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# Executive summary

Health Council of the Netherlands. Contraception for people with mental retardation. The Hague: Health Council of the Netherlands, 2002; publication no. 2002/14

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## Scope

In recent decades, policy-makers and healthcare providers have become increasingly emphatic in their adoption of a specific policy of emancipation for people with mental retardation. At the heart of that policy lies the ambition, wherever possible, to normalise the lives of people with mental retardation and to bring them into line with those of people without intellectual disabilities. This policy has resulted *inter alia* in more attention being paid to the sexual desires of people with mental retardation who are, furthermore, increasingly finding more opportunities for sexual contact.

As a result of this policy of normalisation, medical care providers are increasingly being confronted with requests for assistance with contraception for people with mental retardation. The professional groups concerned have identified a need for more guidelines to assist them in responding to these requests. This same need is said to be felt by organisations representing parents of the mentally disabled.

The Minister of Health, Welfare and Sport (VWS) has therefore requested the Health Council to provide an overview of the medical, ethical and legal considerations that influence decision-making with regard to contraception for people with mental retardation. In order to comply with this request, the Health Council established the Committee that has produced the current advisory report.

The Committee attempts to indicate how a physician (and especially a general practitioner, a physician specialising in the care of people with mental disabilities, a gynaecologist or a urologist) must act upon being confronted with a request for

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contraception for someone with mental disabilities. More particularly, it seeks to answer the following three questions.

- What considerations are relevant when formulating an opinion on the desirability of contraception?
- What considerations are relevant when formulating an opinion on the form of contraception to be used?
- How can the decision-making process with regard to contraception best be organised?

In order to answer these questions satisfactorily, it is necessary to consider contraception in the context of sexuality on the one hand and possible parenthood on the other. After all, contraception is not an end in itself, but a means to achieving a positive perception of sexuality. The desire to prevent pregnancy is usually the principal reason for contraception.

Before embarking on a more concrete investigation of the aforementioned three questions, the Committee first outlines the legal context and the ethical principles underlying the formulation of opinions and the making of decisions with regard to contraception.

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## **Legal context**

As far as the legal context is concerned, a central role is played by the Medical Treatment Agreement Act (WGBO). This law is founded on a number of basic rights and principles of medical ethics.

According to the WGBO, two conditions must be satisfied before a physician is permitted to perform a medical procedure. These same conditions also apply with regard to contraception. Firstly, the physician must have regard for "the standard of care required of a competent care provider" and, secondly, he or she requires the consent of the patient.

These two requirements can give rise to complications in the case of contraception for people with mental disabilities. Firstly, it is not always clear precisely what is meant by "the standard of care required of a competent care provider". In the normal course of events, this is determined with reference to a standard of professional medical care. In the case of contraception for people with mental retardation, however, no such standard exists. Nor is there any societal consensus (regarding, for example, such matters as the circumstances under which it is desirable to prevent pregnancy in people with mental retardation) which can assume the function of a standard of professional medical care.

A second complication lies in the fact that people with mental retardation are more often deemed mentally incompetent than other members of society. A mentally

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incompetent patient is unable to give valid consent to a medical procedure. The physician then requires the consent of a representative.

In principle, anyone older than 12 years is deemed to be mentally competent. This presumption may only be waived if it is proven that someone is not capable of making a reasonable assessment of his or her own interests in relation to a particular decision. This can be said to apply if the patient does not understand all of the information that is relevant to the decision, or does not realise that this information is applicable to his or her own situation, or else if the patient is unable to reach a decision on the basis of that information. In the case of a decision regarding contraception, this could, for example, mean an understanding of the reason for contraception (sexual behaviour, reproduction and the relationship between them), of the goal and different methods of contraception, and of the consequences of not using contraception, namely, pregnancy, childbirth and parenthood. It is particularly important that the patient should be aware that failure to use contraception may possibly entail the assumption of responsibility for bringing up a child.

The Committee has established that no sound method exists for assessing the mental competence of people with mental retardation. Since judging a person to be mentally incompetent can have far-reaching consequences, it is considered that the lack of such a method poses a significant threat to efforts to safeguard the rights of those people with mental retardation whose mental competence is at issue.

If a patient is deemed mentally incompetent with regard to a decision concerning a medical procedure, then the physician and the nominated representative must nevertheless involve the patient as closely as possible in the decision-making process. The fact that the physician and the representative must also take into consideration a mentally incompetent patient's views and utterances that are not based on any degree of competence is evident from the WGBO's "resistance" provision (*verzetsregeling*). According to this provision, it is in principle impermissible to use coercion against a mentally incompetent patient who physically or verbally resists treatment. This is inapplicable only if the treatment is necessary in order to prevent serious harm to the patient. That harm may be both of a medical and psychosocial nature. The former will apply, for example, if someone resorts to self-mutilation as a result of a misunderstood pregnancy and childbirth. The latter case will arise if the social functioning of the patient is seriously undermined during an possible pregnancy, childbirth or parenthood. This may occur, for example, because the patient will be unable to fulfil the parental role with sufficient independence and no alternative parenting options are available.

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## Ethical principles

It is still not sufficiently clear precisely what it means to have regard for the "the standard of care required of a competent care provider" in relation to contraception for people with mental retardation. The Committee therefore bases its interpretation of this requirement on the principle of equal citizenship, the code of medical ethics and the principle of respect for physical integrity.

The principle of equal citizenship implies that people with mental retardation must have the opportunity to develop their own sexuality in an appropriate fashion, that they are able (wherever possible) to reach their own decisions on contraception, and that parenthood must not automatically be ruled out or made illusory for people with mental retardation. For a physician, this principle also means being fully bound by the code of medical ethics with regard to patients with mental retardation. Key elements of the code of medical ethics are the principle of beneficence, the principle of respect for self-determination and the harm principle.

The principle of beneficence has two important implications with regard to contraception. The first implication is that the physician is at all times required to give his or her own opinion with regard to the desirability (and, where appropriate, the form) of contraception. The physician bears a personal responsibility for assessing the need for, and administering, the contraception, which cannot be overridden by the wishes of the patient. The second implication is that the formulated opinion is to be based on the perspective of the patient. The Committee proposes that this perspective should be interpreted in terms of the patient's 'quality of life'. The principle of beneficence means that each decision on contraception is reviewed in terms of whether the contraception contributes to the patient's quality of life.

The principle of respect for self-determination implies that the physician's formulation of a decision must give due weight to the patient's views as to what enhances the quality of life. The weight that is accorded can be increased to reflect the patient's ability to judge which decision most benefits the quality of life. According to the Committee, the principle of equal citizenship demands in this context that a patient with mental disabilities should, where appropriate, be supported in developing and realising his or her residual autonomy. That support may assume three different forms: education (with regard to sexuality, parenthood and contraception), the initiation of a dialogue with the patient and assistance from an advocate.

The harm principle implies that the physician, in formulating the opinion, may put the wishes of the patient into a wider perspective if there is a major risk that the fulfilment of these wishes might result in a disproportionate infringement of the interests of a third party. In the light of the principle of beneficence (which essentially obliges the

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physician to give priority to the interests of his patient) there will naturally be a reluctance to accept that this is the case. Nevertheless, it is not inconceivable that a situation might arise in which the physician will accord greater weight to the interests of a third party than to those of his patient. In such a case, the physician may appeal to the responsibility of his patient to respect the interests of third parties. Such a situation can arise where a person with mental retardation refuses contraception and knowingly runs the risk of spreading a sexually transmissible disease or of fathering a child or becoming pregnant, notwithstanding the fact that he or she is manifestly either unwilling or unable to bring up that child and also that no suitable alternative parenting options are available.

In the light of the principle of respect for physical integrity, the existence of grounds for putting the wishes of the patient into a wider perspective does not in itself justify the coercive use of contraception. If, for example, the patient continues to refuse contraception, whereas the physician is of the opinion that this course of action poses a serious threat either to the patient's quality of life or to the substantial interest of a third party, then all that the physician can do, in principle, is to try to persuade his patient through dialogue.

The Committee has the impression that it is, in many cases, possible to prevent conflict situations from arising (or from escalating) by adopting the approach of persuasion. It suspects that the assumption has hitherto all too frequently been made that people with mental disabilities are not open to reason. Moreover, it is probably significant that physicians frequently work under great pressure of time, do not possess specific knowledge of mental disabilities and the attendant complications, and are not trained in dealing with people with mental retardation. The Committee considers it desirable to formulate specific policy for this matter.

Because it is not always possible to resolve differences of opinion by means of dialogue, it may be morally justified to resort to coercive contraception. According to the WGBO, the use of coercion on a mentally incompetent patient is only permissible if the treatment in question is necessary in order to prevent serious harm to the patient. However, situations also arise in which the non-use of contraception does not result in any serious harm to the patient him or herself. This prompts the question as to whether it ought to be possible to administer contraception coercively purely in the interests of a (future) child. The Committee attaches great value to the prevention of irresponsible parenthood. However, it is not, in this advisory report, advocating extension of the legal opportunities for using coercion. There are, in fact, also important considerations militating against this course of action. The Committee concludes that the relative merits of the various arguments can only be properly assessed once a clearer picture has been gained of the everyday realities of contraception and parenthood for people with mental

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disabilities and once there is more certainty about non-judicial alternatives. It will then be incumbent on politicians and on society as a whole to make the final assessment.

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### **The desirability of contraception**

The most important reason for using contraception is the wish to avoid a pregnancy. This may be motivated by various reasons. Apart from simply not wanting to have a child, there are reasons that will be more common among people with mental retardation than in other circles. These include particular medical (genetic or teratogenic) risks for any child that might be conceived. In addition, the patient's diminished parental competence may pose a threat to the quality of life or to the welfare of any child that might be conceived. It is this latter reason that the Committee examines most closely.

It is impossible to state in general when the patient's quality of life is enhanced or reduced by parenthood. Because the interests of a child and the interests of its parents usually run in parallel, the Committee takes as its benchmark when assessing the parental competence of the patient the assumption that parenthood is in any event undesirable where there is a major risk that the child will suffer serious harm as a result of deficient parenting skills. However, parenthood may also be undesirable because it imposes too great a burden on the functioning of the parent, even though it does not pose any threat to the welfare of the child.

The Committee does not consider it necessary that the patient should always be capable of bringing up a child on its own. It is sufficient if, together with a partner and supported by a sympathetic social network (and, if necessary, professional care) the patient is capable of responsible parenthood. In the event that the patient is not able to bring up the child independently, then demands may well have to be made with regard to his or her social skills and social network.

Although the state of knowledge with regard to parental competence is limited and, moreover, due caution needs to be exercised in interpreting the scientific literature that is available, there is some consensus that people with an IQ below 60 are not truly capable of bringing up a child. Above that threshold, however, IQ is not a dominant factor. The picture that emerges in the case of parents with an IQ in excess of 60 is marked by stark contrasts. While it is not unusual for the outcome of such parenthoods to be disastrous, it is certainly not true to say that it is only successful in exceptional cases. People with mental retardation are not, as is frequently assumed, a "species apart", but they do undoubtedly make more vulnerable parents. They usually have a lower tolerance threshold from a psychosocial, physical and financial/economic point of view. The presence of a child can therefore easily prove to be an excessive burden. This can then lead to some degree of neglect and later to developmental retardation, learning difficulties and behavioural disorders in the child. Whether that vulnerability also

actually stands in the way of a successful upbringing, however, will depend to a great extent on the particular circumstances.

The heterogeneous picture presented by parents with mental retardation who have an IQ above 60 underlines how important it is to make subtle distinctions when formulating an opinion. There is, however, little systematic research available into the influence of specific circumstances. It is nevertheless possible to name a number of risk factors that influence the outcome of child-rearing. These can be broken down into factors linked to the (potential) parents as individuals, factors associated with the family situation, factors that relate to the family's social environment and factors specific to the child.

It is incumbent upon the physician, in collaboration with medical colleagues and/or psychosocial experts, to assess whether these risk factors are present. Furthermore, consideration must be given to the fact that parental competence is not a fixed entity. It is, for example, often possible to further develop parental competence by means of training in parenting skills. It is also possible, to a certain degree, to compensate for diminished parental competence by offering the appropriate care and social services.

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### **Form of contraception**

Once the physician has formed the opinion that contraception is desirable and the patient or (where applicable) the nominated representative is in agreement, the physician must reach a decision as to what form of contraception is most advisable. This decision will also, theoretically, be based on an assessment of the contribution which contraception makes to the patient's quality of life. This means that the method of contraception must satisfy the requirement of effectiveness and the principles of subsidiarity and proportionality.

The requirement of effectiveness means that the contraception must be sufficiently capable of achieving the intended goal. The effectiveness of contraception in people with mental retardation is relatively often influenced by certain medication use and diminished physical, cognitive or psychosocial capacities.

The principle of subsidiarity means that the contraceptive methods that are sufficiently effective in realising the desired goal need to be examined with a view to selecting the least stressful method. It is therefore not possible simply to choose the most effective technique. One factor that contributes significantly to the stress of contraception is the degree of coercion or force that might possibly be required.

The principle of proportionality means that the stress which the least invasive method of contraception entails for the patient must be justified by the benefit that can be expected to be derived from the use of that method. For example, the principle of proportionality is unlikely to be satisfied in cases where non-use of contraception is

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associated with only a negligible risk of pregnancy, e.g. because the likelihood of sexual contact is minimal.

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### **Decision-making process**

The Committee outlines next what implications the above factors have for the manner in which the process of reaching a decision on contraception needs to be organised. In addition, there is a systematic discussion of the different stages of the decision-making process.

Prominent among the topics considered by the Committee is the collaboration between the general practitioners, physicians specialising in the care of people with mental disabilities and psychosocial experts (e.g. from the Social Services for the Learning Disabled (SPD)). Because general practitioners do not, as a rule, possess specific expertise (nor have a significant level of contact with colleagues with regard to patients with mental retardation) such collaboration is often a very important element in the process of formulating opinions and decision-making. This is especially relevant when assessing a patient's mental competence and parental competence. It also applies when attempting to answer the question of whether a particular method of contraception satisfies the principle of subsidiarity. This principle demands that efforts must constantly be made, by means of education and counselling, to create a situation in which it is possible to switch to using a less invasive method of contraception. A general practitioner is usually less well-positioned to assess the possibilities that exist for making such a change.

The Committee endorses, in principle, the advice of the Health Care Inspectorate (IGZ) that a minimum age of 18 years should be applied in relation to the sterilisation of someone with mental retardation. Because people with mental retardation develop relatively slowly, it is generally difficult to make a proper assessment before they reach the age of 18 of their prospects of fulfilling a parental role or using a less invasive form of contraception later in life.

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### **Social context**

In addition to answering the three questions that it has formulated, the Committee examines two social factors: public perceptions of sexuality, contraception and parenthood in relation to people with mental retardation, and the social services that are available to people with mental retardation. Although in individual cases there is often little or nothing that the patient, the physician or any other interested parties can do to influence these factors, they do play a role in determining the outcome of the decision-making process.

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The ways in which sexuality, contraception and parenthood are perceived in relation to people with mental retardation warrant consideration because they can stand in the way of a proper appreciation of the problems at issue and thus an adequate consideration of the whole question of contraception. The Committee states *inter alia* that existing views regarding the sexuality of people with mental retardation either fail to appreciate the fact that, broadly speaking, it is not substantially different from other people's sexuality, or take too little account of the fact that people with mental retardation are highly dependent on the support of others in matters of sexuality.

Sound decision-making on contraception for a patient with mental retardation is also often dependent upon the availability of adequate social services. Especially relevant in this regard are sex education, support during the process of formulating opinions and making decisions about contraception and parenthood, and training and support during any ensuing (future) parenthood. According to the Committee, there is ample room for improvement in each of these three areas of social service provision. The Committee holds, moreover, that the principle of equal citizenship demands that these improvements must be accomplished.

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## **Conclusions and recommendations**

The Committee concludes that the further integration and normalisation of people with mental retardation requires public debate, an expansion of knowledge and improvements in social services. The Committee makes recommendations with regard to:

- scientific research
- sex education
- sexual abuse
- further training for care providers
- collaboration between physicians and psychosocial experts
- advocates for people with mental retardation
- methods of evaluating mental competence
- personally authorised representation
- support given to people with mental retardation in the formulation of opinions and the making of decisions with regard to contraception and parenthood
- parent support services
- public perceptions regarding sexuality and parenthood in relation to people with mental retardation
- prevention of irresponsible parenthood
- public debate and specific guidelines.