"Medical Procedures – Is the Law Effective?"

The Hon. Justice Murray
FCOA, Adelaide

Concurrent Session : 11am-1pm Friday 23 October 1998
"Medical Procedures?"

at the

Third National Family Court Conference

Sofitel Hotel Melbourne
Tuesday 20 – Saturday 24 October 1998

MEDICAL PROCEDURES – IS THE LAW EFFECTIVE? *

The Honourable Justice Kemeri Murray [+]

Background

Only 2 cases involving sterilization have gone to the High Court, Marion's case and P v P.[1] The High Court in Marion's case held that the authorisation of a court or a tribunal is required before a child can lawfully be sterilized, unless it occurs because of surgery to treat a malfunction or disease. Authorisation may only be given where the procedure is in the child's best interests and alternative, less invasive procedures have failed or it is certain that no other procedure will succeed. The Family Court has the power to hear these applications under its welfare jurisdiction. There also exists State legislation regulating the performance of medical procedures upon children and people with intellectual disabilities. However in P v P the High Court held that the Family Court's jurisdiction is not limited by the existence of state laws. The majority of matters that have come before the Family Court since Marion's case have been sterilisation applications. However there has been one matter seeking authorisation to perform a gender reassignment upon a hermaphroditic child and another where parents refused to consent to heart surgery. There also has been an interesting application in Tasmania where the parents applied to transfer the bone marrow of their child for the benefit of a relative. No benefit to the child was asserted. The judge granted the application. The decision is not reported.

If Australia follows overseas trends, it is probable that the diversity of applications will increase involving for example, the cessation of life support, donation of non-regenerative tissue and treatment for anorexia nervosa against a minor's wishes.[2] The sad fact is however, that applications for permission to carry out medical procedures on children under 18 have not increased and Ms Hastings will give the statistics on this – 17 Court (not tribunal) approvals for sterilizations over five years since Marion's case up to 1997 and over 1000 such procedures performed in hospitals. The Family Law Council estimates that only 3% of sterilisations performed have been through the necessary legal channels.

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[1] Secretary, Dept. of Health and Community Services v JWB and SMB (Marion's case) (1992) 175 CLR 218; (1994) 181 CLR 583.

[2] Brady,S "Invasive and Irreversible: The sterilisation of intellectually disabled children" Alternative Law Journal Vol.21, No.4, August 1996, p160.

Between 1996 and February 1998, 3 applications only were made to the Guardianship Board in South Australia for sterilizations of minors and none were made to the Adelaide Registry. Anecdotal evidence shows that there have been no applications made to any Family Court registries in Victoria in the last twelve months.

Following Marion's case there have been wide spread calls for uniformity between the State jurisdictions and the Family Court. The Minister for Justice referred questions concerning sterilisation procedures to the Family Law Council (FLC) who produced a discussion paper in 1993, *Sterilsation and other special medical procedures for Children* which formed the basis of their recommendations to the Commonwealth Attorney General and in 1994, *Sterilisation and other Special Medical Procedures for Children*. The 1994 report is important as it set ground rules for sterilisation applications. It described four circumstances where special medical procedures should never be performed:-

~ for eugenic reasons,

~ only for contraceptive reasons,

~ to mask/avoid sexual abuse consequences,

~ prior to menstruation due to predictions of problems.[3]

This report recommended that no special medical procedure be performed on children under 18 unless it is life-saving or to prevent physical or psychological damage. Where a procedure is non-therapeutic, less permanent forms of contraception must be ruled out, and only where the procedure is in the child's best interests will the court's authorisation be given. The FLC recommended that only the Family Court exercise this power to provide uniformity of decisions and to indicate the seriousness with which such procedures are viewed. It made this recommendation despite its reservations regarding the width of the best interests principle which underpins this jurisdiction as opposed to the narrower tests applied under state legislation.[4] The report also advocates more user-friendly services being available and advice given by the court, that separate representation be given to children and legal aid be provided to them and their parents.[5] The Full Court in P and P also laid down some important guidelines, including the need to appoint a child representative and the representative's role in the conduct of the proceedings.[6]

[3] Brady,S, "The Sterilisation of Children with Intellectual Disabilities" Australian Journal of Social Issues Vol.33, No.2, May 1998 p166.
[4] Keays-Byrne,S, "Sterilisation of Children: the need for uniform legislation" On the Record, April/May/June 1995 p9.
[5] Ibid.
[6] (1995) FLC 92-615.

Many commentators have advocated the introduction of guidelines and protocols to provide consistency between the State and Federal jurisdictions.[7] However they have also warned against the danger of complacency after the introduction of guidelines and rules.[8] The statistics already mentioned show that protocols and guidelines have not been effective in ensuring that the Court or Tribunal is given the role of decision making as the independent third body. The fact remains that most parents regard the need to get the Court's consensus as intrusive or impinging on their parental responsibility. They do not appreciate the nice distinction made by the majority decision of the High Court in Marion's case that the decision to sterilize an intellectually disabled child may involve not only the interests of the child but also the independent and possibly conflicting (though legitimate) interests of the parents and other family members. Nor will they necessarily understand that the High Court seeks to protect the personal inviolability of the child. They are likely to say, "What about my rights and powers as a parent?"

Human Rights and Equal Opportunity Report (HEROC Report)

This Report confirms that doctors and parents are privately agreeing to sterilize intellectually disabled children without a court or tribunal's authorisation. The Minister for Health Dr Wooldridge can identify those doctors who have performed these unlawful procedures, funded through Medicare. However the Minister made it clear this year on the 24th of August, that no retrospective investigations into the medical profession would occur.[9] The Report points out that people with intellectual disabilities must be assured of equality before the law and of their rights to seek compensation for unlawful medical assault in the civil courts.[10] One has to keep in mind however, that intellectually disabled children rarely have the capacity to exercise those rights without assistance and if their

[7] Brady, S, "Family Court to authorise Special Medical Procedures for Children: Tripartite Guidelines in Queensland: The Extended Jurisdiction" Proctor, September 1995; Commonwealth Secretariat, "Sterilisation and other Medical Procedures on Children" Commonwealth Law Bulletin Vol.22, Nos.1 and 2, January and April 1996 p243; Nygh, The Hon. Dr P, "Sterilisation and the Family Court: The Need for Guidelines", Australian Journal of Family Law Vol .10 No.2 August 1996; Brady,S "Invasive and Irreversible: The sterilisation of intellectually disabled children" Alternative Law Journal Vol.21, No.4, August 1996; Brady,S, "TheSterilisation of Children with Intellectual Disabilities" Australian Journal of Social Issues Vol.33, No.2, May 1998 p170.

[8] Keays-Byrne,S, "Sterilisation of Children: the need for uniform legislation" On the Record, April/May/June 1995 p9; Brady, S, "Family Court to authorise Special Medical Procedures for Children: Tripartite Guidelines in Queensland: The Extended Jurisdiction" Proctor, September 1995; Brady,S "Invasive and Irreversible: The sterilisation of intellectually disabled children" Alternative Law Journal Vol.21, No.4, August 1996.

[9] "VIC: Move for Tighter Rules to curb illegal Sterilisations", Melbourne, AAP, Australian Current Law News, Tuesday 25 August 1998.

[10] Brady,S and Grover,S "The Sterilisation of Girls and Young Women in Australia" Human Rights and Equal Opportunity Commission, December 1997 (summary).

parents do not seek the authorisation of the Court or a Tribunal they are unlikely to seek compensation for their child for an unlawful operation in which they have concurred.

The fact that few girls suffer from diseases of the reproductive tract and that this fact is no less true for girls with intellectual disabilities, means that few girls are sterilised as a result of therapeutic surgery. Although in some cases sterilisation is genuinely a last resort, often other alternatives have not been attempted. The problem of ignorance of parts of the medical profession as well as parents continues despite debate and submissions made on their behalf to the Family Law Council in conjunction with the extensive media reporting. The High Court itself acknowledged the difficulty in using the distinction between "therapeutic" and "non-therapeutic" procedures and the question arises as to whether this is too uncertain a test for the court or tribunal to apply. This uncertainty makes it difficult for the medical profession and applicants to know whether to make applications given the expense involved which anecdotal evidence shows is a major reason for the current flouting of the law. Given the savage cuts to legal aid over the past 12 months, expense has become an even greater disincentive for making an application. [11]

Marion's case distinguished special medical procedures from those that are performed to treat a malfunction or disease. Justice Brennan (as he was then) in his minority judgement states that proportionality and purpose are the legal factors to determine the therapeutic nature of medical treatment. Proportionality, he says, is determined as a question of medical fact. Purpose is ascertained by reference to all the circumstances but especially to the physical or mental condition in which the treatment is appropriate.

In P and P the majority of the Full Court of the Family Court were of the view that a distinction should be made between non-therapeutic sterilisations and "planned sterilisations". However one factor is certain: the distinction between therapeutic and non-therapeutic sterilisations is fundamental. The difficulty, as I have already set out, lies in the uncertain boundary between these procedures, which fails to protect those intellectually disabled girls unable to determine their own future. For example the difficulty of describing the special and aggravated problems of menstruation illustrate the grey area that exists between the terms therapeutic and non-therapeutic. The HEROC Report argues that only the treatment of a malfunction or disease qualifies as therapeutic procedures. The Family Law Council and the West Australian Law Reform Commission

state that their research shows that there is no effective way to distinguish between therapeutic and non-therapeutic procedures and therefore sees the distinction as useless. They both conclude that sterilisation is unlawful unless there is Court authorisation, regardless of its purpose. I do not take such a firm view.

For example, this view requires Court authorisation for indisputably therapeutic procedures such as the removal of ovarian cancer. This points to the need for law reform to clarify the therapeutic/non-therapeutic distinction. I believe that it is too pessimistic to say that without Court authorisation procedures will be performed without accountability. It is for the doctors in the first instance to make the decision and if in doubt they must consult the Court. However, this raises the ever-present problem of costs. The solution for this, as I have already intimated lies in the more generous allocation of Legal Aid.

The Full Court in P and P had a "but for" test put to it, viz whether sterilisation would have been recommended in the same clinical circumstances but for the girl's intellectual disability? If yes, it would be indisputably therapeutic, if not it may still be in the girl's best interests, but is non-therapeutic and thus needs Court authorisation. The Court rejected that test.

Views of Government Departments - SA Guardianship Board/Office of the Public Advocate

The Family Court and the State and Territory Guardianship Tribunals are authorised to consent to the sterilisation of persons with mental illness who are regarded as incompetent.[12] In South Australia sterilisation is a prescribed treatment and thus the elective consent of an independent decision-maker is required under the *Guardianship and Administration Act* 1993 SA. Under s61(2) the Guardianship Board cannot consent to a sterilization unless certain conditions are met (see Schedule 1). Because South Australia is a dual forum state a person may apply to the Family Court if they are unhappy with the Board's decision whereas they cannot apply to the Board where they are dissatisfied with a Family Court decision.[13]

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[11] Ibid.
[12] Carney T and Tait D, 1997, *The Adult Guardianship Experiment: Tribunals and Popular Justice*, Federation Press, Sydney in Dawes J, 1998, "Sterilisation, Mental Incapacity and Human Rights" 1998 Australia and New Zealand Criminology Conference.
[13] Dawes J, 1998, "Sterilisation, Mental Incapacity and Human Rights" 1998 Australia and New Zealand Criminology Conference.

Of the 16 applications made to the Board since March 1994 up to the start of 1998: 1 was withdrawn by the applicant, in 11 the applicant was the person's medical practitioner, one was made by a foster mother, 2 by a mother and the only male application was made the person himself. In the final case the Public Advocate was the applicant. 12 of the cases were classed as non-therapeutic, for example fertility control (contraception) and menstrual management rather than therapeutic/sterilisation for life-saving purposes to treat disease. In one case, the removal of large fibroids meant the removal of the uterus thus rendering the person sterile.

In 4 of the cases concerned only 3 were minors and consent was given in three of them. The one refusal was for an abdominal hysterectomy for menstrual/contraception reasons. This was quashed on appeal.[14]

Dawes in his paper argues that the appointment of a guardian by the Guardianship Board to make decisions concerning using medication to control fertility, suppress anti-social or nuisance sexual behaviour can often amount to sterilisation by stealth.[15] Similarly the impact of the medication (for eg Androcur and Depo Provera) accompanying temporary sterilisation renders it akin to sterilisation of a more permanent nature. In each of the eight cases discussed in his paper in some detail, the Public Advocate was appointed as the guardian. Of the professional persons applying for the appointment of the guardians only one was a medical practitioner, although there was significant medical evidence supporting mental incapacity in each case. Dawes notes that four of the eight applications were made by social workers despite the traditional non-interventionist and self-determination principles, which form the foundations of the social work profession.[16]

Many parents are unaware and perhaps would rather not want to know that consent to non-therapeutic sterilisation is not within a parent's legal responsibility. Dawes queries whether guardianship orders represent a less restrictive approach to the issue of consent to sterilisation. Due to the uncertainty which surrounds the appointment of the Public Advocate as guardian, Dawes queries whether its role is to make decisions or **to be available to make decisions should the need arise**? The *Guardianship and Administration Act* is silent on this issue. Dawes argues that the appointment of a guardian strips people of their rights and the appointment should only be used as a last

[14] Ibid.
[15] Ibid.

resort where there is no one else to make these decisions. I agree with him. It is open to the Public Advocate, to apply in the Family Court if thought appropriate, but there has never been such an application, and his reluctance to do so is quite understandable because of budgetary restraints.

Intellectual Disability Services Council's Discussion Paper (IDSC)[17]

The IIDSC sees difficulties with the two-stream system created by having both the Family Court and the Guardianship Board hearing sterilisation applications. Children and young people under 18 years may apply to either forum, people over 18 must apply to the Guardianship Board. However where the person in question is under 18 and they are unhappy with the Guardianship Board's decisions they may still apply to the Family Court. The Family Court is perceived by the IDSC (and it says anecdotally by other groups involved in this issue) as a medically orientated body, whose decisions evince a pro-sterilisation position and that it is a fast-track method to authorisation for the performance of special medical procedures.[18] I strongly disagree with that view and I point out the inconsistency in its approach later when dealing with its attitudes to the Court protocols.

The IDSC fears that the Court and the Board will be played off against each other. The Family Court, it says, deals with these applications in an essentially adversarial way, but I do not believe this to be the case. They argue that the training given to Family Court Judges will never equal the level of understanding the Guardianship Board possesses given its daily dealings with intellectually disabled people. That is a matter of opinion. The Court usually appoints a representative for the child and hears evidence in the usual way. The Court usually requires expert medical evidence and the child representative, who after all, must act in the best interests of the child, may cross-examine the expert, and why not, if the child representative is of the view that the medical procedure is not warranted. Strong questioning should elicit the truth of the matter, and for the child's welfare, I think that is of prime importance. If the IDSC regard that as adversarial so be it. I cannot imagine that the Guardianship Board does not ask questions so as to satisfy itself one way or the other. The Court is not in competition with the Guardianship Board - each has the welfare of the child as its prime consideration. The IDSC argue for a consolidation of

[16] Ibid.
[17] Martin,R and Butler,C "Sterilisation of People with Intellectual Disability – A Discussion Paper", Intellectual Disability Services Council. December 1997.

expertise in a tribunal such as the Guardianship Board, but acknowledge that this is unlikely, given the High Court's decision in Marion's case.

Expert evidence can make both the Family Court and tribunals aware of the gravity of incorrect decisions on sterilization it is apparent (and apparently it is) from the results of long-term research, which documents the effects of hysterectomies such as early menopause, loss of bone density leading to osteoporosis and the risk of fractures increased risk of heart disease and accelerated ageing.[19]

The research done with families, apart from the expense, shows the main reason for applying for the procedure is that they were not aware of management techniques nor were appropriate resources offered to assist families with ongoing fertility management. Thus instead of a problem based focus, there needs to a proactive one which uses case management methods.

The IDSCs approve of the approach of the Family Court in the Northern Region and its emphasis in the protocol developed with Legal Aid, Department of Families, Youth, Community Care that sterilisation is only to be authorised as a last resort where it is in the best interests of the child. That is the view espoused in South Australia although we do not as yet have a protocol. We are working on one however. On 6th October last SES Registrar Cashen met with the IDSC together with representatives from the Public Advocate, the Guardianship Board, the Legal services Commission, Shine (formerly known as Family Planning), the Attorney-General's Department and the Children's Interests Board to discuss a variety of issues including protocols and the need for a seminar along the lines of the one conducted in Melbourne on 28th March last. I regard the organisation of a seminar as most important. Education seems to be the most effective way to go, although I have my doubts for the immediate future, as the anecdotal evidence is that the Victorian seminar, attended by medicos and hospital representatives, has

[19] The emotions clouding the issue of sterilisation is only part of the problem surrounding the sterilisation procedures. The historical position of intellectually disabled women who are viewed as "other" within the patriarchal able-bodied society places these girls and young women in a powerless position vis-a-vis the at times paternalistic medical profession. Brady argues that in comparison to the daily management of bowel and bladder functioning required by some intellectually disabled people, the 5 days of menstrual bleeding per month should not be seen as an insurmountable task. She further states that the fear of pregnancy for intellectually disabled girls and young women is not borne out by the statistics. Brady,S "Invasive and Irreversible: The sterilisation of intellectually disabled children" Alternative Law Journal Vol.21, No.4, August 1996, p162 in Martin,R and Butler,C "Sterilisation of People with Intellectual Disability – A Discussion Paper", Intellectual Disability Services Council. December 1997 p2.

provided little change in the numbers of applications made to the Court. However, we should continue with education, remembering that research shows that it takes between 10 and 20 years for a message to permeate the community and change attitudes.

The IDSC believes that in South Australia the Family Court and the Guardianship Board need to be meshed. As the legislation stands at present, this is not possible. It is the Court's view that it is vital that the rights of people with intellectual disability be the cornerstone of all decision making and informs all parts of the decision making process.

The Protocols

The Queensland Protocol and Guidelines have been entered into by the Northern Region of the Family Court, the Department of Families, Youth and Community Care and the Queensland Legal Aid Office. It aims to enunciate the approach to be followed when an application is made for a special medical procedure. The guidelines contain a statement of its seven objectives, the procedure to be followed in these applications and how referrals between organisations will work. The Primary Dispute Resolution (PDR) model is recommended to provide a structure for negotiation between parties, (if that is necessary) including its 5 aims and the 5 dispute resolution options. Then the post-filing procedures are delineated. The listing of special medical procedures is to be expedited, conciliation conferences should be attended prior to the first return date, at which time the appointment of a child representative will be considered and if made, the matter will be adjourned for 8 weeks. Legal Aid should appoint and fund the child representative. The child representative's role is to put all relevant material in relation to alternatives to sterilisation before the court and make submissions where appropriate on behalf of the child. At the subsequent mention date, orders for further conciliation conferences or PDR options are canvassed, as is the appointment of a Court expert and whether a conference of experts should be held. Special Case Management Guidelines apply to these matters. The role of the Department is to assist the Court with obtaining relevant information and evidence.

The aim of the protocol and guidelines is to promote positive outcomes for the child and their family, provide unambiguous circumstances in the court forum and to improve the calibre of investigation and evidence placed before the court. It appears to have succeeded in diverting applicants from the court and providing them with needs-based

services.[20] In the period from September 1994 and December 1997, 10 out the 11 applications for special medical procedures filed in the Brisbane Registry of the Family Court were diverted, ie procedures other than sterilzation were agreed upon. The guidelines and protocols are aimed at facilitating "a process of informed decision making by encouraging a situation where all parties (and particularly parents) have access to and opportunities for the exchange of relevant information at an early stage" of these very difficult issues they are trying to understand.[21] The emphasis is upon maintaining flexibility in alternatives and the resolution of problems through the identification of, and access to, services. The objective of maximising participation and co-operation between all those involved who seek to advance the welfare of the child requires a co-operative and not an adversarial process. Thus it becomes clear that the remaining problems with the special medical procedures application process is one of information and not medical or legal issues.[22]

The Victorian Guidelines and Protocols aim to inform the court and practitioners (and other interested parties) of the protocols existing between the Southern Region of the Family Court, the Office of the Public Advocate and Victorian Legal Aid (supported by the Victorian Department of Human Services) of the preferred approach to applications for special medical procedures being performed upon children with intellectual disabilities. The guidelines aim to promote positive outcomes for the children involved, discuss with intending applicants the wider issues involved and alternatives available, and to ensure the timely and consistent management of special medical procedures under Order 23B. The court and the VLA will refer enquiries to the OPA that advocate for the child before applications are filed. The OPA will discuss less evasive alternatives. Where applicants choose to proceed, the OPA will assist with obtaining independent medical reports and experts' recommendations, which will be given to the child representative. The Advocate will organise a meeting with the applicant, where they will indicate their attitude to the application. Where the applicant wishes to proceed, the OPA will refer them to the Program Co-ordinator of Family and Civil Law at the VLA.

The VLA will in turn refer enquiries concerning children with intellectual disabilities to the OPA. Should the enquirier decide to proceed to court, the Program Co-ordinator arranges

[20] Brady,S, "The Sterilisation of Children with Intellectual Disabilities" Australian Journal of Social Issues Vol.33, No.2, May 1998 p170.
[21] As above at p172.
[22] Ibid.

for them to obtain initial advice from a VLA lawyer or will refer them to a private lawyer with the necessary expertise. Any application made to the Family Court will be referred to the Designated Registrar who is the only person who can issue an application under Order 23B. They will as soon as practicable inform the OPA and the VLA and in consultation with the Judge Administrator list the application within 14 days. The Court is to give the applicant procedural help, copies of forms, advice viz Rules, Guidelines and Protocols. The applicant must give the OPA all the material filed with the court. On the first return date the court may order the appointment of a child representative and the procurement, filing and serving of relevant material. The VLA should provide and fund the child representative. The child representative's role is to gather and put before the court all material relevant to the decision it must make. They will make submissions concerning the pros and cons of alternative options and of sterilisation itself. If possible the child representative will place the child's view before the court. They will also make submissions about the case management, orders sought and where appropriate their attitude to the procedure. The OPA may attend and act as amicus curiae. The matter is to be adjourned for no more than 8 weeks. The court and other interested bodies have produced a Guide, A Question of Right Treatment, identifying topics the court will consider in the determination of a sterilisation application. The Guide has the following guiding principle: sterilisation should only be considered after all other alternatives and then only as a last resort where it will be in the best interests of the child.

In addition to the guidelines and protocols the Melbourne Registry of the Family Court has produced an impact statement. It sets out the roles of the Judges, Listing Registrar, IUL staff, Listing Manager, and Counsellors. It ensures that Order 23B is followed. The impact statement aims to establish how members of the special medical procedures "team" will work internally and with external organisations to promote the welfare of the children involved in these applications.

The figures I have quoted show that however admirable the protocols and guidelines may be, compliance regarding medical procedures, particularly sterilizations is low. So the answer to the question with which I have headed my paper is a mixture of "Yes and No". The true effectiveness, I believe, lies in patience and persistence in education and awareness building. In addition we need adequate legal aid for child representatives and parents.

Schedule 1

Guardianship and Administration Act 1993 (SA)

S61(2) the Guardianship Board cannot consent to a sterilization unless:

(a) it is satisfied that it is therapeutically necessary for the sterilization to be carried out on the person;

or

(b) it is satisfied –

(i) that there is no likelihood of the person acquiring at any time the capacity to give an effective consent;

(ii) that the person is physically capable of procreation;

and

(iii) that –

(A) the person is or is likely to be sexually active and there is no method of contraception that could, in all circumstances be expected to be successfully applied;

(B) in the case of a woman, cessation of her menstrual cycle would be in her best interests and would be the only reasonably practicable way of dealing with the social, sanitary or other problems associated with her menstruation,

and has no knowledge of any refusal on the part of the person to consent to the carrying out of the sterilization, being a refusal that was made by the person while capable of giving effective consent and that was communicated by the person to a medical pracititoner.

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