

Prenatal Screening for Anomalies: Between Clinical Finality and Selective Finality

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ABSTRACT *This article summarizes the results of two works of research carried out independently of one another in France. What makes it possible to present them together – like two facets of a medical practice – is the question of prenatal screening and the ethical problems which arise for people who are very much involved in this field, albeit in radically different ways: disabled persons on the one hand, and obstetrician-gynaecologists and ultrasonographers on the other. The people interviewed for the purposes of these two works of research throw an interesting light on the matter, based on their experiences and impressions. With regard to the disabled persons, it was a case of trying to remedy the social attitude which considers that they have nothing to say on these questions, despite the fact that they are of direct concern. Regarding the study of ultrasonographers and obstetrician-gynaecologists, the aim was to gain an understanding of how they had got through the intense debate that followed the Perruche ruling and the consequences of “life or prejudicial birth” actions on their professional practices and their views on the finality of prenatal screening.*

Introduction¹

In France, prenatal screening is put forward as technical progress designed to serve unborn children and their future parents. The screening can spot medical problems that might occur during gestation, as well as foetal anomalies, especially during the three ultrasound examinations prescribed during the pregnancy. We know that prenatal screening can save lives, not only of the babies but also of the mothers, or at least can help both to avoid the disastrous consequences of problems that might occur during pregnancy. It can also serve to prepare future parents for the birth of a disabled child, teach them about a treatable anomaly (such as a hare lip) or be useful in organizing surgery or in orienting towards a specialist ward as soon as the child is born. But its aim can also be selective, because in cases where an anomaly “of particular gravity, incurable at the time of diagnosis” is detected, French law authorizes medical termination of pregnancy until time of birth². The argument, accepted by all, or almost all, of the social players working in

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this field and by a large proportion of the able-bodied population, is to spare parents from a life of torment, involving permanent devotion and renunciation, worn down by the “impossible mourning” for the child that had been desired. Regarding the child to be born, we frequently hear that it is preferable by far to spare him/her a cruel fate, that it would be “selfish” to “let him/her” be born like that, not only for the baby itself, exposing it to unspeakable suffering, social rejection and to a “prejudicial” life,³ as has recently been asserted, but also for the community who will have to bear the economic burden. It is sometimes striking to note that certain disabled persons take up some or all of these arguments, thus approving and reactivating the deprecation or even scorn to which they are subjected by able-bodied people. The interiorization of such a negative self-image can lead to such a radical discredit that they feel that it would have been preferable not to have been born. This attitude will tend to be applied to the unborn child if his/her condition is going to be the same as that of the parents.⁴

Consensus in this area, in France at least, would appear to suggest that it is useless to call for ethical reflection. But through the two studies that we carried out, we saw that these attitudes are far from being shared by all disabled persons. Among the medical professions, there is no consensus. Many of the doctors we met clearly stood out by expressing their concerns about the shift from prenatal screening towards eugenics, fears which were recently expressed by the Chairman of the Conseil Consultatif National d’Ethique pour les Sciences de la Vie et de la Santé (CCNE)⁵ (Sicard 2007).

Our two works of research allowed us to explore the way in which disabled persons and professionals feel about and analyse prenatal screening – each on the basis of their own personal experience and social position. This was also an occasion for everyone to discuss the ethical questions that are now being asked about this practice (Moyses & Diederich 2001, 2006):

- The first study, which was carried out between 1998 and 2001 among disabled persons, consisted in finding out how these people perceived prenatal screening when its consequence was to reduce the number of births of children with identical anomalies to their own. Many of these disabled persons had already thought a great deal about the ethical problems relating to this practice.
- The second study was carried out between 2002 and 2004, among birth care professionals; it took place shortly after the major social movement of ultrasonographers and obstetricians following the famous “Perruche affair”, the effect of which had been to intensify questions concerning the practice of prenatal screening. Faced with the ever-increasing risk of legal action for the non-screening of malformations, doctors were predicting either the end of prenatal screening (due to the practice being abandoned) or an “eugenics of precaution”, a term which meant that it would no longer be just “anomalies of particular gravity” that would lead to medical termination of pregnancy, but even the “slightest doubt” as to the normality of a foetus, or the diagnosis of minor anomalies, in order to avoid the risk of being sued. Some thus felt that the introduction

of a “right to a normal child” was almost inevitable, whilst others felt it to be sufficiently worrying to require discussion.

1. Disabled Persons and Prenatal Screening

Objective and Methodology

Unlike families and well-known personalities in the medical world – and able-bodied people in general – disabled persons were never called upon (in France at least) to give their views on a subject which nevertheless concerns them directly, inasmuch as it is a question of what they feel about the selective elimination of a foetus with an anomaly similar to their own. Yet during a seminar in Brussels in 1994, representatives of disabled persons declared:

Bioethics defends the principle that any physical or mental imperfection is unacceptable . . . This ethical opinion is that of able-bodied persons who, through kindness or through ignorance, cannot bear the idea of another person suffering. It is up to us, disabled people with these affections that some say must be genetically eradicated, to run this debate (Zribi & Fontaine 1996).

Whilst the debate on questions relating to the assertion of the dignity of every human being belongs to all of us, it is indeed aberrant to exclude those for whom the ensuing human and social choices would have a direct effect on how they are accepted within the human community.

The aim of this work was thus to gather opinions which have until now been ignored, in order to bring them into the public arena so that they can be included in debates on ethical questions relating to prenatal screening.

A “request for contributions” was distributed via several specialist reviews, during an Association des Paralysés de France (APF) seminar, at a time when there were demonstrations by disabled people, and in Internet news groups. The declaration that had been made at Brussels, mentioned above, was part of the request. The objective was to call for male and female volunteers who would agree to help us to examine this highly delicate subject, one that related to deep hurt or to the “problem of an entire life”, as described by René-Claude Lachal, director of research at the CNRS at the time.⁶ He believed that his own life had been constantly affected by the question of whether, as a tetraplegic man, he had the right to live.⁷

This request led to 50 disabled persons coming forward to take part in the research. All of the interviews were recorded on tape, then transcribed onto paper and sent to the participants for approval. In two cases, it was necessary to gather the opinions of the interviewees through dictation, their difficulties with elocution making it impossible to record them. An email correspondence was established with several interviewees and still continues today, to discuss current ethical problems or personal matters such as the life conditions of disabled persons.

This research lasted three years and involved 45 French participants from 12 French regions, 4 Belgian participants and 1 Swiss participant.

Results

Main characteristics of the interviewees. Of the 50 interviewees, 25 are men and 25 are women, with an age range of 24–65. The aetiology of the disabilities shows that the vast majority of disabilities or illnesses are of genetic origin (see Table 1). The majority of the participants have very serious physical disabilities – there are 27 tetraplegics, 5 paraplegics, 3 hemiplegics and 14 with locomotive problems. More than half (28) use an electric wheelchair, 3 are unable to use any type of wheelchair, even electric, 8 have an ordinary wheelchair and 11 need no wheelchair. Permanent help from a third party is needed by 19 persons, 19 others need partial aid and 12 are autonomous in everyday life.

The disabilities of 27 persons are stable, and progressive in the other 23. Of 13 participants who have a disability related to their main impairment, 9 have elocution or sensorial problems, and 4 suffer from loss of balance, dizziness, depression, psychological problems, etc.

All participants, with the exception of one man who lives in a home run by the Association des Paralysés de France, live outside the institutional network in either a house or a flat; 22 live in a couple, 19 live alone and 6 live with their families. Two women are single parents; another, in the same situation, died after our study ended. Of the 50 participants, 13, 7 of them women, have children.

Overall, the level of education is high: 33 have been to university (29 having either a master's degree or a doctorate). However, only 20 have a corresponding profession, i.e. a position as senior manager, freelancer, a teaching position or studying at university; 18 have no job, even though 5 of these have either a master's degree or a doctorate, and 7 have either the baccalauréat or a BTS (vocational training certificate). One might legitimately wonder about the fact that the participants have such a high level of education. It would seem that only the “strongest” and, amongst those, the

Table 1. Aetiology of the disabilities or illnesses of the participants in the study

Aetiology of disability or illness	Number of participants
Genetic anomaly, of which:	30
Myopathy	14
Imperfect osteogenesis (known as “glass bones” illness)	4
Spina bifida	1
Spinal amyotrophy	6
Myasthenia	1
Freidrich's ataxia	1
Little	2
Neuropathy	1
Road accident	5
Neonatal accident	7
Sequels to poliomyelitis	4
Congenital amputation due to thalidomide	1
Unknown aetiology	3

ones who firmly favoured intellectual capacity, found it in themselves to talk about issues relating to their right to exist.

Of the 50, 10 have insufficient resources⁸ (Allocation Adulte Handicapé) despite the fact that 7 of these have been to university. But whatever their financial situation, university graduate or not, almost all of the participants in this study are involved in thinking about the place for disabled persons in our society; some are active militants and some have even created their own association. Almost all have the objective of gaining as much autonomy as possible and claim the right to citizenship and the right to speak out. With such an attitude, it is not surprising that all of them (with one exception) live in their own homes and not in institutions. Consequently, if the men and women in the study are not “representative” of the entire “disabled” population (but in fact, who could be?), they are nevertheless representatives of the analyses and thoughts that nowadays lead us to reconsider the subordinate place they are allocated.

At the beginning of this research, we thought that it would mainly concern men and women with transmissible impairments. The people taking part in this work certainly include a majority of persons whose problems are caused by a genetic anomaly (30/50), but as we have seen, they also include people who became “disabled” through accident or illness, or who suffer from cerebral motor impairment. These people – a priori “not concerned” – wished to make a contribution to this research, and this seemed perfectly justified, inasmuch as the widely held attitude which considers “any physical or mental imperfection” unacceptable has consequences on neonatal medicine, prenatal medicine and intensive care, as one of the participants, Jean-Marc Bardeau-Garneret, who also happens to be a sociologist, so delicately put it.⁹

How do the disabled interviewees perceive prenatal selection? Only a minority approve of prenatal selection, with 13 persons accepting medical termination of pregnancy or considering it to be progress, whilst 32 feel it to be another form of violence directed at them (5 people expressed no opinion). All of the people who expressed an opinion nevertheless refused to “pass judgment” on families who turn to termination.

In fact, it would seem that it is not the disapproval or approval of prenatal selection techniques which dominates debate, but rather the expression of the feeling that the opinions and wishes of disabled persons are never taken into account during the decision-making process, as if the fact of having a physical impairment makes them forever incapable of taking part in society’s issues. Some comments very much highlight the tensions which prevail in our society, and the world of healthcare professionals in particular. The case of two participants who survived through medical operations that led, in their opinion, to life being imposed upon them, underline the paradox of a world in which before birth we destroy foetuses showing signs of certain anomalies, whereas at the same time we do everything in our power to save newborn babies who would have died without a certain “unrelenting clinical effort”. For example, JMBG clearly stated:

If one day my life as a disabled person becomes unliveable, I demand the right to commit suicide, and I declare that this would be one way for me to recover the power that the doctors took away from me when they put me through excessive medical procedures that were decided without my consent.

Similarly, another participant (Roland Chifflet¹⁰), who owes the fact that he is alive to a series of unpleasant surgical operations, wrote to us about one such operation:

I did not want the operation, because I had had enough, throughout my life, of undergoing operations, hospitalizations and medical treatments of all kinds, just to end up being an isolated outcast of society, with no social or family life, and currently with no prospects of any professional life.

Which is why with regard to post-natal and post-traumatic resuscitations, this same man openly declares:

One might objectively wonder if one should not allow people to disappear, if one is not prepared to take responsibility for their social future. I represent the problem of unrelenting clinical effort or of efforts to keep severe casualties alive, without their milieu being able to care for them.

Whilst this type of question is now the subject of a mediatized debate on the opportunity to make legislation on euthanasia, we can only underline the evidence that it is very hard to assess a milieu's capacities for care. The question of life and death in neonatal resuscitation is among the most difficult questions that exist (Paillet 2007).

Above and beyond the question of birth selection, participants in this study often mentioned the fantasies, so cleverly fostered by the medical profession, of being all-powerful, of being able to eliminate all risks: "Before the birth, what people want is the perfect child; afterwards what they want is medical skill" (JMBG).

And it is often from the stance of contesting a dispossession or negation of self that they expressed their views. They believe that the criticism of birth selection is far less tolerated than its acceptance, and this observation fuels their anger and leads them to attack what they feel to be social violence towards them. "I would never criticize parents who did not have the strength to accept the birth of a disabled child, because it is personal and intimate," says Jean-Christophe Parisot, who suffers from a form of myopathy.¹¹ "On the other hand," he adds, "the fact that journalists and doctors, who have the capacity to convey an attitude, feel that they can orientate research in a given direction makes me indignant. It's no longer a case of individual decision-making. It's ideology".

But whilst doctors are not individually incriminated: "I am convinced that the doctors who advise people to have a clinical abortion are doing so in order to help the families",¹² a certain scientific triumphalism in relation to these practices is nevertheless perceived as violence. In this regard, the comments of a young woman (Alexandra Kramoroff¹³) are very eloquent. Talking to us about one of her myopathic friends, she said:

He's the one who told me this story of tests when I read the book written by a geneticist about Généthon [a scientific project to decode the genome]. It was my dream to work there because that was the only thing I could do for my friend. Even if it was only a little job that could not save him. At one point I came across a page which praised these famous tests. I wondered what it was, and it was when I saw a programme about the Téléthon, I understood. There was always a string of beautiful babies that they called the "Téléthon's miracle babies".¹⁴ In fact, families who had had myopathic children, and who had stopped having kids for that very reason, were starting to have children again, thanks to these tests which enabled them to keep just the healthy ones. In the following pages it was explained that thanks to progress, it was possible to prevent children from suffering by not allowing them to be born. To make matters worse, the author was happy when he said that! I was disgusted that I'd sent money for that.

It must be said that whilst several of our interviewees accept the telethon as a programme which allows people to learn about myopathy, the victorious presentation of the "beautiful Téléthon babies" and the confusion that the programme has often maintained between real genic therapy and selective elimination is seen as an invalidation that AK describes as follows:

I have a major reservation about "babythons" because we think it's due to research that they have been cured, whereas in fact they result from a selection, and clinical abortion has got rid of many others. Hence the question: "what if my parents had aborted me?" I suspect scientific research of being used, not for clinical research, but for a "prenatal" elimination of those who are ill. If we look to eliminate the ill person rather than the illness, there will be few ill people and people won't invest in research. I don't want people to sidetrack part of our hope into the opposite result from the one we wanted. I was dismayed to read an article entitled "Trisomy eradicated" in which I discovered that in fact it wasn't trisomy which had been eradicated but the people suffering from trisomy . . . If someone tells me that the Association Française contre les Myopathies is going to concentrate on prenatal screening [with a view to elimination] I'll immediately stop giving [money] and working to help.

Robert Murphy, an American sociologist who became disabled, wrote: "telling a disabled person that it is better to be dead than to live disabled, is the supreme insult".

GT, born in 1946, is a teacher in a high school and is a paraplegic after contracting polio in 1955. He told us:

I'll never ever forget what a former friend told me when his wife died in a car accident, when he said, amidst his pain and in a peremptory manner, that it was better for her to have died rather than being paraplegic for the rest of her life. I had known them for more than 10 years, and I don't think he understood when I replied "And you are saying that to me?" I helped him through his mourning, but then our roads very quickly separated . . .

The presupposition upon which prenatal selection is based, whereby it is preferable not to be born rather than to be born disabled, was to the majority of our interviewees a negation of their very persons. Whatever the form, this selection is taken as an aggression that several participants spontaneously compared to eugenics, even though we were careful not to use the term ourselves. For example, when we asked JCP if he felt the pre-implantatory

diagnosis to be less violent than medical termination of pregnancy, he replied:

This method seemed more gentle, but it's violent too, because if you are alive and disabled, you become a medical error. [For me it is] a very strong [violence] and according to what I see on the Internet, I'm not the only one ... it's a negation of myself. Michel Pétrucciani [a famous jazz pianist, suffering from imperfect osteogenesis, now deceased] said that if he decided to kill his child who had the same illness as himself and his wife, it would be like killing himself.

Youngest of three myopathic children, ASP,¹⁵ JCP's sister, thus found herself in a family set-up where her parents could have used embryo sorting, which is in principle reserved for families in which there are already children with a genetic illness. She is thus hit hard by this procedure:

It is hard for me to cope with the idea of embryo sorting ... To me it's the medical, social and institutional denial of my basic right to exist. I see it as calling completely into question my intrinsic value as a human being. The idea that parliament is making legislation on this issue to legalize a medical approach which is unfortunately already used in certain laboratories is especially painful to me. It is a feeling even stronger than all the social discriminations I have had to put up with at school and in my everyday life. I see it as an attack that cuts right into me.

And how could Elisabeth Auerbacher¹⁶ have taken in any other way than as a total rejection the question a classmate once asked her: "But why didn't your mother have an abortion?"

DM¹⁷ described the destructive nature of this "attack that cuts right into me" when she told us the following: when she went to see the film *Haut les Cœurs* (Sloveig Anspach), which was showing in cinemas at that time, she said she "almost felt ill" when a young woman in the film, who is fighting cancer, becomes pregnant and says sharply to the doctor who had just done an ultrasound: "If it's abnormal get rid of it!"

With her experience as a psychoanalyst, JSG¹⁸ wanted to show that such an elimination does not leave those involved unaffected. Our world wants it to be a radical solution which rubs out all traces of the disability, but this is not the case. She talks about the after-effects of selective elimination on members of the family. Giving us the example of one of her young patients, she describes how the rejection of the disabled child affected the brothers and sisters:

I wanted to see the brother of one of my patients, to say how he was coping with his sister's disability ... The boy's main question was: "are you going to be able to use therapy to get my sister to walk?" He insisted so much on this question that I ended up saying during the meeting: "I think you want your sister to walk, not just for her, but also for yourself". Suddenly his eyes opened wide as if he'd found someone who understood and he said: "I keep wondering if one day I can't walk any more, will my father reject me like that".

What is very clear from what this psychoanalyst says, is that the question underlying that of selective abortion and embryo sorting is, just as much as the problem of intolerance towards the impairment, that of our capacity to

accept children as they are. If selective elimination is envisaged, it is the entire sibship which is concerned, and not just the disabled brothers and sisters. “We see”, she concludes, “that in families where the decision is made to not allow the disabled child to be born, this has an effect on the other children. It’s the same as for the Jews who survived the concentration camps, they are tormented”.

Yet whilst the medical procedure and attitude are strongly criticized, almost all of the participants recognize the difficulty of choosing alternative solutions to selective elimination. Several of them feel that, in fact, when the choice is given to couples who are bringing children into the world, the pressures to direct their decision towards abortion are so strong that it becomes difficult to resist. This is the reason why Anne-Sophie Parisot had begun by writing to us about the screening tests and the ensuing decisions: “Unfortunately, I fear that nowadays it is no longer possible to prevent them, because they are too deep-rooted in our culture and in current medical practice”. In the same way, AK is highly critical of selective tests and recently told us over the phone: “I confirm what I told you two years ago: I am so happy that these tests did not exist when I was born, but I’m very upset that they exist now. I hope that I would be able to avoid them if I were to bring a child into the world, but I cannot guarantee that that would be the case.”¹⁹

Indeed, it was of all the pressure and all the difficulties facing children and adults suffering from an impairment, and their families, that Marcel Nuss²⁰ wrote to us: “nothing is done to try to keep heavily dependent people at home”. And after discussing financial difficulties, the lack of personnel, the constant lack of consideration given to him,²¹ this highly provocative man concluded: “After [becoming aware of all these difficulties] how can you expect me not to defend eugenics?” Then he added: “When I say ‘I am pro eugenics if . . .’ I’m not defending the theory of eugenics, because everything is in the conditional and in what that implies, but I do brandish the threat of eugenics when faced with bad faith and mercantile and ethical hypocrisy”.

To put it another way, the participants in favour of selective elimination tend to be those who see it from the following point of view: if society – and French society is specifically targeted – cannot do any better for us, pure and simple elimination is preferable. When we informed AK of this stance, she commented: “The problem is that selective elimination will make our society even more intolerant than it is already”.

This is why, rather than sticking to a purely critical position and passing judgment on those who have recourse to medical termination of pregnancy, many of our interviewees offered alternative solutions:

We must not condemn this general rejection [of impairment]. . . . I ask the professionals I train to identify where they have problems with disability, and to accept it as something natural. We all instinctively reject disability, and it is difficult to identify with someone who has over obvious stigmata or castrations But after learning to recognize that it is hard to get over these reactions, we can move forward over open ground, because we have identified the danger (Jean Luc Simon).²²

And JSG, for example, points out the need to dissociate the impairment from the child as a person:

When parents tell me that they still cannot accept their child's disability, my job is not to make them accept it, because I do not think that disability is something that can be accepted. On the other hand, they must accept the child who is disabled. It is one thing to reject the disability, but quite another to reject the disabled child.

Several persons stressed the need to make information available and to help the families concerned:

Unfortunately, parents of disabled children often only have the outlook of a "life as a vegetable" for their children, because there are still far too many relatives who believe that severely disabled people live a life "which is not worth living". And here I am quoting a sentence that has really been spoken verbatim to parents. This is why we encourage parents of disabled children to meet disabled adults who are autonomous and responsible, and who have a similar disability to that of their child, so that they can be given a more positive viewpoint (JLS).

When asked to talk about how they cope with birth selection, participants in the study often related the question to the life conditions of disabled persons and their families. They talked about the major financial precariousness that makes it hard for them to survive, the aid that keeps them in a state of dependence whilst efforts to achieve autonomy remain insufficient,²³ the disrespect, the problems of professional integration, the lack of consideration, the affective suffering, not to mention the inaccessibility which forces them to remain "second-class citizens". Despite the intolerance of a world which has never considered giving them a true place, they don't want to become resigned and freely come up with proposals to change the world and to improve life conditions in order for prenatal selection not to be the only solution. Indeed, many of them feel that other European countries are more welcoming than France and that this might explain the lesser use of birth selection after detection of foetal anomaly.

2. Doctors and Screening for Foetal Anomalies within a Context of Judicialization

Introduction

Within the framework of a study of obstetrician-gynaecologists carried out between October 2002 and October 2004, we interviewed the doctors on how judicialization²⁴ was affecting their profession and, in particular, on its impact on the evolution of prenatal screening. The question had become especially acute following a decision by the Court of Cassation, known as the "Perruche decision"; it was the object of an exceptionally intense controversy which divided lawyers, disabled persons' associations and disabled persons themselves. This question was raised on several occasions after our study. For example, on 11 July 2005 (decision no. 292), the Tribunal de Grande Instance in Reims compensated a sibship for the "prejudice" caused by the birth of their trisomic little sister, who would not have been born if the "doctor in charge of the pregnancy had done his job properly" by discovering the

chromosomal anomaly affecting the child. Her mother would then have ended the pregnancy.

But let us start with a reminder of the main aspects of the decision handed down by the Court of Cassation on 17 November 2000, and which led us to do the research the results of which we are discussing here. The Court asserted the need to compensate Nicolas Perruche, who was born disabled following the effects of the German measles his mother had contracted during the pregnancy, on the basis that she had not been able to request the medical termination of pregnancy as authorized by the French Public Health Code when “there is a high probability that the unborn child suffers from an affection of especial gravity, recognized at the time of diagnosis as being incurable” (Article L2213-1, first paragraph of the French public health code (Code de la Santé publique)). Despite the tests that had been carried out, the German measles had not been diagnosed, and Mrs. Perruche continued her pregnancy even though she had made it clear that she wanted an abortion in the case of any measles infection.

The Court of Cassation felt it was a case of opening up a right to compensation for the child himself and not just for his parents, in a context where social aid for disabilities was very much lacking.

For doctors and for disabled persons and their families, this was to recognize that it would have been preferable for the child not to have been brought into the world, because the choice was not between being born free of any malformation or being born with a disability, but between being born with a disability or not being born at all. Such a presupposition triggered lively arguments among doctors, lawyers, disabled persons’ associations and friends and families of disabled persons. In addition to this presupposition, there were considerable concerns as to the way the decision had been phrased, as it seemed to lay responsibility for the child’s disability on the doctor and laboratory in question, whereas it was not a case of any medical error leading to disability, but a case of non-screening for measles preventing the mother from having an abortion. “When the mistakes made by the doctor and the laboratory during performance of the contract with Mrs. Perruche prevented the latter from exercising her right to terminate the pregnancy in order to avoid giving birth to a child with a disability,” wrote the magistrates, “she may demand compensation for the prejudice which resulted from this disability and which was caused by said mistake.”

After this decision, which ordered the doctor’s and the laboratory’s insurers to pay a considerable amount of money (approximately 750,000 euros) to Nicolas Perruche, the Chairman of the ultrasonographers declared:

We have been through a cataclysm. We are waiting for three more decisions by the Court of Cassation. If the magistrates decide to follow this ruling, it will mean that they are holding us, the doctors, responsible for mistakes of nature. We will be forced to take no more risks. Whenever there is the slightest doubt, we will apply the principle of precaution and advise parents to have an abortion (La Vie, 22nd March 2001).

So when the Court confirmed its ruling in two other cases (13 July and 28 November 2001), the ultrasonographers and obstetrician-gynaecologists

threatened a massive strike, or, if they continued to work, to introduce “precautionary eugenics” whereby medical termination of pregnancy would not be performed in just cases of severe anomaly, but also whenever there was the slightest doubt about the state of the foetus, in order to remove the risk of any further legal action.

But in that case, might prenatal screening not lose its initial role of “preparing for birth” and making it possible “to operate, at birth, on children for whom prenatal screening had revealed an anomaly”, as some medical specialists attest? Was it not going to become a mere instrument for a supposed “right” to have a “normal child”, “abnormality” no longer signifying just pathologies “of especial gravity”, but also even the tiniest anomaly?

Given the major mobilization of birthcare professionals, the Assemblée Nationale finally passed a law on patients’ rights, Article I of which was designed to put an end to Perruche jurisprudence – “No-one may claim a prejudice by the sole fact of being born” (article I of law no. 2002–303 of 4 March 2002 on patients’ rights and the quality of the health system) – and to give disabled persons the wherewithal to exercise full citizenship through national solidarity, and not have to depend on unpredictable legal decisions and insurance companies. This law was passed in 2005 (law no. 2005–102 of 11 February 2005 on equal rights and opportunities, the participation and the citizenship of disabled persons).

Was the law covering patient rights (2002) going to sufficiently reassure doctors doing foetal ultrasounds? Were they going to continue an activity that they were threatening to stop? If they had already stopped it, would they start it again? And would they resist introducing this “eugenics of precaution” which many doctors felt would pervert the role of prenatal screening?

To answer these questions, we carried out 64 interviews with medical personnel linked to these issues, in particular with people carrying out foetal ultrasounds (obstetricians, ultrasonographers and midwives). Prior to this, we had distributed a questionnaire during the *Journées annuelles de médecine fœtale* (foetal medicine week) event which has taken place in Morzine for the last 10 years, receiving responses from 147 people.

The Ceasing of Foetal Ultrasound Activity, Leading to Unequal Access to this Technique

From these comments we can see that whilst the practice of prenatal screening has effectively changed, it would seem that this change is only partially due the ruling of the Court of Cassation.

First of all, this decision clearly reduced the number of people carrying out foetal ultrasound, and has thus made it harder to access prenatal screening. Indeed, following the Court’s ruling, many freelance practitioners, who were not specialists in the activity but who used the technique as part of an overall activity, stopped using it and started sending their patients to specialists. In fact, hospital doctors, protected by the hospital system and not just by their

private insurance as freelance doctors, did not cease activity. The Chairman of the ultrasonographers union offers the following figures:

Among radiologists, for whom obstetrical ultrasounds represented less than 30% of their overall activity, 50% have ceased ultrasound activity. This is also the case for obstetricians who did ultrasounds. We find the same figures among exclusive ultrasonographers.

In a context where there are already simultaneous material difficulties relating to foetal ultrasound, ethical difficulties raised by prenatal screening with some people admitting they are not certain of the objectives, and a fear of an increasing trend towards judicialization in the field of medicine, the Perruche ruling led to a lot of people ceasing ultrasound activity. The authors of a report requested by Bernard Kouchner (Sureau & Henrion 2005) write:

A traumatised profession: three years later, the trauma is still there. Ultrasonographers, never safe from legal action, work under the threat of administrative sanctions or of having their French national health service contract withdrawn.

The result, the report continues, is that a lot of people are leaving the profession. The retirement of existing practitioners and the lack of motivation for young people to replace them raises concerns for the future:

A poll carried out during the Journées Françaises de Radiologie suggested that two thirds of radiologists who until then had been doing ultrasounds have ceased this aspect of their activity. This trend has continued since then, with people ceasing the activity at times when there's a need for renewal, or when a professional insurance contract needs to be updated, or when the social security threatens penalties, or simply when they are fed up with the situation being the way it is.

In our study, a general practitioner specializing in foetal ultrasounds talks about the people ceasing activity in his region:

The Perruche affair has turned this practice upside down, due to the number of practitioners ceasing their ultrasound activity. In the Sarthe region, before Perruche, all radiologists and all obstetrician-gynaecologists did ultrasounds. After Perruche, all the radiologists stopped. This means that from approximately fifty potential ultrasonographers, we are down to 25. . . There's been a very sudden drop in the number of people doing ultrasounds. It really is the Perruche ruling that caused people to cease their activity.

The material difficulties of ultrasonographers specialized in foetal ultrasounds, said to already have been very acute prior to the Perruche affair, have paradoxically worsened for ultrasonographers who have not given up the activity, due to the overloading in their practices since their colleagues ceased their activity.

Another general practitioner in the freelance sector in a big town near to the Paris region explains:

The key point is the financial problem. This is one of the reasons for professional disinterest. Between 2001 and 2002 my turnover plummeted by 30%. Instead of doing 25 obstetric examinations per day, like I do at the moment, I used to do only 20 to 22.

When you do a thyroid, it takes 10 minutes, when you do an obstetric ultrasound in the 5th month it takes 45 minutes. Before, what earned us our living was doing non-obstetric work. But now that we are snowed under, we do less of that.

But not all foetal ultrasound practitioners ceased this activity for financial reasons. Two of the interviews attest to this. One ultrasonographer working in the freelance sector in the west of France, and specialized in foetal ultrasound, stopped the activity because she had the impression that the Perruche decision simply demonstrated the general rejection of disabled children and because the ruling increased her concerns regarding the shift in indications for medical termination of pregnancy towards pathologies which no longer fell under the heading of “pathologies of especial gravity”. She says:

From a financial standpoint, I lost a great deal, but I want to be at ease with my conscience. In a way, I'm proud to be able to say that I didn't do it for money, because from a financial point of view it would have been better for me to pay my extra insurance premium.

(Note that the huge increase in the cost of insurance was mentioned by several of the doctors we interviewed.)

At first giving fear of legal action as his reason for ceasing the activity, one obstetrician-gynaecologist with a private practice in the north of France also talked about his concerns with regard to defining the legitimate framework of medical termination of pregnancy:

What struck me in my daily practice was the demand for the perfect child.²⁵ I cannot accept that. It's a big problem. There was a baby born recently with an agenesis of the ear (where the ear does not develop) . . . the parents were in a real state, they told me: “If we have another baby like that, we'll have an abortion”. To me, that's unacceptable, it's society going mad . . . I can't continue because I no longer know what to do with my patients.

Too risky, not lucrative enough and ethically far too complicated, the foetal ultrasound was on several occasions described as being impossible to continue into the future: “In the current context, there won't be anyone to succeed us” says one general practitioner, with an ultrasound qualification.

Indeed, defections following the Perruche ruling are already having an effect which raises a question. The Chairman of the ultrasonographers explains:

At the present time we can definitely declare that there is unequal access to ultrasound. The doctors who are continuing are totally snowed under. Which means that some of them are ending their contracts with the French national health system: why stay with the social security system? If you have the contract, there's a two-month waiting list for appointments, whereas if you don't have it, the waiting list is only one month. In rural and semi-rural areas, there's a definite inequality. The inequality is twofold: geographical and due to the risk of financial selection. Most practitioners inevitably charge more than what is reimbursed by the state [to make up for the financial difficulties].

Several practitioners gave concrete examples of the way in which this inequality is falling into place. The head of department in a hospital in the

north-east of Paris, with patients from some of the poorest suburbs of Paris, had this to say:

In the county of Seine-Saint-Denis, there's pretty much only private ultrasonographers left. We thought women would complain . . . but no! They are not the ones who are going to demonstrate in the streets because there is no longer any quality health care. On the other hand, women in the posh areas of Paris can still have ultrasounds.

Two years after publication of our study – which, through the comments of practitioners, highlighted the inequality of access to ultrasound and the over-representation they have noticed of the birth of trisomic babies in poor milieus (when it is not a case of a cultural or religious choice), the general management at INSERM is presenting the results of a study which demonstrates the “socio-economic disparities . . . in the spread of births of trisomic babies”. According to the INSERM study, the number of births of trisomic babies is twice as high among women with no profession than among those who belong to higher socio-professional categories, which corroborates the observations of the practitioners we interviewed (Khoshnood *et al.* 2006).

Medical Termination of Pregnancy whenever there is the Slightest Doubt Concerning the “Quality” of the Foetus

Of course, these cessations in activity leading to or seriously aggravating the inequality of access to ultrasounds and, thus to prenatal screening, are not without consequences on the second “risk” put forward by doctors when the Court of Cassation handed down its rulings, i.e. that of the possibility of introducing “eugenics of precaution”, in other words banalizing medical terminations of pregnancy when there is even the slightest doubt about the “quality” of the foetus. This “risk” clearly only concerns women who still have easy access to ultrasounds; other women run the risk of finding themselves deprived of proper monitoring of their pregnancies!

On the other hand, the extension of indications for medical termination of pregnancy and the performance of these terminations whenever there is the slightest doubt as to the normality of the foetus are mentioned as a reality by several practitioners, but none of them suggest that the main responsibility lies with the Perruche decision.

Indeed, two other reasons are mentioned as even more determining factors than that of judicialization: the duty to inform patients²⁶ and the increase in the deadline for requested legal abortion from 12 to 14 weeks.

When asked about the existence of abortions for minor anomalies, or because there is a doubt about the “complete normality of the foetus”, the Chairman of the French ultrasound college said:

It didn't happen directly. Where things have changed, is that people have to be told everything that might happen, all the possibilities, including the exception. But the prenatal trajectory is full of exceptions. So parents tend to opt for medical termination of pregnancy. People say: the general rule in this or that situation is favourable, but in some cases women have complications, there are sequels for the babies. And in their

anguish, the parents only remember the exception. Indirectly, this influences the demand.

One obstetrician ultrasonographer working in the freelance sector in a town in the west of France spontaneously mentioned that the “duty to inform” was sometimes problematical:

What bothered me the most in all of this, is the obligation to inform. We have to tell people everything. And by telling people everything you impose unwarranted anxiety. I have the impression that this obligation throws some people into totally useless confusion. We used to deal with the stress ourselves. I mean that if we had a doubt, we didn't mention it, and we said: “I'd like to see you again in two weeks, because the baby is in the wrong position for me to see properly”. I still continue to do that now. But I know that there are people who tell the patient absolutely everything. It's a problem when it's just a tiny anomaly and you have no idea of the prognosis.

Whilst all the practitioners we met described the duty to inform as a symptom of the end (deemed desirable) of “paternalistic medicine”, they feel that the duty to “tell all” creates an anxiety that can lead to demands for medical terminations of pregnancy which are unneeded.²⁷ Maybe it would be useful to reconsider the way in which things are said, and the conditions for saying them. Some doctors feel that this phenomenon has been strengthened by the increase in the deadline for requested legal abortion from 12 to 14 weeks (law no. 2001–588 of 4 July 2001).

The Chairman of ultrasonographers says:

On average, women in France have three ultrasounds during their pregnancy ... The first determines when pregnancy began, and is used to measure nuchal translucency. During this examination one can diagnose anomalies which are curable but which present a risk. But the deadline for requested legal abortion has been extended to 14 weeks. Given that the first ultrasound is done in the twelfth week, there are fetuses which are not re-examined in the second trimester. But sometimes we are in a situation of curable anomalies, but the emotional aspect of the pregnancy isn't sufficiently strong yet, and a certain number of fetuses don't survive.

“It is possible that medical terminations of pregnancy are allowed under the cover of requested legal abortion”, confirms an ultrasonographer midwife who works at a hospital in the east of France, and a head of department of a maternity hospital in the Paris region.

Yet the law governing the practice of medical termination of pregnancy states that where an anomaly is discovered between 12 and 14 weeks, the patient must be directed to a multi-discipline centre for prenatal screening, which will decide whether or not the patient has the right to medical termination of pregnancy. But doctors then find themselves facing extremely paradoxical situations. One obstetrician-gynaecologist who works in a hospital in the west of France says:

Where an anomaly is discovered at 12 weeks, if women want a requested legal abortion, theoretically they are not allowed to. Normally, requested legal abortions are not allowed for foetal-related causes, only for maternal distress. The healthier the foetus, the more likely a requested legal abortion will be allowed; the greater the risk of foetal

malformation, the more it is likely that requested legal abortion will be refused. It's a totally crazy situation.

This is exactly why certain patients simply change departments by requesting a legal abortion, without saying that they have already had an ultrasound.

The combination of these various elements might well make it possible to have medical terminations of pregnancy where the indication exceeds the criterion of "anomaly of particular gravity, incurable given the current state of science". This said, two weeks is a very short time in which to start and finish the process for a requested legal abortion. As far as the emergence of this phenomenon is concerned, the Perruche decision would appear to have been one element among several. On the other hand, it has strengthened the inequality of prenatal screening, due to the fact that so many ultrasonographers have stopped providing ultrasounds (an inequality seen to be widespread in the INSERM report mentioned above), and has therefore helped reinforce what is now being referred to as "two-speed medicine". Such "inequality" nevertheless raises the crucial question of the legitimacy of being able to select which babies can be born, based on their state of health.

Towards a Redefinition of the Aims of Prenatal Screening?

It is even more worthwhile asking such a question, given that several doctors have underlined the lack of clarity in the objectives of this type of screening. There is a fracture line between two analyses that are difficult to reconcile, one stressing the therapeutic effects of "prenatal screening", the other concentrating on how hard it is properly to grasp any benefits in terms of public health, and fearing that for some illnesses treated thanks to diagnoses made before birth, that the mother – child link is threatened by the possibility of a termination of pregnancy.

One practitioner dealing exclusively with ultrasounds and working in a freelance practice in the south of France says:

In percentage terms, the detection of malformations in our field of activity is tiny. The majority of anomalies during pregnancy are delayed intra-uterine growth, a placenta which is going to bleed at the time of birth and possibly kill the baby, a problematic umbilical cord, a kidney which is not working properly, a virus which will cause poor growth or make the baby ill . . . All that has nothing to do with foetal malformation, even though it's at the heart of foetal medicine.

The Chairman of the ultrasonographers' union thus refuses to consider his profession as being at the service of medical termination of pregnancy. He says:

My profession is something else. My profession is:

1. Saving mothers, if we find a placenta which is badly positioned and she will die giving birth if we don't make the diagnosis, whereas if we do what's needed, she'll go home in good health, with a healthy baby.

2. Saving babies' lives. If their growth curve is broken, for example, or whatever. There's a whole series of situations where we can do something to help the baby. If ever we don't have an effective solution, we can extract the baby and put him in an incubator and the parents can go home with a healthy baby instead of having a baby who would have suffered inside his mother's tummy and who would have necrotized his brain cells, or who would have gone home with his intestines or brain destroyed. So we don't just save babies' lives but also babies' organs. From that point of view it's an amazing examination.

But some practitioners wonder if the advantages of prenatal screening truly outweigh the disadvantages that it causes. One obstetrician working in a Paris hospital says:

The word screening has a positive connotation. But screening doesn't only do good. It creates anxiety, by making people aware of a risk that they had until then not known about, and it can lead to further examinations being done, at a risk. This is the case with amniocentesis. In practice, an initial noninvasive test, without any danger (ultrasound, blood sample), detects an anomaly, lets say 1/100. An amniocentesis is needed to confirm or reject the presence of the anomaly. If we accept that the risk of an amniocentesis causing a complication (miscarriage) is approximately 1/200, we can see that for two cases of diagnosed anomaly, we will have one miscarriage due to the amniocentesis.

"We need to think about the issue of losing normal children", says a paediatrician working in a hospital in a large town, also mentioning the mistaken diagnoses which have needlessly led to terminations of pregnancy.

Finally, to these concerns can be added those which are due to the impact of prenatal screening on the link between mother and child. An obstetrician working in a hospital in big town in the east of France says:

When you give information to a woman at 12 or 13 weeks, and you tell her: "we are going to check the quality of your embryo", what is not said is "if it's not good quality, we'll destroy it". We are forcing every woman in France to think that, and this is not without consequences. I will even say that I think the several hundreds of deaths linked to prenatal screening [due to the miscarriages caused by amniocentesis or caused by terminations of pregnancy carried out following mistaken diagnoses] are a mere detail compared to the huge psychological devastation we are causing and which is not being measured at all.

Laymen must be puzzled when faced with such contradictory analyses and we can but agree with those of our interviewees who feel that the Perruche affair should have been the opportunity to redefine the purposes of prenatal screening and to determine its advantages and disadvantages.

It is for this reason that other studies must be done. In particular, it will be necessary to count the number of medical terminations of pregnancy, the situations where the lives of mothers and children have been saved or improved by prenatal screening and those where, on the contrary, screening has led to complications. We also need comparative studies which will allow us to assess the respective advantages and disadvantages of different methods of monitoring pregnancies, in other European countries where such screening is used less. Do these countries have a higher level of infantile mortality than

France? Do they have more children suffering from anomalies which might have been avoided through prenatal diagnosis?

Without such studies, it would appear difficult to accurately measure the effects of prenatal screening, which is now consubstantial with monitoring pregnancy when women in France have the advantage of medical follow-up.

In any case, the persistence of legal action for compensation for “prejudice” caused by children being born with an anomaly also raises the question of the place allowed in our society for men and women who are not blessed with intact physical and intellectual faculties. The ruling, to which we referred at the start of this article, handed down on 19 July 2005 by the Reims county court (Tribunal de Grande Instance), is, in this respect, particularly problematical. Indeed, for the judges, little Catalina’s (born trisomic) two brothers should be awarded compensation because the birth of their disabled sister “had upset the life conditions of the two boys. The time that their mother devotes to little Catalina”, said the judges, “is devoted to the detriment of her two brothers” who in addition had “witnessed the suffering of the parents”! Furthermore, the magistrates felt that these two children “had been victims of their parents’ separation, which had taken place on 18 February 2003, in other words hardly two years after Catalina had been born; given the trial endured, this short period made it possible, at least in part, to say that said birth had led to the family breaking up”.

We are thus inevitably led to wonder how it will be possible to reconcile the integration or inclusion of “persons in a situation of disability” and the compensation of an increasing number of families for the “prejudice” caused by the birth of a disabled child. In this respect, the limited reaction to the decision of the Reims county court is puzzling: whilst the “Perruche decision” gave rise to considerable controversy, this ruling was given amidst almost total indifference. Should we put this down to lassitude regarding court decisions, to their banalization, or should we attribute this indifference to the modest sums awarded to Catalina’s two brothers, each receiving “only” 6,400 euros? In which case, should we deduce that our capacity for indignation is proportional to the sums of money involved?

Conclusion

In a world where appearance often produces an effect of sideration which inhibits reflection and prevents us from considering people and listening to what they have to say, it is not uncommon for a person with a visible impairment to be carefully segregated, “one foot in, one foot out” as Charles Gardou (1997) so clearly puts it. So it might well be that “changing the way we look at others” involves first of all wanting *to hear* (Diederich 1998) the words that other people have to say, whatever their appearance may be, as words which are simply human. This is why we undertook the first work of research, the results of which we have in part presented here.

The second work of research aimed to look in the wings of a medical world that is struggling with sometimes painful questions about a practice that seems to be taking it away from its initial intentions, and the clearly

expressed fears that it is sliding, almost irreversibly, towards eugenics. In fact, the hunt for the tiniest anomaly will be driven by the “right to a normal child”, a right that with every passing day is rooted ever more deeply into our minds.

Still in shock from the famous “Perruche decision” (following the decision of the Court of Cassation on 17 November 2000), obstetricians and ultrasonographers wanted to warn the general public by announcing the threat of “eugenics of precaution” and a possible widespread resignation of ultrasonographers which would seriously affect the monitoring of pregnancies. Yet it turned out that the implementation of this form of prenatal eugenics depended on the continued practice of foetal ultrasound and prenatal screening: without them, prenatal “eugenics” would of course no longer be possible. These two risks might thus seem to be in potential conflict: if all ultrasonographers specializing in foetal ultrasound had resigned, the risk of “eugenics of precaution” would in fact have been countered, and the demand for a “normal child”, or a “perfect child”, would have suffered. Paradoxically, the increase in the number of legal actions for prenatal screening errors preventing medical termination of pregnancy, which is the legal translation of this supposed right to a “normal child”, would in fact have prevented said right from being exercised!

But what really happened? The phenomenon which followed the Perruche ruling needs to be understood at several levels and through a snowball effect which we might summarize as follows:

- The risk of legal action and the increase in insurance premiums caused the initial massive cessation in foetal ultrasound activity among practitioners who had little activity or who were insufficiently trained or whose equipment needed replacing.
- The intense controversy that followed this cessation had the effect of intensifying the ethical debate which already surrounded prenatal screening practices, which led certain practitioners to abandon them definitively.
- Finally, the consequence of the resignation of the practitioners concerned was to penalize women in poor milieus and women who lived in geographical areas that were already under-equipped for ultrasound examinations. The comments of practitioners working with people with major social problems show that there was a real inequality regarding access to ultrasound. This was confirmed by an INSERM study (Khoshnood *et al.* 2006).

All of this obviously had an effect on the second point we examine in this article: if “eugenics of precaution” exists, paradoxically it can only concern couples sufficiently privileged to be able to “benefit” from it! Which, it has to be said, brings us to a highly unusual form of “eugenics”, as the latter usually affects poor people!

Indeed, if we maintain the term “eugenics” (instead of which, to be more accurate, we personally would often have preferred the phrase “selective birth management” or “prenatal selection” (Moyse 2001a), the inequality of access to prenatal screening creates more of a “differential eugenics”, deliberately “chosen” by some, whilst others have no access to it. Of course, we might have some doubts as to the former’s freedom of “choice”, in a society which does not really allow any room for disabled people and condemns them and their families to situations which are materially and psychologically difficult to cope with, whatever milieu they may belong to.

We hope that these two works of research will help the debate on the ethical questions surrounding prenatal screening, taking into account the specific positions of two of the main social groups involved. For whilst those “without a platform” deplore the fact that “ill and disabled people are currently refused the right to voice their opinions, especially in debates on ethics”, we also need to consider the unease of practitioners. According to some of the latter, “society tends to pass the buck to them, in order to disguise its shortcomings in dealing with disability”. So rather than be “placed on the front line to solve problems of disability by eliminating babies with impairments”, they would prefer to rethink the place for disabled persons in our society and the aid given to their families and, finally, to implement a real “National Solidarity” regarding disabled persons.

Notes

¹ This text sets out the main results of two works of research relating to the social effects of prenatal screening and the ethical questions it raises, especially in regard to birth selection. The first study, which was carried out among disabled persons, was subsidized by the Association des Paralysés de France and the Association Française contre les Myopathies. The second, carried out among doctors, was subsidized by the Mission de Recherche Droit et Justice. These studies led to the publication of articles and of two books (Moyse & Diederich 2001, 2006)

² Doctors might advise a medical termination of pregnancy when the pregnancy seriously endangers the life of the mother, or when during the diagnosis the foetus shows a serious incurable illness. The practical modes of “medical termination of pregnancy” were defined in article 13 of law no. 94-654 of 29 July 1994, which states: “Where termination of pregnancy is envisaged due to there being a high probability that the unborn child has an affection of especial gravity recognized by two doctors as being incurable at the time of the diagnosis. One of these two doctors must be working in a multidiscipline centre for prenatal diagnosis”. (Not to be confused with requested legal abortion which is authorized – on the basis of the mother’s decision alone – up to 14 weeks of amenorrhoea). Multi-discipline centres for prenatal diagnosis were created under decree no. 97-578 of 28 May 1997. Each case requesting a medical termination of pregnancy is presented to all members of the multi-discipline team, which may demand additional investigations or ask for outside opinions in order to support the diagnosis or prognosis.

³ Legal actions for no prenatal screening are due to the mother not having access to medical termination of pregnancy. The legal term for these legal actions is “actions de vie préjudiciable” (in English, actions for prejudicial life). We will discuss the more striking of these cases to have taken place in France over recent years. Note that the notion of “prejudicial lives” was initially used in Nazi Germany to justify the elimination of disabled persons. Such legal actions are now once again becoming more common, especially in the United States with the concepts of wrongful birth and wrongful gestation. Note that the argument put forward “consists in allowing disabled children and their parents to obtain compensation for the relatively high cost of care needed for children with special needs” (Moyse 2001b). Similar arguments can also be found in works by other authors (Nelson & Robertson 2001, Shapira 1998, Jackson 1996, Capen 1995).

- ⁴ This way of perceiving oneself would appear to be frequent among persons maintained in a condition of lesser human and social value. The same is true of certain colonized peoples and of numerous women throughout the world who consider themselves unworthy of living and of not being able to envisage bringing a girl into the world (Moyses 2006).
- ⁵ The CCNE was created by law no. 94–654 of 29 July 1994 (art 23) and by decree no. 97–555 of 29 May 1997. In addition to its Chairman, the committee consists of five persons designated by the French President, and belonging to the main philosophical and spiritual families, and 19 qualified persons chosen on the basis of their competences and utility with regard to ethical issues (doctors, biologists, researchers, philosophers, etc.).
- ⁶ The disabled persons mentioned by name had insisted that their names be mentioned, as it was one way of reappropriating a right to speak out which they deemed, until then, to have been removed.
- ⁷ Born totally paralysed following a medical error at the moment of his birth, René-Claude Lachal (RCL) died in June 2003 at the age of 65 (after being appointed emeritus researcher by the CNRS) due to medical negligence. He had been admitted to hospital for “bronchial congestion”. He was put in a room on his own, at the end of a corridor, and of course he was unable to use the bell to call for help. As a result, he suffocated to death. According to his care assistant, he had already been through something similar a few months earlier in the same pneumology ward where there was only one night nurse: alone in his room, with the door closed, he had had to put up with the television all night long, his voice not being strong enough to call out. When informed, the Ministry for Health was supposedly going to demand an inquiry. Unfortunately no inquiry took place, with the 15,000 people who died in the heatwave in France demonstrating the serious failings of French hospitals. See, for example “Après la mort solitaire d’un chercheur handicapé: les déficiences de l’hôpital” (After the solitary death of a disabled researcher: the deficiencies of a French hospital”), *Libération*, June 21 2003.
- ⁸ “It’s best not to be ill if you receive the Disabled Adult Allocation. 33% of beneficiaries have said that they have had to go without care at least once due to lack of finances. This is what is shown in a study carried out by the research department at the ministry of social affairs, carried out in March 2003 among 5,000 beneficiaries of minimum social benefits appearing in the 2001 census ... (national average: 15%).” APF site (Association Nationale des Paralysés de France)
- ⁹ Jean-Marc Bardeau-Garneret (JMBG) is male, single and suffering from a cerebral motor deficiency caused by problems that occurred when he was born. He is a doctor in sociology.
- ¹⁰ Roland Chifflet (RC) is male, suffers from cranial trauma and lives alone. He has a scientific background, and has a doctorate in sociology.
- ¹¹ Jean-Christophe Parisot (JCP) is male, married with four children, and suffers from myopathy. He is a doctor in political sciences, and is currently a communication consultant and Chairman of the Collectif des Démocrates Handicapés (Disabled Democrats Group).
- ¹² It should be noted here that medical termination of pregnancy used to be called therapeutic termination of pregnancy.
- ¹³ Alexandra Kramoroff (AK) is female, married and has been tetraplegic since birth. She has a doctorate in biochemistry and works as a biochemist.
- ¹⁴ Run by France Télévision on behalf of the Association Française contre les Myopathies (AFM), the programme is broadcast once a year and lasts for 36 hours. “Since the launch of the Téléthon in 1987, 1.2 billion euros have been collected to fight neuromuscular diseases. An absolutely huge amount, with the generous donators knowing next to nothing about how it is used: in 2004 the Cour des Comptes (revenue court) stated that “the content of the programme says little about the exact use of the money collected in previous Téléthons” (in *Le Monde*, 8 December 2006 and *Libération*, 6 December 2003). The last Téléthon was criticized, in particular by the Catholic Church and by disabled persons who feel that calling upon public generosity is only going to help promote the elimination of fetuses with anomalies. Since 2002, one major union of researchers (SNTRS-CGT) has also been alerting the public to the consequences of this media event on medical research – increasing lack of commitment from the government, the orientation of researchers towards “all things genetic” to the detriment of other avenues of research, debatable effectiveness, “research teams in precarious situations due to being dependent on this gesture of solidarity rather than on a real research policy”, etc.
- ¹⁵ Anne-Sophie Parisot (ACP) is female, single, and suffers from myopathy. She has a degree in cultural management, and is a parliamentary attachée.

- ¹⁶ Elisabeth Auerbacher (EA) is female, suffers from spina bifida, is married, and a lawyer. She was part of the anti-establishment group of “handicapés méchants” (the “bad disabled persons”) in the 1970s and 1980s and is the author of *Babette Handicapée Méchante*, published by Stock (1982).
- ¹⁷ Diane Maroger (DM) is female, single and suffering from imperfect osteogenesis. She makes documentary films.
- ¹⁸ JSG is female, married and suffering from imperfect osteogenesis. She is a psychoanalyst and director of a school for polydisabled children.
- ¹⁹ Very recently, AK was faced with this question in a painful manner: her (first) child was going to die at birth; should she, as it was suggested to her, terminate her pregnancy? She chose to keep her child until the end of its short life. It finally died during the 7th month of pregnancy, 15 minutes before its premature birth. On the other hand, she had refused a caesarian section intended to attempt to resuscitate the baby, on the basis that there was little chance of the child living and not suffering from sequels.
- ²⁰ Marcel Nuss (MN) is male, divorced with two children, and in a situation of major physical dependence; he suffers from infantile spinal amyotrophy and is tracheotomized. Chairman of Coordination Handicap Autonomie, he has written several books.
- ²¹ In this letter, MN told us in particular how that very morning his bank manager had considered taking him before a judge because he had decided to move one of his investments!
- ²² Jean Luc Simon (JLS) is male, single and suffering from a paraplegia caused by a car accident. He is Chairman of the Groupement Français des Personnes Handicapées. He has a degree in psychology and in educational sciences. He teaches “dynamics of disability” in several universities and leading colleges.
- ²³ Law no. 2005–102 of 11 February 2005 on equal rights and opportunities, the participation and citizenship of disabled persons. The authors underline that this law represents considerable progress on this issue, but at the beginning of 2007 its application still remains very uncertain and many people deplore the lack of effectiveness of the new measures. Furthermore, disabled people who work are still penalized and lose the benefit of the Allocation Adulte Handicapé (AAH), even when their employment only lasted a short time and when they have no other resources!
- ²⁴ This concept is often now used to designate recourse to legal action in numerous fields of social life.
- ²⁵ The vast technical possibilities that the medical world makes available to future parents to screen for possible anomalies tend to legitimize the fact that parents expect a child free from any malformation. With the fantasy of the child with no faults, or of the perfect child, being constantly fuelled by what is said about technical performances and by social models put forward as representing the norm, it could rapidly become reality. It would seem that here we have artificially created a thirst for the impossible which is hard to quench, and a major confusion between “foetus quality” and the dignity of a human life.
- ²⁶ Law no. 2002–303 of 4 March 2002 relating to patients’ rights and to the quality of the healthcare system. Article L 11 11–1 on “informing users of the healthcare system” and the “expression of their wishes”.
- ²⁷ It is sometimes strange to note that in this study doctors often tend to feel that patients use the existence of even the slightest doubt to request a medical termination of pregnancy, whereas many patients encountered elsewhere, and having no links to these doctors, talk about the pressures they felt from doctors to make a request for medical termination of pregnancy.

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