the other, Nazi mass extermination policies. As a consequence, up to now, any practice or thought that resembled "eugenics" has immediately been discredited.

Currently, reproductive medicine is challenged with charges of eugenics. This paper discusses those charges, focusing on prenatal diagnosis. First, we shall define prenatal diagnosis, in contrast to prenatal detection. In France, prenatal detection is offered to every pregnant woman to

ensure the good state of health of both the woman and the fetus. Conversely, prenatal diagnosis is carried out only for specific patients, when there is a significant risk that the child to be born will suffer from a genetic disease, or when a genetic, chromosomal, or metabolic disorder is suspected.

In France, prenatal diagnosis began developing in the early 1970s. The first amniocentesis procedures were performed at Port-Royal Hospital, in Paris, in 1972. Since, prenatal diagnosis has been developed to investigate the state of health of a fetus identified as being at risk. Prenatal diagnosis can still be called a "young" medical specialty: there are currently around 120 clinical geneticists in France; genetics has been taught in medical schools since 1995; and finally, there are 14 prenatal and multidisciplinary diagnosis centers.

The charge of eugenics confronts pre-implantation diagnosis, prenatal diagnosis and prenatal detection in ways that are specific to each practice. Before a more general, comprehensive picture of the supposed relationship between reproductive medicine and eugenics can be elaborated, each practice must be examined separately. By focusing on prenatal diagnosis, this paper intends to provide one of the elements necessary to assess the danger of a drift towards eugenics.

Prenatal diagnosis has gradually replaced a medical practice that was limited to risk evaluation. It has helped physicians inform couples better about the risk or certainty of the disease liable to affect the fetus, and offer better prenatal care.

Prenatal diagnosis deals with various types of diseases:

- Monogenic diseases such as cystic fibrosis, the result of a single mutated gene; not all of them are identified, but the most frequent are well known today;
- Polygenic diseases such as diabetes, the result of interaction between various genes (the most frequent and less well known diseases);
- Chromosomic anomalies such as Down syndrome;
- Congenital malformations, quite well known today, such as unilateral kidney agenesia.[1]

Today, prenatal diagnosis includes various techniques introduced one after the other since the early 1970s. They are based either on the observation of the fetus (ultrasound scan) or on the sampling of amniotic fluid (amniocentesis) or fetal blood (cordocentesis).[2] Also, prenatal diagnosis occurs at various stages of the pregnancy. Depending on the indication of the prenatal diagnosis, various approaches make it possible to obtain fetal cells necessary for testing: diagnosis of fetal sex from maternal blood (at 10 weeks of gestation), choriocentesis (after 12 weeks), amniocentesis (after 15 weeks).

Generally speaking, prenatal diagnosis is a highly delicate practice. Ideally, it should give clear answers as quickly as possible, to enable parents to make a decision within the limited time of the pregnancy. Moreover, geneticists must also deal with the psychological impact of the test results on the (future) parents. Likewise, prenatal diagnosis cannot detect every genetic disease, and each test aims at a specific problem. Currently, only about 300 of the 8,000 diseases identified as genetic can be diagnosed. Test results are never 100 % certain, because of the various ways a disease may be expressed.

Consequently, if prenatal diagnosis is sometimes the reason parents seek a medical abortion, the decision is an extremely delicate one, and is not based solely on the data from the diagnosis. Figures for the number of medical abortions in France are available from the Biomedicine Agency. In 2005, 6,960 requests for a medical abortion were filed and 6,852 were granted (whereas the number of elective abortions is estimated at roughly 200,000/year).[3] French law states that a medical abortion may be performed at any stage of pregnancy, as long as the disease is considered especially serious and cannot be cured at the time the diagnosis is made. It is essential to emphasize the fact that existing legislation does not enumerate the diseases. The law gives the medical team the prerogative in evaluating the seriousness of the disease on a case-by-case basis.[4]

Is prenatal diagnosis responsible for a drift towards eugenics?

Now that we have clearly defined prenatal diagnosis, we can consider the charge of eugenics in relation to this form of reproductive medicine. The concern about eugenics is a relatively recent phenomenon. As Terrenoire notes, although prenatal diagnosis has always stirred up ethical questions, eugenics was not the battle cry in the early 1970s. At that time, people were more concerned with the link between prenatal diagnosis and abortion, the latter being perceived as a moral dilemma faced by parents and physicians.[5] These concerns coincided with the legalization of elective abortion in France in 1975, after impassioned debate in both Parliament and French society at large. In addition to the subject of abortion, a number of other ethical issues were raised by the debate. The status of the

[1] This description is borrowed from Aymé (2003).

[2] Ibid. p. 10.

[3] http://www.agence-biomedecine.fr/fr/experts/chiffres-rapport.aspx#.

[4] Article L. 2213-1 of the French Public Health Code (Code de santé publique: available online at http://www.legifrance.gouv.fr).

[5] Terrenoire (2003, p. 519).

fetus and its relationship with the mother, a lack of respect for the rights of people with disabilities should the practice of prenatal diagnosis be extended to more diseases, and the decisional autonomy of the future parents vis-à-vis the physician were all widely discussed at the time.[6]

Eugenics has come to the fore as an ethical question as the social vision of reproduction and the medical use of prenatal diagnosis techniques have evolved. On the one hand, reproduction is increasingly viewed as a matter of individual will. People now have the right to choose when they will bear children, and during pregnancy they are concerned about the health of their future baby and any genetic defects. On the other hand, prenatal diagnosis has become a routine medical practice for two reasons, in France. First, the principle of equal access to health resources prevails,[7] and secondly, physicians have made extensive use of prenatal diagnosis to spot an anomaly or problem before birth. These factors have conspired to form a context in which the "social meaning"[8] of prenatal diagnosis is front and center, as the primary subject for debate. One of the ways this question is raised is the concern about eugenics.

Even if the accusation of eugenics is radically discrediting, useful distinctions have been integrated in the bioethical debate in France. Ethicists recognize that eugenics may be driven by either positive or negative values, and that a differentiation should be made between enhancing the genetic identity of the person and eliminating diseases or anomalies when this is possible.[9] Moreover, it is usual to distinguish between collective and state-organized eugenics—associated with the abhorrent Nazi ideology of racial supremacy—and individual eugenics: that is, the choice made by a person or couple free from any institutional constraints.

As we mentioned earlier, fields of reproductive medicine other than prenatal diagnosis are also confronting charges of eugenics. The latest Recommendation, issued by the French National Consultative Ethics Committee, makes such generalized accusations that it includes prenatal diagnosis as a potentially guilty practice within a larger group of medical specialties linked to reproduction.[10] Although state eugenics is rarely considered a danger today,[11] the report points out less visible forms of eugenics. It stresses two distinct risks: that of indirect collective eugenics, and the danger that individual eugenics will become a prevailing social trend. Critics warn that indirect collective eugenics might result from the availability to all pregnant women of an early prenatal diagnosis of Down syndrome. The fact that the test is offered to every future mother, and is often presented as a common if not compulsory procedure, seems to indicate that the French state seeks to avoid the birth of Down syndrome babies. Formulated in these terms, the charge of eugenics deserves to be investigated in relation to prenatal detection.[12]

Likewise, the parents of a fetus diagnosed with a genetic disease may abort the pregnancy. This is the second risk. This time, what is challenged is a form of individual eugenics, and it is directly related to prenatal diagnosis as such. Again, this type of accusation aims primarily at a hidden or subtle form of eugenics. The charges are characterized by their own specific rhetoric, warning of a danger looming in the near future, in a tone that is often overly dramatic and alarmist. Critics like the biologist Jacques Testart became involved in an actual crusade against prenatal diagnosis in the 1990s.[13] They worried that individual choice would usher in a form of collective eugenics, if an overwhelming majority of individual future parents adopted the same criteria for judging whether a life is worth being lived.[14] Finally, they insisted that physicians think twice before recommending medical abortion: the concern for the future baby's suffering from some disease or disability ought not rule out an objective evaluation of his/her potential quality of life.[15]

Even when the drift toward eugenics is not the issue, other critics warn that prenatal diagnosis techniques require

[6] Sociologist Mehl (1999) draws the same conclusions as Terrenoire. She has proposed a brilliant analysis of the French bioethics controversy between 1992 and 1997, that is to say between the birth of Amandine, the first French baby conceived through in vitro fertilization, and the birth of the ewe Dolly, the first cloned sheep. She points out how debate initially centered on the status and uses of the embryo has shifted to express ethical concerns about eugenics.

[7] Up to now, the principle of solidarity has regulated the French healthcare system. See the recent essay by Roth (2010, pp. 329–333).

[8] Ibid., p. 525.

[9] Some thinkers have played an active role in this perspective. In the 1980s and 1990s, Taguieff (1989, 1994) laid the foundations for a collective reflection on the eugenics issue, stressing the conceptual distinctions necessary and emphasizing the fact that culture and environment are just as important as genetic characteristics in shaping the individual. More recently, Gayon and Jacobi (2006) provides a keen understanding of the ethical issues related to the concept of eugenics. See also Gaille, 'De l'enfant projeté à l'enfant né: La famille, un lieu de représentations normatives dans l'accompagnement médical de la procréation', *Corpus*, revue de philosophie, 2008, 54, pp. 93–115.

[10] CCNE (2009).

[11] There is a broad consensus on this point, stated in many publications: for example, in Recommendation 68 from the National Consultative Ethics Committee (CCNE).

[12] For example, in 2007, Didier Sicard, specialist in internal medicine and then president of the CCNE, declared in the daily paper *Le monde* (February the 3rd) that France was "flirting with eugenics", referring to the systematic availability of a Down syndrome diagnosis early in pregnancy.

[13] See his essay: *Le désir de gène*, Paris, Flammarion, 1994.

[14] Mattei et Rauch (1997, pp. 182–186).

[15] Le Coz (2002, pp. 4–9).

some form of regulation.[16] In this more qualified line of thought, obstetrician René Frydman and philosopher Monique Canto-Sperber have imagined a doomsday scenario arising from a laissez-faire policy on prenatal diagnosis: abortion would become more common, along with the spread of prenatal diagnosis techniques. As modern medicine eliminates risk, randomness, and the unknown from procreation, it conspires with individual eugenics to make children a mere instrument for satisfying parental desires.[17]

Conversely, some ethicists note that the fears and the fantasies aroused by prenatal diagnosis obscure its positive impact on thousands of families and children.[18]

Methodology

In this paper, as we have said earlier, we would like to show that accusations that prenatal diagnosis may be driving a drift towards eugenics, or to put it in another way, that prenatal diagnosis serves as a tool and support for individual eugenics, are groundless and devoid of relevance. An examination of contemporary French prenatal diagnosis practices makes this clear. The discrepancy is wide between, on the one hand, the charge of eugenics, implicitly dealt with by French law, which has never stipulated a list of diseases "automatically" leading to abortion, and on the other hand, what transpires when future parents meet with the geneticist. In this regard, public debate and bioethics literature are being quite unfair to the science of prenatal diagnosis.

In their daily practice, geneticists contend with the parents' wish to have a child "like other children," not a "perfect" child. According to the law, the decision to end a pregnancy is supposed to be grounded by medical data. However, geneticists must also consider the families' and couples' histories and their fantasized child. How can such deep and complex psychological parameters emerge, be expressed, and become factors in a final decision, within the very short time of a pregnancy? This question matters more for geneticists and future parents than the risk of a drift toward eugenics. The wish for a child "like other children" raises its own ethical difficulties, and deserves to be considered on its own terms. It cannot be reduced to a matter of eugenics.

The point of view presented in this article has been elaborated jointly by a geneticist and a philosopher. It is the product of a fourfold approach. First, factual data about the contemporary practice of prenatal diagnosis in France was collected. Secondly, in order to give a faithful account of the controversy about prenatal diagnosis and grasp the actual moral issues at stake, we surveyed and compared various opinions on the matter, from specialists in bioethics, philosophy, ethical committees, and the medical profession, as expressed in both professional journals and public debate. Thirdly, the philosopher attended and observed a significant number of the geneticist's office visits, known as "consults", in two different hospitals over a 2-year period, enabling her to confirm or qualify conclusions derived from literature. Fourthly, case studies that elicited shared reflection from both philosopher and geneticist were reviewed.

This fourth point is essential to our methodology, and has already been hinted at by both social scientists and some prenatal diagnosis professionals. Evidence from office visits demonstrated that prenatal diagnosis leads to case-by-case decisions. The geneticist refuses any blanket definition of what constitutes a genetic defect. Moreover, the record showed that most of the time, geneticists toned down the parents' appetite for a "good quality" child. These features make it possible to practice prenatal diagnosis without risking any drift toward eugenics.[19]

Prenatal diagnosis as a practice: a case-study

General presentation of the Cochin prenatal genetics clinic

In 1999, the maternity department of Cochin, one of Paris's largest hospitals, opened its Center for Prenatal Diagnosis and funded a permanent position for a clinical geneticist. More than 10 years later, genetic counseling is offered by a geneticist who usually teams up with a psychologist. These visits account for 75 % of the total number of genetics appointments at the prenatal clinic. They are scheduled to last 45 min, much longer than a routine office visit, because the issues at stake require substantial dialogue: the clinical evaluation (if requested) must be presented and explained to the future parents, and they must be questioned about family history in order to elaborate a hypothetical diagnosis. Also, their questions, anxieties and wishes must be addressed, along with the social and medical context. Some counselling appointments are made after the baby's birth, and they are usually attended only by women (the mother, and sometimes a sister, aunt, or grandmother). However, both parents generally come to prenatal diagnosis appointments.

[16] Frydman (1997).

[17] Canto-Sperber and Frydman (2008, pp. 46–47).

[18] Dommergues et al. (2003, p. 2).

[19] Isambert (1985) and Blanchard (2007). The Center for Prenatal Diagnosis based in Angers, an average city in Western France, dealt with 820 cases in 2005. The medical team recommended a medical abortion in 102 of them, which broke down as follows: 53 presented multiple abnormalities, 27 presented chromosomal anomalies, and 13 genetic diseases.

Couples come in spontaneously or are referred by their physicians because they are aware of a disease or a risk in the family which might affect their future baby. They may also be seeking advice because a prenatal medical exam has prompted doubts about the health of the fetus. The genetics counsellor then tries to determine whether the doubts are grounded, by identifying the nature of the pathology and the risk of transmission. It is to be noted that patients sometimes come in very late in the pregnancy, despite a high risk of transmission of the pathology to the future baby.

Interestingly, a statistical study of the motives leading to an appointment at the Cochin prenatal diagnosis clinic shows that future parents do not always spontaneously come in for a visit before a pregnancy.[20]

	Before the pregnancy (%)	During the pregnancy (%)
Mental retardation	6.45	19
Muscular dystrophy	16	12
Cystic fibrosis	14	3.5
Chromosomal abnormalities	10	9.9
Brain malformation	4.5	2.8
Hemophilia	2.4	3.5

As these figures show, in many cases, parents who seek a prenatal diagnosis wait until the pregnancy is already established. Legally, it is still possible for them to terminate the pregnancy for medical reasons even in the second or third trimester, due to liberal French abortion legislation. However, they do pay a price for delaying genetic counselling: they have much less time to think through their decision on the basis of the advice from the medical team. Moreover, as the chart shows, they do not necessarily come in because they are aware of a disease or a deficiency that runs in either family or has affected their first child, as one might expect. For example, the diagnosis of probable mental retardation is often considered (by critics of prenatal screening) to be decisive in leading to a parental request to terminate the pregnancy. What actually happens is that parents who suspect or know a risk of mental retardation very often seek counselling late in the pregnancy. Conversely, in the case of cystic fibrosis, counselling takes place at an early stage of pregnancy or even before it has begun.

Significant trajectories: parents facing prenatal diagnosis

Beyond the statistical data, observation of counselling clearly reveals that the fear of eugenics is misplaced concerning the link between prenatal diagnosis and abortion. Some parents will decide to maintain the pregnancy;[21] others will request an abortion. In the case of post-natal consults, they describe the challenge of developing a good relationship with their child. In all these cases, their decision has nothing to do with eugenics. Instead, it is related to the personal history of the family and couple. In order to understand what motivates the parents' decision to maintain or terminate a pregnancy once a prenatal diagnosis has identified a disease or an abnormality, familiarity with the details of each case is necessary.

The first case we shall describe concerns a father referred for genetic counselling by his son's pediatrician. The son presented both mental and motor deficiencies. Genetic testing showed that the delays in development were due to a missing fragment of chromosome. A series of appointments ensued, in the course of which the father informed the geneticist that his wife had a slight mental handicap. Further genetic examination revealed that mother and son shared the same chromosomal characteristic. Ten years later, she became pregnant. The couple was already informed there was a 50 % risk the future baby would present the same anomaly. Despite this information and the difficulties inherent to raising two children with disabilities, the father opposed any request for prenatal diagnosis: even if he wished to have a healthy baby, his religious beliefs—as he himself stated—prevented him from taking this path.

Case two also led to a decision to maintain the pregnancy, but for totally different reasons. At an early stage of pregnancy (4 weeks), a woman requested counselling after learning that her first son had been born deaf. Genetic testing showed that the deafness was the result of an autosomal recessive gene, making the risk of transmission 25 %. The patient then applied for prenatal diagnosis, informing the geneticist that she intended to have an elective abortion if the diagnosis did not justify a medical abortion. However, the medical team refused the patient's request for prenatal diagnosis, because deafness is not considered a justification for a medical abortion in France. Next, a series of intense, frequent dialogues took place between the medical team and the patient. In the end, they reached a moral agreement: the team would carry out prenatal diagnosis, because the patient had cited psychological reasons and a specific family context

[20] This chart is based on counselling offered for some significant diseases at the Cochin Hospital Center for Prenatal Diagnosis between 2000 and 2007, from a sample of about 800 cases per year.

[21] The statistics for the Cochin genetic counseling service show that in 65 % of the cases where a genetic problem was detected, parents opted for a medical abortion.

to justify her decision. The test results were available when the patient was 20 weeks pregnant, and seemed to show the fetus was affected. Nonetheless, despite her initial attitude, the patient decided to continue the pregnancy. The ongoing exchange with the medical team had enabled her to develop a more open perception of her future baby. Likewise, the value of time and dialogue was clearer than ever to the medical team.

Still other couples decide not to maintain the pregnancy. Once again, the reasons are varied and deeply personal, remote from any concerns about eugenics. The burden of economic and professional responsibilities often tips the scales. For example, a couple came in for counselling because of the risk of having a baby with cystic fibrosis. Both parents carried a minor mutation of CFTR gene. They wanted a prenatal diagnosis and an abortion if testing revealed that the fetus carried the mutation, because both of them worked at night. They felt this aspect of their lives precluded providing the proper care for a child with an illness like cystic fibrosis.

Another couple sought counselling early in the pregnancy. The woman hoped prenatal diagnosis would reveal whether her future child would be a dwarf, like her husband. His dwarfism was caused by an autosomal dominant gene, so the risk of transmission was 50 %. During the counselling session, the couple appeared to disagree about the necessity for prenatal diagnosis, even before abortion was mentioned. The man rejected both prenatal diagnosis and abortion. However, the pregnant woman stated that marrying a dwarf is one thing, but bearing a child with the knowledge that he or she would be a dwarf was something else again. She did not elaborate, but to her, this distinction was central and insurmountable. This case is interesting, as it shows that the couple does not always agree, as the following case also demonstrates. Moreover, it shows that a decision to abort a child with some rare genetic characteristic can coexist with loving and living with a person who has that very characteristic.

Finally, another case shows how the medical-abortion option following a prenatal diagnosis might have alleviated the personal difficulties of one of the parents in accepting a child with a birth defect. A couple sought advice at Cochin 1 year after the birth of their son, after he had been diagnosed with a chromosomal abnormality that resulted in severe mental retardation and a facial dysmorphism. The results of chromosome testing during the pregnancy had been interpreted as "normal." At the clinic, when the couple was interviewed about the child's development, the mother constantly answered, "I don't know; ask his father." The geneticist then understood that the father was the baby's sole caregiver. The mother had changed the baby's diaper only once. She never took him in her arms, never fed him, and had only kissed him three times, on the back. "You cannot force me to love him," she told the geneticist. She appeared to be unable to accept the birth defect as such. It made a relationship with her son impossible.

We have selected these cases to illustrate what goes on at the prenatal diagnostic clinic, and how the counselling procedure has nothing to do with eugenics. The geneticist is careful to respect the specific history and beliefs each family brings to the clinic. Moreover, the case studies show that the decision to terminate a pregnancy is not necessarily the consequence of prenatal diagnosis of genetic anomalies. As we saw above, one patient who was initially determined to get an abortion decided to maintain her pregnancy after all, even after a problem was diagnosed. Talking it through with the clinic staff convinced her to keep the baby. No concern about eugenics can be detected in the reasons for which the other parents rejected the child—in the last case, after the baby was born.

One could argue that the reasons the parents cited were a "tale" told to avoid uttering a truth which is taboo—i.e. a eugenics concern. But these reasons were so deeply embedded in personal and family history that it is highly improbable they were untrue. Perhaps from an ethical standpoint, medical abortion was not always justified. But if so, the issue deserves a discussion in itself, and the debate would lead to questions that are very different from the problems raised by eugenics.

Conclusion

Our study of whether prenatal diagnosis is a factor in a drift towards eugenics leads us to a number of conclusions. Having ascertained that state-sponsored eugenics is not a danger, we were seeking signs of the emergence of a subtle, hidden form of eugenics. We formulated a hypothesis that once we put aside both criminal eugenics and the belief that intelligent people give birth to intelligent people, some ethical and political problems would still remain. As sociologist François-André Isambert has pointed out, there could be an individual tendency to select birth according to eugenics criteria which, on a national scale, would become a social trend. In this context, prenatal diagnosis would not be a neutral tool. The practice could be legitimized only if we are careful not to confuse the tool itself with its disputable uses. Consequently, Isambert sees the real issue as our tendency to fantasize about the power of genetics medicine. In this line of thought, our moral values and ability to defend ourselves against this tendency will determine the legitimate uses of prenatal diagnosis.[22]

[22] Isambert (1985).

In this paper, we have advocated a different point of view: that no individual decision taken within a genetic consult may rightly be viewed as driven by eugenics-related goals. Future parents certainly do not have these goals in mind, and even less a will to eradicate a genetic anomaly or chromosome defect within a specific population. They are focused on their future child and family. Moreover, when prenatal diagnosis detects a genetic defect, the parents sometimes continue the pregnancy nevertheless. When they choose abortion, it is for reasons related less to the genetic anomaly than to the meaning of the anomaly in the context of their personal histories.

Geneticists often try to defend the practice of prenatal diagnosis by insisting on their moral *phronésis* and the case-by-case approach. Instead, they should simply reject the charge of eugenics as irrelevant. The mottled history and variety of meanings inherent to the word "eugenics" are a hindrance to an investigation of ethics. The use of an inappropriate and irrelevant word promotes confusion and impassioned, subjective judgments.

As we have suggested, this conclusion does not mean that prenatal diagnosis is devoid of ethical issues, and we have identified at least two. The first is related to the evaluation of a decision to abort. The knowledge obtained from prenatal diagnosis entails a thought process about abortion that is probably different from the one developed in a context in which both the physician and the future parents are unaware of the disease of the future baby. If a person is opposed to abortion on moral grounds, the certainty (or significant risk) that one will give birth to a child with special needs may outweigh one's opposition on principle. Abortion may be seen as a solution that is "the lesser of two evils." By providing an abortion, medicine is not curing disease or alleviating pain. Paradoxically, it merely assists parents in bearing healthy children by leaving a door open to interrupt a pregnancy before a child with an illness is born. In this line of thought, a feeling of moral uneasiness may remain, related to the value our society assigns to human life in every form. In many cases, with prenatal diagnosis, abortion is the only option available to avoid giving birth to a child with an anomaly.

The second line of ethical questions arises from the fact that future parents feel they are entitled to "a normal child", "a child like other children", a child who is not "different." They are not seeking the "perfect baby",[23] and even less an "enhanced being."[24] We perceive the vagueness of these various words as a sign of our society's ambiguous attitudes towards disability.

As a matter of fact, French society is deeply ambivalent about disabilities. Today, few people would actually deny that disabled people, or persons suffering from an incurable genetic disease, may be happy to be alive, and feel pleasure and well-being despite their condition. Nonetheless, it is obvious that French policy has lagged in its efforts to offer disabled people decent living conditions and health care. The French National Consultative Ethics Committee, whose recommendations we mentioned above, has also underscored the failure of French society to integrate the disabled minority. People with disabilities tend to remain outsiders and "second-class citizens."[25]

Our country's serious lack of consideration for people with disabilities is clear to any observer. Therefore, social stigmatisation of the disabled is bound to affect a parent's decision to commit to bearing a child with a disability. The most recent statement from the CCNE ethics committee specifically insists on this dimension. It points out that the social climate is an obstacle to the birth of disabled people, and urges the development of a research policy and movement for social education to engender new attitudes towards people with disabilities or special needs.

French society's deeply embedded tendency to reject outsiders certainly does not help future parents contemplating the birth and rearing of a disabled child. Both the future parents and the geneticist may feel constrained by these narrow horizons. The philosopher Canguilhem has written of the importance of the social surroundings in defining disease. In a more favourable environment, certain disabilities would be considered less serious, and would be less likely to entail a decision to abort. This is a point often stressed by the future parents during the genetic consults. Thus, they raise a crucial question: that of the actual "space" to make a decision after a prenatal diagnosis has been made. From this point of view, we could say that the warnings against a drift towards eugenics in the present law aim at the wrong enemy. In France, the problem lies with the way individuals and society at large discriminate against people with disabilities and their families, not the risk of eugenics.

This ambivalence is all the more striking when it comes from a judgment on the "normality" of the fetus, which happens from time to time. France is probably not specific in this respect.[26] Canguilhem ground-breaking essay *The Normal and the Pathologic*, written in 1943 and completed

[23] See Gaille (2010, pp. 66–79).

[24] The "enhancement" of human beings through predictive medicine has so far been a topic of little interest in France. Future parents do not relate to this concept. It is only recently that philosophers have tackled the issue, as shown by various publications: Goffette (2006) and Missa and Perbal (2009).

[25] The phrase is borrowed from Charles Taylor (1997). *Frontiers of justice* by M. Nussbaum (2006), however, shows that discrimination against the disabled is hardly specific to France.

[26] Joëlle Vailly (2008, p. 2552).

in 1966 has led social scientists and philosophers to study the way we define "normality". These studies point out that the concept of normality has crossed over from the medical vocabulary into the general language, bringing with it a confusion between the normal and the norm.[27] In our context, this desire for normality is also noticeable because of its frequent association with a "DNA mystique".[28] Parents tend to define normality in genetic terms, as if genetics, in mysterious but insuperable ways, determined people's destinies, rather than such factors as the love and respect of one's family, the educational, social and institutional context, the economic situation etc.

Undoubtedly, the desire for normality arouses moral dilemmas during the genetic consults. It forces the parents and medical team to establish a threshold or boundary between an anomaly requiring a medical abortion and one deserving a "try". It is difficult, to say the least, to agree on where to draw the line, because each of us has her or his own vision of normality. In this regard, the situation is not easy for geneticists. If their vision of "normality" differs from that of the future parents, it necessarily carries less weight, because the parents alone will be responsible for the baby once she or he is born.

Another factor making geneticists uncomfortable is their knowledge of the limitations of prenatal diagnosis. It cannot give a totally accurate view of the future life of the child, because diseases occur in a variety of ways and their severity varies with the individual. Likewise, prenatal diagnosis sometimes reveals a disease that will occur at a late stage in the life of the future baby. This entails serious difficulties, especially when the geneticist presents her or his findings. Psychologists and psychoanalysts attending genetic consults have stressed the fact that the revelation of this knowledge jeopardizes the psychological bond between the future parents, especially the mother, and the baby, prior to any decision to maintain the pregnancy or abort.[29]

At this stage of reflection, it is not possible to determine if the concept of normality prevails in the cluster of words we mentioned above. In many cases, the word merely expresses the wish to have a healthy baby. Finally, when the idea of "normality" emerges in the dialogue between the future parents and the geneticist, it is important to talk through both conscious and unconscious judgments. The patient in this situation is actually a future baby, *still unborn*. We must be aware there is only one certainty: our imaginations develop conscious and unconscious fantasies about him.

[27] Ibid., p. 2541.

[28] Nelkin and Lindee (1998).

[29] Soubieux (2002, pp. 67–77).

In the wake of this paper, we are elaborating a research project in clinical ethics, comparing data from various centres for prenatal diagnosis, focusing on how geneticists and parents justify a choice between abortion or birth.[30] Among other things, we will evaluate the weight of the judgment on normality in the decision to abort.[31] In any case, our research will not deal with eugenics, which, as we hope to have proved above, is irrelevant to the moral investigation of prenatal diagnosis.

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[30] In this research project, we also intend to compare two different methodological approaches: the one presented in this paper, on personal, couple and family case histories, and the one recently suggested by Häyry (2010), dealing with the various "rationalities" at stake in the moral controversy about prenatal diagnosis .

[31] Fagot-Largeault (1993) suggested the judgment about normality was to be the focus of the moral enquiry on prenatal diagnosis.

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