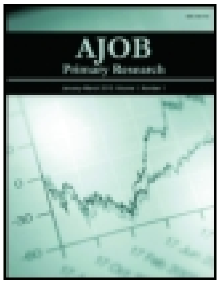

AJOB Primary Research
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/uabr20

State Intervention in Couples' Reproductive Decisions: Socioethical Reflections Based on the Practice of Preimplantation Genetic Diagnosis in France

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Version of record first published: 27 Aug 2010.

To cite this article: Chantal Bouffard, Julie-Kim Godin & Bénédicte Bévière (2010): State Intervention in Couples' Reproductive Decisions: Socioethical Reflections Based on the Practice of Preimplantation Genetic Diagnosis in France, AJOB Primary Research, 1:3, 12-30

To link to this article: http://dx.doi.org/10.1080/21507716.2010.505897

AJOB Primary Research, 1(3): 12–30, 2010
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ISSN: 2150-7716 print / 2150-7724 online
DOI: 10.1080/21507716.2010.505897

State Intervention in Couples' Reproductive Decisions: Socioethical Reflections Based on the Practice of Preimplantation Genetic Diagnosis in France

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Adopting socioethical and anthropological perspectives, this article addresses the impact of state intervention in the reproductive life of couples who consult for preimplantation genetic diagnosis (PGD) in France. Our main objective is to identify and analyze the socioethical problems flowing from French legislation as related to PGD and from its implementation. Methods included review and analysis of the relevant literature, ethnographic research in the three centers accredited to perform PGD, and participant observation (990 hours), with 79 semistructured interviews. Ethical problems identified were: (1) discrimination based on sexual orientation and the requirement for adherence to a traditional model of the couple and the family; (2) inequities in access to PGD; (3) restrictions on couples' autonomy; and (4) breaches of respect for private life. We conclude that the state could improve the ethical conditions in which PGD is practiced by: (1) establishing educational programs in ethics to support members of multidisciplinary centers for prenatal diagnosis; (2) conducting empirical studies on the social acceptability of PGD; and (3) conducting empirical studies on the extent of state intervention in the reproductive life of couples likely to have recourse to reprogenetic services.

Keywords: anthropology, preimplantation genetic diagnosis, reproductive technologies, reprogenetics, research ethics, social science research

Because preimplantation genetic diagnosis (PGD) involves in vitro human embryo creation, manipulation, genetic testing, and selection, it poses a challenge to certain values that underlie some of the West's oldest social institutions. For example, PGD can represent a challenge to certain issues associated with the family: the traditional form taken by the family, modes of reproduction, and the transmission of certain genetic characteristics. PGD also conflicts with religious doctrines about the sacredness of the human embryo and the redemptive role of suffering (Schenker 2005; Jones and Whitaker 2009; Zivotofsky and Jotkowitz 2009). Medically, it is important to bear in mind that, at the beginning of the 1990s, PGD became the first reprogenetic practice[1] to be transferred to a clinical setting. Since that time, because it underlies diagnostic and therapeutic approaches that require the use of the human embryo, it has been playing a precursor role that goes beyond the fields of antenatal genetic testing and assisted reproductive technology (ART), extending to epigenetics and the fields of predictive, regenerative, and transformative medicine.

Today the medical and social uses of PGD are diversifying and developing without showing signs of stopping (Bouffard 2010). It is now possible to have recourse to preimplantation genetic screening (Mastenbroek et al. 2007) in the hope of improving the outcomes from in vitro fertilization (IVF); also, PGD can be used for the conception of a

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The study that underlies this reflection was sponsored by the International Institute of Research in Ethics and Biomedicine (Montreal, Quebec) and the Fonds de la recherche en santé du Québec (FRSQ, Montreal, Quebec). We thank professors Pierre LeCoz (Vice Chair of the Comité Consultatif National d'Ethique and Associate Professor of Philosophy in the Faculty of Medicine at Marseille) and Stéphane Viville (Department of Cell and Developmental Biology, Institute of Genetics and Molecular and Cellular Biology, Faculty Medicine, Université Louis Pasteur, Illkirch, France) for their judicious input. As authors, Chantal Bouffard provided conception and design, acquisition of data, analysis and interpretation of data, and drafting the article. Julie-Kim Godin and Bénédicte Bévière provided critical analysis of legal and bioethical aspects and collaboration in drafting the article.

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[1] The term "reprogenetics" was used for the first time in 1998 by the molecular biologist Lee M. Silver. It is defined as the combined use of genetics and assisted reproduction.

savior sibling (Bennett 2005; Devolder 2005), family balancing (Wilkinson 2008), social sex selection (Gottlieb 2001; Orr-Mongeau 2004), and the implantation of embryos with a disability (Galjaard 2003; Karpin 2007). As it becomes increasingly accessible, and in the context of a market economy that supports reproductive tourism (Storrow 2005; Cohen 2006; Inhorn and Patrizio 2009; Pennings et al. 2009) and direct-to-consumer genetic testing (Hogarth et al. 2008), PGD is rousing the same fears of eugenicism, discrimination, harm to human integrity, and reification of the embryo as are elicited by cloning, germinal gene therapy, and embryonic stem cell research and therapy.

In this context, PGD is necessarily playing a foundational role in the decision-making processes related to the development, governance, organization, and uses of reprogenetic techniques. It is worth noting that the political, religious, economic, and ethical issues raised by PGD are sufficiently significant for international organizations such as UNESCO (Galjaard 2003), the World Health Organization (WHO: Human Genetics Programme 1998), the Council of Europe (Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine), the European Society of Human Reproduction and Embryology (ESHRE: Thornhill et al. 2005), and the European Society of Human Genetics (ESHG: Soini et al. 2006) to have issued guidelines for its practice and development. Finally, many countries, for example, Germany, France, Italy, the United Kingdom, and Canada, have adopted professional-code, ethical, and legislative norms of greater or lesser degrees of specificity for the monitoring of PGD (Knoppers et al. 2006).

The impact of these regulatory approaches is not, however, limited to restricting the practice of a controversial reprogenetic technique. Deeply rooted in their source cultures, these governance measures vary according to social and cultural factors that reveal, through the adoption of ethical or legal positions, the values defended by the decision-making bodies of a given society or a group of countries. Since they apply to a specific mode of reproduction and kind of antenatal diagnosis, these governance measures are also instructive as to the scope of the powers of the state in the reproductive lives of individuals at risk of transmitting serious genetic or chromosomal disorders.

The adoption of any position, however—regardless of the values that states may wish to protect or promote—will necessarily lead to ethical problems for certain categories of people. The reason is simple: No society can avoid the conflicts of interest that subsist between the embryo, the individual, the family, the community, and the state.

Within this perspective, the aim of the present article is to prompt a process of socioethical reflection on state intervention into individuals' reproductive decisions, based on the results of an ethnographic study of representations of PGD in France (Bouffard 2010). Given its impact on the lives of people at risk of transmitting a genetic or chromosomal disorder to their offspring, as well as its impact on social, legal, and medical practice, the French model appeared to us to be especially interesting. Resting on the Constitution (Preamble) and justified and underwritten by the Law on Bioethics (Law 2004–806), the rules that govern the practice of PGD in France are institutionally entrenched and, by that very fact, bring various levels of interest into play.

In what follows, we first provide a description of the methodological background of the study that triggered the present reflection. We then present, in broad strokes, the legal provisions that govern the practice of PGD in France. Next, we identify the ethical and socioethical problems generated by the legislation and its implementation, namely: (1) discrimination based on sexual orientation and requirements for adherence to a traditional model of the couple and the family; (2) inequities in access to PGD; (3) respect for couples' autonomy; and (4) respect for the confidentiality of medical and psychosocial data. Before concluding, we discuss the implications of these socioethical problems.

METHODS

The reflection presented in this article emerges from a multisite ethnographic study on the representations about PGD held by researchers, physicians, and patients (Bouffard et al. 2009; Bouffard 2010). [On multisite ethnographic research, see Marcus (1995).] The study was conducted in France in the three centers accredited to perform PGD (Strasbourg, Paris-Clamart, and Montpellier). It should be noted here, however, that an examination of the issue of state intervention in couples' reproductive lives did not figure among the study's original objectives. Rather, this issue emerged as meriting examination during the process of analyzing the study's data and arriving at results.

We briefly present here the methodological approach taken by the study.

The Ethnographic Approach

Ethnography takes a qualitative, empirical, inductive methodological approach developed largely in the field of medical anthropology. It requires conducting an examination of a phenomenon from the inside, on the basis of the researcher's full physical and intellectual immersion in the field (Labaree 2002; Ezeh 2003). Three methods of investigation are traditionally used in ethnography: (1) analysis of the literature; (2) participant observation; and (3) formal semistructured interviews (Hammersley and Atkinson 1994).

For this study's analysis of the literature, 292 written documents relating to PGD were analyzed. These included documents from the fields of the humanities, the social sciences, and medicine, as well as national and international official documents and reports consisting of ethical guidelines, policy statements, and legislation on PGD.

The next stage of the study entailed 990 hours of participant observation, averaging out to 330 hours per center. These hours of participant observation made it possible to sit in on more than 60 clinical consultations; service and departmental meetings; and seminars, colloquia, and scientific activities (Bouffard 2010). It also allowed for observation of laboratory diagnostic and research activities, in vitro fertilization procedures, the biopsying of embryo cells, diagnostic analyses, and a few embryo transfers. Notes on the events observed, as well as on informal discussions, were entered in a field journal as the research unfolded.

Finally, the use of semistructured interviews allowed subjects the necessary latitude to express themselves on aspects of PGD that were relevant and significant from their own perspective (Spradley 1979; Wolcott 1994; Creswell 2007). Seventy-nine formal semistructured interviews were conducted in the context of the study. Forty patients agreed to grant the investigator interviews. Thirty-nine physicians, biologists, technologists, and health professionals working in the discipline were also interviewed. Note that since, as explained earlier, the topic of state intervention in couples' reproductive lives did not figure among the study's original objectives, the content of the interviews rarely related directly to this theme.

Analytic Levels

First analytic level: It was first necessary to conduct an analysis of each of the sets of data in turn: the data from the literature review, the participant observation, and the interviews.

Second analytic level: Next, a comparative analysis of the results from the three sets of data made it possible to sketch a complex individual, institutional, and social portrait of PGD in France. As regards the aspect of this portrait that is relevant to this article, it was possible to identify a significant discrepancy between, on one hand, representations of what is ethical for participants in the study and more specifically for couples undergoing PGD, and, on the other hand, the representations defended by French law. The problem of respect for private life and for the confidential nature of medical data also emerged clearly.

Analysis at this second level showed that by restricting access to PGD to specific categories of people, some of the ways of applying the Law on Bioethics could give rise to significant socioethical problems (Bouffard 2010). The issue of state intrusion into the reproductive lives of couples likely to have recourse to reprogenetic services, along with the scarcity of empirical knowledge about that issue, constituted one such problem.

Third analytic level: To better explore this problem, the analysis of all the data and results was taken to a third level. An analysis was conducted from a socioethical perspective, with the objective of identifying, based on this ethnographic material, the scope and impact of intervention by the French state in couples' reproductive lives.

To this end, we developed an interpretive framework for identifying the socioethical problems generated by the law and its implementation. The framework was applied to both the raw data and the results obtained from: (1) the review of the ethical, social, and legal literature about PGD and the Law on Bioethics (sociocultural foundations and justifications for the law, values being defended and emergent values, etc.); (2) the participant observation sessions (informal discussions, including discussions about the French assisted reproduction lobby; observations of interactions in the setting of PGD-related medical and laboratory work, during consultations, and among members of multidisciplinary centers for prenatal diagnosis [CPDPN]; and information derived from broader institutional contexts, such as data on divorce rates, etc.); and (3) the semidirected interviews, since, although they were not centered on this specific topic, they were nevertheless rich sources of information.

Proceeding this way conformed to the ethnographic approach, which features a degree of methodological flexibility that allows researchers to adapt data gathering and data analysis tools in order to pursue leads emerging from the field or from the results : "In any study, questions may occur to you during the research that lead you to construct new data-gathering methods and to revise earlier ones" (Charmaz 2006).

RESULTS

From an anthropological perspective, the Law on Bioethics is a source of social and cultural information essential to an understanding of the scope of the French state's powers over the reproductive lives of individuals likely to have recourse to reprogenetic services. Viewed thus, the law is a sociocultural artifact that, when set against the ethnographic data, allowed for the analysis presented in this article.

Thus, before presenting what emerged as problem areas in state intervention in the delivery of reprogenetic services, it is important to provide a clear picture of the legal context in which PGD services are delivered in France. This we do next; following the presentation of this backdrop, we present the four problematic aspects of the legislation and its implementation.

A Socioethical and Anthropological Analysis of the Law on Bioethics

Genetics, ART, and reprogenetics give rise to fear of major upheavals within the oldest human institutions governing the family, filiation, religion, the legislative system, and so on. Thus, societies that are developing these techniques or that use them become watchful about preserving adherence to their own social and cultural values.

In France, these values are explicitly presented in the Preamble to the Constitution of 27 October 1946 (Preamble). There, one reads that the French nation undertakes to "provide the individual and the family with the conditions necessary to their development" (Preamble, al. 12) and to guarantee "to all, notably to children [and] mothers . . ., protection of their health" (Preamble, line 11). There flow from these commitments certain ethical priorities defended by the French state, including: (1) the primacy of the individual and the individual's dignity; (2) respect for the human

Table 1. Mission, function, and composition of multidisciplinary centers for prenatal diagnosis

Under Article R. 2131-10-1 of the Public Health Code, the mission of CPDPNs* includes:

- To allow egalitarian access to all the activities of PND.
- To promote access to all prenatal diagnostic activities and seeing to their implementation by serving as a hub of clinical and biological competency placed at the service of patients and practitioners.
- To provide opinions and advice about diagnosis and prognosis to clinicians and biologists who turn to them when suspecting a disease of the embryo or fetus.
- To indicate whether or not recourse should be had to biological diagnosis based on cells taken from in vitro embryos.
- To have a multidisciplinary and dialectical approach.
- To organize formation activities for practitioners.

Under Articles R.162-17, L. 2131-4, and R. 2131-26-1 of the Public Health Code, the functions of CPDPNs include:

- To provide advice and counsel to clinicians, biologists, couples, and attending physicians regarding the justification for PGD, the diagnostic and therapeutic approaches that are to be favored, and prognoses.
- To determine what indications are required before recourse can be had to biological diagnoses from embryonic cells.

Under Articles R. 2131–12 of the Public Health Code, composition of the multidisciplinary team:

Practitioners practicing in the institution or the health care center wherein the center is created, with at least:

- Physician holding a degree in gynecology–obstetrics or an equivalent;
- Practitioner with a formation and a background in fetal ultrasound;
- Physician holding a degree in pediatric or an equivalent and a complementary degree in neonatology or an equivalent;
- Practicing physician holding a degree in pediatric or an equivalent and a complementary degree in neonatology or equivalent;
- Physician holding a degree in medical genetics or an equivalent.
- People who may not have activity the institution or the health care center:
- Physician holding a degree in psychiatry or an equivalent or a psychologist;
- Physician holding a complementary degree in fetopathology or an equivalent or with an equivalent background;
- Practitioners authorized to carry out the analysis defined in article R. 2131–1;
- Genetics counselor.

*Multidisciplinary centers for prenatal diagnosis (centres pluridisciplinaires de diagnostic prénatal, or CPDPNs).

being and the human body (Article 16-1) from the beginnings of life (Article 16); and (3) "the inviolability and integrity of the human species" (Article 16-3, line 1; Article 16-4, line 1; Rec. 1994. 94-343/344 DC; Law number 94-654 of 29 July 1994, concerning the donation of human body parts and products, medical assistance with reproduction, and prenatal diagnosis, modified by Law 2004-800 of 6 august 2004; Law 2004-800; Law 2004-800, 14040).

Various judgments and orders-in-council subsumed under France's Public Health Code (the Code de la Santé Publique) and the bioethics legislation thus seek to protect: (1) the family in its traditional form; (2) the child; and (3) the embryo, which, by virtue of the child it can potentially become, has been granted the status of a "potential human person" by France's national advisory council on life sciences and health sciences (Comité Consultatif National d'Éthique; known as the CCNE) (National advisory council on ethics [CCNE]; Comité Consultatif National d'Éthique 1984).

In line with this logic, PGD is the subject of measures for preventive action specifically aimed at the health of the child. Moreover, since PGD requires IVF, it is subject to the law on the donation and use of elements and products of the human body, medically assisted reproduction, and prenatal diagnosis (Law number 94-654 of 29 July 1994, concerning the donation of human body parts and products, medical assistance with reproduction, and prenatal diagnosis, modified by Law 2004-800 of 6 August 2004).

Multidisciplinary centers for prenatal diagnosis (*centres pluridisciplinaires de diagnostic prénatal*, or CPDPNs) were constituted (Order-in-Council number 97-578 of 28 May 1997 concerning multidisciplinary centers for prenatal diagnosis) under the bioethics law of 1994 (Law number 94-654 of 29 July 1994, concerning the donation of human body parts and products, medical assistance with reproduction, and prenatal diagnosis, modified by Law 2004-800 of 6 August 2004). Their missions and the powers vested in them are clearly defined by law (Table 1). The CPDPNs must operate within a public or not-for-profit private health care organization or institution with a facility that has an obstetrical unit. Once established within an organization or institution, a CPDPN must form a multidisciplinary committee whose composition is explicitly laid out in the legislation (Table 1). These committees are responsible for the implementation of these measures in every health care center that offers prenatal diagnostic services and PGD.

From the moment when a couple or a couple's attending physician submits a file relating to a PGD application to the CPDPN at a PGD-accredited health care center, the CPDPN multidisciplinary committee indisputably has the explicit mandate to evaluate on a case-by-case basis whether PGD is medically appropriate. However, as shown later, there is also an implicit mandate to deem whether it is socially appropriate.

For example, as regards medical appropriateness, the law requires couples to present with "a strong probability of giving birth to a child with a genetic disease of special seriousness that is recognized to be incurable at the time of diagnosis" (Article L. 2131-4). Moreover, according to the original legislation, the anomaly in question must have first been identified in one member of the couple seeking PGD. However, since the reform of the Law on Bioethics of 6 August 2004, PGD may also be authorized when the disorder is identified in "one of the immediate forebears" (Article L. 2131-4; Law 2004-800, article L. 23(4)): "in the case of a gravely incapacitating disease, that is late-appearing, and that prematurely threatens the prospects of life" (Article L. 2131-4, line 3). This measure makes it possible for individuals who have one parent with Huntington's chorea to access PGD even without learning whether they themselves have it, in order to avoid having children with the disorder (Moutou et al. 2004).

As regards social compliance, the law provides that, in order to access PGD, "The man and woman who constitute the couple must be living, of an age to procreate, and married or able to provide proof they have cohabited for at least two years; and they must consent prior to the embryo transfer." (Article L. 2141-2). If the couple separate or divorce, if one of the two dies, or if one of the two produces a written recantation, the law forbids access to PGD and the continuation of a PGD procedure that has already been begun.

Furthermore, the legislation stipulates that even when PGD is deemed appropriate in principle, the CPDPN committee must know about the couple's motivations for bearing a child and their openness to adoption (Article L. 2141-10; Law 2004-800, article 24 I). All the information required by the legislation, including the information on the couple's private life, must be placed in the file submitted to the CPDPN. Once a couple has been deemed to satisfy all the medical, legal, and social requirements for access to PGD, clinical care may be begun. The couple may then meet with the bioclinical team responsible for carrying out PGD. However, the law requires that a month must elapse following the couple's first consultation with the specialists on the bioclinical team, in order to allow the couple time for reflection[2] (Article L. 2141-10; Law 2004-800, article 24 I).

Since these are legislative measures, any violation of the rules is punishable by law. This gives some sense of the reach of the French state's powers of intervention in reproductive decisions taken by individuals with serious genetic and chromosomal disorders who wish to have recourse to PGD.

Ethical Problems Flowing From Certain Aspects of the Legislation and Its Implementation on the Ground

By placing the health of the child, the protection of the embryo, and the preservation of the traditional family and couple under the protection of the law, the French state protects society from certain kinds of abuse that could flow from reprogenetics. Nevertheless, it is one particular cultural representation of respect for the dignity of the individual that is being defended in this legislation: that of the individual as member of a collectivity, a species. And yet, under the bioethical perspective that grants an important place to physicians' and patients' autonomy, the dignity of the individual cannot be dissociated from the individual's capacity for self-determination.

In this perspective, it is appropriate to reflect on the socioethical problems that can be raised by the legislation and some aspects of its implementation on the ground in the context of reprogenetic services. The third analytic level in the ethnographic study mentioned earlier allowed for the identification of four kinds of ethical problem flowing from French PGD-related law and its implementation: (1) discrimination based on sexual orientation and the requirement for adherence to a traditional model of the couple and the family; (2) inequitable access to PGD; (3) restrictions on couples' autonomy with respect to procreation; and (4) lack of respect for confidentiality regarding private life. The majority of the socioethical problems presented in the following were identified through a comparison of the data and results obtained from the review of the legal and ethical literature with the data and results obtained from participant observation and interviews. An overview of the results is presented in Tables 2, 3, 4, and 5.[3]

Discrimination Related to Sexual Orientation and Traditional Model of the Couple and the Family (Table 2)

By specifying in the legislation that a couple consists of a man and a woman, the French state limits access to PGD to heterosexual couples. Thus, individuals who are homosexual, single, widowed, or single parents cannot access PGD, even if they are at risk of transmitting serious genetic disorders. From an ethical perspective and an anthropological perspective, this approach is subject to examination, to the extent that it discriminates against certain categories of people on the basis of sexual orientation and adherence to traditional models of the couple, the family, and living arrangements.

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[2] Time on the waiting list must be added to all of this; as of now, it stands at 2 years.

[3] Tables 2, 3, 4 and 5, represent an overview of concurring findings emerging from the data, the results, and the socio-ethical and anthropological analyses specific to this article. They don't present the full range of results from the study.

Table 2. Discrimination based on sexual orientation and the requirement for adherence to a traditional model of the couple and the family

Literature review and Law on Bioethics	• "The man and woman who constitute the couple must be living, of an age to procreate, and married or able to provide proof they have cohabited for at least two years; and they must consent prior to the embryo transfer." (L.2141-2).
Participant observation	• No homosexual couples, no individuals who were single, widowed, or single parents, and no couples who had been in a common law union for less than two years were observed in PGD clinics. The reason is that the law prohibits these categories of people from having access to this form of prenatal diagnosis, even in cases of individuals carrying or suffering from a genetic or chromosomal disorder.[5] • They had known each other for a long time. • Couples in a common law unions for less than 2 years applied for these reasons, but were rejected nevertheless: • They had had been through several abortions of affected fetuses. • They already had a child with the identified disease, in some cases a child who had died of the disease. • They had seen family members suffer from the disease or die of it.
Semistructured interviews and informal discussions	• No heterosexual or homosexual couple was asked about this topic. (We plan a future study on the topic.)* • The majority of the physicians met with and half of the health professionals met with were against discrimination on the basis of sexual orientation. • Half of the health professionals deemed this measure acceptable, viewing same-sex parenting as being against nature. • Many health professionals believed it is preferable for a child to have heterosexual parents. • The majority of the physicians recognized that same-sex parenting does not prejudice children's sense of stability.
Socioethical analysis	• Discrimination on the basis of sexual orientation • Discrimination on the basis of adherence to traditional models of the couple • Discrimination motivated by the desire that couples be stable. • The requirement that couples who are given access to PGD be heterosexual is stipulated in the public health code.
Anthropological analysis	• An examination of the manner of regulating access to ART reveals that the French State recognizes only the traditional heterosexual and two-parent models of the family. • For the French State, same-sex parenting and lone parenting represent a risk to the child's well-being; the view is that only heterosexual couples can provide sufficient stability to make a parental application; the members of the couple make a joint application. • The requirement for common-law couples to have lived together for two years is intended as a way for the legislator to ensure the child has a stable home. But this is not in line with the statistical evidence about the stability of unions. Divorce rates rise significantly following four years of marriage. • The desire for couples to be stable and adhere to certain life models does not reflect certain social and clinical realities. • The French state is assuming a "quasi-parental" traditional role in determining what criteria identify an "acceptable" couple and in deciding who may reproduce by means of ART.

*With the issue in question having emerged for analysis after the data-gathering process, no couples were interviewed on this topic. We plan a future study on the topic

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[5] Note that the point we wish to make here is not based on the issue of how many homosexuals wish to have children. The issue is rather that of according homosexuals the same rights as all other people, regardless of the proportion who may want to have children or need access to PGD.

Table 3. Inequitable access to PGD

Literature review (Law on Bioethics)	• PGD is governed in the same way as an ART (Bioethics Law no. 2004-800, on the donation and use of elements and products of the human body, artificial reproductive technologies, and prenatal diagnosis.) • The state's intervention in the context of PGD and IVF is based on its commitment to protecting human beings from the beginnings of life, including embryos conceived in vitro.
Participant observation	• PGD centers are found in the same institutions as centers for IVF done in other contexts. • The medical and social purposes and the techniques involved are entirely different as between PGD and IVF done in other contexts. • In the seeking of recourse to PGD in the context of a serious genetic or chromosomal disorder in the family, the parents' concerns have to do essentially with the health of the unborn child. In standard recourse to IVF, couples are looking for a solution to infertility. Those who seek PGD do not view PGD as a means of conceiving a child. • Many couples find they are denied access to PGD because they do not adhere to the moral imperatives that underlie the laws that govern this technique of prenatal diagnosis (PND). • Some CPDPN members do not differentiate between the features specific to PGD and those specific to IVF done in other contexts. • Under current measures, the interests of the embryo are placed above those of the fetus, the child once born, and the couple. • Representations of the criteria for access to PGD vary depending on whether one is a geneticist, an obstetrician, etc.
Semistructured interviews and informal discussions	• Couples seeking PGD see a big difference between what they experience and what is experienced by infertile couples. They believe that subjecting them to the same rules as those applied to infertile couples just adds to their suffering. • For patients, in cases of PND it is irresponsible to place the interests of the embryo over those of the fetus whose life may be terminated, as well as over those of children who could be born with serious disorders.
Socioethical analysis	• Ethical problems arise in relation to equity, justice, and equality in the matter of prenatal genetic testing. • Inequity in access to PND based on whether the parents are seeking diagnosis of an embryo or of a fetus. • Inequity in access to a form of PND because its purpose is erroneously treated as being the same as that of IVF done in other contexts. • Inequity in access to a form of PND according to whether those applying for it are viewed as "couples" rather than "patients." • Inequity justified on the basis of concern to protect the embryo and avoid eugenicist, utilitarian, etc. abuses. • Inequity in access to a form of PND based on marital status and sexual orientation. • Dissociating prenatal genetic testing from PGD while confusing PGD with standard recourse to IVF leads to problems of justice, equity, and equality in matters of access to health services.
Anthropological analysis	• Since PGD requires the creation of embryos in vitro, it is easy to obscure its diagnostic role and assimilate it to IVF in the context of infertility. This enables the French legislation to fail to differentiate the purposes of PGD from those of standard recourse to IVF. • The power of the social impact of representations about the danger of ART to human beings and their institutions: confusion between PGD and IVF done in other contexts; "patients" transformed into "couples"; PND dissociated from PGD; attention drawn away from problems related to genetic disorders towards the issues that preoccupy PGD's detractors. • Socially, the threat of eugenics, the dangers of harm to the integrity of the human species, and the protection of human

(Continued on next page)

Table 3. Inequitable access to PGD *(Continued)*

	• Research subjects appear more salient than consideration for patients and their needs. • Based on the fact that PGD is conducted on embryos created in vitro rather than on fetuses, couples who apply for PGD must satisfy much more stringent social and moral requirements than is the case with any other kind of PND. • The concern for respect for the human being from the beginnings of life is not in play in the same way when it comes to PND conducted on the fetus. • The measures that result in these circumstances would appear to have been devised with a view more to protecting the moral values surrounding the embryo than protecting the health of the unborn child.

While homosexuality has not been considered a disease since 1986, the French state continues to recognize only the heterosexual model of the couple, legitimizing it by means of the Public Health Code (Article L. 2141-2). Ethically speaking, it is not so much the fact that the legislation defines a model of the couple that causes problems but rather the fact that this legislation, via a public health code, creates inequalities among people who wish to reproduce.

Furthermore, by forbidding homosexuals access to PGD, the French legislation also implies that only heterosexual couples can provide sufficient stability to make a joint parental application (Bévière 2005). Nowadays, however, it is recognized that same-sex parenting does not prejudice the stability of the home (Bos et al. 2004; Roccella 2005; Bos et al. 2007). To take one example of a contrasting approach to homosexuality, under the Canadian Charter of Rights and Liberties, this prohibition would be viewed as state interference in private life and a discriminatory act based on sexual orientation[4] (Charte canadienne des droits et libertés 1982, c. 11, articles 7 and 15).

In the field, opinion was divided. For examples, several professionals shared this view: "They already have the Pacte civil de solidarité [a form of civil union that serves as an alternative to marriage in France], which allows them to make their union official under the law. They have the right to love each other, that's tolerated, but just the same it's against nature for them to have children" (health care professional: field notes). But most of the physicians met with did not approve of excluding homosexual couples: "You know, nowadays it's not normal to forbid gay people access to PGD. They should have the same right as other people to have children free of the genetic disorders they carry"(physician geneticist: field notes).

Also, by limiting access to PGD to two-parent heterosexual families, the French legislation discriminates against single, widowed, and single-parent individuals, disregarding their risk of transmitting a serious genetic or chromosomal disorder to their children. And yet these same categories of individual are granted access to other forms of antenatal diagnosis. Since they are thus precluded from access to a medical technique that would enable them to have children free of the disorder they suffer from or carry, their sole options are to not have children, to take the risk of having a sick child, or to resort to the medical termination of pregnancy following prenatal genetic testing with amniocentesis, chorionic villus sampling, or another technique.

In requiring unmarried couples to prove that they have lived together for 2 years in order to obtain access to PGD (Article L. 2141-2), the legislation is ignoring certain social and clinical realities. Socially speaking, it disregards the fact that a man and a woman may have been seeing each other for several years before deciding to live together. Nor does the requirement to show 2 years of living together respect the trials and tribulations of couples who have lived together for less than 2 years but have lost a child or have seen people close to them suffer and die of the disorder they wish to avoid transmitting. "We're here for PGD because we don't want to have a third child with cystic fibrosis. When we sought PGD for our second child, we were refused because we hadn't been living together for two years. Yet we'd known each other for a long time and I already had a child with the disease. So anyway, we went ahead the natural way. Because the child we conceived also had the disease, we had to resort to abortion . . . We couldn't go through that again" (female patient presenting for consultation for PGD: field notes).

Finally, it is reasonable to wonder about the appropriateness of stipulating this 2-year time period as a way for the legislation to ensure the child has a stable home. Support for questioning this timeline is provided by data from France's National Institute for Statistics and Economic Studies (Institut National de la Statistique et des Études Economiques, known as INSEE) dating from 2006. These data show that the rates of divorce rise significantly following 4 years of marriage (30%), not 2 (16%) (INSEE 2006). Thus, it is debatable whether one can set a specific time period as a warrant of stability. One may also ask whether the French state is assuming a "quasi-parental" role in determining what criteria identify an "acceptable" couple whose legitimacy and stability are incontrovertibly demonstrated.

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[4] Note that the point we wish to make here is not based on the issue of how many homosexuals wish to have children. The issue is rather that of according homosexuals the same rights as all other people, regardless of the proportion who may want to have children or need access to PGD.

Table 4. Restrictions on couples' autonomy with respect to procreation

Literature review (Law on Bioethics)	• The CPDPN committee must know about the couple's motivations for bearing a child and openness to adoption (Article L. 2141-10; Law 2004-800, art. 24 I). • The CPDPN committee must know about the couple's living arrangements and sexual orientation.
Participant observation	• CPDPN committees' decisions may be made on the basis of the individual values of each committee member; approaches can vary from one case to another and from one CPDPN to another. • It can happen that the members of a CPDPN committee can't reach agreement on the seriousness of a given pathology, in particular when it comes to disorders involving blindness, deafness, and infertility. • CPDPN committees may refuse PGD because the couple does not impress them as being sufficiently stable to have a child. • Age difference between partners can be an obstacle to accessing PGD. • CPDPN committees will sometimes require a couple to go through a longer period of reflection. • Couples sometimes ask for PGD for religious reasons. • PGD can conflict with the religious or moral values of some members of CPDPN committees, a situation that can represent one more difficulty for the committee to manage.
Semistructured interviews and informal discussions	• Couples do not like having CPDPN committees decide whether the disorder for which they are consulting is serious. • Couples do not like the fact that a psychological assessment is a prerequisite to making an application for PGD. They view it as a judgment about their mental health and cannot see a connection between seeing a psychologist and having PGD. • Some CPDPN committee members believe that couples cannot decide on their own whether recourse to PGD is justified. • Some members believe that researchers work to make PGD easier in order to further knowledge or to advance their careers. • Some members conceive of PGD as a medical practice that helps couples struggling with serious hereditary disorders.
Socioethical analysis	• In its efforts to protect the embryo and the traditional family, the French state deprives couples of their decision-making power with respect to reproduction and excludes them from the discussion about the ethical feasibility of PGD in their own cases. • By preventing a clear distinction between the scientific, medical, disciplinary, religious, personal, and other levels of reality in relation to PGD, the current situation fails to foster the development of models for ethical inquiry and deliberation positioned between the national prescriptive ethics inscribed in the law, a citizen ethics closer to social reality, and the moral values of the individuals who comprise CPDPN committees. • By giving CPDPN committees the power to decide whether applicants are eligible for PGD based on non-medical criteria, the risk is created of subjecting patients to value judgments or the play of special interests. • Although the legislative measures that govern PGD in France may appear prudent and appropriate in preventing the eugenicist and transformationist abuses that it is feared reprogenetics will lead to, they are based on the assumption that couples are incapable of making ethical and responsible decisions. • Couples at risk of transmitting a genetic disorder are deprived of a portion of their reproductive decision-making power.

(Continued on next page)

Table 4. Restrictions on couples' autonomy with respect to procreation ***(Continued)***

Anthropological analysis	• The present situation fosters the application of prohibitions based on individual values, conflicts of interest, and professional and disciplinary issues that can vary according to gender, personal beliefs, and profession (biologist, obstetrician, geneticist, etc.). • By granting CPDPN committees a decision-making power that exceeds their members' bioclinical expertise, the French state exercises significant control over the reproductive lives of couples who resort to ART in general and PGD in particular. • In order to protect against liberal eugenics, the French state reduces patient autonomy. But this compromise indirectly increases the power that the various religious, ideological, and scientific special-interest groups can exercise over the delivery of ART services. • Based on a desire to protect the embryo from potentially narcissistic, vulnerable, and incompetent parents, the French state intervenes in couples' reproductive lives without taking into account their experiences and capacity for self-determination.

Table 5. Lack of respect for confidentiality regarding private life

Literature review (Law on Bioethics)	• All the information required by the legislation, including the information on the couple's private life, must be placed in the file submitted to the CPDPN. • Even though some members of the CPDPN committee are not members of a couple's care team, all CPDPN committee members have access to medical and psychosocial information about an applicant couple.
Participant observation	• Since CPDPN committees are not necessarily composed exclusively of professionals involved in the couples' clinical care, individuals who do not participate in care have access to information about couples' private lives and state of health. • Sometime several people are present during the couple's clinical consulation. • Information sessions bring several couples together in a single room.
Semistructured interviews and informal discussions	• Couples strongly resent being asked questions about their private lives and living arrangements. • Couples feel intimidated by the presence of numerous professional at their consultation sessions. • Because individuals with genetic and chromosomal disorders tend to experience guilt in connection with the disorder, they fear being judged by the others present at group information sessions.
Socioethical analysis	• The ways of applying matters related to the functioning of CPDPNs make possible a collective intrusion into the private lives of the men and women who apply for PGD. • The sharing of personal, medical, and genetic information among a needlessly high number of people results in a serious impact on the respect for privacy and the protection of confidential information. • This requirement raises ethical questions about the respect for confidentiality and privacy, especially since the file will simply not be considered if it does not contain the information about the couple's adherence to the model stipulated by the legislation. • Not taking into account the fact that genetic information includes confidential data that are especially sensitive, specifically in relation to eugenicist views, stigmatization, and discrimination, poses significant socioethical problems.
Anthropological analysis	• There still appears to be no medical reason for the gathering of personal information about the couples (their motivations, their living arrangements as a couple, their sexual orientation). • These circumstances can only be accounted for on the basis of social reasons having to do with the degree of involvement the state wishes to have in couples' reproductive decisions. • The confidentiality of genetic data is subject to breaches that can have negative repercussions in the family and the community the couple belong to.

Inequitable Access to PGD (Table 3)

Looked at from another angle, the measures surrounding PGD could lead one to wonder why a technique of genetic diagnosis, even if performed pre-implantation, should be governed the same way as an ART. After all, the objectives of PGD and the objectives of ART in general are very different. If the state's intervention is based on its commitment to protecting human beings from the beginnings of life, ethical problems arise in relation to equity, justice, and equality in the matter of access to health services. Three attitudes contribute to these problems: the confusion between PGD on one hand and recourse to IVF as a measure to palliate infertility on the other hand; the transformation of "patients" into "couples"; and the dissociation of prenatal genetic testing from PGD.

Confusion Between PGD and Recourse to IVF for Reasons of Infertility

In the context of PGD, IVF is used to produce embryos to be diagnosed prior to transfer to the mother's womb. It does not constitute a method of helping infertile couples have children. The purpose of PGD is entirely diagnostic. Those who have recourse to PGD are rarely infertile. Most of the time, they have a serious genetic disorder or are carriers of one; many of them already have a child, children, or family members who have the disorder or indeed who have died of it. Also, some people opt for PGD following several abortions of affected fetuses of after the death of one of their children. "You know, all of my three children died in my arms of suffocation. None of them was even two months old. It's not life I'm transmitting, it's death. That's why I've come for PGD" (female patient who was present for her fourth treatment: field notes).

In contrast to recourse to IVF by infertile people, recourse to PGD does not provide an infertile couple or woman with a child. Rather, it is aimed at preventing the birth, to a couple or an individual capable of conceiving a child by normal means but at risk of transmitting a serious genetic disorder, of a child with a severe or fatal pathology.

Since PGD requires the creation of embryos in vitro, however, it is easy to obscure its diagnostic role and assimilate it to IVF used in the context of infertility. This enables the French legislation to fail to differentiate the purposes of PGD from those of standard recourse to IVF. And yet the circumstances in which each of these procedures is indicated are fundamentally different.

In the seeking of recourse to PGD in the context of a serious genetic or chromosomal disorder in the family, the parents' concerns have to do essentially with the health of the unborn child. In standard recourse to IVF, couples are looking for a solution to infertility. Apart from issues directly related to the in vitro conception of an embryo, the problems that couples in the two situations confront and the issues associated with their unborn children have nothing in common, whether ethically or clinically.

When couples were asked, during interviews, why they had not resorted to sperm donation, the women tended to recoil in their seats and express strong disgust. This disgust is not found among women who consult for infertility, because sperm from a donor offers the only way to conceive and carry a child. In the context of PGD, a woman affected by a transmissible disorder will tend to say she is consulting because her male partner has the right to have a normal child; when it's the man who is affected by the disorder, his female partner resorts to PGD so the man won't feel guilty. Either way, the woman consults for her male partner's sake. Since the couple is not infertile, these women view accepting a sperm donation as an added source of suffering for their partners.

The quotation that follows is representative of the way men view sperm donation: "I prefer adopting a child to recourse to a sperm donor, because a child born as the result of a sperm donation will be my wife's child but not mine. That will make a difference to the kind of love I could give the child. If we adopt a child, as parents we will stand in an equal relationship to him or her" (Stéphane, carrier, interview).

It thus seems reasonable to ask why individuals who wish to avoid transmitting the disorder they carry or suffer from to their children should be subject to the same legislative framework as individuals with fertility problems. Put another way, why has the law been framed on the basis of a technical aspect of a procedure rather than on the basis of the procedure's purpose and use? Should the state's decision to protect the embryo be viewed the same way in the two contexts? This situation raises numerous questions.

Transforming "Patients" Into "Couples" (Table 4)

Legislatively speaking, opting to minimize the diagnostic aspect of PGD makes it possible to limit its access to heterosexual couples and to govern it as an ART technique intended to address problems of infertility. This then allows for the people who apply for PGD to be viewed as "couples" and not as "patients." From an ethical perspective, this transformation of patients into couples also allows for the adoption of general measures that foster the confusion of individuals who would like access to PGD for purposes of sex selection or for discriminatory reasons (whether eugenicist or other) with those who live with the knowledge that they carry serious and rare disorders or who live with the disorders themselves. When this confusion prevails, the attention that should be paid to patients and to the health of their unborn children is diverted toward the discourse currently employed by detractors of PGD, including the phrases "new eugenics," "perfect child" (Bouffard et al. 2009), and so on.

These representations, which emerged from depictions of utopias and dystopias (Bouffard 2000), began to appear in the 1970s, a time when our understanding of the clinical realities of genetics, ART, and reprogenetics was largely theoretical. This was an era in which concerns over the threat of eugenics, the dangers of harm to the integrity of the human species, and the protection of human research subjects were more salient than consideration for patients and their needs. It is startling to realize how influential the discourse of that era continues to be and the extent to which it plays a determining role in ethical and legal deliberations about genetics, ART, and reprogenetics (Bouffard et al. 2009) and casts a shadow of suspicion over all patient applications.

Dissociating PGD From Prenatal Genetic Testing

If it is the case that protection of the embryo allows for confusion between PGD and standard IVF, this also justifies dissociating PGD from prenatal genetic testing. For example, the French state has no difficulty with guaranteeing access to prenatal genetic diagnosis and sonograms to all women, whether homosexual, single, or members of couples. Yet this equality of access vanishes when it comes to PGD.

Similarly, based on the fact that in PGD genetic diagnosis is conducted on embryos created in vitro rather than on fetuses, couples who apply for PGD must satisfy much more stringent social and moral requirements than is the case with any other kind of antenatal diagnosis. We repeatedly observed some categories of couple finding they were refused access to this medical technique of antenatal diagnosis because they did not adhere to the moral imperatives that underlie the laws that govern PGD. The result is that discrimination is practiced among couples at risk of transmitting serious genetic and chromosomal disorders to their children, depending on whether those couples have recourse to diagnosis on a fetus or on an embryo.

However, since the cost of PGD is assumed by the French health care system, the state is in a position to justify taking greater responsibility for an embryo fertilized in vitro than for an embryo conceived naturally and without medical intervention, as the result of sexual relations between a man and a woman. Whatever the case, given that prenatal genetic testing and PGD pursue the same goals, it is important to question this instance of disparity, which supports inequities and inequalities that cannot be justified by the state's commitment to protect the human being from the beginning of life. Why is the concern for respect for the human being from the beginnings of life not in play in the same way when it comes to prenatal diagnosis conducted on the fetus? For the patients met with in the context of the study, in cases of prenatal diagnosis it is irresponsible to place the interests of the embryo over those of the fetus, whose life it is permitted to interrupt, as well as over those of children who could be born with serious disorders and suffer painful life conditions. The latter consideration is made all the stronger by the fact that the risk is known in advance because it is known that the future parents carry or suffer from the disorder.

To sum up: Differentiating prenatal genetic testing from PGD on one hand while confusing PGD with standard recourse to IVF on the other hand inevitably leads to problems of justice, equity, and equality in matters of access to health services. First, couples who carry or suffer from a genetic disorder experience discrimination among themselves depending on the kind of diagnosis they choose—preimplantation or prenatal. Second, if they resort to PGD, they are assimilated, even though most of them are actually fertile, to couples who are consulting for infertility problems. The measures that result in these circumstances would appear to have been devised with a view more to protecting the moral values surrounding the embryo than protecting the health of the unborn child.

Restrictions on Couples' Autonomy in Relation to Reproductive Issues (Table 5)

In its efforts to protect the embryo and the traditional family, the French state deprives couples at risk of transmitting serious genetic disorders of their decision-making power with respect to reproduction. Also, certain legislative measures governing PGD raise numerous ethical questions about patient autonomy.

One example among others is the obligation laid on CPDPNs to inquire into couples' motivations and their openness to adoption: "They asked us whether we'd thought of adopting! What are they, sadists? This disease gives us enough grief; we don't need to be treated as if we were sterile! After all, we're capable of conceiving our own children, why add to our problems?" (female patient, following a meeting with the clinical team: interview). CPDPNs are also required to learn about the couple's living arrangements and sexual orientation. These provisions require the CPDPN committee members to assess not just the seriousness of the heritable disorder and the suitability of PGD, but also to pass judgment on couples' moral and social conformity. Since this last role can only be fulfilled on the basis of the individual values of each committee member, approaches can vary from one case to another and one CPDPN to another.

For example, within a single CPDPN committee it may be possible to identify individuals who view PGD as a blanket solution to the problem of abortion and others who consider it a eugenic practice. "This is a eugenic practice we're talking about, an expensive technique. We can't let it serve as a way of avoiding abortions for psychological or religious reasons. That would be an unacceptable misuse" (physician involved in PGD service delivery: interview). And of course there is a continuum of positions between those two extremes. Furthermore, some members believe that researchers work to make PGD easier in order to further knowledge or to advance their careers, while others conceive of it as a medical practice that helps couples struggling with serious hereditary disorders. Finally, it can also happen that the members of a CPDPN committee can't reach agreement on the seriousness of a given pathology, in particular when it comes to disorders involving blindness, deafness, and infertility.

It is also the case that some CPDPN committees may refuse access to PGD because a couple does not impress them as being sufficiently stable to have a child. Even a large age difference between partners can be an obstacle to accessing PGD, in particular if the woman is older than the man. When doubt exists, following CPDPN committee members' efforts to determine what seem to be the best interests of the child, an application may be rejected or couples may be required to wait out a further period of reflection. Long time periods often result in couples giving up of their own volition. CPDPN committees can also encounter difficulties in relation to an application for PGD motivated by religious opposition to abortion, an issue that produces considerable debate. Conversely, PGD can conflict with the religious values of some members of CPDPN committees, a situation that can represent one more difficulty for the committee to manage.

By preventing the making of a clear distinction between the scientific, medical, disciplinary, religious, personal, and other levels of reality in relation to PGD, the current situation fails to foster the development of models for ethical inquiry and deliberation positioned between the national prescriptive ethics inscribed in the law, a citizen ethics (Levitt 2003; Harvey 2009) closer to social reality, and the moral values of the individuals who comprise CPDPN committees. Instead, despite the goodwill of members of CPDPN committees, the present situation fosters the application of prohibitions based on individual values, conflicts of interest, and professional and disciplinary issues that can vary according to gender, personal beliefs, and profession (biologist, obstetrician, geneticist, etc.).

What strikes us as more serious still, however, is that the present circumstances wholly exclude couples from the discussion about the ethical feasibility of the PGD they are applying for.

By granting CPDPN committees a decision-making power that exceeds their members' bioclinical expertise, the French state exercises significant control over the reproductive lives of couples who resort to ART in general and PGD in particular. The objective may well be to protect against the possible abuses of liberal or consumerist eugenics, even though this means reducing patient autonomy; however, the trade-off is that the various religious, ideological, and scientific lobbies exert indirect power over ART. Finally, by giving CPDPN committees the power to decide whether applicants are eligible for PGD based on nonmedical criteria, the risk is created of subjecting patients to value judgments or to the play of special interests.

Thus, although the legislative measures that govern PGD in France may appear prudent and appropriate in preventing the eugenicist and transformationist abuses that it is feared reprogenetics will lead to, they assume that couples are incapable of making ethical and responsible decisions. Further, they allow a great deal of room for the play of the moral influence of the individuals who make up the decision-making committees. Without challenging the Law on Bioethics, it is important to reflect on the ethical problems raised by this approach.

In the name of ethics and with the desire to protect the embryo from parents who are deemed to be narcissistic (Weil 1997), vulnerable (Asch 2003), or inadequate, the French state is failing to take into account couples' experience and capacity for self-determination. It is thus depriving couples at risk of transmitting a serious genetic disorder of a portion of their reproductive decision-making power.

Lack of Respect for Confidentiality (Table 6)

The law stipulates that a CPDPN must assess the suitability of PGD for a given couple, yet CPDPN committees are not necessarily composed exclusively of professionals involved in the couples' clinical care. This means individuals who do not participate in care have access to information about couples' private lives and state of health. Thus, the method of implementing Article L. 2141-10 of the Public Health Code makes possible a collective intrusion into the private lives of the men and women who apply for PGD. This requirement raises ethical questions about the respect for confidentiality and privacy, especially since the file will simply not be considered if it does not contain the information about the couple's adherence to the model stipulated by the legislation. Even though some members of the CPDPN committee are not members of a couple's care team, all CPDPN committee members have the same access to medical and psychosocial information about an applicant couple.

While it is true that CPDPN committee members are under an obligation of confidentiality stipulated by law and codes of professional ethics, there still appears to be no medical reason for the gathering of personal information about the couples (their motivations, their living arrangements as a couple, their sexual orientation). And yet it is just this kind of information that is gathered, entered in a medical chart, and made accessible to individuals who play no direct role in the provision of PGD and openly discussed when files are discussed during CPDPN committee meetings. These circumstances can only be accounted for on the basis of social reasons having to do with the degree of involvement the state wishes to have in couples' reproductive decisions.

Another aspect of this issue is that these measures do not take into account the fact that genetic information includes confidential data that are especially sensitive, specifically in relation to eugenicist views, stigmatization, and discrimination (Browner and Press 1995; Parens and Asch 2003; Galton 2005; Shakespeare 2006; Lowstuter et al. 2008; Pilgrim 2008; Raz 2009; Ricci 2009). On this basis alone, these data deserve to be treated with the highest level of confidentiality. This is all the more important given the fact that the availability of genetic information about individuals with genetic disorders or chromosomal anomalies affects not just those individuals themselves but also some members of their families (Knoppers 2002; Godard et al. 2006) and communities (Foster et al. 1999; Godard et al. 2004).

And yet many publications in the field of ethics have drawn attention to the fact that genetic information has repercussions that go beyond the medical sphere. This kind of information affects the private lives and the beliefs of individuals, couples, and families at the deepest levels (Bouffard 2000). Some sense of the importance of confidentiality in this domain can be gained by considering the guilt and shame that genetic disorders giver rise to and the potential for discrimination they produce. Details of this kind should by their nature be assigned a high level of confidentiality. The sharing of personal, medical, and genetic information among a needlessly high number of people results in a serious impact on the respect for privacy and the protection of confidential information.

DISCUSSION

By positioning itself within the logic of preserving the human species and the embryo, French legislation advocates a preventive attitude toward the eugenicist, consumerist, and transformationist abuses about which reprogenetics elicits fear. Further, in basing itself on the Preamble to the Constitution and by legally decreeing that a couple consists of a man and a woman, the legislation preserves the traditional Western models of the family and the couple, setting those models up as guarantees of the child's welfare. Note that the association of prenatal diagnosis with preventive measures related to the health of the child was recently challenged in Opinion no. 107 of the CCNE, on "ethical problems related to prenatal diagnosis: prenatal diagnosis and PGD" (CCNE, Notice No. 107, 15 October 2009).

Regardless of the regulatory methods that a state may privilege in matters of human reproduction and regardless of their governance powers, whether formal or less formal, all states aim either to strengthen the sociocultural values embodied in tradition or, on the contrary, to promote a new moral order. The prohibition against sex selection and the one-child policy in China (Lai-wan et al. 2006), the decriminalization of abortion, the prohibition against interethnic marriage, and screening for trisomy all illustrate this.

Even when they apply only within a highly restricted sphere like that of access to reprogenetic services, regulatory methods of this kind are still revealing of the values defended by the various social and community interests, whether religious, ideological, scientific, disciplinary, economic, or other. Ultimately, the issue is that of extending the influence of certain groups over states' regulatory methods so that they can determine who can reproduce, with whom, and under what conditions.

To some degree, on the pretext of protecting the in vitro embryo and preserving the family in its traditional form, French legislation removes the embryo from the sphere of the couple's parental responsibility from which it emerged and places it under the protection of the state. The legislative prescriptions about sexual orientation, the constitution of the couple, and the specifics of living arrangements leave little room for the individual child-bearing projects of individuals who are carriers of or sufferers from serious genetic and chromosomal disorders. Also, given the current context of cross-border reproductive care (Pennings et al. 2009), we may also ask about the effectiveness of formal norms that uncompromisingly advocate a family model that aligns better with tradition than with the social realities of present-day families.

Thus, we may ask why the French state, by means of legislation intended to protect patients and preserve the human individual (Bévière 2004), controls what modes of filiation are to be deemed deviant among people who need access to reproductive biotechnologies but not among other people. What message is the state sending through its dealings with these marginalized groups? Does recourse to technology in order to have children justify the imposition of requirements about living arrangements and sexual orientation that adhere to a certain morality? Is the ability to provide a child with a balanced and healthy home limited exclusively to heterosexual couples who have lived together for 2 years? In fact, we know that these criteria are far from guaranteeing a child's happiness.

By withdrawing the right to have children free of serious genetic disorders from couples and individuals deemed not to satisfy certain norms, we are preparing the ground for state abuses in the form of discrimination in the reproductive sphere.

Sexual Orientation, a Couple's Living Arrangements, The Child's Well-Being, and State Responsibility

The gathering of information about sexual orientation and a couple's living arrangements is an example of this, because this information is not necessary to good clinical management. In any case, it is unlikely such measures really guarantee the child's welfare. Rather, they appear to reveal anxieties that lead to discriminatory attitudes based on sexual orientation and couples' presumed instability. Finally, a further motive for the observance of strict measures relating to couples and to living arrangements when it comes to ART would appear to be to ward against polygamy—a marital arrangement increasingly encountered by workers in French medical services.

These forms of discrimination are considered a necessary evil designed to assure the child of a suitable family environment; why are they not imposed on the public at large? In reality, the notion of preventing people who are violent, alcoholic, or drug-addicted, or people who have a criminal record, from having children appears like unthinkable eugenicism. For any one of the categories of people named, an attempt to deny them children would be viewed as a serious infringement of autonomy. Are we to assume that the state is obligated to protect only those children—a very small minority—who are born as a result of reprogenetics and ART? If that is so, it is curious that the medical follow-up for children born following PGD is not systematically undertaken in order to ensure PGD did not result in harm to their physical integrity.

Whatever the case, what is clear is that more severe constraints on reproduction are placed on individuals who carry or suffer from serious genetic disorders, simply by virtue of their recourse to PGD, than on the rest of the population. Considering that such individuals are struggling with pathologies that often have already meant the death of children or close family members, it appears to be ethically imperative to look into the appropriateness of sparing them the suffering associated with abortion, not to mention the suffering associated with having a child with a disease that it could have been protected from (Bouffard 2010).

Questions arise in connection with other issues as well. Is it the fact that in France the state reimburses the cost of four PGD attempts that leads to the state's assuming a part of the responsibility that would belong wholly to parents in normal conditions? Should legislative measures like those adopted in France raise concerns about the excessive monitoring of reproductive methods, or do they represent the responsible management of the state's medical resources? Does the state's assumption of financial responsibility necessarily imply taking over certain parental responsibilities?

Couples' Private Lives and Self-Determination

While the members of the CPDPN multidisciplinary committees do remarkable work, by conferring upon them significant decision-making powers over the reproductive lives of couples who consult for PGD, the legislation has opened the door to abuses specific to each CPDPN. Besides this, by requiring these committees to make determinations about the moral, legal, medical, and social compliance, the law also allows them to decide on the level of confidentiality assigned to personal information, medical data, and genetic information.

On one hand, the personal information the law obliges couples to reveal goes significantly beyond the bounds of medical practice. As we saw earlier, the criteria for eligibility for PGD and CPDPNs' decision-making methods emerge more from cultural and social norms than biomedical ones. Couples are inevitably subjected to an arbitrary component of the decision, one associated with professional-code, disciplinary, religious, and moral values defended by the CPDPN committee members. As indeed emerged from the ethnographic work done in the field that this article is based on, the history of PGD's development, the varied objectives it can serve, the moral questions it raises, and its very nature, which requires direct intervention on human embryos, can give rise to varying professional perspectives on what constitutes good medical practice. On the other hand, by associating PGD with recourse to IVF as an infertility solution, the law minimizes the issue of the level of confidentiality with which medical data in general and genetic data in particular ought to be treated. Note that a lively debate is currently under way in France about the confidential nature of genetic information, leaving little room for anyone to plead unawareness of the relevance to this particular context of concerns about confidentiality.

In these circumstances, it becomes difficult to draw a clear line between what should be viewed as medical information and what should be viewed as information related to private life. The law could inadvertently empower CPDPNs to encroach on couples' private lives and their capacity for autonomous action by depriving couples of the power to determine the appropriateness of their undertaking (Knoppers et al. 2006). Under current conditions, and especially when a couple's application for PGD is rejected on account of an aspect of their private life, couples have no choice but to submit to the decisions of others, since they are never invited to take part in CPDPN committees' decision-making processes or debate those committees' points of view, and since they have no right of appeal.

As we have seen, despite the sound reasons for their existence, these legislative measures, adopted with the child's welfare and the prevention of discriminatory and eugenic practices in view, do not offer protection against all forms of ethical failure. Problems of a socioethical nature are especially at issue here.

Possible Solutions

Our objective in this paper has been to prompt reflection that, while retaining concern for the protection of the family and the embryo, will take into account respect for the individual and the individual's private life, patient autonomy, and fair, equitable, nondiscriminatory access to PGD as a form of antenatal diagnosis.

In the short term the French state could, without altering its legislation, take steps to improve the ethical conditions in which PGD is practiced and support CPDPNs in the performance of their highly sensitive mandate. For example, the development of knowledge about the acceptability of single-parenthood and same-sex parenting, studies on the impact of CPDPN committees' decision-making processes on practice and on couples, and an assessment of the methods of implementing the legislation on bioethics could allow for: (1) the improved functioning of CPDPN committees; (2) support to the committees' members in the form of training sessions on ethical issues; (3) a review of the appropriateness of some of the conditions of eligibility for PGD; and (4) a determination of levels of confidentiality that would ensure better respect for individuals without infringing on the law.

These mechanisms would enable members of CPDPN committees to acquire specific knowledge about the diagnostic and psychosocial needs of the patients who consult. Also, in the field it was observed that couples' clinical care would be significantly facilitated if the state placed a higher priority on the training of human resources and increased the material resources needed for providing PGD so that patients could receive the service within reasonable timelines.

The Need to Review the Socioethical Impact of the Conditions of Access to PGD

It should be noted that, in suggesting that the appropriateness of some of the conditions for eligibility for PGD should be reviewed, we are not referring only to CPDPN multidisciplinary committees' decision-making processes. The review, in our view, should address the impact of the legislation on these processes. From this perspective, far more questions than answers emerged from the analysis we conducted.

First, as regards access to PGD, can we discriminate on the basis of applicants' sexual orientation, adherence to a certain model of the couple, genetic circumstances, and preference for having diagnosis performed on a fetus or an embryo? Are bioethical requirements for medical practice fulfilled when CPDPN committees are given this kind of power over couples' reproductive lives? Is the dignity of the individual preserved when others are passing judgement on the social conformity, stability, and motivations of couples who apply for PGD?

As regards the preservation of an acceptable level of confidentiality, observations in the field showed that certain approaches are effective in producing the climate of trust necessary to any claims to confidentiality. The cultivation of personal, professional, and organizational attitudes designed to enhance the level of confidentiality allows for (among other things) mitigating some of the undesirable effects of the legislation. In this connection, the state could help improve conditions for the storage of patients' charts. Thus, the concept of confidentiality would go beyond the observance of professional secrecy and be instead as an organizational and relational model.

From our North American perspective, we are inclined to ask whether the good practice of PGD requires access to information of such a personal nature about people's private lives. Once a CPDPN committee has reached agreement regarding the admissibility of the pathology the couple wishes to screen for and determined the couple satisfies the law's requirements, is it necessary to go further and examine the couple's motivation and openness to adoption? Further, is it relevant to pass judgment on the couple's stability when, given that in most cases they are not infertile, they could go ahead and have children without state intervention? Also, is it justifiable to disseminate the genetic information so widely?

For a realistic chance of finding informed, ethical, and equitable answers to these questions, it is imperative that we develop empirical knowledge about the various forms of state intervention in couples' reproductive lives, on both the national and international levels.

PGD in an International Context

In the international context of developments in reproductive genetics and reprogenetics, numerous countries are either ruling on the practice of PGD or reviewing their existing regulatory approaches (Bouffard et al. 2009). For example, in Austria, Ireland, Italy, Switzerland, and Western Australia, PGD is prohibited by law (Jones and Cohen 2007). In some countries, including Belgium, Denmark, France, Greece, Iceland, India, Netherlands, New Zealand, Norway, South Australia, Spain, the United Kingdom, Germany and the Australian state of Victoria, the law allows PGD, but under varying conditions and with varying provisions (Jones and Cohen 2007). Finally, it is also possible to practice PGD under a more general legislative framework, as in Canada, Israel, Japan, Singapore, and South Africa (Jones and Cohen 2007). In the United States, no single law governs the practice of PGD across the whole nation (Adams 2003). On the other hand, it is regulated under professional guidelines (Knoppers et al. 2006). Finally, in most of these countries social uses of reprogenetic techniques are prohibited. Social uses include social sex selection, cloning, and the selection of embryos with diseases ("negative enhancement").

As may be seen in Table 6, the Australian states of Victoria and South Australia also limit access to PGD to married, heterosexual couples and couples in a common-law union. In contrast, states including Belgium, Canada, Denmark, Israel, the Netherlands, Spain, the United Kingdoms, and the United States opt for more liberal legislation that excludes no group of patients or recognizes the plurality of family forms and the diversity of ethical positions regarding the acceptability of medically assisted reproduction. Among the countries in which PGD is permitted, France is the most restrictive of access when it comes to criteria regarding marital status and sexual orientation.

Distinguishing Between Bioethical and Socioethical Concerns

Be that as it may, it is certainly key to keep in mind that the regulation of human reproduction has always been a social matter and thus a matter of the moral, religious, ideological, political, and economic values advanced by the state by means of its legislation and policies. That being so, it is important on one hand to examine as objectively as possible the implicit and explicit stakes that are being protected by the governance systems in force in a society, especially when some categories of patient are deprived of access to a certain kind of antenatal diagnosis.

On the other hand, from a conceptual perspective, it is important to distinguish bioethical from socioethical concerns. Even if regulatory measures are aimed to limit both medical and social abuses, it is wise to avoid confusing the two categories so that we can properly measure the medical, social, and individual benefits yielded by the measures adopted by any given state.

This position gains further justification in a context in which cross-border reproductive care is becoming increasingly difficult to control. The bioethics/socioethics distinction could contribute to determining the level of intervention that the collectivity really wishes the state to have in couples' reproductive lives and more specifically in the lives of people who carry or suffer from serious genetic disorders or chromosomal anomalies. But this will only happen if we have field-derived data to rely on.

Finally, our objective in this paper has been to prompt reflection that, while retaining concern for the protection of

Table 6. Access to PGD, by marital status and sexual orientation

Country	Married heterosexual couples	Heterosexual couples in a common-law union	Lesbian couples	Single women	Widows who want a posthumous child	Insurance coverage
Belgium	X	X	X	X	X	Complete
Canada	X	X	X	X	X	No coverage
Denmark	X	X	X	X	—	Partial
France	X	X	—	—		Complete
Israel	X	X	X	X	X	Complete
Japan	X	—	—	—	—	No coverage
Netherlands	X	X	X	X	X	Partial
Singapore	X	—	—	—	—	No coverage
South Africa	X	X	X	X	X	No coverage
South Australia (Australia)	X	X	—	—	—	Partial
Spain	X	X	X	X	X	Partial
UK	X	X	X	X	X	Partial
USA	X	X	X	X	X	Private insurance
Victoria (Australia)	X	X	—	—	—	Partial

Note: Allowed = X, Prohibited = —.

the family and the embryo, will take into account respect for the individual and the individual's private life, patient autonomy, and fair, equitable, nondiscriminatory access to PGD as a form of antenatal diagnosis.

However, in the effort to deal with the ethical problems raised by the governance measures for reprogenetics and their implementation, while it is important to add to the discourse of experts the discourse of users and the general public, we must resist the temptation to confuse the discourse of patients with that of the general public. Two distinct sets of empirical data requiring different socioethical analyses are at issue. From an ethical perspective, it could be useful to understand the position held by patients in the power relations that exist between individuals and the state.

The situation is all the more important given that the political, medical, and community policymakers will have a foundational not just on the conditions for service delivery but also on the future of new medical paradigms whose diagnostic and therapeutic approaches are based on the use of the human embryo.

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