BELGIAN ADVISORY COMMITTEE ON BIOETHICS

Opinion no. 8 of 14th September 1998 on the issue of sterilising persons with a mental retardation

Request for an opinion of on 10th September 1997,
From MsW. Demeester-de Meyer,
Flemish Minister of Finance, the Budget and Health Policy

In her letter dated 10/09/97, Wivina Demeester, noting that sterilisation of the mentally retarded is usually sought by parents and healthcare professionals, stated thaat it is important to determine what the mentally retarded want and whether they are in a fit state to make their own decision.
She asked the Advisory Committee on Bioethics to determine the criteria on which an individual is deemed incapable and who should make the final decision on sterilisation. Since the mentally retarded are sterilised regularly, she asked the Committee to determine whether sterilising a mentally retarded person should be permitted, even though they do not, either legally or de facto, have the capacity to grant their own consent.
If so, the Minister asked if the Committee could provide an argumentation on what basis such a decision should be made and by whom.
If not, she asked if the Committee could inform her how the aforementioned medical-social issue should be tackled.

I. Introduction

Mental handicap: a definition.

The American Association for Mental Deficiency defines mental handicap on the basis of three essential criteria:

- intellectual capacity measured on an intelligence scale as being significantly below average
- whether a person also suffers from behavioural adaptation deficit
- diagnosis before the age of 18

There is a distinction between so-called "borderline" mental handicap (IQ between 70 and 85), and mental handicap which is "slight" (IQ between 50 and 70), "moderate" (IQ between 35 and 50), "severe" (IQ between 20 and 35) or "profound" (IQ below 20).

The more than 200 etiological factors which explain mental handicap which is slight, moderate, severe and profound include:

- hereditary factors
- early embryonic developmental factors
- problems during pregnancy and childbirth
- health problems acquired early in childhood
- environmental influences and other mental disorders

There is no clearly defined etiology in 30 to 40% of cases.

A multitude of factors determine intelligence. Both hereditary factors and environmental factors play a role in it. Genetic factors determine an individual´s potentiality. On these potentialities, factors related to medium determine a person´s Intelligence Quotient.

Below average intelligence suggests an IQ of 50, the problems are essentially congenital and mental handicap is usually associated with other deficiencies.
Above an IQ of 50-55 suggests slight mental handicap. Some people state that this is a normal variation. Here, environmental factors impose a significant impact. Absence of stimulation and insufficient stimulation, dietary deficiency and poor treatment, etc have a negative influence.

Diagnosis and slight mental handicap may not be seen before the age of 7, in other words, when a child starts to attend primary school. In general, being significantly behind at school is the first sign of limited intellectual capacity. As we know, performances obtained in IQ tests have a lot to do with whether or not someone has had learning opportunities.

A lot has been written on mental handicap, and there are now several theories:

- a "deficient" position, confirming that a mentally deficient person differs from a non-deficient child both in quantitative and qualitative terms;
- a "developmentalist" position, confirming that a person who is mentally retarded only differs from a non-deficient child in quantitative but not qualitative terms. Here, the concept of heterochromia is important: children with a mental retardation are not all mentally handicapped to the same degree at all stages of their development: in some

stages they develop identically to those of normal children;
- a "behaviouralist" position, which states that mental handicap is a "construction" made from a series of insufficient interactions between the subject and their environment;
- a "psychodynamic" position, which considers that mental retardation results from interactions between a deficient biological substrate and a pathological relational experience.

In practice, these different positions are not mutually excluded.

Reviewing the literature, it is unanimously accepted that they generally account for 3% of the population. 2.5%, or 250,000 people in this country, have some form of borderline or slight mental handicap, whilst 0.5%, or 50,000 people in Belgium suffer from moderate, severe or profound mental handicap.

In fact we know relatively little about the reproductive potentialities of most cases of moderate, severe or profound mental handicap. In trisomia 21 (Down´s syndrome or mongolism), the chromosomal abnormality which generates the most common mental retardation, girls may be fertile, but boys´ sperm may or may not be fertile. In some cases of chromosomal abnormality determining sex as 48 XXXY (a rare form of Klinefelter syndrome), patients are infertile. In certain cases of a genetic mental handicap, fertility may be completely normal. Depending on the cause of the mental handicap, risk of transmission to children varies by anything from one to fifty per cent.

However, most cases of mental retardation concern borderline or slight mental handicap and the person is presumed fertile. In this case, the mental handicap may be the consequence of a poor quality environment. However, it may be the result of hyperperforming education of children who were far from talented in the first place. In many cases of trisomia 21, when those surrounding the person pay sufficient attention to them, their IQ will rise over the time they are learning. The scope of the impact of environmental factors must incite us to be very careful when it comes to sterilising the mentally handicapped.

The Committee would like to stress that this report only concerns persons with a mental retardation in the very sense defined previously. The report does not in any way concern psychiatric patients, in other words, patients suffering from mental pathologies (for example, psychotics) and cannot in any way be extended to apply to them.

Sterilisation

Although theoretically reversible in a certain number of cases, surgical sterilisation must be perceived as the definitive denial of the ability for an individual of either sex to procreate. It must therefore be distinguished from any other contraceptive method which has a temporary, reversible effect which does not affect someone´s physical integrity.
Nowadays, sterilisation is practised when requested by men and women who no longer wish to procreate and consider it a comfortable, definitive contraceptive method. To this end, we would like to cite Article 54 of the Belgian Medical Ethics Code, which states thus: "Although usually benign, surgical sterilisation is surgery which implies a whole host of consequences. So a doctor may only go ahead with it once the spouses or partners have been correctly informed of inherent procedures and their consequences. Anyone who undergoes the surgery must be able to make a decision of their own free will and their spouse or partner may not oppose it" .

When practised on someone who is mentally retarded, most of the time on women, this obliges us to ask ourselves about the quality of the informedconsent of the person concerned and the capacity of any guardian to act on their behalf when such a request is made. In many cases, sterilisation of the mentally retarded is requested by parents seeking to ensure freedom of relations, including sexual ones, for their mentally retarded children. However, they fear pregnancy, especially if they believe that their child is incapable of providing education to any descendant, they themselves no longer feel young enough to provide this, and they doubt the quality of the education provided by the existing institutional system. In addition, most of the time, admission to an institution for mentally retarded adolescents and/or young adults is subject to them being sterilised first. Only in recent times have most institutions given their residents more freedom of movement, and have resigned them to being surgically sterilised. These requests for safety and security, made by both parents and institution managers, are understandable and are sometimes justified too. This does not mean that they cannot oppose us, either legally or ethically, and so it requires a regulatory framework to be produced, one which also grants mentally retarded people fundamental rights.

II Legal perspective

First of all, the Committee recalls the essential principle, which is fundamental to our democracy, the fact that any human being, whoever they may be, is legally fully subject, and there is no question whatsoever of this not being the case.

It also recalls that the law governing marriage and having a family is acknowledged, from the age of consent, by Article 12 of the Belgian Convention on Safeguarding Human Rights and Fundamental Liberties.

As sterilising the mentally retarded may compromise these fundamental rights, it is imperative to determine the conditions under which it may be practised.

Accordingly, the Committee recalls that for adults, there are only two grounds for total legal incapacity, prolonged minority and legal ban, which imply the interested party being placed under guardianship and the nullity of all of their legal acts, including those affecting their person.

The **prolonged minority** system (Article 487a to 487h of the Belgian Civil Code) seeks legal protection for the seriously mentally retarded who are incapable by virtue of the significant reduction in their mental faculties. This protection has radical consequences, since the people subject to the system retain minor status even after they have legally become adults. Thus, they remain subject to parental authority or are placed under guardianship when it comes to administering their person and their property. They are deemed not to have reached the age of 15 (making it impossible for them to marry or perform managerial acts or provide for themselves).

The **legal ban** system (Articles 489 *et seq.* of the Belgian Civil Code) is now rarely applied to the mentally retarded.

Then there is the **temporary administration** system (Article 488a, a to k of the Belgian Civil Code) which institutes protection of adults when it comes to administration and provision of their property when they are not in a state in which they can manage them for reasons of limited or disturbed physical or mental faculties (including mental handicap).
This protection is provided by the magistrate appointing a temporary administrator, who, on

behalf of the protected person, administers their property.

Usually, a mentally retarded person is not placed under legal guardianship unless their mental state justifies it. The parents provide *de facto* guardianship and sometimes wish to save their retarded child the traumatic effects of proceedings or see no need for them. Absence of any gauge of legal incapacity is therefore not sufficient to deem a mentally retarded person always capable of granting consent when appropriate. In terms of placement under legal guardianship for property administration, the system does not in any way imply that a mentally retarded person is deemed incapable of making decisions concerning their own person, even though this may be the case.
So, as with anyone who does not hold legal incapacity status and *a fortiori* in the case of a mentally retarded person, when the doctor agrees to go ahead with sterilisation, he is responsible for conscientiously assessing the quality of the informed consent of the person where the surgery is concerned. In fact, mentally retarded people usually tend to consent to injunctions by their next-of kin, something over which and over whose consequences they do not necessarily have any control.

However, legal incapacity status does not necessarily imply that a mentally retarded person is incapable of making decisions which concern them. In certain cases, *de facto*, they may duly consent to be sterilised. Granting of legal incapacity status cannot therefore, on its own, be used to erect a barrier to the consent principle, *a fortiori* when it entails denying previous reproductive ability. However, if a mentally retarded person´s legal representative is opposed to this, it may not be practised, even if the interested party has granted their informed consent.

When a mentally retarded person is not granted legal incapacity status and when he or she is opposed to a sterilisation request made by a third party, it cannot be accessed in any way, and the mentally retarded person is legally fully subject to it.

Therefore, we note that existing legal provisions cannot on their own be used to resolve issues pertaining to sterilisation of the mentally retarded. Hence, in its final recommendations in this report, the Committee is proposing new procedures.

III Ethical perspective

In the ethical debate on sterilising the mentally retarded, over and above the consent principle, we must consider several interests which must be reconciled. First of all, there is the right of any individual to experience their sexuality and procreate; then, firstly, the interest of the newborn "with all of its faculties", and secondly, the wishes of the community to see it grow up under optimum family, educational and socio-health-related conditions. Finally, there is the general interest, which obliges the public authorities to protect everyone´s freedom to procreate but also grant everyone, born or unborn, the right to "protection of their health through appropriate disease prevention measures and healthcare, and the resources to obtain an optimum state of health which they are capable of providing", as stipulated in Article 1.6 of the Declaration of Amsterdam on promotion of patients´ rights in Europe.

When the mental handicap is not hereditary and a mentally retarded person is fertile - which accounts for most situations -, above all, it is about assessing the mentally retarded person´s ability to educate children under acceptable conditions. In cases of slight mental handicap, *a fortiori* in cases of borderline mental handicap, it should be stressed that it is usually associated psychic and/or psychiatric problems (mood swings, behavioural disorders, emotional and affective disorders) which justify the inability to educate, more than the mental

handicap itself. In these cases, it may be desirable to help the persons learn about the limits of their ability to educate, and if necessary, support them in sterilisation request proceedings. Forcing them to be sterilised against their wishes is only justified in exceptional circumstances.

When a person is suffering from moderate or severe mental handicap or when it is established that their condition is hereditary and the mentally retarded person is fertile and at risk if they procreate, the Committee believes that preventing them from bringing a mentally retarded child into the world is justified if they are personally incapable of making a decision.

Precise rules governing conduct must always be observed.

Hereafter, the Committee examines the ethical issue from three perspectives - that of a mentally retarded potential parent, that of the child and that of society - and then makes recommendations as to *ad hoc* measures to be taken.

a) The perspective of the mentally retarded potential parent

From a mentally retarded person´s perspective, the general ethical rule must, as far as possible, be to grant them all of the rights which other citizens are granted. Limiting these rights in any way must be exceptional and very definitely justified.

For several years, actual acknowledgement of mentally retarded people´s rights has been one of the main concerns in society, which as far as possible wants to ensure their social insertion, and so their relational and affective independence. In many cases, the participation of the mentally retarded in active life is compromised by the fear on the part of their parents and/or professionals around them that increased freedom of action will lead to fertility, even though this is anything but desirable in their eyes. Although it is therefore important to ensure observation of the law governing procreation by the mentally retarded and the consent principle, it seems equally important to consider the anguish, often deep-seated, of those around them when it comes to a pregnancy whose consequences neither the mentally retarded individual, nor their family, could bear. Agreeing to sterilisation in some cases to prevent restrictions on a mentally retarded person´s freedom, and even the reflex action of being enclosed imposed by those around them, who fear the consequences of their freedom of movement, is therefore justified both ethically and in the interests of the person themselves. And again, it is the interests of the actual retarded individual who imposes it, when they believe that they are completely incapable of providing education to a child, whatever the quality of the psychosocial support which may be provided to them, to assess the suffering which would be inflicted upon them were they sterilised and the suffering which they would endure having to be separated from their child, when placed in an institution.

However, before examining the issue of sterilisation of mentally retarded people, we must remember the duty to provide them with education on sexuality and parenting.

More and more, it is noted that even severely mentally retarded children and adolescents may benefit from sex education programmes which will enable them to better grasp how important it is to track contraceptive practices and increase their capacity to decide whether or not to engage in sexual relationships. In parallel with the sex education programmes, biology lessons and training on parenting will increasingly enable them, depending on their situation, to participate in a very informed way in a decision concerning their wish to have a child and to assess the consequences of parenthood. The Committee would like to stress the importance of

generalising these training and information programmes to considerably increase the capacity of the mentally retarded to experience harmonious sexuality, so that they are aware of the dangers of pregnancy and sexually-transmitted diseases, and if necessary, can decide for themselves whether or not to be sterilised. Currently focussing on integrating the mentally retarded in society fully, this aspect of their development is of paramount importance, especially since, until very recently, their sexuality was regularly denied, and they themselves were frequent victims of abuse.

b) From the child´s perspective

It seems generally agreed that in the absence of mood or behavioural swings and affective and emotional problems, a slightly mentally retarded parent can educate a young child correctly. This does, of course, require support, both material, social and educational. When there is an associated disorder, it is important to provide medical and psychological follow-up to the parent to prevent any negative impact on the child´s development.

Here, we recall that borderline and slight mental handicap are very often associated with social and environmental factors and that it is therefore highly desirable to ensure that these do not mar the future of the new generation.

So as far as possible, it is vital to help the parents overcome their socio-economic, cultural and educational difficulties to ensure the child optimum development and prevent them from being placed in an institution.

From puberty, once the child is normally endowed, a certain number of psychological problems may manifest themselves. It may be difficult for these children, for reasons of loyalty, to allow themselves to do better than their parents socially. Difficulties identifying themselves may also be seen. Problems of authority may be seen, especially when the father is mentally retarded and *a fortiori*, when both parents are.

We recall that the quality of child development will also depend on the mental and physical state of a mentally retarded person´s spouse.

Although, ethically, it is therefore important to observe the wishes and the right to physical and moral integrity of the mentally retarded, so too is it true that their children do not always develop adequately. So it is in the interests of these children and it is society´s duty to as far as possible help mentally retarded people to make responsible choices, especially since recent research tends to show that over and above the impact of socio-economic precariousness factors when it comes to children´s development, mental handicap on the part of one or both parents will have a negative impact on their future.

c) From society´s perspective

Although it is society´s ethical duty to ensure respect of independence and human dignity where the mentally retarded are concerned by preventing any forced sterilisation, it is also its responsibility to prevent hereditary transmission of serious mental handicap, and encourage children to be born into the world under good conditions. These two duties may come into conflict with one another when it comes to the issue.

The Committee is opposed to any eugenic policy.

It believes that no generalised recommendation to sterilise may be imposed as a general rule to protect society´s economic interests. In an abundant society such as our own, no economic interest may be guaranteed to the detriment of even the slightest liberties. Quite the opposite: society has a duty to provide them with the material support they need.
The Committee also believes that recommending sterilisation as a generalised way of preventing pregnancy amongst the mentally retarded to protect any children they have should be banned. Generally recommending sterilising the mentally retarded would merely result in significant injustice. By its general nature, it would prevent some mentally retarded people from procreating, and their personality, education and support which they find would make them perfectly capable of educating children. Moreover, such a measure would create a significant risk of demotivating society to make the effort necessary for educating and supporting the mentally retarded. And, as we have already stated earlier, it is society´s duty to provide for this education and support.

Furthermore, sterilisation is no more acceptable when it is induced by the mere desire for peace of mind on the part of the mentally retarded person´s carers and parents. *A fortiori*, it may never be sought as a condition of access to an institution. Usually, it merely prevents fear amongst parents and/or professionals from being justified where the risk of procreation is concerned. So it will always be important to hear them in any proceedings concerning sterilisation.

Sterilisation is thus only justified on a case-by-case basis, once the mentally retarded person´s situation and that of those around them have been analysed in full, to prevent the birth of children whose health and/or appropriate care are not guaranteed.

Society has a duty to strictly define conditions for examining a request for sterilisation of the mentally retarded. It must also ensure that the authorities firstly pursue *ad hoc* preventive policies (training on sexuality and parenting, application of contraceptive measures, material social, cultural and educational support to the mentally retarded), and secondly, a regulatory framework stipulating the conditions for ensuring the appropriate nature of a request for sterilisation emanating from a third party or someone incapable of granting their informed consent. The absence of any regulations on the subject would remove any possibility of replying, responsibly, to someone who is legally incapable, or someone who is *de facto* mentally retarded, leaving them exposed to the consequences of exclusion.

IV The Committee´s recommendations

In response to the issues raised by the Minister, above all, the Committee believes that it is always the doctor who performs the sterilisation who should be liable for it.

Nowadays, sterilisation is practised when requested by men and women who consider it a comfortable, definitive contraceptive method.

When a request for sterilisation emanates from a mentally retarded individual who holds all of their rights, and the doctor to whom the request is sent believes that they are able to understand the impact of surgery, the Committee believes that they must be treated like any other adult. When the doctor who should perform the surgery considers the person incapable of making an informed judgement on the subject, they must contact a psychiatrist, who will examine the mentally retarded person and rule on the quality of their consent. When the

psychiatrist quashes the doubt signalled by the doctor asked to perform the surgery, they may go ahead with the sterilisation.
Otherwise, the surgery may only go ahead in agreement with the mentally retarded person´s guardian, which implies that they must previously be deemed legally incapable.

When the mentally retarded person refuses to be sterilised and they hold their rights, there is no question of it going ahead. If necessary, the person will be subjected to guardianship previously.

When sterilisation is applied to mentally retarded individuals incapable of judging whether it is appropriate, this ethically denies the right of each and every one of us to procreate on the wishes of the people around us and society to see children born with all of their faculties under good conditions in terms of education and family, and also the child´s right to be born under the same conditions.

Once the aforementioned considerations have been made, the Committee believes that sterilising mentally retarded people incapable of granting their informed consent for the surgery is justified in certain cases. However, it recalls that no sterilisation of anyone incapable of granting their informed consent is legally possible if that person is not subject to prolonged minority status or a legal ban.

Whenever a mentally retarded person is subject to legal incapacity status, a decision on sterilisation legally requires the guardian´s agreement. Given how difficult it is to make an objective judgement in a certain number of these cases, the Committee believes that any request for the sterilisation of a legally incapable person must also be subject to the opinion of a multi-disciplinary team to be appointed.

The Committee believes that when a mentally retarded person is subject to legal incapacity status, they are, however, quite capable, in a great many cases, of allowing themselves the opportunity to be sterilised. So there is every reason to distinguish between incapacity justifying the legal measure and incapacity to make a decision on sterilisation.

Hence the diversity of situations.

Even if a mentally retarded and legally incapable person is however, considered able to grant informed consent, and they are opposed to sterilisation, the Committee believes that it would breach ethics to constrain them. If, however, in this situation, they consent to sterilisation or request it, the Committee believes that both the guardian and the multi-disciplinary team should respect the desire as far as possible.

If a mentally retarded, legally incapable person is unable to grant their informed consent regarding their sterilisation, it goes without saying that the doctor will only anticipate the surgery if he deems it necessary. As stated previously, he must then seek the prior opinion of the multi-disciplinary team to be appointed, which here assumes its full powers.

It goes without saying that the doctor will only summon the multi-disciplinary team when he is ready to operate.

The team will include at least one doctor (either a psychiatrist or a paedo-psychiatrist), a social worker or nurse, and a teacher or psychologist, all specialising in mental handicap. If necessary, the team must summon specialists in other fields. It will issue a report on the grounds for sterilisation.

The professionals in the expert team must necessarily not be the carers of the person concerned. Although it goes without saying that the multi-disciplinary team must interview all carers of the mentally retarded person - their opinion being of paramount importance -, it does, however, seem vital to recommend that this team should not include the mentally retarded person´s carers insofar as there would be concern that anyone too close to the interested party or those around them would not give an objective opinion.

The team must consider the risk of genetic transmission of the handicap, the ability of the mentally retarded person to develop and educate themselves and their capacity to educate a child.

The team will also be interested in the socio-educational qualities of the people around the interested party and their attitude towards procreation, as well as the teams of professionals on which they may rely when a child is born.

When the person lives as a couple, their partner´s view is of course of vital importance, in terms of their educational contribution towards any children with a mentally retarded partner.

Of course, the team must also consider the medical risks of pregnancy for the woman and the teratogenic effects on the embryo of any drugs she may take. It is not impossible for maintaining the health of the woman and/or the wellbeing of the foetus for there to be arguments in favour of sterilisation.

When it comes to such expert proceedings, the multi-disciplinary team must hear the mentally retarded person, all of the people around them (including professionals and *a fortiori* their treating doctor), plus any third party requesting sterilisation.

It will ensure that the mentally retarded person is assisted by their chosen person of trust, who will support them morally throughout the expert proceedings and at the time of any resulting surgery.

For certain members of the Committee, when the multi-disciplinary team´s report concludes that there is an opportunity for sterilisation, the doctor will be entitled to go ahead with it and assume inherent liability, whilst a negative report will oblige him, if he still believes that the request for sterilisation is justified, to seek appeal proceedings.

To prevent any dilution of medical liability, other members believe that it is appropriate to allow the doctor to go ahead with the sterilisation and assume sole inherent liability, whatever the opinion of the multi-disciplinary team. These members recommend setting up a national assessment committee analogous with the national Committee for assessing the Act dated 3.4.1990 on interruption of pregnancy, to which it will be compulsory to declare any surgery to sterilise mentally retarded people. They thus hope to optimise transparency of sterilisation practices, at the same time limiting abuse. Going ahead with sterilisation against the opinion of the multi-disciplinary team will incite care and doctors will only be inclined to take such a risk when they have major arguments to by-pass the opinion of the specialist team.
These members also fear that proceedings which oblige respect of the multi-disciplinary team´s decision, despite the imposition of the opportunity to take action, will incite doctors requested to perform sterilisation either to as far as possible engage in the procedure if there is any doubt as to the person´s capacity to grant their consent, or to contribute towards the team automatically by waiving their medical liability.

Therefore, the Committee believes, contrary to what is recommended by the Council of Europe in its Resolution dated 16.09.1992 on the rights of the mentally retarded and contrary to what the national Council of the *Ordre des médecins* states in its report dated 15.01.1994 that consulting a multi-disciplinary team is preferable to consulting a second or third doctor. It believes that adding a psychosocial dimension to the medical approach will enable better assessment of all of the psycho-educational capacities of a mentally retarded person for whom sterilisation is requested and better confront imperatives. The Council of Europe Resolution also foresees that the final sterilisation ruling should be passed by a competent court. In accordance with the report from the national Council of the *Ordre des médecins*, the Committee believes that *a priori* intervention of a competent court is inappropriate. It could further complicate proceedings and pointlessly traumatise the interested party. The Committee also believes that magistrates do not have the necessary expertise on the subject which would enable them to rule on the grounds of the conclusions of the multi-disciplinary team. So it only proposes to seek the intervention of the court *a posteriori*, to process any complaints. However, it repeats that in the absence of the mentally retarded person´s informed consent, it is impossible to sterilise them if they have not previously been declared legally incapable in light of the supposed serious reduction in their mental faculties.

The Committee also believes that the competent authorities must also ensure that they provide training on sexuality and parenting to young mentally retarded people to promote their informed participation in all of the choices which they are led to make both in terms of contraception and in terms of sexual relationships and parenting. Similarly, they must provide for economic, social, cultural and educational aid to mentally retarded parents to ensure optimum development of their children in their original family.

By virtue of its usually irreversible nature, sterilising a mentally retarded person, incapable of duly consenting to it, is only justified when it is noted that any other contraceptive method would not be particularly reliable, would be poorly tolerated or unpleasant, that the person really is at risk of procreating and that the indication has been made that it should be prevented.

It is essential that a mentally retarded person subject to sterilisation has reached an age at which they may judge that their mental state will remain deficient. Mental handicap usually in fact implies that maturing processes are slower and that development of relatively normal adaptation capacities will still be taking place after the age of 18. For these young people in particular, the existence of new contraceptive measures using effective implants for five-year periods will minimise the risk of unwanted pregnancies.

Officially or generally sterilising mentally retarded people is always unacceptable.

The opinion was prepared in the select commission 97/6, consisting of:

Joint chairperso chairpersonsmen	Jointreporters	Members	Member of the Bureau
R. Lambotte	P. Lardinois	F. Kruyen	L. Cassiers
F. Van Neste	M. Roelandt		

A member of the Secretariat: M. Bosson

Experts interviewed

- J.J. Detraux, Psychologist, Professor at the Faculty of Psychology and Education Sciences, Department of Psychology and Teaching of the Handicapped at the University of Liège.
- J.P.M. Denekens, Geneesheer, Docent Huisartsgeneeskunde, Hoofd van het Departement Geneeskunde aan de Universiteit Antwerpen (U.I.A)
- Representatives of the ANAHM:
  - T. Kempeneers, general secretary
  - E. Buysse, deputy secretary general
  - E. Oleffe, Vice-chairman
  - M-C. Bogaert, ondervoorzitter
- M. Mercier, Doctor of Psychology, Ordinary Professor of Psychology and Medical Psychology at the Faculty of Medicine at the *Facultés universitaires Notre-Dame de la Paix* in Namur (F.U.N.D.P)
- J. Delville, Doctor and graduate in Psychology, Head of Works, Master of Conferences and Director of the Medico-psychological Centre at the F.U.N.D.P. (Namur)

The working documents of the select commission 97/6 – request for opinion, personal contributions ofthe members, minutes of the meetings, documents consulted - are stored as Annexes 97/6 at the Committee´s documentation centre, where there may be consulted and copied.

The list of documents appended hereto forms an integral part of this report.

List of documents (only available in French)

1. *Demande d'avis de Mme Wivina Demeester du 10.09.97*
   Vraag om advies van Mevr. Wivina Demeester d.d. 10.09.97

2. *Note de travail aux membres concernant l'aspect juridique*
   Werknota aan de leden m.b.t. het juridische aspect

2a-c) *Articles du Code Civil (C.C.)*
   Artikelen van Burgerlijk Wetboek (B.W.)

3a-c) *Loi du 26.06.90 relative à la protection des malades mentaux et ses arrêtés royaux d'application du 18.07.91*
   Wet d.d. 26.06.90 betreffende de bescherming van de persoon van de geesteszieke en zijn uitvoeringsbesluiten d.d 18.07.91

4. *Rapport au Sénat relatif à la loi du 26.06.90 susdite – Doc. parl. Sénat (1988-1989) – N° 733-2*
   Verslag aan de Senaat i.v.m. de bovenvermelde wet d.d. 26.06.90 – Parl. Doc. Senaat (1988-1989) – Nr 733-2

5. *Ph. Lardinois «Images et usages de la nature en droit», publication des Facultés Universitaires Saint-Louis – 57 -, Bruxelles, 1993*

6. Problématique éthique en ce qui concerne la stérilisation des handicapés mentaux : Bibliographie – Propositions de Monsieur R. Lambotte
   Ethische problematiek betreffende de sterilisatie van mentaal gehandicapten : Bibliografie – Voorstellen van de heer R. Lambotte

7. *G. Hottois et M-H Parizeau, « Les mots de la bioéthique – Un vocabulaire encyclopédique » , Bruxelles, éd. De Boeck – 1993 -*

8. *M-Th. Meulders-Klein, »Considérations juridiques sur la stérilisation chirurgicale», Annales du droit 1967, p 4 à 54*

9. *M. Horimont – Dombrowicz, « Aspects bioéthiques et psychologiques de la contraception chez les handicapés », thèse de doctorat – Université de Liège – Département de Gynécologie-Obstétrique – 1987*

10. *« Levensbeëindigend handelen bij wilsonbekwame patiënten - Deel III : Ernstig demente patiënten » - Discussienota van de Commissie Aanvaardbaarheid Levensbeëindigend handelen - uit de koninklijke nederlandsche maatschappij tot bevordering der Geneeskunst in Utrecht*

11. *J. Denekens, «Sterilisatie en mentaal gehandicapten. Wie beslist ? », proefschrift – W.I.A. – Departement Geneeskunde – 1992*

12. *V.V.J.G.-dossier : « Een ethisch debat over sterilisatie van personen met een mentale handicap. » bestaan uit 13 documenten – o.m. – Doc. 6 : « Les cahiers du Comité Consultatif National d'Ethique pour les sciences de la vie et de la santé, N° 8, p 3 à 23, relatif à la contraception chez les personnes handicapées mentales »*

13. Réponses aux trois questions posées à chacun des membres de la commission 97/6
Antwoorden op de drie vragen gesteld aan de leden van de beperkte commissie 97/6
13 A : document de travail R. Lambotte
13 B : werknota F. Van Neste
13 C : document de travail Ph. Lardinois

14a Avis du Conseil National de l'Ordre des Médecins du 13/06/81 « Stérilisation des débiles mentales », Bulletin du Conseil de l' Ordre des médecins - n°29

14b Avis du Conseil National de l'Ordre des Médecins du 15/01/94 : « Stérilisation des Handicapés mentaux », Bulletin du Conseil National de l'Ordre des médecins - n°64

15. J.P.M. Denekens, « Sterilization of incompetent mentally handicapped persons » (doc. de base à une intervention du Conseil de l'Europe).

16a J. Detraux « Handicap mental : une définition » (Doc. de base à l'exposé de Mr J. Detraux, expert)

16b J. Detraux, « Sexualité Procréation des Personnes Handicapées », dossier du XVI° Colloque A.I.R. du 24-25/10/97 à Besançon

16c Bibliographie proposée par Monsieur J. Detraux, expert

17. « Mesures de protection à l'égard des personnes qui souffrent de graves troubles de Santé », (Doc.de base à l'exposé de Mr Ph. Lardinois)

18. J. Gillerot, « Stérilisation des handicapés mentaux » (approche génétique et quelques chiffres) (réponse écrite à des questions posées par la commission)

19a-g Données chiffrées produites par l'Agence Wallonne pour l'Intégration des Personnes Handicapées (AWIPH)

20. J.L. Chapellier, «Sexualité des personnes handicapées : Quels repères déontologiques pour l'éducateur ? » (doc. de base à la conférence du 07.11.97)

21. Ch. Lavigne, « Entre Nature et Culture : la représentation de la sexualité des personnes handicapées mentales » in les cahiers du CTNERHI n° 72 – 1996

22. Bibiographie en matière de sexualité et handicap – proposition de l'AWIPH

23. « La stérilisation » avec exemple de protocole de validation, article paru dans le bulletin de l'UNAPEI de Mars 1995

24. Doc. de base à l'exposé juridique de Monsieur Ph. Lardinois

25F J.P.M. Denekens, « La stérilisation d'handicapés mentaux 'incapables de prendre des *décisions' » (Doc. de base à l'exposé de Mme Denekens, expert)*
25N J.P.M. Denekens, « Sterilisatie van 'beslissingsonbekwame' verstandelijke *gehandicapten »*
(basisdoc. voor de uiteenzetting van Mevr. Denekens, externe deskundige)

26F « La stérilisation des personnes mentalement handicapées : le point de vue d'une association de parents », Doc. de l'A.N.H.A.M. – fév. 98
26N « Sterilisatie van personen met een verstandelijke handicap : een visie vanuit een ouder- en familievereniging », Doc. van A.N.H.A.M. – feb. 98

27. J. Delville et M. Mercier, « Sexualité, vie affective et déficience mentale » éd. De Boeck

28. J. Delville, « Procréation et déficience intellectuelle : quelles interventions », article à paraître in DIEDERICH « La Stérilisation des personnes déficientes mentales »

29. M.A. Feldman, N. Walton-Allen,
« Effects of Maternal Mental Retardation and Poverty on Intellectual, Academic, and Behavorial Status of School-Age Children » in American Journal on Mental Retardation 1997, Vol. 101, N°4, 352-364

30. Dr. G. Van Hove, « Ouders met een verstandelijke handicap : een stand van zaken » (uitgeverij Acco Leuven – tel (016)23.52.64) – onderzoek dat naar heel recente studies (o.a. 96/97) verwijst

31F Classification OMS en matière d'arriération mentale.
31N Classificatie van de WGO inzake mentale achterstand

32. J. Delville « Procréation et déficience mentale : quelles situations ? quelles interventions ? » Doc. de base pour le colloque « Déficiences intellectuelles et parentalité » à Lille 5-7 novembre 1997

33. J. Delville, « Expériences d'accompagnement de personnes déficientes mentales autour du thème de la parentalité », Doc. de base pour le colloque de Lille, 5-7 novembre 1997, op cit. N° 32

34N « De verklaring van de rechten van de patiënt », Tijdschrift van de Nationale Raad van Geneesheren, Nr 77

34F « La déclaration des droits du patient », Bulletin du Conseil National de l'Ordre des Médecins, N° 77

35. Colette – Basecqz, S. Demars, M.-N. Verhaegen, « L'enfant mineur d'âge dans le contexte de l'activité médicale », Revue de Droit de la Santé – Tijdschrift voor Gezondheidsrecht, 1997-98 – 3

36. A. Bernard et D. Siroux, « Réglementation de la stérilisation chez les personnes handicapées mentales à l'étranger », C.C.N.E. n°8, 1996

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39. R. De Guchteneere, « A propos de la loi allemande sur la stérilisation », éd. de la Cité chrétienne, Bruxelles.