

THE STERILISATION
provide a short introduction to the law, legal terminology
AND YOUNG WOMEN

issues & progress

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introduction

It is common in the legal commentary to refer to child sterilisation as if it is a gender neutral issue,¹ but the overwhelming majority of sterilisations and certainly all the cases heard by relevant Australian courts and tribunals, involve female children with intellectual disabilities. There is social problem at the centre of the debate about sterilisation. Sterilisation is a procedure that is notorious for having been performed on young women with disabilities for various purposes ranging from eugenics² through menstrual management and personal care,³ to the prevention of pregnancy,⁴ including pregnancy as a result of sexual abuse.⁵

Sterilisation of children⁶ in the Australian context is related primarily to two characteristics – gender and disability.

¹ Graycar, R. (1994). Sterilisation of young women with disabilities: towards a regulatory framework *Australian Journal of Human Rights* (1) 1 pp 380-381.

² Secretary, Dept of Community Services and Health v JWB and SMB, 1992 CLR 218. See discussion by Judge Brennan at 275. An acknowledgment to Mr Baldwin Reichwein RSW, former Assistant Director of Child Welfare, and Associate Professor Gayle Gilchrist James, University of Calgary, Alberta, who contributed research materials on the issue of sterilisations and compensation.

³ Carlson, G., Taylor, M., Wilson, J., & Griffin, J. (1994) “*Menstrual Management and Fertility Management for Women who have Intellectual Disability and High Support Needs : An Analysis of Australian Policy*”, Project funded through a Research and Development Grant from the Commonwealth Department of Health, Housing and Community Services.

⁴ Family Law Council (1993), “*Sterilisation and Other Medical Procedures on Children*” : A Discussion Paper and Family Law Council (1994) *Sterilisation and Other Medical Procedures on Children : A Report to the Attorney-General*, Canberra

⁵ *ibid* and see Little, H. (1993). Non-consensual sterilisation of the intellectually disabled in the Australian context: potential for human rights abuse and the need for reform, *Australian Yearbook of International Law* p 203, and see Rhoades, H. (1995). Intellectual disability and sterilisation - an inevitable connection? *Australian Journal of Family Law* 9, p234.

⁶ This report is about the sterilisation of girls and young women up to 18 years of age. We use the terms “child,” “girl,” or “young woman” interchangeably, because sterilisation procedures are carried out on minors who are not teenagers and/or have not commenced menstruation. We are conscious of the potential criticisms that by so doing we are using language which trivialises the rights and capacity of young people who are yet to reach 18 to have expressed and considered views about their sexuality, reproduction rights, health and well being. By “sterilisation” we mean a surgical intervention that results either directly or indirectly in the termination of an individual’s capacity to reproduce. Typically we refer to “sterilisation procedures”, by which we mean those medical interventions which are known to or are reasonably likely in all circumstances to cause sterilisation whether or not that is the purpose for which they are carried out.

The High Court of Australia held in 1992, in a case known as Marion's case,⁷ that court or tribunal authority is required before any child can lawfully be sterilised, unless the sterilisation occurs as a by-product of surgery carried out to treat some

malfunction or disease. It said authorisation may only be given if sterilisation is determined to be in the child's best interests after alternative and less invasive procedures have all failed or it is certain that no other procedure or treatment will work.

The former Disability Discrimination Commissioner, the late Elizabeth Hastings, subsequently became concerned that the principles laid down by the High Court were not being complied with, and commissioned and published "*The Sterilisation of Girls and Young Women in Australia: a legal, medical and social context*" hereafter called the 1997 Report.⁸

It described the legal framework that applies to decision-making in respect of sterilisation of children post Marion, and provided commentary on the distinction between therapeutic and non-therapeutic sterilisation and the key principles of best interests of the child and procedure of 'last resort'.

It described the reasons that are commonly given in support of the sterilisation of girls and young women and the medical procedures by which they are sterilised. It also described the alternative and less invasive ways by which the apparent 'problems' might be resolved.

And finally, it also analysed the available data in relation to the numbers of girls and young women who are being sterilised, lawfully or otherwise. It found that sterilisations of girls and young women since Marion's case far exceeded those authorised by courts and tribunals, and concluded that the law had failed to protect significant numbers of children from abuse of their fundamental human right to bodily integrity.

⁷ Secretary, Dept of Community Services and Health v JWB and SMB, 1992 CLR 218

⁸ Brady, SM & Grover, S.(1997). "*The Sterilisation of Girls and Young Women in Australia: a legal, medical and social context*, commissioned by the Disability Discrimination Commissioner HREOC.

This report summarises some developments since the 1997 Report, including responses to it most notably debate about the numbers of sterilisations being performed. It provides up-to-date information on the number of applications to the Family Court or relevant State Guardianship Tribunals.⁹ It is written to contribute to further community discussion in this sensitive area.

⁹ The raw data used in this report is derived from PhD research on special medical procedures for children by SM. Brady, University of Queensland, School of Social Work & Social Policy. Special thanks to the Family Court of Australia, the New South Wales Guardianship Tribunal, the Guardianship Board of South Australia and the Office of the Public Advocate, South Australia, for their support and assistance.

CHAPTER ONE

the legal framework

(a) the High Court's decision in 'Marion'

In 1992 the High Court of Australia decided in *Marion* that the scope of parental authority did not extend to special medical procedures like sterilisation. It noted that:

- court authorisation is required because procedures like sterilisation require “invasive, irreversible and major surgery” (*Marion* at 250);
- there is a significant risk of making a “wrong decision” about both the child’s present or future capacity to consent. This is true for all children, however, the potential for wrong assessment about capacity is “affected by commonly held misconceptions about the abilities of those with intellectual disabilities” (*Marion* at 250);
- doctors play a central role in what is not just a medical decision (*Marion*, at 232), but absolute faith in the integrity of all medical practitioners is not warranted (*Marion* at 251);
- it is possible that parents, other family members, and carers may have conflicting interests which would influence their decision, (*Marion* at 306);
- the consequences of making a wrong decision are particularly grave taking into account the “fundamental right to personal inviolability existing in the law” (*Marion*, at 253), the “invasion of the right to personal integrity” represented by sterilisation (*Marion*, at 266), and the resulting inability to have children in circumstances where “the decision to sterilise ... is not merely a medical issue” (*Marion*, at 250-252);
- the requirement of court authorisation “ensures a hearing from those experienced in different ways in the care of those with intellectual disability and from those with experience of the long term social and psychological effects of sterilisation.” (*Marion*, at 259).

The High Court proscribed guiding principles, setting the benchmark for future directions in decision-making for children.¹ It said that:

¹ See Joint Standing Committee on Treaties.(1998). *United Nations Convention on the Rights of the Child : Executive Summary*: United Nations Convention on the Rights of the Child (17th report) (1998) Parliament of the Commonwealth of Australia Canberra. p 7.

- the issue for the court in considering whether to consent to a sterilisation procedure is whether in all the circumstances of the particular child the procedure is in the child's best interests (Marion at 259);
- sterilisation procedures should never be authorised unless "some compelling justification is identified and demonstrated" (Marion, at 268); and
- to come to the view that a sterilisation procedure is in a child's best interests the court has to be satisfied that sterilisation is a step of "last resort", or in other words that "alternative and less invasive procedures have all failed or it is certain that no other procedure or treatment will work" (Marion, at 259-260).

Having decided that a sterilisation procedure should be a step of 'last resort,' the High Court then acknowledged that:

- taking the child's best interests as paramount necessarily means excluding the interests of others except to the extent that they have a bearing on the best interests of the child (Marion, at 270-272);
- caring for a child with an intellectual disability "adds a significant burden to the ordinarily demanding task of caring for children" and that subject to the child's best interests, "the interests of other family members, particularly primary care-givers, are relevant to a court's decision whether to authorise sterilisation. However, court involvement ensures, in the case of conflict, that the child's interests prevail" (Marion at 306);
- "in the circumstances with which we are concerned, the best interests of the child will ordinarily coincide with the wishes of the parents" (Marion at 260), but "on occasion, the courts may refuse to authorise a sterilisation desired by the parents" (Marion at 315).

The decision in Marion reflected a shift in the law in attitudes towards children with disabilities by adopting a rights-based focus consistent with international conventions on human rights, and is an Australian case study of the interplay between law, social theory and disability.²

It was seen as a major advance for the human rights of people with disability. The High Court explored policy issues inherent in past discriminatory approaches to

² Jones, M. & Marks, LAB. (2000). Valuing People through Law - whatever happened to Marion? In (Eds.) M, Jones, and LAB, Marks, *Law in Context Special Issue: Explorations on Law and Disability in Australia*, Sydney: The Federation Press p153.

people with disabilities, and was especially concerned for girls and women given the social and political history during the infamous eugenics period.³ It acknowledged that sterilisation was not about medical issues per se but rather gender issues⁴ and disability discrimination.⁵

From a disability perspective the most significant aspect of Marion is the articulation that children with disabilities have a right to bodily integrity. The right to bodily integrity is a fundamental principle of common law and by proclaiming that girls and young women with disabilities are entitled to personal inviolability the law treats them as having equal value as other children, and in this way affirms the inclusion of people with disabilities as citizens in the life of the community.

More broadly, from a social policy perspective, Marion's case acknowledged the traditional reluctance of courts to interfere with family privacy and autonomy⁶ but noted the need to balance respect for family interests⁷ with the protection of the child's right to bodily integrity. It acknowledged that children and parents co-exist in a social context and that their rights may be both interdependent and conflicting. It highlights the public interest in scrutinising differential and ethically contentious medical procedures for children⁸ and clearly articulated the need for heightened accountability in this type of decision making.

While it acknowledged human rights and broader socio-political issues, the High Court appears at the same time to have adopted a 'child welfare' approach by using the "best interests of the child" as the paramount principle for decision making. Socio-legal commentary is divided on this interpretation and remains undecided about what

³Goldhar, J (1991). The Sterilisation of Women with an Intellectual Disability, *University of Tasmania Law Review* 10 pp 157-195.

⁴ Graycar, R.(1995). The Gender of Judgements - an introduction, In (Ed.) M,Thorton *Public and Private - feminist legal debates* Melbourne : OUP pp 262-305

⁵ Fulcher,G.(1995).Disability : a social construction In (Eds.) Lupton,G & Najam.J. *Sociology of Health and Illness - Australian Readings* : OUP pp 47-61

⁶ Carmichael & Sarre, 1994; Legal issues: the welfare of and responsibility for children under the law in Australia. In (Ed.) F, Briggs *Children and families: Australian perspectives.*, St Leonards NSW : Allen and Unwin pp 102-125

⁷ Petersen, K.(1992). The Family v the Family Court :sterilisation issues *Australian Journal of Public Health* 16, (2) pp196-201

⁸ Jones, M & Marks, LAB.(1997).Female and Disabled: A Human Rights Perspective on Law and Medicine In (Ed.) K, Petersen, *Intersections: Women on Law Medicine and Technology* Dartmouth: Ashgate.

the High Court meant. Some commentators see the decision as endorsing an approach to decision making in these matters based on fundamental human rights, whereas others see it as endorsing a paternalistic child welfare approach. The decision can be read either way, and is. Both the Joint Standing Committee on Treaties⁹ and the Australian Law Reform Commission¹⁰ have recognised the potential for discrepancies in outcomes for children.

Judge Brennan of the High Court noted that the application and interpretation of the best interest principle in sterilisation matters raises questions of policy which:

“involve issues that are as much social or moral as they are legal and the answer to them is inevitably affected by personal perceptions of the current social conditions, standards, and demands”¹¹

The debate about the proper approach to the sterilisation of children with intellectual disabilities raises issues of how to balance competing social and moral interests in these sensitive cases, how to address the issue of differential or discriminatory treatment on the basis of the characteristics disability and gender, and how to ensure that the child’s rights and interests are protected whilst respecting the rights of others.

Marion’s case also raised issues about the potentially broader scope of federal political authority to legislate for the protection of children. In coming to its decision the High Court recognised it brought with it a need for law reform:

“[We] acknowledge that it is too costly for most parents to fund court proceedings, that delay is likely to cause painful inconvenience and that the strictly adversarial process of the court is very often unsuitable for arriving at this kind of decision. These are clear indications of the need for legislative reform, since a more appropriate process for decision making can only be introduced that way.”¹²

There has been debate subsequently about the appropriate process, and whether the decision to sterilise should be governed by clear and legislated criteria or be

⁹ Joint Standing Committee on Treaties (1998). *United Nations Convention on the Rights of the Child : Executive Summary (17th Report)*, Parliament of Australia. Canberra.

¹⁰ Australian Law Reform Commission (1997). *Review of the adversarial system of litigation: rethinking family law proceedings*. (ALRC:IP 22) Sydney.

¹¹ Marion at p 234

¹² Marion at p 253

discretionary, but it has not resulted in the sort of reform the High Court envisaged.¹³ The Family Court has rejected the need for legislation about when a sterilisation can be authorised and prefers an ‘individualised’ case-by-case approach.¹⁴

(b) the decision-makers

The High Court in *Marion* decided that the scope of parental authority does not extend to special medical procedures like sterilisation, and that only a court has authority. In practice, that court is the Family Court of Australia exercising its welfare jurisdiction under the Family Law Act.

Two States, however, New South Wales and South Australia, enacted legislation prior to *Marion*¹⁵ prohibiting sterilisation of children (emergencies aside) without the approval of their respective Guardianship Tribunals in accordance with specific legislative criteria. Guardianship Tribunals in all Australian States deal primarily with adults with impaired decision making abilities, but in NSW and South Australia, also exercise concurrent jurisdiction alongside the Family Court in relation to the sterilisation of children.¹⁶

The Family Court and State Guardianship Tribunals have different traditions and processes.

The Family Court is a federal court and is constitutionally protected. It is essentially adversarial although it has features that are inquisitorial in approach. It prefers parties to proceedings to have legal representation, which is costly. Judges in the Family Court are given life long appointments. The application for sterilisation is heard by a single judge. The decision-maker, the judge, decides whether to authorise the

¹³ See Family Law Council (1993). “*Sterilisation and Other Medical Procedures on Children*” : A Discussion Paper and Family Law Council (1994) *Sterilisation and Other Medical Procedures on Children : A Report to the Attorney-General*, Canberra

¹⁴ *ibid* and see *P v.P* (no 2) (1994-1995), 19 Fam LR 1

¹⁵ See Brady, SM & Grover, S.(1997). “*The Sterilisation of Girls and Young Women in Australia: a legal, medical and social context*, a report commissioned by the Disability Discrimination Commissioner Human Rights and Equal Opportunity Commission, December .Sydney. See discussion at pp 8-10

¹⁶ *ibid*

sterilisation on the basis of arguments put by the applicant and other parties to the application.¹⁷ Appeal of a decision is made to the Full Bench of the Family Court.

The Guardianship Tribunals are characterised as ‘inquiring’ in approach. They take a more active role in shaping how a matter develops, what information needs to be collected, and how it is to be collected. They do not require legal representation and charge no fees. Appeals of tribunal decisions are to the Supreme Court in NSW, and the Administrative Appeals Tribunal in South Australia. Alternatively because it exercises concurrent jurisdiction, aggrieved applicants may take the matter to the Family Court for ‘re-hearing’ and the Family Court’s decision takes precedence.

The tribunals are not constitutionally protected like the Family Court. They comprise of people from multi-disciplinary backgrounds with experience in disability issues.¹⁸ Multi-disciplinary evaluation has been identified as “*one of the most controversial yet one of the most important protections that can be extended*”¹⁹ to marginalised groups like people with disabilities. Tribunal members are mostly part-time and appointed by the State government for fixed terms, usually three years.

(c) disability legislation & medical treatment decisions

There was considerable legislative activity in the disability field before Marion’s case with the implementation of anti-discrimination legislation, guardianship legislation and legislation in relation to service funding. Disability law by its nature sets up a framework for the consideration of ‘social facts’ like the recognition of past discriminatory and differential responses to people with disabilities. The guiding principles for decision making espoused in Australian disability law and in

¹⁷ For a discussion of the issues relating to adversarial court based systems and children’s matters see generally, ALRC. (1997). *Review of the adversarial system of litigation: rethinking the federal litigation system* (ALRC IP 20), Sydney, and ALRC. (1997). *Review of the adversarial system of litigation: rethinking family law proceedings* (ALRC IP 22) Sydney, and ALRC.(1999). *Review of the federal civil litigation system* (ALRC DP 62) Sydney.

¹⁸ It is a requirement that applications for sterilisation are heard by a minimum of three people at least one being a woman. Each panel comprises a chair person who is a lawyer versed in human rights law, a professional member, usually a doctor, and a ‘community’ member with a social science background or direct disability experience as person with disability or as an advocate or carer. Some board members have both a professional background and personal experience.

¹⁹ Galt, B. (1986). A Critique and Revision of the Utah Guardianship Statute for Incapacitated Persons *Utah Law Review* 629-663 at p645

guardianship legislation (which is part of it) have an international character, and are modelled on United Nations Charters and Conventions.

The guardianship 'model' in Australia operates within a legal tradition based on common law protection of vulnerable persons but incorporates modern notions of self-development and inclusion in the life of the community. The model replaces the traditional paternalistic approaches of courts (ie; the ancient *parens patriae* role). The model presents as having multiple objectives that appear philosophically incompatible the most obvious being a policy tension between promoting rights and paternalistic protection.²⁰

Disability legislation relating to decisions about health and life-style matters adopted a rights based focus and a minimalist role for intervention in the lives of people with disability. Intervention must be the least restrictive alternative possible in all the circumstances and be the last resort confining interference in the lives of people with disability to cases of demonstrated and immediate need. Whether issues involve personal autonomy or bodily integrity, the guiding principles in disability legislation act as 'gate keeping devices' by limiting possibilities for discriminatory and differential interventions on the basis of the characteristic 'disability.'

Historically guardianship and family autonomy have been closely linked and the use of the word 'guardian' is most commonly associated with a person who has legal authority for a child. Guardianship thus has a parent-child signification which could arguably shape expectations about the type of decisions tribunals should make. Evaluation research indicates that the Guardianship Tribunals engage in verbal '*affirmation of the family as a caring institution*' during the hearing process making exhortations for family relationships and bonds to be maintained even though in many cases the tribunal decides against the expressed wishes of the parents or family members.²¹ In this way both the Family Court and the Guardianship Tribunal models

²⁰ See for discussion of these issues Carney, T.(1992). Civil and Social guardianship for intellectually handicapped people *Monash Law Review* 8 (3) pp 199-232

²¹ See Carney, T & Tait, D (1991). *Balanced accountability: an evaluation of the Victorian Guardianship and Administration Board*, Melbourne, OPA ; and see Carney, T. and Tait, D. (1997). *The Adult Guardianship Experiment : tribunals and popular justice*, Sydney: The Federation Press.

acknowledge the importance of the family, their expressed wishes, and the maintenance of existing relationships.

Legal researchers and commentators espousing the merits of guardianship tribunal approaches place emphasis on their links with local communities and service delivery systems.²² Linkages with services are viewed as promoting a practical response in developing supports for the child and family²³ and alternatives to surgical sterilisation.²⁴ The model aims to deliver socially integrative solutions to complex social problems by recognising the need for links with service delivery systems. Linkages with local service delivery systems is a critical factor in the ability of families to address issues of concern that may arise regarding fertility and menstrual management for their daughters.²⁵ A decision-making forum that has linkages or has the capacity to develop them at a local service level is a practical response to meeting the needs of families who may wish to pursue an application for sterilisation. Evaluation research has shown that this approach works well for adults with decision making disabilities.²⁶

²² See Carney, T.(2000). "Protection, Populism and Citizenship" *Law in Context* : Special Issue 17 (2) in Jones,M & Bassar Marks, LA (Eds) *Explorations on Law and Disability in Australia*, The Federation Press, Sydney and Carney,T and Tait, D. (1997). *The Adult Guardianship Experiment : Tribunals and popular justice*, Sydney: The Federation Press. The guardianship 'culture' is different to that of the court-based model. Professionals providing services to people with disabilities are bound by the objectives of disability legislation and services policy, including objectives in regard to community participation and inclusion, and services must promote a positive image of persons with disabilities. Refer footnotes 21-25.

²³ See Brady, SM. (1996). Invasive and Irreversible - The Sterilisation of Children with Disabilities *Alternative Law Journal* 21 (4) pp 160-165

²⁴ See Grover, S. (1997). Menstrual and contraceptive management for women with intellectual disabilities *Royal Australian College of Obstetricians and Gynaecologists Bulletin* 11 (2) pp 12-14

²⁵ See Carlson, G., Taylor, M., Wilson, J, & Griffin, J.(1994) "Menstrual Management and Fertility Management for Women who have Intellectual Disability and High Support Needs : An Analysis of Australian Policy"; Project funded through a Research and Development Grant from the Commonwealth Department of Health, Housing and Community Services.

²⁶ refer footnotes 21 and 25

CHAPTER TWO

the debate about numbers

The 1997 Report found that the number of sterilisations far exceeded those authorised by courts and tribunals. It concluded that:

“Courts and tribunals have authorised a total of 17 sterilisations of girls since Marion’s case. Meanwhile data collated by the health insurance commission shows that at least 1045 girls have been sterilised over this same period, and this figure counts only those sterilisations which qualify for a medicare benefit and for which a claim has been processed. It excludes sterilisations carried out by hospital doctors on public patients in public hospitals. Comparisons with other data sources suggest that the true number may be much greater, perhaps by a factor of several times”¹.

(a) the most recent ‘official data’ on sterilisation of young women

The Federal Minister for Health at the time of the 1997 Report disagreed with the numbers and said there were about two hundred sterilisations performed on female minors not the thousand reported.² More recently the Senate Report on “Sterilisation of Women and Young Girls with an Intellectual Disability” tabled in December 2000 by the Minister for Family and Community Services and the Minister assisting the Prime Minister for the Status of Women (hereafter called the Senate Report) puts the numbers even lower. It notes on the basis of the Australian Institute of Health and

¹ Brady, S & Grover, S. (1997) *The sterilisation of girls and young women in Australia - a legal, medical and social context*, Human Rights and Equal Opportunity Commission, Disability Discrimination Commissioner Sydney. Other research projects examining the numbers of sterilisation procedures for girls and young women in Australia and used by Brady & Grover (1997) include the Family Law Council (1993) *Sterilisation and Other Medical Procedures on Children: A Discussion Paper* Canberra; Intellectual Disability Review Panel (1992) *Report to the Minister for Community Services Victoria on Menstrual Suppressants*, Melbourne; Carlson, G et al (1994) *Menstrual Management and Fertility Management for Women who have Intellectual Disability and High Support Needs : An Analysis of Australian Policy*, Department of Social Work and Social Policy, University of Queensland. Each of these research projects has suggested there is non-compliance with the law regarding court authorisation. The Federal Parliament’s Multi-Party Joint Standing Committee on Treaties reported on the United Nations Convention on the Rights of the Child (UNCROC) and raised the issue of unlawful sterilisation of children as a matter of great concern. See Joint Standing Committee on Treaties. (1998). *United Nations Convention on the Rights of the Child : Executive Summary*: United Nations Convention on the Rights of the Child (17th report) (1998) Parliament of the Commonwealth of Australia Canberra. p 46.

² See for discussion Sandor, D. (1999). Sterilisation and Special Medical Procedures on Children and Young People: Blunt Instrument? Bad Medicine? In I. Freckleton, and K, Peterson. (Eds.). *Controversies in Health Law*, Sydney: The Federation Press

Welfare (AIHW) data that a total of only 22 sterilisations were performed between 1993-1999 on girls under 18 years “*with a recorded diagnosis of intellectual disability*”³ who were “*admitted patients in both private and public hospitals.*”⁴ It also notes that Medicare data (HIC)⁵ records a total of only 11 sterilisations of “*all females aged under 18 ... performed in Australian private hospitals and on private patients in public hospitals*”⁶ between financial years 1996/97 to 1998/99. It suggests, on the basis of the AIHW and the HIC data, that the number of sterilisations since 1994 has declined.⁷

Very considerable care should be taken in interpreting this data. Identifying rates of sterilisation procedures for girls and young women involves the collection of relevant statistical and other data and ideally such data will be consistent, comprehensible and comparable across agencies involved in collection.⁸ This is unfortunately not the case at this time in Australia, and this is one of the reasons for the discrepancies.

The Senate Report acknowledged that a significant reason for these discrepancies was that “*each [data base] has some limitations*”.⁹ There appear to be differences or changes in coding across agencies and over time, and inconsistent coding and coding errors undermine the reliability of the data. For example, the Senate Report says there are “*...processing errors such as incorrect recording of the service against the child rather than the mother, errors in itemisation by the doctors rooms or date of birth errors on the Medicare enrolment file.*” The other problem is that “*the Health Insurance Commission was only able to verify the data against actual claims records for the period 1997-2000, as Medicare claims’ histories are culled after two years*”¹⁰

³ The Report to the Senate on “*Sterilisation of Women and Young Girls with an Intellectual Disability*” tabled by the Minister for Family and Community Services and the Minister assisting the Prime Minister for the Status of Women on 6th December, 2000 p4 . Hereafter referred to as the Senate Report.

⁴ *ibid* at p 2

⁵ These data have two major limitations, there is no way of knowing how many of the young females undergoing sterilisation procedures may have an intellectual disability, and the data do not include public patients undergoing procedures in public hospitals. See Senate Report at page 3

⁶ See Senate Report, Attachment 1 at p 8

⁷ See Senate Report at p 3

⁸ See for example, national data collection agencies include the Health Insurance Commission (HIC), the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW). There is also State based data collection. For example in Victoria the Department of Human Services has introduced Diagnosis Related Groups and the Victorian Admitted Episodes Dataset (VAED).

⁹ See discussion in the Senate Report at pp 2-4

¹⁰ *ibid* at pp 9-10

The efforts of the AIHW¹¹ and the Victorian Health Department (eg; VAED case mix data) highlight the commitment to improving the reliability of data. It may be possible to secure more reliable information as the process of finalising, refining and implementing the development of uniform codings for medical treatments comes to fruition.

In the meantime the data remains problematic. One indication of the problem is that the Family Court and State Guardianship Tribunals authorised more sterilisations than the Senate Report says have been performed. That is an anomaly indeed.

As indicated already, the Senate Report, on the basis of the AIHW data, identified 22 sterilisations of girls under 18 years “*with a recorded diagnosis of intellectual disability*” between 1993-1999, including 7 in 1994/95 and 2 in 1998/99.¹² Yet the Family Court and State Guardianship Tribunals authorised 9 sterilisations of girls under 18 years for calendar years 1994 & 1995, and 7 in 1998.¹³ The Senate Report also identified, using the HIC data, that 11 girls under 18 years were sterilised between 1996/97 and 1998/99 - 7 in 1996/97 and 4 in 1998/99. Yet the Family Court and State Guardianship Tribunals authorised 7 sterilisations of girls under 18 years in 1998 alone. It suggests on the basis of the AIHW and HIC data that the number of sterilisations has declined.¹⁴ Yet the Family Court and State Guardianship Tribunals authorised more sterilisations in 1998 than any previous year since Marion, and the numbers of authorisations year by year suggest that the rate remains relatively stable.¹⁵

There are other concerns with the way the Senate Report has used the AIHW data.

Firstly, it counted only women with intellectual disabilities. Personal communication with medical professionals suggests many young women with mild intellectual disabilities will not be recorded as having an intellectual disability. The HIC data on

¹¹ See National Health Morbidity Database collated by AIHW

¹² The Family Court and the tribunals cannot guarantee that all authorisations or applications for sterilisation of children have been located. Data bases have been inadequate to the task. The methodology employed to collect data however has been rigorous including searches for reported and unreported cases, contacts with all statutory bodies who may have been involved in cases and written requests forwarded by the Chief Justice of the Family Court to all judges asking for details of cases. The writers are not aware of any sterilisation procedures authorised by the Family Court or Guardianship Tribunals between Jan 1999-June 1999.

¹³ See Chapter 3 and Table 3.2

¹⁴ See Senate Report at p 3.

¹⁵ See Chapter 3

the other hand, does not identify how many of the young women undergoing sterilisation procedures have intellectual disability, and does not include public patients undergoing procedures in public hospitals.¹⁶ That is why the 1997 Report was not limited to girls with intellectual disabilities but referred to instead girls and young women who had a sterilisation procedure for whatever reason, including disease (eg; cancer). The writers proposed most of these procedures would be related to intellectual disability because medical practitioners would be reluctant to sterilise young women who did not have intellectual disabilities.¹⁷

Secondly, the Senate Report did not count hysterectomies undertaken for “therapeutic reasons” – “*in the context of treatment of disease, such as endometriosis, pelvic inflammatory disease, tumours*”.¹⁸ Notably the legislation in both the NSW and South Australia requires Guardianship Tribunal authorisation irrespective of the reasons for the procedure unless the situation is immediately life threatening to the child, for example carcinoma.

Thirdly, the Senate Report specifically excluded endometrial ablation as a sterilising procedure.¹⁹ This is somewhat misleading. The surgical treatment of endometrial ablation in the early 1990’s was being described as a less invasive option to hysterectomy with similar benefits for the menstrual suppression of women with intellectual disabilities.²⁰ Professor David Healey et al in the Medical Journal of Australia said:

“The short and long-term complications of hysterectomy are significant. We have described the successful use of endometrial ablation as an alternative means of menstrual suppression in seven intellectually disabled women²¹ ..We propose that endometrial ablation be the treatment of choice if surgical

¹⁶ See Senate Report at p3

¹⁷ There is anecdotal evidence however to suggest girls and young women with physical disabilities are also at risk of sterilisation. The WWDA is funded by the federal government to provide a report on this issue relating to sterilisation of women with disabilities. It is due to be released in 2001.

¹⁸ See Senate Report Attachment 1 at p 9

¹⁹ The Senate Report did this on the basis that these procedures were “*specifically for the treatment of certain pathological conditions*”. See at p 9

²⁰ At the same time Guardianship Tribunals viewed endometrial ablation as a special medical treatment requiring the authorisation of the tribunal. The procedure of endometrial ablation is considered by the Family Court as a sterilisation procedure. Refer footnote 22.

²¹ See Wingfield, M., McClure, N., Mamers, PM et al (1994) “Endometrial ablation: an option for the management of menstrual problems in the intellectually disabled” *Med J Aust* 160: pp 533-536

*suppression of menstruation is required for women with intellectual disability. Fertility is significantly impaired after endometrial ablation...*²²

At the same time Carlson et al predicted that:

*“as hysterectomies decline in numbers, there may be an increase in endometrial ablation or resection procedures”*²³

The 1997 report noted, however, that there appeared to be an “*on-going trend in the use of ablations but they too are dropping in numbers post 1995/96*”.²⁴ The HIC data recorded a drop from a high of 201 endometrial ablations in 1994/95 to 98 in 1996/97. Three years later less than half that number were being performed in the age group (0-17 years) suggesting that endometrial ablation for menstrual suppression has not had the successes hoped for by medicine. On this basis it is likely that the numbers of endometrial ablations undertaken may not have necessarily resulted in permanent sterility for this group of young women.

Research conducted in Victoria has examined the coding for endometrial ablation:

*“...it is now possible to propose that the coding for endometrial ablation has occasionally been applied to the ablation by diathermy or laser of the endometriosis in the pelvis, rather than the ablation of endometrium within the uterus. The first one is a procedure to treat endometriosis, the latter a procedure to eliminate or substantially reduce menstrual loss that must be considered a sterilising procedure as it is unsafe to have pregnancy following”*²⁵

The issue of coding in endometrial ablation is problematic in terms of reliable data on sterilisation procedures however further studies will add light to its use in young women.

(b) the anecdotal information

²² See Wingfield, M., Healey, D., Nicholson, A (1994) “Gynaecological care for women with intellectual disability”: *Med J Aust* 160, p 537

²³ Carlson, G., Taylor, M., Wilson, J., & Griffen, J. (1994) *Menstrual Management and Fertility Management for women who have intellectual disability and high support needs: an analysis of Australian policy* (2nd ed). Department of Social Work & Social Policy, University of Queensland . The original work was funded by the Commonwealth Department of Health and Housing.

²⁴ See Brady, S & Grover, S. (1997) *Sterilisation of girls and young women in Australia: a medical, legal & social context*, HREOC commissioned by the Disability Discrimination Commissioner. P 43

²⁵ Research conducted by S Grover, forthcoming 2001.

The major problem with the ‘official data’ however, as the Senate Report notes itself, is that it was reliant on figures derived :

“...only from official sources [emphasis]. It is possible that there are unrecorded and unauthorised non-therapeutic sterilisations of young women with intellectual disabilities being undertaken in Australia.”²⁶

“it is not possible to ascertain the precise number of unauthorised sterilisation procedures that may be being performed on women with intellectual disabilities”²⁷

The anecdotal information provided by young women, service providers and practitioners suggests that the possibility to which the Senate Report refers is in fact a reality. There is long-standing and persistent anecdotal information provided by parent and community groups, churches, disability service providers (both government and non-government), medical and non-medical professionals, and State statutory agencies that unlawful sterilisations continue to occur.

The NSW Guardianship Tribunal notes that:

“the tribunal is not aware of the figures, but we agree that there is a large discrepancy between the numbers of applications to the tribunal and the numbers of sterilisations that take place in NSW”²⁸

The Public Advocate in Victoria:

“is concerned and questions whether the number of applications accurately reflects the number of sterilisations being conducted. Obviously no data exists where the doctor/hospital has proceeded on the (illegal) consent of the family or the (dubious) consent of the person with a disability”²⁹

The South Australian Intellectual Disability Services Council said:

“IDSC has no information about sterilisations that have been performed without the proper consent but are aware that it is highly likely that a number have been performed in this state”³⁰

An experienced health educator notes:

²⁶ See Senate Report at p 4

²⁷ *ibid*

²⁸ Written communication from the NSW Guardianship Tribunal dated 9th February 2001.

²⁹ Written communication from the Office of the Public Advocate in Victoria dated 2nd March 2001.

³⁰ Written communication from South Australia IDSC dated 20th February 2001

“...it seems that women and pre-menarchal girls with high support needs are having hysterectomies ...the practices continue”

“workers from both camps [government and non-government service providers] seem very well aware of the illegality of hysterectomy, as do GP’s ...however, the practices continue”³¹

There is no way to quantify the anecdotal information. In any event, advocacy groups representing women with disabilities have made it clear that the ‘debate’ about the sterilisation of girls and young women with disabilities should not be reduced to arguments or claims making about numbers.³² They insist that the primary issue is that of the human rights of the girls and young women concerned, and more generally of service providers, family, and community attitudes to reproduction, menstruation and sexuality.³³

It is a pity that the debate about the sterilisation of girls and young women has reduced to a debate about the numbers of procedures being performed. It’s a human rights issue whether the numbers are one thousand, or two hundred as the Minister for Health said in response to the 1997 Report, or something less again as the Senate Report suggests. It has remained an on-going issue over time.

In March 1998 as key note speaker for the launch of the Family Court protocols for special medical procedures in Victoria the late Elizabeth Hastings highlighted the real issue when she commented on the Minister’s assessment, following the 1997 Report, that he did not propose to initiate an investigation into the discrepancy, whatever it is, between lawful and unlawful sterilisations. She said:

“A world in which government cannot be bothered to investigate potential illegal medical assault on nearly 200 of its citizens, in which those with no authority feel free to make decisions which are blatantly against the law and to carry out serious and irreversible procedures on those with little or no capacity to give or withhold consent, is a world in which people with disabilities can have no certainty or confidence about their human being or their future...”³⁴

³¹ Written communication from health educator dated 4th January 2001

³² The writers express sincere regret to all those who have been hurt by the focus on ‘data’ and acknowledge the legitimacy of persistent anecdotal and personal histories regarding sterilisation. We thank all respondents who have been candid.

³³ This is a consistent theme in respondents comments.

³⁴ Elizabeth Hastings (1998) *The right to right treatment* the key note speech for the launch of “A Question of Right Treatment” University of Melbourne March 28th, 1998 at page 4.

A year later in October 1999, the Chief Justice of the Family Court, the Honourable Justice Alastair Nicholson AO RFD, concerned about unlawful sterilisation of children raised the issue in his keynote address to the 7th Australasian Conference on Child Abuse and Neglect. He said:

“I still adhere to what I said in the 1989 case of In re Jane, a view that would seem to have been shared by the majority in Marion’s case. In In re Jane I said:

“like all professionals, the medical profession has members who are not prepared to live up to its professional standards of ethics and experience teaches that the identity of such medical practitioners becomes known to those who require their assistance and their services are availed of. Further, it is also possible that members of that profession may form sincere but misguided views about the appropriate steps to be taken”³⁵

In December 2000, the Attorney-General Honourable Daryl Williams AM QC MP sent an “Open Letter to the Australian Medical Profession” saying:

“It has come to my attention that some sterilisation procedures are being undertaken on children without the proper authorisation. Though I believe the number of these unauthorised procedures to be small, I also believe that the legal obligation to obtain court authorisation may not be widely known among medical professionals”

Progress in terms of medical and community education about the need for the lawful authorisation of sterilisation is occurring.³⁶

³⁵ Nicholson, A. (1999). Court management of cases involving child abuse allegations Keynote address at the 7th Australasian Conference on Child Abuse and Neglect. See also case In re Jane (1989) FLC 92-007 at 77,257.

³⁶ Refer Chapter Five.

CHAPTER THREE

a national profile of lawful sterilisation¹

(a) the family court & guardianship tribunals

In Australia the majority of applications made for the sterilisation of girls and young women under 18 years are approved. Table 3.1 compares decisions made by the Family Court and Guardianship Tribunals. (For visual comparison see Bar Charts at pages 23-24). The Family Court of Australia and the Guardianship Tribunals of New South Wales (NSW) and South Australia (SA) have jurisdiction to authorise the sterilisation of minors. These jurisdictions are the focus of this analysis.

Table 3.1 : Comparison between the Family Court and Guardianship Tribunal/s decisions in sterilisation cases between 1992-1998**

Decision	Family Court		Guardianship	
	N*	%*	N	%
Approved	17	90	10	53
Not Approved	1	5	7	32
Withdrawn	1	5	3	16
Total	19	100	20	100

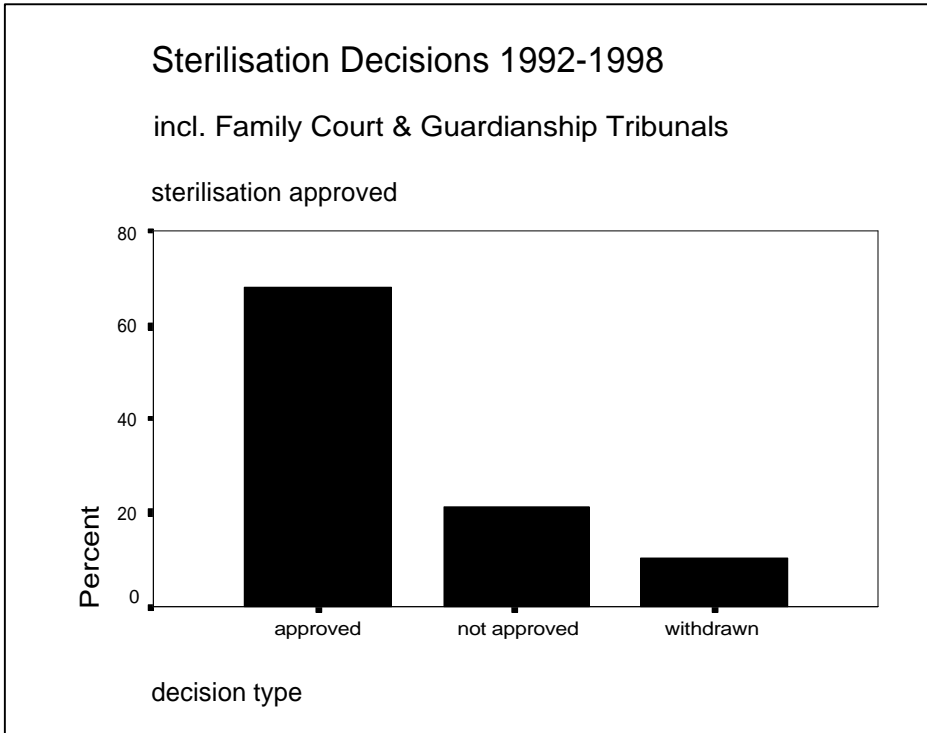
** Note this Table does not include the (NSW) Supreme Court case.

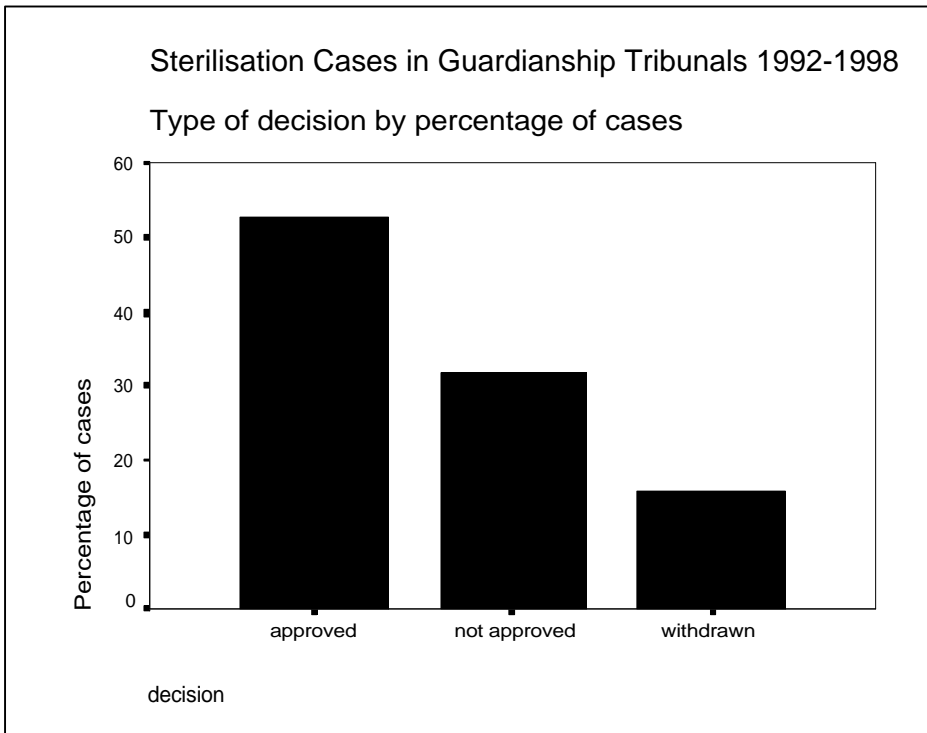
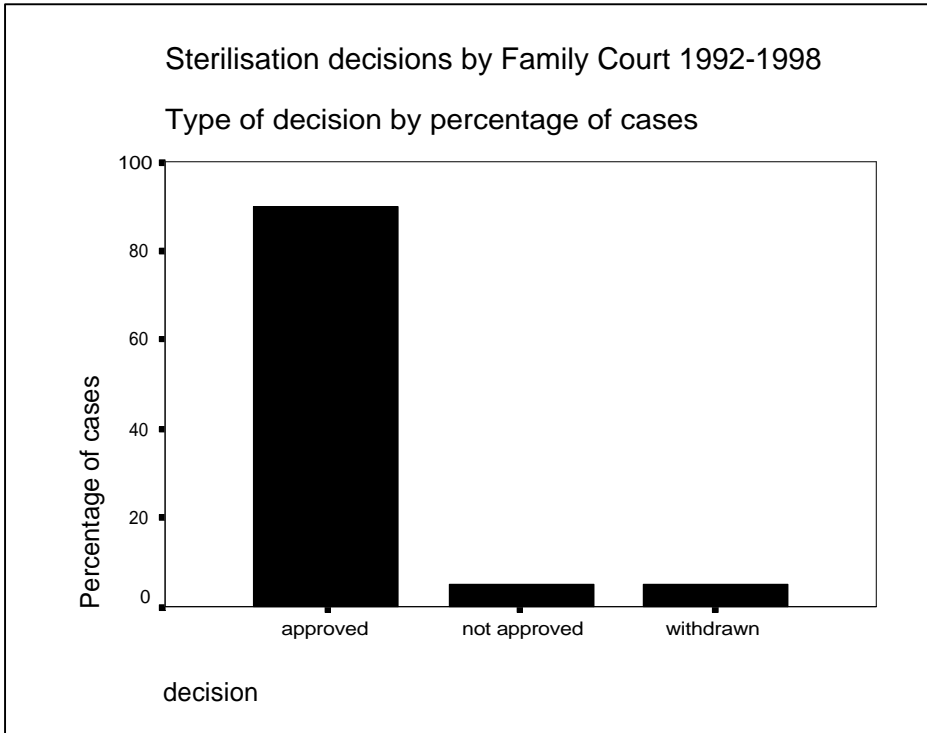
*N = the actual number of cases and % = cumulative percentages

There are differences in approvals for sterilisation between the Family Court and Guardianship Tribunals (NSW & SA).

- The Family Court is more likely to approve a sterilisation procedure compared to the Guardianship Tribunals.
- Of the applications that proceed to hearing the Family Court approves 95% of applications for sterilisation compared to the Guardianship Tribunal approval rate of 43% in New South Wales and 78% in South Australia.
- The Guardianship Tribunals are more likely to have applications that are withdrawn prior to hearing compared to the Family Court.

¹ The findings in this chapter are based on an analysis of all applications for sterilisation to the Family Court or Guardianship Tribunals (NSW and SA) from Marion to the end of June 1999. The raw data used in this report is derived from PhD research on special medical procedures for children by SM Brady, University of Queensland, School of Social Work & Social Policy. It is the property of SM Brady and its accuracy her responsibility. Refer to footnote 12 in Chapter Two about data accuracy.





The following pages 33 - 34 identify in table form the total number of approvals for sterilisation by year (see Table 3.2) and by legal forum and state (see Table 3.3).

Table 3.2 : Type of Decision by Year of Decision in Australian Courts & the Guardianship Tribunals of NSW & Sth Aust, 1992-1998.

Decision	1992	1993	1994	1995	1996	1997	1998	Total
Approved	4*	1	4	6#	4**	2	7	28
Not approved	1	2	1	2		1##	1	8
Withdrawn	-	3	1	-	-	-	-	4
Total	5	6	6	8	4	3	8	40

The total number of approvals for sterilisation in both the Family Court (incl. Family Court of Western Australia) and the State Guardianship Tribunals of NSW and Sth Australia is 27, and one case was approved by the NSW Supreme Court, making a total number of 28 approvals for sterilisation of children aged 10-17 years between 1992-1998.

Notes:

Of these 6 approvals two of them had in the first instance not been approved but on review were approved. One case was initially heard by the Guardianship Tribunal (NSW), and the application was not approved. The parents took the application for hysterectomy to the Family Court (NSW) and the Court approved the hysterectomy. In 1994 in the Family Court (NSW) a first instance decision was not to approve a hysterectomy. The decision was appealed to the Full Bench of the Family Court, and it approved the hysterectomy with reasons dated May 1995.

** One of these cases includes the Supreme Court (NSW) approval

This decision was originally approved by the Guardianship Tribunal (SA) but was taken by the Office of the Public Advocate (SA) on appeal to the AAT (SA). The AAT reversed the decision and sterilisation was not approved.

Table 3.3 : Number of sterilisation authorisations by State by Courts and Tribunals, 1992 – 1998.

FORUM	VIC	NSW(a)	WA	SA(b)	ACT	NT	QLD	TAS	TOTAL
Family Court of Australia	3	7	1	2	None known	1	2	1	17
<i>State Supreme Court</i>	None known	1	None known	None known	None known	None known	None known	None known	1
State Guard'ship Tribunal	Not applicable	3	Not applicable	7	Not applicable	Not applicable	Not applicable	Not applicable	10
TOTAL	3	11	1	9	-	1	2	1	28

The total number of sterilisations of girls and young women (up to 17 years) authorised by Courts and Tribunals in Australia during calendar years 1992 - 1998 is 28. Guardianship Tribunal/s authorised 10; Family Court authorised 17, and the NSW Supreme Court authorised one.

The highest number of applications are in NSW & SA where State Guardianship Tribunal/s share jurisdiction with the Family Court. Both the SA and NSW Guardianship Tribunals also have jurisdiction to authorise sterilisation procedures for adults with decision making disabilities.

Notes:

- (a) In NSW, at the time of data collection the Family Court exercised concurrent jurisdiction with NSW Supreme Court (children up to 16 years) and the Guardianship Tribunal (16 and 17 year olds). Recent amendments to NSW legislation (*Children & Young Persons (Care & Protection) Act 1998*, s. 175) proclaimed 18th Dec 2000 has extended the jurisdiction of the NSW Guardianship Tribunal to include children 0-17 years.
- (b) In SA, the Family Court exercises concurrent jurisdiction with the Guardianship Board. Children 0-17 years are included in both.

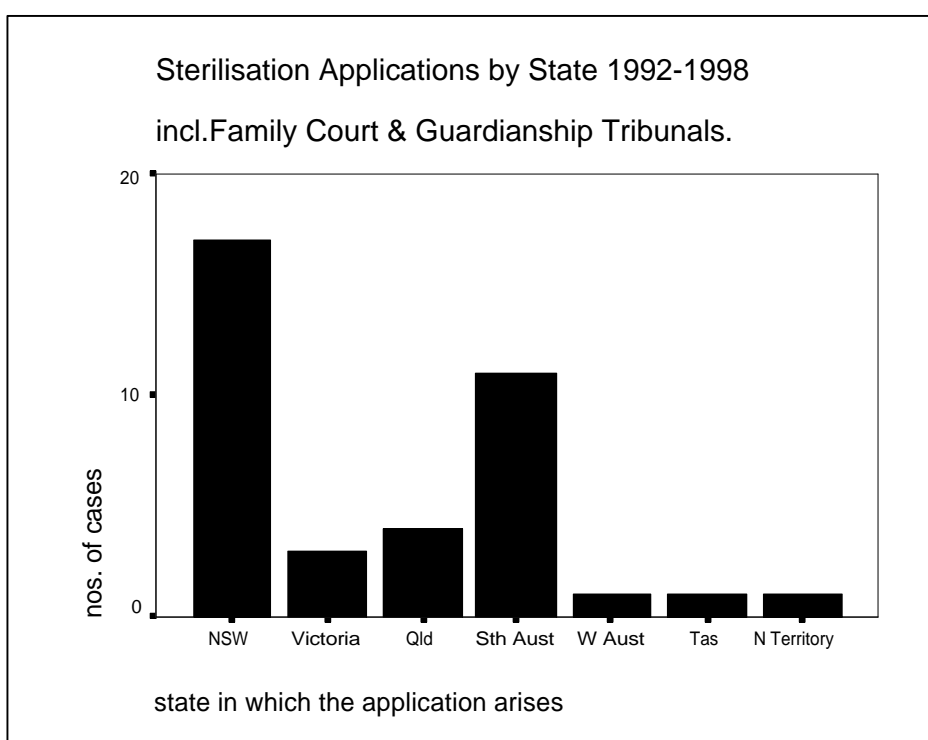
(b) numbers of applications by State

NSW and South Australia have a higher number of applications for sterilisation compared to other States. This suggests that families use the Guardianship Tribunal option where it is available. The table below gives the numbers of cases in each State and Territory. For a visual comparison see the Bar Chart below.

Table 3.4 : State in which an application for sterilisation arises including Family Court & Guardianship Tribunal/s

State	Nos of cases	% of cases
New South Wales	17	45
Victoria	3	8
Queensland	4	10
South Australia	12	29
Western Australia	1	3
Tasmania	1	3
Northern Territory	1	3
Total	39	100

Data does not include the case heard in the NSW Supreme Court



- Families are more likely to seek legal authority for sterilisation where the Guardianship Tribunal option is available.¹

The number of sterilisation applications made to either the Family Court or Guardianship Tribunal/s (NSW & SA) is small (n=39). They can be characterised as follows:

- Parent/s usually make the application
- The applicant and/or mother always support the proposed sterilisation.
- All sterilisation applications involve girls and young women with intellectual disabilities.
- All applications are for hysterectomy.

(c) characteristics of the girls and young women subject to a sterilisation application

The girls & young women subject to sterilisation applications are not a homogenous group and have varied competencies. Not all them have severe intellectual disabilities. The severity of intellectual disability (eg; high support needs) may not be a determinative factor regarding the decision to sterilise.

- The girls and young women are aged between 10 - 17 years.
- About 45% are aged 14 years or younger at the time of the application.
- About 13% of girls have not commenced menstruation at the time of the application.
- Their competencies move along a continuum from mild intellectual disability (low support needs) to severe intellectual disability (high support needs).
- More than half the girls and young women have some form of physical and/or sensory impairment ranging from minor to significant.

¹ The Family Law Council in the context of family law disputes in relation to child abuse allegations has commented that the new Federal Magistry will be preferred by litigants for a practical reason because of “*the (in)ability or (un)willingness of parties to pay the more expensive legal cost applicable in the Family Court*” p 20 see Family Law Council (2000) *The best interests of the child? The interaction of Public and Private Law in Australia*, Discussion Paper No.2 October, Canberra. It is generally recognised that legal costs are a significant issue in family court matters, and applications in guardianship jurisdictions do not incur legal costs for the applicants.

- Diagnostic information identifies 37% have a congenital disability, 40% a disability of unknown aetiology, and 13% have acquired brain injury.

(d) characteristics of applicant families

The legal commentary and judgments on sterilisation cases in Australia have concentrated on the girls and young women with little or no reference to their family circumstances. An analysis of Court and Tribunal files shows that:

Household Type:

- About 65% of the girls and young women live in two parent families on a full-time basis.
- In almost 30% of families the natural father is estranged providing no financial support.
- In over 20% of families the mother (who is primary carer) has some form of physical disability or chronic illness.
- In about 10% of families the father (including step-father) has some form of physical disability or chronic illness.
- No families were of Aboriginal or Torres Strait Islander descent
- About 10% of families came from culturally and linguistically diverse backgrounds

Siblings:

- About 85% of the girls and young women have siblings.
- The age range of the siblings is from 2 – 34 years. Nearly 70% are 18 years and younger.
- About 60% of teenage siblings are males
- About 20 % of families care for more than one child with some form of intellectual disability and/or physical disability.

Socio-economic factors²:

- Just over half of the families live in a capital city or suburban area. About 8% live in rural/remote areas.
- In two parent families about 66% of fathers (including step fathers) have full time employment.
- About 45% of mothers (including foster mothers) are not employed outside the home
- Just over 30% of mothers are employed on a full-time basis.

² There was minimal reference to family financial matters in either court or tribunal files.

- Just over 30% of families receive benefits usually supporting parent or disability benefits

Other:

- About 15% of families have been subject to some form of child care and protection intervention.

The written reports on the court and tribunal files provide little information about the types of services they use.

(e) profile of services provided to the child and family³

The Tribunals tended to explore these issues during the hearing process but they were not raised in applications heard in the Court.⁴ The written reports provided little information about the types of services that are used, but:

- The majority of families rely on government funded services.
- Over 80% of the girls and young women attended on a full-time basis a special school for children with disabilities while the others attended a mainstream school.
- About 60 % of families had access to non-government services usually out-of-home respite, with about 15% also having in home respite.
- About 20% received some form of home help assistance during the school week.
- About 16% of families received support from local church groups (eg; youth groups).
- Specialist programs are utilised by 20% of families. Over 55% of families had been offered special programs⁵
- About 3% of families received personal counselling and support.
- About 2 % of families purchased private services⁶.

³ Reference to assistance provided by way of service packages from government and non-government sectors was noted in the tribunal files, indicating concern about support services for families.

⁴ Written reasons and member file notes illustrate this point. Transcripts from hearings in the Family Court also did not refer to services.

⁵ These are programs not part of the school curriculum but specifically designed for the individual child. They are usually behaviour management programs or menstrual management programs.

⁶ For example, physiotherapy services from private practitioners.

(f) primary care and type of decision

- Applications for sterilisation are made by parents or on behalf of the parents by doctors.⁷
- No applications for sterilisation are made by residential facilities, community-based agencies or statutory guardians.⁸
- All applications for sterilisation to the Family Court were authorised where the young woman resided in community-based accommodation or at a boarding school returning home for weekends and/or school holidays. In all applications where the child resides on a full time basis with her family or foster family the sterilisation was approved. All approvals are for hysterectomy.⁹
- In the Guardianship Tribunals where the child resides on a full time basis with her family or foster family applications for sterilisation are approved in nine cases and not approved in six cases. In one case where the young woman resided in community based accommodation and had regular contact with her family the application was approved.¹⁰
- In the Guardianship Tribunals two applications are withdrawn prior to hearing where the children resided in community based care returning to family during school holidays.
- Where parents had rare or no contact with the girl or young woman the sterilisation was not authorised by either the Family Court or Guardianship Tribunals.

The child's primary care arrangements (ie; who provides for the day to day needs of the young woman) may influence the decision to approve the sterilisation. For example, where parents have rare or no contact with the young woman the sterilisation is not approved in either the Family Court or Guardianship Tribunals. It is a defining feature in Family Court cases because all other sterilisation applications are approved. Judge Warnick said in his summing up in the only case which has not been approved by the Family Court said that:

“...the parents wishes did not carry significant weight...their wishes did not impact on her at all. The child had no concept of their wishes and no feelings about whether their wishes were met or not. The parents were not involved in her daily care and there was no suggestion that their attitudes to or

⁷ In the Guardianship Tribunals an application may be made on behalf of parents by a doctor.

⁸ Discussions with government and non-government organisations providing any form of congregate or group home care have confirmed policy does not support the surgical sterilisation of children or adults with intellectual disabilities unless for therapeutic reasons.

⁹ One included hysterectomy with bilateral oophorectomy and another endometrial ablation with hysterectomy as a last resort.

¹⁰ The young woman had a 'dual' disability with intellectual disability and a poorly managed psychiatric illness, and the procedure authorised was a tubal ligation.

interaction with the child would change in any way dependent upon the outcome of their application.¹¹”

(g) other factors

- In both the Family Court and the Guardianship Tribunals the majority of girls and young women reside on a full-time basis with at least one parent.
- About 40% live with both biological parents
- The mother or foster mother in the majority of cases is the young woman’s primary carer.
- In Family Court cases about one-fifth of all families are second marriages and the young women is not a child of the current marriage compared to none in the Guardianship Tribunals.
- The Family Court and Guardianship Tribunals have an equal representation of one parent families with the Guardianship Tribunals having a slightly higher representation of foster parent families.
- Less than one-fifth of the young women have residential carers providing day to day care.
- About one-third of the young women have at least one parent with physical disability or chronic illness
- About one-fifth of the families care for more than one child with a disability in the household

The girls and young women subject to sterilisation applications are not a homogenous group and have varied competencies. Not all of them have severe intellectual disabilities.

Most of the girls live with their families who provide primary care and in these cases the expressed wishes of parents carry significant weight.

¹¹ In re: Sarah., *L and GM v. MM; the Director-General, Department of Family Services and Aboriginal and Islander Affairs* (1994) FLC 92-449

CHAPTER FOUR

rules, guidelines and protocols

This chapter describes the formalised rules set out in practice notices, protocols and guidelines in both the Family Court and the Guardianship Tribunals of NSW and SA. It aims to ascertain the meaning ascribed to the rules or guidelines, the types of inquiries they appear to invite, and implications for experts and other stakeholders involved in these matters.

(a) family law rules

The Family Court is able to modify the strictly adversarial process by using its rule making power. It has done so in the exercise of its ‘welfare’ jurisdiction for children acknowledging that special medical cases like sterilisation involve different considerations from those relevant to the responsibility owed to litigants in child contact (access) and residence (custody) cases.

After the High Court decision in *Marion* the Family Court ratified Family Law Rules Order 23B¹ in relation to the approval of special medical matters for children. These rules follow on from Order 23A concerning the notification by the Family Court of child abuse allegations to state child protection agencies. They are not statutory rules but rather practice guidelines.

Order 23B contains a set of specific rules describing what is expected in affidavit materials filed by the applicant (usually the parent). These rules advise the applicant to provide affidavits and/or relevant reports by medical, psychological or other experts setting out:

- the exact nature and purpose of the procedure;
- the likely long term social and psychological effects of the procedure on the child;
- that alternative and less invasive procedures would be or have proved to be inadequate;
- why the procedure is necessary for the welfare of the child;

¹ First appeared in *CCH Australia Ltd*, 1993.

- whether the child is unlikely to develop sufficiently to be able to make an informed judgement within the time in which the procedure should be carried out or within the foreseeable future, and
- any other reasons for granting the procedure. (*Family Law Rules 1992, Order 23 B, rule 5*).

The rules make it clear that the burden of proof is with the applicant to prove that the proposed procedure is in the best interests of the child. They focus on the child's competence and capacity, and are intended to encourage objective examination of the development of the child. They refer to the child's future social and psychological wellbeing but do not spell out in any further detail what needs to be taken into account. They make no mention of the child's or the parents' expressed wishes, or the child's cultural heritage and identity, though these issues can be dealt with under 'any other reasons'.

A number of the Court's other practice rules have potential to shape its approach in these matters. Judges can:

- dispense with compliance with procedural rules (*Order 4 Family Law Rules*),
- call any person as a witness, appoint expert assessors (*Order 30B Family Law Rules*) and/or call experts to inquire into and report on any issue (*Order 30A Family Law Rules*),
- allow relevant 'social facts' to be placed before the court including journal and research material.²

The Family Court also takes a liberal view of who can bring proceedings,³ assigns only specially designated judges, and requires that written reasons are given for any decision to authorise a sterilisation or any other special medical procedure.⁴ These rules demonstrate the court's flexibility and procedural responsiveness in these matters.⁵ However, the Australian Law Reform Commission (ALRC) and the Human Rights and Equal Opportunity Commission (HREOC) has pointed out that although

² See Sarah's case: *L and GM v MM* (1994) FLC 92-449.

³ See *In Re Michael* (1994) FLC 92 471.

⁴ *Case Management Guidelines*(1996)*Family Court of Australia* .

⁵ See Sandor, D.(1999).Sterilisation and special medical procedures on children and young people - Blunt instrument? Bad medicine? In Freckelton, I. & Petersen, K. (Eds) *Controversies in Health Law*, The Federation Press, Sydney

the Family Court has flexibility to adopt procedural innovations, it rarely does.⁶ The Court's approach to applications for sterilisation has been criticised because it has "...not halted the apparent loosening both by interpretation and by outcome of cases of the best interests test..."⁷ and because there has been a 'slippage' in the value accorded to children with disabilities since Marion.⁸ There is a general view that legislative change encouraging a more child-centred focus has not done so nor occasioned a change in the culture of family law.⁹

In an early sterilisation decision Chief Justice Nicholson outlined a list of factors to be considered in determining whether sterilisation was in the best interests of the child concerned.¹⁰ They were adapted from *In re Grady*, an early sterilisation case decided in the USA in relation to the proposed tubal ligation of a woman with intellectual disability.¹¹ The factors are:

- the possibility that she can become pregnant;
- the possibility that she will experience psychological damage if she becomes pregnant or gives birth and conversely the possibility that she will experience psychological damage if she is sterilised;
- the likelihood of sexual activity or rape;
- her ability or otherwise to understand reproduction or contraception
- the feasibility and medical advisability of less drastic means of contraception;
- the advisability of sterilisation at the time of the application rather than in the future;
- her ability to care for a child;
- any evidence of medical or scientific advances within the foreseeable future, and

⁶ ALRC & HREOC. (1997). *Seen & heard : priority for children in the legal process*, Report no:84 p 418. See also Freckelton, I., Reddy,P & Selby, H. (1999). *Australian Judicial Perspectives on Expert Evidence: an empirical study*. AIJA, Melbourne.

⁷ O'Neill, N. (1996). Sterilisation of Children with Intellectual Disabilities, *Australian Journal of Human Rights* 2 (2) p262

⁸ Jones, M. & Marks, LAB. (2000) Valuing People through Law - whatever happened to Marion? In (Eds.) M. Jones and LAB. Marks, *Law in Context* Special Issue: Explorations on Law and Disability in Australia, Sydney: The Federation Press pp 147-180.

⁹ Carmichael,J. & Sarre,R.(1994). Legal issues: the welfare of and responsibility for children under the law in Australia, In (Ed.) F Briggs, *Children and families: Australian perspectives*. Sydney: Allen and Unwin pp 102- 125; and see empirical study by Rhoades, H., Graycar, R. & Harrison, M. (1999). *The Family Law Reform Act 1995: Can Changing Legislation Change Legal Culture, Legal Practice and Community Expectations?* Interim Report, Family Court of Australia.

¹⁰ *In re Jane* (1989) FLC 92-007.

¹¹ *In re Grady* (74) (1981) NJ 426 A 2d 467.

- a demonstration that the applicants seeking sterilisation are seeking it in good faith and in her best interests, and not for public convenience.¹²

These factors refer to fertility and focus on child-birth and capacity for mothering. The Grady case did not canvass issues relating to menstrual management or its social consequences for her family in terms of an extra personal care. The Full Bench of the Family Court in Lessli's case¹³ referred to the Grady set of factors to assist it in deciding whether a hysterectomy was in the best interests of 16 year old Lessli, and most recently Grady has been cited *In the matter of 'A.'*¹⁴ One reading of Grady and its subsequent application in Lessli's case is that it allows speculation in the decision to authorise sterilisation or otherwise. It uses terms like 'possibility', 'feasibility', and 'advisability'. On another reading it takes a social policy position suggesting that pregnancy and motherhood are unacceptable risks for girls and women with intellectual disabilities.

The Family Law Council recommended four circumstances in which sterilisation should never be authorised. These are:

- Sterilisation for eugenic reasons;
- Sterilisation purely for contraceptive purposes;
- Sterilisation as a means of masking or avoiding the consequences of sexual abuse;
- Sterilisation performed on young women prior to the onset of menstruation, based on predictions about future problems that might be encountered with menstruation.¹⁵

The Family Court has supported the introduction of broad discretionary guides but have rejected prescriptive criteria recommended by law reform agencies.¹⁶ It adopted this position because in its view prescriptive responses might only compromise consideration of the particular circumstances of individual children. The Full Bench of the Family Court said in Lessli's case that:

¹² *ibid*

¹³ *PvP (no 2) (1994-1995) 19 Fam LR, 1*

¹⁴ *In the matter of A.* Unreported, Jerrard, J. 5th June 2000

¹⁵ Family Law Council. (1994). *Sterilisation and Other Medical Procedures on Children : A Report to the Attorney-Genera*, November. See Recommendation 3, p v

¹⁶ *ibid* and Law Reform Commission of Western Australia.(1994). *Report on consent to sterilisation of minors.* Report no. 77, Perth, WA.

"the key issue becomes whether a proposed treatment is a benefit or a burden having regard to that individual child's circumstances. It must not be forgotten that the "step of last resort" criterion must be satisfied for the child having regard to that child's needs or capacities..."¹⁷

The judgment was not embraced by disability service sector or indeed the Human Rights and Equal Opportunity Commission which appealed the Full Bench decision to the High Court. The appeal was dismissed on technical grounds.

(b) family law protocols and practice guidelines

The Chief Justice of the Family Court has commented, rightly, that the most enduring difference to children's quality of life and the protection of their rights is a service landscape providing accessible support services for them and their families.¹⁸ He noted in another context that "*authorisation may only be given as a matter of law if the Court is satisfied that the procedure is the step of last resort*", and added that:

"To this end, the court has been developing case management protocols with key stakeholders ...in essence, the protocols entail two components.

- *The first aspect of the protocols is diversionary by creating early processes for case conferencing that seek to ensure that resources which could avert the application are identified, proposed and marshaled; and*
- *The second element of the protocols lays down for the timely progress of an application that cannot be met with diversionary responses, through to the point of determination by designated judges"¹⁹*

Protocols and practice guides have been developed in Queensland²⁰ and Victoria.²¹ They have been explained and promoted by plain english guide-books²² which seek to assist families, doctors, allied health professionals, teachers and other service providers to think through whether sterilisation is in the child's best interests. The guides set out the standard approach (see Diagram 6.1 The Standard Approach) and provide a short introduction to the law, legal terminology and court process.

¹⁷ *PvP (no 2) (1994-1995) 19 Fam LR, 1.*

¹⁸ Nicholson, A. (1993). *The medical treatment of minors and intellectually disabled persons: United Nations Convention on the Rights of the Child, Article 23*, First World Congress on Family Law and Children's Rights - Congress Papers, Sydney Convention and Exhibition Centre, Sydney.

¹⁹ Nicholson, A. (1999). "*Court management of cases involving child abuse allegations*" a Key-note address to the 7th Australasian Conference on Child Abuse and Neglect, Perth, October. P 15

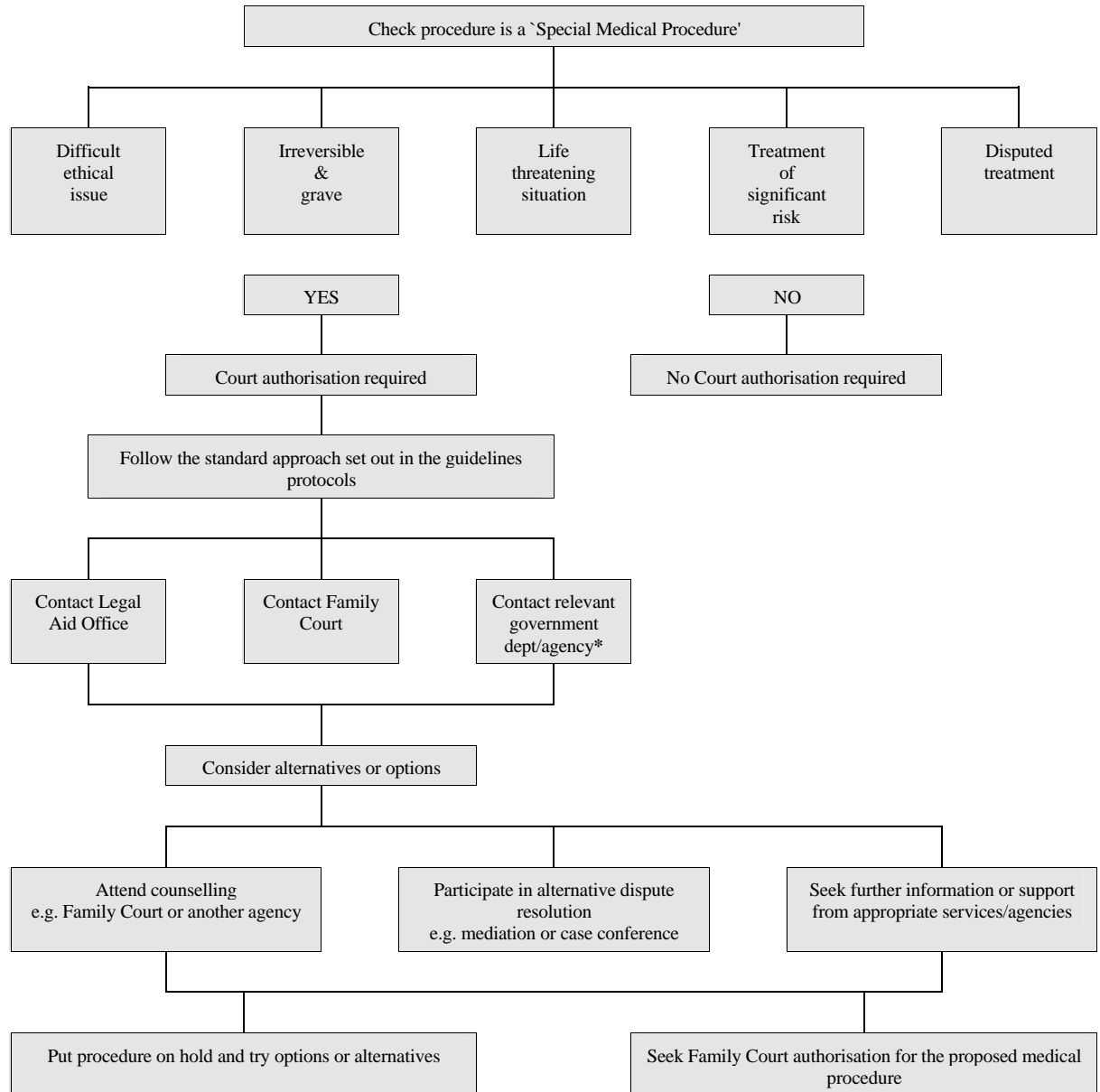
²⁰ Brady, SM & Cooper, D.(1996) *A Question of Right Treatment – the Family Court & special medical procedures for children: an introductory guide*”, Family Court of Australia.

²¹ Family Court of Australia. (1998). *A Question of Right Treatment – the Family Court & special medical procedures for children: an introductory guide,*” Family Court of Australia Southern Region .

²² Refer footnote 20-21

Diagram 6.1

the standard approach²³



- includes direct service departments (eg State Departments of Human Services and/or Disability Services) and/or Statutory Agencies like the Office of the Public Advocate in both Victoria and South Australia.

²³ Based on Brady, SM. & Cooper, D. (1996). "A Question of Right Treatment: an introductory guide to special medical procedures in the Family Court" Family Court Publications Unit

The Special Medical Procedure Protocols seek to ensure effective collaboration between the court and other key agencies in the best interests of the child. In Queensland they include the Legal Aid Office and the Department of Families Youth and Community Care and in Victoria, the Legal Aid Commission, the Office of the Public Advocate and the Department of Human Services. Similar arrangements are being negotiated in both NSW and South Australia.²⁴

The Protocols serve three main purposes. The first is to secure support services for the child and family which will assist them with the care and management of their child, including specialised behaviour and menstrual management programmes and more generally respite care and other like services which will relieve the stresses which may have prompted contemplation of sterilisation in the first place.²⁵ The Joint Standing Committee on Treaties (UNCROC) noted its concern:

*“at reports that disabled children may be sterilised in situations where this could be avoided if there was sufficient support for the families of the children with disabilities.”*²⁶

In theory, then, the protocols ensure that applications proceed to court only ‘as a last resort’ after applicants have had the opportunity to explore less invasive alternatives to sterilisation.

²⁴ In NSW the Family Court had convened a working group including the Department of Community Services (NSW), a non-government advocacy agency People with Disability (NSW), HREOC, and the Legal Aid Commission (NSW) to develop protocols and guidelines for special medical procedures like sterilisation. In South Australia an Interagency Focus Group is working on finalising inter-agency protocols and adapting the original introductory guide to reflect the South Australian situation. The Intellectually Disabled Services Council made the comment that: “the collaboration has led to an increased knowledge of the issues by all agencies and a commitment to provide quality services to children and women with intellectual disability. IDSC is committed to continuing to work collaboratively with key stakeholders.” Written communication from the IDSC, 21 February, 2001.

²⁵ Nicholson, A. (1993). *The medical treatment of minors and intellectually disabled persons: United Nations Convention on the Rights of the Child, Article 23*, First World Congress on Family Law and Children's Rights - Congress Papers, Sydney Convention and Exhibition Centre, Sydney; Brady, S.(1995). *The Rights of the Child to be Heard : The Extended Jurisdiction - Potential Hearing Impairments in the Legal Process* 29th Australian Legal Convention, Law Council of Australia, Brisbane pp101-117; Brady, S. (1998). *The Sterilisation Of Children with Intellectual Disabilities - Defective Law, Unlawful Activity and the Need for a Service Oriented Approach*, *Australian Journal of Social Issues* 33 (2) pp 155-177

²⁶ Joint Standing Committee on Treaties. (1998). *United Nations Convention on the Rights of the Child : Executive Summary*, The Parliament of the Commonwealth of Australia , Canberra. p. 46

The second is to ensure, if applications can't be diverted and do proceed to court, that the court is provided, through the child representative, with comprehensive evidence about the less invasive alternatives to sterilisation, in particular expert reports which:

- Establish whether all alternative and/or less invasive options have been addressed in the material filed with the Court
- Identify alternative and/or less invasive options and provide advice on less restrictive alternatives to the proposed procedure that will promote the welfare and best interests of the child
- Obtain reports by appropriate experts and any other relevant material.²⁷

In theory, then, the protocols take on board criticisms about the court's penchant for accepting evidence of anticipated rather than real difficulties in sterilisation matters,²⁸ and for placing too much importance on the evidence of medical practitioners and too little on the contribution of non-medical professionals who may have more understanding of developmental options for people with disabilities. It is important to reiterate in this context the criticism of courts to the effect that:

"... judges will all too often accept or prefer the views of the medical profession to the exclusion of other relevant evidence and in some cases elevate opinions and assertions to the status of fact."²⁹

The High Court in *Marion* made it clear that sterilisation is not merely a medical issue. It made the point that:

"to characterise intervention comprising sterilisation as "medical treatment" is already to make assumptions and to narrow the inquiry, perhaps inappropriately."³⁰

The majority said:

²⁷ Family Court of Australia. (1998). *A Question of Right Treatment – the Family Court & special medical procedures for children: an introductory guide*, Family Court of Australia Southern Region at p 54.

²⁸ Family Law Council. (1994) Recommendation 3 p v; and see Carlson, G & Wilson, J. (1996). Menstrual management and Women who have Intellectual Disabilities: Service Providers and Decision-Making. *Journal Intellectual Developmental Disability* 21, pp 39-57.

²⁹ Blackwood, J. (1991). Sterilisation of the intellectually disabled: The need for legislative reform. *Australian Law Journal of Family Law*, 5, 138-170 at page 151.

³⁰ *Marion* at p 253

“the requirement of court authorisation ensures a hearing from those experienced in different ways in the care of those with intellectual disabilities...”³¹

The third is to ‘neutralise’ the impact of the adversarial nature of court proceedings on the applicants, almost always the child’s parents. In an early sterilisation case³² the presiding judge observed that the adversarial nature of proceedings generated a hostile atmosphere that was detrimental to the family.

The majority in Marion took the point further. They acknowledged that:

“it is too costly for most parents to fund court proceedings, that delay is likely to cause painful inconvenience, and that the strictly adversarial process of the court is very often unsuitable for arriving at this kind of decision. These are clear indications of the need for legislative reform, since a more appropriate process for decision making can only be introduced in that way.”³³

(c) the effectiveness of the protocols

The Family Court hasn’t dealt with any applications for sterilisation (or any other special medical procedure) in Victoria since the protocols there were ratified,³⁴ and only one in Queensland, in 2000.³⁵ Clearly it is too early to assess their effectiveness.

There is good reason to believe, however, that many applications will be diverted if appropriate services are offered early in the piece, before partisan legal involvement. The experience in Queensland has been relatively positive. It has shown that where services are accessed by families, before lawyers are engaged or an application is made to the court, they will more often than not chose less invasive options:

“Between September 1994 and December 1997 ten out of eleven matters in Queensland were successfully diverted from court. The ‘guidelines and protocols’ have facilitated the identification and delivery of information and advice to the child’s parents and referral for needs-based programs and support.”³⁶

³¹ Marion at p 259.

³² See Cook, J., in *Re a Teenager* (1989) FLC 92-006. Refer to Chapter Five for further discussion.

³³ Marion, at p 253

³⁴ Written communication from the Office of the Public Advocate dated 2nd March 2001.

³⁵ *In the matter of A*, Unreported, Jerrard, J. 5th June 2000.

³⁶ Brady, S. (1998). The Sterilisation Of Children with Intellectual Disabilities - Defective Law, Unlawful Activity and the Need for a Service Oriented Approach, *Australian Journal of Social Issues* 33 (2) pp 155-177 at p 170.

That said the protocols will be only as good as the service landscape and availability of support services for the child and family, and only to the extent that families are prepared to consider alternatives and the Court is prepared to give genuine consideration to non-surgical alternatives. The spirit and success of the protocols rely on all these conditions being met.

The Protocols for special medical procedures like sterilisation are similar in spirit and intention to the child protection protocols between the Family Court and relevant State and Territory authorities.³⁷ Those protocols too are designed to encourage cooperation between key stakeholders, clarify procedures and promote best practice, and ensure the development and implementation of an individual case management program which meet the needs of children and their families.³⁸ However the Family Law Council has identified ongoing problems with the implementation of protocols regarding allegations of child abuse because the family law system is fractured and difficult to coordinate.³⁹ Recent research suggests that protocols between the child welfare authorities and the Family Court are infrequently and inconsistently applied if at all.⁴⁰

The special medical procedures protocols face the added problem that applications are few and far between, and it is likely that the Court will experience difficulties in identifying an application as a special medical procedure and administratively responding to it in a timely and coordinated way. As noted by the recent research programme in Victoria⁴¹ even in the child protection area where arguably more cases proceed to hearing there is a critical need for greater attention to be paid by court

³⁷ Family Law Council (1998) *Principles and Minimum Standards, Discussion Paper No 1, The Care Support & Protection of Children: Interaction between the Family Law Act and State and Territory Child & Family Services Legislation*, Canberra.

³⁸ *ibid* and see for an example the Protocol between Department of Human Services and the Family Court of Australia (1996) (Vic)

³⁹ *ibid*

⁴⁰ *ibid* and see Fehlberg, B & Kelly, F.(2000) Jurisdictional overlaps between the family division of the Children's Court of Victoria and the Family Court of Australia, *Australian Journal of Family Law* (forthcoming) cited in FLC (2000) *The best interests of the child" The interaction of the Public and Private Law in Australia*. Canberra p34

⁴¹ *ibid*

staff and legal representatives to the protocols.⁴² Clearly improvements in communication and cooperation between key stakeholders is required.⁴³

Some general observations about the operation of protocols include:

- the critical point is the point of first contact. The chances of families giving meaningful consideration to non-surgical alternatives to sterilisation reduce significantly once applicants are legally represented and an application is filed with the court. Filing alters the dynamics between the various stakeholders, and tensions are more likely to be evident. Applicants readily become committed to ‘winning’⁴⁴;
- the attitude of the applicant’s legal representatives is crucial to whether the protocols will work. Adversarial lawyers will promote the outcome wanted by their clients and are therefore unlikely to encourage them to engage with service providers in a cooperative exploration of potentially less invasive alternatives⁴⁵;
- the adversarial nature of the court process and partisan legal representation make it almost inevitable that professionals who provide alternative assessments and opinions will be portrayed as ‘spoilers’, and by so doing discourage rather than promote collaboration and cooperation.⁴⁶
- the way the problem is constructed shapes what evidence is collected, from whom, how it is assessed, and the weight it is accorded in deciding how the child’s best interests will be served.

(d) guardianship rules and guidelines

Both the NSW and SA Guardianship Tribunals are closely linked with the disability service systems in their respective States. The members of tribunals are chosen because they have specialised knowledge and experience with people with disabilities

⁴² *ibid.* See particularly p 46

⁴³ One case has used the protocols. A description of what happened in that case is not provided however all the problems identified on page 44 occurred. The service provider of disability services in the case did an outstanding job in terms of funding and service provision for the child and family.

⁴⁴ For a discussion of the issues relating to adversarial court based systems and children’s matters see generally, ALRC.(1997). *Review of the adversarial system of litigation: rethinking the federal litigation system* (ALRC IP 20), Sydney, and ALRC. (1997). *Review of the adversarial system of litigation: rethinking family law proceedings* (ALRC IP 22) Sydney, and ALRC.(1999). *Review of the federal civil litigation system* (ALRC DP 62) Sydney.

⁴⁵ *ibid* and see also footnotes 6, 37 and 40

⁴⁶ *ibid.* This observation is fully consistent with the findings of Law Reform Commissions and other applied research in the area of adversarial process and procedure.

and their families.⁴⁷ Their specialised knowledge is part of the ‘equipment’ of the tribunal and places it in a position where it can independently assess evidence put before it from both a professional and/or personal perspective.

Both Tribunals provide applicants with detailed information sheets in plain English advising them of the requirements which must be met before applications for sterilisation can proceed, as well as the type of information the tribunal requires in order to make a decision. The information sheets provide details on a wide range of support services and options which the child and family may wish to access. In both States, once an application for sterilisation has been made, linkages with services are encouraged and in some cases alternative options are identified and implemented, and as a result the application is withdrawn.⁴⁸

The NSW Guardianship Tribunal appoints an investigation and liaison officer (ILO) to case manage applications prior to hearing. The ILO is a member of tribunal staff and has the specific role of seeking the views of the person with a disability subject to application and all other relevant persons, and arranging medical and non-medical assessments, for example by psychologists, family planning educators, and others.

It has developed extensive questionnaires for reporters to assist them in providing the information it requires. The questionnaire for medical reporters seeks information on their history of contact with the child, whether alternative approaches of a less restrictive nature have been trialed, for how long, and why they are considered to be inadequate. Doctors are asked to consider “*what other alternatives would usually be recommended to a non-disabled patient, of similar age, with these difficulties?*” and whether they have liaised with other service providers who are involved with the child and her family. The questionnaire ends by asking whether the proposed treatment meets the statutory criteria – is it “*necessary to prevent serious damage to the patient’s health*” and does it “*promote and maintain the health and wellbeing of the patient*”. The non-medical questionnaire is similar in its approach except it does not ask whether the proposed treatment meets the statutory criteria but asks instead

⁴⁷ See discussion in Chapter One

⁴⁸ Written communication from NSW Guardianship Tribunal dated 9th February 2001. Refer also to Chapter 3 results.

whether it is “*likely that the client could develop adequate understanding to be able to consent to the proposed procedure herself?*”

The focus of each questionnaire is on establishing how well the reporter knows the child, whether he/she has engaged her in discussion about the proposed procedure, whether less restrictive approaches have been investigated, and whether the proposed surgery would be justified ‘but for’ the child’s intellectual disability.

The ILO provides the tribunal with a detailed investigation report, materials and reports collected during the course of the investigation, but does not make a recommendation. The report is provided to the parties prior to the hearing. It is tested in the same way that other reports are tested, and has similar evidentiary status.⁴⁹ The child is separately represented, usually by a legal officer with the Disability Legal Rights Centre.

The practices and procedures in South Australia are broadly similar to those in NSW. The investigation reports, however, are provided by staff of the Office of Public Advocate (OPA), an independent statutory agency that advocates on behalf of persons with a disability. OPA attends the hearings and make recommendations. Investigation reports in both NSW and South Australia may contain hearsay material⁵⁰, but there is a general policy not to include unsubstantiated material.

The proactive inquiring role of the ILO and OPA investigators suggests that their investigation reports are more comprehensive in their approach to the issues than the ‘single viewpoints’ presented, for example, by an individual medical practitioner or psychologist.⁵¹ The OPA and ILOs develop content knowledge and are embedded in a culture which is imbued with disability services policy and principles which stress

⁴⁹ Tait and Carney in an early evaluation of the NSW and Victorian Guardianship Tribunals queried whether there was undue reliance upon ‘investigation’ reports and found that there was not. See Tait, D., Carney, T., & Deane, K. (1994). Legal regulation of sterilisation: the role of guardianship tribunals in NSW and Victoria, *Australian Journal of Family Law* 8 (2) pp 141-165.

⁵⁰ Family reports are equivalents used in the Family Court. They are provided by in-house counsellors or nominated agencies and also contain hearsay material.

⁵¹ *ibid.* See also Carney, T & Tait, D. (1997). *The Adult Guardianship Experiment : tribunals and popular justice*, Sydney: The Federation Press and Carney, T.(2000). “Protection, Populism and Citizenship” *Law in Context : Special Issue 17 (2)* in Jones, M & Basser Marks, LA (Eds) *Explorations on Law and Disability in Australia*, The Federation Press, Sydney

least restrictive alternatives to intervention.⁵² The Guardianship Tribunals are inquisitorial in approach and do not rely only on the evidence and arguments put to them by the parties.

The Tribunal approach has strengths which makes it easier for both the young woman and her parents:

“The Guardianship Tribunal (of NSW) and other Tribunals in other states and territories of Australia are in a strong position to deal with applications for sterilisation. The NSW Guardianship Tribunal is well placed to determine these matters, in particular, because, we sit not only Presiding members but Professional and Community members identified as having experience and expertise in relation to these issues. This expertise informs the way that they seek and deal with the evidence. We handle applications for sterilisation in a way that is easier than the Family Court with its formal procedures and traditional court room atmosphere for the person, parents and other witnesses to provide their evidence”⁵³

The Tribunal approach is referred to as a ‘popular justice’⁵⁴ enabling an active participation and inclusion in the decision-making process.

⁵² Refer to discussion of the guardianship model in Chapter One

⁵³ Written communication from the NSW Guardianship Tribunal dated 9th February 2001.

⁵⁴ See for a full discussion Carney, T & Tait, D. (1997). *The Adult Guardianship Experiment : tribunals and popular justice*, Sydney: The Federation Press and See Carney, T.(2000). “Protection, Populism and Citizenship” *Law in Context* : Special Issue 17 (2) in Jones,M & Basser Marks, LA (Eds) *Explorations on Law and Disability in Australia*, The Federation Press, Sydney

CHAPTER FIVE

developments since 1997

(a) responses to the 1997 Report

The Report triggered a number of responses, not least a debate about the ‘true’ numbers of girls and young women being sterilised.

The most significant responses included the following:

(i) The Federal Attorney-General’s Department convened a meeting in June 1998 of interested agencies including representatives from the Attorney-General’s Human Rights and Law Reform branch, the Family Court of Australia, Human Rights and Equal Opportunity Commission (HREOC), and the Office of Disability to canvas opinion on what options for reform might be available.

(ii) At the same time HREOC worked directly with the Commonwealth Department of Health & Aged Care for changes to the Medicare Benefit Schedule. On 1 November 1998 the “Notes for Guidance” in the Medicare Benefit Schedule were amended to include the following guidelines:

- *“It is unlawful throughout Australia to conduct a sterilisation procedure on a minor (under 18 years of age) which is not a by-product of surgery appropriately carried out to treat malfunction or disease (eg; malignancies of the reproductive tract). Parents and guardians have no legal authority to consent on behalf of minors to such sterilisation procedures.*
- *Practitioners may be subject to criminal and civil liability action if the sterilisation procedure is not authorised by the Family Court of Australia or a Court or tribunal with jurisdiction to give such authorisation”.*

HREOC considered a more comprehensive approach was needed. In August 1998 Commissioner Sidoti wrote to the Federal Minister for Health welcoming the proposed changes to the Medicare Benefit Schedule, but drawing attention to the need for more rigorous requirements to be imposed. A higher level of accountability similar to that required of doctors making claims in relation to

rhinoplasty procedures (ie ‘nose jobs’) was considered appropriate. Rhinoplasty procedures require full clinical notes justifying why the procedure is therapeutically necessary before the Medicare payment is made. No action subsequently resulted from this HREOC recommendation.

In response Commissioner Sidoti said:

“I intend to advocate for further changes to this item including a requirement that claims for Medicare funds by doctors in relation to sterilisation of minors should be accompanied by either an order of the appropriate court or tribunal or full clinical details of the need for such a procedure”¹

(iii) The HREOC proceeded to make its strategy clear. It announced that its objective in relation to the sterilisation of girls and young women is *“to promote legal, policy and program measures to ensure that sterilising surgery is not performed on people with disabilities where it is not consistent with human rights”* and to:

- *assist in identifying what action can be taken by appropriate bodies to ensure that illegal sterilisations are not performed on people with disabilities*
- *encourage appropriate bodies to identify the most effective and accessible mechanism for gaining approval – to undertake sterilisations legally*
- *encourage appropriate bodies to address issues relating to the availability of family support and advice on alternatives to sterilisation”².*

(iv) Women With Disabilities Australia (WWDA), a federally funded advocacy organisation,³ undertook a literature review in 1999 on the sterilisation of girls and women with disabilities and highlighted concerns about potential unlawful sterilisations and human rights breaches.⁴ It lobbied the Senate with the result that a motion was passed on 15th March 2000 requesting that the Federal government:

¹ From HREOC Home Page dated November, 1998, www.hreoc.gov.au see “Disability Rights Update”

² *ibid*

³ See WWDA website <http://www.wwda.org.au> for information on the organisation’s aims and objectives

⁴ see above website for a literature review by Cathy Spicer

- *conduct a review of the legal, ethical and human rights mechanisms in place, or needed, to protect the rights and interests of the reproductive health of women with intellectual and other disabilities;*
- *commission research on the practice, effect and implications of the sterilisation of women with intellectual and other disabilities*⁵.

(v) In response to the motion on the 15th March 2000, the Minister for Family and Community Services and the Minister Assisting the Prime Minister for the Status of Women tabled the Senate Report.⁶ The 14 page report “...covers the background to the issue of sterilisation of women with disabilities, provides recent statistics on sterilisation procedures, and details a cross Departmental response to the Senate’s calls for a review of relevant legal, ethical and human rights mechanisms and the commissioning of research.”⁷

The Senate Report notes that WWDA was provided a \$25,000.00 grant from the Commonwealth Office of the Status of Women to “...undertake a National Project on sterilisation and reproductive Health of Women and Girls with Disabilities. The Project has two main components:

- *background research which will examine international and national developments in the area; and*
- *a National Forum which will draw together women with disabilities, academics and researchers, and policy makers to critically analyse the issue and develop strategies to advance debate and action.*”⁸

The Senate response referred specifically to girls and women with intellectual disabilities whilst the WWDA response was broad based including all women with disabilities. Women and girls with intellectual disabilities are less likely to be able to make an informed decision

⁵ See Australian Democrats Media Release “Democrats win action on sterilisations” from Senator Lyn Allison dated 22nd December 2000.

⁶ Report to the Senate on “*Sterilisation of Women and Young Girls with an Intellectual Disability*” was tabled by the Minister for Family and Community Services and the Minister assisting the Prime Minister for the Status of Women on 6th December, 2000.

⁷ *ibid* p 1

⁸ *ibid* pp 6-7. The National Forum was conducted as an adjunct to the Conference “Disability with Attitude” held in Sydney in 15-16 Feb 2001. The forum was split into two components. The specific aim of the first component was to provide a secure and confidential environment so that women with disabilities can tell their own stories and as such it was open to women with disabilities only. The second component included a special interest meeting for service providers, academics, policy workers

about sterilisation compared with girls and women with physical disabilities. For women who are able to give a valid consent sterilisation at a young age raises questions about the lack of voluntariness or coercion in decision-making. The opportunity for legal redress for involuntary sterilisation is different in these two cases.

(vi) WWDA wrote to the Federal Attorney-General in April 2000 regarding its concerns about the unauthorised sterilisation of girls and young women who have disabilities. In a reply dated 28th July 2000 the Commonwealth Attorney-General's Department advised of progress in the area, including:

"...providing information to the medical profession and members of the public as a means of ensuring such procedures are not carried out without the appropriate authorisation".

It noted amendments to Legal Aid Guidelines came into effect on 1 July 2000 which:

"... reflect the Government's policy of encouraging parents to act lawfully by seeking a court order for special medical procedures such as sterilisation, by making legal aid more accessible and clarifying who is eligible."

*"The Guidelines also provide that legal assistance should be granted for the separate representation of a child in any Family Court case relating to special medical procedures..."*⁹

The means test for legal aid is not applied to child representation but is applied to the parents of a child. Therefore parents (or anyone else) making an application for a special medical procedure for a child or young person will not receive legal aid unless they meet the means test. This raises the problem about accessibility to the courts and the burden of the financial costs associated with purchasing legal representation to present an application.

(vii) The Attorney-General, Mr Daryl Williams issued a news release on 17 December 2000 saying he had written to:

"... Australian medical colleges and associations to inform them of the law and procedure surrounding the non-therapeutic sterilisation of minors with an intellectual disability" and that

etc who have an interest in the issue but were not eligible to attend the closed forum. Sex Discrimination Commissioner Susan Halliday chaired and addressed the special interest meeting.

⁹ *ibid* p 5

he had also sent an “*Open Letter to the Australian Medical Profession*” and to “...selected Australian medical journals for publication.”¹⁰

In his “*Open Letter to the Australian Medical Profession*” the Attorney-General said:

“I wish to bring to your attention an issue that I consider to be of concern to readers of this journal. That issue is the need for authorisation from an appropriate court or tribunal prior to undertaking a sterilisation procedure on a minor unless as a by product of surgery carried out to treat some malfunction or disease.

I am bringing this to your attention as a lack of awareness among some professionals may be leaving children without the protection of the law. Professionals who perform unauthorised procedures are at risk of liability...

It has come to my attention that some sterilisation procedures are being undertaken on children without the proper authorisation.”

In his letter to Australian Medical Colleges the Attorney-General also advised on jurisdictional issues. He said:

“...the Family Court of Australia and the Federal Magistrates Service are appropriate bodies to decide such matters” and that “*in New South Wales and South Australia there are some circumstances in which the Guardianship Board may be able to approve a sterilisation procedure for a 16 or 17 year old child who is unable to give consent. The Family Court and the Federal Magistrates Service, however, have the power to authorise sterilisations for all children under the age of 18 years in all Australian States and Territories, including New South Wales and South Australia*”.

The NSW and South Australian Guardianship jurisdictions both have jurisdiction to authorise sterilisation procedures for children of all ages (0-17 years) as well as for adults with decision making disabilities. The NSW Guardianship Tribunal had its special medical procedure jurisdiction extended to include all children not just 16 and 17 year olds as was the case previously.¹¹ This ‘extended’ jurisdiction is part of the package of recommendations from the Department of Community Services review in

¹⁰ *ibid* p 4

¹¹ See section 175 of the Children and Young Persons (Care and Protection) Act 1998 (NSW). There are three treatments that require the consent of the Tribunal under this provision. They are: sterilisation, the use of depo provera or similar, vasectomy or tubal occlusion. The provision includes children who may or may not have a disability. A letter to the Editor was issued by the NSW Tribunal and published 23-25 December 2000 edition of the Sydney Morning Herald.

1996 of the *Children (Care & Protection) Act 1987 (NSW)* headed by Professor Patrick Parkinson of the Law School of the University of Sydney.¹²

(b) ongoing medical and community education

(i) A number of agencies undertake educational activities, including the Developmental Disability Units (DDUs) attached to medical schools at Monash Medical Centre, and the University of Queensland. The DDUs are actively involved in training medical students, general practitioners and postgraduate psychiatrists, psychologists, direct care workers, people with disability and their families and others. The training includes discussion of menstrual management, sterilisation, sexual abuse, capacity to consent to medical treatment and guardianship legislation.

The DDUs also carry out research, develop resources for medical practitioners¹³ and other disability service providers, and provide clinical services to adults with intellectual disability. Associate Professor Nick Lennox says that:

*“Menstrual management is often an issue addressed during these consultations. Operative procedures such as endometrial ablation and hysterectomy are occasionally raised in consultation, however a past history of a hysterectomy is more commonly seen clinically.”*¹⁴

He adds that hysterectomy is not unusual in the adult population although he noted that:

“...occasionally this issue [the sterilisation of children] is mentioned” and
“gradually there is more people who question the ‘need’ for sterilisation.”

He draws attention to:

“...the need for professionals to question such requests” and for
*“a global attitudinal change to people with an intellectual disability”*¹⁵

¹² See NSW Department of Community Services, October 1996 “Review of the Children (Care & Protection) Act 1987: Summary of Key Issues (several volumes)

¹³ See resource book for information on issues relating to sterilisation and medical best practice raised by the report in Therapeutic Guidelines (March, 1999). “Management Guidelines for People with Developmental and Intellectual Disabilities” Melbourne.

¹⁴ Written communication from Associate Professor N Lennox, DDU, University of Queensland, dated 26th January 2001.

¹⁵ *ibid.* These views were reflective of the majority views from respondents.

The College Obstetricians & Gynaecologists (RANZCOG) have also been active since Marion (1992) informing their members about the need for legal authorisation before a sterilisation may be performed on children and women with intellectual disabilities. It has published several Resource Units about best practice regarding menstrual and contraceptive management for women with intellectual disabilities.

(ii) The South Australian Office of the Public Advocate (OPA) has a very active role in educating and informing the public on the legislative requirements¹⁶ and has built service linkages and referral options.¹⁷ It has its own resource collection and works with the Sexual Health Information Network (SHINE, formerly the Family Planning Association), and closely with the specialist government service for people with intellectual disabilities, the Intellectual Disability Services Council (IDSC) of South Australia.¹⁸ IDSC has been active for many years in the area of the sterilisation of children and women with an intellectual disability and has commissioned a number of internal reports.¹⁹ It plays a key role in both developing and providing skills development and education relating to menstrual management and sexuality to individuals, their families and support workers. The Developmental Services Team is a specialised team within IDSC which collates information and resources on issues such as menstrual management and can assist front line workers to develop individual and group programmes. IDSC also works very closely with SHINE in the delivery of direct services.

“IDSC is committed to upholding the rights of people with intellectual disability and considers that sterilisation for purposes other than for treating

¹⁶ OPA (SA) gives about 80 presentations a year to the general public on sterilisation issues, and regular education sessions to disability workers. It also runs public and professional forums the most recent in November 2000 which drew over 100 participants from the community sector and service providers.

¹⁷ For example, a highly successful referral system has been developed with the Women and Children’s Hospital, in particular the Obstetrics and Gynaecology Department regarding options for fertility and menstrual management

¹⁸ IDSC is the state government organisation within the Department of Human Services IDSC has responsibility for assisting people with intellectual disability and their families; the overall coordination, planning and development of services for people with intellectual disability within South Australia; purchasing services from non-government organisations and private providers on behalf of people with intellectual disability; advising the State Government on issues concerning people with intellectual disability; assisting people with intellectual disability access quality services, and promoting community awareness and acceptance of intellectual disability.

¹⁹ See “*Sterilisation of People with Intellectual Disability*” 1996 and “*Sterilisation of People with Intellectual Disability: A Discussion Paper*” 1997 and “*Practice Guidelines on Sterilisation Issues for Women with Intellectual Disability*” 2000. IDSC (SA).

a life threatening disease should only occur as a last resort. The Guidelines provide workers with an overview of the issues, clarify the roles and responsibilities of other agencies and the roles and responsibilities of workers”²⁰.

In South Australia there is an active community education network in relation to sterilisation matters. The attitude to who should have jurisdiction in sterilisation matters is interesting in the context of South Australia where legislation has existed for nearly two decades. It appears that families and service providers:

“would much prefer matters to be dealt with by OPA and GB [Guardianship Board] but I am not sure whether [these] sentiments would be echoed by all of the legal fraternity. The reason for this is that OPA and GB “have a broader perspective and also the knowledge and resources to respond more appropriately [to] these matters”²¹

The Office of the Public Advocate in Victoria, has conducted:

“an intensive and targeted community education program including some media, development of a Fact Sheet, speaking engagements and (with the Department of Justice) distribution of 20, 000 copies of a booklet to doctors, hospitals, lawyers etc”²².

It too has an active community education program which explains the guardianship legislation in relation to special medical procedures, including sterilisation, and the approaches taken to these applications. Its approach to children is similar, and part of the same programme.

²⁰ Written communication from IDSC dated 20th February 2001. The following is a summary of the roles and responsibilities of IDSC workers:

To provide information, advice and referral options about all alternatives for fertility and/or menstrual management for the child/adult; To develop a range of strategies to assist the child/adult (where appropriate) to: develop partial or independent skills in menstrual management; accept menstruation; develop protective behaviours and personal relationship skills. To ensure access to behaviour management for the child/adult. To work in collaboration with other key agencies, such as SHINE SA and the Department of Education, Training and Employment, to ensure that information and appropriate programs are made available to both the child/adult and their family. To provide information and assistance to obtain relevant reports and, where appropriate, psychological assessments. To facilitate discussion of the issue with the individual/family and other professionals as requested/required. To liaise, where appropriate, with the Office of the Public Advocate, Legal Services Commission, Children’s Interest Bureaux and other advocacy services. To provide information and access to a broad range of services to assist in the day to day care of the child/adult eg respite, day options, based on the identified needs of the individual and their family. To provide referral to IDSC specialist support services such as the Intensive Family Intervention Team and the Adolescent/Adult Intervention Team. To have available up to date information/research on the issue of sterilisation and intellectual disability.

²¹ Written communication from OPA (SA) dated 31 January 2001.

²² Written communication from the OPA (Vic) dated 2nd March 2001.

(iii) Since the 1997 Report's publication there has been a continuing progress regarding the range of practical resources and literature available (both international and local) in relation to fertility and menstrual management for women with disabilities. An excellent clinical and educational resource assisting girls and young women with intellectual disabilities, their families and carers is the FPA Health formerly Family Planning (NSW). Part of its service includes the Healthrites Bookshop²³ (NSW) which provides an extensive range of resource materials and publications available through a mail order service. There are similar services available in other States.

Overall there appears to have been marked progress in the area of disability service provider's education and skills development relating to menstrual management programmes and parent education. Still a lot needs to be done. An important area that does not appear to have kept pace is special education.

Empirical research and recent respondent's comments highlights an unmet need for skills development and practical supports for special school-teachers and aides.²⁴

²³ Contact by email bookshop@fpahealth.org.au

²⁴ Carlson, G., Taylor, M., Wilson, J, & Griffin, J.(1994) "*Menstrual Management and Fertility Management for Women who have Intellectual Disability and High Support Needs : An Analysis of Australian Policy*", Project funded through a Research and Development Grant from the Commonwealth Department of Health, Housing and Community Services and see and SM Brady.(2001). *The sterilisation of girls and young women with intellectual disabilities in Australia: an audit of family court and guardianship tribunal cases between 1992-1998* in Conference Proceedings Disability with attitude : critical issues 20 years after International Year of the Disabled, International conference 16-17 February 2001, University of Western Sydney. Pp 108-122.

CHAPTER SIX

where to from here?

(a) the current situation, in overview

The High Court in Marion in 1992 sought to ensure heightened accountability in decision making in relation to the sterilisation of children. It decided that the law requires that sterilisation of children has judicial or quasi judicial authority in all circumstances other than those in which it occurs as a by product of surgery appropriately carried out to treat some bodily malfunction or disease.

The official data is unreliable, at least for the time being, and the anecdotal data by its very nature can't be quantified, but there is good reason nonetheless to believe that girls continue to be sterilised, and sterilised in numbers which far exceed those that have been lawfully authorised.

There might be a number of reasons why, but there is little reason these days to believe that ignorance of the law among the medical profession is one of them. The issue has been canvassed widely in medical journals for a decade or more, and in the mass media too, most recently at the Commonwealth's initiative in December last year.¹

The High Court anticipated one of the likely reasons in Marion. The majority in that case made the point that:

*“it is too costly for most parents to fund court proceedings, that delay is likely to cause painful inconvenience, and that the strictly adversarial process of the court is very often unsuitable for arriving at this kind of decision. These are clear indications of the need for legislative reform, since a more appropriate process for decision making can only be introduced in that way.”*²

Legal Aid Guidelines which came into effect in 2000 ensure that children subject to applications for sterilisation are legally represented free of charge, but parents who

¹ See Chapter Five

² Marion, at p 253

might wish to bring an application must still satisfy the stringent means test that applies to legal aid generally.³

The Family Court has introduced protocols and procedures in a number of States which are designed to divert matters from court until all less invasive non surgical alternatives have been explored and excluded, but protocols are difficult to implement for structural, organisational and professional reasons. The Court has also amended its rules in ways that enable it to pre-empt or at least ameliorate its adversarial process in these matters, but it rarely uses them.⁴

Two states, New South Wales and South Australia, have enacted legislation which gives their guardianship tribunals concurrent jurisdiction. The guardianship tribunals are inquiring in nature and don't require applicants to be legally represented, and the anecdotal evidence, which is borne out by the statistics, is that parents will use that option where it is available to them.⁵ Those two States aside, however, there has been no other legislative reform.

It is quite clear, whatever legal forum is available to act as decision maker, that families who may be contemplating sterilising their daughter should have the earliest possible opportunity to trial less invasive alternatives, before any legal process begins.

(b) key areas for reform

A lot of work needs to be done, much of it directed to achieving medium to longer term cultural and attitudinal change.⁶ There are a number of practical measures that

³ See Chapter Five

⁴ For a discussion of the issues relating to adversarial court based systems and children's matters see generally, ALRC.(1997).*Review of the adversarial system of litigation: rethinking the federal litigation system* (ALRC IP 20), Sydney, and ALRC.(1997). *Review of the adversarial system of litigation: rethinking family law proceedings* (ALRC IP 22) Sydney, and ALRC.(1999). *Review of the federal civil litigation system* (ALRC DP 62) Sydney and with reference to the use of protocols see the Family Law Council (2000) *The best interests of the child? The interaction of Public and Private Law in Australia*, Discussion Paper No.2 October, Canberra, and with reference to judges views on intervention see Freckelton, I., Reddy, P & Selby, H. (1999). *Australian Judicial Perspectives on Expert Evidence: an empirical study*. AIJA, Melbourne.

⁵ See Chapter Three

⁶ This is a theme consistently identified by respondents in this report however for further discussion see Brady, SM. (2001). The sterilisation of girls and young women with intellectual disabilities in Australia: an audit of family court and guardianship tribunal cases between 1992-1998 in Conference Proceedings *Disability with attitude : critical issues 20 years after International Year of the Disabled*, International conference 16-17 February 2001, University of Western Sydney. pp 108-122 and Brady, SM. (2001). Sterilization of girls and young women

might be taken, however, which would address specific problem areas. They include the following:

- to require that claims for Medicare funds by doctors in relation to the sterilisation of children should be accompanied by either an order of the appropriate court or tribunal or full clinical details of the need for such a procedure.⁷
- to engage the Commonwealth and State Attorney's General in a renewed debate about the need first identified by the High Court in Marion for legislative reform which achieves heightened accountability in these matters in a way which is neither costly for parents nor adversarial.

Such reform might be achieved in a number of ways, but the most hopeful model, given the precedent in New South Wales and South Australia⁸, is one in which the States give jurisdiction to their respective guardianship tribunals. Those tribunals are specialist bodies which already have jurisdiction in these matters in respect of adults with diminished capacity. They have the great advantage over any Commonwealth forum of having well established links, or the capacity to develop such links, with government and non-government service providers to children with disability and their families. Non-therapeutic sterilisation is euphemistically termed a special medical procedure but it is related to the characteristic 'disability' rather than clinical need and logically decision-making must be better off in a jurisdiction experienced in disability issues and linked to disability services. Family members of adults with intellectual disabilities have this option and it should also be an option for parents of children with intellectual disabilities.

As recommended by the Family Law Council there is a need for specific criteria, and uniform national standards which prescribe the circumstances in which children may, or may not, be sterilised.⁹

with intellectual disabilities: past and present justifications, *Violence against Women* 7 (4) April pp 432-461. Special Edition Sage Publications, Inc.

⁷ See Chapter Five and Commissioner Sidoti's comments.

⁸ See Chapter Three which identified parents tend to use the tribunal model if it is available to them.

- to engage government and non-government service providers to children with disabilities and their families, including Departments of Education and special educators, in consultation about the need to have coordinated policies and procedures in place which enable them to provide effective assistance to families who need assistance in managing their daughter's menstruation or concerns about fertility.

Service providing agencies and in particular their frontline staff should have ready access to concise and accurate information about the law in relation to sterilisation of children, and ready access to a range of practical resources and literature about fertility and menstrual management for girls and women with disability. There is no paucity of good resources available, but there may be a problem accessing them.

It is impossible to over-emphasise the importance of parents having early access to opportunities to explore less invasive alternatives to surgical sterilisation. Special schools have a key role in providing those opportunities, or having effective links with other service providers with whom they can collaborate. It is therefore critical that special school-teachers and their aides have access to the knowledge and skills necessary to provide information and practical assistance to girls with disabilities and their families.¹⁰ They, and other service providers, play a vital role in ensuring families are not encouraged to seek sterilisation rather than pro-active programmes designed to support families in an exploration of non-surgical alternatives.

The protection of the rights and integrity of girls and young women with intellectual disabilities, as envisaged by the High Court in Marion's case, remains dependant upon appropriate law reform and the service landscape for children and their families.

⁹ See Family Law Council (1994) *Sterilisation and Other Medical Procedures on Children : A Report to the Attorney-General*, Canberra

¹⁰ Special schools play an important role in the lives of families and children with disabilities. Children are at school for significant parts of the day and families are dependent upon the services they offer.