

CONGENITAL HANDICAPS AND PREJUDICE

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The National Consultative Ethics Committee

Contribution Henri Caillavet

Madame Elisabeth Guigou, Minister for Employment and Solidarity, referred to the National Consultative Ethics Committee on March 15 2001, concerning speculation arising out of a judgment made on November 17 2000, by the Cour de Cassation (Supreme Court of Appeal) regarding reparation to be made, in the form of judicial remedy, for the prejudice done to a child who was severely handicapped since birth. The Minister particularly requested the National Consultative Ethics Committee's opinion on three points :

- 1.The place in society of handicapped adults and children;
- 2.The intrinsic value of a handicapped life as related to non birth ;
- 3.Good medical practices entailing liability on the part of prenatal diagnosis practitioners.

Professor Pierre Corvol, Professor of Experimental Medicine at the Collège de France, and President of the Scientific Council of Inserm, had made a similar request to the National Consultative Ethics Committee on December 18, 2000.

In the past, CCNE has considered on several occasions issues of ethics and good practices as they relate to prenatal diagnosis (Opinions n° 5 dated 13-5-85, n°25 dated 24-6-91, n°37 dated 22.6.93, n°46 dated 30.10.95) and pre-implantation diagnosis (Opinions n°19 dated 18.7.90 and n°42 dated 30.3.94), and also neonatal resuscitation (Opinions n°65 dated 14.9.2000). Therefore, the present Opinion will deal more specifically with society's responsibilities as regards its handicapped members, and with the issues arising out of the notion of a personal prejudice suffered because of being born handicapped.

Handicaps and society

Of necessity, the problem of the inclusion of the handicapped into our society must be viewed before considering the core issues raised by the judgment of November 17 2000. In France today, there are more than two million people whose deficiencies, whether acquired or congenital, and disabilities, generate a severe handicap , which demonstrates the extent of the problem.

In spite of considerable progress during the last decade in the recognition by government and civil society of the rights of the handicapped, there are still serious shortcomings which all too frequently cause dramatic situations and lead to despair.

These shortcomings touch upon every aspect of the lives of handicapped children and adults: education for children, access to training and employment for adults, adapting the habitat to the needs of the impaired, access to public transport and more generally to the urban environment - or even to hospitals - , recognition and support for carers...

All the communities, institutions, or other bodies concerned by one of these vital sectors, agree that despite legal encouragement, there is still insufficient consideration of the social dimensions of care for the handicapped so that their status as fully entitled citizens is not always recognised.

Employment is a significant example, in that legal requirements for 6% of manning strengths to be reserved for the handicapped are far from satisfied, including in certain public sector companies.

This difficulty of integration - short of calling it exclusion - is more or less alarming depending on the type of handicap. Some impairments are more specially rejected by society, as we are reminded by an Ethics group of the Association des Paralysés de France (French paralysis patients' association) :

"Mental handicaps more than physical handicaps, visible deficiencies rather than intimate ones, are rejected, and the rejection threshold is constantly lowered..."

A person suffering from a severe handicap, more than anyone else, therefore cannot find a place in a society engrossed by its image to the extent that it cannot tolerate a variance, or all too frequently, that it exhibits a "handiphobic" attitude. In this context of conforming to a standard, a couple who decide that they will not terminate a pregnancy leading to the birth of a "different" child, increasingly find themselves misunderstood so that the help and support which they can rightfully expect from society are of lesser quality. Such a couple even runs the risk of being criticised as "irresponsible" and thus becoming the object of discrimination.

A recent judgment by the Plenary Assembly of the Cour de Cassation on November 17 2000 (the Nicolas Perruche case) drew the conclusion that a severely handicapped child should receive compensation, on the basis of the link of causality between a medical failure and the status of that child. This was a way of granting the child lifelong protection against financial difficulties added to his existing distress, in particular when his parents died. Therefore, this ruling has a bearing on the more general issue of the inclusion and quality of life of the handicapped, and consequently on the resources devoted to ensuring decent care and not simply survival.

This case emphasises the essential need for humane solutions to the recurrent problems that plunge the handicapped, and in particular those who suffer from severe impairment, into isolation and torment, sometimes so great that it has led parents to prefer putting an end to their child's life rather than be witness to constant rejection and pain.

The present shortage of special accommodation, which is frequently an essential alternative, must be remedied urgently. The predicament is particularly acute for ageing handicapped people, for whom most specialised establishments are unsuitable. It is therefore essential that central and local governments do their utmost to create life-easing resources instead of simply waiting to support projects put together, often with the greatest difficulty, by associations of limited means.

Another subject for review should be aid given to families who choose to look after their handicapped child at home, both as regards moral and psychological assistance or essential financial support.

At this point, there are no supporting and help structures for carers and the amount of compensation offered to the families of the severely handicapped receiving continuous care from a member of the family or from another person, is 5882 Francs + 703 Francs (897 Euros + 107 Euros) per month. This sum, which is barely the equivalent of one person's income, is quite inadequate to cover both the carer's time investment and the many items of extra expenditure.

This means that the Caisse d'Assurance Maladie (centre for the reimbursement of health care expenditure) whose primary task is to ensure national solidarity and risk sharing, provides aid which is very much less than what is necessary to cover the needs of the severely handicapped. Furthermore, in the Nicolas Perruche case, mentioned above, the Caisse actually requested repayment of financial outlay which it considered to be unjustified. Such a position is worrying in that it reveals a reluctance to be, as a matter of principle, the expression of national solidarity in favour of the handicapped. Furthermore, is this not an explicit position taken in favour of the recognition of the "right not be born with a handicap", since the involvement of the Caisse can only be unjustified on the basis of such a right, which the National Consultative Ethics Committee rejects.

All necessary steps must be taken to avoid adding unacceptable living conditions to a life burdened by a handicap. This is one of the priorities of a caring society and is, in the noblest acceptance of the term, a political responsibility.

The National Consultative Ethics Committee is aware of the tensions and of the social and economic constraints that are too frequently raised in opposition to this expression of solidarity by society, which was the subject of its Opinion N° 57 on "Technical progress, health and societal models : the ethical dimension of collective choices" (20.3.98). However, the Committee noted in the introduction to that report that "it can be postulated that since the aim of economic development is the well being of all citizens, they could consider that it is legitimate to allocate an increased share of wealth they produce, or help to produce, to the protection and the improvement of their health."

This thought applies very obviously to assistance given to the handicapped. If rich countries enjoying a high degree of economic and technical development, such as our own and other European countries, did not consider that this kind of solidarity is one of the objectives of their development, would it not lose its main purpose ?

Congenital handicaps

A congenital handicap may be the result of a great variety of causes : infections, toxic episodes, medication, genetics, obstetrical incidents, deprivation, accidents, etc. It is society's duty to do all that is possible to avoid them (see Report n° 57 , dated 20-3-98). The law dated January 17, 1975 on elective abortion for therapeutic reasons, defines the circumstances in which the in utero diagnosis of a proven or probable handicap "of particular severity" may lead the duly informed mother to request a termination. Evidently, this is not an attempt to introduce into law discrimination between lives which deserve to be maintained and those which it would be preferable to avoid the occurrence of. However, the lawmakers recognised that the threats overshadowing certain pregnancies, the risk of their culminating in the birth of severely handicapped children in body and often in mind, justified giving women the legal option

of accepting or refusing a situation of which they would chiefly bear the consequences. The 1975 law is therefore a commitment by society to women in that situation. The exercise of freedom of choice which they are given implies on the part of society a determined action in two directions which may seem contradictory : continuing improvement of screening methods on the one hand, and the improvement of chances offered to handicapped persons, on the other. The first of these, aims to provide pregnant women with all pertinent information and explanation so that they can take an enlightened decision. Such information must inter alia be as detailed as possible on the prognosis and suffering which the child could be exposed to. The second aim is to give a decision on the part of parents to continue with the pregnancy a chance of being realistic, despite the risk of giving birth to a child suffering from some degree of handicap, so that they can choose to accept such a child. The success of this course will then depend on everything possible being done to help families and to create the conditions prevailing in a caring and welcoming society for those children and the adults which they may become. One must admit that the two aspects of this collective commitment, implicit in the 1975 law, have only been imperfectly discharged. As proof, there are on the one hand the deficiencies - which cannot ever completely disappear - in prenatal diagnosis and information given to the women concerned; but above all the aforementioned solitude and lack of understanding which very frequently await parents and their handicapped child.

When a handicapped child is born, whether the handicap was really unpredictable or not, whether its birth is the result of a conscientious decision on the part of correctly informed parents, or whether errors in medical practice or diagnosis can be incriminated, the solidarity of society must be similarly demonstrated. It is evidence of the commitment of the national community to its more fragile and unfortunate members, and of the will to avoid adding to the misfortune of suffering a handicap, that of leaving the handicapped and their families alone confronted with a multitude of problems : financial difficulties, shortage of supporting care at home or in specialised institutions, social isolation of carers. These duties of a caring society in favour of the handicapped who are part of that society have been referred to in the first part of this opinion. They are without prejudice to judicial recourse for reparation which could be legitimately made by victims of harm suffered through malpractice, i.e. the handicapped persons themselves, or their parents, or even the institutions which take care of them.

The application of this fundamental principle of full and entire solidarity with the handicapped would also make it possible to totally dissociate the issue of the assistance to be given to them - which is an obligation on the community - and the legal analysis of possible liability claims.

There are cases in which diagnosis of an affection or disorder of development in utero has never been made, and the handicap is only discovered following birth. This may be the case for genetic diseases, chromosomal accidents, defective development for a variety of reasons, or infection due to parasitic or viral infestation (toxoplasmosis, rubella, or cytomegaloviral infection).

Diagnosis of such conditions was possible but, either the test was not done whereas the context - and sometimes existing legislation - demanded it to be done, or else the results were misleading because of technical and/or medical failings. In the circumstances, parents were unable to choose between continuation and termination of the pregnancy, and so risk giving birth to a seriously handicapped child. They often state that, if they had been informed they would have chosen termination.

These parents are surely justified in seeking reparation according to conditions previously discussed in this paper, by implementation of the usual rules applying to liability claims. But what is the situation for the handicapped child ?

The central issue, in a legal context, is whether there is a cause and effect connection between the faulty diagnosis and the handicap. In the theoretical event of a diagnosis in utero which would have made it possible to initiate treatment and thus avoid the handicap, or if a medical action of diagnosis or therapy is directly responsible for the handicap, such a connection can be upheld. Prenatal therapeutic intervention may one day become possible in view of developments in in utero chemical, surgical, and gene therapy. As of now, however, this hypothesis remains largely theoretical : when a diagnostic test detects a mother's rubella, a genetic disorder, or a foetal malformation syndrome, the only way to avoid the birth of a handicapped child is to perform a medical abortion - which is not therapy for the foetus. The cause and effect link between an error of diagnosis and the handicap is therefore, in this case, very remote. When the parents say that their choice, if a correct diagnosis had been made known to them, would have been to terminate the pregnancy, it can be argued that the birth of a handicapped child - and therefore its sufferings - are in fact the result of the error or fault, the alternative being so-called "therapeutic" abortion. However, the handicap itself is in no way connected to the malpractice; it is due to the infection which affected the mother, or the genetic disorder, or to the developmental anomalies which are the only true causal factors. Independently of the prejudice suffered by the parents, which may, it is true, legitimately give rise to a right to reparation, recognising the responsibility of healthcare providers in a prejudice of which the child is a victim, leads to the conclusion that it would have been preferable for the child not to be born, or even that the child had a right not to be born with a handicap, in view of the shoddy quality of life with which he is burdened.

Is there a right not to be born with a handicap ?

Recognition or assertion of a "right not to be born with a handicap" does, however, raise serious issues, both regarding the logic of such an assertion and the practical consequences which could ensue. The first of these, particularly alarming, is that it could apply even more appropriately to parents who were correctly informed as to the diagnosis of a probable handicap affecting their unborn child, and who decide on the basis of deep-seated conviction, that they will allow the foetus to develop and that they will cherish a handicapped child. In such a case, these parents voluntarily reject this new right given to children, the right not to be born with a handicap which is judged unacceptable.

It is true that the freedom of choice given to the mother as it is recognised by the 1975 law, would be in principle here opposable to the claim of such a right being granted to the child. Nevertheless, according to certain current trends, a different interpretation is emerging according to which the logic of the law would in fact be the recognition of a "subjective" right of the child to be spared a prejudicial life. The National Consultative Ethics Committee does not adhere to this reading of the letter and spirit of the law dated January 17, 1975. The Committee sees this text as being based on the recognition of the value of a choice expressed by a responsible and correctly informed woman, and certainly not as an injunction in favour of a form of "prenatal euthanasia". However, this discussion does demonstrate that it is difficult to foresee how this text might be interpreted in the future.

Indeed parents would only be safe from litigation if their child suffered permanent mental incompetence, since they could not lodge a complaint against themselves.

In fact, two situations could occur. On the one hand, the all too frequent case when psychoneural disability is so severe that the case is brought to court fictitiously in the name of the child, although in reality no one is in a position to know what the child's opinion would be if it could be expressed. On the other hand, the authentic plaintiff would

actually be the handicapped person who would be holding responsible for the suffering and difficulties of life, the physicians who misdiagnosed the case, or even parents who knowingly rejected a diagnosis or refused a termination of pregnancy.

Legal action in the name of an incompetent handicapped person.

In this situation, rightful claimants for the handicapped child, request in the child's name reparation of an injury for which they hold responsible healthcare providers whose diagnosis was defective, by fault, technical error, or flawed interpretation. This action in the name of the child is independent of any action taken by parents as discussed above. The mental incompetence in this case casts even graver doubts on the fiction according to which the child would be asking for reparation in the name of a right not to be born handicapped. Indeed, let us suppose that, despite severe mental retardation, a person is able to judge the quality and meaning of a life, which gives pleasure and satisfaction, allows relationships with others, and also apportions trials and tribulations. Who can then say - assuming the absurd theory that such a person could be clearly aware in the abstract of his best interests - whether this person would systematically draw the conclusion that his parents would have been far better advised to terminate the pregnancy which led to his birth ? All those who care for the mentally retarded know full well that, despite the severity of their disablement, they are as capable as anyone else of showing signs not only of pleasure and well being, but also of an appetite for life and communication with their loved ones in a truly reciprocal mode. There are tender gestures, which are visible proof of love.

Legal action taken by a handicapped person able to exercise judgment.

A claim may be made personally by the handicapped person : a child out of infancy or an adult with normal mental development may consider that he suffers so greatly from his handicap (or what he considers to be such) that it would be preferable never to have come into the world. He therefore sues those he sees as responsible for such a birth taking place, either the healthcarers who did not give his parents the possibility of choosing therapeutic abortion, or the parents themselves, since they either refused to undergo a diagnostic test, or even knowingly decided to give birth. Recognition of the right of the child not to be born with a handicap would lead logically to this type of consequence.

The plaintiff could, because of moral suffering, claim reparation for moral prejudice far in excess of the assistance that society should, in any case, provide because of his physical condition. Such a situation has never as yet arisen in France, but is similar to actual cases submitted to courts in the United States.

If a court were to recognise the validity of such a claim against parents and if jurisprudence were to build up along those lines, parents would come under very severe pressure, since a refusal to terminate a pregnancy in a society which is ever more prone to litigation, would expose them to proceedings in compensation of the prejudice suffered by their child. Their liability, not as regards the handicap itself, but as regards the birth of the handicapped child, would in this case be direct and irrefutable.

Today, this scenario seems improbable, and the National Consultative Ethics Committee can only hope that so will it remain. French judges are unlikely to take the risk of penalising parents willing to accept and cherish a child although that child is different and handicapped. However, this attitude would make it all the more difficult to blame healthcare workers who, in any event would be less directly responsible than parents who had been correctly informed and yet, on the basis of their moral convictions, decided to allow the handicapped child to be born.

The risk of "normative" pressure on the medical profession and on parents.

Many prenatal diagnosis specialists, cytogeneticists, geneticists, and echographers, have recently expressed concern regarding possible repercussions on the practice of their professions of the recognition of a "right not to be born handicapped". These physicians, biologists, and echographers, point out that determining the level of handicap beyond which this right would be applicable would be extremely dangerous, and in fact inapplicable. If termination of a pregnancy was based purely on objective criteria to determine the severity of a handicap, this would mean that no account would be taken of the mother's evaluation of what she considers to be a legitimate choice based on the information she was given - in particular as regards the probable suffering endured by the child - and on her own moral convictions.

The National Consultative Ethics Committee can do no better than draw attention to its writings concerning the freedom to choose according to one's conscience for parents of children who could suffer serious impairment after neonatal resuscitation (Opinion n°65 dated 14.9.2000) : In a situation where a child is obviously incapable of consenting to anything, and will always remain so, no one is more directly concerned by the child's fate than are the parents. They see their child in a singular light : the birth, the trials and tribulations, the fragile survival, have left impressions which cannot be overestimated. In such dramatic situations, a human approach calls for the possibility of expressing parents' deep feelings but not allowing these to be totally distorted by unendurable feelings of guilt...The outcome chosen (gives) due regard to the wishes of parents who alone are able to measure the burden of the life ahead of them". It is sufficient to replace in these lines the words "the birth and the fragile survival" by wording such as "the pregnancy, hoped for and precarious" for the text to apply to a justification of the woman's freedom of choice advocated by the 1975 law.

Should there be any desire to appreciate the degree of prejudice giving access to the right not to be born with a handicap, this would probably be impossible because of the total absence of proportionality between the objective measure of a handicap - which is meaningless due to lack of any certainty regarding a standard - and its repercussions on the psyche of the person concerned. For that matter, one cannot help but be struck by the priority to appearance frequently given by our society over any other factor which determines a being - and prenatal healthcare does contribute to this. There are many men and women who cannot accept themselves as they are even though they may be devoid of any noticeable handicap. Such attitudes can lead to behavioural anomalies, recourse to plastic surgery, or to surgical sex change, and sometimes to suicide.

The prospect of a gradual increase of litigation seeking reparation for prejudice suffered by being born afflicted by subjectively unbearable anomalies, or even the simple possibility that such legal action could be taken, would probably provoke a normative self-protecting reflex on the part of medical professions and families. Over and above the tests actually necessary for detecting a risk of being born very severely handicapped, specialists in the field of prenatal diagnosis would be inclined, in order to protect themselves, to recommend to the mother the full range of available screening

methods that are constantly developing. For themselves, they would want the full range of legal protection. As a result, a pregnant woman who was in fact ready to accept a child into her family, in spite of any handicap, might be discouraged from her original plan of allowing her pregnancy to go to term.

The law, as it now stands, allows women who are informed of the risk that their child could be severely handicapped, to choose in all conscience whether they wish to medically terminate the pregnancy or not. On the part of the legislator, this is a token of trust for the mother's sense of responsibility and a mark of respect for her freedom of choice. Recognition of a singular right "not to be born handicapped", in view of the legal proceedings that would ensue, would probably lead to strong social pressure being exerted in favour of eliminating abnormal foetuses according to medical criteria for the degree of abnormality. This trend in the direction of a social definition of criteria, be they medical and scientific or otherwise arrived at, for "a good birth", can be etymologically and historically described as eugenic .

The National Consultative Ethics Committee

1) reiterates its constant position as regards the imperious duty of solidarity of society, in particular in favour of its most unfortunate members (Cf. in particular Report n°57, dated 20.3.1998). The handicapped are in that group, be their handicap acquired or congenital, hereditary or sporadic. This social duty must apply to all those in need without distinction, regardless of the circumstances at the origin of their handicap. When the handicap can be related to human intervention, there must be an a priori for the provision of care, independently of possible legal recourse on the part of parents for reparation of the prejudice, and regardless of the outcome of such proceedings. Giving preference to situations in which the handicap can be attributed to medical malpractice and ascribed to individual liability, would introduce unacceptable discrimination between handicapped persons. Furthermore, such a position would encourage a systematic search for liability due to fault, however implausible and whatever the handicap, since this would be the only possibility of providing for the persons concerned. Identifying individual or collective human responsibility, in the event of a handicap, may legitimately lead to reparation through judicial means. The fate of handicapped persons must not, however, depend on their outcome. The handicapped must be taken care of, regardless of legal proceedings, as the expression of the collective responsibility of society to its more vulnerable members.

2) As regards congenital handicaps, social solidarity must be guaranteed so that a mother who has been informed of the risk of giving birth to a handicapped child, decides solely on the strength of her personal assessment of the situation and of her responsibility to the future child, in particular of the sufferings that child might endure, and not in the light of practical difficulties to accommodate and care for the child which she and her spouse would encounter without the benefit of necessary and possible assistance.

3) Recognition of the right of the child not to be born in certain circumstances appears to be highly disputable in law, unnecessary to ensure the future support of those afflicted by congenital handicaps, and ominous in ethical terms. Indeed, such a right could lead to burdening parents, prenatal diagnosis specialists, and obstetricians, with a eugenically flavoured normative pressure.

4) As stated repeatedly since 1985, the National Consultative Ethics Committee is attached to the respect of ethical principles and practices in the conduct of prenatal diagnosis and neonatal resuscitation. The Committee is giving further thought to several of these issues and will shortly make its opinion known. However, the aim of guidelines in these matters is to give every chance to the children and full information to the parents so that their choice can be enlightened. The creation of normative criteria

sufficient on their own and independently of the mother's feelings on the matter, to define a severity threshold justifying the elimination of abnormal fœtuses, can never be acceptable in the light of ethical reflection based on the freedom of choice of responsible and worthy human beings.

Contribution

Henri Caillavet

This debate involves - as does the debate on the decriminalisation of euthanasia - the dignity of life. Any metaphysical considerations should be set aside so as to achieve the greatest possible objectivity.

As a matter of course, every effort should be made to prevent children being born with a handicap. Solidarity imposes the need for collective effort. We must refrain from adding distress, hardship, and incongruencies, to a situation already fraught with injustice and pain. For that purpose, substantial budgetary allocations are a necessity to provide on the one hand care centres, live-in accommodation, teams of specialists, and on the other, more pre-natal and pre-implantation diagnosis facilities, and prenatal supervision using ultrasound examination and amniocentesis, etc .

One absolute imperative is providing information to the parents. Information must be objective, exhaustive, and comprehensible so that freedom of choice remains entire in an unexpected situation entailing accountability. The worst possible result would be the birth of an unwanted handicapped child, rejected by next of kin because of being different. We must not forget that giving life commits conscience at the highest level. The Perruche judgment observed a causal connection between medical malpractice and the handicap, so that it naturally granted compensation to the victim of that error, true to jurisprudence. I would suggest however that we are faced with legal novelty when the Caisse de maladie plays a part in the proceedings, claiming to recover what it should not have paid out. Because of this action, the Caisse de maladie accepts the notion that a child has a right not to be born handicapped.

I am not personally shocked by these legal proceedings and conclusions for several reasons :

- 1 - A woman's right not to give birth to a child was recognised by the 1975 law allowing therapeutic abortion. Such a woman, being informed of danger, decides whether she will terminate or continue her pregnancy. If she aborts, then she has decided in all conscience that a handicap would be an excessive and inhumane ordeal for her baby to bear. She therefore does not wish to give birth to an unacceptable child. That is her freedom of choice and no one is entitled to argue against her decision. Now, I would like to understand for what motive and reason we could not accept that what is considered admissible, respectable, appropriate, for the mother is none of those things for the handicapped child. I reject that contradiction. This genuine right granted to the mother simply becomes a virtual right of the handicapped child. The mother delegates her own right to her "abnormal" child. This delegation of a right is not shocking precisely because morally it only concerns a potential handicapped human who may be the victim of, for instance, a disease, a biological disorder, etc. In the circumstances, there should certainly be no mention of eugenic deviation for this singular event. The nature of eugenics is very different : the target is a human group. Thus we can conclude from the 1975 law that it implicitly recognises the right for a person not to be born with a handicap.

2 - For that matter, if this right of a child not to be born with a handicap were not recognised from now on, then all the pre-natal and pre-implantation diagnoses, the investigations, the biological research, which sometimes lead to abortion when the mother so chooses, must be clad in some other legal garment. Do not all these activities aim to unveil the anomalies of an embryo or of a foetus so that parents or mother can decide whether or not to pursue the pregnancy ? Therefore, by this admission alone, we accept at least intellectually that a handicap is both unacceptable for the mother and unacceptable for the child she bears. A fortiori, what is judged acceptable for the mother must also be acceptable for the conceptus who by delegation holds the right the mother was granted. In turn, therefore, the conceptus has the right not to be born afflicted with a handicap.

3 - Were this right not to be born handicapped not fully recognised by French substantive law, then we should prohibit and disallow - and fortunately this is not the case - "physical modifications". For example, a sex change would no longer be permitted although this is a particularly traumatic handicap. And yet, no one disputes the legitimacy of a sex change. A contrario, this legal situation demonstrates irrefutably our recognition that a mature and cognisant individual has the right not to be born and remain handicapped . There is no need to even mention in passing that very frequently, all this is explained by "self-rejection" (dwarfism, grave physical degradation, etc.).

In conclusion, I am very ready to consider that recognition of a right not to be born handicapped, beyond ethical or religious preoccupation, does raise an authentic cultural debate. Since the mildly or severely handicapped child, in particular when a victim of medical failure, can obtain compensation, then the child whose parents have decided and chosen to allow the birth to take place with, and despite, a handicap, has the right to claim his parents are liable. A handicapped child, because he was born with a handicap which he finds unacceptable, may sue his parents. The line of argument will be a simple one : "I did not ask to be born, and I particularly did not ask to be born with a handicap. Your choice is responsible for my handicap. You are in my debt on every count, and in particular financially". In America, there have already been some lawsuits on those lines. Personally, I consider these to be legally receivable because to allow a handicapped child to be born is a fault on the part of parents and may even be evidence of intemperate selfishness. In order to avoid such occurrences, I would like the mother, the parents, to be scrupulously informed of the personal and legal consequences of their choice and of the impact on their family because they should not forget that they could also for instance choose to have another healthy child or to adopt another baby. I am convinced reason will prevail. Freedom is not solely positive. To be free also means, frequently, to abstain and refuse.

In conclusion, since the Opinion does not recognise the right not to be born handicapped, but that, nevertheless, it also puts forward arguments and considerations of which I approve, I shall abstain on this Opinion, while still remaining convinced that in the very near future, children will finally obtain the indisputable right not to be born handicapped.

All members of the Committee approved this Opinion with two exceptions: Henri Caillavet abstained (document attached), and Jean-Pierre Changeux expressed a negative opinion.

1. P.Risselin, Handicap et Citoyenneté au seuil de l'an 2000. ODAS Ed, 1998
2. D.Mazeaud, Naissance, Handicap et lien de causalité, Revue le Dalloz, N°44, 2000.
3. F.Dreiffus-Netter, Observations hétérodoxes sur la question du préjudice de l'enfant victime d'un handicap congénital non décelé pendant la grossesse. Med. & Droit, 2001; 46: 1-6