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Sexuality and Contraception for Developmentally Handicapped Persons

SUMMARY

Marked changes are occurring in the manner in which developmentally handicapped persons are being incorporated into society. These changes necessitate careful planning and review of the consequences of social interactions, including those of sexual development and fertility. Physicians and other health care workers should familiarize themselves with the current techniques of contraception as they apply to the developmentally handicapped and the current status of consent as it applies to therapeutic and non-therapeutic interventions, including advice about temporary and permanent contraception. (*Can Fam Physician* 1986; 32:1631-1637)

SOMMAIRE

Il se produit d'énormes changements au niveau de l'intégration sociale des personnes congénitalement handicapées. Ces changements nécessitent une planification et une révision minutieuses des conséquences de ces interactions sociales, qui comprennent celles du développement sexuel et de la fécondité. Les médecins et autres professionnels de la santé devraient se familiariser avec les dernières techniques de contraception, appliquées à la personne handicapée congénitalement, et avec la notion de consentement, qui s'applique aux interventions thérapeutiques et non thérapeutiques, comprenant des conseils sur la contraception temporaire et permanente.

Key words: contraception, developmentally handicapped, women

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WE ARE IN A PERIOD of marked change in the manner in which developmentally handicapped persons (a descriptor clarifying "mentally retarded" as including persons who, in their formative years, suffer mental impairment associated with limitations in adaptive behaviour) are integrated into society. Advances in care, support, education and law have occurred in conjunction with demonstrable changes in societal attitudes. These advances have provided new opportunities for the developmentally handicapped to enjoy more normal life experiences, including sexual experiences.¹ The approach to medical care for developmentally handicapped individuals

should be adapting to and evolving in a manner parallel to these changes.

The historic approach to the care of the developmentally handicapped has been paternalistic and protective; it has been based upon an attitude that the Crown must protect those unfortunates from the outside world and from themselves. Roman Law in the 5th century B.C. provided for non-judicial guardianship: "If a person is a fool, let his person and his goods be under the protection of his family or his paternal relatives, if he is not under the care of anyone."² From mediaeval English common law is derived the doctrine of *parens patriae*, the jurisdiction underlying the appointment of guardians for persons

found mentally incompetent by the courts today. Under this jurisdiction, the King took over the responsibility for "lunatics" and "idiots" and their assets, but only after a hearing to determine their mental status and in accordance with a number of due process guaranties.

The care of "lunatics" and "idiots" differed widely. In the case of lunatics, or mentally disturbed persons, who owned land, the King became guardian, maintaining the person and the family out of the profits from the land; if the lunatic regained sanity, the King had to return the property. "Idiots" fared less well: the King seized the idiot's land, depriving the person of the important rights attendant on land ownership until death occurred, when the land was returned to the family. The King was allowed to profit from the lands held during this interval without any corresponding duty to maintain the person's family. Juries became extremely reluctant to declare anyone an idiot, given the dire consequences; as a result few persons were found to be idiots and many more to be lunatics during this period.³ As the jurisdiction over mentally incompetent persons developed, it changed from a prerogative exercised for the benefit and profit of the Crown to a parental and protective jurisdiction exercised for the benefit of the incompetent person.³

The changing approach to developmentally handicapped persons includes both the philosophy of "normalization"⁴ and a shift from paternalistic approaches to those which enhance the rights and autonomy of handicapped persons.⁵ "Normalization", as defined by Wolfensberger, states that the environment and daily lives of handicapped individuals should be as normal as possible, given the handicapping condition, and establishes integration into the community as a goal.⁴ As a result there has been a move to de-institutionalize the developmentally handicapped from large hospital-like settings into community-based facilities such as group homes and into foster care. At the same time increasing efforts have been made to define and defend the rights of these persons. Legal protection may be found in provincial Human Rights Codes which prohibit discrimination on the basis of mental disability, and in the Canadian Charter of Rights and Freedoms, most

notably in Section 15.⁶ This section states that:

Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination based on . . . mental or physical handicap.

The rights set forth in section 15 as well as the remainder of the Charter are subject to Section 1, the interpretation of which will be a key feature of constitutional jurisprudence.⁷ Section 1 states that:

The Canadian Charter of Rights and Freedoms guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.⁶

Since it is estimated that 2.5% of all children have mild to severe retardation, and since one-third of this group (0.9%) have significant impairment of adaptive behaviour in adult life,⁸ a substantial part of our health care system is involved in providing services to developmentally handicapped persons. De-institutionalization has resulted in family physicians providing the majority of primary care for these persons, 95% of whom are only mildly or moderately handicapped, and 90% of whom are living in the community, outside large institutions.^{8,9}

Ethical, Social and Legal Issues

Sexuality is a natural integral aspect of human growth and development and is reflected in the expressions and perceptions of the individual and in his or her relationships with others.¹⁰ Given the shift of more developmentally handicapped individuals to the community, supported by effective programs in body awareness, social interactions and sexuality, it is predictable that sexual activity will increase. Chamberlain's study demonstrated no differences between the sexual activity of mildly retarded females aged 15-19 and that of comparable "normal" adolescents in a metropolitan setting.¹

With the opportunity for increased sexual freedom comes the responsibility for the consequences of exercising that freedom. This responsibility includes consent of the sexual partner,

for sexual activity is acceptable only when both partners consent to that activity. It also includes responsibility for that activity's possible outcomes, including pregnancy. Traditional approaches to care, influenced by paternalism, largely prevented this possibility by providing custodial care in institutions where sexual expression was not encouraged. In Alberta and British Columbia, additional "protection" was introduced in the form of eugenic sterilization laws for certain categories of persons, including "mental defectives"; these laws were not repealed until 1972 in Alberta and 1973 in British Columbia.¹¹

Two arguments have often been cited in defence of preventing developmentally handicapped individuals from having progeny: first, such persons may be unfit to be spouses or parents, as they may lack an appreciation of the nature and consequences of marriage and parenthood; secondly, their offspring may be more likely than children of non-developmentally handicapped parents to have mental handicaps. With respect to the capacity to enter into marriage, statutory prohibitions in force in seven Canadian provinces in 1971, against marriage of persons considered to be mentally incapable, appeared to have had little influence on actual marriage rates.^{12, 13} Legal barriers to marriage for developmentally handicapped persons, formulated simply on the basis of the handicap, without any assessment of actual capabilities, may be subject to challenge on the basis of the Charter of Rights and Freedoms. Societal attitudes may remain relative barriers, to be overcome by successful education programs directed to society at large, as well as to developmentally handicapped individuals.

Considerable research has been done in attempting to document the state of offspring of developmentally handicapped parents. Reed and Reed surveyed families in the U.S.A., using a sample size of over 80,000 persons.¹⁴ The researchers, using an IQ of 69 as a threshold of retardation, found that nearly 40% of the children in families where both parents were retarded demonstrated retardation, with a mean IQ of 74.^{14, 15} When only one parent had an IQ below 80, 14% of the children were considered to demonstrate retardation, but over 50% had IQs higher than 90. When neither parent had a

documented mental handicap, 1% of the 7035 children were considered to be retarded.¹⁵

Before attempting to draw conclusions of a familial or genetic nature from the above data, one must consider the results of the Heber and Garber study conducted in Milwaukee in 1975.^{13, 16} The authors attempted to ascertain whether ghetto children considered at risk for developmental delay on the basis of low maternal IQ could be helped by pre-school education programs and training for the mothers. At age 5½ years, the experimental group (which had received special attention for five years) had a mean IQ score of 122, the control group a corresponding score of 91. This study, while not without its critics, suggested that children of mentally handicapped parents can potentially achieve normal educational development, at least in the early stages, given extensive support.¹³ It is evident that the causes of developmental handicaps are often multifactorial, involving complex interactions of birth trauma, diseases and accidents, environmental factors and genetics. As a consequence, a "blanket" restriction against parenthood or removal of fertility of developmentally handicapped persons cannot be supported.¹¹

The evaluation of effective parenting is a task complicated by the lack of generally accepted standards in the community. Opinion is divided, too, on the treatment of mental disability in child-welfare law.¹⁷ Czukar has reviewed the legal, medical and social issues involved in parenthood for developmentally handicapped people and has reached these conclusions:

- Assumptions about the ability of developmentally handicapped persons to parent based solely on IQ scores are erroneous.

- Some retarded parents can provide loving, safe and secure home environments.

- Special supports for the children of developmentally handicapped parents, particularly in the early years can compensate for deficiencies in intellectual stimulation at home.¹³

Developmentally handicapped persons are increasingly being integrated into the community, with some of their necessary social and health supports defined and their rights strengthened. Those remaining in institutions either because of the severity of their handi-

caps or the lack of community alternatives should also be supported with the goal of full expression of their sexuality within their own limitations. The same consequences of sexual expression apply in institutions, and account must be taken of the added factor of living at close quarters with many other individuals. Since obstacles exist to marriage and parenthood, contraception is clearly a major health care priority for the developmentally handicapped in all settings, as it is for other groups in society.

Assessment of Contraceptive Needs

As with all patients, the family physician must attempt to define the specific contraceptive needs of the developmentally handicapped person and match these with the techniques available, taking into consideration the applicable risk factors, such as smoking, and the supports available, such as someone to assist with daily medication if necessary. Just as with other patients, the physician must be satisfied that the appropriate consent for the contraceptive treatment is obtained. In addition there are particular issues to be considered in providing such service to members of this population.

Is the Individual Fertile?

Several genetic conditions seem to render the developmentally handicapped infertile. There have been no reported conceptions fathered by males with Down's syndrome.¹⁸ Klinefelter's syndrome (X, XY) is characterized by azoospermia; only rarely is spermatogenesis sufficient to permit fertility.¹⁹ Turner's syndrome (45, X) prevents sexual maturation and fertility unless mosaicism (45, X/46XX) is present, as it is in 25% of cases.¹⁹

Is the Individual Likely to be Sexually Active?

This is a very difficult question to answer for many groups in society. The extent of an individual's developmental handicap is frequently described in two ways: the degree of handicap (mild → profound, usually determined by measurements such as IQ tests) and the level of functioning high → low, usually consisting of an assessment of the performance of daily living activities by family members and care-givers). Chamberlain confirmed that sexual activity correlated

positively with the level of functioning.¹

Is the Individual at Risk for Sexual Abuse?

As developmentally handicapped individuals mature, whether they move into group or foster homes, remain at home, or are institutionalized, physicians must be aware that they are potential victims of sexual assault, as are other individuals in the community. Chamberlain's survey of developmentally handicapped women living in the community revealed that one-third of mildly retarded and one-fourth of moderately retarded adolescents had been victims of rape or incest.¹ As determined in studies of rape in the general community, the assailants were likely to be family members or persons well known to the family. No comparable Canadian data could be found, but the practitioner should consider developmentally handicapped women at risk for sexual abuse and should help to organize supports appropriately; this response includes consideration of contraception.

Can the Individual Give Consent?

The right to self-determination is fundamental, and the patient's autonomy and right to inviolability are protected through the doctrine of informed consent in Canadian common law. Before medical treatment may be provided to an individual, that person must make an informed decision to choose that particular treatment from that particular practitioner.²⁰ For consent to be valid in law, it must include the following three components:

- The consent must be voluntary, that is, free of coercion.
- The patient must have the necessary information to make the decision.
- The patient must have the mental capacity to appreciate exactly what she/he is consenting to and the implications of that consent.²¹

Dickens has advocated replacing the term 'informed consent' with 'informed decision making', since informing and consenting are actions moving in opposite directions.²² The core issue is the process of disclosing and assessing information between the two members of the relationship, the patient and the physician.

Since the Supreme Court of Canada's decisions in two cases in 1980,²³ Canadian doctors have been bound by

a duty of disclosure which requires them to disclose, except in certain circumstances, "the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation", and to answer the patient's specific questions.^{24, 25} Failure to disclose adequately may result in an action for negligence, while failure to obtain any consent at all may result in a battery action.^{26, 27} The application of consent law to developmentally handicapped persons requires particular care, legally and medically. This is partly because the law is developing as the radical change brought about by the Supreme Court is integrated with and elaborated on in other decisions, and partly because the law of mental incompetency requires reform.

The mental capacity of the patient is a matter of obvious concern when treatment to prevent conception is being considered for a person with a developmental handicap. Many such individuals have the capacity to consider the consequences, and to assess the risks and benefits of treatment, as well as to make the decision about treatment. Where this is so, the decision of the individual should be respected. In other cases, a guardian or substitute decision maker may have been empowered by a court to make decisions, either through a general power or through a power restricted to making medical care decisions. Such a guardian is appointed only when the individual under consideration has been found mentally incompetent by a court, applying the provincial legislation on mental incompetency.

The legislation in most provinces provides neither a standard by which the guardian's conduct can be measured nor any limitations on the types of decisions that may be taken. A case currently before the Supreme Court of Canada, *Re Eve* poses the issue of whether the court has jurisdiction, under its *parens patriae* power, to order a sterilization for contraceptive (*i.e.*, non-therapeutic) purposes for a developmentally handicapped woman (see discussion below).²⁸ Complicating that case is the lack of a finding of mental incompetency by the trial judge, which may mean that the court does not have *parens patriae* jurisdiction, since the person before the court does not have the legal status of a mentally incompetent person. The case

raises the issue of limitations on the power of guardians, particularly to order non-therapeutic procedures. American jurisprudence is beginning to distinguish decisions that must be made by courts from those that must be made by guardians, considering such dimensions as the degrees of intrusiveness and risk, the urgency of the decision, conflict of interest and good faith, and the novelty of the treatment.²⁹ Set against the right to refuse treatment has been the state's interest in preserving life, protecting the interests of innocent third parties, and preventing suicide.^{29, 30} Cases concerning withholding treatment, such as *Re Quinlan*, raise some similar legal and ethical issues.³¹

In Ontario, where current legislation is similar to that of most other common law provinces, few developmentally handicapped adults, even among those who are severely or profoundly retarded, have been found mentally incompetent by a court, a time-consuming and costly process. All other developmentally handicapped persons are presumed to be competent in law and retain all the rights individuals in society possess. The physician, however, must still satisfy him- or herself that the handicapped patient is mentally capable of making an informed decision and has given an informed consent before treatment can begin. In instances where the individual appears to lack the appropriate mental capacity, a second opinion concerning that capacity may be both helpful and advisable. It may be necessary to examine the legislation governing any institution in which the person is located, for provisions authorizing substitute decision making, such as: legislation governing public hospitals, facilities for developmentally handicapped persons, or psychiatric facilities.

In some limited situations, such as emergencies where death or serious and permanent physical harm would result if action were not taken, and where the patient is unconscious or otherwise incapable of reaching a decision, it is generally permissible to treat without consent.³² In the remaining instances where the individual is considered mentally incapable of deciding on treatment, where no guardian has been appointed, where no emergency exists, where there is no special legislation mandating action or authorizing substitute decision making, both the physician and the patient

find themselves in an extremely difficult position. If no one is willing or able to make an application for guardianship at this stage, the handicapped person has legal rights, but they are rights which cannot be realized. Reform of provincial guardianship statutes (which has been carried out in Alberta and has been under consideration in several other provinces, including Ontario) may lead to enhanced service for such persons on an authoritarian basis. In the meantime physicians advocating a course of treatment for such patients might best seek legal advice.

Another change occurring in the area of consent for persons found mentally incompetent by the courts is in the nature of the directions given to the court-appointed guardian. A legal guardian has traditionally been expected to use a "best interests" test to make a decision on behalf of an incompetent person; this test required that the guardian "employ his own (presumably "normal" and "rational") attitudes and values in assessing the options and reaching the "best" decision."³³ An alternative test, gaining some currency is the "in the shoes of" test, which requires the guardian to choose as it is anticipated the incompetent person would choose, in his or her own environment and according to her or his own values if he or she were competent.^{33, 34} This test has potentially major implications for decision making with respect to pregnancy avoidance and management if it should be adopted by the courts and the legislatures.

Contraceptive Techniques

Oral Contraceptives

Oral contraceptives (OCs) have been widely used in effecting contraceptive control in the developmentally handicapped, as in the general population. They were the second most common form of contraception used by developmentally handicapped adolescents in Chamberlain's review,¹ and they are probably the most common form of contraception used in Canada by developmentally handicapped women.

The advantages of oral contraceptives for developmentally handicapped women are largely congruent with those for the general population: a high rate of efficacy, few side effects, and a reduction in dysmenorrhea. This last attribute is a definite advantage for de-

velopmentally handicapped women with behaviour disorders, as these often increase during menses.

The general cautions about OCs apply to the developmentally handicapped population (see paper by Dr. Marion Powell, pp 1661–1664 in this issue).³⁵ There are, however, some very specific concerns about their use in this population:

- **Informed Consent.** Recent court decisions, supported by the 1985 report for Health and Welfare Canada,³⁵ oblige practitioners to explain, in significant detail, the material and substantial risks of oral contraceptive use.³⁶ It is clear that the physician cannot abrogate this duty because of an opinion that the patient cannot comprehend the information.

- **Compliance.** Special education may be necessary, as well as the involvement of a care giver, to ensure daily pill taking. The use of 28-day packages is helpful to reinforce regularity.

- **Drug Interactions.** Many developmentally handicapped persons are on anticonvulsants, and it is well recognized that these medications reduce the efficacy of oral contraceptives, as do many antibiotics and psycho-active drugs.³⁵ Correspondingly, the fluid retention commonly associated with OCs can precipitate seizures.³⁵

- **Contraindications.** Homocystinuria results in an increased likelihood of thrombosis. Several conditions associated with mental retardation result in liver disease. These include tyrosinemia and other aminoacidopathies, glycogen-storage diseases, and other diseases with defects in the metabolism of carbohydrates, Wilson's disease and other inborn errors of metabolism.³⁷ OCs are not indicated if there is active liver disease or a hypercoagulable state.

- **Women over 35.** All oral contraceptives (including the progesterone-only preparation) available in Canada now carry the precaution: "After the age of 35 years, for purposes of fertility control, oral contraceptives should be considered only in exceptional circumstances". Practitioners will need to decide in collaboration with others whether developmentally handicapped persons who are aged 35 or over are persons in exceptional circumstances. This decision is particularly critical, as one of the most common contraceptive options chosen at this age by persons who are not developmentally handi-

capped is sterilization, and the legal aspects make this choice extremely problematical at the present time (see below).

Intra-Uterine Devices

Intra-uterine devices (IUDs) have been widely used for conception control in the developmentally handicapped population. Chamberlain found them the third most commonly used technique,¹ and one author has recently recommended them as the ideal contraceptive.¹⁵ We cannot agree for several reasons:

- IUDs require placement under exacting conditions. The positioning of the patient and technique of placement may be perceived as highly threatening to some developmentally handicapped patients, and the re-checks required may accentuate this perception.⁹ Counselling and careful explanation of the procedure in advance may alleviate these fears.

- IUDs are associated with a much higher incidence of pelvic inflammatory disease than are other contraceptives.^{35, 38} The common symptoms of this disease are lower abdominal pain, fever, cramps and vaginal discharge. Developmentally handicapped persons may not be able to convey new symptoms easily to a care provider, and increased morbidity may result.

- Partly as a consequence of the last point mentioned, IUDs are now not generally recommended for nulliparous women.^{35, 39}

Barrier Methods

Little published work describes the use by developmentally handicapped persons of barrier methods such as condoms, foam and diaphragms. Chamberlain found no users of these methods,¹ and one author has stated that these methods have no relevance for the mentally handicapped.¹⁵

These contraceptive methods could be considered for particular developmentally handicapped persons for whom education was deemed possible and whose level of compliance was anticipated to be high. Cervical caps may be a possible option, as they could be inserted and changed by a health care worker at regular intervals if the person is unable to manage the insertion. They have the theoretical risk of toxic-shock syndrome in an analogous fashion to tampons, and this risk would need to be taken into consideration.

Long-Acting Progestins

Injectable contraceptives such as depo medroxyprogesterone acetate (DMPA, available in Canada as Depo-Provera) have been widely used throughout the world for fertility control, including that of developmentally handicapped women. DMPA, which has no estrogenic or androgenic properties, substantially reduces related side-effects as compared with combination OCs.³⁵ It has also been described as having fewer known risks of serious adverse reactions than the other highly effective means of contraception such as OCs and IUDs.^{35, 40} Pregnancy rates for women using a 150 mg injection of DMPA every 90 days have ranged from 0.0 to 1.2 per 100 women/years.

There are several advantages in using DMPA as a contraceptive for developmentally handicapped women:

- Compliance and education are not as important for efficacy as they are with OCs and barrier methods.

- The three-month timing of injections provides an opportunity for regular contact with the health care system.

- The resultant amenorrhea and subsequent avoidance of dysmenorrhea may prove beneficial both for hygiene and for behaviour.

On the other hand, there are also concerns about the use of DMPA:

- Awareness of the severity of the second-generation consequences of the use of diethylstilbestrol (DES) in the 1940s and 1950s supports caution before general adoption, despite lack of similarity of the compounds.

- One Canadian report has suggested a higher incidence of breast cancer in users of DMPA,⁴¹ although this report has been criticized extensively for its methodology.⁴² A higher incidence was not found in a subsequent historical cohort study, although only five years' follow-up was reported.⁴³

- Groups such as the Canadian Association for Community Living and the Canadian Association for the Mentally Retarded have urged a moratorium on the use of DMPA, citing both health and rights concerns.

- Concerns have been expressed about the effect on gender identification for developmentally handicapped women whose periods have been stopped by other means.⁴⁴ Similar arguments could conceivably be raised concerning DMPA.

At the time of writing, the Drug Directorate, Health and Welfare Canada, is actively considering the approval of DMPA as a contraceptive, and a decision is expected shortly. DMPA is currently licensed as a contraceptive in 85 countries, including the United Kingdom, but not the United States. It is also uncertain whether DMPA, if approved in Canada, will carry a warning about use by women over the age of 35 as do other OCS. A physician now using the drug for menstrual control or contraception would be prescribing a licensed drug for an unapproved use. In fact, "approval" by the Health Protection Branch of Health and Welfare Canada permits the manufacturer to promote or advertise the use of a given drug for a particular clinical indication. Physicians may prescribe a drug for other indications where, in their judgment, the benefits outweigh the risks, the appropriate information has been disclosed to the patient, and consent has been established.⁴²

Sterilization

Few issues concerning handicapped persons have been the source of as many divergent viewpoints and articles as has sterilization. Following the rise of the eugenics movement in the 19th century came efforts, in the first half of this century, to impose involuntary sterilization on the developmentally handicapped of this country as well as elsewhere.⁴⁵ Only relatively recently have eugenics laws been rescinded.¹¹

Since 1978, a moratorium has been imposed on the use of public hospitals for the non-therapeutic sterilization of minors in Ontario; non-therapeutic reasons include contraception.^{46, 47} The issue has been enhanced both in visibility and in importance by the Charter of Rights and by the "Eve" case, now before the Supreme Court of Canada. It is hoped that this case will provide guidance on the legal issues relating to the whole continuum of fertility, contraception and sterilization.^{44, 48} In this case the mother of a developmentally handicapped young woman sought in the P.E.I. courts an order declaring her daughter mentally incompetent, appointing herself as guardian, and authorizing her to consent to a tubal ligation for her daughter.²⁸ The trial judge refused to authorize "Eve's" mother to consent to the tubal ligation. He stated that the court

itself did not have the authority or jurisdiction to authorize a surgical procedure purely for contraceptive reasons. The P.E.I. Court of Appeal found that the court itself had jurisdiction, under its *parens patriae* power, to authorize a non-therapeutic sterilization of a mentally incompetent person. The appeal from this decision has been heard by the Supreme Court of Canada, and a judgment is pending.

The appeal to the Supreme Court in the *Re Eve* case has much broader relevance than simply the issue of sterilization. This case may give our country a ruling on whether there is any authority in statute or common law which would allow substituted consent to be given by a third party to non-therapeutic procedures for developmentally handicapped adults⁴⁹ and may clarify issues such as the prescription of contraceptives.

Some issues related to the choice of sterilization method for developmentally handicapped persons are similar to those for persons not so handicapped. Where stable relationships are involved, strong consideration should be given to male sterilization, since the procedure is less intrusive and less risky. Hysterectomy is an inappropriate treatment for contraception alone; there should be strong medical reasons for the removal of menses.

Conclusions

The increased integration of developmentally handicapped persons into the community has focused attention on issues common to the general population, such as sexuality and contraception. Health care providers are faced with the increased complexity of choice in ensuring the safety of persons with impaired intellectual and adaptive functioning, while not infringing on their rights, and while making certain that the consequences of the assumption of those rights are not overlooked. The balance is extremely delicate. ●

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