Opinion on the contraception for the mentally handicapped. Report.

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Opinion

Contraception for mentally handicapped people raises a great many issues, related to their condition, which varies with individuals and circumstances, and to the respect of their rights. The problem is so complex that there is a tendency sometimes to restrict it simply to a discussion on whether sterilisation is or is not advisable. Physicians in receipt of requests for sterilisation on behalf of these individuals from their families or from institutions, have asked the National Consultative Committee of Ethics to express an opinion. They are concerned about the acceptability of such requests in particular as regards the present state of law. It is true that article 16-3 of the *Code Civil* only accepts an injury to physical integrity if there is therapeutic necessity and on the condition that the person concerned has consented to it. The therapeutic justification of a procedure essentially aimed at contraception is highly disputable. In any case, mental deficiency cannot be the sole justification. Furthermore, free and informed consent of the mentally handicapped for a medical or surgical procedure of any kind is in itself a problem. The authorities are also involved in the issue since it is their responsibility to clarify the situation and to provide a regulatory framework to prevent abusive action directed at the mentally handicapped, young women in particular.

In order to judge whether sterilisation is appropriate it has to be viewed in the general context of various contraceptives practices. To be valid, the discussion must take into account technical progress, in particular hormonal contraception.

Available techniques are identical to those which can be offered to the general population of child-bearing age. Most of them are for women and so it is mostly mentally handicapped women for whom contraception is on offer.

The specific problem which arises is to define the parameters of decision on a case by case basis, whilst being alert to the conditions in which the choice of contraception is to be made. The choice must necessarily take into account, on an equal basis, constraints due to medical and/or biological considerations, and the specific characteristics of the history, behaviour, and environment of each mentally handicapped individual.

An important aspect of the situation taken as a whole is to know who originated the request for contraception and why. It is not always clear that the request is based on a desire for

actual sexual activity expressed by the mentally handicapped person. Therefore, the first priority is making sure the person concerned agrees. Indeed, consent is a principle which applies to all methods of contraception and there is the problem of knowing whether a woman understands what she is doing (by taking the pill) or what is being done to her (fitting a intrauterine device - IUD).

Contraceptive methods are mostly reversible and can be classified in increasing order of medical difficulty :

For a woman in harmony with her surroundings (family or institution), conventional methods of oral contraception (oestrogen and progestogen) may be offered since it can be assumed that someone will be in charge of making sure that the pill is taken regularly as is often the case for any other kind of medication being taken by the mentally handicapped.

If daily administration is a problem, injections of slow release progestogens may be proposed. In certain cases, insertion of an IUD may be appropriate.

The possibility of contraceptive and medical follow-up being available on a regular basis plays an essential role in the choice of the most appropriate method for a given case. This observation leads the Committee to underline the great social inequality of the mentally handicapped as regards possibility of access to quality follow-up.

Sterilisation is sometimes said to be a particularly appropriate choice of contraception for the mentally handicapped. And yet, this method is almost always aimed at a permanent suppression of reproductive functions. Although progress in surgical procedures is such that reversibility is now a possibility in a certain percentage of cases, further surgery is required to achieve it, and success cannot be guaranteed for an individual, so that the decision to sterilise is far from trivial.

Sterilisation for the mentally handicapped is a very emotional subject for all sorts of reasons which frequently are related to the specifics of each case and to the history of the family concerned. Furthermore, since the history of sterilisation has frequently crossed the path of eugenic policies in their most regrettable aspects, the very notion of sterilisation bears a heavy negative ideological burden. It is true that such sterilisation procedures were performed before the introduction of reliable hormonal methods of contraception, but this cannot justify the questionable, or even clearly abusive, nature of a large number of these interventions.

The CCNE considers that a request for sterilisation made by third parties on behalf of a mentally handicapped person is not acceptable if there has been no prior consideration of other contraceptive options. Before third parties can consider contraceptive sterilisation, it would seem essential that certain conditions should be observed as follows :

- Incapacity of the individual concerned must be defined by thorough and multidisciplinary evaluation. Care must be taken to make sure that the state of health and behaviour of the individual is not likely to improve.

- The person concerned must be potentially fertile, sexually active, and be at least about 20 years of age. In all cases, an effort to consult him/her must be made.

- Sterilisation should only be considered if proof is given that no other form of contraception can, in practical terms, be used by the individual concerned. If that is the case, the most potentially reversible technique of sterilisation should be used.

In order to guarantee the most equitable conditions for evaluation and decision making for each particular case , the CCNE suggests that the following steps and decision making procedures should be followed :

- ask other consultants besides the attendant physician to inquire into the request made by the person concerned or the entourage ;

- ask those who request sterilisation to explain fully their motives and justifications ;

- rather than delegation of authority, establish a system of collective decision- making with very strict procedures (and if necessary, in case of conflict, a possibility of appealing to the courts) so as to offer maximum protection of the rights and interests of the disabled ;

- make sure that follow-up of the person concerned is provided, whatever method of contraception or even sterilisation is finally adopted.

A very small number of specialised centres must alone be allowed to practise such operations and the micro-surgeons considered to be the most competent should be responsible.

The CCNE underlines the importance it attaches to collective decision-making. Indeed, evaluation of a request for sterilisation is too complex a task and too serious a decision for a single person to undertake. This kind of evaluation requires such expertise and entails so much responsibility that it seems essential for the task to be given to a commission composed of experts in the field of mental handi including physicians, legal advisers , and social workers. Independent status for the commission as regards the family or guardians of the mentally handicapped is also of paramount necessity : it is clear that those making the decision must not be both judge and party to the decision.

We must point out that sterilisation procedures for those incapable of consent most frequently concern mentally handicapped women. The aim is to protect them from pregnancy. It should not be forgotten however that this in no way protects them from sexual aggression. The problem of violence perpetrated on the mentally handicapped goes beyond the limited problem of contraception and therefore requires separate and specific response bearing on the entourage and environment of the mentally handicapped.

In any case, sterilisation is not the only, nor even the best, contraceptive policy for the mentally handicapped. Most mentally handicapped women can use reliable hormonal contraception. However, for any form of contraception, reversible or otherwise, the principal difficulty remains validity of free and informed consent. Furthermore, prescription and follow-up of contraceptive programmes should not be a pretext for abusive control of a mentally handicapped person's activities, sexual or otherwise.

The CCNE further points out that the specific needs of the mentally handicapped for contraception must not obliterate their need for follow-up and assistance by competent professionals when it so happens that they wish to have a child and favourable conditions prevail.

Report

Contraception for the mentally handicapped is a problem for which no ready-made solution can ever be found. Too much depends on their condition which varies with individuals and circumstances (1). These are highly complex questions into which, inevitably, enters the matter of respect of rights. Furthermore, the request for contraception is almost always made by a third party which raises serious issues demanding in depth ethical consideration.

The question of adequate contraceptive protection obviously concerns to the highest degree the mentally handicapped themselves. It is of particular concern to young girls and women who run the risk of becoming pregnant and giving birth to a child which they may feel unable to look after or which they are in fact unable to take care of despite what they may

believe to be the case. Families are also worried for the same reason since they have to face the fact that their child has reached the age of puberty, and therefore of sexuality and reproduction, but may in some cases be unable to take pertinent decisions on these subjects. Families also have fears about the future of the unborn child. In a small number of cases children will be born with identical retardation, but more often than not, perfectly normal children will be born and may be exposed to shortcomings in their educational, emotional, and intellectual environment if they are brought up by their parents in spite of any help that can be given by the family or by appropriate social services. Otherwise, they may run the risks inherent to adoption.

On a practical basis, families and medical staff have to find appropriate solutions for the day to day problems of mentally handicapped individuals depending on their circumstances, past and present; their abilities, their environment, and also on the validly expressed will and opinion of the person concerned. However, the complexity and intricacy of these problems are such that there is sometimes a tendency to restrict the discussion to the sole issue of sterilisation.

Physicians who were asked by families or institutions to perform sterilisation procedures on the mentally handicapped, have turned to the National Ethics Committee for advice on the subject. They are hesitant about whether such procedures are well-founded and about their status in the light of present legislation. Indeed, article 16-3 of the *Code Civil* only accepts prejudice to physical integrity if there is therapeutic necessity and if consent has been duly given by the person concerned. Therapeutic justification for a procedure performed essentially for contraceptive purposes is highly debatable, and in any case, mental retardation cannot on its own be that justification. Furthermore, free and informed consent from the mentally handicapped to any medical or surgical procedure is in itself a problem. The authorities are also implicated in this issue because it is their task to clarify the situation and define a regulatory framework to avoid any abusive action inflicted on mentally handicapped persons, young women in particular.

In order to judge whether sterilisation should or should not be performed, the first step has to be setting the problem in context, i.e. considering the whole question of contraceptive methods and also of their aims. A valid argument needs to take account of technical progress in particular as regards hormonal contraception.

Deficiency and handicap

There are as many kinds of retardation and handi as there are handicapped individuals. The extreme difficulty of defining a deficiency and the handi it engenders must be underlined at the outset. A multiplicity of approaches is required to meet this challenge, using both qualitative and quantitative data, taking into account the nature of the retardation, its main characteristics, history, prognosis, whether it is genetically transmitted or not, and global severity not just in medical terms but also from the point of view of social interaction. Entirely different conceptual approaches for the definition of a mental handicap will be used by the various disciplines : neurology, biology (biochemical and/or genetic), behaviourism, psychology, sociology, etc. In practice, approaches have to adapt to each individual case. It would probably be absurd to try and approach such problems globally since this would inevitably lead to a denial of the amazing potential diversification of individuals although they may be affected by the same syndrome. To take but one of the best known examples, Down's syndrome, there is the greatest variety of severity in a population suffering from the disorder.

Specialists have been trying for a long time to tackle the difficult problem of producing quantitative evaluation procedures for measuring mental retardation. Results are usually expressed in terms of IQ (intelligence quotient). The result must be taken into account but with extreme caution. Many external factors may bias considerably the subject's performance in test conditions and invalidate results to some degree. Only highly qualified

specialists can approach a global evaluation of a mentally handicapped person, taking into account not only the I.Q. but also motor skills, sensory defects, mental processes, emotional factors, etc. Nor should it be forgotten that such tests are most questionable when there are major cultural differences between populations to which belongs the subject being tested and those for which the tests were designed.

The above must also take into account that mental retardation cannot ever be defined independently of its context. A definition of retardation cannot ignore existing psychological and social dimensions, because its severity greatly depends on the quality of social, familial, educational, and medical support which is given. In some cases, the environment can be an aggravating handicap. For a given handicapped person, there are innumerable social and family possibilities which range from an "ideal" environment to rejection. For an environment to be adapted to retardation - not forgetting the risk of social exclusion - it needs to be able to reduce the cognitive, emotional, and social consequences of retardation to the greatest extent possible. The sorrow of relations must also be considered and clearly the family's feelings in the presence (or absence) of the patient, their reactions to events which may be viewed as success or failure, are part of the factors which determine the quality of various management strategies.

An image comes to mind here. It applies mainly to constitutional abnormalities which are present since birth or even since conception. The image is of childhood defined as a period of time when there has to be a state of dependence on the adult environment. For a normal child, the whole range of social and family responses exists, from optimal to worst scenario. For a disabled child, born with a difference, it is as though the deficiency prolonged into adulthood to varying degrees the situation of dependency of a child with all the needs that such dependency entails : physical, educational, emotional, relational... The needs of a mentally handicapped person are seen for their major part as being in quality identical to those of childhood. An essential difference is that a child develops towards autonomy whereas the mentally handicapped will never (except for some rare cases) become totally free of the dependency generated by their deficiencies. In some cases, the rule is inexorable aggravation of the patient's condition.

But depending on the environment, identical failings are catastrophic or fully accepted. What matters is competence and tolerance which gives a relative dimension to the concept of handicap. It is too frequently forgotten that love enters into this equation. One still sees many examples of institutions which expect the mentally retarded to adapt to them because they are incapable of adapting to the needs of the mentally handicapped.

Mentally handicapped individuals and sexuality

There is little difference between the sexuality of the mentally handicapped and the sexuality of the population at large. Firstly, as regards sexual maturation, observing the vast group of early or even constitutional deficiencies, those which interfere with the physiological onset of puberty are rare (2). In France, the age at which girls experience their first menstrual cycle ranges from 10 to 13 (average age being 12 and a half). In boys, puberty comes a little later, between 12 and 15. So in fact adolescents - handicapped or not - are very young when they become fertile. These facts are worthy of note for anyone who needs to reflect on the method of contraception which one can offer to the mentally handicapped, especially girls.

With a minimum of encouragement these girls are ready to speak of sexual desire but also of desires or even plans to give birth. It sometimes happens that this is the only project to which they seem to cling because they hope, or know, that this project is one which they can achieve in spite of their handicap. Physicians who attend adolescents observe that some young mentally handicapped girls speak of such matters in a more animated way than their "normal" contemporaries. They speak more directly and are less inhibited.

As regards the sexual behaviour of the mentally handicapped, it differs very little from what can be observed in a non handicapped population. The main difference is that education about sex does not necessarily lead to self-regulation in the mentally handicapped. In contrast, one of the characteristics of sexual experience in the mentally handicapped, particularly young girls, is violence and sexual abuse inflicted in an institutional or familial environment or during runaway episodes, such as rape, incest, or indecent exposure. This is the most visible abuse since pregnancy and requests for sterilisation frequently ensue . (3) However, though sterilisation may solve permanently the problem of unexpected pregnancies, it in no way solves the problem of sexual violence nor of more general sex-related issues. All too frequently, it is thought that the most logical solution in view of the severity of disability or because of institutional rules, is to prohibit sexual activity altogether but this again leads to violent episodes. For these reasons, in some cases discerning efforts are made to facilitate the formation of mentally handicapped couples.

Pregnancy and delivery in mentally handicapped women are also occasions for logic forcibly imposed on them through the insistence of institutions and families with the support of medical staff. Abortions - which are only elective in name - are sometimes forced on them and are all the more traumatic since signs of pregnancy are frequently tardily noticed in the mentally handicapped. Pregnancy itself and even more so delivery can be traumatic if the woman does not receive appropriate assistance.

Preventing pregnancy ?

Some minor or mild retardation in young women is entirely compatible with pregnancy, delivery, and motherhood. For that matter, a good number of mild deficiencies are never treated medically and even less institutionally. However, for a large number of women whose deficiencies are more severe, preventing pregnancy is a constant preoccupation for relations and institutions. A satisfactory state of equilibrium is in itself difficult to achieve and requires a great deal of patience, incessant effort, competence, attention and authentic sacrifices. It seems legitimate to wish to reap the benefits of all these efforts by maintaining the balance of any handicapped woman who has been fortunate enough to benefit from such successful attention. It cannot be denied that giving birth might well upset it durably.

Little is known about the possibility for a mentally handicapped woman to take on a parental role in a structured society such as our own. Such an evaluation can never be made without taking the father, if he is known, into account, nor without referring to the attitudes of family and environment. However affectionate the father and mother, the question arises of how far along the process of education a mentally handicapped couple or a mentally handicapped single mother can manage without the help of others. The family and environmental context have to be part of the evaluation and are revealing as regards the major inequalities in the life of a mentally handicapped couple who may or may not readily obtain acceptance of their wish to have a child.

The future life of a child born in these circumstances is a legitimate preoccupation. Indeed, the issue must be faced. Either the child will live with the parents (which is the case, according to an enquiry carried out by the National Union of Associations of relatives and friends of the mentally handicapped (UNAPEI (4)), in a little less than half of the cases. However, permanent assistance from family or institution will frequently be required. In these circumstances, what kind of relationship will build up between child and parents, what kind of identity model will the parents provide for their child, what kind of education will they be able to supply, will they be able to stimulate the child's development and give assiduous care ? Or the child is taken away from parental care and raised by grandparents, or brought up by foster parents in view of adoption (which is presently the case for more than half of the children born to this kind of family, according to the enquiry mentioned previously). How will this early separation affect the child. What will be the impact of a

possible disclosure of origins ? Nor can it be forgotten that a certain number of known deficiencies and disorders present higher genetic risks for the future child.

The mentally handicapped parents also face a trying time. If it is thought that the child can live with them, they may still find it difficult to bear the full burden of responsibility at all times. The couple's independence, dearly won, may be compromised or even destroyed by the complex tasks that beset parents. As is the case for all new parents, their equilibrium may be severely put to the test by the burdens of child rearing which in their particular case may be incompatible with their condition. If the child is removed from their home, frustration will be all the more severe if there is some delay, particularly for the mother. She will have given birth to the child, held the baby in her arms, and become attached. The departure of a child may turn out to be a more severe trial than wanting a child and not having one.

The aim of the UNAPEI enquiry was to encourage revision of some false assumptions and it underlined that situations were very complex and particularly that there was a very wide diversity of cases. The children included in the study had very different circumstances depending on whether one or both parents were handicapped and on the severity of those handi ; whether they lived as a couple or were married ; and whether they were effectively and affectionately helped by their entourage. Although a certain number of cases are an encouragement not to totally exclude at the outset the possibility for a mentally handicapped woman to successfully withstand the trials of pregnancy and shoulder the responsibilities of motherhood either with a partner or with the help of her family, there are also many arguments in favour of providing means of contraception for the mentally handicapped. In this case, medical follow-up and adequate contraceptive counselling must be planned for.

Choosing a method of contraception

Theoretically, methods available are identical to those offered to the general population of child bearing age. Most of these methods are for women, and although they are not alone in producing children, they are alone when it comes to bearing the consequences of faulty or absent contraception. As is the general case, contraception for the mentally retarded is mainly for women.

No choice of contraceptive method can reasonably be offered if there has not been a systematic analysis of the case of each woman and of her partner, regular or occasional, handicapped or not. For a handicapped person, such an analysis must take into account not just the characteristics of his/her deficiency, but also the concrete expression of sexuality in the context of their life style : life as a couple (5), in the family or in an institution or a mixture of both. The extreme variety of circumstances is a factor but so is the quality of follow up given by the entourage (stable, fraught with problems, fragile). Any method of contraception requires follow-up in such patients and one of the major difficulties is preventing such follow-up from becoming abusive control over the individual. A complete analysis of the situation is an absolute necessity so that a choice can be made of one of the available methods of contraception.

The problem which arises is how to define the parameters of the decision on a case by case basis and keeping a close watch on the conditions in which a contraceptive choice is made. Medical and/or biological factors, such as hypertension, obesity, epilepsy, congenital heart disease, or hyperlipidemia on the one hand, and case history including behavioural and environmental factors for each mentally handicapped person concerned on the other hand, are some of the constraints - sometimes cumulative - which the choice of contraception must take into account. Although the choice is made on the basis of technical considerations, the ethical dimension is always present. Any technical choice always includes a moral option as to the best course to follow in view of the constraints of a given situation.

An important aspect of the situation taken as a whole is to know who originated the request for contraception and why (6). It is not always clear that the request is based on a desire for actual sexual activity expressed by the mentally handicapped person. In certain cases, it may in fact be an expression of anxiety on the part of parents faced with giving education about sex to a child who has reached puberty. Or it may be a wish to take "preventive" measures of control over the body of a child which no one else is ready or able to undertake by other means (for example when contraception is a mandatory pre-condition for entry into an institution). In fact, the characteristics of the behaviour of the mentally handicapped in many cases depend as much on relations with their environment as on the specific nature of their deficiencies. In other words, a dual dimension - behavioural and social - is to be considered.

This is why offering a choice of contraceptive methods must give priority to the actual wishes of the handicapped person, must also discover with what other partners the choice is being negotiated, and how to go about making sure that the person concerned consents to it. Consent is indeed a notion which applies to any method of contraception and the problem is to find out whether the mentally handicapped person, a woman more often than not, understands what she is doing (taking a pill) or what is being done to her (fitting an IUD).

The possibility of enjoying regular contraceptive and medical follow-up also plays a major role in the task of finding the best possible method for a given case, and this needs to be underlined. This observation encourages the CCNE to emphasise the huge social inequality in possibilities for the handicapped to obtain good medical follow-up, in part due to lack of motivation and training of medical staff for dealing with difficult patients whose medical and social needs are not commonplace.

Contraceptive methods are mostly reversible and can be classified in increasing order of medical difficulty. However, in each case possible drawbacks must be weighed against the special circumstances of the life of the individual and ease of access to medical follow-up which ensures good health and successful use of the method.

If there is no particular medical problem (7), the following contraceptive methods are available : local methods : diaphragm, sponges impregnated with spermicide ; condoms, combination oestrogen and progestogen formulations (the pill), oral contraception for "the day after", intrauterine devices (IUDs), delayed action progestational medication.

Unexpected pregnancy is however a possibility with any of these methods. In such cases, a decision to abort may sometimes be taken. However, repeated abortion cannot be accepted as a contraceptive solution.

How can an attempt be made to rationalise the choice of a contraceptive for a mentally handicapped woman (8) in view of the multiplicity of factors to be considered ?

When good quality problem-free supervision is available, combination oral contraception is a possibility. Unless significant behavioural disorders interfere, a close relative or a carer in an institution can make sure the pill is taken on a regular basis. For this type of contraception, a pill particularly suited to the needs of the mentally handicapped is again being marketed. It consists of an ordinary combination of oestrogen and progestogen but administration is continuous because instead of being prescribed in cycles of 21 days of use and 7 days without, it is taken daily since there are 21 "active" pills, and 7 placebos.

If no such assistance is available, two other possibilities may be discussed :

- One option is the use of depot medroxyprogesterone acetate in 150mg injections every three months. This slow acting substance is used as a contraceptive by several million women (10 to 30 million according to some evaluations) in more than 90 countries world wide. For that matter it has also been used for more than 20 years for other indications

such as metastatic endometrial cancer or some renal cancers. There are no known iatrogenic metabolic or oncongenic effects. Some bleeding, which can be frequent, in the first few weeks of administration seems to be the only drawback, but it may make acceptance difficult. In the long term, amenorrhea may ensue (9). As soon as contraception ceases, fertility returns (10) (11). The Food and Drug Administration authorised use of the substance as a contraceptive in the United States in 1992.

The obligation to perform quarterly injections does not seem to be an argument against the technique since it is most desirable to provide medical and/or gynaecological follow-up for these patients independently of contraception, and this is frequently neglected in France.

- A second possibility if high quality supervision is unavailable on a daily basis, is inserting an intrauterine device (IUD). IUDs are not considered a good choice for the nulliparous in the general population since an IUD can be the cause of tubal infection, which in turn is a frequent cause of infertility.

Sterilisation considered as a means of contraception

In spite of all these contraceptive options, parents and/or entourage may feel helpless when the mentally handicapped female patient's behaviour, and her sex life in particular, is uncontrollable. In the circumstances, no satisfactory contraceptive follow-up can be provided and if they fugue they may be vulnerable to violence and become pregnant, unless they are infertile (12). Difficulties encountered for contraceptive follow-up may be compounded by multiple pregnancies, the outcome of which is a matter for discussion with the patient. Those in charge of such mentally handicapped women tend to favour sterilisation, generally by occluding the tubes with clips.

Sterilisation is sometimes seen as a good contraceptive choice in the special case of the mentally handicapped. It may well seem to be the easiest way of solving difficulties which, in some cases, are due to inadequate response by families and institutions as regards education about sex. However, sterilisation compromises or even destroys reproductive capacity for these women and the possibility of their behavioural improvement is not always considered. Sterilisation is a serious decision.

Is sterilisation reversible ?

Contraceptive sterilisation may be masculine (vasectomy) or feminine (tubal section, ligation, occlusion with clips) (13). Vasectomy is a simple and speedy procedure which requires only local anaesthesia. Usual techniques for closing the vas deferens rarely fail (0 to 2.2% pregnancy rate for female partners) (14). Reversal is possible, but the various micro surgical techniques used for reanastomosis are much more difficult and results are uncertain (15).

Section, ligation or occlusion of oviducts is a more complex procedure requiring general anaesthesia. There again, failure is unusual (pregnancy rate is about 1% after surgery). To reinstate procreative capacity, further complex microsurgery and general anaesthesia are required. A recent review of the results of tubal reanastomosis in an experienced hospital environment (16) gives a pregnancy rate of 60 to 80% at two years. These figures are similar to those in earlier studies reviewed by the author.

However, one cannot honestly put forward the reversibility argument. Although progress in surgical techniques makes it a possibility, it still requires further surgery for which it is not possible to guarantee success in individual cases. It must also be stated that in the special case of the mentally handicapped, sterilisation almost always aims to suppress reproductive functions permanently.

For these reasons, tubal occlusion with clips (17) is a decision which should only be taken after strict evaluation of the circumstances motivating the request, lest at a future date, a second surgical procedure has to be considered to recover - if possible - a state of fertility. If such a step is taken, it is preferable to recognise that the objective is permanent surgical sterilisation.

For that matter, medico-surgical and obstetrical literature on reversal is very discreet and what data can be found is almost entirely devoted to women who are volunteers and do not suffer from any mental handicap. It does not, therefore, throw any light on the specific problems of mentally handicapped women, nor on the reasons which might justify sterilisation, nor on conditions for decision-making and operative procedure. On the contrary, such problems seem to be ignored although it would be very desirable to examine them carefully.

Sterilisation of the mentally handicapped : a grave decision

Sterilisation of the mentally handicapped is an extremely emotionally charged subject for a variety of reasons which, frequently, are specific to the history of their families. Furthermore, the very notion of sterilisation bears a heavy ideological burden because its history and that of eugenic policies in their most reprehensible aspects have frequently merged. It is true that such sterilisation was performed before reliable hormonal contraception existed, but this is no justification for the questionable or even clearly abusive nature of many of these procedures.

The previously mentioned problem of some mentally handicapped women whose sexual behaviour may lead parents or professional staff to propose tubal ligation should be seen in this context. To obtain consent, or even take into consideration their agreement or their refusal, is considered an impossibility because of their handicap. Such sterilisation is designated in the medical literature under the name of non consensual or non elective sterilisation (18). Eugenic sterilisation is another expression used to designate sterilisation specifically aimed at preventing transmission of a deficiency thought to be hereditary. It could be used just as appropriately in the case of individuals who know that they are carriers of a serious disease and themselves choose to put an end to their reproductive capacities.

Such situations highlight the extreme complexity of available options. There is, on the one hand, the difficulty of defining a deficiency and taking into account its consequences, and on the other hand the even more important consideration of society's concern for the respect of the rights and of the person of the mentally handicapped. The full significance of this respect implies costs for society which cannot always be fully assessed but nevertheless exist since vigilance and competence are required to hear and take care of the handicapped.

A brief reminder of the history of sterilisation as it was practised in the early years of this century serves to put into perspective the present day issue of sterilisation of the handicapped.

Sterilisation of the mentally handicapped. Historical summary.

Non voluntary surgical sterilisation of the mentally handicapped, men and women, was a common practice world-wide, particularly during the first half of the twentieth century. The practice started at a time when the very concept of mental deficiency was very vague and designated individuals in a broader category of the population considered to be "socially inapt" (the poor, criminals, alcoholics, those afflicted by sensory or motor infirmities, the mentally ill,). Sterilisation was one of a range of measures such as segregation of the sexes

in institutions, ban on marriage, restricted immigration, etc. justified by eugenic, social and economic arguments so as to reduce the proportion of disabled people in the population. They were based on the conviction that some conditions and behaviours such as epilepsy, "imbecility", or even violence and delinquency, were hereditary pathologies. Countries had preferences for one or other of these measures or a combination of several of them. In some cases, there were also measures taken to encourage the so-called upper classes to have more children.

It was in this context that eugenic sterilisation laws were voted in certain countries. In the United States, the first of these laws was passed in 1907 by the State of Indiana. Fifteen other states followed suit with similar laws in the next ten years. Although on more than one occasion, such laws were opposed, a committee of the American Neurological Association (19) reported in 1936 that 27 States (20) had passed such laws. In a 1927 decision by the Supreme Court, Buck vs. Bell, to judge whether a 1924 law passed by the State of Virginia was constitutional, eight of the nine judges were of the opinion that a State could legitimately order sterilisation for eugenic reasons, that this possibility did not exclude recourse to defensive action in a court, and that sterilisation did not constitute a form of "cruel or unusual punishment" (21). In certain States, the sterilisation laws were fortunately not always applied and in the 50s and 60s a great many of them were abrogated. It is estimated however that more than 60 000 people judged to be socially inapt were sterilised on the basis of these laws, mostly in Virginia and California (22).

In Canada, a law on "eugenic sterilisation" was voted in the province of Alberta in 1928 (Alberta Sterilization Act). During the 44 years in which the law applied, 2822 sterilisation procedures were officially authorised. The law was invalidated in 1972 owing to pressure from jurists and geneticists who argued that in a great many of these cases genetic risk had not been proved and that involuntary sterilisation was a patent violation of human rights (23). The Commission for the Reform of Canadian Law reported that the application of the law had led to a great deal of abuse in particular as regards ethnic and socio-economic bias in a number of decisions.

There is good reason to believe that the excesses of the nazi sterilisation programmes which started in 1934 had no influence whatsoever on North American practices before the 1950s (24). On the contrary, there was some interest in the German law and measures adopted to enforce it, and it was even admired (25). Excesses were committed in many other countries, with or without the benefit of the law (Switzerland, Sweden, and other Nordic countries in particular), and it was in reaction to this state of affairs that commissions were created, discussions took place, and various steps were taken to erect legal barriers to such practices (26). The Parliamentary Assembly of the Council of Europe, in a recommendation on psychiatry and human rights adopted on 23rd March, 1994, specially requested that no irreversible injury should be inflicted on the reproductive capacity of individuals.

Nevertheless, in South Africa, the 1975 Abortion and Sterilization Act declares licit surgical sterilisation of the mentally handicapped, and in 1989, the official number of such procedures was given as 1817 cases. In a study carried out in the Groote Schuur Hospital where 291 of them were referred, 37 were "white", 233 were "coloured persons", and 21 were "black". None of them were considered fit to give free and informed consent. It was found appropriate to sterilise 79% of these cases, i.e. 231 people.

In China, a law whose purpose it was to "improve the quality of neonates" was passed in 1994, despite protests from many international sources. The law advises, *inter alia*, "deferment" of marriage if one of the future spouses suffers from mental disorders or sexually transmitted diseases ; and contraception or even sterilisation if one of the spouses has a severe genetic affection. The law also imposes an obligation on physicians to advise abortion if they find that the foetus has deficiencies or severe genetic disorders (27).

However, the world over, the introduction of hormonal oral contraception has contributed to modifying contraceptive practices for mentally handicapped women. Improved understanding of hereditary transmission of mental deficiency (which in fact concerns only a

minority of the mentally handicapped) has also contributed to discredit justification advanced for sterilisation. But this reversal of attitudes mainly reflects a move to reject eugenic ideologies which prevailed in some countries right up to the 50s. At the same time, more thought was given to the rights of the disabled and social services were improved to take care of their specific needs in everyday life and their possibilities of gainful employment.

The situation in France : the law and the code of deontology

The only reference to sexuality and the disabled is in the *Code Pénal,* in which it is written that if the victim of sexual violence is disabled, this constitutes aggravating circumstance as regards sentence passed on the aggressor(s) (28). Furthermore, though not in writing, the right to sexual activity is recognised de facto for minors (defined as incapacitated by law) through their right of access, with no age limitation, to anonymous free-of-charge contraception (29). There is no mention of any restrictive measure aimed at the mentally handicapped.

It should also be pointed out that an unmarried girl, if she is under age, needs authorisation from "at least" one parent to undergo elective induced abortion. In contrast, if, whatever her age, she is delivered of a child, she enjoys immediate and full parental authority as soon as the child is born.

As for sterilisation, there is no specific article of law on the subject. However, article 16-3 which was introduced into the *Code Civil* by law n° 94-653 dated 29th July 1994, states : "The integrity of the human body cannot be impaired except if there is therapeutic necessity. Prior consent of the person concerned must be obtained except if his/her condition makes it necessary to practise a therapeutic intervention to which he/she is not able to consent". Article 222-9 of the new *Code Pénal*, which sanctions the offence described as "violence resulting in mutilation or permanent disablement", may apply to surgical intervention performed without therapeutic necessity. However, since a decision taken by the *Cour de Cassation* (Supreme Court of Appeal) in 1937, in which medical staff were not involved, no court proceedings were ever initiated, either at the request of those concerned, nor by public prosecution.

Article 41 of the Code of Deontology of 1995 states, in almost the exact words used in the Code of 1979, the state of present French law : "No mutilating intervention can be undertaken, without very potent medical motive nor without the patient's knowledge or consent, except in cases of emergency or impossibility". As regards the legality of contraceptive sterilisation for the mentally handicapped, both therapeutic necessity and consent of the patient are questionable concepts.

Proposals for decision-making procedures

Sterilisation is not the only, nor even the best method of contraception for the mentally handicapped. Most mentally handicapped women can use reliable hormonal contraception. For a woman in harmony with her environment (family or institution), an ordinary contraceptive protocol combining oestrogens and progestogens is acceptable which supposes that a responsible carer will be making sure that the pill is taken on a regular basis. In the same way, for many handicapped individuals, supervision is provided for the administration of a variety of other medications : anti-convulsant, antibiotic, chelating agent, insulin, special diet, etc. When the circumstances of everyday life make supervision difficult, pure progestogen contraception i.e. 150 mg of depot medroxyprogesterone acetate injected at three month intervals is a possibility. This method is very safe. Fertility can be restored if it is felt at some future date that the method could be interrupted on an experimental basis. Yet another advantage is that after twenty years of follow-up no

iatrogenic effect has ever been found. There are also techniques involving sub-cutaneous implants of slow-acting progestagenic agents the effects of which last up to six months. However, these substances are not available in France at this time. Time of follow-up (mainly in the United States) is not yet sufficient to determine indication with complete security.

Insertion of an IUD may also be satisfactory for some cases.

Unlike present practice in France, surgical procedures such as "tubal clips", also called tubal sterilisation in medical and surgical publications, should only be considered if no other reversible contraception can be used. Sterilisation must only be decided according to extremely strict procedures, and protection of rights and best interests of patients must be of the highest degree. It must be emphasised that no one can guarantee reversible sterilisation with these techniques.

Furthermore, it is important to remember that tubal procedures in no way protect a mentally handicapped woman from sexual aggression ; on the contrary, sterilisation may make her even more vulnerable. The fact that sterilisation only protects against pregnancy cannot be over emphasised.

For any form of contraception, reversible or otherwise, the key problem is still free and informed consent.

To obtain consent is one thing. Judging its validity is another. Thus, in this respect it is unwise to offer certainties. It is more useful to underline difficulties, hesitations, limits of expertise, and also the brittleness of some evaluations in spite of the quality and variety of methods used for the purpose.

Can consent be considered "informed" ?

Validity of consent obviously depends on the capacity of the mentally handicapped person to understand the nature and consequences of sterilisation. This assumes that he/she has at least some idea of the connection between sexual activity, pregnancy, and motherhood ; understands the difference between fertility and sterility; and is able to comprehend the real significance of looking after a real child (30). But this depends first of all on the possibility of obtaining clear, simple and, precise information, suited to the supposed intellectual capacity and given by a person who is prepared to make the necessary effort to be understood. If all of these fairly difficult notions seem to be reasonably accessible to the mentally handicapped person, then one can accept the idea that consent (or refusal) as expressed stands a good chance of being valid.

Was consent given freely ?

If consent was obtained to the satisfaction of conditions outlined above, it remains to be seen whether it was given in conditions which may be seen as compatible with freedom of choice. The problem here is the conditions in which consent was obtained. Consent to induced abortion for a non emancipated and unmarried minor (31) has to be obtained during a one-to-one interview without the presence of the girl's parents. It is easy to imagine that parents convinced of the fact that sterilisation is the best possible contraception option, might well put pressure on their mentally handicapped child (32) so as to obtain consent to this plan. The same might be true of an institution, in particular if the professional staff is experienced in the management of the mentally handicapped. These are conditions which are particularly likely to bring about feelings of obligation which may impair the freedom of choice of the mentally handicapped individual. It is for these reasons that it is felt that parents and/or institutions are not always the best judge and protectors of the interests and legitimate rights of the mentally deficient since they are so involved in the daily task of caring for them that they may confuse their own interests and those of the mentally deficient person in their care.

In case of disagreement, or even of conflict on the best contraceptive plan, in particular if sterilisation is an issue, it would seem necessary to provide a framework for collective decision with extremely strict procedures in order to judge the degree of freedom of consent and whether what is proposed is really necessary. In this way, the handicapped person may be better protected although it is not a total guarantee of the quality and impartiality of the decision.

As regards sterilisation, with due regard to past experience, the French National Consultative Ethics Committee recommends that the following precautions be taken :

Certain conditions must be met before *considering* whether sterilisation should be *proposed.*

Before these conditions are listed, it seems essential to make clear who should make the evaluation.

It would be unreasonable to give the task to one person alone. The responsibilities are too great and the task too complex. Several domains of expertise are involved and the responsibility is such that it is essential to gather together for collective evaluation, specially trained experts on problems affecting the mentally handicapped, including doctors (neurologists, gynaecologists, psychiatrists, geneticists, pediatricians), legal experts and social workers (33). It should be pointed out, however, that for this type of problem in other countries, courts (Family Courts, in particular), act together with other professionals.

It is important that those sitting on such committees are not members of the family or the guardians of the mentally handicapped person. The members of the committee must imperatively be unconnected with the family. It is clear that those making the request cannot be both judge and party to the decision. In all democratic countries where sterilising the mentally handicapped was practised, it transpired that the interests, albeit perfectly legitimate, of the parents did not always coincide with those of the children (34), regardless of how affectionate the relationship. Furthermore, certain parents were so attached to their handicapped "perennial child", that they found it impossible to face an awakening of the child's sexuality. However, even so, there is no guarantee that a committee will arrive at a better decision.

The committee of experts must try and evaluate the data and give answers to some questions. The following outline might serve as a guide :

- The mentally handicapped person must be known to be potentially fertile. This is an important point because certain pathologies associate mental handicap and sterility from various causes.

- The mentally handicapped person must be sexually active. Furthermore, for each person the kind of sexual activity, which will greatly depend on the degree of autonomy (35), will need to be evaluated if possible. However, an absence of autonomy is no guarantee of immunity from sexual aggression.

- Sterilisation can only be considered an option if proof is given that any other form of contraception is a practical impossibility for the person concerned. In that situation, the sterilisation procedure offering the best chances of reversibility should be chosen.

- Taking into account late maturing, not only intellectual but also emotional, the mentally handicapped person should be at least about 20 years of age (as a rough

guide). It must be clear that legal majority means little in the case of the mentally retarded. In all cases, efforts must be made to inquire into the wishes of the person concerned.

- The handicap must be severe although this concept needs to be detailed somewhat. An evaluation of the IQ. is insufficient. The behaviour of the person concerned must also be taken into account, such as use of toxic substances (alcohol, medication, drugs...) or potentially dangerous sexual activity, for women particularly, which may expose them to violence and unwanted pregnancy (36). But neither contraception nor sterilisation can solve the issue of violence.

- Genetic risk must be evaluated on a case by case basis.

- Sufficient information must be gathered before considering as highly likely that the mentally handicapped person is probably incapable of shouldering responsibly the duties of motherhood (or fatherhood) : severe handicap, possibly in development, motor and emotional instability, high risk repetitive behaviour, personality disorders, short life expectancy.

A very few specialised centres must alone be allowed to practise such operations, and the micro-surgeons considered to be the most competent in France should be responsible for them.

The CCNE recommends in conclusion that expert services should be set up to give assistance to mentally handicapped parents who are bringing up children.

Notes

1. The word *handicap* covers a vast field of affections, not limited to mental deficiency, and refers to a number of often hazy phenomena and situations which are not all solely the concern of health authorities or social services. The notion *handicapped person* itself covers a broad spectrum of deficiencies, ranging from mild mental debility to profound retardation. It is precisely this diversity of deficiencies and of their management which makes it impossible to adopt a single solution. The expressions 'mental handicap' or 'mentally handicapped person' are more the result of administrative definition than of clinical classification. A Giami, "Handicap as an object of study of representations of a handicap'. (Du Handicap comme objet dans l'étude des représentations du handicap), *Sciences Sociales et Santé*, vol. XII, n° 1 (March 1994,) 31-60.

2. Some of these will cause an absence of pubertal development or delayed puberty. Others, however, give rise to abnormally early onset of puberty.

3. Courtecuisse V. "Pregnancy as a result of violence in adolescents" in *L'adolescence enceinte,* vol. 1, directed by W. Pasini). Acta of the 6th Symposium of early parent-child relationships. 1993 Ed. Médecine et hygiène. Geneva.

4. Union Nationale des associations de parents et amis de personnes handicapées mentales (UNAPEI, *Le devenir des enfants nés de parents ayant un handicap mental)* (Future of children born to mentally handicapped parents). report of an enquiry by Mr. P. Echavidre, June 1984.

5. Couple living in an institution or "outside".

6. A. Giami, C. Lavigne, "Sterilisation of mentally handicapped women and 'free and informed consent'", (La stérilisation des femmes handicapées mentales et le 'consentement libre et éclairé'), *Revue de médecine psychosomatique,* 35 (1993), 35-46.

7. If there is a combination of mental handicap and another pathology, contraception may raise special problems. These will not be listed here. The most frequent problems are associated with contraindication to oestrogens and progestogens, or their use at unusual doses if the patient has anticonvulsant medication. Essential medical follow-up will naturally take account of this kind of contraceptive problem.

8. Condoms are so far the only method of contraception available to men. One advantage is that it protects partners from HIV contamination. If, however, the partner is mentally handicapped, it is hardly a good choice.

9. Amenorrhea is found in a little more than 50% of cases after a year of use. It is generally welcome for young mentally handicapped women for whom hygiene, particularly menstrual, is usually a problem.

10. "A comprehensive review of injectable contraception with special emphasis on depot Medroxyprogesterone acetate.." *Med. J. Aust.* 1981 Jan; Special Suppt. 3-19.

11. Kaunitz-AM; Rosenfield A. "Injectable contraception with Depot Medroxyprogesterone acetate. Current status." *Drugs.* 1993; 45-(6) 857-865.

12. Sterility is sometimes a component of certain handi.

13. A distinction should be made between contraceptive sterilisation as such and sterility as a consequence of therapeutic surgery (hysterectomy, endometrectomy, castration because of, for instance, cancer of the uterus, ovaries, or testicles; massive uterine haemorrhage). These surgical procedures are to be considered in the usual deontological setting of medical practice and do not raises the same issues as first intention sterilisation.

14. "Vasectomy : New opportunities." *Population Reports*, Male Sterilisation, Series D, n° 5 (March 1992), 23 pp.

15. One author, comparing results from several studies, considers that chances of functional pregnancy in the female partner, followed by delivery, are about one in two : Hendry W.F. "Vasectomy and vasectomy reversal", *British Journal of Urology*, 1994, 73, 337-344. However, a recent review of literature on this subject in the Medline data base gives a lower rate of success, i.e. about 20 to 40%.

16. J.B. Dubuisson, C. Chapron, C. Nos, P. Morice, F.-X. Aubriot, P. Garnier, "Sterilization reversal: fertility results, *Human Reproduction*, 1995, 10, 5 : 1145-1151.

17. Fitting of clips is one of the various tubal techniques. Ligation, bands, fulguration, or even intratubal injections of various materials are further possibilities. However, the clips seem to be the preferential method if future reversal is to be retained. See article quoted in the preceding footnote, by Dubuisson *et al.*

18. *This expression is offered in contrast to the notion of voluntary sterilisation which designates the case when a man or woman specifically requests surgery to put an end to potential fertility. Such elective sterilisation (which is not permitted in France) should not be confused with surgery performed without the patient's knowledge while undergoing genital surgery. The woman finds out after the operation that her surgeon decided to perform tubal ligation without informing her beforehand. Such an initiative is only justified if exceptional and unpredictable therapeutic emergency arises during surgery (which is a rarity). Sadly, it cannot be said that such practices are entirely a thing of the past.*

19. *The Committee of American Neurological Association for the Investigation of Eugenical Sterilization. Eugenical Sterilization. New York : The Macmillan Company, 1936. Reprinted by New York : Arno Press, 1980.*

20. It is interesting to find in the history of eugenic sterilisation laws in the United States, that some of them, more specifically aimed at people held in specialised institions, qualified the procedures as "elective". In fact, it was not a free choice. It was a condition in order to be allowed to leave the institution. The alternative was, of course, continued internment.

21. This decision of the Supreme Court was never abrogated but has been severely limited by later decisions.

22. Smith-J.D; Polloway-E.A. "Institutionalization, involuntary sterilization, and mental retardation : profiles from the history of the practice." Ment-retard. 1993 Aug : 31(4): 208-14.

23. Commission for the Reform of Canadian Law. *Sterilisation of the mentally handicapped.* 1979.Working document n° 24.

24. Reilly-PR. "Involuntary sterilization in the United States : a surgical solution." Q. Rev-Biol. 1987 Jun; 62 (2): 153-70.

25. See for example in the Report of the Committee of the American Neurological Association for the Investigation of Eugenical Sterilization, mentioned above, a comment on the German Law dated 14th July 1933, page 22.

26. Apart from the Canadian report, quoted above, ethical and legal literature on the subject is abundant. See, *inter alia*, Rivet-M. "Sterilization and medical treatment of the mentally disabled; some legal and ethical reflections." *Med Law*. 1990; 9(5) : 1150-71; Price-DP. "Comparative approaches of the non consensual sterilization of the mentally retarded." *Med Law.* 1990; 9(3) : 940-9, Petersen-K. "The family vs. the family Court: sterilization issues." *Aust-J-Public Health* 1992 Jun; 16(2): 196-201, Mair-ML. "The right to procreate: intellectual disability and the law." *J.-Aust-Coll-Midwives*. 1992 Dec; 5(4): 16-20, Van Kamp-K; Denekens-J."Sterilization and the mentally handicapped : who decides ? ?" *Verh-K-Acad-Geneeskd-Belg.* 1993; 55(1): 27-37; discussion 37-43; Applebaum G.M. & La Puma J., "Sterilisation and a Mentally Handicapped Minor: Providing Consent for One Who Cannot" , *Cambridge Quarterly of Healthcare*, 1994, 3: 209-215; Wingfield M; Healey-DL; Nicholson-A. "Gynaecological care for women with intellectual disability." *Med-J-Aust*. 1994 May 2; 160 (9): 536-8; Munoz Condé F., "Sterilisation of the mentally handicapped : comments on the Ruling of Spain's Constitutional Court, July 14, 1994", *Law and Human Genetics Review*, 1995, 2: 175-196.

27. "China, published eugenic law", *Le Quotidien du Médecin*, 16th November 1994. See also "Les troubles relents de l'eugénisme chinois", (Unsavoury aspects of Chinese eugenics), *Le Figaro,* 2nd January 1994; and "Pékin prône l'amélioration de l'espèce" (Peking favours improvement of the species), *Libération*, 4th January 1994.

28. In the case of rape or other sexual violence, if violence is inflicted on a person who is particularly vulnerable because of age, sickness, infirmity, physical or psychic disability, pregnancy, these circumstances being known to the author of aggression or being apparent, then penalties may be more severe". (New Penal Code March 1994: art. 222-24 and 222-29).

29. Law dated 4th Dec. 1974.

30. Repetition is to underline the reality and frequency of the "imaginary child" or of "the child in your mind".

31. Therefore, in the eyes of the law, incapacitated.

32. Child is used here to mean offspring, regardless of age.

33. This list is simply indicative, not exhaustive.

34. The non coincidence of the interests of parents and children is for that matter a commonplace situation also found in families with no mentally handicapped children.

35. Autonomy is meant here not simply in terms of mobility, but also from the point of view of socialisation, i.e. capacity to relate.

36. The same remark can be made about S.T.D. risks.