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Abstract

Discusses some recent court decisions concerning applications for hysterectomies to be carried out on young women with intellectual disabilities. Usually the application is made by the parents but the article is not concerned with the ethics of this. Instead, the authors focus on the reasons usually put forward and indicate the problems with this reasoning. It also covers the decisions made in recent cases and relates the issues involved. Note: Family Advocacy also holds a copy of an expanded version of this article appeared in the International Journal of Disability, Development & Education, Vol. 40 No. 2 pp.133-157 (1993). **Keywords: Legal, Women**

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The Legal Trends - Implications for Menstruation/ Fertility Management for Young Women who have an Intellectual Disability

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Introduction

In many countries around the world, women who have an intellectual disability continue to have their menstruation and/or fertility eliminated by hormonal or surgical means. Since 1988, there have been a number of Family Court of Australia cases where permission was sought for a hysterectomy (surgical removal of the uterus) to be performed on young premenarchal women (that is, women who have not yet begun to menstruate) who have an intellectual disability. Although the judges' opinions varied about whether parental or Court consent was appropriate, all of the judges supported the hysterectomies for the young women in the cases they heard.

The young women involved in these six cases ranged from 12 to 17 years of age. All were said to have a `severe' intellectual disability. All of the decisions (except in **re Marion**) were made on the basis of anticipated rather than actual difficulties, as the young women involved were premenarchal. In each case, the hysterectomy was said to prevent pregnancy, menstruation and possible psychological and behavioural problems.

After variations in decisions by individual judges in the previous cases, concerning the appropriateness of Family Court involvement, the **re Marion** case was referred to the Full Court of the Family Court of Australia. The Full Court decision was referred on appeal to the High Court of Australia for a decision on who had the authority to authorise `sterilisation'.

On 6 May 1992, the High Court ruled that the parents as guardians of Marion could not lawfully authorise the `sterilisation' procedure to be carried out without the order of a Court. A majority of four of the seven High Court of Australia judges concluded that "Court authorisation is required, first, because of the significant risk of making the wrong decision ... ▶

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and secondly, because the consequences of a wrong decision are particularly grave." (In the case of Secretary, Department of Health and Community Services and JWB and SMB, 1992:25). The High Court rules that judges of the Family Court of Australia can authorise the carrying out of such a procedure.

In each Court case, the young women's parents were seeking a hysterectomy. The integrity and good intentions of parents seeking hysterectomies is not being questioned. However, comprehensive information and practical support relating to a wide range of menstrual and fertility management approaches and the possibility of unknown long term effects of surgical or pharmaceutical approaches, does not appear to be readily available to parents. In addition, counselling to assist parents to consider their concerns and fears relating to their daughter's menstruation and potential to become pregnant does not appear to be available.

In addition, it is recognised that all professionals involved in these cases were seeking to assist the young woman and her family. However, the following commentary highlights some aspects of the Court cases which suggest that service provision organisations and schools could become more involved in supporting young women and their families in aspects of menstrual management and preparation.

Decision Making Criteria and Limits In The Family Court Cases

The basis for the Family Court decision was, in all cases, the `best interests and welfare' of the young women concerned. The concept of "best interests" in each of the cases was interpreted as the protection of young women from the possibility of distress from menstruation and pregnancy.

It was not perceived by any of the Family Court judges that allowing the women to experience menstruation and to receive reassurance and educational support was preferable or practicable. No decision making criteria have been suggested which refer to age of the young women and type of disability.

The Reasons Given for the Surgery

Statements or assumptions from the cases include: the use of mental age; the implication that menstruation is unnecessary and unhealthy; that removal of the uterus will have no long term health effects on the young woman; menstruation is inevitably painful; the young women will react negatively to her menstruation; inappropriate menstrual behaviour will inevitably develop and will be impossible to change; teaching menstrual skills is stressful and impractical; the young women are at significant risk of pregnancy; and independence in menstrual self-care is a necessary criterion for ongoing menstruation. It is only possible here to discuss some of these assumptions.

Several research studies have reported positive outcomes in teaching menstrual management skills to young women who have an intellectual disability and high support needs; for example, Demetral et al, 1983; Epps et al, 1990; Hamilton et al, 1969; Hamre-Nietupski & Williams, 1987; Richman et al, 1984; Richman et al, 1986.

However, in most of the judgments, teaching menstrual skills was viewed negatively. In the cases, suggested skill development approaches appeared to imply a high degree of structure. No information appears to have been discussed about informal approaches of facilitating the acceptance of menstrual experiences and the development of menstrual management skills with these young women. Partial independence in menstrual management seems not to have been considered. Toilet regulation for these young women often involves verbal or physical prompts and is perceived as an acceptable management goal. However, a requirement for complete independence and cognitive understanding in menstrual management that appears to be implied in the Family Court cases. If assisting young women who are dependent for toileting and bathing is acceptable, then assisting with menstrual tasks should also be considered.

In each premenarchal case, it appears to be assumed that menstruation will inevitably be a frightening or distressing experience for the young women involved.

Premenarchal preparation will not be discussed in detail in any of the Court cases. Preparation can include skill development and/or facilitating the young woman's acceptance of menstruation. Any young women who is not reassured that almost all women menstruate, and that this is a healthy bodily function, is likely to react negatively to the onset of menstruation. Preparation would need to be individualised according to abilities. Observing other women changing pads, basic explanations, reassurance, and pad wearing practice are some preparation approaches. ▶

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In all of the Court cases, fertility management was discussed, in addition to menstrual management, as a reason for surgical intervention. Potential pregnancy and its possible effects of the young women who has an intellectual disability and high support needs becoming pregnant, are not easy to access. In some of the cases, it was assumed that an attractive appearance and affectionate behaviour would lead to pregnancy. It was not clear whether there had been attempts to assist the young woman to learn more appropriate affectionate behaviour.

The risk of sexual abuse has been mentioned in some of the cases. If the women is perceived to be at risk of sexual abuse, the limited research available (for example, Chamberlain et al, 1984), suggests that the abuser is likely to be someone who knows her. It follows, therefore, that the risk of abuse may be increased if the potential abuser knows that detection through pregnancy will not occur, (Edwards, 1988; Hill, 1987).

Perhaps approaches to managing the young women's environment to minimise opportunities for sexual abuse could be considered.

The number of pregnancies among women who have an intellectual disability and high support needs appears to be very small. If a women who has a disability is choosing to be sexually active, a range of fertility management options (which do not involve menstrual suppression or elimination, and are used by many women without a disability) are available. It appears that it was mostly members of the medical profession who provided evidence favouring the proposed hysterectomy. Evidence from non-medical persons appeared to be either equivocal or not in favour of the hysterectomy.

The High Court of Australia judgment states that it "is not *merely* a medical issue".

The judgment states "that the consequences of sterilisation are not merely biological but also social and psychological".

The judgment states that "those experienced indifferent ways in the care of those with intellectual disability and ... those with experience of the long term social and psychological effects of sterilisation" should be given a hearing in the Court process. (In the case of Secretary, Department of Health and Community Services and JWB and SMB, 1992:26-27).

Medical professionals may not be contacting families and young women with high support needs who are managing menstruation and fertility without difficulties. Medical professionals may not be aware of alternative approaches.

In the Court cases, it appears to be assumed that long term effects of hysterectomy are not significant. Within the international medical literature, a body of research has been identified which suggests that long term effects of hysterectomy (ovaries not removed) for premenopausal women may occur. These include possible early menopause with hormone deficiency effects (Gordon et al, 1978; Riedel et al, 1986; Siddle et al, 1987). Recent research has also identified active secretory functions of the uterus which may have implications for a range of bodily functions, (Tseng, 1982; Petraglia, 1986; Cowan, 1986). No research has been identified which investigates the long term effects of hysterectomy (or ovariectomy, endometrial ablation, tubal ligation), on very young women over a long period of time. This gap in information may not have been recognised by those involved in the cases.

Rights

In each of the cases, it is assumed that the young women would be unaware of the implications of the hysterectomy. However, "A right does not depend for its existence on the capacity to make a rational informed decision whether to exercise it. It would be appalling if it were such, for then people with a profound disability would have no rights". (Carne, 1988:9) ▶

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The right to menstruate and the right to an intact anatomy and phycology was upheld by Justice Heilbron in a British Court case, **(In re D (a minor) 1976:7244)**. The recent High Court of Australia judgment concluded that the right to inviolability of the body and the right to reproduce are seen to be upheld in our common law, (In the case of Secretary, Department of Health and Community Services, and JWB and SMB, 1992:29-30).

Rights of the family and potential unborn child needs to be considered. However, these could be viewed in terms of rights to support services, rather than being in conflict with the rights of the young woman who has a disability. The recent High Court of Australia decision stated that "sterilisation is a step of last resort...so that...regard will necessarily be had to the various measures now available for menstrual management and the prevention of pregnancy". (In the case of Secretary, Department of Health and Community Services and JWB and SMB, 1992:36).

It is possible that, if relevant information and support is provided to young women, their families, and others involved in service provision, then the number of individual situations requiring Family Court decision making would be minimised.

This type of information and practical support could be made available through schools and other service provision organisations. Policies, resources and staff training need to be considered.

Menstruation is a normal physiological process in the lives of women with or without a disability. In most of the Family Court of Australia cases, menstruation and its management appears to be perceived as problematic for young women who have an intellectual disability and high support needs. Montgomery (1988:59-60) suggests that a `pessimistic' view of the young woman and of menstruation has been presented to the Courts and suggests that `assumptions' based on these views need to be clarified. A number of less restrictive alternatives to hysterectomy do not appear to have been explored. A proactive, supportive approach to assisting young women and their families prior to menarche would appear to be preferable to a potentially confrontational approach after decisions have been made on the basis of possibly limited information.

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