Creating Saviour Siblings:
Reconsidering the Role of the Welfare of the Child Principle in Regulating Pre-Implantation Tissue Typing in Australia

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ABSTRACT

Preimplantation tissue typing (PTT) is a form of assisted reproductive treatment (ART) used to conceive a child who is a direct tissue match for an existing sibling suffering from a life-threatening illness. The child born as a result of PTT is called a saviour sibling as s/he has the capacity to save the life of the existing sibling through stem cell donation. PTT raises concerns about the welfare of the child to be born, which are currently addressed in Australia through ART regulation.

This thesis critiques the current regulation of PTT in Australia and proposes a revised regulatory framework for PTT that is supported by clear ethical principles. It argues that the current focus in Australian ART law and policy on the welfare and interests of the child to be born is inappropriate for PTT. PTT is a procedure affecting not only the interests of the child to be born but also those of the parents and their existing ill child. Furthermore, the welfare of the child to be born is inextricably connected to the welfare of his/her family as a whole. Decisions about PTT should therefore involve consideration of the interests of all family members likely to be affected by the procedure, not just those of the putative child.

Two key issues for the regulation of PTT are the welfare of the child to be born and the role of the state in regulating ART. This thesis uses applied ethics to analyse the nature and role of the welfare of the child principle in relation to PTT. A relational approach to regulating PTT is proposed, based on a broad conceptualisation of the welfare of the child that includes both individual and collective family interests. Instead of treating the interests of the child to be born as paramount, this approach requires the child’s interests to be considered in connection with the interests of other family members.

The ethical analysis is then applied to develop an improved regulatory framework for PTT in Australia. As part of this process, the thesis explores how the two key issues I have identified have been dealt with in practice by policy-makers, legislators, regulators and courts in the United Kingdom (UK). In contrast to Australia, the regulation of PTT and the welfare of the child principle have been extensively considered in the UK. The lessons learnt in the UK about regulating PTT are used to refine the proposed regulatory framework for PTT in Australia.
DECLARATION

This is to certify that:

(i) the thesis comprises only my original work towards the PhD except where indicated in the Preface;
(ii) due acknowledgement has been made in the text to all other material used;
(iii) the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.
ACKNOWLEDGEMENTS

Writing this thesis has been an enjoyable and satisfying process. This is largely due to the amazing support and guidance I have been given along the way.

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I received assistance from various other people within the Melbourne Law School. Thank you to Professor Carolyn Evans and Associate Professor Matthew Harding, my Completion Seminar Assessment Panel, for their positive feedback and comments. Carolyn also provided me with helpful advice in her role as Associate Dean (Research). Thanks also to the Law Library staff and to Anthony McCosker for his advice on writing style and structure. Finally, I’d like to thank the University of Melbourne for awarding me a Melbourne Research Scholarship and for allowing me to take leave without pay to write this thesis.

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Last but not least, I would like to thank my family. A major theme throughout this thesis is the intrinsic value of family. I am grateful to my parents and family, not only for their love and support over the years but also for providing me with an insight into family relationships and for fostering an inquiring mind. I have been able to draw on my own experience, as the member of an intimate family, in writing this thesis.

In more recent years, I have been fortunate enough to have formed my own family, who are the heart of who I am. I’d like to thank my loving husband, Michael, for his unerring support and respect for my work and for giving me the space to treat my thesis as a job. Finally, thank you to my three beautiful children and muses – Gabriel, Amelie and Juliet – who inspire me every day!
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### ABBREVIATIONS

<table>
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<tbody>
<tr>
<td>ACART</td>
<td>Advisory Committee on Assisted Reproductive Technology (NZ)</td>
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<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
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<td>AHEC</td>
<td>Australian Health Ethics Committee</td>
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<td>AI</td>
<td>Artificial Insemination</td>
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<td>ART</td>
<td>Assisted Reproductive Technology</td>
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<td>ART Act (NSW)</td>
<td>Assisted Reproductive Technology Act 2007 (NSW)</td>
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<td>ART Act (SA)</td>
<td>Assisted Reproductive Treatment Act 1988 (SA)</td>
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<td>ART Act (Vic)</td>
<td>Assisted Reproductive Treatment Act 2008 (Vic)</td>
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<tr>
<td>CEC</td>
<td>Clinical Ethics Committee</td>
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<tr>
<td>COAG</td>
<td>Council of Australian Governments</td>
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<tr>
<td>CORE</td>
<td>Comment on Reproductive Ethics</td>
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<tr>
<td>Cth</td>
<td>Commonwealth of Australia</td>
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<tr>
<td>DI</td>
<td>Donor Insemination</td>
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<td>ECART</td>
<td>Ethics Committee on Assisted Reproductive Technology (NZ)</td>
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<td>FSA</td>
<td>Fertility Society of Australia</td>
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<td>HFEA</td>
<td>Human Fertilisation and Embryology Authority (UK)</td>
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<td>HFE Act 1990</td>
<td>Human Fertilisation and Embryology Authority Act 1990 (UK)</td>
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<td>HFE Act 2008</td>
<td>Human Fertilisation and Embryology Authority Act 2008 (UK)</td>
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<td>HGC</td>
<td>Human Genetics Commission (UK)</td>
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<td>HREC</td>
<td>Human Research Ethics Committee</td>
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<td>HRT Act (WA)</td>
<td>Human Reproductive Technology Act 1991 (WA)</td>
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<td>HSC</td>
<td>Haematopoietic Stem Cells</td>
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<td>HTA</td>
<td>Human Tissue Authority (UK)</td>
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<td>ICSI</td>
<td>Intracytoplasmic Sperm Injection</td>
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<td>ITA</td>
<td>Infertility Treatment Authority</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>IT Act (Vic)</td>
<td><em>Infertility Treatment Act 1995 (Vic)</em></td>
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<td>IVF</td>
<td><em>In Vitro</em> Fertilisation</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council (Australia)</td>
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<tr>
<td>NSW</td>
<td>New South Wales</td>
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<td>NT</td>
<td>Northern Territory</td>
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<td>NZ</td>
<td>New Zealand</td>
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<td>PGD</td>
<td>Preimplantation Genetic Diagnosis</td>
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<td>PTT</td>
<td>Preimplantation Tissue Typing</td>
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<tr>
<td>RATE</td>
<td>Regulatory Authority for Tissue and Embryos (UK)</td>
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<tr>
<td>RTAC</td>
<td>Reproductive Technology Accreditation Committee (Australia)</td>
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<tr>
<td>SA</td>
<td>South Australia</td>
</tr>
<tr>
<td>STC</td>
<td>House of Commons Science and Technology Committee (UK)</td>
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<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>US</td>
<td>United States</td>
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<tr>
<td>VARTA</td>
<td>Victorian Assisted Reproductive Treatment Authority</td>
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<tr>
<td>VCAT</td>
<td>Victorian Civil and Administration Tribunal</td>
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<tr>
<td>VLRC</td>
<td>Victorian Law Reform Commission</td>
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<td>WA</td>
<td>Western Australia</td>
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CHAPTER 1

PTT REGULATION IN AUSTRALIA

An heir and a spare: this was a custom that went back to my ancestors in England. It sounded callous – having a subsequent child just in case the first one happens to die – yet it had been eminently practical once. Being an afterthought might not sit well with this kid, but the truth is that children are conceived for less than admirable reasons every single day: to glue a bad marriage together; to keep the family name alive; to mold in a parent’s own image. ‘They had me so that I could save Kate’, the girl explains. ‘They went to special doctors and everything, and picked the embryo that would be a perfect genetic match.’

My Sister’s Keeper

I INTRODUCTION

In October 2000 in the United States, Adam Nash was the first saviour sibling reported to have been born using a form of assisted reproductive technology (ART) known as preimplantation tissue typing (PTT). PTT enables parents to conceive a child who is a direct tissue match for an existing sibling suffering from a life-threatening illness. Adam Nash’s cord blood was successfully transplanted to his sister Molly, which cured her Fanconi anaemia. Despite its success, Adam Nash’s birth opened up a new area of controversy in ART and raised ethical concerns about the welfare of the child to be born. In particular, two concerns have dominated the debate over saviour siblings. The first is whether the child to be born is treated as a commodity, as simply a means to save the life of his/her sibling. The second is whether the child to be born will be harmed as a result of PTT, either physically, psychologically or socially.

The concerns about the potential commodification and harm to the child born as a result of PTT are addressed in Australia through regulation. In particular, law and policy regulating ART in Australia centre on the welfare of the child to be born. In this thesis, I critically analyse the regulation of PTT in Australia. I focus on Victoria, as it is the only state to have specifically regulated PTT. Using applied ethics, I

1 Jodi Picoult, My Sister’s Keeper (Allen & Unwin, 2005), 22.
2 Adam’s sister, Molly, was suffering from Fanconi’s anaemia (a rare hereditary blood disease). Doctors treating Molly’s parents used preimplantation genetic diagnosis (PGD) to identify an embryo that was both free of Fanconi’s anaemia and a direct tissue match for Molly. After four attempts, the couple conceived a healthy son, Adam: Jess Buxton, ‘Unforseen Uses of Preimplantation Genetic Diagnosis – Ethical and Legal Issues’ in Kirsty Horsey and Hazel Biggs, (eds), Human Fertilisation and Embryology: Reproducing Regulation (Routledge-Cavendish, 2007) 109, 115.
3 PTT is also known as Human or Histocompatability Leukoocyte Antigen (HLA) tissue matching.
examine the role of the welfare of the child principle in the context of PTT. I propose an alternative ethical approach for regulating PTT to that which is currently applied in Victoria. I then turn to the United Kingdom (UK), which has a similar framework for regulating PTT to that in Victoria. In contrast to Victoria, the ethical issues surrounding PTT regulation have been considered in detail by several major reviews of ART law and policy in the UK. I draw on some key insights about the regulation of PTT in the UK in order to propose a new regulatory framework for PTT in Australia.

This Chapter introduces the thesis by explaining how the key ethical concerns arising in relation to PTT have been dealt with by legislators, regulators and policy-makers in Australia. In Part II of this Chapter, I provide a brief overview of the medical, legal and ethical issues surrounding PTT. I begin by explaining the process of PTT and other treatment options available. I then explain the ethical concerns PTT raises about the welfare of the child to be born and how these have been addressed through regulation in Australia. Finally, I flesh out some of the more complex ethical issues that are often overlooked in the ethical debate surrounding PTT. Some of these ethical issues have, however, been explored effectively through narrative. I refer to two recent novels – *My Sister’s Keeper* and *Never Let Me Go* – to illustrate the ethical dilemmas and the various interests affected by the use of reproductive technologies to treat the illnesses of others.

In Part III, I provide a general overview of how PTT is regulated throughout Australia. In particular, I explain how the constitutional limitations on the Commonwealth Parliament have led to a fragmented regulatory framework for ART in Australia. This, in turn, impacts on the availability of PTT throughout Australia, which varies according to the eligibility requirements for ART in each state or territory. The weight attributed to the interests of the child to be born also varies throughout Australia. Victorian ART legislation requires the welfare and interests of the child to be born to be treated as paramount. I argue that this approach is fundamentally inconsistent with PTT – a procedure primarily motivated by the interests of the parents and the existing ill sibling.

The Commonwealth and the state of Victoria are the only two jurisdictions that have developed policy specifically addressing PTT. In Part IV, I analyse Commonwealth and Victorian policies on PTT and identify three gaps in the current regulatory
framework for PTT in Australia. The first gap is the lack of ethical guidance given to parents in the decision-making process for PTT. The second gap is the insufficient consideration given to the interests of other family members affected by a decision to use PTT. The third gap relates to the lack of effective monitoring of the short and long-term consequences for children born as a result of PTT. This sets the scene for the remainder of the thesis, which is outlined in Part V.

II MEDICAL, LEGAL AND ETHICAL ISSUES FOR PTT

A What is PTT?

PTT is a form of genetic screening technology used to conceive a donor sibling for an existing child who requires a stem cell transplant. An embryo biopsy is carried out to identify an embryo that is an exact tissue match for the existing sibling. Embryo biopsies can also be used to screen embryos for genetic disease in a process known as preimplantation genetic diagnosis (PGD). In cases where the existing child is suffering from a heritable disease, PTT is carried out in conjunction with PGD in order to select an embryo that is a direct tissue match and also free from any genetic disease.

The child born as a result of PTT is often described as a ‘saviour sibling’ as s/he has the capacity to save the life of the existing sibling through umbilical cord blood stem cell donation. Cord blood stem cells are one of three sources of allogeneic haematopoietic stem cells (HSC). The other two sources of HSC are peripheral blood and bone marrow. HSC transplantation has become standard procedure for treating a number of malignant and non-malignant conditions.

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4 The term ‘PGD’ is often used more generically, to refer to any form of genetic screening, including PTT. In this thesis, I use the term PGD to refer specifically to the screening of embryos for genetic disease.
6 Ibid.
7 Ibid. HSC transplantation is used to treat a variety of diseases in children and adults, including selected hematologic malignancies, immunodeficiencies, hemoglobinopathies, bone marrow failure syndromes, and congenital metabolic disorders. In the future, it may be possible to use autologous stem cell therapy to treat some of these conditions. For example, French and US researchers have recently treated a patient suffering from beta-thalassaemia using genetically-altered stem cells obtained from his own bone marrow: Lux Fatinathas, ‘Beta-Thalassaemia Patient Successfully Treated with ‘Gene Therapy’ BioNews 20 September 2010 http://www.bionews.org.uk/page_70902.asp.
bone marrow transplant may be carried out at a later date. However, transplanting hard organs (such as kidneys) from minors is generally prohibited in Australia. Although it is possible for parents to naturally conceive a child who is a direct tissue match, there is only a one in four chance of this occurring. PTT enables parents to actively select a child who will be an exact tissue match with an existing sibling, thereby removing the element of chance involved with natural conception.

Tissue-matched siblings are not the only potential source of HSC. HSC may also be obtained from other family members or unrelated donors with a compatible tissue type. There are currently more than 7 million living adults on the National Marrow Donor registry in the US and 6 million additional donors and cord blood units in registries around the world. However, not everyone who needs a HSC transplant will find a compatible tissue donor, particularly if they are from an ethnic minority group. For example, in Australia only 50% of patients for whom a search was initiated through the Australian Bone Marrow Donor Registry between 2003 and 2005 found a suitable unrelated cord blood, peripheral blood or bone marrow donor.

Lower success rates were found for patients in the Asian (38%), aboriginal Australian

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8 The likelihood of success of any HSC transplant varies according to the type of disease being treated and the stage of the disease. For example, the success rate of HSC transplants ‘ranges from 50% to 70% in more favourable cases and from 10% to 25% for patients with less favourable conditions or advanced disease’: Kendra D MacLeod, et al, ‘Pediatric Sibling Donors of Successful and Unsuccessful Hematopic Stem Cell Transplants: A Qualitative Study of Their Psychosocial Experience’ (2003) 28(4) Journal of Pediatric Psychology 223, 223. The number of stem cells present in units of cord blood is significantly lower than those in standard transplants (about one-tenth): Sophie Pryor, ‘Early Cord Blood Trial Points to Treatment for Blood Disorders’ BioNews 25 January 2010 http://www.bionews.org.uk/page_53584.asp. Therefore, if the recipient is large, the number of cord blood stem cells obtained may not be adequate: AAP, above n 5, 395. However, a new technique is currently being developed for multiplying the number of stem cells found in umbilical cord blood: Pryor, above n 8.

9 See, for example, Human Tissue Act 1982 (Vic), s 14(1). See discussion in Chapter 2, Part VA2.

10 In 1991, Marissa Ayala featured on cover of Time Magazine as a naturally-conceived donor for her sister Anissa, who was suffering from leukaemia. It is also possible for parents who conceive naturally to use prenatal diagnosis to determine whether the foetus is a direct tissue match and terminate the pregnancy if necessary. See, for example, the Abortion Law Reform Act 2008 (Vic), ss 4, 5.

11 AAP, above n 5, 392-3.

12 AAP, above n 5, 393. Cord blood stem cells need not be as perfectly matched to the recipient as conventional bone marrow transplants because cord blood stem cells are less likely to trigger immune rejection: at 395; Pryor, above n 8. However, due to the smaller number of stem cells in a unit of cord blood, transplants using cord blood stem cells engraft more slowly than stem cells from peripheral blood or bone marrow. Because transplant patients are at risk of developing life-threatening infections until engraftment occurs, cord blood recipients have a higher risk of infection than peripheral blood or bone marrow recipients: The Leukemia and Lymphoma Society, ‘Cord Blood Stem Cell Transplantation Facts’ (Fact Sheet No. 2, August 2007) http://www.leukemia-lymphoma.org/attachments/National/br_1286569435.pdf.

(33%) and Indian (0%) populations. Even where a compatible unrelated donor exists, tissue-matched siblings are generally preferred as donors by physicians because the risks of graft-versus-host disease and other transplant-related complications are more common with unrelated donors.

B Protecting the welfare of the child to be born

The two main ethical concerns arising in relation to PTT are that the child to be born is commodified and that s/he may be harmed, either physically, psychologically or socially.

The physical risks for the child to be born arise in relation to the embryo biopsy and donation processes. Although current evidence suggests that the physical risks to the selected embryo associated with embryo biopsy are minimal, more scientific evidence is needed about the safety of the process and any long-term outcomes for the child who is born. The physical risks associated with donation depend on the type of stem cells donated. These range from no material risk arising out of cord blood donation to significant risks associated with bone marrow donation, which involves general anaesthesia.

The psychosocial risks to the child to be born as a result of PTT are speculative. Being created to save the life of another may have a negative impact on a saviour sibling’s sense of self-worth or identity. While there is no empirical evidence on the risks of psychological or social harm to saviour siblings, there is evidence that some sibling bone marrow donors suffer psychosocial harm. The risk of harm is increased where a donation is unsuccessful.

The welfare of the child born as a result of PTT can be protected by various forms of regulation. Governments throughout the world have taken different approaches to regulating PTT. At one end of the spectrum, PTT is prohibited in countries such as

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14 Ibid.
15 AAP, above n 5, 392.
16 For a detailed discussion of the risks associated with PTT, see Chapter 2, Part VA and B.
18 See Chapter 2, Part VA2.
20 See Chapter 2, Part VB.
Italy and Germany. At the other end of the spectrum, there is virtually a free market for genetic screening technologies such as PTT in the United States, subject to professional regulation and general criminal and civil law. Australia and the UK fall somewhere in between by taking a permissive regulatory approach to PTT. The Victorian and UK governments have adopted similar facilitative regimes with broad legislative frameworks that delegate decisions about PTT to statutory bodies. In both jurisdictions, the welfare of the child to be born is a key consideration that is enshrined in legislation.

C Regulating PTT in Australia

Due to federalism, PTT is currently regulated in Australia by a combination of state legislation and national professional standards and ethical guidelines. According to Szoke, ‘Australia may be described variously as a rich tapestry of diversity in terms of the regulatory structure, or a patchwork of regulatory stitching lacking cohesion and order.’ I argue in this thesis that PTT regulation in Australia is fragmented, inconsistent, and lacks a clear ethical foundation. Fragmented regulatory frameworks with deficient ethical underpinnings operate at a significant cost. According to Karpin and Bennett, the complex nature of Australia’s regulatory framework for ART ‘results in regulatory gaps and general confusion for individuals, clinicians, policy-makers,

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21 Human Genome Research Project, Choosing genes for future children: the regulatory implications of preimplantation genetic diagnosis (2006) Dunedin, New Zealand, 307. PTT may be forbidden either expressly or implicitly by prohibitive legislation: 307, footnote 431. In Italy, preimplantation testing is permitted, but all embryos must be implanted so selecting embryos for implantation is forbidden. Article 13 of law 40/2004 only allows diagnostic and therapeutic interventions on the embryo aiming to protect its health and development: E Turillazzi and V Fineschi, ‘Preimplantation Genetic Diagnosis: A Step by Step Guide to Recent Italian Ethical and Legislative Troubles’ (2008) 34(1) Journal of Medical Ethics 1, 1. However, three recent court rulings have held that couples have a constitutional right to PGD to screen for genetic disease. Embryo biopsy is expressly prohibited in Germany under the Embryo Protection Law: German National Ethics Council, Genetic Diagnosis Before and During Pregnancy (2003), 58. However, a German court recently ruled in favour of PGD where ‘there is a danger of grave genetic defects for the desired children of the patients’: BioEdge, ‘German Court Allows Genetic Diagnosis of IVF Embryos’, 9 July 2010 http://www.bioedge.org/index.php/bioethics/bioethics_article/9095/.

22 There is no federal regulation of ART in the US. Although some US states have legislated in relation to ART generally, there are no laws that explicitly address PTT: Human Genome Research Project, above n 21, 295. See also: John Seymour and Sonia Magri, ART, Surrogacy and Legal Parentage: A Comparative Legislative Review (Victorian Law Reform Commission Occasional Paper, August 2004), 6.

23 See Assisted Reproductive Treatment Act 2008 (Vic) (ART Act (Vic)), s 5; Human Fertilisation and Embryology Authority Act 1990 (UK) (HFE Act 1990), s 13(5).

24 Helen Szoke, ‘Australia – A Federated Structure of Statutory Regulation of ART’ in Jennifer Gunning and Helen Szoke (eds), The Regulation of Assisted Reproductive Technology (Ashgate, 2003) 75, 75.
parents and potential parents. I argue that greater consistency and certainty could be achieved through uniform national regulation of ART and, specifically, PTT. Given the controversial nature of PTT, national regulation should be supported by clear ethical principles set down by Parliament.

Commonwealth guidelines regulating ART deal briefly with PTT, providing some level of national consistency. However, the availability of PTT throughout Australia depends on how ART is regulated in each particular state and territory. Legislation on ART has been enacted in Victoria, Western Australia (WA), South Australia (SA) and New South Wales (NSW). PTT is not expressly mentioned in any of the ART legislation in these states. However, detailed policy guidelines on PTT in conjunction with PGD were developed in Victoria by the former Infertility Treatment Authority (ITA) in 2002. Until recently, these guidelines were imposed on ART clinics as conditions of registration under the Assisted Reproductive Treatment Act 2008 (Vic) (ART Act (Vic)) by the ITA’s successor, the Victorian Assisted Reproductive Treatment Authority (VARTA). A copy of the previous VARTA Conditions on PTT appears as Appendix A to this thesis.

I focus in this thesis on the regulation of PTT in Victoria as it is the only state in Australia to have specifically regulated PTT through detailed policy guidelines. Victoria is an international leader in ART regulation, being the first jurisdiction in the world to enact comprehensive legislation on the use and development of ART. The original Infertility (Medical Procedures) Act 1984 (Vic) was based on the findings of the Waller Committee, which investigated the social, legal and ethical consequences of reproductive technologies. At the time of enactment of this early ART legislation in Victoria, the technology for PTT had not yet been developed. The Victorian Law Reform Commission (VLRC) has recently conducted a substantial review of the law

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26 Infertility Treatment Authority, Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis (at January 2004).
27 See ART Act (Vic), s 75(1). VARTA, Conditions for Use of Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis (February 2010) (previous VARTA Conditions on PTT). The previous VARTA Conditions on PTT were removed from the VARTA website in July 2010. The Victorian Department of Health is currently reviewing policy on PTT and the scope of VARTA’s authority: telephone conversation between the author and Tracey Petrillo (Policy Officer, VARTA) on 16 July 2010.
29 The Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilization, Consolidated Reports of the Inquiry into IVF and Related Issues (1982-4) (2nd Reprint, August 1990).
on assisted reproductive treatment. However, the Commission gave little consideration to the ethical issues surrounding PTT.  

I argue in this thesis that the lack of ethical consideration in relation to PTT has led to a flawed framework for regulating PTT in Victoria. In particular, I argue that the paramount importance attributed to the welfare and interests of the child to be born as a result of ART in Victoria is inconsistent with PTT, a procedure designed to save the life of an existing child. The obligation to treat the interests of the child to be born as paramount may have been appropriate for reproductive technology that was initially used to assist infertile couples to conceive a baby and, more recently, at risk couples to conceive a baby free of genetic disease or abnormality. However, the decision to use PTT is primarily motivated by the interests of the parents in saving the life of their existing ill child and the interests of the existing child in living a healthy life. It is therefore inappropriate to prioritise the interests of the child to be born over the interests of other family members in the context of PTT.

PTT raises significant and complex bioethical issues

Although the number of cases of parents seeking PTT is small, the stakes are extremely high for the families directly involved. PTT also has wide-ranging social import as it raises ethical concerns about the use of reproductive technology to create human tissue donors. The moral permissibility of conceiving human beings for the purpose of treating the illnesses of others has been explored recently in modern literature, reflecting the public interest in this area of reproductive technology. As Storrow points out, ‘[b]ioethicists have long embraced literature as a valuable tool for

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30 The Commission focused on questions of access, surrogacy and parentage.
31 I argue in my Conclusion that attributing paramount importance to the interests of the child to be born as a result of ART may not, in fact, be appropriate. I suggest that a relational approach may be appropriate not just for PTT but for ART generally.
32 More than 15 saviour siblings have been born in NSW: Western Australian Reproductive Technology Council Annual Report (1 July 2008 – 30 June 2009), 33. In Victoria, there have only been two applications for PTT, of which one was withdrawn and the other did not go ahead. There is no record of any births from PTT in Victoria: email from Tracey Petrillo (Policy Officer, VARTA) to Michelle Taylor-Sands, 13 May 2010. As at the beginning of 2010, there had been 24 licenses issued for PTT in the UK since 2001: David King, ‘The Case for Case-by-Case Regulation’ BioNews 18 January 2010 http://www.bionews.org.uk/page_53438.asp. See also Danny Edwards, ‘Case by Case Decision-Making in PGD’ (Paper No ELAC (12-09) 3, submitted at Human Fertilisation and Embryology Authority Ethics and Law Advisory Committee Meeting on 15 December 2009) [4.10]. Only two births resulting from PTT have been recorded in the UK: Human Fertilisation and Embryology Authority (HFEA), Minutes of Authority Meeting (20 January 2010) [10.6].
Two recent novels – *Never Let Me Go* and *My Sister’s Keeper* – highlight the ethical dilemmas that ought to be addressed in relation to the use of reproductive technologies to create human tissue donors.

As discussed above, one of the primary ethical concerns arising out of PTT is that the child to be born is treated as a commodity. Kazuo Ishiguro conjures an extreme example of commodification in *Never Let Me Go*. In this science fiction novel, Ishiguro depicts a future world in which human clones are bred and raised solely to become organ donors later in life. The novel focuses on the lives of three cloned children – Kathy, Tommy and Ruth – in a boarding school called Hailsham. The children of Hailsham have been cloned as part of a governmental program researching cures for cancer and heart disease. Once the children become adults their vital organs will be used in medical treatment. The novel is written as a memoir by Kathy, who is reaching her final stage of life when she will donate her vital organs. Described as an ‘existential fable about people trying to wring some happiness out of life before the lights go out’, *Never Let Me Go* does not purport to discuss the ethics of cloning in any detail. However, the novel inevitably raises important ethical questions about identity, sacrifice and the importance of treating all humans with respect in the context of developments in reproductive technology.

Jodi Picoult addresses similar themes in her novel, *My Sister’s Keeper*, which deals directly with saviour siblings. In *My Sister’s Keeper*, Jodi Picoult gives a fictional account of Anna Fitzgerald, a 13 year old girl who was conceived using PTT as a saviour sibling for her sister Kate. Kate, who is 16, is suffering from acute promyelocytic leukaemia. Anna’s parents initially intended to use cord blood stem cells from Anna’s birth, but this was unsuccessful in curing Kate. Anna subsequently donates peripheral blood stem cells and bone marrow to her sister. Finally, Anna is called upon by her family to donate a kidney to Kate. The novel commences with Anna pursuing legal proceedings to obtain the right to make her own decisions about her body. Picoult’s novel reveals the ethical complexities surrounding PTT. In particular, the novel highlights the crises faced by a family with a terminally ill child,

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34 Kazuo Ishiguro, *Never Let Me Go* (Faber and Faber, 2005).
35 Picoult, above n 1.
the complex nature of family relationships, the impact of family on identity, the limits of family obligation, and the potential for donor children to be commodified or harmed by PTT. Although melodramatic in style, Picoult effectively uses a multiple first-person narrative to portray the interconnected and conflicting interests within a family that can arise in relation to PTT. By exposing ‘the rarely glimpsed complexity of family dynamics’, the novel reveals the complex and interrelated interests that exist within families, which are often neglected in ethical debate over PTT. *My Sister’s Keeper* also serves as a reminder that ‘families who create saviour siblings remain in crisis long after the saviour’s birth’.38

*Never Let Me Go* and *My Sister’s Keeper* raise fundamental ethical issues about using reproductive technology to conceive tissue donors, although they represent different ends of the moral continuum. There are significant differences between the plight of the Hailsham children in *Never Let Me Go* and Anna in *My Sister’s Keeper*. First and foremost, human cloning technology is different to the genetic screening technology used to select a child with a compatible tissue type for a sibling. Second, family relationships are a central theme in Picoult’s novel, whereas the cloned children of Hailsham do not have parents or family. Third Anna was conceived as a result of a reproductive decision made by her parents. In contrast, Kathy, Tommy and Ruth are created as part of a governmental program in pursuit of public health care goals. Finally, Anna’s parents at no time contemplate Anna giving her life to save her sister Kate. By way of contrast, the cloned children in Ishiguro’s novel are expected to die in order for their vital organs to be harvested. In this sense, the Hailsham children are genuinely commodified as they are effectively born as ‘spare parts’.

Despite the differences between the subject matter of the two novels, there are strong analogies between the two stories. In particular, the technologies used to create saviour siblings and clone humans to become organ donors raise broader questions of whether it is morally permissible to create human beings for the purpose of treating others and how far families or the state should be allowed to go in resolving difficult health care issues. A central concern in relation to PTT is the potential commodification of the child to be born. *Never Let Me Go* and *My Sister’s Keeper*

37 Storrow, above n 33, 264.
38 Ibid. This point is made by Anna’s guardian ad litem, Julia. Storrow comments how this issue has been largely neglected in the ethical debate surrounding PTT.
39 Human cloning is prohibited in Australia under the *Prohibition of Human Cloning Act 2002* (Cth).
40 See discussion by Storrow, 264, 270-1.
provide stark reminders of the dangers that lie at the end of the slippery slope for tissue and organ donors and the importance of ensuring that the most vulnerable members of society are treated with respect. *My Sister’s Keeper* takes the ethical debate over PTT further by highlighting the complex and interrelated interests that exist within families, which are not always easily reconciled. By exposing the ethical dilemmas posed by the use of reproductive technology to create tissue donors, *Never Let Me Go* and *My Sister’s Keeper* highlight the importance of ethically-considered regulation in this area. According to Storrow, ‘both novels counsel against ill-considered policymaking at the intersection of reproductive technology and human tissue and organ donation.’

Despite the various interests that are affected by PTT, the law and policy regulating PTT in Australia focus primarily on the welfare of the child to be born. In the next Part, I outline how PTT is regulated throughout Australia.

### III OVERVIEW OF PTT REGULATION IN AUSTRALIA

As PTT is a form of ART, the availability of PTT in Australia varies according to how ART is regulated in each state and territory. ART is considered to be a health service, which the Commonwealth Constitution deems to be the responsibility of the states and territories. In this Part, I outline how the current fragmented approach to ART regulation in Australia impacts on the availability of PTT throughout Australia. I begin by explaining the constitutional barriers to uniform national regulation of ART.

#### A Constitutional barriers to uniform national regulation

The Commonwealth Parliament does not have explicit constitutional power to legislate in relation to the provision of ART services or health and medicine generally in Australia. It has, however, managed to overcome constitutional limitations to enact federal legislation in some areas. For instance, Commonwealth legislation has been enacted in relation to human embryo research and cloning technologies through a cooperative federal agreement by the Council of Australian Governments

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41 Storrow, above n 33, 271.
43 Constitution Act 1901 (Cth), s51.
Commonwealth-State cooperative legislative schemes rely on states referring their powers to the Commonwealth. In the absence of a specific referral of power or agreement by the states, the Commonwealth could potentially use one or more of its powers under the Constitution to indirectly legislate on ART.

Despite calls for a unified national approach to ART in Australia, particularly in relation to ‘social issues’ such as eligibility and genetic testing technologies:

... there has been no systematic review or analysis of the adequacy of Australian law and regulations at the intersection of ART and human genetic technologies such as PGD. Nor has

44 In 2002, COAG agreed that the Australian Government and State and Territory governments should introduce nationally consistent legislation to ban human cloning and regulate research involving human embryos that had been created for ART but were no longer required. The agreement resulted in the passage of the *Prohibition of Human Cloning Act 2002* (Cth) and the *Research Involving Human Embryos Act 2002* (Cth). Under the COAG agreement, all Australian states and the Australian Capital Territory (ACT) have enacted legislation intended to “mirror” the Commonwealth Acts. The Northern Territory (NT) is in the process of drafting legislation: National Health and Medical Research Council (NHMRC), *Commonwealth and State Legislation*, [http://www.nhmrc.gov.au/research/embryos/information/legislation/index.htm](http://www.nhmrc.gov.au/research/embryos/information/legislation/index.htm).

45 *Constitution Act 1901* (Cth), s 51(xxxvii). Another example of a Commonwealth-State legislative scheme is corporations law. Although these schemes have a long history in Australia, they are not without their problems. The decision of the High Court in *R v Hughes* (2000) 202 CLR 535 casts some doubt over the constitutional validity of Commonwealth-State cooperative schemes: Jennifer Norberry, Information and Research Services (Cth), *Bills Digest: Research Involving Embryos and Prohibition of Human Cloning Bill*, No 17 of 2002-03. National frameworks are also undermined where states fail to pass corresponding legislation. For example, in December 2006, the ban on therapeutic cloning was lifted by the Australian Parliament. Although COAG leaders agreed in April 2007 to use their best efforts to introduce corresponding legislation in their respective jurisdictions by 12 June 2008, the proposed legislation was defeated in the WA Parliament in May 2008: Irene Nemes, ‘Therapeutic Cloning in Australia: One Small Stem from Man, One Giant Leap for Mankind’ (2008) 16 *Journal of Law and Medicine* 139, 142-3. Legislation has been passed in Victoria, NSW, Tasmania and Queensland but SA is still debating the issue: Yasmine Phillips, ‘Saviour Siblings and Cloning a Step Closer for WA Scientists’, *The West Australian* (Perth) 12 October 2009, 1.

46 For example, the Commonwealth Parliament could rely on its financial assistance power under s 96 of the Constitution to finance ART services in the states and territories subject to terms and conditions set out in Commonwealth legislation. For a discussion of other potential heads of power that may support ART legislation, see: Sharon Scully, ‘Does the Commonwealth Have Constitutional Power to Take Over the Administration of Public Hospitals?’ (Research Paper No 36, Parliamentary Library, Parliament of Australia, 2009). Although this paper specifically considers whether the Commonwealth has constitutional power to take over the administration of public hospitals in accordance with the former Rudd government’s proposed national health care reform, the discussion is relevant to ART services. A last, although less likely, option would be for the Commonwealth to call a referendum to amend the Constitution. However, referendums in the past have been largely unsuccessful: at 6, footnote 41.

47 In the 1980s, the Family Law Council of Australia recommended a consistent national approach to ART in their report, *Creating Children: A Uniform Approach to the Law and Practice of Reproductive Technology in Australia* (AGPS, 1985). In 1996, the Australian Health Ethics Committee (AHEC) recommended that uniform legislation should be enacted throughout Australia on ART: NHMRC, *Ethical Guidelines on Assisted Reproductive Technology* (1996) (now rescinded) [5]. See also NHMRC, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004* (as revised in 2007 to take into account the changes in legislation) (June 2007) (NHMRC Guidelines on ART) [1.3].
there been a substantive consideration of the legal and ethical dimensions these technologies pose for reproductive decision-making.\textsuperscript{48}

However, the National Health and Medical Research Council (NHMRC), a Commonwealth statutory authority,\textsuperscript{49} has published non-legislative ethical guidelines on ART.\textsuperscript{50} Although the NHMRC Guidelines themselves do not have the force of law, compliance with the Guidelines is a key element in the national accreditation system for state and territory based ART clinics by the Reproductive Technology Accreditation Committee (RTAC). The RTAC was established by the Fertility Society of Australia, a peak body representing scientists, doctors, researchers, nurses, consumer groups, patients and counselors in reproductive medicine in Australia and New Zealand.\textsuperscript{51} All clinics offering ART services in Australia must comply with the NHMRC Guidelines as well as the RTAC’s Code of Practice, in accordance with the accreditation requirements of the RTAC.\textsuperscript{52} Accreditation by the RTAC is linked to federal funding\textsuperscript{53} and is now mandatory under Commonwealth legislation regulating embryo research and human cloning.\textsuperscript{54} Under new Victorian ART legislation, clinics accredited by the RTAC are deemed to be registered by the relevant state authority to carry out ART services.\textsuperscript{55} The relevant state authority in Victoria, VARTA, can impose conditions of registration in relation to specific ART services.\textsuperscript{56}

The NHMRC Guidelines apply to all Australian states and territories, except to the extent that they are inconsistent with legislation in those jurisdictions.\textsuperscript{57} There is no specific legislation dealing with ART in Queensland, Tasmania and the Australian Capital Territory (ACT). Reproductive technology clinics in these jurisdictions are

\textsuperscript{48} Karpin and Bennett, above n 25, 128.
\textsuperscript{49} The NHMRC is established under National Health and Medical Research Council Act 1992 (Cth).
\textsuperscript{50} NHMRC Guidelines on ART, above n 47.
\textsuperscript{51} Fertility Society of Australia, About FSA, \url{http://www.fsa.au.com/about/}.
\textsuperscript{52} Fertility Society of Australia, Reproductive Technology Accreditation Committee, Code of Practice for Assisted Reproductive Technology Units (revised May 2008).
\textsuperscript{54} It is an offence to use human embryos in any way without accreditation by the Fertility Society of Australia: Research Involving Human Embryos Act 2002 (Cth), ss 8 and 11. See Malcolm Smith, ‘Reviewing Regulation of Assisted Reproductive Technology in New South Wales: The Assisted Reproductive Technology Act 2007 (NSW)’ (2008) 16 Journal of Law and Medicine 120, 121. Because the Guidelines are an indication of accepted practice, non-compliance may also constitute negligence or may attract adverse publicity and damage reputation and career: Loane Skene, above n 42, 48.
\textsuperscript{55} ART Act (Vic), s 74.
\textsuperscript{56} ART Act (Vic), s 75.
\textsuperscript{57} NHMRC Guidelines on ART, above n 47 [2.11], [3.1].
therefore regulated by the NHMRC Guidelines as well as any applicable common law principles. Four states in Australia have expressly legislated in respect of ART – Victoria, SA, WA and NSW. Although there is no ART legislation in the Northern Territory (NT), NT clinics adhere to SA legislation subject to some minor changes.

State legislation on ART does not specifically address PTT. However, the availability of PTT varies throughout Australia depending on whether parents are eligible for ART and the weight attributed to the interests of the child to be born in the particular jurisdiction. Table 1 outlines how ART regulation throughout Australia impacts on the availability of PTT.

B Eligibility for ART

In Victoria, SA and WA, access to ART is limited by legislation to women who are either unlikely to become pregnant without ART or at risk of passing on a genetic disease or abnormality. Accordingly, parents are only eligible to use PTT when it is carried out in conjunction with PGD to screen embryos for a genetic abnormality or disease. Parents are not eligible under the legislation to use PTT solely to create a tissue matched donor sibling in these states. In Victoria, parents may still be able to access ART, even though they do not satisfy the eligibility criteria, in certain circumstances. A Patient Review Panel is established under the ART Act (Vic) to ‘consider applications for treatment in circumstances in which the applicant does not meet the criteria for treatment’. The role of the Patient Review Panel in considering applications for PTT was specifically canvassed in the parliamentary debate over the

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58 ART is regulated in Victoria by ART Act (Vic), in SA by the Assisted Reproductive Treatment Act 1988 (SA) (ART Act (SA)), in WA by the Human Reproductive Technology Act 1991 (WA) (HRT Act (WA)), and in NSW by the Assisted Reproductive Technology Act 2007 (NSW) (ART Act (NSW)).

59 Victorian Law Reform Commission (VLRC), Assisted Reproductive Technology & Adoption, Final Report (2007) (VLRC Report), 44. Reproductive medicine services in the NT are provided by SA clinicians. Although SA legislation complies with the Sex Discrimination Act 1984 (Cth) and allows access to infertility treatments for all infertile women, the NT Government has deemed that legislation regarding reproductive technology is exempt from the Sex Discrimination Act 1984 (Cth): Health Gains Planning Branch of Department of Health and Community Services, The Health and Wellbeing of Northern Territory Women: From the Desert to the Sea (2005), 70 [http://www.health.nt.gov.au].

60 The basic structure of Table 1 is based on a table prepared by Szoke, above n 24, 92-4.

61 This limb was extended in the ART Act (Vic), following the recommendation of the VLRC. The VLRC found that the previous requirement of clinical infertility in the IT Act (Vic) was discriminatory. See discussion in VLRC Report, above n 59, 67-8. As Table 1 reveals, clinical or medical infertility is still required in SA and WA.

62 See: ART Act (Vic), s 10(2)(a); ART Act (SA), s 9(1)(c); HRT Act (WA), s 23(1)(a). As Table 1 reveals, the precise nature and seriousness of the genetic condition for which PGD is permitted varies between these states.

63 ART Act (Vic), s85(e).
ART Act (Vic). The Panel could determine that PTT should be allowed in circumstances where there is no risk of the mother transmitting a genetic abnormality or disease to the child to be born. Applicants seeking ART in Victoria must also satisfy ‘fit for parenting’ criteria. These additional eligibility criteria were introduced as a means of assisting clinics to protect the welfare of the child to be born.

Neither the NHMRC Guidelines nor ART legislation in NSW imposes eligibility requirements on patients seeking ART services. Clinics in Queensland, Tasmania, the ACT and NSW are therefore free to develop their own protocols for ‘access to, and eligibility for, treatment’. Although the NHMRC Guidelines require clinics to seek advice from a clinical ethics committee when they receive a request for PTT, the decision to allow PTT is otherwise left to the clinic. The lack of eligibility criteria under the NHMRC Guidelines leaves open the possibility for clinics to provide PTT whether or not there is also a need to test for a genetic disease or abnormality. There is, however, no guarantee that clinics will be consistent in their approach to eligibility for PTT. While some clinics may take a broad approach to eligibility for PTT, others may implement narrow eligibility criteria, requiring participants to be clinically infertile or at risk of passing on a genetic disease. Although the NHMRC Guidelines require clinics to ‘use an open and consistent approach to ethical issues that arise in practice’, allowing clinics and medical practitioners to be the gate-keepers for ART services may lead to inconsistent practices for PTT throughout Australia and potential discrimination by individual clinics. Walker argues that ‘[i]f people are to be

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64 Victoria, Parliamentary Debates, Legislative Council, 10 October 2008, 4192 (Gavin Jennings, Minister for Environment and Climate Change). See also VLRC Report, above n 59, 68.
65 In Victoria, there is a presumption against treatment where a woman, or her partner, has been found guilty of a sexual offence, convicted of a violent offence, or has had a child protection order made in relation to one or more children in their care: s 14 ART Act (Vic). Where a presumption against treatment applies, the Patient Review Panel may consider the application for treatment: s 15(1)(a) ART Act (Vic).
66 VLRC Report, above n 59, 63-5.
67 NHMRC Guidelines on ART, above n 47, [5.3.1].
68 Ibid [12.3].
69 For a detailed discussion of how access to treatment can be limited even in states where there are no eligibility criteria, see Smith, above n 54, 127-8.
70 NHMRC Guidelines on ART, above n 47, [5.3].
71 For example, clinics that restrict access to ART to clinically infertile women discriminate against lesbians and single women who may be described as socially infertile.
excluded [from ART], this should not simply be at the discretion of the doctor – there should be legislative guidance’.72

C Weight attributed to the welfare of the child to be born

A further factor affecting the availability of PTT in Australia is the weight attributed to the interests of the child to be born, which varies throughout Australia. In Victoria and SA, legislation requires the welfare and interests of the child to be born to be treated as paramount.73 In contrast, in the remaining states and territories in Australia, the interests of the child to be born must be considered but are not treated as paramount. For example, legislation in WA requires consideration to be given to the welfare and interests of both the participants and any child likely to be born as a result of the procedure.74 The NHMRC Guidelines, which regulate the remaining states and territories, simply require that PTT ‘not adversely affect the welfare and interests of the child to be born’.75

The requirement in Victorian and SA legislation to treat the welfare and interests of the child to be born as paramount is inconsistent with PTT, a procedure motivated by the interests of the existing child and his/her parents. In Chapter 2, I explore in detail how PTT may impact on the interests of the child to be born. I argue that PTT involves certain risks for the child to be born and does not necessarily promote his/her individual interests. A strict interpretation of the welfare of the child principle in Victoria and SA would therefore not allow PTT in those states.76 The approaches to the welfare of the child to be born in WA ART legislation and the NHMRC Guidelines are more appropriate for PTT as they protect the welfare of the child to be born without making it the paramount consideration. The requirement in WA to specifically consider the interests of the participants is particularly pertinent as it

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73 For example, the first guiding principle in the ART Act (Vic) states that ‘the welfare and interests of persons born or to be born as a result of treatment procedures are paramount’: s 5(a) ART Act (Vic). The ART Act (SA) similarly states that ‘[t]he welfare of any child to be born as a consequence of the provision of assisted reproductive treatment in accordance with this Act must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of this Act’: ART Act (SA), s4A.
74 HRT Act (WA) s23(1)(e). Interestingly, the Select Committee on the HRT Act (WA) recommended in 1999 that the Act be amended to reflect and give priority to the paramount welfare of the child in all human reproductive technology procedures: WA Select Committee on the Human Reproductive Technology Act 1991, Report (1999), recommendation 3b. The recommendation has not been adopted.
75 NHMRC Guidelines on ART, above n 47, [12.3.1].
76 See Chapter 2, Part VD.
highlights the fact that the interests of more than one party are at stake in relation to PTT.

D Summary

Although there is no uniform national regulation of ART in Australia, the NHMRC Guidelines provide some national oversight of ART services. PTT is briefly addressed in the NHMRC Guidelines, providing some level of national consistency in relation to this procedure. However, the availability of PTT throughout Australia varies according to the different eligibility criteria for ART and different approaches to the welfare of the child to be born between jurisdictions.

The first guiding principle in the ART Act (Vic), which attributes paramount importance to the welfare and interests of the child to be born, is fundamentally inconsistent with PTT. The purpose of PTT is to save the life of an existing child. The decision to use PTT is primarily motivated by the interests of the parents and the existing ill child, not the interests of the child to be born. It is therefore disingenuous to treat the interests of the child to be born as paramount in the context of PTT. The welfare of the child principle should be reviewed in the context of PTT. I endeavour to do this in Chapter 2.

The VLRC conducted a major review of ART regulation in Victoria, which commenced in 2002 and lasted for five years. However, little attention was given in the review to the welfare of the child principle or PTT. At a national level, there has also been little ethical analysis of the welfare of the child principle in the context of PTT. Although the NHMRC Guidelines do not expressly require the welfare of the child to be born to be treated as paramount in the context of PTT, this is a central principle in the Guidelines generally.77

In the next section, I briefly outline the current Commonwealth and previous Victorian policies on PTT and discuss their benefits and limitations.

77 The NHMRC Guidelines state in their introduction that ‘the welfare of people who may be born as a result of the use of ART is paramount’: NHMRC Guidelines on ART, above n 47, [2.5].
IV COMMONWEALTH AND VICTORIAN POLICIES ON PTT

A Outline of Policies

The Commonwealth and Victoria are the only two Australian jurisdictions to have specifically addressed PTT. At the Commonwealth level, the NHMRC Guidelines recognise that PGD is currently used to detect serious genetic conditions and, ‘in rare circumstances, to select an embryo with compatible tissue for a sibling’.78 In Victoria, the previous VARTA Conditions on PTT recognised that technology is available to ‘simultaneously test’ for genetic disease and tissue typing.79 Unlike the previous VARTA Conditions, the NHMRC Guidelines do not expressly restrict PTT to cases where it is used in conjunction with PGD to screen for a genetic disease or abnormality. There are otherwise a number of similarities between the NHMRC Guidelines and the previous VARTA Conditions.

First, both the NHMRC Guidelines and the previous VARTA Conditions on PTT provide clear guidance on the nature of cases for which PTT is available. For example, they limit treatment to serious cases where the existing child is suffering from a severe or life-threatening illness and where the child to be born will be a sibling of the existing child.80 Second, the policies impose similar requirements on clinics seeking to provide PTT. For example, both policies require clinics to provide parents with information on treatment options, the risks associated with treatment for the woman and the child to be born, the likelihood of achieving a successful pregnancy, and alternatives to treatment.81 They also require clinics to provide counselling to parents to address the implications of treatment.82 Counselling is mandatory under the ART Act (Vic).83 The Assisted Reproductive Treatment Regulations 2009 outline requirements for counselling in Victoria.84 Finally, both the

78 Ibid [12.1].
79 Previous VARTA Conditions on PTT, above n 27, 3.
80 NHMRC Guidelines on ART, above n 47, [12.1], [12.3]. Previous VARTA Conditions on PTT, above n 27, [2.2].
81 NHMRC Guidelines on ART, above n 47, [12.5], see also [9.1]. Previous VARTA Conditions on PTT, above n 27, [2.1].
82 The NHMRC Guidelines require all clinics offering ART services to provide counselling to parents: NHMRC Guidelines on ART, above n 47, [9.3]. Previous VARTA Conditions on PTT, above n 27, [2.1].
83 ART Act (Vic), s 13.
84 Assisted Reproductive Treatment Regulations 2009, cl. 6. For example, the woman and her partner must receive counselling in relation to the options available, possible treatment outcomes, and any issue or concern raised by the woman or her partner in relation to the treatment procedure: cf 6(a), (b) and (c). See also, Australian and New Zealand Infertility Counsellors Association, Guidelines for
NHMRC Guidelines and the previous VARTA Conditions on PTT require clinics to seek advice from a clinical ethics committee, on a case by case basis. The clinical ethics committee must specifically consider whether the parents seek another child in his/her own right.

B Benefits and limitations of policies

The NHMRC Guidelines and previous VARTA Conditions on PTT provide clear and useful guidance on the availability of PTT and the support that clinics should provide parents contemplating PTT. The case by case consideration of PTT applications by clinical ethics committees is appropriate given the complex ethical questions that arise in relation to PTT, which may vary according to the individual circumstances of each case. However, there are three important matters that are not addressed in either the NHMRC Guidelines or the previous VARTA policy on PTT.

First, while the NHMRC and previous VARTA policies require parents to be given comprehensive information and counselling, they do not require any ethical guidance to be given to parents when making decisions about PTT. Given the ethical complexities surrounding PTT and the various interests at stake, I argue in this thesis that parents should be given clear ethical guidance in the decision-making process for PTT. In Chapters 2 and 3, I highlight the ethical complexities surrounding PTT and the various interests at stake. In Chapter 4, I outline a relational approach to PTT under which parents receive ethical guidance as part of the decision-making process.

Second, there is insufficient regard paid in the NHMRC and previous VARTA policies to the interests of other family members who are directly affected by the decision to use PTT. I explore the interconnected family interests at stake in

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ANZICA Guidelines (October 2003). The ANZICA Guidelines apply to all infertility counsellors attached to an ART clinic: [1.1].

The NHMRC Guidelines require clinics to seek advice from a clinical ethics committee (or a relevant state or territory regulatory agency): NHMRC Guidelines, above n 47, [12.3]. Previous VARTA Conditions on PTT, above n 27, [2.4].

Under the current national and Victorian schemes, clinics must consult a clinical ethics committee in relation to the ethical implications of PTT during the application process, but this does not ensure that parents themselves receive ethical guidance.

The previous VARTA Conditions on PTT touch on the welfare of the family as a whole by requiring ethical consideration of ‘the status of the child within the family and the relationships, which grow, with the growth of all children within the family.’: Previous VARTA Conditions on PTT, above n 27, [2.3] (iii). While this is a helpful guideline as it highlights the relational nature of interests within a family, there is no further guidance on the nature of other interests within the family and how the various interests should be addressed in decisions about PTT.
relation to PTT in this thesis and propose an approach to PTT that accommodates these interests in the decision-making process. In Chapter 3, I explore in detail the nature of individual and collective interests within families, particularly in relation to PTT. The relational approach I propose in Chapter 4 attempts to accommodate these interconnected interests within the decision-making process.

Third, neither the NHMRC Guidelines nor the previous VARTA Conditions on PTT require clinics to establish procedures to monitor the short and long-term outcomes for children born as a result of PTT and their families. Given the lack of longitudinal research on children born as a result of PTT, improved monitoring of any adverse effects on these children is essential for improving future regulation of PTT. In Chapter 2, I discuss the lack of longitudinal research on children born as a result of PTT. My discussion in Chapter 4 highlights the importance of ongoing monitoring of the impacts of PTT on children born for the future regulation of PTT.

I return to these three missing links in the regulatory matrix in Chapter 6, when I propose a new regulatory framework for PTT.

V OBJECTIVE OF THESIS AND CHAPTER OUTLINE

The objective of this thesis is to propose a unified regulatory framework for PTT in Australia that is supported by clear ethical principles. I propose a relational approach to regulating PTT, which I argue is better suited to dealing with the ethical issues arising in relation to PTT than the current approach based on the ‘best interests’ of the child to be born. I then apply my ethical analysis to develop an improved regulatory framework for PTT in Australia. As part of this process, I explore how two key issues I have identified – the welfare of the child to be born and the role of the state in regulating ART – have been dealt with in practice by policy-makers, legislators, regulators and courts in the UK. In contrast to Australia, the regulation of PTT and the welfare of the child principle have been extensively considered in the UK. I use the lessons learnt in the UK about regulating PTT to refine my proposed regulatory framework for PTT in Australia.

I begin my ethical analysis in Chapter 2 by exploring in detail two ethical concerns about the welfare of the child to be born that have dominated the debate over saviour siblings. The first concern about commodification arises out of Kant’s second
formulation of the categorical imperative that we should treat people ‘never simply as a means, but always at the same time as an end’. \(^{89}\) The second concern about harm is based on the principle of nonmaleficence, which asserts an obligation not to inflict harm intentionally. I conclude that both of these ethical concerns reflect an individualistic approach to the welfare of the child to be born, whose interests are treated as largely separate to and distinct from the interests of other family members. I argue that, while the individual interests of the child to be born should be protected in relation to PTT, a solely individualistic approach to the welfare of the child fails to adequately take account of the interests of the child as part of a family. Furthermore, the nature of PTT requires a broader consideration of interests beyond those of the child to be born. In particular, the interests of the parents, their existing ill child, and any other siblings likely to be affected should be considered in connection with the interests of the child to be born in respect and protection from harm.

In Chapter 3, I propose a broader approach to the welfare of the child to be born based on the notion of human flourishing. I draw on relational feminist and communitarian ethics to argue that the welfare of a child is inextricably connected to the welfare of the intimate collective that is his/her family. A comprehensive account of the welfare of the child therefore requires consideration of both the individual interests of the child to be born as well as the collective interests the child shares with his/her family. By recognising the importance of connection and interdependence within a family, this broader approach to the welfare of the child not only protects the child to be born but also the family which is necessary in order for that child to flourish. This approach is particularly apposite for PTT, a procedure that affects the whole family. Recognising that the welfare of the child to be born is not necessarily synonymous with the welfare of the family as a whole, I examine the role of familial duty as a justification for compromising some of the individual interests of family members in favour of the welfare of the family as a whole. However, given the vulnerability of the child to be born, I argue that there should be limits on PTT in order to protect the child to be born from exploitation, abuse or neglect.

Building on the ethical theory in Chapters 2 and 3, I propose a new ethical approach to regulating PTT to that currently applied in Victoria in Chapter 4. I argue that a

\(^{89}\) Imanuel Kant, *Groundwork of the Metaphysics of Morals* (Cambridge University Press, first published 1785, 2005 ed) [4.429].
A relational approach, which recognises and accommodates individual and collective interests within a family, is more appropriate for regulating PTT than the current approach in Victoria, which treats the welfare and interests of the child to be born as paramount. Drawing on an ‘ethics of intimacy’, a relational approach requires the interests of other family members to be considered in connection with the interests of the child to be born as a result of PTT. In particular, I emphasise the importance of developing an effective process to assist parents in making decisions about PTT. However, as I flagged in Chapter 3, there comes a point at which compromise becomes sacrifice and the child to be born as a result of PTT should be protected from exploitation, abuse or neglect. I propose that, in regulating PTT, the state should provide a minimum threshold level of protection for the child to be born as a result of PTT. I return to the two main ethical concerns about PTT discussed in Chapter 2 to formulate a minimum threshold of respect and protection from harm for the child to be born as a result of PTT.

Having formulated an ethically principled approach to regulating PTT, I then turn to the UK where the key issues surrounding PTT have been dealt with in practice. In contrast to Australia, there has been significant debate and reform in relation to PTT and the welfare of the child principle in the UK in recent years. In Chapter 5, I examine in detail the development of the law and policy on PTT and the welfare of the child principle in the UK. I also discuss the insights on PTT provided by the Hashmi and Whitaker cases in the UK. Several major reviews of ART regulation in the UK have specifically addressed PTT, the role of the state in regulating ART and the relevance of the welfare of the child principle. Some significant improvements have been made to the law and policy regulating PTT as a result of these reviews. The current approach to regulating PTT in the UK has some features that are similar to the relational approach I propose in Chapter 4. I argue that further improvements could be made to the regulation of PTT in the UK. In particular, there is a lack of clear ethical guidance on the application of the welfare principle to PTT in UK legislation. I use the lessons learnt about regulating PTT in the UK to inform my proposals for the reform of PTT regulation in Australia.

I outline my proposed regulatory framework for PTT in Australia in Chapter 6, based on the relational approach discussed in Chapter 4 and drawing on the lessons learnt in the UK in Chapter 5. As a threshold question, I ask whether PTT should be regulated
at all if a relational approach is to be adopted. I argue that regulation is not only necessary to protect the child to be born from exploitation, abuse and neglect, but it can also improve the decision-making process for PTT. I explore different regulatory frameworks and conclude that a flexible permissive regulatory framework should be applied to PTT. I then outline the features of my proposed regulatory framework for PTT in Australia. I propose that decisions about PTT should be made on a case-by-case basis by parents in conjunction with their health care team, according to guiding principles laid down by Parliament and detailed national guidelines prepared by the NHMRC. In particular, I discuss how the health care team can support parents in the decision-making process by providing information, counselling and ethical guidance. I also argue that decisions should be subject to ethical oversight by clinical ethical committees to ensure that the welfare of the child is adequately protected.

In Chapter 7, I conclude that a relational approach to the welfare of the child principle provides an appropriate ethical framework with clear criteria on which to base the regulation of PTT. I also explain how a relational approach is more responsive to the individual circumstances of each case than the current approaches in Australia and the UK. For example, a relational approach would not necessarily limit PTT to donation between siblings if the family was sufficiently close to justify a donation by the child to be born to another family member, such as a parent. Finally, I highlight the potential for the application of a relational approach to ART more generally.
CHAPTER 2

WELFARE OF THE CHILD TO BE BORN

I INTRODUCTION

As discussed in Chapter 1, the welfare of the child to be born is a key issue in the regulation of ART. ART regulation is most commonly justified on the basis that the state has a responsibility to protect the welfare and interests of children who are ‘incapable of participating in the decision-making process in relation to their own conception.’¹ In this Chapter, I analyse the role of the welfare of the child principle in regulating ART and its application to PTT. As Chapter 1 revealed, the welfare of the child to be born is central to ART legislation in Victoria, SA, WA and NSW. However, the weight attributed to the welfare of the child to be born varies between these states. The welfare of the child principle also underlies the Commonwealth National Health and Medical Research Council (NHMRC) Guidelines on ART.² Despite the strong focus in ART regulation on the welfare of the child to be born, there is little guidance in Australian ART law or policy on how the welfare principle should be applied in practice.

In this Chapter, I use applied ethics to analyse how the welfare of the child to be born is conceptualised in the context of PTT. There are two primary ethical concerns about the welfare of the child to be born as a result of PTT that have dominated the debate over saviour siblings. The first is that the child to be born is treated as a commodity, as simply a means to save the life of his/her sibling. The concern about commodification arises particularly out of Kant’s second formulation of the categorical imperative that we should treat people ‘never simply as a means, but always at the same time as an end’.³ The child to be born is wronged if Kant’s moral imperative is breached, even if the child is not harmed as a result. The second ethical concern is that the child to be born will be harmed as a result of PTT, either physically,

² NHMRC, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004 (as revised in 2007 to take into account the changes in legislation) (June 2007) (NHMRC Guidelines on ART) [2.5].
³ Imanuel Kant, Groundwork of the Metaphysics of Morals (Cambridge University Press, first published 1785, 2005 ed) [4.429].
psychologically or socially. The concern about harm is based on the principle of nonmaleficence, which asserts an obligation not to inflict harm intentionally.  

In this Chapter, I argue that the concerns about commodification and harm provide valuable guidance on how PTT impacts on the welfare of the child to be born. In particular, these ethical concerns highlight several legitimate interests of the child to be born as a result of PTT: (1) an interest in respect (and ongoing care); and (2) an interest in protection from harm. However, the concerns about commodification and harm reflect an individualistic approach to the welfare of the child to be born, whose interests are treated as largely separate to and distinct from the interests of other family members. I argue that conceptualising the welfare of the child in terms of the child’s individual interests is unsatisfactory for two reasons. First, while the individual interests of the child to be born should be protected, a solely individualistic approach to the welfare of the child fails to adequately take account of the interests of the child as part of a family. Second, the nature of PTT requires a broader consideration of interests beyond those of the child to be born. PTT is a procedure primarily designed to save the life of an existing child. The interests of the parents, their existing ill child, and any other siblings likely to be affected should therefore be considered in connection with the interests of the child to be born in respect and protection from harm.

I begin my analysis of the welfare of the child principle in Part II by briefly exploring the origins of the principle in ART law. There is a lack of legislative guidance on the welfare principle in Australia, although some commentators have equated the welfare principle with the “best interests” of the child approach found in international and other domestic laws. One important distinction between ART law and other laws involving children is that ART deals with a child who does not yet exist. In Part III, I argue that, although a child does not technically have any interests until s/he is born, it is appropriate to impute certain ‘generic’ interests to the putative child in ART. I then draw on the ethical debate over saviour siblings to explore how the welfare of the child to be born is conceptualised in the context of PTT.

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4 The principle of nonmaleficence is one of Beachamp and Childress’ four core ethical principles in medical ethics: Tom L Beauchamp and James F Childress, Principles of Biomedical Ethics (5th ed, 2001).
In Part IV, I discuss the ethical concern about commodification, which reveals that the child to be born as a result of PTT has an interest in respect. In Part V, I discuss the putative child’s interest in protection from the potential physical, psychological and social harms associated with PTT. I also rebut two primary arguments in support of PTT based on individual ‘net benefit’ for the child to be born. In Part VI, I contend that, although the ethical debate over saviour siblings has highlighted some relevant interests of the child to be born, these interests reflect a narrow and individualistic account of the welfare of the child. I propose an ethical pluralist approach to the welfare of the child, which supplements the two key deontological and consequentialist ethical concerns about PTT with relational feminist and communitarian ethical considerations.5

I conclude in Part V that the welfare of a child should be conceptualised more broadly than it currently is in the context of PTT, to include both the child’s individual interests as well as the collective interests the child shares with his/her family. I explore this broader conception of the welfare of the child in detail in Chapter 3.

II ORIGINS OF THE WELFARE PRINCIPLE IN ART REGULATION

A Lack of legislative guidance on ‘welfare and interests’

There is insufficient guidance in Australian legislation on how the welfare of the child principle should be interpreted in the context of ART. Pennings argues that while there may be general agreement ‘on the fundamental importance of the welfare of the child when judging the applicability of new reproductive technologies’, there is no consensus in relation to the ‘choice of the principle to interpret the level or measure of welfare’.6 Legislation in Australia remains similarly vague on the precise meaning of the welfare of the child. There is no clarification of the terms ‘welfare’ and ‘interests’ in any of the State Acts on ART. For example, although the guiding principles in the Assisted Reproductive Treatment Act 2008 (Vic) (ART Act (Vic)):

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5 Ethical pluralism recognises that there are different values by which moral action can be defined, depending on the context in which they are applied and the question which is being asked. For a detailed discussion of ethical pluralism see: Judith Jarvis Thomson, ‘The Right and the Good’ (1997) 94 Journal of Philosophy 273.

...express a theoretical commitment to the welfare and interests of children conceived through assisted reproduction, there are no provisions which specify how this should be achieved in practice.7

Nor was there any clarification of the phrase ‘welfare and interests’ under the previous Infertility Treatment Act 1995 (Vic) (IT Act (Vic)). This is not surprising given that the welfare of the child principle was unanimously supported by Parliament with little discussion about what it would mean in practice.8

The lack of guidance on the welfare principle in the ART Act (Vic) means that there is ‘a lack of transparency and accountability’ in the way clinics apply the welfare of the child principle, which impacts on whether a person is permitted treatment under the Act.9 Assessments about the ‘welfare and interests’ of the child to be born in Victoria are therefore likely to vary from clinic to clinic. The Honourable Alastair Nicholson, the former Chief Justice of the Family court of Australia, criticised the previous IT Act (Vic) for ‘leaving a void as to what is intended by this phrase’.10 According to Nicholson, the lack of guidance on the welfare of the child principle in the IT Act (Vic) explains some of the difficulties that have arisen in its interpretation.11 Although family law courts have applied the welfare of the child principle for many years, ‘judicial practice is based on extensive and time consuming investigation of the parties’ situations by social workers and, often, evidence from the child.’12 As Walker points out, this investigative process would be cumbersome and inappropriate in the context of ART.13

7 VLRC Report, above n 1, 54.
8 Victoria, Parliamentary Debates, Legislative Assembly, 4 May 1995, 1244; Victoria, Parliamentary Debates, Legislative Assembly 30 May 1995, 1919, 1925, 1928; Victoria, Parliamentary Debates, Legislative Assembly, 1 June 1995, 2104. See also Victoria, Parliamentary Debates, Legislative Council, 6 June 1995, 1214; Victoria, Parliamentary Debates, Legislative Council, 7 June 1995, 1292. A similar approach was taken to the inclusion of the welfare principle in ART legislation in the UK. In relation to the parliamentary debates leading up to the passage of the Human Fertilisation and Embryology Act 1990, Jackson notes that ‘the inclusion of the welfare principle was neither challenged nor defended’: Emily Jackson, ‘Rethinking the Pre-Conception Welfare Principle’ in Kirsty Horsey and Hazel Biggs (eds) Human Fertilisation and Embryology: Reproducing Regulation (Routledge-Cavendish, 2007) 47, 47.
9 VLRC Report, above n 1, 54.
11 Ibid.
13 Ibid.
The welfare and interests of the child are often interpreted by reference to certain rights of the child, which are enshrined in international convention. For example, in relation to Victorian ART legislation, Tobin argues that:

…the substantive content of what constitutes a child’s welfare and interests should be informed by the articles under the [United Nations Convention on the Rights of the Child (UNCRC)] in the same way that the best interests principle is defined by reference to the Convention.14

Nicholson has expressed a similar view by stating that he doubts there is any significant difference between the phrase ‘welfare and interests’ contained in ART legislation and the ‘best interests of the child’ principle found in the UNCRC.15 The Victorian Law Reform Commission (VLRC) has treated the two phrases as interchangeable, by stating that ‘[t]he principle of best interests of the child is central to ART legislation in Victoria... albeit using different terminology’.16 The Commission also noted that the phrase ‘best interests of the child’ is used in other domestic laws dealing with family law and child protection.17 The ART Act (Vic) reinforces a ‘best interests’ approach to the welfare of the child by requiring the Patient Review Panel to have regard to whether treatment ‘is consistent with the best interests of a child who would be born’.18

Although the phrase ‘welfare and interests of the child’ is often equated with the ‘best interests of the child’ principle in international and domestic law, there are good reasons to avoid reference to the latter terminology in ART law. There is one important distinction between ART law and other domestic laws involving children. In contrast to family and child protection law, the child to be born as a result of ART is not yet in existence. Therefore, in the context of ART, ‘[w]hat is ordinarily a child-centred test becomes necessarily centred entirely on the merits of the parents-to-be.’19

The real question in ART law is whether a child should be brought into existence, not

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15 Nicholson, above n 10, 4.
16 VLRC Report, above n 1, 46.
17 For example, s 60CA of the Family Law Act 1975 (Cth) requires the Family Law Court to have regard to the best interests of the child as the paramount consideration in making parenting orders. See also Children Youth and Families Act 2005 (Vic), s 10.
18 ART Act (Vic), s 15(3)(b)(ii).
what should be done to achieve the best outcome for a living child’. Several commentators also object to the ‘best interests of the child’ principle generally, which they argue is indeterminate and speculative. By way of contrast, Coady argues that ‘[t]he principle can be used to rule out parents who are obviously unfit’ because, for example, they have a history of child abuse. Coady contends, however, that the term ‘best’ should be avoided in ART law as it may ‘suggest that what must be decided is the best possible future of all the possible futures’ for the child born as a result of ART. As Parker states, it is difficult to determine which of a number of choices is in a child’s best interests.

B Review of ART regulation in Victoria – a missed opportunity

The VLRC engaged in a major review of ART regulation in Victoria from 2002 to 2007. However, there was little discussion in the Commission’s Final Report about the role of the welfare principle in ART law. The Commission discussed how ART has, in practice, impacted on the welfare of children born. However, the Commission’s research focused on the psychological and social outcomes for children born as a result of donated gametes or embryos, including children born to same-sex parents, single mothers, or through surrogacy arrangements.

The Commission’s Final Report briefly mentions the debate over the applicability of the ‘best interests of the child’ principle to ART. However, it concluded that the principle should remain the paramount consideration in ART regulation, without adequately addressing the limitations of the principle in the context of ART. Instead, the Commission concluded that:

...our consultations revealed that almost everyone believes the promotion of the best interests of the child should remain the primary concern in the regulation and provision of ART.

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23 Ibid 449.
24 Stephen Parker, above n 21, 30. See also Mumford, Corrigan and Hull, above n 19.
25 VLRC Report, above n 1.
26 Ibid, Chapter 2, 30-38. For example, a report by Ruth McNair focused on the welfare of children born as a result of ART in a diverse range of families: Ruth McNair, Outcomes for Children Born of ART in a Diverse Range of Families, VLRC Occasional Paper, August 2004.
27 VLRC Report, above n 1, Chapter 3, 46-7.
services, even if they differ on precisely how a child’s interests should be protected in the context of access to ART.\(^\text{28}\)

Whether or not ‘almost everyone believes’ that the best interests of the child should be the paramount concern in ART regulation, the ‘best interests’ principle does not sit easily with PTT. This is because PTT is primarily motivated by the interests of the existing child and his/her parents.

The VLRC briefly discussed PTT when it considered eligibility for treatment. The Commission recognised that:

…the conception of a child to act as a ‘saviour sibling’ is controversial and the particular circumstances of the case would need to be carefully considered to ensure protection of the health and welfare of that child.\(^\text{29}\)

The VLRC recommended that a review panel, established under the ART Act (Vic), should be able to approve PTT, provided it is in the ‘best interests’ of the child to be born.\(^\text{30}\) However, there is no further analysis of how the welfare of the child should be conceived in the context of PTT. The lack of analysis of the welfare of the child principle in the context of ART is reflected in the fact that there are still no definitions in the ART Act (Vic) of the terms ‘welfare’ and ‘interests’. The lack of legislative guidance on the meaning of the welfare principle makes the principle difficult to apply in practice.

**C Should the welfare principle be retained in ART law?**

Some critics argue that the welfare of the child principle should be removed from ART regulation altogether.\(^\text{31}\) Jackson, a staunch opponent of the ‘welfare principle’s colonisation of reproductive choice’, argues that the welfare of the child principle should not be relied on as a justification for interfering with an individual’s reproductive liberty.\(^\text{32}\) According to Jackson, ‘[e]xtending the “welfare principle” to decisions taken prior to a child’s conception is shown to be unjust, meaningless and inconsistent with existing legal principle.’\(^\text{33}\)

\(^\text{28}\) Ibid 47.
\(^\text{29}\) Ibid 68.
\(^\text{30}\) Ibid 68.
\(^\text{33}\) Ibid.
The criticisms levelled at the welfare of the child principle refer to principle and practice. As a matter of principle, the welfare principle has been criticised as discriminatory, paternalistic and unnecessary. Some commentators argue that the principle, which is not applied to people who are able to conceive naturally, may result in discrimination against infertile, single or same-sex parents. Jackson argues that the principle is paternalistic because it unjustly ‘deprive[s] some citizens of the zone of privacy that surrounds most people’s reproductive decision-making’. Finally, the welfare of the child principle has been criticised as unnecessary because it adds little to ‘good medical practice’. The welfare of the child principle has also been criticised in practice for being difficult to apply in the context of ART and ineffective in safeguarding the child’s welfare.

The criticisms of the welfare of the child principle arise out of its current formulation, which is vague and imprecise. Walker suggests this ‘may result in prejudice being dressed up as concern for the welfare of the child’. I argue in Chapter 6 that the state has an important role in regulating ART (including PTT) and that a clear formulation of the welfare of the child principle can both protect the putative child and assist parents in making ethically complex and emotionally charged reproductive decisions. The welfare of the child principle also has ‘important symbolic and moral value’ as it reminds us that ‘children must be protected from harm and given every opportunity to become healthy, well-developed adults’. However, if the welfare principle is to be meaningful in the context of ART, the welfare and interests of the child to be born must be clearly defined to ensure that the principle is consistently and effectively applied in all cases.

In the remainder of this Chapter, I examine the interests of the child to be born that are likely to be affected by PTT. In particular, I discuss in detail the child’s interests in respect and protection from harm, which have been highlighted by the ethical...

34 Ibid 182; Walker, above n 12, 131.
36 In the UK, the STC stated that ART physicians should be encouraged to minimise any risks to the child to be born ‘through the promotion of good medical practice not legislation’: House of Commons Science and Technology Committee Fifth Report of Session 2004-05, Human Reproductive Technologies and the Law HC7-1 (24 March 2005) (STC Report) [107].
37 Walker argues that it is difficult to effectively assess the welfare of a child who is not yet in existence: Walker, above n 12, 130. Jackson similarly contends that the welfare of the child principle fails to provide clinics with the means to realistically assess the future welfare of the child to be born: Jackson, ‘Conception and the Irrelevance of the Welfare Principle’, above n 31, 178, 194.
38 Walker, above n 12, 131.
39 Mumford, Corrigan and Hull, above n 19, 2353.
debate over saviour siblings. A threshold question in defining the interests of the child to be born in assisted reproduction is whether a child who is not yet born can in fact have any interests. While it may be conceptually difficult to attribute interests to a future or ‘hypothetical’ child, I argue in the next Part of this Chapter that this problem is not insurmountable. It is possible to contemplate the likely foreseeable or generic interests of the child to be born as a result of PTT. The remaining Parts of this Chapter discuss the child’s interests in respect and protection from harm.

III FUTURE INTERESTS AND THE CHILD TO BE BORN

A The future child as a ‘hypothetical person’

There are obvious conceptual difficulties in attributing interests to a child that does not yet exist. Gavaghan notes that, given that the putative child only has a ‘hypothetical existence’ at the time of the decision to use PTT, s/he does not possess any interests. Dutney contrasts the application of the welfare principle in the family law context, where the child is in existence and it is therefore possible to ascertain the nature of his/her interests.

It seems artificial to attribute interests to the child to be born as a result of assisted reproduction. As I argue below, a child does not in fact have any interests before s/he comes into existence. It is also impossible to predict what the specific interests of any particular child will be. A child who does not yet exist does not have an identity and therefore cannot have any individual preferences. This is because in the context of assisted reproduction, the decision-making itself is ‘identity-affecting’. It is possible, however, to impute certain ‘generic’ interests to the putative child in ART. As Gavaghan suggests, the welfare principle may require the ‘likely foreseeable interests’ of the child to be born to be taken into account.

40 Colin Gavaghan, Defending the Genetic Supermarket: Law and Ethics of Selecting the Next Generation (Routledge-Cavendish, 2007), 151.
42 See discussion below, Part VC2.
44 Ibid.
Coady similarly argues that the conceptual problems involved in discussing the interests of a hypothetical person are not insuperable.\footnote{Coady, above n 22, 450.} According to Coady, ‘[h]owever puzzling it may be to attribute interests to those who do not yet exist, it is clear that we do this intelligibly … in all sorts of fields’.\footnote{Ibid.} For example, governments consider the interests of those who do not yet exist when they frame present environmental policies for future generations. Coady also argues that the fact that a child does not technically have any interests at the critical time of decision-making in assisted reproduction does not prevent others from imputing certain basic interests to the putative child. She points out that such ‘surrogate decision making’ is already well established for those who may not be conscious or rational, including minors, unconscious persons and the psychiatrically disturbed.\footnote{Ibid.}

In the context of ART, certain universal interests of the putative child should be protected. We can draw on the language of Gavaghan to determine the ‘likely foreseeable interests that the child will possess if it is brought into existence’.\footnote{Ibid 151.} Bringing a child into existence entails a level of responsibility in respect of that child’s future. If there are reasonably foreseeable risks to that potential child, responsible regulation should address those risks.

**B Likely foreseeable or generic interests of the future child**

Assuming that we should promote certain universal or generic interests of the child to be born, a question arises as to what type of interests we can expect future children to have. Several commentators have addressed the interests of the future child from a practical perspective.\footnote{See, for example: Gavaghan, above n 40; Coady, above n 22; Tobin, above n 14; Nicholson, above n 10. See also C L Ten, ‘A Child’s Right to a Father’ (2000) 19(4) *Monash Bioethics Review* 33}

For example, Coady states that we have some general knowledge of what persons need, including food, health, housing and freedom from violence. Assuming that future children will at least in fundamental ways be like existing people, we can assume that they will ‘have an interest in being, at a minimum, nourished, sheltered and respected as persons.’\footnote{Coady, above n 22, 451.} Coady points out that ‘[m]any of these needs with regard to children are spelled out in the United Nations Convention on the Rights of the
Child (UNCROC). There are several rights of the child that are particularly relevant in the context of assisted reproduction technology, such as the right to be cared for by his/her parents as far as possible, to an identity, to be protected from harm, and to be provided with a safe and secure environment.

The approach proposed by Coady to attributing interests to a putative child based on the universal rights of the child established under international law is a legitimate starting point for ascertaining universal interests of the child to be born. The two key interests of the child to be born as a result of PTT (in respect and protection from harm) reflect key human rights found in international law on the rights of the child. However, my discussion in Parts IV and V of this Chapter reveals some fundamental problems in conceptualising the welfare of the child to be born solely in terms of the individual interests of the child.

IV INTEREST IN RESPECT

In this Part, I explore the interest of the child to be born in respect, which stems from Kant’s second formulation of the categorical imperative to treat people ‘never simply as a means, but always at the same time as an end’. I begin by asserting that PTT does not breach Kant’s injunction against commodification unless the parents’ sole purpose for conceiving another child is to save the life of the existing child. Provided the parents want another child in his/her own right, then the child to be born is not commodified in a Kantian sense. I therefore argue that parental motivation is relevant in the context of PTT. However, given the complex nature of procreative motivation in general, I argue that the state should only intervene in relation to PTT in extreme cases where parents clearly have no interest in the child to be born beyond his/her role as a stem cell donor. Finally, I suggest that how the child will be treated once s/he is born is more important than parental motivation for having the child.

51 Ibid
53 Ibid, Art 8(1).
54 Ibid, Art 19.
55 Ibid, Art 27(2).
56 Blyth has also relied on the UNCRC to ‘flesh out some general expectations’ in relation to the interests of the child in UK law: see Eric Blyth, ‘Conceptions of Welfare’ in Kirsty Horsey and Hazel Biggs (eds), Human Fertilisation and Embryology: Reproducing Regulation (Routledge-Cavendish, 2007) 17, 37.
57 Kant, above n 3 [4.429].
Is PTT morally acceptable given Kant’s categorical imperative?

A commonly cited objection to PTT is that selecting a child to be a donor for a sibling treats the child to be born as a commodity – as simply a means to saving the life of an existing child. Kant’s categorical imperative against treating people as commodities represents a deontological approach to the welfare of the child principle, whereby the moral value of the action is measured by its conformity with moral duties rather than simply by the consequences that flow from it. Thus a child can be wronged if Kant’s principle is offended, even if no harm flows to the child as a result. It is the parental motivation in wanting the child that is morally significant. As Gavaghan points out, even ‘if all parties involved are net beneficiaries in terms of harms and benefits, we may have done something ethically wrong if, in the process, we treated some of them as mere instruments.’

The concern about commodification has been raised by ethicists in both the UK and Australia in the context of PTT regulation. For example, in its 2001 deliberations over PTT, the UK Human Fertilisation and Embryology Authority (HFEA) Ethics Committee stated that the ‘positive consideration of the welfare of the child requires respect for beings as ends and that the putative child be treated not simply as a means to a further end but also as an “end in itself”’. The Victorian Infertility Treatment Authority Ethics Panel raised similar concerns about PTT and emphasised the importance of ascertaining parental motivation for PTT to ensure that parents want a child in his/her own right and not simply as a donor for an existing child.

There is a threshold question as to whether Kant’s categorical imperative applies to embryos or future children at all. According to Ram, given that Kant defines personhood by reference to rationality, the categorical imperative may not apply to embryos of future children which do not exhibit rationality. Alan Donagan, a leading interpreter of Kantian Ethics, rejects this argument. Donagan claims that

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58 For a discussion of the complex philosophical debate over the difference between wronging and harming, see Rahul Kumar, ‘Who Can Be Wronged?’ (2003) 31(2) Philosophy & Public Affairs 99.
59 Gavaghan, above n 40, 157.
60 Human Fertilisation and Embryology Authority (HFEA) Ethics Committee, Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors (22 November 2001) [2.9]. See also Gavaghan, above n 40, 155.
Kant’s imperative to respect a being as a rational creature does not depend on it being capable of rational thought. Donagan’s conception of a ‘rational creature’ would include an embryo, by virtue of it being a genetically human organism. For the purposes of my discussion, I will assume that Kant’s moral imperative applies to the child to be born as a result of PTT.

Arguments against PTT based on commodification have been widely discredited for being based on an incorrect interpretation of Kant’s categorical imperative. According to Beauchamp and Childress, Kant’s moral imperative has often been misinterpreted to mean that one should never use another person as a means to achieving one’s objectives, whereas it in fact prohibits treating another person solely as a means to an end. Kant’s formulation envisages that people may be treated as a means, provided they are also treated as an end. It is therefore acceptable to use someone as a means, provided you ‘do not lose sight of the fact that s/he is also an end in him/herself’. According to Donagan, Kant’s imperative is essentially about treating human beings with respect. PTT would not, therefore, offend Kant’s moral imperative if the parents desire a child in his/her own right as well as for the benefit of their existing child.

Several commentators have argued that provided parents love the child who is born as a result of PTT, the child is not commodified. Sparrow and Cram argue that this claim is ‘tendentious’ because, although the parents may love the child in his/her own

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66 Gavaghan, above n 40, 156. As Gavaghan points out, everyday transactions between customer and vendor, employer and employee and client and service provider all involve treating someone as a means to an end and are not considered morally objectionable.
67 Donagan, above n 63, 65. Donagan restates Kant’s moral imperative in the following way: ‘Act always so that you respect every human being, yourself or another, as being a rational creature.’
right, ‘it is in many cases less clear that they would have had this child were it not for
the desire to source tissue for transplant.’\textsuperscript{69} Sparrow and Cram are effectively
applying a ‘but for’ test to parental motivation. Their argument seems to suggest that
the child to be born as a result of PTT is commodified where the parents would not
have had the child \textit{but for} the fact that their existing child needed a stem cell
transplant. However, the reasons people choose to procreate are multi-factorial and
may change depending on the circumstances in which people find themselves. The
fact that parents may be initially motivated to use PTT by a desire to save an existing
child does not mean that the parents will not also develop a genuine desire to have
another child in his/her own right. The impetus for the parents’ change of mind does
not mean that the putative child is commodified provided the parents genuinely want
another child for his/her own sake in addition to helping the existing child. I explore
the complex nature of procreative motivation in more detail in the next section.

\textbf{B Ascertaining parental motivation for using PTT}

The ethical concern about commodification raises parental motivation as an important
consideration in relation to PTT. The previous VARTA Conditions on PTT attempted
to ascertain the motivation of parents in seeking to have an additional child using PTT
through counselling. The Conditions stated that:

\begin{center}
If this motivation is solely for the purposes of furthering the interest of an existing sibling,
then this may raise concerns. However, if the child is wanted for his/her own worth, then this
may be justifiable.\textsuperscript{70}
\end{center}

However, ascertaining why parents choose to have a child is complex. The Ethics
Panel of the former ITA acknowledged the complex nature of parental motivation for
procreating generally. One member stated that ‘the urge to have children in natural
procreation is multifaceted and not always altruistic’.\textsuperscript{71} In the UK, the HFEA Ethics
Committee conceded that it may be impossible to ascertain parental motivation for
having a child by empirical interrogation.\textsuperscript{72} As Devolder points out, ‘it is extremely
difficult, if not impossible, to separate the reasons that lead to the conception of a
child because of a “genuine desire for a child” from those linked to an attempt to save

\textsuperscript{69} Robert Sparrow and David Cram, ‘Saviour Embryos? Preimplantation Genetic Diagnosis as a
\textsuperscript{70} VARTA, \textit{Conditions for Use of Tissue Typing in Conjunction with Preimplantation Genetic
Diagnosis} (February 2010) (previous VARTA Conditions on PTT) [2.3].
\textsuperscript{71} ITA Report, above n 61, 5.
\textsuperscript{72} HFEA Ethics Committee, above n 60 [2.11].
another child’. An additional complicating factor is that ‘plans to have children typically change according to the circumstances and experiences of childrearing.’

People often have children for a variety of instrumental reasons, which do not preclude the parents from loving their children in their own right. Some common reasons that people have children include the desire to provide companionship for an existing child, to carry on the family line, to care for parents in their old age, to inherit the family business, to satisfy peer expectation, to save a failing marriage, or as a subconscious quest ‘for some sort of genetic immortality’. In other cases children are completely unexpected, either because contraception failed or was not used. There is no specific motivation – either good or bad – for conceiving a child in these latter cases. As Bennett states, although we might not agree with some of the reasons (or lack of reason) on which people base their reproductive choices, ‘[t]hese reasons are left to the private decision-making of the individuals and couples concerned and generally do not lead to debates over public policy’.

Given that people’s motivations for having children are not generally scrutinised, a question arises as to whether the state should examine the motivation of parents seeking PTT at all. As Gavaghan points out, ‘[i]t is perhaps unlikely that any pregnancies are commenced wholly or predominantly out of beneficence towards the future child’. According to Harris, ‘it’s difficult… to find evidence or even persuasive anecdotes that if people are treated as means, they are necessarily treated as mere means, or exclusively as means or solely as means’. It would be inappropriate to impose an unrealistically high standard of altruism on parents seeking

73 Devolder, above n 68, 584.
74 Ibid.
77 Bennett, above n 76, 203.
78 Ibid.
79 Gavaghan, above n 40, 161.
PTT, considering the multitude of self-interested reasons for which parents have children. Parents seeking PTT to save the life of an existing child are perhaps even acting more altruistically than most parents who decide to have children, as their dedication to saving their sick child demonstrates a high level of commitment to the welfare of at least their existing children.

There are, however, certain reasons for which it would be unacceptable to bring a child into the world. Conceiving a child to become a slave or a ‘tissue farm’ would clearly contravene Kant’s categorical imperative. It would be inappropriate for the state to assist parents by providing them with ART services in these sorts of cases. Given the potential for a child to be born as a result of PTT to be commodified, the state has an obligation to at least explore the motivation of parents seeking PTT through counselling. The mere fact that the birth of a child can assist an existing sibling should not be seen as prima facie evidence that the child will not also be treated with dignity as an end in his/herself. However, if counselling revealed that parents seeking PTT had no interest in another child and were, for example, proposing adoption of that child following successful stem cell donation, then PTT should not be allowed.

There is another very important reason for parental motivation to be explored through counselling. Helping parents examine their own motivations for wanting another child assists them in making a genuinely informed decision about PTT. It is important for parents to thoroughly explore and understand their own motivations for wanting another child as they will have to live with the outcome for the rest of their lives. The difficult and sometimes neglectful relationship the mother in My Sister’s Keeper has with her daughter Anna, a saviour sibling, highlights the complex issues faced by families with a seriously ill child. Counselling can assist parents by helping them come to terms with their own reasons for seeking PTT. This should help parents in dealing with future challenges, including the possibility of further stem cell donations.

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81 As discussed below in Part VA2, there are protections in Australian law against organ and excessive tissue donation by minors. However, these legal protections do not protect the child to be born from damaging attitudes by parents who intended to conceive the child purely as a donor. Such parents may not ultimately care for the child as a person in his/her own right.

82 Parents can always attempt to conceive a donor sibling for a sick child without using ART. For example, Dr Robertson Parkman from Los Angeles Hospital has stated that he personally knows of cases going back to 1974 in which families have had additional children to obtain bone marrow transplants for a sick child: Rachels, above n 76, 70. However, parents seeking PTT require assistance from government regulated and funded ART service providers in order to achieve this goal.
In Chapter 4, I discuss how parents themselves can benefit from counselling to explore their motivation for using PTT.

C Real issue is how the child is treated once born

Finally, it is important not to lose sight of the real issue raised by Kant’s moral imperative – how the child to be born is treated – by focusing too much on the parents’ motivation for having the child. According to Pennings, ‘the morally relevant point is the way the child is treated by its parents once it is born rather than their reasons for having it.’

Ultimately, what matters is that a child born using PTT ‘is loved, nurtured and cherished in ways that we would hope all children would be by their parents’. The fact that parents have a preference for a particular type of child does not prevent them loving the child that is born in his or her own right.

According to Davis, selecting a child which has particular traits prior to conception is not inconsistent with unconditional parental love for the child who is born. Even where the child’s conception is motivated by the parents’ desire to save an existing child, the parents are not thereby prevented from becoming loving and devoted parents of the child to be born. As Robertson, Khan and Wagner state:

The birth of a child creates a powerful bond regardless of the circumstances of conception. Indeed, the fact that the parents are willing to conceive another child to protect the first suggests that they are highly committed to the well-being of their children, and that they will value the second child for its own sake as well.

A similar sentiment was recently expressed by the first parents of twin saviour siblings, born in the UK in 2009. The parents, Laurence Maguire and Wendy Plant, decided to conceive a saviour sibling to cure their eldest son’s aplastic anaemia. Mr

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83 Pennings, ‘Saviour siblings’, above n 68, 311.
84 Bennett, above n 76, 203. See also: Rachels, above n 76, 69; Devolder, above n 68, 584.
85 Davis distinguishes between the decision by parents to choose a particular type of child and how a parent relates to a child once it is born: John Davis, ‘Selecting Potential Children and Unconditional Parental Love’ (2008) 22(5) Bioethics 258, 261-3. As Pennings has pointed out, the postnatal attitude of parents toward a child does not depend on the preconceptional desire for a child. If this were the case, then most children conceived ‘by accident’ would not be the recipients of unconditional parental love. See Pennings, ‘Saviour siblings’, above n 68, 313.
Maguire stated that ‘[o]nce you see your children, any notion that they are spare parts is gone. We wouldn’t change anything, they are our children and we love them all.’

Parental motivation for seeking PTT should not be over-scrutinised by the state. As Devolder notes, ‘[w]e judge people on their attitudes toward children, rather than on their motives for having them.’

To put it another way, ‘how one is treated by others over the course of one’s life is more morally significant than the reasons for causing one to exist’.

**D Summary**

The debate over PTT based on commodification highlights the putative child’s interest in being treated with respect. A saviour sibling is not commodified if his/her parents genuinely want the child in his/her own right. Parental motivation is therefore relevant to the welfare of the child to be born using PTT and should be explored through counselling. The reasons why people have children are generally multifactorial and rarely altruistic and should not, therefore, be over-scrutinised. However, the state should at least attempt to protect children from being treated solely as a source of stem cells, particularly where parents do not have an ongoing commitment to care for the child who is born. This might occur, for example, where parents express an intention to offer the child for adoption after successful donation occurs. The use of counselling to ascertain parental motivation for PTT can also assist parents in making a genuinely informed decision about PTT and in preparing for future challenges that may arise.

A narrow interpretation of Kant’s categorical imperative, which focuses on parental motivation for having a child, provides an insufficient account of the welfare of the child to be born. A more important question is how the child is treated once s/he is born. Children need more from their parents than to be respected as individuals in their own right (although this is clearly important). This is not a general criticism of Kantian theory but rather a critique of how Kant’s theory has been interpreted and applied in the debate over PTT.

Given a child’s dependence on his/her parents, the

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88 Devolder, above n 68, 584. See also Bennett, above n 76, 203.


welfare of a child must be situated within the context of his/her family. As Hilde and James Lindemann Nelson argue, ‘[w]hat’s morally important about our interactions with those whom we love isn’t easily captured by impersonal accounts of our duties to others.’91 In Part VI, I introduce a more comprehensive account of the welfare of the child, based on a relational nature of the self.

A key concern about how the child is treated once s/he is born relates to whether or not the child is harmed. The risk of physical, psychological or social harm to the child to be born as a result of PTT is the second major concern in the debate over PTT. In contrast to commodification, the concern about harm reflects a primarily consequentialist approach to the welfare of the child. Consequentialism measures the moral value of an action according to the value of the consequences that it is intended to bring about. The welfare of the child to be born is therefore assessed by looking at the potential consequences for that child. In the next Part, I explore the interest of the child to be born in protection from harm.

V INTEREST IN PROTECTION FROM HARM

In its more traditional formulation, the welfare of the child principle refers to the child’s interest in being protected from harm or experiencing a ‘balance of benefit over harm’.92 According to the VLRC, the need to protect children from harm is ‘[t]he most common justification for regulation of ART’.93 The ethical concern about harm is based on the principle of non-maleficence, which asserts an obligation not to inflict harm intentionally. The principle of non-maleficence is reflected in the Latin edict *primum non nocere* (meaning ‘first, do no harm’), which is one of the principal precepts of medical ethics.94 There are various risks of harm for the child to be born

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91 Hilde Lindemann Nelson and James Lindemann, Nelson The Patient in the Family: An Ethics of Medicine and Families (Routledge, 1995)
92 Gavaghan, above n 40, 151. For a detailed discussion of the distinct approaches to harm and benefit by utilitarians, ethical pluralists and harm theorists, see Gavaghan, above n 40, 45-9.
93 VLRC Report, above n 1, 46.
as a result of PTT. There is a potential risk of physical harm to the putative child associated with ART and the embryo biopsy process used for PTT. There is also a future risk of physical harm associated with peripheral blood and bone marrow donations by the child once s/he is born if the initial cord blood donation is unsuccessful. Finally, there is a theoretical risk of psychological or social harm to the child associated with being conceived as a donor for an existing sibling.

I begin this Part by examining the various risks of harm to the child to be born as a result of PTT. Although there are at least some clear risks of harm to saviour siblings, proponents of PTT have attempted to justify the procedure on the basis that the saviour sibling is benefitted overall. I critically analyse the two primary arguments in support of PTT and conclude that there is no overriding or individual ‘net benefit’ for the child to be born that outweighs the risks of harm associated with PTT. PTT is therefore not in the individual interests of the child to be born. I argue that PTT can only be justified if the welfare of the child is conceived more broadly to include the collective interests the child shares with his/her family, a notion I explore more fully in Chapter 3.

A Physical harm

1 ART and embryo biopsy

Several risks of physical harm to the child to be born as a result of ART have been identified, although findings vary. Research indicates that there is some impact on the health of children conceived by ART, who are more likely to be stillborn or to die shortly after birth.95 This higher death rate is largely attributable to a higher incidence of pre-term delivery and multiple births associated with ART.96 There is ongoing debate about whether the use of ART generally increases the risk of birth defects, and, if so, how it causes those defects.97 Outcomes for ART also vary depending on the form of ART used. For example, ART may involve various procedures, including in

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95 VLRC Report, above n 1, 30. See also McNair, above n 26.
96 Ibid. However, a recent Australian study revealed that IVF twins are far more likely to need hospital treatment than naturally-conceived twins: BioEdge, ‘Health of IVF Twins Worse’ 23 May 2009 http://www.bioedge.org/index.php/bioethics/bioethics_article/8596/.
97 Ibid. A recent French study has revealed that the birth defect risk is twice as high for children born as a result of ART: Rachel Panizzo, ‘Assisted Reproduction Could Lead to Increased Risks of Congenital Malformations, Say Scientists’ BioNews 14 June 2010 http://www.bionews.org.uk/page_64300.asp.
vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI) and donor insemination (DI).

There has been conflicting evidence from different countries about the risk of birth abnormalities in children born as a result of IVF. A recent Japanese study suggests that babies born using IVF do not face an increased risk of birth defects. Other recent studies have revealed adverse outcomes associated with IVF. For example, a Swedish study suggests that there is a small risk that children born using IVF are more likely to develop childhood cancers than children conceived naturally. A Belgian study has also recently revealed that IVF babies are more prone to diseases like diabetes and obesity later in life. Finally, a recent Danish study suggests that women who undergo IVF are four times more likely to have a stillborn baby than those who conceive naturally.

The physical risks to the selected embryo associated with embryo biopsy appear to be minimal, although there is insufficient evidence about the safety of the process. According to the UK Human Genetics Commission (HGC), ‘the indications so far are that the incidence of birth abnormalities is not significantly higher in children produced by these techniques than in the general population’. However, more

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103 Human Genetics Commission (HGC), Making Babies: Reproductive Decisions and Genetic Technologies (January 2006) (Making Babies Report) [4.13]. An editorial in the Lancet in 2001 stated that ‘embryo biopsy for PGD does not seem to produce adverse physical effects in the short term, but it is too early to exclude the possibility of later effects.’ Editorial, ‘Preimplantation Donor Selection’, (2001) 358 Lancet, 1195. These findings were recently supported by a large scale study of genetically screened embryos: Vivienne Raper, ‘Study Shows Preimplantation Screening Is Safe for Singletons’
scientific evidence is needed in this area, particularly in relation to longer term outcomes for the child born using PTT. To date, no rigorous long-term studies have been conducted on the health of children conceived from biopsied embryos. Given that one or more cells are removed from the embryo during the biopsy procedure, trauma is possible. A recent study of mice conceived using PGD suggests that the developing nervous system may be sensitive to embryo biopsy. The study revealed that successful births from biopsied embryos were significantly lower than normal embryos. Furthermore, some mice from biopsied embryos had increased weight gain and memory decline in adulthood.

Aside from any harm to the child to be born, there is also potential harm to the embryos that are rejected in the PTT process. Those embryos that are rejected are disposed of in compliance with the relevant regulatory regime, one option being destruction of the embryo. Gavaghan argues that ‘[t]hose de-selected embryos which will never attain sentience will simply never develop interests of any kind, never attain the capacity to be harmed’. Whether or not one accepts that an embryo is ‘harmed’ by destruction ultimately depends on the view taken of the status of the embryo. Applying a gradualist view of the status of the embryo, embryo selection (and destruction) is acceptable provided there are legitimate reasons for the procedure. The same issue arises with PGD, ART and embryo research more generally, and is not an issue specific to PTT. Embryo destruction has been accepted practice in relation to PGD, ART and embryo research for many years and its role in

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Under the NHMRC Guidelines, embryos may be stored for future reproductive treatment by the original participant, donated to another recipient for reproductive treatment, used in research (where it is an “excess ART embryo”) or destroyed: NHMRC Guidelines, Sections 7, 8 (esp [8.5.1]) and 17. For the definition of “excess ART embryo”, see Research Involving Human Embryos Act 2002 (Cth), s 9.

Gavaghan, above n 40, 156.

For example, Catholicism views the embryo as a human life entitled to full human rights. Accordingly, the embryo would be considered to be harmed by its destruction.

The gradualist approach provides that the development of personhood is a gradual process but the embryo is entitled to some protection. In contrast to the absolutist or “pro-life” approach, which affords full human rights to the embryo, the gradualist approach permits infertility treatment and embryonic research provided there are sound reasons for the creation and use of embryos in a specific manner.
PTT raises no new issues. From a gradualist perspective, the embryo destruction involved with PTT is arguably less problematic than using prenatal diagnosis and terminating a more developed foetus to conceive a child who is a direct tissue match.

2 Sibling donation

The physical risks for a saviour sibling associated with donation depend on what type of stem cells s/he will be required to donate. Cord blood stem cell transplants pose no physical risks to the baby provided the mode of delivery of the baby is not modified. As Pennings, Schots and Liebaers state, ‘when treatment is possible with the umbilical cord stem cells, no intervention or risk is imposed on the donor child’. The umbilical cord is generally considered waste material and is ordinarily discarded. However, success rates for HSC transplants vary significantly according to the type of disease being treated and the stage of the disease.

Where an initial cord blood stem cell transplant is unsuccessful, a saviour sibling may be required to donate peripheral blood or bone marrow at a later date. There are clear risks of harm to saviour siblings associated with future stem cell donations. Peripheral blood donors experience short-term physical pain and fatigue but there have been no reported cases of long-term serious adverse physical effects on child donors. The major risk of harm for bone marrow donors are the risks associated with general anaesthesia. Bone marrow donors also experience short-term adverse effects, including fatigue and pain, for which recovery is generally longer than in the case of peripheral blood donation.

110 Although accepted practice does not necessarily legitimise de-selection of embryos, PTT is consistent with the ‘ruling synthesis’: Roger Brownsword, ‘Reproductive Opportunities and Regulatory Challenges’ (2004) 67(2) The Modern Law Review 304. As Sparrow and Cram state, IVF ‘requires a willingness to create multiple embryos knowing that most of them will not be implanted and will eventually be destroyed’: Sparrow and Cram, above n 69, 669. A recent US study has revealed that only 5% of all eggs fertilised in an IVF laboratory will become live births: BioEdge, ‘How Many Embryos are Destroyed in IVF?’ 11 April 2008 http://www.bioedge.org/index.php/bioethics/bioethics_article/8552/.

111 AAP, 395. New research suggests that delaying clamping of the umbilical cord after birth by several minutes brings statistically significant benefits to babies: Rosemary Paxman, ‘Wait Before Cutting the Umbilical Cord, Say Researchers’ BioNews 28 May 2010. Delaying clamping of the umbilical cord is likely to reduce the number of stem cells collected for transplant.

112 As discussed in Chapter 1, the likelihood of success of any HSC transplant varies according to the type of disease being treated and the stage of the disease. See discussion in Chapter 1, Part IIA, esp n 8.


114 Ibid.
There are existing legal protections in Australia in relation to future donations by saviour siblings beyond umbilical cord blood. In the UK, Gavaghan has argued that:

[t]he decision as to whether the retrieval of tissue and subsequent transplant should take place would be determined at a later time, by weighing up the harms and risks and benefits attendant to the donation, and would be likely to require judicial approval. There is no question that the procedure would go ahead merely on the parents’ say-so. We might think, then, that the interests of the child, once born, will adequately be protected by the courts… 116

The types of tissue that may be the subject of future donation are generally divided into regenerative and non-regenerative tissue. Regenerative tissue is tissue that the human body can replace, once removed, by natural processes of growth or repair. Bone marrow is a form of regenerative tissue. Non-regenerative tissue refers to organs that cannot be replaced by the human body, such as a kidney. Australian law distinguishes between the donation of regenerative and non-regenerative tissue.

Any future donation by the child born as a result of PTT would be covered by legislation governing tissue donation by minors. 117 While there are variations between the different state and territory Acts regulating tissue donation and transplantation, children are generally permitted to donate regenerative tissue for the benefit of an immediate family member. 118 Donation of non-regenerative tissue by minors is either expressly prohibited 119 or not mentioned in the specific provisions applying to minors, suggesting that it is prohibited by implication. 120 The Australian Capital Territory (ACT) is the exception, in that it expressly permits the donation of non-regenerative tissue from minors under very strict conditions. 121

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116 Gavaghan, above n 40, 154. In contrast to Australia, there is no specific legislation in the UK dealing expressly with tissue donation by minors. However, the UK common law is not likely to approve the removal of non-regenerative tissue from a minor: Ram, above n 62, 280.

117 See, for example, Human Tissue Act 1982 (Vic). For a summary of the legislation regulating human tissue donation in Australia, see Bennett, above n 76, 205-7. The Human Tissue Transplant Act (NT) does not specifically deal with tissue donation from children in the Northern Territory.

118 Bennett, above n 76. See, for example, Human Tissue Act 1982 (Vic), s 15(1).

119 This is the case in Victoria, South Australia and Western Australia. See, for example, Human Tissue Act 1982 (Vic), s 14(1).

120 The legislation is silent on this issue in New South Wales, Queensland, Tasmania and the Northern Territory.

121 These conditions include: fully informed consent by the donor child; a 24-hour cooling-off period; written consent of both parents; that the recipient is in danger of dying without the transplant; detailed explanation to the parents and donor child of the nature and effect of the procedure by doctor; and referral of the matter to a committee consisting of a Supreme Court judge, a doctor and a social worker or psychologist. See Transplantation and Anatomy Act 1978 (ACT), s 14.
The removal of regenerative tissue is allowed in most states and territories, subject to certain requirements designed to safeguard the interests of the donor child. Most states require the child to understand the nature and effect of the proposed tissue donation and to consent to the procedure. In addition to legislation, the Family Court of Australia has general jurisdiction to make orders in relation to the welfare of the child. This jurisdiction is relevant to medical decision-making for minors in respect of treatments where the interests of the child are at risk.

Despite these protections under both legislation and common law in Australia, the potential for future tissue donations by saviour siblings is inevitably ‘imprinted’ into the child’s destiny. Physical harm from future peripheral blood or bone marrow tissue donation is therefore a distinct possibility for the child who is born as a result of PTT. This may be exacerbated by parental expectation that a saviour sibling will continue to help save the life of the ill sibling, which may or may not be openly expressed. It is therefore important to at least recognise the future risk of physical harm associated with tissue donations by the child born as a result of PTT at the time decisions about PTT are being made.

B Psychological and social harm

The psychosocial risks to the child to be born as a result of PTT are more speculative than the physical risks. There is a theoretical risk of psychological or social harm associated with being conceived in order to save the life of another. Given that PTT is a relatively new technology, there is currently no empirical evidence on the psychosocial harms to children born using PTT. According to Ram, psychosocial

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122 The Northern Territory is the exception as the Human Tissue Transplant Act (NT) does not specifically address tissue donation by children.
123 This requirement limits the removal of regenerative tissue to minors of a sufficient age and maturity to understand the nature of the procedure. See, for example, Human Tissue Act 1983 (NSW), s 11. Victoria and Queensland make specific provision in relation to donation by children not yet competent to consent. See, for example, Human Tissue Act 1982 (Vic), s 15(1).
124 Family Law Act 1975, s 67ZC(1).
125 The Family Court will make decisions about the welfare of the child by treating the ‘best interests’ of the child as the paramount consideration: Family Law Act 1975, s 67ZC(2).
126 HFEA Report on PTT, above n 104 [17]. PTT has only been available since 2000, so that the oldest children born using PTT may have not yet reached adolescence, at which point they become psychologically independent from their family and seek their own identity: Ram, above n 62, 280. See also, J A Daniels, ‘Adolescent separation-individuation and family transitions’ (1990) 25 Adolescence 105.
evidence from teenage children conceived using PTT is critical to assessing the real harms and benefits of being born, in part, as a tissue donor.\textsuperscript{127}

Various sources of potential psychosocial harms to saviour siblings have been raised in the debate over PTT. Some commentators have suggested that knowing that s/he was brought into existence to save the life of an existing sibling could have a negative impact on a saviour sibling’s sense of self-worth or identity or on his/her ongoing relationship with the ill sibling.\textsuperscript{128} This potential harm is related to the commodification argument discussed above in that it may be a consequence of a breach of Kant’s moral imperative. There is also the possibility that other members of the family might actively stigmatise the donor child for having been brought into existence for instrumental reasons.

Grundell refers to the ‘psychological impact of selectivity’ on a child who is selected for a particular purpose.\textsuperscript{129} Such children may not feel important in and of themselves, but instead feel that they have been selected to serve the purpose of another. A related harm is that the child may lose some sense of unconditional parental love in being born to serve a specific purpose.\textsuperscript{130} Other commentators have described a child conceived to be a donor as having a ‘closed future’.\textsuperscript{131} In this respect, the use of PTT is inconsistent with what Feinberg describes as the child’s ‘right to an open future’, pursuant to which the child’s future interests or options be kept open until that child has the capacity of self-determination.\textsuperscript{132}

Commentators also refer to the psychological burden on the future child, who may suffer guilt if treatment fails or if s/he is reluctant at a later stage to undergo further donation procedures.\textsuperscript{133} The potential psychological impact of donation between siblings should not be underestimated, particularly where donation has been unsuccessful. Several studies indicate that some sibling bone marrow donors suffer

\textsuperscript{127} Ram, above n 62, 280.
\textsuperscript{128} Thomas, above n 64, 123. See also STC Report, above n 36 [127]. See also HGC Report, above n 103 [4.22].
\textsuperscript{129} Grundell, above n 64, 48.
\textsuperscript{133} Grundell, above n 64, 47-8. See also Pennings, Schots and Liebaers, above n 76, 537.
psychosocial harm and that the risk of harm is increased where there was a negative outcome. For example, in cases where a donation was not successful or the sibling died, feelings of anger, guilt and blame generally overshadowed any positive feelings experienced by the donor child. A significant portion of sibling bone marrow donors have been reported to experience a moderate level of post-traumatic stress. The trauma experienced by sibling bone marrow donors should not automatically be transposed to saviour siblings (who may or may not ultimately donate bone marrow) without further qualification. The impact of sibling donation will vary considerably according to the circumstances of each individual case. Thomas argues that the trauma suffered by sibling bone marrow donors could be largely a result of the distress suffered by a family in which a child is critically ill, compounded by the effects of involvement in medical procedures. Other commentators have pointed out that as the impact of donation depends on the conscious experience of the child, the ‘psychosocial effects will have become diluted’ when a saviour sibling is able to understand the nature of his/her conception. If an umbilical cord blood transplant is successful in curing the existing child, a saviour sibling is not likely to experience the type of trauma suffered by sibling bone marrow donors. However, if the existing child requires further treatment, then a saviour sibling will inevitably have to deal with the critical illness and possible death of a sibling very early on in life. The potential trauma to the child to be born should not therefore be overlooked.

Some commentators have turned arguments against PTT based on psychosocial harm on their head to become potential benefits for the child to be born. This only serves to highlight the speculative nature of this harm/benefit analysis. In the next section, I outline the alleged psychosocial benefits to the child to be born as a result of PTT.


136 Ibid.

137 Thomas, above n 64, 138. In the case of PTT, there is no invasive medical procedure as the stem cells are harvested from the placenta after birth. There is therefore no intervention or risk imposed on the donor child: Pennings, Schots and Liebaers, above n 76, 537.

138 Pennings, Schots and Liebaers, above n 76, 537.

139 See discussion below, Part VC3.
Given the potential risk of harm to saviour siblings, PTT has been justified by some commentators on the basis that the saviour sibling benefits overall. The two primary arguments given in support of PTT are: (1) that it is better to be born than not; and (2) that the saviour sibling experiences psychosocial benefit from being a donor.

1 Better to be born than not born

The first commonly cited argument in support of PTT is that the child selected is better off as existence is better than non-existence, subject to the exception of a life ‘not worth living’. According to Feinberg, people are harmed only if they are caused to be worse off than they otherwise would have been. Feinberg’s conception of harm is used to argue that children’s interests are served by being born, since non-existence cannot be better than existence. This argument is based on Parfit’s principle of non-identity. According to Parfit, if someone lives a life that is worth living, it cannot be worse for that person than if s/he had never existed. Sheldon and Wilkinson explain the philosophical problem of non-identity in the following way:

When we choose to implant one embryo rather than another, we are making decisions that are identity-affecting. We are not choosing to make one determinate future person better (or worse) off. Rather we are choosing to create one person rather than a different person. This does not necessarily mean that child welfare considerations should be completely disregarded. But it does make it almost impossible to construct a child welfare argument against creating the child whose welfare is under consideration.

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‘to give the highest priority to the welfare of the child to be born is always to let that child come into existence, unless existence overall will be a burden rather than a benefit’. Similarly, Boyle and Savulescu argue that given the alternative for the child to be born is ‘not another life in which he or she was conceived in another way, but non-existence’, it is difficult to argue that PTT harms the child who is born.

The argument in favour of existence does not apply to ‘a life not worth living’. It is therefore worth exploring what this phrase means. Glover explains that ‘some kinds of life are perhaps worse than not being alive at all’. Cases involving non-treatment decisions for infants and wrongful life claims have been used as a benchmark for defining ‘a life not worth living’. For example, adopting the standard applied in ‘wrongful life’ cases, Robertson describes a condition that renders life so ‘horrible’ and ‘full of unavoidable suffering’ that it is worse than ‘no life at all’. Feinberg expands on this standard by referring to the most extreme cases where ‘it is rational to prefer not to have come into existence at all’, and refers to ‘some of the more severely victimised sufferers’ of brain malformation, spina bifida, Tay-Sachs disease, polycystic kidney disease and Lesch-Nyhan syndrome.

In a similar vein, Gavaghan refers to ‘a life of such wretched quality that, from the subjective perspective of the child itself, it would have been better never to have been born’. He notes that such cases are rare, but suggests that it is plausible to conceive of lives ‘affected by genetic disorders that guarantee brief, severely cognitively impaired and pain-filled lives’ as being not worth living. Gavaghan refers to UK case law involving non-treatment decisions for infants, in which the courts have recognised that there will be cases where the life of the child is ‘so bound to be full of

146 Harris, above n 140, 33. See also: Sheldon and Wilkinson, ‘Hashmi and Whitaker’, above n 43, 152; Blyth, above n 56, 28.
147 Boyle and Savulescu, above n 64, 1242.
150 Feinberg, above n 141, 158. See also Cohen, above n 98, 23.
151 Gavaghan, above n 40, 92.
152 Ibid.
pain and suffering’ that life is a burden rather than a benefit and life-prolonging treatment would not be justified.\footnote{Re B (a minor) (wardship: medical treatment) (1981) 3 All ER 927, per Lord Templeman, 929. See also, Re J (a minor) (wardship: medical treatment) [1991] Fam 33. Interestingly, Gavaghan notes that the UK courts have been reluctant to apply the same test to ‘wrongful life’ cases as they have to non-treatment decisions: Gavaghan, above n 40, 93-6.}

Coady describes another way in which a life may be considered not worth living, apart from those lives that are severely affected by genetic disorders. She suggests that it is possible to think of an extreme example where a child is born into a family where there is a very high probability of the child being seriously abused.\footnote{Coady, above n 22, 455.} In such a case, it is conceivable that the child would prefer non-existence.\footnote{In practice, it should possible to safeguard against this possibility if people convicted of child abuse are prohibited access to ART and if government social services took appropriate action to protect any child at risk under child protection legislation.} Whichever way ‘a life not worth living’ is defined, Sheldon and Wilkinson argue that the chances of a child born using PTT having a life worse than death is ‘surely remote’.\footnote{Sheldon and Wilkinson, ‘Should selecting saviour siblings be banned?’, above n 64, 536.} Therefore, according to the argument in favour of existence, the child to be born as a result of PTT will generally be better off than had s/he not been born.

2 Rebutting the ‘better to be born’ argument

Rachels considers that there are significant problems in using the non-identity principle to argue that a child is made better off by being born. He argues that the presumption you confer a benefit on a child merely by bringing it into existence is easily disputed.\footnote{Rachels, above n 76, 69.} In this section, I explore two main criticisms of the ‘better to be born’ argument that render it ultimately unconvincing in justifying PTT.

First, the argument in favour of existence incorrectly assumes prior to existence, a person has an interest in existing. As Cohen points out, the ‘Interest in Existing argument… is an after-the-fact argument meant to apply at a time when children are already born’.\footnote{Cohen, above n 98, 21.} According to Cohen, those who promote the Interest in Existing argument adopt the standard applied in ‘wrongful life’ cases and incorrectly assimilate non-existence before life and non-existence after death.\footnote{Jackson similarly argues that the welfare principle is inconsistent with ‘wrongful birth’ and ‘wrongful life’ tort actions, which assume that the benefits accruing from existence normally outweigh any disadvantages: Emily Jackson, ‘Conception and the Irrelevance of the Welfare Principle’, above n 31, 178 and 196-9.} In doing so, they fail to
distinguish between the interest a person, once born, has in existing, and the fact that prior to existence, there is no person with interests. Cohen argues that, in contrast to death, non-existence before birth is ‘neither good nor bad’ so a life of substantial suffering can still be harmful.\(^{160}\)

To say that it was good for someone already in existence to have been born does not… imply that if he had not been caused to exist, this would have been bad for him. Although a wealth of possible children can be conceived, their interests cannot be diminished if they are not.\(^{161}\)

Brazier, Golombok and Campbell similarly rebut the assertion in favour of existence based on Feinberg’s conception of harm by arguing that ‘[b]y not bringing them into being we do no harm to a child, since none exists’.\(^{162}\)

A second problem with the argument in favour of existence is that by logical extension it justifies allowing assisted reproductive technologies to create almost any harm to children conceived as a result, provided they do not have a ‘life not worth living’. Cohen distinguishes between ‘devastating harm’ and ‘serious harm’. The former creates such suffering that the person’s life is rendered not worth living, whereas the latter does not render life worse than death but includes serious detriments, including major impairment and considerable pain and/or suffering.\(^{163}\)

Proponents of the argument that being born is an overriding benefit to the child to be born would argue that the child to be born using assisted reproduction is ultimately better off being brought into the world, even where it is at risk of suffering ‘serious harm’.\(^{164}\)

The criticisms of the argument that existence is generally better than non-existence are compelling. It may well be that a child who is born as a result of PTT will lead a worthwhile life. This is not, however, the same as saying that the child fares better on the harm/benefit scale than if it never existed, as it makes little sense to talk of non-existence before birth as a harm or a benefit. It has, perhaps, seemed appropriate to rely on the argument in favour of existence in relation to PTT because, as Sheldon and Wilkinson have pointed out, the child to be born as a result of PTT is not likely to

\(^{160}\) Cohen, above n 98, 23.
\(^{161}\) Ibid 21-2.
\(^{163}\) Cohen, above n 98, 21.
\(^{164}\) The argument applies only to children who suffer harm that is a necessary result of the use of the assisted reproduction techniques: Ibid.
suffer ‘serious harm’. In this context, the argument is never really put to the test that Cohen poses of evaluating those types of lives that fall short of ‘not worth living’ but yet are filled with substantial suffering. However, the fact that the Interest in Existing argument justifies the creation of children who will suffer ‘serious harm’ means that it is not an ethically sound argument on which to rely to justify PTT.

3 Psychosocial benefits for sibling donors

The second argument in support of PTT claims that there are psychological and social benefits for saviour siblings, which outweigh the potential harms. In contrast to the psychosocial harms associated with PTT discussed above, some commentators argue that being selected to assist an ill sibling may ultimately benefit the child to be born.

Sheldon and Wilkinson argue that ‘it is far from obvious that consideration of child welfare should count against, rather than for, the practice of saviour sibling selection.’ Some commentators argue that knowledge of selectivity may in fact have a positive impact on the child to be born, giving the child a greater sense of self-esteem and self-worth and a feeling of pride about his/her role in attempting to save the life of a sibling. Others suggest that the donor may be cherished and derive increased self-esteem for its saviour status, and have an enhanced relationship with the sibling recipient, who otherwise would have died. As Savulescu points out, ‘[n]o child has an interest in living in a family under the shadow of avoidable, premature death’.

Savulescu argues that we should not undervalue the extent to which our wellbeing is intertwined with those to whom we are strongly attached. Thus in the case of siblings, the donor child’s wellbeing is indirectly enhanced when s/he is able to help a sick sibling. Even where the bond is potential (as is the case with a child yet to be born) Savulescu claims that donors may in the future enjoy a sense of achievement. The donor may also enjoy the love and gratitude from the sibling who was saved and the rest of the family. Sheldon and Wilkinson have similarly suggested that a saviour

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165 Sheldon and Wilkinson, ‘Should Selecting Saviour Siblings Be Banned?’, above n 64, 536.
166 Pennings, Schots and Liebaers, above n 76, 537. See also Sheldon and Wilkinson, ‘Should Selecting Saviour Siblings Be Banned?’, above n 64, 536.
167 Thomas, above n 64, 123, 138. See also: Sheldon and Wilkinson, ‘Should Selecting Saviour Siblings Be Banned?’, above n 64, 536; Julian Savulescu, ‘Substantial Harm but Substantial Benefit’ (1996) 312(7025) British Medical Journal 241.
168 Savulescu, ‘Substantial Harm but Substantial Benefit’, above n 167.
169 Ibid.
sibling may benefit from their sibling’s company and derive pleasure from knowing that s/he has saved the sibling’s life.\textsuperscript{170}

Some commentators have also suggested that, even where a sibling dies, there may be benefit in the knowledge that the family exhausted all possible treatment options.\textsuperscript{171} Gavaghan contrasts the lot of a child born using PTT who is a direct tissue match to an existing child and that of a child born from a normal pregnancy in the hope that it will be a direct tissue match, to argue that psychological harm is not restricted to children born using PTT. He suggests that given the low likelihood of the latter child being a tissue match, it could suffer unique psychological burdens knowing that it was conceived as a saviour but ‘failed’ in this role.\textsuperscript{172}

The sibling bone marrow donor studies cited above\textsuperscript{173} also suggest that some donors experience psychosocial benefits. Some of the reported benefits include an increase in self-esteem and a closer relationship with the recipient sibling.\textsuperscript{174} A recent empirical study on paediatric sibling stem cell donors revealed that successful donation had a positive impact on many aspects of their lives, including relationships and self-worth.\textsuperscript{175} There is also anecdotal evidence that a child conceived naturally in order to donate stem cells to an ill sibling has had a positive experience overall. Marissa Ayala was born in 1990 as a result of a concerted attempt by her parents to have a child that could serve as a tissue donor to their sick child, Anissa. Marissa, who is a healthy, happy and loved member of her family, is a ‘positive example of the psychological impact of being a “saviour sibling”.’\textsuperscript{176} Although Ayala’s case does not prove that being born to serve as a donor to a sick sibling will always be a positive experience, it does suggest that the psychological outcome for the saviour sibling is not necessarily a negative one.\textsuperscript{177}

\begin{footnotes}
\item[170] Sheldon and Wilkinson, ‘Should Selecting Saviour Siblings Be Banned?’, above n 64, 536.
\item[172] Gavaghan, above n 40, 155. See also Sheldon and Wilkinson, ‘Hashmi and Whitaker’, above n 43, 152.
\item[173] See discussion above, Part VB, esp ft 137.
\item[174] Thomas, above n 64, 138. See also: B L Freund and K Siegel, ‘Problems in Transition Following Bone Marrow Transplantation: Psychosocial Aspects’ (1986) 56 \textit{American Journal of Orthopsychiatry} 244.
\item[175] MacLeod et al, above n 134.
\item[176] Ram, above n 62, 280.
\item[177] Ibid. See also Devolder, above n 68, 584.
\end{footnotes}
Problems with attributing psychosocial benefits to sibling donors

The psychosocial benefits to the child to be born can be roughly divided into 2 distinct categories: (1) altruistic benefit; and (2) indirect instrumental benefit. These benefits are, however, unconvincing and speculative.

The first category, which suggests that the child will experience self-worth from donating to a sibling, assumes that the child to be born has altruistic or other-regarding interests. However, a young child does not have the capacity for altruism, let alone a child who is not yet born. So any altruistic benefit is, at best, retrospective but most likely non-existent. Cheyette warns that imputing psychological benefits of altruistic behaviour to minors who lack the cognitive ability to act altruistically is misleading.178 In the specific context of organ donation,179 Cheyette, argues that neither the language nor the imputed benefits reflect the experience of the minor donor:

While the term ‘organ donor’ is an efficient catchall phrase for the process by which human organs are obtained for transplantation, in this context, verbal efficiency masks meaningful differences between the affirmative act of giving and the passive experience of having something taken away.180

Crouch and Elliott have also criticised imputing what Feinberg has described as ‘other-regarding interests’ to a minor.181 Other-regarding interests are the interests that an agent has for the well-being of another person. Crouch and Elliott argue that this picture of human agency does not apply to minors who are not yet mature or sufficiently mentally developed to have an ‘other-regarding interest’ in a sibling. In such a case, the donor may not receive any psychological benefits from donation.182

The second category of psychosocial benefit suggests that the child to be born will experience indirect benefit because the family into which s/he is born will be better off as a result of the donation. This argument suggests that, if stem cell donation is

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178 Cara Cheyette, ‘Organ Harvests from the Legally Incompetent: An Argument Against Compelled Altruism’ (2000) 41 Boston College Law Review 465, 508. See also Thomas, above n 64, 139.
179 As previously discussed, my thesis does not contemplate the donation by saviour siblings of non-regenerative tissue or organs. Cheyette’s argument can, however, be extended to the donation of non-regenerative tissue such as bone marrow, bearing in mind that the impact of the removal of regenerative tissue is likely to be less significant than it is for the removal of non-regenerative tissue.180
180 Cheyette, above n 178, 506.
181 Crouch and Elliott, above n 171, 280-3.
182 Crouch and Elliott go on to propose an alternative approach to viewing donation in the context of a minor’s best interests, by appealing to the importance of strongly ‘shared significances’ within a family: Crouch and Elliott, above n 171, 282-3.
successful, the parents and sibling will be grateful to the donor child, the donor child will have the company of a healthy sibling, and the ability of the parents to care for the donor child will not be compromised by the trauma of having suffered the death of a child. \(^{183}\) Although the discussion of indirect psychosocial benefits recognises the relational element of interests within a family, these benefits are ultimately framed as individual interests of the child to be born. However, as with the alleged psychosocial harms to saviour siblings discussed above, the psychosocial benefits for saviour siblings are indeterminate and speculative. Furthermore, the empirical studies of bone marrow sibling donors suggest that where donation is unsuccessful, the psychosocial benefits to the donor child are outweighed by the psychosocial harms.

While it is difficult to prove that the child to be born will benefit individually from PTT, I argue in Chapter 3 that the child will benefit as a member of a collective – namely, an intimate family. \(^{184}\) The nature of this collective benefit requires a more holistic view of the human agent within the family, one that goes beyond notions of retrospective altruism and indirect instrumental benefit to the child to be born. Rather, the child’s welfare is conceived as being ‘inextricably intertwined’ \(^{185}\) with the interests of the family as a whole. By situating the welfare of the child to be born within the social context of his/her family, we recognise that the child not only has individual interests but also collective interests as a member of an intimate family.

**D Summary**

There are potential risks of harm to the child to be born as a result of PTT. There is a potential risk of physical harm associated with ART and the embryo biopsy process and a future risk of physical harm associated with peripheral blood and bone marrow donations. There is also a theoretical risk of psychosocial harm associated with being conceived as a donor, particularly if the child is required to make ongoing donations or if the ill child dies. Some of these risks are more speculative than others and further empirical research is needed into the short and long-term effects of PTT on the child to be born.

\(^{183}\) The last-mentioned instrumental benefit is not in fact a ‘benefit’ to the child to be born because the alternative to PTT for that child is not to grow up in a family traumatised by the death of a child but to not exist at all. The ‘benefit’ for the child to be born could only be that it gets born. However, as I argued above, a child is not necessarily better off being born than not: see discussion above, Part VC2.

\(^{184}\) Although a child conceived through PTT is clearly biologically related to his/her sick sibling, not all biological families are intimate and not all members of an intimate family are necessarily biologically related. I discuss the definition of ‘intimate family’ in detail in Chapter 3IIB.

\(^{185}\) Crouch and Elliott, above n 171, 284.
Proponents of PTT have generally attempted to justify the procedure on the basis that the benefits to the child to be born outweigh the potential harms. In other words, PTT is justified on the basis that the putative child receives an individual ‘net benefit’ overall. I have argued that the alleged benefits to saviour siblings are unconvincing and speculative. Moreover, if we are honest about the parental motivation behind PTT, the alleged benefits to the child to be born begin to look like rationalisations for a procedure that is really designed to save the life of the ill sibling. PTT is arguably not justified on the basis that it is in the individual interests of the child to be born. This is because, when viewed in isolation, it is difficult to prove that the putative child will experience any individual benefit as a result of PTT. As Elliston has pointed out in the context of sibling donations generally:

> [T]he fact remains that in any donation scenario the primary motivation is to provide benefit to the recipient and any benefits to the donor child are incidental and uncertain.\footnote{Sarah Elliston, \textit{The Best Interests of the Child in Healthcare} (Routledge-Cavendish, 2007), 258.}

If there is no individual ‘net benefit’ to the child to be born as a result of PTT, a threshold question arises as to whether PTT can be justified at all. Several commentators have suggested that a broader approach is needed in the context of sibling donation generally. Aside from the speculative nature of weighing potential harms and benefits to the donor child, Crouch and Elliott suggest that this equation is inadequate to deal with deeper questions in family medical decision-making and has resulted in an artificial conception of what is in the ‘best interests’ of the child to be born.\footnote{Crouch and Elliott, above n 171, 275. See also Thomas, above n 68, 125.} Dwyer and Vig similarly argue that to focus on a child’s individual interests leads to rationalisations about what is in the best interests of the child to be born. Pennings, Schots and Liebaers suggest it is better to accept that the individual interests of the child to be born are not really being served by PTT and apply a different standard altogether.\footnote{Pennings, Schots and Liebaers, above n 76, 536.}

In Part VI, I argue that PTT may be justified if we look beyond the individual interests of the child to be born to the other interests within the family that are at stake. A utilitarian approach is one way of taking into account all relevant interests at stake.

\footnote{A similar complaint has been made about justifying organ or bone marrow donation on the basis of psychological or social benefits for the donor: Pennings, Schots and Liebaers, above n 76, 536. See also: James Dwyer and Elizabeth Vig, ‘Rethinking Transplantation between Siblings’ (1995) 25(6) Hastings Center Report 7, 12; Crouch and Elliott, above n 171.}
However, given the vulnerability of the child to be born, a utilitarian approach may not adequately protect his/her welfare. I argue that the various family interests should be viewed in a way that reflects the interconnectedness of family members and does not sacrifice the members of any individual person to promote the ‘greatest good’. I conclude that a more nuanced approach to the welfare of the child to be born is needed, which views the child as an individual as well as the member of a family. An approach to the welfare of the child that simply balances harms and benefits to that child cannot do this.

VI AN ALTERNATIVE APPROACH TO THE WELFARE OF THE CHILD

The narrow Kantian and consequentialist approaches to the welfare of the child discussed above provide some useful insights into the interests of the child to be born as a result of PTT. However, as discussed, children need more than respect and protection from harm. Children are highly dependent on the intimate relationships they have with their parents and other family members. The welfare of the child therefore needs to be viewed within the social context of the family into which the child is born.

The contemporary interpretation of Kant adopted in the PTT debate, which focuses on parental motivation for having a child, is too narrow. The child to be born clearly has an interest in being respected as valuable in his/her own right. However, as I discussed in Part IV, a more important question is how the child is treated once s/he is born. This question involves a broader exploration of the child’s needs and the relationships within his/her family that supply those needs. Given that the welfare of a child is inextricably connected with the welfare of his/her family, welfare assessments must take account of the child’s relationships with other family members. Moral theories that focus on individual interests are therefore generally ill-equipped to explain the moral significance of intimate relationships such as those found in families.190

190 O’Neill argues that although various forms of contemporary Kantian ethics may be criticised for being overly individualistic and ignoring personal relationships, these criticisms are less apt for Kant’s ethics: O’Neill, above n 90, 76. The field of applied ethics and bioethics has not, however, always kept up with the more sophisticated debate in moral and political philosophy.
A consequentialist net benefit approach to the welfare of the child is also problematic for PTT. As discussed in Part V, there are certain risks of harm to the child to be born as a result of PTT with no clear overriding net benefit. PTT is arguably not justified at all if a net benefit approach to the welfare of the child principle is adopted. A more holistic approach to the welfare of the family as a whole is needed. If we remove the focus on the welfare of the individual child to be born, a utilitarian approach can take into account other family interests and balance them against those of the putative child. These include the interests of the parents, the ill child and any other siblings who are likely to be affected by the death of a sibling. Utilitarianism focuses on bringing about the ‘greatest good’ in terms of happiness, utility or satisfaction for all concerned. According to Held, ‘[u]tilitarianism is better than Kantian and other deontological approaches in recognising the importance of satisfying needs, because it can weigh them heavily in the calculus of preference satisfaction.’ 191 At first glance, utilitarianism seems well-suited to deal with the issues arising out of PTT. PTT is a procedure that affects the interests of all members within a family. It is therefore important to consider the interests of not only the child to be born, but also his/her parents and all existing siblings. However, a utilitarian approach would not adequately protect the welfare of the child to be born as his/her interests may be sacrificed in order to achieve the greatest good. For example, the greatest good may be served by allowing PTT, even if the child to be born may be seriously harmed as a result. The risk of harm to the child to be born may be outweighed by the potential benefits to the ill child (whose life may be saved) and his/her parents (who are given an opportunity to save their child’s life). Given the vulnerable position of the child to be born, it is important to retain some version of the welfare of the child principle in the context of PTT.

Another problem with applying utilitarian principles to PTT is that families are more than ‘aggregates of individuals’. 192 As Held states, ‘utilitarianism still relies on an abstract universal principle appealing to rational individuals.’ 193 Utilitarianism undervalues the moral significance of families and the relationships within them.

191 Virginia Held, The Ethics of Care: Personal, Political, and Global (Oxford University Press, 2006), 63.
193 Held, above n 191, 63.
Families have an inner focus or communal purpose that cannot be measured by the sum of their parts. As Patricia Smith suggests ‘aggregate good is probably too individualistic an ideal to capture the moral relations of the family’,194 Alison Jost similarly argues that:

Good ethical deliberation requires weighing the many competing values in any difficult ethical dilemma. Weighing values doesn’t mean pitting them against one another, but considering the contextual and relational heft in a given case.195

By failing to situate the child within the context of his/her family, utilitarianism suffers from the same shortcomings as the contemporary Kantian and net benefit approaches to the welfare of the child discussed above. A more nuanced approach than utilitarianism is needed to reflect the relational nature of interests within families.

Over the last 20 years, there have been various attempts to put the ‘relational’ into the moral realm, particularly by feminist theorists. Early feminists rejected ‘mainstream moral philosophy’ in order ‘to account for women’s moral experience’.196 More recently, some feminists have revised traditional moral concepts to take account of the relational nature of the self.197 Virginia Held has developed an alternative moral paradigm, based on Carol Gilligan’s work on moral psychology and the ethics of care.198 In contrast to contemporary Kantian and consequentialist moral theories that treat moral agents as rational, independent and autonomous individuals, the ethics of care views persons ‘as relational and as interdependent’.199 According to Held:

A caring relationship requires mutuality and the cultivation of ways of achieving this in the various contexts of interdependence in human life. Noticing interdependencies, rather than thinking only or largely in terms of independent individuals and their individual circumstances is one of the central aspects of the ethics of care.200

194 Smith, above n 192, 49.
198 Held, above n 191.
199 Ibid 46.
200 Ibid 53.
The ethics of care recognises the moral significance of a person’s relationships with his/her families and focuses ‘on persons responding with sensitivity to the needs of particular others with whom they share interests.’\footnote{Ibid 63.}

Communitarian theory has also influenced the debate over how the welfare of the child should be conceptualised. Some theorists have emphasised the importance of collective endeavour or ‘affiliation’ to human flourishing.\footnote{See, for example, Nancy Sherman, ‘The Virtues of Common Pursuit’ (1993) 53(2) Philosophical and Phenomenological Research 277.} Family members have certain shared interests that cannot easily be separated. The welfare of a child is therefore inextricably connected with the welfare of the intimate collective that is his/her family. The collective welfare of families has been explored by some commentators in the specific context of sibling donations. Crouch and Elliott argue that:

\[\text{[t]he picture of human agent as independent and self-interested that has fuelled so many errors in this context is an inadequate picture of the human agent within the family. To think of family members in this way is to miss what is of importance in family life and to human agency.}\footnote{Crouch and Elliott, above n 171, 283.}

Other commentators have emphasised the importance that the child to be born ‘not be viewed in isolation’\footnote{Grundell, above n 64, 49.} but rather as part of a ‘social circle of shared relationships’.\footnote{Cynthia Cohen, ‘Wrestling with the Future: Should We Test Children for Adult Onset Genetic Conditions?’ (1999) 8(2) Kennedy Institute of Ethics Journal, 111. See also Grundell, above n 64, 49.}

In Chapter 3, I draw on relational feminist and communitarian ethical theories to explain the instrumental and inherent value of families to the children within them. I propose an approach to the welfare of the child to be born that acknowledges the interdependence between family members and situates the child within the social context of his/her family. In particular, I argue that a child has both individual interests and collective interests that s/he shares with other family members. Although PTT may not be in the individual interests of the child to be born, I argue that the procedure enhances the collective interests the child shares with his/her family.
VII CONCLUSION

The welfare of the child principle has an important role in protecting the child to be born as a result of PTT. However, Australian ART regulation provides insufficient guidance on how the welfare principle should be applied in practice.

The preliminary problem of attributing interests to a child who is not yet in existence can be addressed by acknowledging the ‘generic interests’ of all children. The ethical debate over PTT provides some valuable insights on how PTT is likely to impact on the welfare of the child to be born. In particular, the ethical concerns about commodification and harm highlight the putative child’s interests in respect, ongoing care and protection from harm. These individual interests of the child to be born are clearly relevant to decisions about PTT and raise important considerations about how PTT should be regulated. For instance, the child’s interests in respect and ongoing care could be safeguarded through appropriate counselling of parents seeking PTT. The current speculative nature of harm to the child to be born also highlights the need for further empirical research into the long and short-term impacts of PTT on the child who is born.

The ethical debate over saviour siblings has, however, tended to focus on the individual interests of the child to be born. This is reflected in the arguments by proponents of PTT who have attempted to justify the procedure on the basis that the child to be born receives an individual ‘net benefit’ overall. As I have argued in this Chapter, PTT does not appear to be in the individual interests of the child to be born. Families should also not be viewed as a collection of distinct and separable interests that can be weighed against one another in order to promote the ‘greatest good’. Such an approach undervalues the moral significance of families and the relationships between family members.

In Chapter 3, I propose a broader conception of the welfare of the child to be born, which recognises that the child’s welfare is inextricably connected to the welfare of his/her family. Instead of treating the interests of the child to be born as separate to the interests of his/her family, I argue that the child has interests as an individual and as a member of a family. In the context of PTT, my broader conception of welfare requires the interests of other family members to be considered in connection with the interests of the child to be born in respect and protection from harm.
CHAPTER 3
RE-CONCEPTUALISING THE WELFARE OF THE CHILD

I INTRODUCTION

As discussed in Chapter 2, the debate over PTT has been dominated by a narrow interpretation of Kant’s categorical imperative and the principle of nonmaleficence. As a consequence, the welfare of the child to be born has been generally conceptualised in terms of the child’s individual interests in respect and protection from harm. In this Chapter, I argue in favour of a broader conception of the welfare principle based on the notion of human flourishing. This broader conception of welfare recognises that the welfare of a child is inextricably connected to the welfare of the intimate collective that is his/her family. A comprehensive account of the welfare of the child must therefore acknowledge both the individual interests of the child to be born as well as the collective interests the child shares with his/her family.

I argued in Chapter 2 that an individualistic approach to the welfare principle does not satisfactorily take account of two important factors arising in relation to PTT. First, the welfare of the child to be born using PTT is inextricably linked to the welfare of his/her family as a whole. It is therefore unsatisfactory to focus on the interests of the child to be born in isolation. Rather, the welfare of the child needs to be considered in the social context of the family in which that child will be raised. Second, PTT affects the whole family and is primarily motivated by the interests of the parents in saving the life of their existing sick child and the interests of the sick child in living a healthy life. It would therefore be disingenuous to ignore the interests of other family members by focusing solely on the interests of the child to be born in the context of PTT. A more holistic ethical approach to the welfare of the child to be born – one which recognises the importance of connection and interdependence within a family – is needed in order to protect not only the child to be born but also the family which is necessary in order for that child to flourish. A broader conception of welfare based on human flourishing recognises that the child to be born as a result of PTT not only needs to be treated with respect and protected from harm but also needs the intimacy, love and meaning that comes from being involved in the collective endeavour of family.
In Part II of this Chapter, I explore the welfare of the child to be born in the broader social context of his/her family. In particular, I examine the role of intimate families in promoting human flourishing. I use the term ‘intimate family’ to encompass a diverse range of family structures in which members are closely connected. Drawing from relational feminist and communitarian ethics, I argue that intimate families are not only instrumentally valuable to the children they rear but also inherently valuable as they provide opportunities for the type of collective endeavour that is integral to a meaningful life. I conclude that the welfare of the child born as a result of PTT is inextricably tied up with the collective interests of his/her family.

In Part III, I argue that it is important to consider the welfare of the family as a whole in the context of PTT because PTT affects the whole family, in particular the interests of the parents and the existing sick child. Recognising that the welfare of the child to be born is not necessarily synonymous with the welfare of his/her family, I examine the role of familial duty as a justification for compromising some of the individual interests of the child to be born in favour of the welfare of the family as a whole. I also argue that the compromise entailed by familial duty need not necessarily be voluntary or based on constructive consent. Instead, I contend that membership alone provides the foundation for moral responsibility to the family. Finally, I argue that the duty owed by family members to one another is greater than the duty owed to strangers because intimate relationships involve a higher level of mutual obligation and reliance than non-intimate relationships. Accordingly, a different range of principles and objectives apply to obligations of family membership than the universal moral obligations grounded in modern liberal theory. This is not to suggest that there are not some universal moral constraints that operate within families to protect children from exploitation, abuse or neglect. I discuss these constraints in detail in Chapter 4.

II WELFARE OF THE CHILD WITHIN HIS/HER FAMILY

A Introduction

As discussed in Chapter 2, a child has certain basic interests, which ought to be protected. The debate over PTT has focused on these individual interests of the child to be born. However, a child’s welfare is also intimately and inextricably connected
with the collective welfare of his/her family. The collective interests that are shared by intimate family members are integral to human flourishing. We therefore need to view the child to be born as a human agent within his/her family and understand the welfare of the child from this perspective. It is important to stress that this conception of the welfare of the child is not merely one where the child’s individual interests are indirectly enhanced by the welfare of his/her family as a whole, but one where the child’s welfare as a member of a collective is enhanced. I begin my discussion in the next section by clarifying what I mean by the phrase ‘intimate family’.

B Nature of intimate family

The family is a complex social unit and no two families are the same. Families come in all shapes and sizes. The development of ART has increased the diversity of family structures. The term ‘family’ is not confined to biological heterosexual two-parent nuclear families. It includes adoptive families, foster families, step-families, blended families, extended families, and families whose parents have separated or divorced. It also includes families created through assisted reproduction, which may consist of households with a single parent, same sex parents, or with children created through gamete donation or surrogacy arrangements.

1 The diverse and dynamic nature of family

The fact that families take various forms is reflected in the multiple definitions that are available for the term ‘family’. For example, the Macquarie Dictionary defines family in various ways, including: ‘parents and their children, whether dwelling together or not’; ‘any group of persons closely related by blood, as parents, children, uncles, aunts, and cousins’; or ‘a group of persons who form a household and who regard themselves as having familial ties’. Elsewhere, ‘family’ is defined as ‘a fundamental social group in society typically consisting of one or two parents and their children’ and ‘two or more people who share goals and values, have long-term commitments to one another, and reside usually in the same dwelling place’. These

1 Blended families are families in which there is a least one biological child from both parents and at least one step-child of either parent: Ruth McNair, Outcomes for Children Born of ART in a Diverse Range of Families (Victorian Law Reform Commission Occasional Paper, August 2004), 17.
2 The term “family” is given 16 separate definitions in the Macquarie Dictionary and 11 separate definitions in the Oxford English Dictionary.
3 Macquarie Dictionary, definitions 1, 3 & 6.
definitions of “family” clearly extend beyond biological connection to include, at the broadest level, a group of persons in a household who regard themselves as family.

Not only are family structures diverse, they also change and evolve over time. Individual family structures are never static. Children grow up and move out of home and many begin their own families. Family members pass away or become estranged. Not uncommonly, parents separate due to irreconcilable differences and children either live with one parent or according to shared-parenting arrangements. Despite the dynamic and changing nature of family, an individual’s identity is continually shaped by the ongoing narrative of his/her family. As Hilde and James Lindemann Nelson point out, a ‘family reconfigures as the people within it grow, but the story that is lived out within the successive configurations preserves its continuity’.5

2 What makes a family intimate?

For the purpose of the following discussion, I shall focus on a particular type of family, which I describe as ‘intimate family’. Not all family members are sufficiently close to one another to be classified as ‘intimate’. The important feature of an intimate family is not the particular structure of the family but the closeness of its members.6 To be ‘intimate’ with someone is to be ‘associated in close personal relations’ with that person.7 According to Kuczewski, describing the family in terms of ‘closeness’ as opposed to biology is ‘commonplace in medical ethics’. 8 The importance of function over form within families was highlighted recently in a report commissioned by the Victorian Law Reform Commission and written by Dr Ruth McNair, which explores the outcomes of children born of assisted reproduction in a

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7 Macquarie Dictionary, definition 1.
diverse range of families. McNair reported that, overall, family functioning or processes were more important than family structure to children’s outcomes. The one element of structure that McNair found did influence outcomes directly is consistency of family structure, which impacts on a child’s feeling of security.

Like other forms of intimate groupings, intimate families involve ‘enduring relationships in which people’s interests are complexly entwined, and in which people care deeply about one another.’ It is the interconnectedness between family members that make them intimate, rather than the specific structure of the family itself. Families are not the only examples of close personal relationships. Longstanding friendships also provide opportunities for intimacy. Much of what I discuss in the following section about the value of intimacy is also pertinent to these other types of intimate relationships. One way in which we can distinguish families from other intimate relationships is by acknowledging their role in child-rearing. In the context of PTT, I focus on families that are actively engaged in child-rearing. Parents have specific functions in relation to raising children, which include protecting the child from harm, nurturing and socialising the child.

So far, I have argued that intimate families are defined by the closeness of their members rather than by their particular structure. One important point to bear in mind in relation to PTT is that any donor sibling must be conceived by the biological mother and father of the existing sick child in order to obtain a direct tissue match. In cases involving PTT in Australia and the UK, both parents seeking PTT have been the biological parents of the existing child and have been in agreement about their decision to conceive a donor child. More diverse family structures may result in a broader number of people with an interest in PTT than the biological parents. There may also not always be consensus between biological parents. In principle, the

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9 McNair, above n 1.
10 Ibid 2.
11 Ibid 18. This does not necessarily prevent families in which parents are separated or divorced from being intimate. According to McNair, evidence suggests that it is conflict rather than separation or divorce itself, which is most damaging to children.
13 See, for example, Marilyn Friedman, What are Friends For? (Cornell University Press, 1989).
14 Sara Ruddick describes these tasks as ‘maternal work’, which is in principle open to either gender: Sara Ruddick, Maternal Thinking: Toward a Politics of Peace (Beacon Press, 1989), 17.
availability of PTT should not be limited to families in which both parents are the biological parents of the sick child. However, in practice, the consent and agreement of both biological parents would be necessary in order for PTT to take place.

3 When families become dysfunctional

Intimate family members generally love, care for, and support one another within a relationship of mutual interdependence. However, no family is perfect and, as with all relationships of intimacy, family members have the ability to damage as well as benefit one another. I do not use the term ‘intimate family’ to invoke a romantic notion of a perfectly functioning family, in which the members are always kind, thoughtful and caring toward one another. While many parents may strive to emulate a perfectly functioning family unit, it is doubtful that such a family exists in reality. Parents and children will inevitably argue, parents will at times treat children unfairly because they are tired or stressed, and children will continue to aggravate their parents and each other as they learn the boundaries of what is acceptable behaviour. This is what makes us human and it is why families are important social units.

Unlike in other relationships, family members cannot easily disassociate from one another. As Hilde and James Lindemann Nelson state, ‘seeing families as composed of replaceable parts is inconsistent with our understanding of what an intimate relationship is, and with the ability of such relationships to convey the special goods of intimacy.’15 We may not always like our family members but we need to learn how to ‘get along’ with one another. As Blustein points out, ‘the family is the center of most people’s lives, for better or for worse.’16 Conflict and reconciliation are an integral part of intimacy. Bearing in mind that individuals within families will differ in their needs and preferences, it is the ‘business of families’ to maintain a constant tension between fusion and individuation for their members.17

In some cases, families are unable to accommodate the basic needs of their members to the extent that they become dysfunctional and lose their value as intimate collectives. Irresolvable conflict, oppression, exploitation, neglect and abuse within families are all extremely damaging, particularly because they occur inside a

15 Nelson and Nelson, above n 5, 76.
17 Nelson and Nelson, above n 5, 34.
relationship of trust. 18 Vulnerable family members, in particular children, need protection from dysfunctional families. I discuss the point at which families become dysfunctional and require state intervention in detail in Chapter 4. This is not, however, an issue specific to families involved in PTT and I argue that families seeking PTT are no more likely to be dysfunctional than any other family. It is also important to bear in mind that the value of intimate family relationships is not negated by the existence of dysfunctional families. As Patricia Smith points out:

…bad families are not counterexamples to the value of good families. It is clear that human beings cannot survive in isolation, and institutional childrearing seems most successful when (familylike) arrangements allow personal relationships to grow and flourish… Family living (at least in the sense of small group living) is a fundamental value for humanity as a whole and for every human being individually.19 (emphasis added)

In the next section, I draw on relational feminist and communitarian theories to argue that intimate families are both instrumentally and inherently valuable. Intimate families are instrumentally valuable as they enable human beings to thrive. They are also inherently valuable as a primary source of collective endeavour, which is essential to a meaningful life. Thus, whether we view families through a romantic lens or as a ‘necessary evil’, they play a profound role in human flourishing. The welfare of a child is therefore inextricably connected to the welfare of the intimate collective that is his/her family.

C Role of families in promoting human flourishing

1 Instrumental value of family

Children require more than nourishment, shelter and protection from harm to flourish or thrive. They also need the less tangible benefits that come from being part of an intimate collective, such as love, intimacy and affection. Held argues that when children are provided with the necessities ‘without the relational human caring’ they need, they ‘do not develop well, if at all.20 There is empirical evidence to suggest that children who are raised in institutions are substantially less likely to thrive physically,

18 Research indicates that people who are abused by intimates tend to suffer more deeply than those who have been abused by strangers: Nelson and Nelson, above n 5, 70.
cognitively, psychologically and socially than those who are raised within an intimate family.\textsuperscript{21}

Intimate families are important for the development of self-esteem and self-understanding as they provide their members with a source of identity, connection, support and love.\textsuperscript{22} Parents play a key role in fostering intimate relationships within families by ‘providing opportunities for the emergence of meaning, intimacy, identity, and character.’\textsuperscript{23} These inner qualities cannot be developed outside intimate relationships. Patricia Smith argues that ‘family living is very probably a necessity for human existence.’\textsuperscript{24} According to Smith families provide the essential conditions for human beings to thrive:

These sorts of values, connection, commitment, support, and love can be provided only by a small intimate group founded on assumptions of mutual reliance and communal cooperation. One name for such a group is family.\textsuperscript{25}

Hilde and James Lindemann Nelson describe the primary role that families play in forging human identity in the following way:

When we live in close and affectionate proximity with others, we can be seen and celebrated specially; we can be known more fully than our relationships in the workplace, in civic life, or in causal friendships permit. Being known well – being seen lovingly and particularly, in a way that singles us out from the billions of others who walk in the world – reinforces our understanding of who we are.\textsuperscript{26}

Although our identity is also defined by non-intimate relationships, through culture, language, practices and customs of our society, ‘the unit of family permits each member to be seen more particularly and specially than is possible, say, in an orphanage or boarding school.’\textsuperscript{27} The intensity of family relationships, ‘for good or

\textsuperscript{21} For a discussion of studies of the negative impacts of children raised in institutions, see S Matthew Liao, ‘The Right of Children to Be Loved’ (2006) 14(4) The Journal of Political Philosophy 420, 423-4. Liao also compares studies of infant monkeys in laboratories, which show similar results.
\textsuperscript{22} Liao describes the love that intimate relationships engender as ‘an essential primary condition for a good life’: ibid 424.
\textsuperscript{24} Smith, above n 19, 54.
\textsuperscript{25} Ibid 56.
\textsuperscript{26} Nelson and Nelson, above n 5, 36-7.
\textsuperscript{27} Ibid 37.
ill, leaves its mark more deeply than the impersonal relationships formed in early life.’  

2 Inherent value of family

The value of family goes beyond the benefits it confers on its individual members. In addition to the instrumental value of family as a means of achieving the ‘primary goods’ of protection, nurturing, socialisation and identity, families are inherently valuable in themselves. The inherent value of intimate families should not be confused with some conservative notion of ‘family values’ that undermines women and same-sex relationships. Intimate families, whatever their form, are inherently valuable for the collective endeavour they entail, which gives our life meaning. Interaction between family members ‘that shows mutual interest and responsiveness’ is valuable, irrespective of the outcome of that interaction. As Sherman states, ‘the value of group dynamic’ is ‘independent of specific products and activities’ that arise out of the interaction.

According to Hilde and James Lindemann Nelson, the value of family goes ‘beyond its ability to promote self-respect, or to give people a personal identity, or physical care, or social and moral education’. Similarly, Schoeman argues that intimate families have value not merely because of their instrumental benefit to the individual children within them. They are also inherently valuable in and of themselves as sources of shared intimacies, which are essential to a meaningful life.

Crouch and Elliott also highlight the inherent value of the family by emphasising what is important in family life and to human agency:

In families, the important factor is that family members cherish each other simply for each other’s sake, and that being devoted to “the family” and its members is a source of deep meaning and value in our lives and the lives of those around us.

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28 Ibid 37.
30 Ibid.
31 Ibid 44.
Crouch and Elliott describe these shared or collective interests within families as “strongly valued goods”, that come (to an extent, at least) from the fact that we are engaged in a shared journey.\footnote{Robert A Crouch and Carl Elliott, ‘Moral Agency and the Family: The Case of Living Related Organ Transplantation’ (1999) 8 Cambridge Quarterly of Healthcare Ethics 275, 283.} In part, ‘the sharing in itself is valued’, \footnote{Ibid 284.} not just the benefits that arise out of the sharing.

The importance of sharing intimate connections to human flourishing has been identified by several commentators. In explaining the value of collective endeavour or affiliation, Nancy Sherman describes the ‘pleasure of mutuality and the expansion of self that comes with it’ as ‘a part of human flourishing.’\footnote{Sherman, above n 29, 278.} Crouch and Elliott add that ‘[t]he importance of this mutuality runs deeper than an expansion of self’ and use the term ‘union’ to describe the nature of family relationships.\footnote{Crouch and Elliott, above n 33, 284.} The idea that human beings flourish through intimate connection within a family has been expressed by Schoeman as follows:

\textit{We share our selves} with those with whom we are intimate and are aware that they do the same with us. Traditional moral boundaries, which give rigid shape to the self, are transparent to this kind of sharing.\footnote{Ferdinand Schoeman, ‘Rights of Children, Rights of Parents, and the Moral Basis of the Family’ (1980) 91(1) Ethics 6, 8.}

Similarly, James Lindeman Nelson emphasises the importance of recognising ‘the special moral value of intimacy’ in bioethical debate when he argues for a greater role for families in medical decision-making generally.\footnote{J L Nelson, above n 12, 6-7.} Hilde and James Lindemann Nelson highlight the connection between intimacy and collective identity by stating that ‘intimacy changes the very identities of the persons involved, so that to destroy the relationship is to damage the selves within it.’\footnote{Nelson and Nelson, above n 5, 70.}

\section*{D Collective interests and PTT}

\subsection*{1 PTT is a shared family journey}

The collective interests of intimate family members are particularly relevant in the context of PTT. PTT is, by its very nature, a shared enterprise. PTT is used to create a child who can donate cord blood stem cells to save the life of an existing ill sibling.
The role of the child to be born is integral to the survival of the existing ill sibling and the welfare of the family as a whole. Even more than in other families, families involved in PTT are inextricably connected as the members engage in a shared journey to save the life of an ill child.

The decision to use PTT is primarily motivated by the interests of existing family members, in particular the parents’ interest in saving the life of their existing child and the existing child’s own interest in leading a healthy life. From the family’s perspective as a whole, it is preferable that PTT take place. However, as I discussed in Chapter 2, PTT may not promote the individual interests of the child to be born. The individual interests of the child to be born as a result of PTT should therefore be considered alongside the collective family interests in saving the life of an existing child. Given the importance of family to human flourishing, it is preferable to view the interests of the child to be born in connection with, rather than in opposition to, the collective interests the child shares with his/her family.

If we accept the collective nature of agency within family, we can begin to see how the welfare of the child to be born may be enhanced by experiencing the intimacy, devotion and meaning that comes from being part of the shared journey of his/her family to save the life of one of its members. It is not important that the child to be born as a result of PTT does not have the capacity to realise the nature of his/her involvement at the time of donation because the issue is one of human flourishing, which takes place through the journey itself. Being a donor sibling is one of many shared experiences the child will have with one or more members of his/her family, all of which will contribute to the child’s identity and development as a human being with intimate connections. While children who donate tissue to a sibling can experience some physical and/or psychosocial harm, successful donations between siblings have been shown to have a significant positive impact on sibling relationships.41

I am not suggesting that the collective interests of a family seeking PTT should necessarily outweigh the individual interests of the child to be born. As explained in Chapter 2, there are certain individual interests of the child to be born that require protection. In particular, the interests of the child to be born in respect and protection

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41 See discussion in Chapter 2, Part VC3.
from harm require careful consideration. But, as Crouch and Elliott point out, we need to:

…replace the discrete and separable interests of family members with a more realistic view of the family, one that recognises the conflict, confluence, and confusion of interests characteristic of life within a family.42

Jansen similarly makes the point that, although family members ‘share interests and concerns, they also have interests and concerns of their own that can and often do come into conflict with the interests and concerns of other family members.’43 However, in order to have a realistic and comprehensive understanding of the welfare of the child to be born, we need first to recognise the often neglected collective benefit that comes from being part of a shared and intimate enterprise, before we tease out the areas of conflict. Once we have done this, we can then move on to developing an approach which recognises and reconciles the ‘conflict, confluence, and confusion of interests’ within a family.

2 Are collective interests legitimate?

Several critics have rejected the notion that the family exists as an intimate group with collective goals and interests. For example, Buchanan and Brock argue that ‘to speak of the family as having its own goals and purposes and to speak of the familial perspective and family objectives is to engage in dangerous reification.’44 They claim that decisions made by the family are, in reality, decisions that the parents impose on the family. Jansen similarly argues that it is a mistake to focus on the interests of the family as if it were a ‘freestanding entity’.45 Jansen claims that to do so ‘unnecessarily reifies the family, making it look as if it has purposes and goals of its own that stand over and above the purposes and goals of individuals within it.’46

These criticisms are misguided in three respects. First, the claims of reification appear to be based on a misunderstanding of the nature of collective interests within a family. Second, collective interests are not synonymous with parental interests, as

42 Crouch and Elliott, above n 33, 284.
45 Sarah Elliston, The Best Interests of the Child in Healthcare (Routledge-Cavendish, 2007), 258. See also Jansen, above n 43, 137.
46 Jansen, above n 43, 137.
Buchanan and Brock suggest. Third, just because we acknowledge the existence of collective interests within families does not mean that those interests should necessarily override the interests of individual members. Rather, it means that we need a strategy for dealing with individual and collective interests when they come into conflict. In the next section, I clarify the nature of collective interests within a family. In Chapter 4, I argue that collective family interests are not, in fact, synonymous with parental interests and propose a strategy for reconciling individual and collective interests within a family.

3 Distinguishing collective interests from abstract family goals

The argument that attributing collective interests to families constitutes reification is based on a conception of family as an abstract entity, rather than as a group of individuals who share a common purpose. Patricia Smith provides a helpful distinction, in the context of family obligation, between the ‘family in the abstract’ and the ‘family as household’ or a group of intimates. She uses the phrase, ‘family in the abstract’ to refer to ‘a family name or genetic line, the extended family in the largest sense, whose boundaries or members extend over both space and time.’ By contrast, she uses ‘family as household’ to refer to ‘an aggregate or group of actual (living) members, who are closely associated by living arrangement or by commitment, for better or worse.’

Abstract family goals, such as maintaining family traditions, can generally be distinguished from family household goals, which involve promoting the common good of the members by accommodating their special needs. It is this latter notion of family as an intimate group of people or community on which I have based my discussion of collective interests. This is not an abstract notion of ‘the family’ but rather a very real notion of a group of people with interconnected interests. The collective interests I have been discussing are not about abstract group ends, such as ‘continuing the family line’ or ‘upholding the family’s good reputation’ but are related to the act of sharing or the collective endeavour itself.

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47 Smith, above n 19, 47-51.
48 Ibid 47.
49 Smith explains that there may be some overlap between the goals of a household and those of family in the abstract: Smith, above n 19, 49.
Sherman similarly highlights the inherent value of sharing or collective endeavour by distinguishing between the value of abstract group ends and the collective dynamic that promotes them. Sherman argues that:

…apart from the particular activities and products that may define a species of community, we value doing things with others. We value creating a shared world, and the mutuality that is defined by our interactions.  

My discussion of collective interests within a family is based on the value that human beings derive from being collectively involved with other family members in the common pursuits of a household. According to Sherman, collective endeavour or ‘affiliation’ among a group of people is ‘an important constituent of good living’. Human beings:

…are supported by pleasurable interactions with other people, and depend upon these connections for our sense of self-esteem and self-understanding. It is in the act of relating and being reflected in the opinions and judgments of others whom we respect that we refine our sense of who we are and how worthwhile our lives have been.

The value of PTT for the child to be born lies in the child’s collective involvement with other family members in the family’s shared journey, which includes attempting to save the life of an existing member. It is the child’s involvement in this shared journey of the family that is important, irrespective of whether the family goal of saving a sick family member is ultimately achieved. The journey itself becomes a collective endeavour from which the child will develop a sense of ‘self-esteem and self-understanding’. The ‘shared world’ into which the child is born will shape the child’s identity as a human being and provide meaning through intimate connections with others.

III WELFARE OF THE FAMILY AS A WHOLE

A Introduction

In the above discussion of collective family interests, I explained how PTT can enhance the donor child’s welfare by promoting the collective welfare of his/her family. This approach addresses the first issue raised at the end of Chapter 2, namely

50 Sherman, above n 29, 278.
51 Ibid.
52 Ibid.
that we need an approach to the welfare principle that recognises the interests of the child to be born, as both an individual and a member of an intimate family. The second issue raised was that the regulation of PTT must take account of other interests within the family, beyond those of the child to be born. This issue arises from the fact that PTT is a medical procedure affecting the whole family and primarily motivated by the interests of the existing sick child.

Considering the interests of other family members is not inconsistent with the welfare of the child to be born if we conceptualise the child’s welfare in terms of human flourishing. If, as I have argued above, a child’s interests are intertwined with those of his/her family, it makes sense to consider the interests of other members of the family as the welfare of the child is interconnected with the welfare of the family as a whole. However, the individual interests of the child will not necessarily be synonymous with the collective interests of his/her family. There will be times at which the interests of an individual family member will be in conflict with the collective interests of the family. In such cases, the interests of the individual may need to be compromised to promote the interests of the wider family. As Chapter 2 revealed, the child to be born as a result of PTT is in a vulnerable position and in need of some protection. The question therefore arises as to whether, in considering the collective family interests, it is acceptable for the individual interests of the child to be born to be compromised.

In the next section, I explore the role of familial duty in intimate families. I argue that the individual compromise entailed by familial duty is essential for the continued existence and welfare of intimate families because intimacy necessarily involves compromise. Individual compromise by a child within a family is therefore not only acceptable but also integral to a conception of the welfare of the child based on human flourishing.

B Familial duty as a justification for individual compromise

1 Intimacy and compromise – ‘taking the good with the bad’

In Part II, I discussed the importance of intimacy to human flourishing and the instrumental and inherent value of intimate families. Intimacy does not, however, come without a price. Intimacy necessarily involves compromise. Patricia Smith describes the compromise within intimate families as one of the ‘shared costs in a
Compromise is an essential part of being ‘bound to one another’. This is partly because intimate groups share basic finite resources that must somehow be divided between members of the group. For example, parents with more than once child may have unlimited love for all their children but they have limited time and financial resources that must be shared amongst the various children. Compromise is also a natural consequence of living in a shared space where individuals may have conflicting, as well as confluent, interests. For example, if one parent wishes to pursue an attractive job offer in a foreign country but the rest of the family wishes to continue to live in their home country, then, if the family is to live together, compromise is essential. The other parent and the children may be required to compromise their interest in remaining in their own home country in order to accompany the parent who wishes to move to a new country. Alternatively, the parent offered the job may need to compromise his/her own professional interests by refraining from taking the new job in order to accommodate the needs and wishes of the rest of the family. Compromise by one or more members for the benefit of another is an essential part of intimate family life. As Hardwig suggests:

> Because the lives of those who are close are not separable, to be close is to no longer have a life entirely as you choose. To be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself.\(^{55}\)

This raises the important question of how decisions ought to be made within families. I discuss the general nature of familial decision-making in more detail in Chapter 4.

### 2 The notion of familial duty

The compromise intimate families require of their members is sometimes described as ‘familial duty’. Familial duty or obligation has been described as ‘probably the oldest and possibly the least questioned form of obligation that human beings have.’\(^{56}\) Smith argues that:

> …the intrinsic value [of family] is the justification of its general obligations of cooperation and support. This, I suggest, is the essence of family obligation and family membership.\(^{57}\)

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\(^{53}\) Ibid 55.

\(^{54}\) Crouch and Elliott, above n 33, 284.


\(^{56}\) Smith, above n 19, 46.

\(^{57}\) Ibid 56.
Doing things for intimate others enables family members to flourish as humans in a way that can only occur from being part of an intimate collective such as a family. So although the interests of an individual member may at times be compromised for the welfare of the family, the welfare of the individual member is enhanced if we accept a picture of human agency that recognises the value of intimate relations to human flourishing. There will obviously come a point beyond which individual compromise becomes so great that it will ultimately have a negative impact on a person’s welfare or ability to flourish. I deal with this issue in Chapter 4, when I argue that parents should not be able to sacrifice the interests of individual members for the sake of the family.

The prospect of a conflict of interests between family members is not a remote possibility for PTT. The discussion in Chapter 2 revealed that there is a risk that the child to be born as a result of PTT could experience physical and/or psychosocial harm. Given this potential risk, we must consider whether it is acceptable for the individual interests of the donor child to be compromised in favour of the collective interests of the family or one of its members. Crouch and Elliott raise a similar question in the context of sibling organ donation by asking ‘whether parents can legitimately expect their children to bear some burdens for the sake of family interests, even interests that the children might not yet endorse.’

In this section, I have argued that the inherent value of intimate family provides a justification for compromising some interests of individual members for the benefit of the family as a whole and underlies the notion of familial duty. This is particularly relevant in the context of PTT, where the very nature of the family will change if the ill child dies. One important issue which arises for the child to be born is the fact that the child does not choose to become a part of the intimate family into which s/he will be born. In the following section, I argue that the fact that a child does not choose to be a part of his/her family does not exempt that child from familial duties. This is because membership alone (irrespective of consent) provides the foundation for moral responsibility to the family.

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58 Crouch and Elliott, above n 33, 285.
Membership as a foundation for moral responsibility

1 Family duty arises out of membership rather than consent

Unlike modern legal and social contract models of obligation, which rely on actual or constructive consent as a justification for moral obligation, familial obligation or duty is (at least for children) involuntary. \(^{59}\) Generally speaking, families are ‘nonvoluntary social units that ill fit the social contract model’. \(^{60}\) Children do not choose to be born into their respective families, nor do they play a significant role in determining their family’s particular character or projects, at least in the early years. Many of the duties parents impose on their children, such as assisting with family chores, visiting sick grandparents and helping out their siblings, are not necessarily sanctioned by the children themselves. Rather they are imposed on them as duties to the family of which they are members. In this section, I argue that familial duty legitimately arises out of family membership.

The idea that membership provides the foundation for moral responsibility has been mooted in the past, most notably by ancient philosophers and some communitarian philosophers. \(^{61}\) In the specific context of international relations, Haskell Fain has developed a similar notion of political obligation based on the idea of ‘communal tasks’. \(^{62}\) More recently, Patricia Smith has drawn from Fain’s ideas about what it means to be a member, and how membership creates obligation, in her exploration of familial obligation. \(^{63}\) She highlights the necessity of sharing common tasks between the members of a common enterprise.

A household is the epitome of a shared enterprise. Where people not only pool their resources but merge their lives, then a common sharing of burdens – the idea of communal tasks mentioned earlier – is most appropriate. \(^{64}\)

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59 See discussion by Smith, above n 19, 41.
61 Smith cites ancient philosophers (Plato and Aristotle) and communitarian philosophers (Alasdair MacIntyre and Michael Sandel): Smith, above n 19, 45. Smith argues that the idea that membership provides the foundation for moral responsibility has not yet been carefully developed.
62 Haskell Fain, Normative Politics and the Community of Nations (Temple University Press, 1987). See also Smith, above n 19, 45
63 Smith, above n 19, 45. Schoeman also relies on the notion of communal tasks in a shared enterprise, when he states that familial ‘responsibilities are aimed at making the family as such a working entity’: Schoeman, ‘Parental Discretion and Children’s Rights’, above n 23, 49.
64 Smith, above n 19, 55. Smith also uses the notions of debt (arising from the benefit members gain from the family in the abstract) and mutual reliance (between family members) to explain the elements
Smith argues that membership provides an alternative justification for familial obligation to the predominant social contract theory used by liberal theorists to justify universal moral obligation and the requirements of justice. Unlike social contract theory, which is strongly connected to the individualistic idea of contract based on individual consent, family obligations are not individualistic nor are they necessarily based on voluntary consent. Smith proposes that membership not only provides the source of familial obligation but also defines its nature:

[Familial obligation] is derived from and determined by family connection and commitment. The reason you have this sort of obligation is that you are part of something, you belong to something larger than yourself, with which you are partly identified; you are connected.

Within intimate families, family members (including siblings) have obligations to one another, by reason of the fact that they are in the same family. We expect more from those with whom we are close because intimate relationships give rise to obligations. To put it another way, ‘family relationships have ethical import’. Obligation to intimate family members ‘generally refers to the promotion of the common good of the members’. Familial obligations or duties may require individual members to, at times, compromise their own interests for the welfare of the family as a whole. For example, parents have a general duty to provide care and support for their children, which includes a duty to try to save the life of an existing child. Similarly, siblings also have duties to one another, albeit not as extensive as those of parents.

Parents can, and do, expect their children to make compromises for one another or for the family as a whole. Some family duties relate to maintaining the ongoing collective enterprise of family. For instance, simple chores parents impose on children, such as washing the dishes or tidying up their mess, are viewed by many families as necessary for the efficient functioning of the family unit. Other duties are
grounded in debt or gratitude. For example, parents may require unwilling children to visit their elderly grandparents as a sign of respect and appreciation for the sacrifices they have made in their life so that their children and grandchildren may thrive.\footnote{Possible scenarios may include grandparents who worked hard throughout their lives in order to educate their children or who sacrificed their own lives by migrating to another country in order to give their children ‘a better life’.
}

Many family duties arise out of the immediate needs of individual family members. This is particularly relevant in families with several children, where one child has the capacity to meet the needs of a sibling. Parents often require one child to help out a sibling simply because of the sibling relationship. For example, a parent may request a child to ‘look out for’ a younger sibling at school or attend a sibling’s music concert, even though that child may prefer to keep some distance from their younger sibling at school or stay home and play X-Box. How many parents have exhorted a child to help out a younger sibling, with the only explanation being ‘because you’re family’?\footnote{This is in fact an appeal to the child’s developing sense of moral responsibility toward those close to him/her.}

The familial duties parents impose on children that I have discussed all arise out of family membership rather than by choice. The duties arise as a natural consequence of being bound together with one another in an intimate relationship. Crouch and Elliott describe the nature of familial duty in the following way:

\begin{quote}
We do things, and \textit{should be expected to do things}, for the family and for particular family members that we simply would not do for non-family members. For the most part, such burdens come with the very fact that we are bound to one another within a particular family.\footnote{Crouch and Elliott, above n 33, 284. Emphasis added to highlight the fact that, in the case of the child to be born as a result of PTT, this duty is imposed on the child before s/he is even capable of having an opinion in the matter (in other words, prior to his/her existence).}
\end{quote}

Similarly, Schoeman argues that each family member has a moral responsibility to the family by virtue of his/her membership. According to Schoeman, ‘it is the role as a member of a family unit that defines an individual’s responsibilities’.\footnote{Schoeman, ‘Parental Discretion and Children’s Rights’, above n 23, 57.} He describes ‘the child as having a status within the family by virtue of which certain liabilities and responsibilities accrue.’\footnote{Ibid.}

I have argued that family members have duties to one another by virtue of membership rather than consent. Applying this reasoning to PTT means that the family relationship provides the justification for imposing some risks on the child to be born in order to save the life of an existing child. A question arises as to how far
familial duties extend and, in the specific context of PTT, what risks we should allow families to impose on the child to be born. Clearly some risks would be too high and children need protection from being ‘treated as mere conveniences to advance others’ ends.’

In Chapter 4, I argue that parents should not be able to sacrifice the basic interests of the child to be born for the sake of the family as this would amount to abuse or neglect. As Hilde and James Lindemann Nelson point out:

To acknowledge the non-consensual element in families and in other settings of intimacy is not to deny that there are general (universalizable, impartial) moral constraints that operate within them as well.

Abuse of intimates is particularly wrongful as it ‘backlights, as it were, the special moral significance of intimate relationships.’

2 Critique of the involuntary nature of family duty

The involuntary nature of familial obligation is not without its critics. In particular, some feminist theorists are sceptical about the role traditional families have played in reinforcing gender inequalities and emphasise the importance of choosing relationships voluntarily.

As Brennan states, it ‘has been important for women to say, and be able to say, that they are more than someone’s daughter, or someone’s wife, to assert that one’s identity transcends the roles assigned to women.’

Similarly, it is important for children to be able to forge their own identities within their families, as they become independent and develop preferences of their own that may not coincide with those of other family members. The involuntary nature of family duty, when coupled with power imbalances within families, clearly has the potential to become ‘a major source of oppression’. It is therefore important to recognise that members of a family are individuals as well as members of a collective and should be given sufficient freedom to choose their path in life.

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76 Donchin, above n 6, 243.
77 Nelson and Nelson, above n 5, 70.
78 Ibid.
81 Nelson and Nelson, above n 5, 70. Vulnerable family members not only include women and children, but also those who are chronically ill, frail and elderly or dependent on family members with ‘greater prestige, mobility and resources’.
Recognising individuality and respecting choice does not mean that children, parents and siblings do not have specific responsibilities to one another by virtue of their intimate relationship. In some ways, intimacy has very little to do with choice. Children do not choose to be born into a particular family any more that parents can choose the nature of their children. There are also many who would argue that we do not necessarily choose whom we will fall in love. According to Donchin, ‘our most significant social relations will often not actually be voluntary.’82 Hilde and James Lindemann Nelson point out that ‘even where we choose our intimates freely, once the choice is made we are not free to leave at will.’83 This is because, to a certain degree, intimacy impedes choice. This is what we mean by the term ‘commitment’, in the sense of being bound emotionally to another person. Emotional commitment is essential to intimacy because ‘if you are always free to leave you can’t get the good of settled, abiding relationships.’84

While intimacy does not require a complete embedding or loss of self, being in an intimate relationship with others entails a sense of union, which inevitably impacts on our sense of self and the choices we make. Clearly there are limitations on the ‘moral sacrifices family members can be expected to make for another.’85 In Chapter 4, I explore in detail the limitations that ought to apply to PTT. However, if we accept that intimate families are both instrumentally and inherently valuable, there are good reasons why family members should make compromises for one another for the welfare of the family as a whole. Because these compromises are not necessarily made out of choice, we need a different account from the social contract model found in liberal theory to explain the nature of moral responsibility within families and other intimate relationships. Relational and care-based accounts provide a better explanation of the nature of moral responsibility within families.

According to a relational account of moral development,86 the responsibilities siblings have to one another are important for the child’s future development:

In actual families, children have responsibilities to one another long before they develop capacities to avow them voluntarily. Preparation for autonomous adulthood includes

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82 Donchin, above n 6, 241.
83 Nelson and Nelson, above n 5, 70.
84 Ibid.
85 Donchin, above n 6, 243.
experience in caring for others one cares about and coming to recognise one’s own needs by responding to theirs. Adults who lack such grounding are ill-fitted to build enduring relationships with others on a foundation of mutual reciprocity.\textsuperscript{87}

This relational approach to moral responsibility has been heavily influenced by the ethics of care and the groundbreaking work on moral psychology by Carol Gilligan.\textsuperscript{88} In contrast to liberal theory, the care perspective views people as interconnected and inherently social. Accordingly, the ‘moral self is a self-in-relation.’\textsuperscript{89} The ethics of care recognises the potential for inequality in intimate relationships but attempts to address the problem from a relational rather than individualistic perspective:

Indeed, the experiences of self-in-relation are often experiences of inequality – of dependency as a child, of power as a parent, of dependency in old age. …Thus, the care perspective regards inequality not as a degenerative moral condition, but rather as a central moral reality.\textsuperscript{90}

The care perspective responds to this inequality, not through the promotion of individual interests or rights but with ‘general injunctions to avoid harm, give care and maintain relationships’ and to ‘respond sensitively to distinctive needs of individuals in concrete situations.’\textsuperscript{91} I draw from relational models and the ethics of care in Chapter 4, when I propose a relational decision-making approach to PTT. Adopting a relational approach does not necessarily entail abandoning all of the protections offered by liberal or rights-based theories, which are based on a more generalised, account of morality. In dealing with the specific context of family, generalised accounts of morality can be helpful for ‘making comparative assessments of morally relevant features of specific situations.’\textsuperscript{92} There are limits on what an intimate family can require of those within it that I address in Chapter 4.

In the next section, I argue that the level of obligation between family members will vary according to their role within the family and the general character of the family. However, generally speaking, the level of duty owed to members of a family is

\textsuperscript{87} Donchin, above n 6, 242.
\textsuperscript{88} Gilligan, above n 86.
\textsuperscript{89} Meyers, above n 60, 16. Meyers notes that ‘people’s relationships with others are often unchosen yet constitutive of their identity’.
\textsuperscript{90} Ibid.
\textsuperscript{91} Ibid.
\textsuperscript{92} Anne Donchin, ‘Reworking Autonomy: Toward a Feminist Perspective’ (1995) 4(1) Cambridge Quarterly of Healthcare Ethics 44, 51. See also Brennan, above n 80, who argues that ‘[a]s long as the interests of individuals and the interests of the group can diverge, there is a role for moral rights to play.’
greater than that owed to strangers by virtue of the intimate relationship between family members.

D Higher duty to family than strangers

Some commentators have expressly argued, in the specific context of bone marrow donation between siblings, that ‘[g]iving bone marrow is a sacrifice that does “not exceed the ordinary sacrifices family members make and expect from one another.”’\textsuperscript{93} Given that the risks to the child to be born from PTT are likely to be less than the risks involved in bone marrow donation,\textsuperscript{94} there is arguably an even stronger case that becoming a donor sibling through PTT can be justified on the basis of the familial duty owed between siblings. The duty to help save the life of a family member through donation is a higher level of duty than that which we would expect from a stranger. According to Nancy Jecker, ‘family members are governed by stronger ethical responsibilities than strangers, and we expect them to serve each other’s welfare to a greater extent.’\textsuperscript{95} There is, of course, a natural duty to help others, which is generally accepted by liberal theorists.\textsuperscript{96} However, most people would not expect a stranger to donate bone marrow to someone else’s child, even if this was the only means of saving that child’s life. This raises the question as to why we owe a higher duty to family members than to strangers.

Put simply, the intimacy or ‘close relationship’ of family members creates a higher level of duty than that imposed on individual members of society in accordance with liberal theory.\textsuperscript{97} Liberal theory proposes minimal universal obligations, including obligations not to harm or interfere with another, whereas family obligations or duties are greater than minimal. Many of the most important moral obligations human


\textsuperscript{94} Certainly the physical risks of cord blood donation are smaller as there is no need for anaesthesia and no pain involved for the child to be born. As previously discussed, the potential psychological harm caused by being brought into existence to save the life of an existing child has not yet been fully explored: see Chapter 2, Part VB. See also: Jecker, above n 93, 102; Pennings, Schots and Liebaers, above n 93, 537.

\textsuperscript{95} Jecker, above n 93, 102.

\textsuperscript{96} See, for example John Rawls, \textit{A Theory of Justice} (Oxford University Press, 1972) 114-117, esp 114.

\textsuperscript{97} Jecker argues that even though parents are required to do far more for offspring than offspring are required to do for siblings, offspring still owe far more to siblings than to strangers because of the presence of a ‘close relationship’: Jecker, above n 93, 103.
beings have to family ‘are not simply obligations not to harm or interfere, but obligations to cooperate, reciprocate, or even to aid or support’. 98 According to Smith, obligations of family membership are different from the universal moral obligations grounded in liberal theory in two ways. First, they invoke affirmative obligations of cooperation and support that go beyond non-harm and non-interference. Second, familial obligations are collective in that ‘all are committed to all’. 99 As Smith notes, ‘family obligation is potentially the most burdensome – depending on the nature of the particular family membership – and the most beneficial obligation human beings can have.’ 100 It is the beneficial nature of familial duty and the intimacy it promotes that provides a justification for imposing a higher duty on family members. According to Virginia Sharpe, intimacy cannot be sustained without a ‘nucleus of well-wishing (benevolence) and well-acting (beneficence)’. 101

The individual compromise required by familial duty may appear overly burdensome to some proponents of liberal theory. 102 Requiring a higher level of duty from family members seems to contradict fundamental liberal tenets, such as individual autonomy and the rights of the child, which have dominated Western bioethics. 103 However, it would be more accurate to say that the scope of familial duty highlights the inadequacy of liberal theory in dealing with family relations and its inability to capture ‘the emotional density of most family ties’. 104 Schoeman argues that:

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98 Smith, above n 19, 41.
99 Ibid 51.
100 Ibid.
102 I am referring to traditional liberal theory, including the works of Kant and Mill, which still largely dominate Western bioethics. In more recent years, feminist philosophers have introduced a relational element into liberal theory. See, for example, a detailed discussion of ‘relational autonomy’ in Catriona Mackenzie and Natalie Stoljar (eds), Relational Autonomy: Feminist Perspectives of Autonomy, Agency, and the Social Self (Oxford University Press, 2000). The notion of relational autonomy is more consistent with a relational approach to familial decision-making. However, to date, Western bioethics and medicine’s own ethical tradition have remained ‘ruggedly individualist’: J L Nelson, ‘Taking Families Seriously’, above n 12, 7.
103 In particular, bioethical debate has been dominated by Beauchamp and Childress’ ethical framework known as “principlism”, which includes autonomy, nonmaleficence, beneficence and justice. In response to feminist criticisms that their notion of autonomy underestimated the importance of intimate relationships, Beauchamp and Childress offered what has been described as a form of ‘weak relational autonomy’, which suggests that individuals can always choose their social relations: Donchin, above n 6, 238.
The welfare and autonomy of the child are only part of what should be considered when judging how children may be limited in the range of their discretion. It is also only part of what the parent must keep in mind in making medical decisions for a child.¹⁰⁵

The difficulty in applying liberal theory to familial relations is that it does not give due regard to the value of intimacy and the intrinsic benefits of collective endeavour that are associated with intimate family. Liberal theory therefore fails to provide a satisfactory justification for the higher level of obligation or duty we expect from family members.

We owe a higher level of duty to family members than to strangers because we generally favour intimates over strangers. Favouritism within families stands in direct contrast with Jeremy Bentham’s impartial ideal that ‘everyone counts for one, nobody more than one’ underpinning general universal theories of morality.¹⁰⁶ Bernard Williams’ famous discussion (of the man who decided to rescue his wife over another) highlights the limitations of impartial principles in explaining family relations. Williams criticises the man for justifying his action by appealing to the impartial moral principle that it is permissible for husbands to save their wives over others. According to Williams, the man has had ‘one thought too many’.¹⁰⁷ The favouritism we show to our intimates is based not on some impartial moral principle but on love itself. Favouritism is integral to love. According to Hilde and James Lindemann Nelson, ‘[b]oth letting ourselves be vulnerable to those we love and being prized by our loved ones over others are part of what it means to us to be loved.’¹⁰⁸ Favouritism explains why we would do certain things for family members above and beyond that which we would do for strangers. The interpersonal ties that give rise to the demands of intimates ‘number among the ground projects that are constitutive of our integrity as individuals and that give us vital reasons to live.’¹⁰⁹ According to Bernard Williams, without deep attachments to others, ‘there will not be enough substance or conviction in a man’s life to compel his allegiance to life itself.’¹¹⁰

¹⁰⁶ For a discussion of favouritism within families, see: Nelson and Nelson, above n 5, 64. See also: J L Nelson, ‘Taking Families Seriously’, above n 12, 7; Smith, above n 19, 49.
¹⁰⁸ Nelson and Nelson, above n 5, 65.
¹⁰⁹ Meyers, anove n 61, 15.
¹¹⁰ Williams, above n 107, 18.
The family is a very different entity from the state and the requirements of intimacy do not fit neatly within liberal theory. In contrast to the state, which occupies a formal relationship with the child, ‘parents occupy an intimate relationship – one in which a different range of principles and objectives applies.’ Although the state may be constrained in its treatment of children by the ‘best interests’ principle, parents are not constrained in the same way. The basis on which decisions are made within a family is far more complex than simply in accordance with the ‘best interests’ of the child and will differ according to the character and preferences of each family. I discuss the complex basis on which families make decisions and the role of parental discretion in detail in Chapter 4.

This does not mean that there should not be limits on what parents can expect from their children. Rather, state interference in the distribution of benefits and burdens within families should be limited to preventing abuses of parental discretion. Schoeman highlights the limitations of liberal theory in dealing with intimate arrangements between family members by suggesting that:

If the family is to be thought of as an intimate arrangement having its own goals and purposes, it is inappropriate to impose upon that arrangement … abstract liberal principles… This is not to say that these liberal principles do not have any moral weight in the context of the family, but that they are not exhaustive of the principles which may legitimately bind people together and structure their relationship.

Similarly, Sharpe considers it ‘inappropriate to speak of “respect for persons” in the context of intimate or filial relationships.’ Rather, ‘we care for our intimates because they are our intimates and we need not filter our concern through the principle of respect for persons.’ It is only when the nucleus of well-being and well-acting essential to intimacy breaks down that ‘it is appropriate to revert to the language of strangers.’ In the context of PTT, the element of utility in the parents’

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111 Schoeman, ‘Parental Discretion and Children’s Rights’, above n 23, 48. I will discuss the ‘relational ethic’ that applies to families in detail in Chapter 4.
112 Despite the non-consensual element in families, certain universal impartial moral constraints still apply to them. For example, clearly abuse within intimate contexts is wrong.: see discussion above, Part III IC. I discuss the limits on parental discretion in detail in Chapter 4.
114 Sharpe, above n 101, 104.
115 Ibid 105. This is consistent with the Aristotelian idea that where there is friendship there is little need for justice [NE 1155a27]: see Sherman, above n 29, 295.
116 Sharpe, above n 101, 106. Not all theorists believe that impartialist ethical theories are incompatible with intimate relationships. See, for example, Nancy S Jecker, ‘Impartiality and Special Relations’, in Diana Tietjens Meyers, Kenneth Kipnis and Cornelius F Jr Murphy (eds), Kindred Matters: Rethinking
decision to conceive the child to be born does not necessarily cancel out the parents’ intention to love and care for that child. Despite some potential risk of psychological harm to the child to be born, the nucleus of well-wishing remains intact. 117

Not all families will impose the same level of duty on their members. The nature and level of obligation of an individual family member within a family will depend on several factors, including the individual’s characteristics, level of involvement and the character of relations within the particular family. Smith points out that ‘[a] tightly knit family may generate extensive particular obligations’ whereas ‘a more loosely structured family may have few particular obligations.’ 118 As previously discussed, all families are different, and different family structures will promote different levels of obligation between their members. 119 So, for instance, a child who is a compatible tissue match for an existing sick sibling would, by virtue of his/her particular genetic characteristics, have a higher duty to save the life of the sick sibling than a non-compatible tissue matched sibling. This does not mean that every family would expose a child to the risks of bone marrow donation or even bring a child donor into existence using PTT, but many would. When dealing with families involved in PTT, we therefore need a decision-making model that recognises the higher duty owed to intimates and can accommodate the variation in levels of obligation between different families. In Chapter 4, I argue in favour of a relational decision-making approach to PTT.

IV CONCLUSION

Children require more than nourishment, shelter, protection from harm and respect in order to flourish. The welfare of the child is inextricably tied up with the collective interests of his/her family in intimacy, love, affection and the collective endeavour that gives life meaning. These collective interests that are shared by intimate family members are integral to human flourishing. If we reconceptualise the welfare of the

the Philosophy of the Family (Cornell University Press, 1993) 74. Jecker attempts to reconcile ‘moderately impartial’ principles with the morality of intimate relations. Jecker is one of four authors who present different theoretical approaches to family morality in Part I of Kindred Matters. Despite their different theoretical approaches, however, all authors agree that family members have special obligations to one another: Meyers, above n 60, 19.

117 Sharpe, above n 101, 106.
118 Smith, above n 19, 50.
119 See discussion above, Part IIB.
child in terms of human flourishing, we must therefore look beyond the individual
interests of the child and also consider the collective interests of his/her family. To
put it another way, the welfare of the child depends, at least in part, on the welfare of
his/her family as a whole.

It is particularly important to consider the collective interests or welfare of the family
as a whole in the context of PTT because PTT is a shared enterprise that affects the
whole family. Families who undertake PTT are inextricably connected in a shared
journey to save the life of a sick child. Furthermore, PTT is primarily motivated by
the interests of the parents and the existing sick child. It would therefore be
disingenuous to ignore the interests of family members other than the child to be born.

This is not to suggest that PTT necessarily promotes the individual interests of the
child to be born or that the collective interests of the family should override the
individual interests of its members. While familial duty requires compromise on
behalf of individual family members, there are limits on how far an individual should
be expected to compromise to promote the welfare of his/her family as a whole.
Given the vulnerability of the child to be born as a result of PTT, safeguards should
be in place to protect that child from exploitation, abuse or neglect. In Chapter 4, I
propose a framework for PTT, which promotes both the welfare of the child to be
born and the welfare of his/her family. I also recommend guidelines for determining
when compromise becomes sacrifice in order to protect the child to be born from
exploitation, abuse or neglect.
CHAPTER 4
DEVELOPING A RELATIONAL APPROACH TO PTT

I INTRODUCTION

In Chapter 2, I discussed the traditional approach to the welfare principle in Australia, which focuses on the individual interests of the child. Of particular relevance to PTT are the child’s interests in respect and protection from harm. In Chapter 3, I reconceptualised the welfare principle to include not only the individual interests of the child but also the collective interests the child shares with his/her family in intimacy and collective endeavour. However, the individual interests of the child to be born and the collective interests of his/her family may not always coincide in the context of PTT. We therefore need an ethical approach to regulating PTT, which recognises and accommodates individual and collective interests within a family. In this Chapter, I argue that a relational approach is more appropriate for regulating PTT than the current approach in Australia, which focuses on the ‘best interests’ of the individual child. A relational approach acknowledges the complex and relational nature of the welfare of the child, who is both an individual and a member of a family. Accordingly, a relational approach requires the interests of other family members to be considered in connection with the interests of the child to be born as a result of PTT. Instead of drawing from liberal deontological or utilitarian ethics, a relational approach draws from an ‘ethics of intimacy’\(^1\) in reconciling familial interests.

In contrast to the current approach to PTT in Australia, a relational approach acknowledges that some of the individual interests of the child to be born may need to be compromised in favour of other interests within the family. In this sense, a relational approach reflects the way in which decisions are generally made within families. A relational approach should, however, ensure that the basic needs of the child to be born are not sacrificed. It is therefore important to determine the point at which acceptable compromise becomes unacceptable sacrifice to prevent the child from being exploited, abused or neglected. There is increasing support for a relational approach in the context of medical decision-making involving families. Rather than

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detracting from the welfare of the child to be born, a relational approach promotes a broader conception of the welfare of the child by acknowledging the relational nature of the interests of the child within the context of his/her family and the importance of intimacy to human flourishing.

I begin this Chapter by examining, in Part II, the nature of general decision-making within families. In particular, I examine the scope of parental duties and discretion and the impact of familial character on family decision-making. In Part III, I propose a test for determining when necessary compromise becomes unacceptable sacrifice in order to protect the child to be born as a result of PTT from exploitation, abuse and neglect. In Part IV, I examine the role of the family in medical decision-making and explore some relational approaches to general medical decision-making. In particular, I investigate a ‘process model’ for informed consent, whereby the values and preferences of the patient take shape through a shared process of decision-making with his/her family. The idea of a relational medical decision-making approach is not novel. It has gained some momentum in recent times by ethicists who are sceptical of the bias in Western bioethics toward the individual patient. To date, however, a relational decision-making approach has not been specifically applied in the context of PTT. Finally, in Part V, I draw from the relational approaches discussed in Part IV to develop a relational approach to decision-making for PTT. A relational approach to PTT allows some of the interests of the child to be born to be compromised in favour of other interests within the family, provided the child’s basic needs are not sacrificed.

II GENERAL FAMILIAL DECISION-MAKING

The welfare principle, conceived in terms of the individual or ‘best interests’ of the child, is rarely the sole or predominant test applied in family decision-making. Parents often make decisions for their children that are not necessarily based on their individual or ‘best interests’. Everyday decisions that have a life-shaping impact on children, such as place of residence, type of education, and division of leisure and

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work within a family are not (and cannot be) made solely on the basis of the individual interests of any particular child. Rather, these decisions are made based on a myriad of factors, including the needs and interests of individual members, the capacity of family members to satisfy those needs and interests, the nature of the relationships within a family, and the character of a particular family. In Chapter 3, I argued that compromise is an essential part of intimate family life, particularly in families where there is more than one child. In this Part, I explore the basis on which parents make everyday decisions about their children. In particular, I consider the duties parents have to their children and the nature of parental discretion. I also explore the impact of familial character on family decision-making.

I begin by arguing in the next section that parents have a duty to ensure that the basic needs of their children are met but, beyond this, parental decision-making is largely discretionary. Significantly, parents are not required to make decisions based on the ‘best interests’ of any particular child. Instead, parents can and should take account of the interests of other family members, including themselves, when making familial decisions.

A Parental duty and discretion

Parents have a general duty to care for and nurture their children by virtue of their fiduciary relationship with them. Children require nourishment, shelter, education, care, protection, respect, intimacy and love in order to develop physically, intellectually and emotionally. Many of these ‘primary goods’ are enshrined as rights under international convention. Parents must attend to the basic needs of their children by providing them with a threshold level of each of these ‘primary goods.’ If parents fail to satisfy their child’s basic needs, they ‘waive their right to be their child’s surrogate voice’.

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3 For a discussion of the ethical basis of parental duties, see David William Archard, *Children, Family and the State* (Ashgate, 2003), 94.


Provided parents satisfy the basic needs of their children, parental decision-making is discretionary. Parents can choose how they will attend to their children’s basic needs. For example, some parents may decide to enrol their children in an exclusive private school, whereas others may prefer ‘home schooling’ for their children. Furthermore, while parents must satisfy the basic needs of each child, they need not maximise the procurement of primary goods for their children. The level of each primary good provided by parents will depend to a large extent on their priorities and preferences. As Lainie Friedman Ross points out, ‘[p]arents will place different emphases on different primary goods’. Ross argues that in a ‘liberal pluralistic society in which there is no agreed conception of the good’, parents should have flexibility in ‘procuring primary goods for their children’. Parents must ensure that their children’s basic needs are met, by providing:

...a threshold level of each primary good for their child, but beyond that, parents can consider not only the child’s self-interests but also the interests of the child as a member of a particular family and community.

So, for example, parents are not required to give their children the best education they can afford, provided they give them an adequate level of education to enable them to develop normally. Similarly, while parents must satisfy their children’s basic nutritional needs, they need not provide their children with the highest quality diet available to them.

Parents are also responsible for the welfare of their family as a whole and should take into consideration the interests of all family members who are likely to be affected by a decision. Many decisions parents make in respect of one child will impact not just on the individual child but on the whole family. This is particularly pertinent where there is more than one child. In ordinary life, it is common for children within the same family to have conflicting interests. Parents with more than

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(1972), 237-41. The Supreme Court held in this case that Amish parents could remove their children from high school on religious grounds. However, Justice White stressed that a blanket exemption from all schooling would breach parental duties to their children.

7 Archard, above n 3, 96; Ross, Children, Families, and Health Care Decision Making, above n 6, 43.
8 Ibid.
9 Ibid 49.
10 Ibid 49.
11 Ibid 50.
12 This was the approach taken by the US Supreme Court in Wisconsin v Yoder 406 US 205 (1972). The Supreme Court was influenced in that case by the fact that Amish parents allow their children to acquire a basic education.
one child regularly make decisions that require compromise by one child for the welfare of another sibling or the family as a whole. For example, if one child has special needs and requires special education, the parents may decide to uproot the family and move closer to a special educational facility. The decision to accommodate the special needs of one child is likely to compromise the interests of other children in the family who may be forced to leave their friends and familiar environment. Similarly, families may devote more family resources to a child with an exceptional talent to enable that child to pursue that talent. For example, if one child is a gifted pianist, the parents may devote considerable time and effort into helping that child achieve his/her full potential as a concert pianist. This may impinge on some of the activities of the other siblings, who may not get an equivalent share of the family’s resources. Obviously, it would not be satisfactory for parents to neglect or abuse one family member to benefit another. However, the collective nature of family sometimes requires a family to give ‘a preferential share of what it has to a particular member, because of her particular vulnerabilities or talents’. Ultimately the parents must judge whether the compromises required from the other children are justified by the gains to the needy child.

In addition to the interests of their children, parents have their own interests that will legitimately impact on their decision-making. Most significantly, ‘parents have an interest in parenting – that is, in sharing a life with, and directing the development of, their child.’ Thus, although parents have parental duties in relation to a child, parents should not be viewed purely as ‘agent(s) of the child’s welfare’. Thomas Murray proposes a more apposite model for the parent-child relationship based on ‘mutualism’, which focuses on ‘the central importance of the relationship, without losing sight of the individuality of the parties’. Mutualism recognises that the interests of the parents and child are interconnected and that parents have an

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13 Example adapted from G Pennings, R Schots and I Liebaers, ‘Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling’ (2002) 17(3) Human Reproduction 534, 537. For a series of examples in family life where a child might be expected to compromise his/her interests for the sake of a sibling, see: James Dwyer and Elizabeth Vig, ‘Rethinking Transplantation between Siblings’ (1995) 25(6) Hastings Center Report 7, 10.

14 Nelson and Nelson, above n 1, 64.

15 Archard, above n 3, 97. Archard describes this as a ‘stewardship’ account of parenting, as opposed to a proprietarian account of parenting where the child is viewed as the property or extension of the parent: 96-7. See also: Thomas H Murray, The Worth of a Child (University of California Press, 1996).

16 Murray, above n 16, 61.
interest in promoting the child’s flourishing. According to Archard, ‘the shared life of a parent and child involves an adult’s purposes and aims at the deepest level.’\textsuperscript{18} It is therefore important to respect a parent’s parenting choices, provided they meet the child’s basic needs, as these go to the heart of parental identity. Outside parenting, parents also have their own self-regarding interests, which may not directly relate to their child’s flourishing. These interests include building a career, having an independent identity (beyond that of a mother or father), and leading a satisfying life. It would be unreasonable to expect parents to give up all interests outside their children when they become parents. These interests should also be recognised in family decision-making.

\textbf{It is important for parents to openly acknowledge the various interests that impact on family decision-making.} In openly acknowledging broader family interests, parents are better placed to address potential conflicts between the interests of the child and those of the family, honestly and fairly. This, in turn, enables parents to genuinely promote the interests of their children. Parents sometimes feel compelled to rationalise their decisions on the basis that they are in the best interests of their children, when this is neither true nor necessary. Such rationalisations can be dangerous and may ultimately erode the genuine interests of children. Parents regularly make decisions about childcare, education, where their family lives, what type of car they drive, how much time they spend with their children, even how much television their children watch, based on their own interests as well as their children’s needs. Families and parents, in particular, need to acknowledge their own interests when making decisions that impact on family members if they are to make responsible decisions. Parents may feel uncomfortable justifying decisions that impact on their children on a basis other than the best interests of the child. No parent wants to believe that they are not looking out for their child’s ‘best interests’. However, we need to openly recognise that, while parents have certain duties in respect of children, there are other interests beyond those of children that influence family decision-making.

For example, the decision to put an infant or child into formal childcare\textsuperscript{19} is not a decision based solely on the interests of the child. Rather, it is a decision generally

\textsuperscript{18} Archard, above n 3, 96.
\textsuperscript{19} I am referring here to a childcare centre, crèche, or daycare facility.
motivated by the interests of other family members, particularly parents. There are many reasons why parents choose childcare, including: affordability; it enables parents to pursue careers and financially support the whole family, particularly women who are freed from traditional gendered roles; and it gives parents, particularly single parents, a break from the constant demands of parenting. While childcare may provide some benefits to a child, there is ongoing debate about whether childcare facilities provide optimal care, particularly for infants and children under two. In this sense the debate becomes unrealistic as there are many care arrangements, both in and out of the home, that are unlikely to be optimal for children. If we accept that the decision to use childcare, as with many other familial decisions, is based on the interests of the family as a whole, the debate can move from arguments over what is in the child’s best interests to one focused on ensuring that childcare facilities satisfy the basic needs of children. In reformulating the debate, it is important to bear in mind that a child’s basic needs extend beyond the physical needs for care, food and shelter and include the child’s need for love, intimacy and affection.

B The impact of familial character on family decision-making

1 The nature and value of familial character

Compromise within families is not limited to accommodating the varying needs and interests of children and parents, but is also related more broadly to familial character or identity. Familial character imbues family members with a sense of collective identity and meaning. As with any other collective, ‘a family can affirm certain values and repudiate others en famille, so that the small details of the daily routine

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20 The literature on the childcare debate is vast and beyond the scope of this thesis. Purported benefits of childcare include stimulation, socialisation, and immunity-building. Purported disadvantages of childcare include an increase in childhood illness, lack of privacy, and inflexibility in daily routine. Historically, the main concerns about childcare have arisen out of attachment theory and the work of John Bowlby. See, for example, Steve Biddulph, Raising Babies: Should Under 3’s go to Nursery? (Harper Thorsons, 2006). However, other studies suggest that good quality childcare is not harmful to child development: Osnat Erel, Yael Oberman, Nurit Yirmiya, ‘Maternal versus nonmaternal care and seven domains of children's development’ (2000) 126(5) Psychological Bulletin 727. Whether childcare is beneficial or harmful ultimately comes down to the quality of care provided. Despite national accreditation of childcare in Australia, quality care is not always consistent, affordable or available to parents seeking this option.

21 Children cared for in the home by parents or extended family may not always be better cared for than children in formal childcare. For example, a parent who is constantly stressed and unable to cope with the demands of a small child or a grandparent who puts the child in front of the television for extended hours are not providing optimal care for the child.
form a mosaic of shared meaning.’ 22 In other words, families are viewed ‘as institutions with independent ideals and as invested with meanings of their own’. 23 According to Nelson, contributing to the family mosaic ‘can promote a feeling of solidarity among family members which is in itself a deep source of personal satisfaction.’ 24 Families need a certain degree of freedom to pursue their own projects, which in turn provide their individual members with meaning and identity.

Familial character is influenced by the particularities within a family, including ‘the personalities and life situations of specific family members, as well as common practices or traditions to which families may have allegiance.’ 25 At least in the early years, familial character is shaped significantly by parental preferences and values. For example, parents who value sport or the arts may take a child to weekly football matches or ballet performances in the hope of instilling in the child a passion for that particular form of recreation. Or perhaps the parents hold no such illusions, but simply want to take the family along in any event simply because they value the institution of football or ballet. The parents’ actions may have little to do with the child’s welfare, as they are unlikely to be able to demonstrate the specific value of attending football or ballet performances. Rather, ‘parents intervene in their children’s lives on the basis of undemonstrable views that there are things that matter apart from a child’s own interest’. 26 Parents also, on occasion, expose their children to small risks of serious harm in pursuing these interests. For example, by driving to the football on a rainy winter’s night, parents are subjecting their child to a small risk of being involved in a car accident. 27

Within families, decisions are made on the basis that ‘the interests of some members sometimes give way to the interests of others, or to the interests of the family as a whole.’ 28 This does not mean that parents should make decisions without regard to the interests of the individual members of the family. Familial character does not justify a *carte blanche* on parental authority. Parents in intimate families are not only

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22 Nelson and Nelson, above n 1, 68.
24 Nelson and Nelson, above n 1, 68.
25 Ibid.
26 J L Nelson, above n 2, 8.
27 In fact it is not uncommon for parents to expose children to such risks for their own ends. Nelson uses the example of making ‘your toddler accompany you on a car ride through snowy streets to pick up wine for the dinner guests’: J L Nelson, above n 2, 8.
28 Ibid.
agents for their own interests but also act as representatives of the welfare of the family as a whole. However, provided parents attend to the basic needs of their children, they should be able to distribute benefits and burdens according to the priorities of their family. Nelson argues that it is important to allow families the freedom to pursue family projects, which provide meaning, definition and character, even though the pursuit of such projects may deviate from impartial theories of justice.

The way in which families choose their projects, distribute their energies, and assign their burdens and benefits may serve goals other than those picked out by general theories of justice... They express what might be regarded as familial character, as those reasons for which people have the deep and abiding interest they do in forming and maintaining families.

According to Nelson, a life focused on the impartial good is ‘a life without any deep loyalties, and without the personal commitment that is central to love.’ It is therefore integral to a meaningful life that families are able to pursue their own interests and distribute benefits and burdens in a way that reflects the family’s particular character. Schoeman similarly argues that, in relation to family decisions concerning a child, ‘factors other than the parents’ responsibility for promoting the child’s interests may be taken into account legitimately:

These other factors can roughly be characterised as concerns emerging from the desire to promote the family’s welfare or character. Such a perspective does not entitle parents to sacrifice their children’s lives or welfare, although it does permit parents to compromise the child’s interests for ends related to family welfare.

It is important to recognise the value of familial character in order to understand the intricate basis on which decisions are made within a family and the individual compromise that this sometimes entails. Families have their own identities, which will influence the way in which decisions are made and vary according to the

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29 Ross, Children, Families, and Health Care Decision Making, above n 6, 31-2. Ross argues that parents can and should distinguish between these two roles when making decisions for the family. According to Ross, because parents relate to the child in an ‘intimate interdependence’, they are able to act for the well-being of the family as well as the individual child: 44.

30 J L Nelson, above n 2, 8. Nelson argues that families make choices that may not reflect distributive justice or utilitarian principles.

31 Ibid

32 Ibid. Nelson cites Bernard Williams, who states that ‘[t]here can come a point at which it is quite unreasonable for a man to give up, in the name of the impartial good ordering of the world of moral agents, something which is a condition of his having any interest in being around in that world at all.’ See Bernard Williams, Moral Luck (Cambridge University Press, 1981), 14.

particularities of each family. If parents are restricted in their decision-making by the ‘best interests’ principle, much of the familial character that creates meaning and fosters identity would be eroded. In the following section, I argue that although parental preferences influence familial character in the early years, family character is not synonymous with parental authority.

2 Family character not synonymous with parental authority

The notion of familial character has been criticised for masking what is, in reality, parental authority. Buchanan and Brock argue that decisions by the family as a whole are essentially decisions imposed on other members of the family by the parents:

Given the very great inequality of power between parents and children, reference to the family’s interest or “familial objectives” is all too likely to serve as a cover for the parents’ interests precisely in those cases in which the latter conflict with those of the child.

However, Ross points out that this interpretation:

… ignores the possibility that the parents are acting not only as agents of themselves but also as agents of the family as a group. It ignores the possibility that within intimate families, one member’s well-being is an integral part of the other member’s well-being. Intimates take on one another’s goals, even as they retain their independent goals and identity.

Schoeman similarly supports a view of parents as ‘representing the interests of the family as an integrated whole in addition to representing their own particular interests.’

Furthermore, parents are not the only members of a family that can influence its direction or projects. Clearly, parents have greater input into the direction of the family, particularly when children are still very young and incapable of either understanding or satisfying their own needs. However, children form preferences very early on and have ways to influence those around them. For example, a crying infant has a powerful impact on his/her parents. Steinfels cites research which ‘confirms the experience of many parents that “behaviour control” is by no means

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34 See, for example, discussion of Houlgate and Ladd in Ross, Children, Families, and Health Care Decision Making, above n 6, 30-2.
36 Ross, Children, Families, and Health Care Decision Making, above n 6, 31.
exclusively in the hands of the adults of the family. She argues that infants have ‘compelling powers to control behaviour and elicit responses in adults’ that can ‘effectively establish the modus vivendi of family life’. Clearly a child who is not yet conceived has no influence on familial character whatsoever before s/he comes into existence. It is therefore important to ensure that safeguards are in place to protect the basic needs of the child to be born as a result of PTT. I discuss how this may be achieved in more detail in Part III. Once a child is born as a result of PTT, however, that child will begin to influence the character of his/her family.

As children grow as individuals within a family, they develop more distinct preferences, become more capable of expressing their independent wishes, and begin to have more influence over the family’s projects. The family is not a rigid unit but is in a constant state of evolution as it grows to accommodate the needs and preferences of all its members. Notwithstanding the increasing independence of children within a family, the family will continue to operate as an intimate community with collective goals until the children move out and live independently. Even then there will still be some level at which the family is bound together, despite their different locations. For example, family members may continue to help each other out in times of need, share significant occasions such as birthdays and religious or cultural events, and visit or care for sick or ageing parents. Interestingly, toward the end of one’s life, it is the children who tend to have a greater influence on familial character, by caring and making decisions for their elderly parents when they are no longer capable of independently caring for themselves. Acknowledging the role of familial character in family decision-making is not therefore a thinly veiled attempt to promote parental authority. Familial character is influenced by the individual preferences and needs of all family members, which are continually evolving, and by the family history, religion, culture and values that its members inherit.

Clearly there are limits to what parents can require of their children in order to promote familial character or the interests of other family members. A child’s interests should not be unacceptably sacrificed for the welfare of the family as a

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39 Ibid.
40 For a discussion of adult children’s duty to care for their ailing parents, see Nelson and Nelson, above n 1, 69, Chapter 5.
whole. There is no simple solution to where the limits on parental discretion should lie and how the law should enforce those limits. Furthermore, limits on parental discretion will vary according to the context in which the discretion is exercised. For example, it is particularly difficult to draw a line on the types of risks to which parents should be allowed to expose their children in the context of religious or cultural identification, when the decision conflicts with accepted public standards relating to education or bodily integrity.\(^41\) In the next Part, I discuss in detail the point at which necessary compromise becomes unacceptable sacrifice for the child to be born as a result of PTT.

III NECESSARY COMPROMISE AND UNACCEPTABLE SACRIFICE

The power imbalance that exists among family members demands that children be afforded some independent protection ‘lest they be treated, Cinderella-like, as mere conveniences to advance others’ ends.’\(^42\) For example, conceiving a child through PTT to be a slave or as a ‘tissue farm’ is clearly unacceptable. All children should be protected from abuse, neglect and exploitation. Children who are not yet born are in a particularly vulnerable position as they have no opportunity to influence the decisions made by the rest of the family prior to their birth. The child to be born as a result of PTT clearly requires some protection. The more difficult issue is how far the state should intrude into family decision-making in order to protect the welfare of the child.

A Limiting state involvement in family decision-making

There are strong reasons for limiting state involvement in family decision-making. Given the inherent and instrumental value of intimate families discussed in Chapter 3, a high threshold should apply before the state interferes with parental discretion. According to Schoeman, ‘state scrutiny of, and intervention into, family affairs is

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highly disruptive of familial relationships’ and should therefore be kept to a minimum. Elliston points out that state oversight of parental decision-making would not only undermine parents’ ability to care for their children and family but ‘would in any event be impossible for the state to effectively monitor and police.’ Furthermore, in families with more than one child, parents have obligations to all their children. Buchanan and Brock argue that failure on the part of parents to maximise the individual interests of any particular child is not an adequate reason for state intervention.

Parents’ obligations toward their other children as well as their own legitimate self-interests can conflict with doing what maximises the child’s well-being, and sometimes may take precedence over it.

According to Buchanan and Brock, state intervention should be limited to cases in which parents fail to promote the basic needs of the child. Ross similarly argues for a high threshold for state intervention into parental discretion:

Parents need the moral and legal space within which to make decisions that will facilitate their child’s long-term autonomy, not only her present-day autonomy. Moreover, third party intrusion, by physicians or the state, should be resisted unless negligent and abusive decisions are in the making.

Clearly the state should protect all children from abuse, neglect and exploitation. However, what constitutes abuse, neglect or exploitation will vary according to the circumstances and the particular relationship in question. Different types of relationships carry different moral obligations. As previously discussed, parents have a fiduciary duty to attend to the basic needs of their children. Failure to do so will constitute abuse, neglect and/or exploitation on behalf of the parents. In such circumstances, state intervention is justified.

A relational approach to PTT can and should provide a threshold level of protection to the child to be born to ensure that his/her basic needs are met. A question arises as to

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45 Buchanan and Brock, above n 35, 236.
46 Ibid 235.
47 Ross, ‘Health Care Decisionmaking by Children’, above n 5, 41.
48 For a detailed discussion of how the nature of a relationship impacts on whether a child is abused or neglected, see Ross, Children, Families, and Health Care Decision Making, above n 6, 47-8.
49 These terms are overlapping to some extent. For example, a child conceived solely as a source of body parts is not only exploited and physically abused, but also neglected in the sense that his/her basic need for respect is ignored.
what constitutes a threshold level for each of the ‘primary goods’ discussed above in order for the basic needs of a child to be satisfied. While there is no evidence to suggest that families seeking PTT are more likely to deny the basic needs of a child than any other family, there are two aspects of PTT that require special consideration. These are the possibility that PTT may commodify the child to be born and the potential for PTT to harm the child to be born. These two aspects of PTT pose a potential threat to two primary goods, namely respect and protection from harm. In the remainder of this Part, I outline a minimum threshold for respect and protection from harm, below which state interference is justified in order to protect the child to be born from exploitation, abuse or neglect.

B Respecting the child as an individual in his/her own right

The first concern raised in relation to PTT is the possibility that some parents may commodify the child to be born by creating him/her for the sole purpose of saving their existing child. Although a remote possibility, society would be derelict in its duty to children to not only allow, but assist, parents to conceive children as commodities. In Chapter 2, I argued that parental motivation is therefore a relevant consideration in relation to PTT. However, the reasons people have for wanting a child are complex and often multi-factorial. I therefore contended that the state should only intervene in decisions involving PTT (on the basis of parental motivation) in extreme cases where parents clearly have no interest in the child to be born beyond his/her role as a stem cell donor. I recommended that counselling is an important process for exploring parental motivation for PTT, not only to protect the child to be born from commodification but also to assist parents in making genuinely informed decisions.

The difficulty lies in ascertaining when parents intend to conceive a child solely as a commodity as opposed to wanting a child for his/her own sake. Exploitation of a child is not something parents would readily admit to. Furthermore, as I mentioned in Chapter 2, it is likely to be extremely difficult to separate parents’ reasons for conceiving a child because of a genuine desire for a child from those linked to an

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50 See discussion above in Part IIA.
51 Parents seeking PTT rely on ART services to conceive.
52 See Chapter 2, Part IV, esp Part IVB.
53 See Chapter 2, Part IVB and C.
attempt to save another child.\textsuperscript{54} While the parental motives for seeking PTT are likely to be mixed and complex, at least some attempt should be made to identify parents who do not genuinely desire a child for his/her own sake through counselling.

The previous Victorian Assisted Reproductive Treatment Authority (VARTA) Conditions on PTT\textsuperscript{55} attempted to address commodification by requiring that the ethical consideration of an application review ‘the motivation and level of understanding of the parent in seeking to have an additional child’.\textsuperscript{56} The process of ART counselling aims to assist parents to explore and understand their own motives in seeking treatment, thereby enhancing their capacity to make fully informed decisions.\textsuperscript{57} ART counsellors help patients reflect on the long and short term implications of the proposed treatment for themselves, their family and the child to be born. Counsellors also encourage patients to develop realistic expectations about treatment outcomes and explore appropriate coping strategies.\textsuperscript{58} Counsellors aim to create a supportive environment, which is conducive to honest exploration of parental motives, by developing rapport, establishing a relationship of trust, using empathy and breaking down barriers.\textsuperscript{59}

Using PTT to conceive a child is morally complex. Clinics should provide family members with sufficient information, appropriate counselling and ethical guidance to explore and develop their values and preferences in relation to their decision. A multidisciplinary health care team would assist in creating an ‘open moral space’ within which parents can explore and reflect upon their motivations for PTT.\textsuperscript{60} Decisions about PTT should be reviewed by a separately constituted clinical ethics committee to ensure that the parents do not intend to exploit the putative child. If counselling reveals that parents do not genuinely desire a child for his/her own sake,\textsuperscript{61}

\textsuperscript{54} See Chapter 2, Part IVB.

\textsuperscript{55} VARTA, \textit{Conditions for Use of Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis} (February 2010) (previous VARTA Conditions on PTT).

\textsuperscript{56} ibid [2.3].

\textsuperscript{57} Telephone conversation between the author and Rita Alesi (Monash IVF) on 17 July 2009; telephone conversation between the author and Kay Oke (Melbourne IVF) on 25 September 2009. See also Australian New Zealand Infertility Counsellors Association, \textit{Guidelines on Professional Standards of Practice Infertility Counselling} (October 2003) (ANZICA Guidelines) [1.2.2].

\textsuperscript{58} ANZICA Guidelines, above n 57, [1.2.1].

\textsuperscript{59} Telephone conversation between the author and Rita Alesi (Monash IVF) on 17 July 2009.

\textsuperscript{60} For a discussion of the importance of ethics consulting in keeping moral space open in health care settings, see Margaret Urban Walker, ‘Keeping Moral Space Open: New Images of Ethics Consulting’ (1993) 23(2) Hastings Center Report 33.

\textsuperscript{61} As discussed, it may not always be possible for counselling to reveal the exact motivation for using PTT and parents are unlikely to admit they are commodifying a child. However, counsellors employ
the counsellor should record this as a concern about the welfare of the child to be born for consideration by clinical ethics committee. The complex nature of parental motivation highlights the importance of process in deciding whether to allow PTT. Counselling and ethical guidance form an integral part of the process by creating a supportive environment in which parents can explore their own motivations for seeking PTT. This exploration of parental motivation also acts as a safeguard for the interests of the child to be born.

C Protecting the child from harm

As I mentioned in Chapter 2, there are potential risks of physical harm to the child to be born as a result of PTT associated with embryo biopsy and ART and a future risk of physical harm if future donations are required. There is also a theoretical risk of psychosocial harm associated with being conceived as a donor. An assessment of what constitutes acceptable risk of harm is therefore necessary in order to ensure that the child to be born as a result of PTT receives a threshold level of protection from harm. According to the individual ‘net benefit’ approach discussed in Chapter 2, the risk of harm to a child is acceptable if the child experiences a balance of benefit over harm. However, I argued above that parents frequently expose their children to small risks of harm for which there is not necessarily an overriding individual benefit.62 The individual ‘net benefit’ approach to PTT is therefore inconsistent with general decision-making within families as it ‘ignores the benefits to the family as a group’.63 A more realistic approach is needed to determine what constitutes an acceptable risk of harm to the child to be born.

In this section, I propose an alternative principle for determining when state intervention is necessary to prevent unacceptable risk of harm to the child to be born as a result of PTT. I begin by discussing several slightly different approaches to determining unacceptable risk of harm in medical decision-making involving families, in the specific context of intra-familial donations. All of these approaches differ from the individual ‘net benefit’ test in that they allow for the child to be exposed to some risk of harm without necessarily requiring any individual net benefit to that child. In

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62 See discussion above, Part IIB1.
63 Ross, Children, Families, and Health Care Decision Making, above n 6, 43.
this respect, the approaches more accurately reflect general decision-making within families, where the welfare of the family as a whole is a relevant consideration. Applying each of these approaches to PTT, I conclude that, on the current evidence available, PTT does not generally pose an unacceptable risk of harm to the child to be born. I then propose a threshold level of protection from harm for the child to be born as a result of PTT.

1 ‘Constrained parental autonomy’

Ross adopts an approach to medical decision-making involving children, which she describes as ‘constrained parental autonomy’. According to Ross, parents can expose their children to procedures involving ‘minimal risk’ and ‘minor increase over minimal risk’ of harm. For any greater risk, a competent child’s consent is necessary and an incompetent child’s participation is impermissible. Ross’ categories are based on ‘the likelihood and degree of risk and harm.’ Ross defines ‘minimal risk’ as:

No more risk than that which a child typically experiences, or… no more risk than that which is encountered in many activities to which parents typically expose their children for educational purposes. 

In the context of intrafamilial donations, Ross classifies blood donation as carrying the minimal risk of a small bruise and slight fatigue. By way of contrast, she claims that the main risks and harms of bone marrow donation, namely anaesthesia and temporary pain, involve a minor increase over minimal risk but ‘are within the realm of risks to which parents often subject their children’. On the other hand, kidney donations, which involve anaesthesia, major surgery, potential major complications and a long recuperation period, are classified by Ross as involving more than a minor increase over minimal risk.

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64 Ibid, Chp 3, esp 50-2.
65 Ibid 119.
66 Ibid 112.
67 Ibid 83-5. Ross prefers the latter variation as children may face some risks in their everyday lives, with which they may not cope well and to which parents would not intentionally expose them. For example, a child may be bullied at school or a child with cancer may be exposed to regular lumbar punctures. These possibilities would not justify exposing a child to risk of harm commensurate with bullying or a lumbar puncture for non-therapeutic purposes.
68 Ibid 113.
69 Ibid 29, see also 43, 113.
70 Ibid 113.
2 Significant risk of serious harm that is unreasonable

Elliston suggests a slightly different test to Ross, based on ‘whether the parents’ decision poses a significant risk of serious harm to the child and whether it is unreasonable.’\(^71\) According to the first limb of Elliston’s test, judicial scrutiny is justified where there is a significant risk of serious harm to the child. However, the second limb of Elliston’s test provides that a parental decision involving significant risk of serious harm to a child may be acceptable if it is considered by a court to be reasonable.\(^72\) In the context of parents consenting to bone marrow donations by their incompetent children, Elliston argues that ‘it is reasonable for parents to make decisions that take account of the needs of all their children, rather than because they are in the donor child’s best interests’.\(^73\) Elliston’s standard of significant risk of serious harm appears to roughly correlate with Ross’ standard of ‘more than a minor increase over minimal risk’. However, Elliston cautions that:

…given the uncertainty about potential risks and benefits, and the possibility for parents and those concerned with the care of the sick child to underestimate harm to the proposed donor, [sibling donation] is a situation where I consider that some independent scrutiny is justified.\(^74\)

Elliston suggests that, in most cases, judicial scrutiny would not be necessary and independent review by a statutory authority ‘would provide an appropriate level of oversight.’\(^75\) She concludes that parents who consent to bone marrow donation between siblings would not generally be deemed to be acting unreasonably. However, Elliston considers that some cases of bone marrow donation may pose a significant risk of serious harm to the child which is unreasonable. For example, Elliston argues that the degree of distress for a child who is a reluctant donor may increase the level of risk of harm to the child ‘beyond acceptable limits’.\(^76\)

3 Role of relationship in determining acceptable risk of harm

The final two tests I shall discuss differ from the tests examined above in that they expressly highlight the direct bearing that relationship has on determining an

\(^{71}\) Elliston, above n 44, 257, see also 37-40. Schoeman proposes a similar standard to Elliston by arguing that state intervention be limited to preventing ‘imminent and serious harm’: Schoeman, ‘Parental Discretion and Children’s Rights’, above n 23, 60.

\(^{72}\) Elliston, above n 44, 37.

\(^{73}\) Ibid 258.

\(^{74}\) Ibid, 260.

\(^{75}\) Ibid 261.

\(^{76}\) Ibid.
acceptable risk of harm. Analysing the approach by US courts to sibling donations, Dwyer and Vig offer a general formula for determining what constitutes acceptable risk of harm as an alternative to the ‘best interests’ test applied by the courts. They state that there must be a ‘moral match between the relationship and the risks to the donor relative to the benefits to the recipient’. According to Dwyer and Vig, ‘[d]ifferent relationships justify different risks relative to various benefits.’

Jansen offers a slightly different approach based on ‘intimate attachment’ between persons, which recognises that a child’s well-being can be bound up with the well-being of another. According to Jansen, when an intimate attachment exists between a donor and recipient, ‘the interests of the child donor will be furthered by the donation.’ Jansen concludes that intimate attachments usually exist between members of a family but are not limited to family relationships. She further contends that parents should be considered the ‘presumptive authorities’ in determining when an intimate attachment exists between their child and another person. Finally, Jansen provides a similar limitation on parental decision-making to Ross by stating that where the donation involves a significant increase over minor risk to the donor there should be routine judicial review of parental decisions.

4 Does PTT cause unacceptable harm to the child to be born?

On any of the above formulations of threshold risk, PTT is not likely to cause unacceptable harm to the child to be born. Arguably the most significant risk posed by PTT is the future risk of physical harm associated with a bone marrow donation in the event that the initial cord blood transplant proves unsuccessful. This risk seems acceptable according to any of the above approaches, provided the relationships

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77 The importance of relationship is implicit in the other tests. For example, Ross argues that parents should be able to consent to a child’s participation in intrafamilial donations that entail minimal to a minor increase over minimal risk. Ross contends that such transplants promote the well-being of the sick child and the well-being of the family as a whole, on which the donor child’s well-being depends: Ross, Children, Families, and Health Care Decision Making, above n 6, 115. Similarly, the second tier of Elliston’s test, based on reasonableness, is an attempt to view the assessment of risk within the social context of the family.

78 Dwyer and Vig, above n 13, 11.

79 Ibid 11.


81 Ibid 141.

82 Given that intimate relationships can exist between friends as well as siblings, Jansen argues that ‘to restrict child organ donations to siblings would be arbitrary’: ibid 139.

83 Ibid 140.

84 Ibid 134, 140.
within the existing family are sufficiently close. On current evidence, the other risks posed by PTT appear to be less significant than the risks posed by a bone marrow transplant. There is therefore a strong likelihood that a child born as a result of PTT will have a sufficiently intimate relationship with the existing sibling to justify the level of risk involved.

Nevertheless, PTT regulation should outline a threshold level of protection from harm for the child to be born and establish mechanisms for ongoing review and guidance in relation to the risk of harm posed by PTT. It is possible that further empirical evidence may reveal a higher risk of physical or psychosocial harm to the child to be born than that which is currently understood from studies on the embryo biopsy process, ART and sibling bone marrow donors. It is also possible that the individual circumstances of a case may pose a greater risk than usual to the child to be born. For example, counselling may reveal that the parents seeking PTT are not sufficiently psychologically stable to support the child to be born in the event that the cord blood donation was unsuccessful.

As with other sibling donations, parents and treating physicians may not, on their own, be able to objectively assess the risk of harm to a child to be born as a result of PTT. Family members may also disagree, either between themselves or with the treating physician, about the level of harm posed to the unborn child. Given the ethical complexities surrounding intra-familial donations, a clinical ethicist should work in conjunction with parents, the treating physician and the counsellor in assessing the risk of harm to the child to be born in each case and in mediating any disputes that arise.

5 A threshold level of protection from harm

Drawing on the above approaches, I shall propose a threshold level of protection from harm for the child to be born as a result of PTT. All of the approaches outlined above provide that independent scrutiny of decisions is required when the risk of harm reaches an unacceptable level. Although the approaches differ on how they define unacceptable risk of harm, they roughly equate to the same standard. For simplicity, I will adopt the language used by Elliston of ‘significant risk of serious harm’ as the threshold for state intervention. Elliston acknowledges that the terms ‘significant’ and ‘serious’ may be criticised as indeterminate. However, ‘there will always be an
interpretive element in judging whether a parental decision crosses the threshold for State intervention.’\textsuperscript{85} It would be helpful to include a definition of ‘significant risk of serious harm’ in legislation regulating PTT. For example, the phrase might be defined as ‘more than a minor increase over the harm than that which a healthy child normally experiences’.\textsuperscript{86} The health care team should guide parents in determining what constitutes a significant risk of harm in each case. A clinical ethics committee should review decisions on a case by case basis to ensure that there is no significant risk of serious harm to the child to be born.\textsuperscript{87}

The clinical ethics committee should also apply a relational conception of the welfare of the child rather than the ‘best interests’ standard. The committee should therefore be directed to not only consider the interests of the child to be born, but also the interests of his/her parents and siblings, the collective interests of the family and the nature of existing relationships within the family. A relational conception of the welfare of the child represents a significant divergence from the current approach to PTT in Australia, which focuses on the individual or ‘best interests’ of the child to be born. There has, however, been growing recognition in recent years of the importance of broader family interests in relation to general medical decision-making.

In Part IV, I examine the role of families in the context of medical decision-making. I argue that the interests of family members who may be affected by a medical decision should be taken into account in connection with the interests of the patient. Although the child to be born is in a different position to a patient facing medical treatment, similar issues arise in both scenarios. In Part V, I argue that relational models for general medical decision-making discussed in Part IV can, and should, be adapted to apply to PTT.

IV THE ROLE OF FAMILIES IN MEDICAL DECISION-MAKING

Given the traditional emphasis in bioethical debate on individual patient autonomy, the role of the family in medical decision-making may seem, at best, marginal. There are good reasons for protecting patient autonomy, given that patients are in an

\textsuperscript{85} Elliston, above n 44, 36.
\textsuperscript{86} This is based on Ross’ formulation for constrained parental autonomy discussed above: Part IIIC1.
\textsuperscript{87} The circumstances of an individual case or further scientific evidence might reveal that PTT poses a significant risk of serious harm to the child to be born.
especially vulnerable position by virtue of their illness and will be directly and often profoundly affected by the consequences of treatment decisions.\textsuperscript{88} However, there are several bioethical writers who have ‘begun to shift the balance in bioethics so that family interests are weighed in concert with – not against – patient autonomy.’\textsuperscript{89} For example, James Lindemann Nelson argues that ‘standard accounts of medical ethics obscure what is particularly morally significant about families.’\textsuperscript{90} Some bioethicists argue for a greater role for the family in medical decision-making, even when the patient is a competent adult.\textsuperscript{91} Rather than rejecting patient autonomy, these bioethicists are essentially proposing different conceptions of relational autonomy in the field of bioethics.\textsuperscript{92}

Relational autonomy is based on a premise that persons are ‘socially embedded’.\textsuperscript{93} In contrast to the traditional approach to individual patient autonomy, a relational perception of patient autonomy ‘requires active concern for others.’\textsuperscript{94} The justification for a relational approach to medical decision-making lies in the notion that persons are, at least partly, ‘defined by their relationships and their interconnectedness with others’.\textsuperscript{95} A relational conception of patient autonomy suggests that ‘autonomy can be developed only in the context of social relationships with others who cultivate this capacity, and that personal autonomy can be implemented through reference to shared social norms and values.’\textsuperscript{96} Relational

\begin{itemize}
\item \textsuperscript{88} In fact, this is the very reason for the emphasis on patient autonomy and the doctrine of informed consent in traditional medical ethics. See, for example, J L Nelson, above n 2, 9.
\item \textsuperscript{89} Carol Levine, ‘Family Caregiving’ in Hastings Bioethics Center Briefing Book (2009) 63, 65.
\item \textsuperscript{90} J L Nelson, above n 2, 6.
\item \textsuperscript{91} Ibid. See also Hardwig, above n 2.
\item \textsuperscript{92} Roy Gilbar and Ora Gilbar, ‘The Medical Decision-Making Process and the Family: The Case of Breast Cancer patients and their Husbands’ (2009) 23(3) Bioethics 183, 185. For a detailed discussion of relational autonomy, see Mackenzie and Stoljar, above n 42. MacKenzie and Stoljar point out that some care ethicists, such as Held, recommend that autonomy be ‘reconceptualised so that it is not defined in opposition both to femininity and to relations of dependence and connection.’: 10. For example, Held argues that ‘mutual autonomy’ is important in caring relationships: Virginia Held, The Ethics of Care: Personal, Political, and Global (Oxford University Press, 2006), 55.
\item \textsuperscript{93} MacKenzie and Stoljar, above n 42, 4.
\item \textsuperscript{94} Gilbar and Gilbar, above n 92, 185. See also Onora O’Neill, Autonomy and Trust in Bioethics (Cambridge University Press, 2002).
\item \textsuperscript{95} Paul Lauritzen, Michael McClure, Martin L Smith and Andrew Trew, ‘The Gift of Life and the Common Good: The Need for a Communal approach to Organ Procurement’ (2001) 31(1) The Hastings Center Report 29, 32.
\item \textsuperscript{96} Gilbar and Gilbar, above n 92, 185. See also Jennifer Nedelsky, ‘Reconceiving Autonomy: Sources, Thoughts and Possibilities (1989) 1(1) Yale Journal of Law and Feminism 7, 11.
\end{itemize}
autonomy therefore requires the interests of intimate family members, who will be affected by a medical decision, to be taken into account.97

A Position of the child to be born is analogous to that of a patient

It may seem misplaced to discuss the notion of autonomy in relation to a child who is not yet born. The child to be born as a result of PTT does not have any decision-making capacity because s/he is not yet in existence. However, the position of the child to be born as a result of PTT is analogous to that of the patient requiring general medical treatment in two significant respects. First, both the prospective child and the patient will be directly affected by the relevant decision. Decisions about general medical treatment and decisions to use PTT are likely to directly impact on the bodily integrity of the patient and the child to be born, respectively. In the case of the child to be born, the decision will impact on the child’s very existence and the use of that child’s tissue, at the time of birth and possibly in the future. As discussed in Chapter 2, the fact that a child is not yet in existence does not mean that policy-makers should ignore the future interests of the child in relation to PTT. The future interests of the child to be born may conflict with the interests of the family as a whole. For example, the prospective child has a future interest in being treated as an end rather than a means, cared for, and protected from harm – all of which may potentially be compromised by PTT. Like a patient facing a treatment decision, the child to be born as a result of PTT has interests, albeit future ones, that will be affected by the relevant decision.

Second, both the child to be born and the patient are vulnerable and in need of some protection in the decision-making process. A competent patient’s decision-making capacity may be significantly compromised or diminished due to illness and the patient may not be able to defend his/her interests. In relation to patients facing treatment, Nelson points out that ‘considerations about vulnerability and personal privacy and integrity must be acknowledged’.98 The plight of the child to be born is even more precarious because s/he is not in existence at the time a decision is made and therefore has no capacity to influence the decision or defend his/her future interests. The prospective child has no input into the decision, which will ultimately determine not only that child’s very existence but his/her role within the family in a

97 Gilbar and Gilbar, above n 92, 185. See also Donchin, above n 42 at 240.
98 J L Nelson, above n 2, 10.
profound way. As a consequence of their vulnerable positions, both the patient and the child to be born rely, to varying degrees, on others to defend their interests in the decision-making process.

The following discussion of relational autonomy in medical decision-making reveals the impact that family relationships have on medical decision-making and explores different approaches for dealing with potentially conflicting individual and collective interests within families in relation to medical decisions. In Part V, I address some of the specific issues that arise for a child born as a result of PTT, who is not yet in existence.

B A relational conception of autonomy

Kuczewski describes the increased focus on the role of family in medical decision-making in recent years as ‘the natural progression and development of medical ethics.’

Having focused on the rights of the patient for so long, it follows that ethicists now wish to map the relationships surrounding the individual that may affect medical decision-making. In this section, I argue that Kuczewski’s ‘process model’ for medical decision-making provides a new lens through which to view family relationships in the medical decision-making process. According to Kuczewski, a patient’s family members have a critical role to play in the process of informed consent to medical treatment. Instead of perceiving the patient’s interests as separate to, and in potential conflict with, those of his/her family, Kuczewski views informed consent as a process of genuinely shared decision-making in which the patient’s decision is influenced by discussions with his/her physician and family. Before I discuss Kuczewski’s process model to family decision-making and its potential application to PTT, I shall briefly outline and critique three different relational approaches to medical decision-making that have influenced Kuczewski and bioethical debate on the role of family in medical decision-making generally.

1 Three relational approaches to medical decision-making

Hardwig instigated the debate over the role of the family in medical decision-making in 1990 when he argued that the focus should shift from the individual patient toward

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99 Kuczewski, above n 2, 30.
100 Ibid 30.
a broader consideration of the patient’s family.\textsuperscript{101} Hardwig proposes a radical approach to relational autonomy in medical decision-making by advocating that the traditional patient-centred medical ethic be replaced with a presumption that the interests of the patient and family members that are of the same magnitude should be given equal weighting. However, he argues that this presumption will generally be overridden by the patient’s interests in optimal health and longer life.\textsuperscript{102}

Because a patient’s medical decisions often dramatically affect the interests of members of that patient’s family, Hardwig argues that medical decisions should be made by taking into account the medical and nonmedical interests of both the patient and other family members:

To be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself.\textsuperscript{103}

For example, certain treatment options may be more costly than others and may have a significant financial impact on the patient’s family. There may also be significant burdens placed on family members who provide ongoing care and support for the patient. Hardwig proposes that medical treatment decisions be made by the \textit{family} rather than just the \textit{patient}. To this end, he argues that ‘family conferences’ should be required when a treatment decision is likely to impact on the lives of family members. Such family conferences would not be limited to an advisory or supportive function but would operate as decision-making forums.

Nelson builds on Hardwig’s view of family relationships as involving overlapping and mutually affecting interests by claiming that they also provide contexts of intimacy. Nelson argues that the intimacy and mutual commitment on which families are based create a sense of moral responsibility between family members, giving further weight to the claim that family interests ought to be included in medical decision-making.\textsuperscript{104}

According to Nelson, the intimate nature of family relationships creates not only a potential clash of individual interests but also a clash between interests of individuals and the collective interests they share as members of a family. It is therefore also

\begin{footnotes}
\item[101] Hardwig, above n 2.
\item[102] Hardwig argues that ‘life, health and freedom from pain and handicapping conditions are extremely important goods for virtually everyone’ and are therefore highly significant considerations in all treatment decisions: ibid 7.
\item[103] Ibid 6.
\item[104] J L Nelson, above n 2, 10.
\end{footnotes}
important to protect the character of the family as an intimate collective in the
decision-making process.

When a dispute emerges between a patient and family members, Nelson recommends
that ‘conflicts [be] met with efforts to mediate, to facilitate consensus, or to forge
acceptable compromise.’ 105 He suggests that the interests of incompetent patients
should be represented in mediation by an independent advocate. 106 In contrast to
Hardwig, Nelson suggests that we should begin with the presumption that a competent
patient has decision-making authority, but acknowledge that this presumption is
rebuttable and a family should have an option to challenge patient authorisation on the
basis of family interests. 107 Nelson’s model represents a view of medical decision-
making involving families that is sensitive to both the values protected by patient-
centeredness in current medical practice and the inherent value of intimate
relationships. 108

Blustein’s approach to relational patient autonomy is slightly different as he separates
out the decision from the process of making the decision. Blustein argues that ‘the
locus of decisional authority should remain with the individual patient’ but that:

…family members, by virtue of their closeness to and intimate knowledge of the patient are
often uniquely qualified to shore up the patient’s vulnerable autonomy and assist him or her in
the exercise of autonomous decisionmaking. 109

According to Blustein, families are ‘an important resource for patients’ in helping
them make fully informed treatment decisions. 110 Short of giving family members
any share of decisional authority, Blustein suggests that procedures need to be devised
‘that acknowledge the moral weight of their legitimate interests’. 111 It is the role of
the physician to enhance the patient’s autonomy by facilitating discussion between

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105 Ibid 11. It is questionable whether a physician can realistically discharge his/her fiduciary duties to
the patient, while attempting to objectively mediate family disputes about treatment. Hardwig
foreshadowed this dilemma when he stated, ‘[p]hysicians are trained to be especially responsive to
medical interests and we may well want them to remain that way.’ See Hardwig, above n 2, 8. See
also Gilbar and Gilbar, above n 92, 186.
106 J L Nelson, above n 2, 11. Nelson stresses that the advocate should represent the patient ‘as a
person, not simply as a self-interest maximizer’.
107 Kuczewski argues that the practical outcome of this right of rebuttal means that Nelson’s position is
virtually identical with Hardwig: Kuczewski, above n 2, 31.
108 J L Nelson, above n 2, 6-7, 10.
109 Blustein, above n 2, 6. Blustein draws on the work of Jay Katz, who distinguishes between
‘choices’ and ‘thinking about choices’: 12. See Jay Katz, The Silent World of Doctor and Patient (Free
Press, 1984), 111.
110 Blustein, above n 2, 6.
111 Ibid 11.
patients and those with whom they are intimate to give patients ‘opportunities for serious reflection on their choices’. However, although patients should be encouraged to include the interests of family members in medical decision-making, Blustein stresses that the choice itself belongs to the patient. Blustein argues that it is necessary to protect individual decision-making rights because, even in harmonious families, the interests of individual members will at times conflict with those of the rest of the family. According to Blustein, ‘[i]ndividual rights are needed because a significant degree of diversity may exist even in a group united by a common conception of the good.’

2 Critique of the three approaches to medical decision-making

While the approaches to medical decision-making involving families discussed above reflect varied conceptions of relational autonomy, Kuczewski claims that all three ethicists ultimately ‘remain trapped by the individualism implicit in the doctrine’ of informed consent, which dominates medical ethics. All three approaches recognise that the patient is generally in a vulnerable position and requires ‘advocacy and protection’. They all entail a presumption in favour of the decisional authority of the patient but recognise that family interests should be taken into account to some degree in the decision-making process. Finally, and significantly, the debate is ultimately framed in terms of a conflict between the interests of the patient and those of the family. The debate focuses on the question of whose interests should take precedence when those of the patient and family conflict. With some exceptions, most conflicts are settled in favour of the patient. Kuczewski acknowledges that framing the issue in terms of conflicting interests ‘has an initial attraction because of its clarity and practicality’. However, he concludes that simply providing an answer fails to explain ‘the more general phenomenon of the family’s place in medical decisionmaking’.

Kuczewski rejects the way in which Hardwig, Nelson and Blustein frame the problem of conflicting interests within families as one which must be answered in either/or

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112 Ibid 12
113 Ibid 10.
114 Kuczewski, above n 2, 31.
115 Ibid.
116 Ibid.
117 Ibid.
terms and should generally be resolved in favour of the patient.\textsuperscript{118} The problem, according to Kuczewski, is that medical ethics has developed in the shadow of a legalistic doctrine of informed consent, which is in turn based on an ‘individual profile rather than a family portrait’.\textsuperscript{119} As a result, the family is usually conceived of as comprising competing interests, which leads to ethicists arguing about the relative merits of these rival interests.\textsuperscript{120} This confuses the role of the family in medical decision-making as ‘[t]he profundity of the links and bonds between family members is hidden from view in these legalistic discussions of interests and rights.’\textsuperscript{121} Kuczewski describes this legalistic approach as an ‘event model of informed consent’\textsuperscript{122} because the focus is on the event of receiving consent from the patient, who is assumed to have a defined set of values. According to this approach, the role of the family is generally confined to vouching for the patient’s competence.\textsuperscript{123} Kuczewski contrasts this approach with a ‘process model’ of informed consent, in which consent is viewed as a process of shared decision-making whereby the values and preferences of the patient take shape through discussions with his/her physician and family.\textsuperscript{124}

3 Developing a ‘process model’ for medical decision-making

Kuczewski offers an alternative approach to the role of family in medical decision-making that focuses on process and the respective roles of the patient, family and physician.\textsuperscript{125} Instead of asking whose interests should take precedence when those of the patient and family conflict, Kuczewski says we should be asking what are the respective roles of the patient, family members and physician in the medical decision-making process. In this sense, Kuczewski goes further than Blustein, who separates out the decision from the process, by making the process the main focus of his

\textsuperscript{118} Ibid, 31, 36. This criticism is perhaps less apt for J L Nelson’s approach, which recognises the inherent value of intimate families and the attempts to preserve intimate relationships through mediation.\textsuperscript{119} Ibid 30.\textsuperscript{120} Ibid.\textsuperscript{121} Ibid 31.\textsuperscript{122} Ibid 32.\textsuperscript{123} Ibid 33.\textsuperscript{124} Ibid 32-3. Kuczewski makes a further distinction between two types of process model. He uses the term ‘interpretive model’ to describe a situation where the patient already has well-developed values and the physician and family assist the patient in interpreting those values and translating them into preferences and treatment decisions. He uses the term ‘deliberative model’ to describe the situation where the patient does not have the necessary values relevant to a given case and the physician and family assist the patient in developing new values.\textsuperscript{125} Ibid 31.
decision-making model. According to Kuczewski, the discussions through which the patient’s values and preferences take shape are ‘not prior to the event of giving consent, but, in a sense, [are] the process of informed consent.’ Kuczewski’s process model of decision-making sees family members not as representing a separate group of interests to be weighed against the interests of the patient, but as performing an integral role in the decision-making process. By engaging in the decision-making process, family members assist the patient by taking part ‘in the patient’s narrative self-discovery that helps her to reconnect with her values and give them meaning as expressed in choices.’ In cases where the patient’s values have not yet been developed, family plays an important role in discovering and shaping those values. Kuczewski argues that ‘[b]ecause we discover our values in dialogue with those closest to us, the family is naturally an integral part of this process.’ He does, however, recognise that family members can sometimes exert undue influence over patients, which does not assist them in forming their views but amounts to coercion. In such cases, a physician may need to seek recourse through formal institutional mechanisms to protect a vulnerable party.

Of all the approaches discussed in this section, Kuczewski’s approach comes closest to a genuinely shared medical decision-making model. For Kuczewski, the process model of informed consent is a collaborative form of decision-making that involves ‘active roles for physicians and families in the medical decisionmaking process.’ As these roles will vary according to the circumstances of each case, clear guidance is needed to define and circumscribe the various roles in the relevant context. In the next Part, I explore a process model for decision-making in relation to PTT and outline the various roles played by health professionals and parents in this context.

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126 Kuczewski acknowledges that there will be cases of unresolvable conflict between a patient (who has developed and stable views) and his/her family, for which a legalistic event-based model is appropriate. However, he argues that this ‘either/or’ way of thinking has wrongly dominated the debate about the role of family in medical decision-making: ibid 36.
127 Ibid 34.
128 Ibid.
129 Ibid.
130 Ibid 36.
131 Ibid 35.
V APPLYING A RELATIONAL APPROACH TO PTT

A relational approach, which reflects the importance of intimate family to the welfare of the child, can be adapted for PTT. In this Part, I argue that a modified version of the process model developed by Kuczewski should be applied to decisions involving PTT. A relational approach requires a broader consideration of the welfare of the child to be born and his/her family than the current regulation of PTT in Australia, which focuses on the individual interests of the child to be born. In the next section, I draw from the relational models of patient autonomy discussed above to justify a relational approach to decision-making for PTT. I then explain how a process model can deal with the various interests within the family. Finally, I outline some general features of a relational model for PTT.

A Shift of focus for PTT from child to be born to family as a whole

In Part IV, I argued that family often plays an important role in the medical decision-making process. The interests of a patient’s family should be considered in medical decision-making – not just because the family is likely to be affected by the treatment decision, but also because the intimacy and mutual commitment on which intimate families are based creates a sense of moral responsibility between family members. Furthermore, families play an integral part in the personal narrative on which a patient’s values and preferences are formed and transformed. Despite the recent bioethical debate about the importance of family input into medical decision-making, the role of the family in medical decision-making involving minors has been impeded by a strong focus on the ‘best interests’ of the child in paediatric and reproductive medicine.132 Ross has observed that, ironically, in pediatrics there has been a move away from the role of the family. In this area of medicine, ethicists and policymakers have sought to limit parental discretion in relation to a child’s health care decisions in favour of a ‘best interests’ test.133 In this section, I argue that, just as some bioethicists have argued for a shift in medical decision-making from a patient-centred approach to a relational approach, the approach to PTT should shift from one that is


133 Ross, ‘Health Care Decisionmaking by Children’, above n 5, 41.
centred on the child to be born to one in which the interests of the family are also taken into consideration.

Notwithstanding the direct impact on and particular vulnerabilities of the child to be born as a result of PTT, the underlying justifications for a relational approach to medical decision-making are also applicable, and arguably even stronger, for PTT. PTT is a clear example of a medical decision in which the whole family has an interest or stake in the outcome. In fact, the interests of family members are affected in the most profound way as PTT can save the life of the existing ill sibling. I have assumed for the purposes of this thesis that the existing ill child is agreeable to stem cell transplantation following PTT, so that his/her consent to treatment is not in issue. However, if the existing sick child’s wishes were not consistent with the parent’s wishes to pursue PTT, a separate issue involving consent of a minor would arise. The decision-making capacity of non-competent patients raises similar issues to those arising for the child to be born. Although the existing child may in some cases need independent representation, this does not mean that his/her interests should be isolated from the social context of the family. In particular, a process model would assist the child in formulating his/her values and preferences, on which the treatment decision will be based.

Nelson’s additional justification for a relational approach to medical decision-making, based on the intimate nature of family relationships, also applies to PTT. Children, in particular, depend on intimate families for love, protection, nurturing, socialisation and identity. Furthermore, the future interests of the child to be born will be influenced by his/her family in the same way that a patient’s values and preferences are influenced by family. The decision to use PTT should not, therefore, be based solely on the individual interests of the child to be born but should also openly and honestly reckon with the interests of other members of the family. Even where the future child’s interests are independently assessed by a clinical ethics committee, those interests should be represented as ‘not necessarily estranged from those of her family’. In the next section, I argue that Kuczewski’s process model for dealing with the various interests within a family can and should be adapted and applied to PTT.

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134 Nelson and Nelson, above n 1, 36. See discussion in Chapter 3, Part IIC.
135 J L Nelson, above n 2, 11.
B Adapting a process model for dealing with family interests

The current approach to PTT in Australia, which focuses on the individual interests of the child to be born, gives priority to the child’s individual interests over those of the rest of the family. In Chapter 3, I highlighted the relational nature of the welfare of the child to be born by arguing that the child has both individual and collective interests that are shared with his/her family. If we adopt a relational approach to PTT, we need an effective process for dealing with the various individual and collective interests that exist within a family. In this section, I draw from Kuczewski to argue that instead of focusing on the potential conflict between the interests of the child to be born and those of his/her family, attention should be redirected to collaborative decision-making.

While much of Kuczewski’s discussion is not directly relevant to PTT as it relates to competent patients, we can draw from his approach by not approaching questions about the various family interests in relation to PTT in ‘either/or’ terms. Instead we should view the welfare of the child to be born within the context of the family into which s/he will be born, as the child’s future values and preferences are likely to be influenced by his/her family’s values and beliefs. For example, you would not apply Catholic doctrine to a Jewish family wishing to use PTT, as the child to be born would not be raised according to Catholic values. The prospective child will ultimately emerge from his/her initial role as a sibling donor to become an individual with his/her own values and preferences. However, those values and preferences (including those in relation to further tissue donations) will necessarily be shaped by the values and belief systems of his/her family. Furthermore, as the child’s future welfare depends not only on satisfaction of his/her individual interests but also on his/her interrelationships with the rest of the family, any conflict of interests cannot be solved by simply balancing the child’s individual interests against the interests of his/her family.

Clearly, Kuczewski’s process model, which involves a genuine collaboration between the patient, his/her family and the physician, cannot be entirely replicated for PTT. First and foremost, the child to be born as a result of PTT is unable to have any input into the decision-making process that will determine his/her very existence. Another

136 Kuczewski, above n 2, 36.
significant point of difference is that the treating physician is not primarily representing the interests of the child to be born, but is in fact treating the parents seeking PTT. A modified collaborative decision-making model should therefore be pursued in relation to PTT. Importantly, the interests of the child should be viewed within the social context of the family into which s/he will be born rather than as essentially separate to, and to be balanced against, the interests of his/her family. In the next section, I sketch out the general features of a relational approach to PTT, based on a modified version of Kuczewski’s process model.

C General features of a relational approach to regulating PTT

Some of the general features of Kuczewski’s process model can be adapted to PTT. In proposing some general principles for a modified relational approach to PTT, I highlight some of the distinguishing features of PTT that require special consideration. I draw from these principles in Chapter 6 when I propose a revised regulatory framework for PTT.

1. A relational approach to PTT requires consideration of the interests of all family members, not just those of the child to be born.

Not only will family members be affected by the decision to use PTT, but the child to be born will share collective interests with his/her family. It is therefore important to clearly identify the various interests at stake in relation to PTT in the decision-making process, some of which are individual and others which are shared. These include the future interests of the child to be born, the interests of the existing ill child in receiving a stem cell transplant, the interests of the parents in saving the life of their existing child, the interests of the parents in having another child, the interests of any other siblings who will be affected by the decision, and the shared interests of the family as an intimate collective. I discussed the nature of the future interests of the child to be born in Chapter 2 and the collective interests of intimate family members in Chapter 3.

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137 I have assumed for the purposes of this thesis that the existing ill child is agreeable to the bone marrow transplantation following PTT.
2. A ‘process model’ is preferable to a conflict-based model for managing individual and collective interests within a family.

A balance needs to be struck between protecting the individual interests of the child to be born and promoting the interests of the family in the decision-making process. However, instead of asking whose interests should take precedence when the interests of the child to be born appear to conflict with the interests of his/her family, regulation should focus on the decision-making process and the respective roles of the family and their health care team. It is important that individual and collective family interests be explored, as far as possible, in a supportive environment that promotes the intimate nature of family. By creating an ‘open moral space’ within which to explore the various interests of family members, decisions can be made that promote the welfare of the child to be born as well as the valuable intimate relationships that exist within a family. In some cases, entrenched conflict between family members may require more formal mediation. I clarify the roles of family and the health care team in the decision-making process in more detail below.

3 The decision-making process for PTT should openly and respectfully explore the family’s values, beliefs and preferences as these are relevant to the welfare of child to be born.

Ascertaining the values, beliefs and preferences of the family seeking PTT is an important part of the decision-making process because the future values, beliefs and preferences of the child to be born will be influenced by those of his/her family. If the family is ‘the soil out of which the [child’s] values and preference grow’, a realistic assessment of the welfare of the child to be born requires an understanding of the values, beliefs and preferences of the family into which that child will be born. Given that existing family members will not have faced a decision about PTT before, they are unlikely to have fully developed the value system necessary to support the decision. The decision-making process is therefore an important collaborative project of ‘mutual self-discovery’ for the whole family, whose values and preferences are likely to be in transformation. Clinical ethicists can play a key role in keeping open

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138 For a discussion of the importance of open moral space within health care institutions generally, see Nelson and Nelson, above n 1, 116-8; Walker, above n 60. Walker specifically envisages a role for clinical ethicists in guiding this process.

139 Nelson and Nelson, above n 1, 36.

140 Kuczewski, above n 2, 35.
the moral space necessary to explore the values, beliefs and preferences of all family members.

4. **The roles of parents, the health care team (PTT physician, counsellor and clinical ethicist) and the clinical ethics committee should be clearly outlined.**

Given the active roles I have proposed for families and members of the health care team in the decision-making process, the various roles should be clearly defined and differentiated to avoid confusion.

**(a) Role of parents in determining the welfare of the child to be born**

Parents often play an important role in determining the welfare of a child.\(^{141}\) Parents seeking PTT should actively contribute to a determination about the welfare of the child to be born. Because the welfare of the child to be born is intertwined with the welfare of his/her family, it is reasonable for parents to make decisions that take account the needs of all family members and not just the child to be born. However, because the child to be born is noticeably absent from the decision-making process for PTT, s/he requires some independent protection to ensure that his/her interests are not subordinated to the interests of existing family members. This does not, however, mean that the child’s future interests should be removed from the social context into which the child will be born. As discussed above, the child’s values, beliefs and preferences will inevitably be influenced by those of his/her family.

Although I propose that parents should be the primary decision-makers, existing children within the family should also be actively involved in the decision-making process where appropriate. Parents and family members should be given information, counselling and ethical guidance in relation to their role in the decision-making process. General guidance on the welfare of the child to be born might be provided through legislation or policy guidelines and reinforced by the treating clinic. Case specific information and support in relation to PTT should be provided by a multi-disciplinary team of health care professionals within the treating clinic. I discuss the various roles of the treating health care professionals in more detail below.

\(^{141}\) For a detailed analysis of why parents are generally well-placed to make treatment decisions on behalf of their children, see Buchanan and Brock, above n 35, 233-4. Buchanan and Brock provide four reasons to support their position: (1) parents care deeply about their children; (2) parents bear the consequences of treatment choices; (3) parents have a right, within limits, to raise their children according to their own standards and values; and (4) family is a valuable social institution, particularly in its role in fostering intimacy, and family members must have significant authority to carry out their roles as carers. See also Ross, *Children, Families, and Health Care Decision Making*, above n 6, 39-40.
(b) Role of health care professionals in treating the family as an intimate collective and protecting the welfare of the child to be born

Given the medical, psychological and ethical complexities surrounding PTT, clinics should provide families with relevant information, counselling and ethical guidance to enable them to make fully informed and ethically sound decisions.

The role of the treating health care team should be clearly defined to ensure that they are not solely representing the interests of the parents seeking PTT any more than they are acting solely as advocate for the child to be born. Rather, the team should aim to treat the family as an intimate collective. The focus should be on a collaborative, inclusive and supportive decision-making process that promotes the welfare of the family as a whole, without sacrificing the welfare of the child to be born. To this end the health care team’s role is to assist family members in determining and promoting their collective interests in an open collaborative decision-making process. Within the team, different health care professionals will provide different forms of assistance.

A physician’s primary role is to relieve a patient’s pain and suffering and restore his/her health. In the context of PTT, the physician’s role is to assist parents to conceive a healthy baby who is a direct tissue match for an existing ill sibling. The PTT physician must also respect the welfare of the child to be born. To help families make informed decisions about PTT, the PTT physician should provide family members with all relevant information on PTT, including: all other treatment options for the existing sibling; the likely success rates for conceiving a direct tissue match; and the risks associated with PTT for all family members. In alerting parents to the risks for the child to be born, the PTT physician should assist in promoting the welfare of the child to be born throughout the decision-making process.

Counselling should play an integral role in the decision-making process. Parents and relevant family members should be given specific counselling on the welfare of the child to be born as a result of PTT and how the interests of the family interlace with those of the prospective child. In particular, counsellors should encourage parents to consider all family interests, both present and future, so that they are not blinded by their desire to save their existing child and appreciate that a new child will be created with his/her own interests and needs. Counsellors should attempt to ascertain the motivation of parents in seeking to have another child, in particular whether the
parents desire a child in his/her own right. Counselling should also address the implications for the whole family in the event that the donation of cord blood stem cells is unsuccessful. Finally, family members may require counselling to explore and further develop their own value system in the context of PTT. Counselling should at least attempt to be value-neutral. There is, however, significant debate about whether or not nondirective counselling is achievable.142

Given the complex ethical questions arising out of PTT, a clinical ethicist should actively participate in the decision-making process. The role of the clinical ethicist should not be that of an expert moral authority who ultimately determines the ‘right’ outcome in any particular case. Rather, a clinical ethicist should facilitate moral deliberation that can lead to consensus.143 Where consensus is more difficult to achieve, the clinical ethicist can attempt to resolve conflict through mediation.144 As Margaret Urban Walker explains, ‘ethicists are architects of moral space within the health care setting, as well as mediators in the conversations taking place within that space.’145 As previously discussed, parents and other family members should be given sufficient moral space within which to explore the various family interests affected by PTT. By openly acknowledging the various interests at stake, decisions can be made that promote the welfare of the child to be born as well as the welfare of the family into which it will be born.

(c) Role of clinical ethics committee in ensuring that the welfare of the child to be born has been given due consideration in accordance with law and policy on PTT

Finally, decisions to use PTT should be independently reviewed to protect the child to be born from exploitation, abuse or neglect. This can be done by a separately constituted clinical ethics committee. The clinical ethics committee should apply a

5. **Guidance should be given as to how the welfare of the child to be born is likely to be adversely affected by PTT**

In Part III, I highlighted two aspects of PTT that pose a potential threat to the child to be born. The first is the risk that the child will be commodified and the second is the risk that the child will be harmed. I then outlined a minimum threshold level of respect and protection from harm for the child to be born in order to protect the donor child from exploitation, abuse or neglect.

National guidelines should clarify when the risk of commodification or harm is likely to be unacceptable. For example, where counselling reveals that the parents do not genuinely desire a child for his/her own sake or where there is a significant risk of serious harm to the child to be born, applications for PTT should be refused. In line with a relational approach, any potential harm to the child to be born should be considered within the context of the family into which that child will be born. For example, a greater risk of harm to the child to be born might be allowed in families with an exceptionally stable and supportive network that could mitigate any negative effects on the donor child.

6. **Decisions about PTT should be recorded and clinics should attempt to monitor the long-term effects of PTT on children born as a result.**

Given the importance of process in the relational approach I propose, transparency in decision-making is essential. To enable clinical ethics committees to assess whether the welfare of the child to be born has been effectively safeguarded in the decision-making process, decisions about PTT should be recorded. In particular, physicians, counsellors and ethics counsellors should independently report on their consultations with families seeking PTT.
As discussed in Chapter 2, the full extent of the impact of PTT on the welfare of the child to be born is, as yet, unknown. Clinics should make efforts to monitor the long-term physical and psychosocial effects on children born as a result of PTT to improve welfare assessments in the future. National guidelines should therefore require detailed recording of decisions about PTT and encourage ongoing monitoring of children born as a result of PTT.

VI CONCLUSION

In this Chapter, I have argued that compromise is an integral part of family life. While parents generally seek to promote the welfare of their children, familial decisions are not based solely on the individual or ‘best interests’ of any particular child. Instead, decisions are made according to the needs of family members, the capacity of family to meet those needs, the nature of relationships within a family, and the character and preferences of a particular family. In the context of general medical treatment decisions, there is increasing support for a relational approach to decisions that impact on family members. A relational approach to PTT reflects the complex basis on which decisions are generally made within families by acknowledging that some of the individual interests of the child to be born may need to be compromised in favour of the welfare of the family.

However, a relational approach to PTT should not sacrifice a child’s basic needs for the welfare of the family as a whole. In order to protect the welfare of the child to be born, PTT regulation should require that the child to be born receives a threshold level of respect and protection from harm. PTT should be allowed provided the parents genuinely desire a child for his/her own sake and there is no significant risk of serious harm to the child to be born. Physicians, counsellors, clinical ethicists and parents all play key roles in creating an open moral space within which to explore the welfare of the child in the context of the family into which s/he will be born. A separately constituted clinical ethics committee should review decisions to proceed with PTT to ensure that the child to be born is not at risk of exploitation, abuse or neglect. Instead of applying a ‘best interests’ of the child test, the ethics committee should make an

146 See Chapter 2, Part VA, B. See also discussion above, Part IIIC4.
assessment of the welfare of the child based on considerations of risk, benefit and relationship.

In Chapter 6, I propose a detailed regulatory framework for PTT. It is clear from this Chapter that I am not proposing a simple formula for promoting the welfare of the child in the context of PTT. However, ‘the notion of an intimate attachment and the corresponding notion of a child’s well-being being bound up with another are not precise ideas’.147 As Nelson points out:

Recognising that the concerns of intimacy can have a legitimate call upon the way a person lives makes of morality a messier thing, but if that mess were cleaned up, much of significant human value would be lost.148

Before outlining my proposed regulatory approach for PTT in Australia, I highlight and address some remaining questions of principle and practice for PTT regulation in the next Chapter. I answer these questions, at least in part, by reviewing the recent debate over, and reform of, PTT in the UK.

147 Jansen, above n 80, 139.
CHAPTER 5
PTT REGULATION IN THE UK

I INTRODUCTION

In Chapter 4, I devised an ethically principled approach to regulating PTT. I proposed a relational approach to PTT – one that recognises and accommodates individual and collective interests within a family in the decision-making process. Instead of focusing on the individual or ‘best interests’ of the child to be born, a relational approach requires the interests of other family members to be considered in connection with the interests of the child to be born. Recognising that interests within a family will not always coincide, I highlighted the importance of process in reconciling familial interests. I also proposed a threshold level of respect and protection from harm to prevent the child to be born from being exploited, abused or neglected. Although I have proposed a broad ethical framework for regulating PTT, some questions of principle and practice remain: Who should ultimately make decisions about PTT? What is the role of the state in regulating PTT? How far should the state interfere with individuals’ reproductive choices? Should the welfare principle be retained in ART regulation? If so, how should the principle apply to PTT?

The residual questions I have posed can be answered, at least in part, by turning to the UK. Experience and practice in the closely related UK jurisdiction raise possibilities and challenges for the regulation of PTT in Australia. PTT regulation in the UK also incorporates some features of the relational approach that I proposed in Chapter 4. For example, the welfare of the child provision in UK ART legislation requires consideration to be given not only to the welfare of the child to be born but ‘to any other child who may be affected by the birth’.¹ Recent policy on the welfare of the child developed by the Human Fertilisation and Embryology Authority (HFEA) ensures a threshold level of protection for not only the child to be born but any existing child in his/her family. The HFEA policy applies a minimum threshold approach to the welfare of the child by creating a presumption in favour of treatment

¹ Human Fertilisation and Embryology Act 1990 (UK) (HFE Act), s13(5).
unless there is a ‘significant risk of harm or neglect’ to either the child to be born or any existing child.\(^2\)

The UK has adopted a facilitative approach to regulating ART, including PTT, with a strong focus on the welfare of the child to be born.\(^3\) The UK approach is similar to that in Victoria, with a broad legislative framework delegating a range of decision-making powers to a statutory body.\(^4\) As in Victoria, the UK government has recently undertaken a major review of ART law and policy. However, while the Victorian review focused on access, surrogacy and parentage questions, the review of ART regulation in the UK canvassed the issues surrounding PTT and the role of the welfare principle in detail. The recent reforms to PTT regulation in the UK and the surrounding ethical debate have illuminated some issues about PTT regulation that are relevant to Australia.

In this Chapter, I discuss how the key issues surrounding PTT have been dealt with in practice by UK policy-makers, legislators, regulators, and courts. In particular, three key issues for PTT regulation in the UK are relevant to the regulation of PTT in Australia. First, legislation should clearly sanction PTT to prevent future legal challenges. The arbitrary distinction between PTT in conjunction with PGD and PTT should also be removed. Second, clear ethical guidance is needed in relation to the welfare of the child principle and its application to PTT to assist those making decisions about the welfare of the child to be born. Ongoing research into the short and long-term impacts of PTT on the child to be born could further improve welfare assessments in the future. Third, the role of the state in regulating PTT must be carefully assessed to ensure that the reproductive choice of individuals is not subjugated. As far as possible, decisions about PTT should be made by parents in consultation with their health care team.

I begin my analysis in Part II by summarising UK law and policy reforms relevant to PTT. In Part III, I focus on the development of PTT policy by the HFEA arising out the Hashmi and Whitaker cases. In Parts IV and V, I discuss the major reviews of ART regulation in the UK that have specifically addressed PTT. In Part IV, I critically examine the welfare of the child provision by asking whether it is should be

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\(^3\) See Chapter 1, Part IIIB.

\(^4\) Ibid.
II SUMMARY OF LAW AND POLICY REFORM IN THE UK

PTT is an area of assisted reproduction that has been the subject of significant and controversial law reform over the past eight years in the UK. A detailed summary of the development of UK law and policy relevant to PTT is contained in Table 2. PTT is regulated in the UK by the HFE Act 1990, which was passed following the deliberation of the Warnock Committee.\(^5\) While the HFE Act 1990 does not restrict access to fertility treatment, it limits the provision of such treatment by imposing a duty to take the welfare of the child into account as a condition of licensing.\(^6\) Prior to the recent amendments made by the Human Fertilisation and Embryology Act 2008 (UK) (HFE Act 2008), which came into force on 1 October 2009, the HFE Act 1990 did not mention PTT or PGD.

In the absence of specific legislation on PGD and PTT, the HFEA developed its own policy on PTT in response to requests for licenses by clinics. In 2002, the HFEA made two contrary decisions on PTT in the Hashmi and Whitaker cases. These decisions led to a legal challenge in relation to the HFEA’s authority to license PTT and debate

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5 Following the birth of Louise Brown, a Committee of Inquiry chaired by Dame (now Baroness) Warnock was appointed in 1982 to examine the social, ethical and legal implications of new developments in the field of human assisted reproduction. In 1984, the Committee recommended in its report the enactment of new legislation setting out legal limits on assisted reproduction and embryo research and the establishment of a licensing authority: Report of the Committee of Inquiry into Human Fertilisation and Embryology Cm 9314 (July 1984) (Warnock Report).

6 HFE Act 1990, s13(5). Unlike the Assisted Reproductive Treatment Act 2008 (Vic), the HFE Act 1990 does not treat the welfare and interests of the child to be born as paramount but requires consideration to also be given to the interests of other siblings who may be affected.
over the HFEA’s interpretation of the welfare principle in the context of PTT. The widespread criticism of the HFEA’s decisions in these two cases highlights the need for clear legislative guidance on controversial procedures like PTT. The HFEA subsequently reviewed its policy on both PTT and the welfare of the child in 2004 and removed the arbitrary distinction it had previously made between PTT in conjunction with PGD and PTT alone. In April 2004, the HFEA commenced a review of its existing policy on the welfare of the child. The HFEA published a report and announced new guidance on the welfare of the child in November 2005. The availability of PTT and the role of the welfare of the child principle were also firmly placed on the agenda for regulatory review in the UK.

Several major reviews of ART regulation in the UK were being conducted at roughly the same time as the HFEA was revising its policy on PTT and the welfare of the child. On 24 October 2003, the House of Commons Science and Technology Committee (the STC), dissatisfied with the ‘inadequate’ response by the Department of Health to medical and scientific developments in reproductive technology, announced it would undertake an independent review of the HFE Act 1990, ‘to reconnect the Act with modern science’. On 21 January 2004, the Government announced its own extensive review of the HFE Act 1990 in light of new technologies in assisted reproduction, possible changes in public attitudes on ethical issues, international developments, the need to ensure the continued effectiveness of regulation, and to reduce uncertainty and the scope for legal challenges. Around the same time, the Human Genetics Commission (HGC), a government advisory body, canvassed the complex ethical issues arising out of genetic screening technologies, including PTT.

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8 The HFEA consulted professionals, patients and other stakeholders to inform its review: HFEA, Tomorrow’s Children: A Consultation on Guidance to Licensed Fertility Clinics on Taking in Account the Welfare of Children to Be Born of Assisted Conception Treatment (January 2005) (Tomorrow’s Children Consultation).
12 Ibid [1.6], [1.7].
The STC reported its findings in March 2005\(^1\) and the UK Government provided a detailed response in August 2005.\(^2\) The UK Government presented its policy proposals for revised ART legislation in a White Paper in December 2006.\(^3\) These and other proposals were incorporated into the Human Tissue and Embryos (Draft) Bill (the Draft Bill), which was published on 17 May 2007 for pre-legislative scrutiny by a Joint Committee. While the Draft Bill did not go as far as the STC recommended in 2005, it reflected a libertarian approach to infertility treatment.\(^4\) The Joint Committee reported its findings on 1 August 2007\(^5\) and the UK Government published a response in October 2007.\(^6\) The UK Government review of ART law culminated in the passage of the HFE Act 2008, which amended the existing HFE Act 1990. Two key issues raised by the various reviews of ART legislation in the UK are: (1) the role of the state in regulating ART; and (2) the relevance of the welfare of the child principle to ART regulation.

### III HASHMI, WHITAKER AND HFEA POLICY ON PTT

In the space of a few months, the HFEA made two contrary decisions about the availability of PTT in the Hashmi and Whitaker cases, based on the welfare of the child principle in the HFE Act 1990. These decisions led to widespread debate in the UK over the role of the HFEA and the application of the welfare of the child principle to PTT.

#### A Background to Hashmi and Whitaker cases

Following the internationally reported success of the Nash family’s use of PTT in the US, two UK families sought similar treatment to conceive a donor child for a sick sibling. The HFEA made an arbitrary distinction between the applications by the two

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\(^1\) STC Report, above n 10.
\(^5\) Joint Committee on the Human Tissue and Embryos (Draft) Bill HL 169/HC 630-I and II (August 2007) (Joint Committee Report).
\(^6\) United Kingdom, *Government Response to the Report from the Joint Committee on the Human Tissue and Embryos (Draft) Bill* Cm 7209 (October 2007) (Government Response to Joint Committee Report).
families, which resulted in the Hashmi family being given access to PTT while the Whitaker family was denied treatment.

In 2001, the fertility clinic treating the Hashmi family applied to the HFEA for a licence to carry out PTT in conjunction with PGD. Mr and Mrs Hashmi sought treatment to help them conceive a healthy baby who would be a direct tissue match for their son, Zain, who was suffering from beta-thalassaemia (a genetically inherited disease). On February 2002, the HFEA granted a licence to carry out treatment to simultaneously test the Hashmi’s embryos for genetic disease and to determine their tissue type. The licence granted in the Hashmi case was consistent with the HFEA’s interim policy on PTT, which allowed PTT only in conjunction with PGD. The welfare of the child provision in the HFE Act 1990 was a central consideration for the HFEA in formulating its interim policy on PTT. The HFEA reasoned that, given the concerns at the time about the physical and psychological safety of children conceived using PTT, the invasive and potentially harmful procedure could only be justified where the embryo could be said to benefit from the procedure in the sense that the embryo was free from a genetic disorder. The HFEA therefore restricted PTT to cases where it was used in conjunction with PGD to avoid a genetic disorder.20

Only a few months after the decision in the Hashmi case, the HFEA made the opposite decision in the Whitaker case. The HFEA refused an application for treatment by the Whitaker family that fell outside the scope of its interim PTT policy. On 29 July 2002, the HFEA refused a licence for the Whitaker family to use PTT to conceive a direct tissue match for their existing child, Charlie, who had a non-inherited strain of Diamond-Blackfan anaemia.21 As the child to be born was not at risk of inheriting the condition, there was no need to screen for the disease. Screening embryos for tissue type alone was not in line with the HFEA interim policy on PTT.

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20 This is contrary to the advice given by the HFEA Ethics Committee on 22 November 2001, which recommended that the HFEA licence PTT both with and without PGD: HFEA Ethics Committee, Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors (2001) [3.14].

21 Other non-inherited conditions (for which couples have sought PTT alone, without concurrently testing embryos for a genetic condition) are acute lymphoid leukaemia and acute myeloid leukaemia: Jess Buxton, ‘Unforeseen Uses of Preimplantation Genetic Diagnosis – Ethical and Legal Issues’ in Kirsty Horsey, and Hazel Biggs (eds), Human Fertilisation and Embryology: Reproducing Regulation (Routledge-Cavendish, 2007) 109, 116.
The Whitaker family subsequently travelled to the US to undertake PTT. The procedure was successful and James Whitaker was born in June 2003. James was a direct tissue match for his brother and Charlie underwent a successful bone marrow transplant using cord blood stem cells a year later.

The Hashmi and Whitaker cases raised two issues about PTT licensing decisions and HFEA policy development. The first relates to the legal jurisdiction of the HFEA to license PTT. The second relates to the HFEA’s interpretation of the welfare of the child provision. I discuss these two issues in sections B and C, respectively.

B CORE challenge to HFEA’s authority to license PTT in Hashmi case

The HFE Act 1990 did not expressly authorise the HFEA to grant a licence for PGD or PTT at the time the requests were made on behalf of the Hashmi and Whitaker families. However, ‘faced with a licence application, the HFEA had little choice but to make a decision’. The pro-life interest group, Comment on Reproductive Ethics (CORE), issued a formal judicial challenge to the authority of the HFEA to issue a licence for PTT in relation to the Hashmi family. The legal challenge by CORE reinforces the need for legislation to clearly sanction controversial technologies like PTT to prevent future legal challenges.

The legal challenge to the HFEA’s decision in the Hashmi case was issued by Josephine Quintavalle on behalf of CORE in late 2002. Quintavalle applied for judicial review of the HFEA’s decision, claiming that the Authority acted outside its power in authorising PTT and that it was for Parliament to make decisions of such significance. On 20 December 2002, the High Court ruled that the HFEA had no legal power to authorise PTT in any circumstance. The HFEA successfully appealed this decision and in April 2003 the Court of Appeal overturned the High Court decision, applying a broad ‘purposive’ reading of the HFE Act 1990. A

22 PGD is not specifically regulated in the US, allowing clinics to provide PGD for any technically possible reason within the limits of the professional guidelines issued by the American Society for Reproductive Medicine: ibid 112.
23 STC Report, above n 10, [246].
24 Ibid [250].
26 R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority [2003] 2 All ER.
27 R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority [2003] 3 All ER 257. A purposive approach to statutory interpretation treats the purpose or object of the legislation as more important than its literal meaning. The Court of Appeal applied the seminal reasoning of Lord
Further appeal by CORE was unsuccessful and the House of Lords confirmed the decision of the Court of Appeal in April 2005 that the discretion to license practices under Schedule 2 of the HFE Act 1990 covered PGD and PTT.\textsuperscript{28}

The HFEA ultimately succeeded against Quintavalle before the House of Lords by arguing that it could licence PTT under Schedule 2 of the HFE Act 1990 as a procedure ‘designed to secure that embryos are in a suitable condition to be placed in a woman or to determine whether embryos are suitable for that purpose’.\textsuperscript{29} The House of Lords affirmed the broad application of Schedule 2 by the Court of Appeal, which treated PTT as the same as other activities, such as PGD, that the HFEA had ‘regularly licensed for the purpose of assisting women to bear children free of hereditary disease’ on the basis that they both involved the same biopsy procedures.\textsuperscript{30}

However, as Brownsword points out, the Court of Appeal failed to distinguish between the different purposes of the two procedures:

‘...this glosses over the possibility that there is a significant difference between a standard PGD test designed to confirm that an embryo is healthy (and, thus, suitable for implantation) and a test of the kind authorised for the Hashmis where the purpose is to confirm that an embryo has a profile that will render it suitable to serve as a donor for the benefit of an already born child.’\textsuperscript{31}

According to Brownsword, the Hashmi case highlights the dilemma of finding the right balance between flexibility and certainty in achieving ‘regulatory connection’ between law and technology.\textsuperscript{32} In areas such as ART, where technology is rapidly accelerating, regulatory connection is a recurring issue. Where technology goes beyond an existing regulatory framework, a purposive interpretation of legislation can avoid disconnection between the law and technology. However, while a flexible purposive approach is ‘an intelligent response to what would otherwise be
unproductive disconnection’, it is not appropriate where there is a genuine question about whether a new reproductive technology has moved beyond the spirit and intent of the existing regulatory framework. As Brownsword points out, ‘disconnection is not always a bad thing.’ In cases facing ‘productive disconnection’, a purposive approach simply ‘papers over a problem that really needs to be addressed by regulators.’

As Brownsword states:

‘...if there is a genuine question about whether (and, if so, where) the new technology falls within the spirit and intent of the regulatory scheme, then the courts do us no favours by stretching the regulatory framework in such a way that the issues are not freely debated.’

Given that the purpose of PTT is to save the life of an existing child, the procedure may not have fallen as clearly within the spirit and intent of the HFE Act 1990 as the Court of Appeal found. The Quintavalle case raises questions about where, within the regulatory spectrum, decisions about novel technologies such as PTT are best made. Given the highly controversial nature of PTT, arguably it would have been better for the Court of Appeal to have returned the question about the HFEA’s authority to license PTT to Parliament to be clearly addressed through democratic debate. Brownsword argues that returning the question about PTT to the HFEA, to be decided on a case-by-case basis, raises problems of incrementalism in the regulation of ART, lack of institutional accountability and regulatory uncertainty.

The HFE Act 1990, as amended, now expressly states that PTT is a licensable activity, where the existing sibling suffers from a ‘serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue’ (excluding whole organs). The clarification of the law on PTT is a welcome development as it

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33 Ibid 32. Brownsword uses the term ‘unproductive disconnection’ to describe the unproductive use of regulatory resource to have to translate an unproblematic regulatory intent into regulatory letter in relation to a new technology that is clearly within the spirit and intent of an existing regulatory framework: 31.

34 Brownsword, ‘Reproductive Opportunities and Regulatory Challenges’ above n 31, 320.

35 Brownsword, ‘Regulating Human Genetics’, above n 32, 32. Brownsword uses the term ‘productive disconnection’ to describe a situation where there is a genuine question as to whether or not a new technology falls within the spirit and intent of the regulatory scheme and it is therefore entirely appropriate to commit regulatory resource to further debate and decision about the new technology: 31-2.

36 Ibid 319-320.

37 Ibid 319-320.

38 HFE Act 1990, Schedule 2, para 1ZA(1)(d), (4).
creates ‘more certainty’ than previous HFEA policy and there is less reliance on discretionary HFEA decision-making. One criticism that has been raised in relation to the amendments is that the role of parents in the decision-making process is not mentioned. This is in contrast to the previous HFEA policy on PTT, which stated that ‘the seriousness of the condition [of the existing sibling] should be a matter for discussion between the people seeking treatment and the clinical team’. In Part V, I argue that parents should be directly involved in decisions about PTT and that significant weight should be attributed to parental views about the seriousness of the existing child’s condition.

C Unjustifiable distinction between Hashmi and Whitaker cases

The contrary decisions made by the HFEA in the Hashmi and Whitaker cases led to considerable public and professional debate over the role of the HFEA and its ability to apply the welfare of the child principle in the HFE Act 1990. The HFEA removed the arbitrary distinction between PTT in conjunction with PGD and PTT alone in 2004. However, the Authority’s policy ‘back-flip’ suggests a need for clear ethical guidance by Parliament in relation to the welfare of the child principle and its application to PTT.

Embryo screening solely for the purpose of tissue typing, as requested by the Whitaker family, was contrary to the HFEA interim policy on PTT. According to the HFEA, PTT alone was not a desirable use of embryo biopsy because there was no benefit to the child to be born to outweigh the potential risks of the procedure. In its own words, the HFEA:

...had doubts about the desirability of using PGD to select on the basis of tissue typing alone and not in order to avoid a particular genetic condition because of the possible risks, both physical and psychological, to the child to be born as a result of the procedure.

The HFEA took what it described as a ‘precautionary approach’ to PTT, given the lack of evidence about either the physical risks associated with the biopsy process or

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42 HFEA Report on PTT, above n 7, [10].
43 Ibid [8].
the psychological risks for a child who is born as a donor. The HFEA’s interim policy followed detailed consideration of the issues by the HFEA’s Ethical Committee. In determining whether PTT is compatible with the welfare of the child to be born, the Ethics Committee considered whether the child is likely to be commodified as well as the risk of physical and psychosocial harm.\(^{45}\) Interestingly, however, the Ethics Committee did not distinguish between PTT alone and PTT in conjunction with PGD and recommended that PTT be available in both cases.\(^{46}\)

While a precautionary approach to PTT was arguably appropriate in the circumstances, the HFEA was not justified in drawing a distinction between PTT alone and PTT in conjunction with PGD. The HFEA has been widely criticised for its policy on PTT and, in particular, its application of the welfare principle. As several commentators have pointed out, the risk/benefit analysis for the child to be born as a result of PTT is the same, whether or not PTT is carried out alone or in conjunction with PGD.\(^{47}\) This is because genetically screening an embryo using PGD does not confer any direct benefit on the embryo in the sense that it ‘cures’ the embryo in any way. Rather, it simply detects those embryos that are already free from genetic disorders.\(^{48}\) Ultimately, for both PTT alone and PTT in conjunction with PGD, the embryo is being selected on the basis that it is a direct tissue match with an ill sibling.

The HFEA reviewed its policy in 2004 and passed new PTT policy on 21 July 2004.\(^{49}\) The new policy stated that PTT should be available for the sole purpose of creating a tissue matched donor sibling where there is a genuine need for potentially life-saving tissue. The current HFEA policy on PTT is contained in Guidance Note 10 of the HFEA Code of Practice.\(^{50}\) The policy requires centres to consider the circumstances of each PTT application individually.\(^{51}\)

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\(^{44}\) Ibid [9]. The HFEA was subsequently criticised by the STC for its application of the precautionary principle in relation to PTT: STC Report, above n 10, [274-7].

\(^{45}\) HFEA Ethics Committee, above n 20, [2.9]-[2.15].

\(^{46}\) Ibid [3.14].


\(^{48}\) Sheldon and Wilkinson, above n 47, 156.


\(^{50}\) HFEA 8th Code, above n 2, Guidance Note 10.

\(^{51}\) Ibid [10.18].
the condition of the existing sibling, the possible consequences for any child who may be born as a result of PTT, and the family circumstances of the people seeking treatment. The policy also requires detailed information to be given to patients considering PTT about the procedure, associated risks, the likelihood of success, the likely impact on family members, and other sources of treatment. Finally, the HFEA policy requires centres offering PTT to have arrangements in place to facilitate long-term medical and psychosocial follow-up studies of children born as a result of PTT.

The HFEA justified its change of policy on its review of the latest research, which suggested that the physical risk associated with embryo biopsy was insufficient to warrant the previous policy distinction. The HFEA also considered the psychological effects of being a saviour sibling and the success of blood stem cell transplant treatments. The HFEA stated that no evidence had been found that the procedure would harm the psychological welfare of the child to be born but that careful consideration of each case is required in the absence of long-term follow up studies of PGD offspring. Buxton has suggested that the rationalisation by the HFEA for its change in policy may have been partly a ‘face-saving’ exercise as the scientific evidence in this area was not much different to that available in 2002.

The welfare principle in UK legislation has proven difficult for the HFEA to apply in cases involving PTT. The difficulties faced by the HFEA in the Hashmi and Whitaker cases suggest that clearer guidance is needed in the HFE Act 1990 on the availability of PTT and the application of the welfare principle. The STC welcomed the change in HFEA policy on PTT but stated that the HFEA’s previous policy and licensing decisions on PTT ‘raised concerns about decisions of such importance – even controversy – being taken in this forum’. According to the STC, by invoking the welfare of the child provision in PTT decisions, the HFEA ‘tied itself in ethical

53 Ibid [10.22].  
54 Ibid [10.24].  
55 HFEA Report on PTT, above n 7, [13]-[14].  
56 Ibid [15]-[23].  
57 Ibid [17].  
58 Buxton, above n 21, 120. It could be argued that while the amount of data has not changed significantly in this time, ‘the efforts of the HFEA in surveying that evidence has’: STC Report, above n 10, [270].  
59 STC Report, above n 10, [248].
knots’. To prevent future problems, the STC recommended that revised legislation ‘must make it clear that preimplantation genetic diagnosis and preimplantation tissue typing can be undertaken within legal constraints.’ Gavaghan has similarly criticised the HFEA for demonstrating an inability to coherently and consistently apply the welfare of the child principle in relation to PTT.

D Case-by-case approach to PTT

On 1 October 2009, the HFEA commenced licensing PGD on a condition-by-condition basis. This means that once a condition has been licensed by the HFEA, any clinic in the UK holding a PGD licence can test for that condition. The decision did not, however, apply to PTT, which continues to be licensed on a case-by-case basis. The HFEA reviewed its case-by-case approach to licensing PTT in late 2009 and in January 2010 determined to continue this approach for the time-being. A key factor in favour of this approach is the fact that ‘there are still unresolved ethical and social concerns’ regarding PTT and very little information on the benefits and risks of the treatment.

A primary concern in relation to a case-by-case approach to PTT is the time taken to make a decision. However, the HFEA was influenced by the fact that there is a ‘significant minority’ in Parliament and society at large with ethical and social concerns about the treatment. As King points out, although an in-principle decision has been taken by the Parliament in relation to PTT, the ethical issues surrounding PTT ‘are still alive in the details and variability between individual cases’. Coupled with the fact that there is very little information on the risks and benefits of PTT and subsequent transplant treatment, the HFEA concluded that PTT should be ‘closely

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60 Ibid [251].
61 Ibid.
62 Gavaghan, ‘Designer Donors?’, above n 28, 10-19, esp 18.
64 HFEA, Minutes of Authority Meeting (20 January 2010) (HFEA Minutes) [10.13].
66 The timeframe for licensing PTT in the UK has been shortened in the last year. However, ‘one month is still a significant delay’ where the existing child is suffering: Danny Edwards, ‘Case by Case Decision-Making in PGD’ (Paper No ELAC (12-09) 3) submitted at ELAC meeting on 15 December 2009) (ELAC Paper) [4.14].
67 Ibid [4.21]. See also HFEA Minutes, above n 64, [10.7]-[10.8].
68 David King, above n 65.
scrutinised’. The HFEA committed to quicker processing of PTT applications in the future and further review of the case-by-case approach in due course.

E Lessons for Australia

The Hashmi and Whitaker cases raised concerns about the legal jurisdiction of the HFEA to license PTT and the HFEA’s interpretation of the welfare of the child provision. These issues arose because PTT was not explicitly addressed in the HFEA Act 1990 and there was little ethical guidance on how the welfare provision should be applied.

The lessons learnt in the UK are relevant to the regulation of PTT in Australia, and Victoria in particular. PTT is not explicitly addressed in the Victorian Assisted Reproductive Treatment Act 2008 (Vic) (ART Act (Vic)), reflecting a lack of democratic debate on this contentious procedure in Australia. Even more than in the UK, there is a real issue in Victoria as to whether PTT falls within the legislative intent of the ART Act (Vic). The Parliamentary debate surrounding the ART Act (Vic) suggests that Parliament intended the Patient Review Panel to make determinations about PTT. However, PTT appears to be inconsistent with the first guiding principle in the ART Act (Vic) (to treat the welfare and interests of the child to be born as paramount) because the procedure is primarily motivated by the interests of the existing child and his/her parents. In Chapter 3, however, I argued that PTT is justified if we apply a broader conception of the welfare of the child – one that includes both the child’s individual interests and the collective interests s/he shares with his/her family.

Similar challenges to that made by CORE against the HFEA in the UK could be made against Victorian clinics or the Patient Review Panel in relation to decisions authorising PTT, based on the first guiding principle in the Victorian ART Act (Vic). To avoid future challenges, the ART Act (Vic) should specifically sanction PTT and the first guiding principle in the Act should either be removed or substantially amended to reflect a broader conception of welfare of the child to be born.

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69 HFEA Minutes, above n 64, [10.8].
70 See STC Report, above n 10, [246].
71 Victoria, Parliamentary Debates, Legislative Council, 10 October 2008, 4192 (Gavin Jennings, Minister for Environment and Climate Change).
72 Brownsword argues that it is clearly debatable as to whether PTT advances the best interests of the child, which is ‘the standard test for a medical intervention’ on a minor: Brownsword, ‘Regulating Human Genetics, above n 32, 36-7.
previous VARTA Conditions on PTT distinguished between PTT alone and PTT in conjunction with PGD in Victoria in the same way as the HFEA’s interim policy on PTT. This distinction no longer applies in the UK and should be removed in Victoria. To avoid similar arbitrary distinctions in the future, clearer guidance is needed in the ART Act (Vic) on the nature and role of the welfare of the child principle.

A significant problem faced by the HFEA in formulating its policy on PTT was the lack of evidence about the risks of physical and psychosocial harm to the child to be born as a result of PTT. Clearly there is a need for further empirical research in this area, which will require the ongoing monitoring of children born using PTT. In Part V, I argue that, given the lack of information currently available on the risks associated with PTT for the child to be born, decisions to allow PTT in individual cases should be made by parents in conjunction with their health care team on a case by case basis. Detailed policy is needed to guide the decision-making process and ensure that parents are given adequate information, counselling and ethical support. Decisions to proceed with PTT should also be subject to ethical oversight by clinical ethics committees.73

In the next Part, I consider the role of the welfare of the child principle in detail, as this has been the subject of considerable debate in the UK.

IV WELFARE OF THE CHILD PRINCIPLE

The welfare of the child principle underpins ART law and policy in the UK. In this Part, I examine the welfare of the child provision in the HFE Act 1990 and HFEA policy on the welfare of the child. Both law and policy on the welfare principle have provoked considerable controversy because they effectively leave decisions about access to ART to the discretion of individual clinics.74 There have been calls by some to abolish the UK welfare of the child provision altogether,75 whereas others have argued that the provision should be strengthened to make the child’s welfare the

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73 This is consistent with the recommendation by the STC that difficult cases should be resolved by recourse to local clinical ethics committees rather than by a statutory body like the HFEA or local clinics: STC Report, above n 10, [107].


‘paramount’ consideration in reproductive decisions. Clear guidance on the welfare of the child provision is necessary in order to promote consistent decision-making for ART and prevent clinics or statutory bodies from making decisions about access to ART that unfairly discriminate against certain members of society.

In the next section, I discuss the origins of the welfare of the child provision and its subsequent review by the STC and the UK Department of Health. I then explore how the provision has been interpreted and applied by the HFEA.

A The welfare of the child provision

The availability of PTT is restricted by the duty to consider the welfare of the child to be born under the HFE Act 1990. The Act provides that ‘a woman shall not be provided with treatment unless account has been taken of the welfare of the child who may be born as a result of the treatment (including the need for a father), and of any other child who may be affected by the birth’. The welfare of the child has been described ‘in the broad sense of rights, interests and well-being’. Because the welfare of the child provision is ‘intrinsically discretionary and not supported by a coherent ethical framework, its application has become arbitrary and problematic’.

The duty to consider the welfare of the child arose out of the Warnock Report, which recognised the need to protect the interests of any child to be born as a result of infertility treatment. This issue arose in the context of access to treatment and the relevance of family structures. While the Warnock Committee concluded that access to treatment should not be restricted to married couples, it took the view that ‘as a general rule it is better for children to be born into a two-parent family, with both father and mother’. Ultimately, however, it proposed that the responsibility for treatment eligibility decisions be devolved to clinicians, recommending only that where treatment is declined, a patient should always be given a full explanation of the

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76 Joint Committee Report, above n 18, [221], STC Report, above n 10, [93]. One of the main justifications for this approach is that it is in line with adoption law. But see discussion by STC rejecting the validity of this argument: [93].
77 For example, a clinic should not refuse ART to lesbian or single women on the basis of an unsubstantiated view that the welfare of a child is compromised if s/he is not raised by a mother and father.
78 HFE Act 1990, s 13(5).
79 Department of Health Public Consultation, above n 11, [3.1].
80 McDonald, Fenton and Dabell, above n 39, 295.
81 Warnock Report, above n 5, [2.5].
82 Ibid [2.11].
reasons. Despite the Warnock Committee’s deliberations on the welfare of the child, neither the 1987 White Paper on human fertilisation and embryology nor the subsequent Human Fertilisation and Embryology Bill mentioned the welfare of the child to be born.

The welfare of the child re-emerged as a major issue in parliamentary debate during the second reading of the Human Fertilisation and Embryology Bill, published in 1989. There was significant disagreement between parliamentarians as to whether, on the one hand, only married couples should be given access to treatment, and, on the other, there should be any social screening of prospective parents. The majority of parliamentarians ultimately reached a compromise position that the welfare of the child to be born should be taken into consideration before treatment is provided, but that it should not be the paramount consideration. Essentially the UK Parliament declared that there should be limits to the availability of fertility treatment but left the nature of those limits largely undefined. As discussed in Part III, the lack of clarity of the welfare of the child provision in the HFE Act 1990 led to the HFEA developing ad hoc policy on PTT that resulted in legal challenge and public criticism.

The welfare of the child provision came under considerable attack by the STC in its review of the HFE Act 1990. The STC was critical of the HFEA’s application of the welfare of the child provision in its policy and licensing decisions in the Hashmi and Whitaker cases. However, the STC’s criticism extended more generally to the welfare of the child provision itself. The STC recommended that the provision ‘be abolished in its current form’ as it ‘discriminates against the infertile and some sections of society, is impossible to implement and is of questionable practical value in protecting the interests of children born as a result of assisted reproduction’.

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85 Tomorrow’s Children Consultation, above n 8, [2.1].
87 Tomorrow’s Children Consultation, above n 8, [2.1].
88 Ibid. In effect, the question of who should access ART could not be democratically determined at the time.
89 STC Report, above n 10, Recommendation 24, [107].
STC recommended that, instead of the welfare provision, a ‘minimum threshold principle’ should apply to prevent the ‘risk of unpreventable and significant harm’ to a child born using ART.  

The UK Government chose not to abolish the welfare of the child provision. In response to the STC Report in August 2005, the UK Government chose to retain the welfare of the child provision on the basis that it ‘is a central tenet of the HFE Act’, and one of the key guiding principles which informs the HFEA and its Code of Practice. According to the Government, the welfare provision recognises that the welfare of children cannot always be adequately protected by satisfying the interests of the parents involved and there needs to be a balance between the rights and interests of parents and the welfare of any child who may be born. While recognising the difficulty in framing these considerations in national legislation and policy guidance, the Government opted to retain the provision. It agreed, however, to seek wider public views on how the welfare of the child may best be secured, as part of its review on the HFE Act 1990.

The Government engaged in a public consultation in 2005 to determine whether the welfare of the child requirement should remain in the HFE Act 1990 as a legal obligation on clinics providing treatment services and, if so, how that requirement should be expressed. The Government also sought views on whether the requirement to take account of ‘the need of a child for a father’ should be removed from the welfare provision. Following the public consultation, the Department of Health commissioned an independent report on the responses obtained. The report, which is qualitative in nature, covered a broad range of views on the purpose and scope of the welfare of the child provision. However, the Government took the view in its White Paper that the responses to the public consultation ‘generally favoured retention of a “welfare of the child” consideration in some form’. The Government therefore proposed retaining the duty to take account of the welfare of

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90 Ibid. The STC stated that doctors should be encouraged to minimise the risks to any child to be born through the promotion of good medical practice rather than legislation.
91 Government Response to STC Report, above n 15, [37].
92 Ibid [37]. [38].
93 Department of Health Public Consultation, above n 11, [3.23]-[3.26].
94 Ibid [3.22].
96 White Paper, above n 16, [1.11].
the child in providing fertility treatment but removing reference to ‘the need for a father’.

The Joint Committee, which reviewed the earlier Human Tissue and Embryos (Draft) Bill, also supported the retention of the welfare of the child provision, stating that ‘the welfare of the child is a key area where consistent, understandable and enforceable legislation is needed’. The Joint Committee considered the debate over whether the welfare of the child to be born should be paramount but supported the current position of ‘taking into account’ the welfare of the child, rather than treating the welfare of the child ‘above all else’.

B HFEA policy on the welfare of the child

There is no guidance in the HFE Act 1990 on how clinics should interpret the welfare of the child requirement. The HFEA is required under the HFE Act 1990 to give guidance on the welfare of the child provision in its Code of Practice, and it may take into account compliance with the Code in its licensing decisions. HFEA guidance on the application of the welfare of the child provision is contained in Guidance Note 8 of the HFEA Code of Practice.

The first HFEA Code of Practice was published in 1991. Initially, the Code required assessment for treatment to be based on a wide range of factors, including the demonstration of a commitment to raising children, age, immediate and family medical histories, the needs of any child who may be born, any risk or harm to the child that might be born, and the effect of a new baby on any existing child.

Changes have been made to the Code over time in a piecemeal fashion and additional factors have been added from time to time. The broad range of factors set out in the Code allowed for treatment decisions to be made by clinics, based on a variety of social reasons. The Code was not properly reviewed until after the 6th edition was

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97 Ibid [2.23]-[2.26]. Ultimately, the reference to ‘the need for a father’ was replaced with ‘the need for supportive parenting’ by the HFE Act 2008, following a free vote of both Houses of Parliament.
98 Joint Committee Report, above n 18 [241].
99 Ibid [221]. In support of its position, the Joint Committee quoted Professor Raanan Gillon, Emeritus Professor of Medical Ethics at Imperial College London who told the Committee: ‘It seems to me that one needs to be very careful about the welfare of the child being paramount, it does not seem to me that this is the normal reason for having a child.
100 HFE Act 1990, s 25(2), (6).
101 HFEA 8th Code, above n 2, Guidance Note 8.
published in January 2004. The need for review arose due to substantial criticism that the wide discretion afforded to clinics caused discrimination and that the application of the welfare principle was ‘ad hoc, inconsistent and dependent upon each individual clinic’s general policy, the attitude of their ethics committees and the views of individual clinicians.’

The HFEA launched a review of existing policy on the welfare of the child requirement in April 2004. As part of its review, the HFEA undertook a public consultation on the guidance it gives to fertility clinics on the welfare of the child provision. The consultation document outlined various approaches to taking into account a child’s welfare. According to the first ‘maximum welfare’ approach, ‘one should not knowingly and intentionally bring a child into the world in less than ideal circumstances’. The HFEA stated that this approach ‘considers a child’s welfare to be of paramount importance’. The second ‘reasonable welfare’ approach provides that the child to be born must have ‘an adequate future, cared for by a “good enough” family’. Finally, the ‘minimum welfare’ approach only condemns treatment where the child to be born is at ‘high risk of serious harm’. The consultation document also posed options for revising the welfare of the child guidance, including: the factors which should be taken into account in an assessment of the welfare of the child; how those factors should be weighed in the decision to provide or refuse treatment; and what enquiries should be made to gather information.

In its 2005 report on the welfare of the child, the HFEA acknowledged that a balance needs to be struck between patient autonomy and the welfare of the child to be born. It concluded that the current guidance erred too much towards the latter at

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103 Tomorrow’s Children Consultation, above n 8, Chair’s Foreword.
106 Tomorrow’s Children Consultation, above n 8, [2.4].
107 Ibid.
108 Ibid.
109 Ibid. This third approach is consistent with the ‘minimum threshold principle’ for ART proposed by the STC. See discussion, above, Part IVA.
110 Tomorrow’s Children Consultation, above n 8, [3].
111 Tomorrow’s Children Report, above n 9.
the expense of patient choice.\textsuperscript{112} The HFEA decided that there should be a general presumption in favour of treatment, ‘but that treatment should be refused where clinics conclude that the child to be born, or any existing child of the family, is likely to suffer serious harm’.\textsuperscript{113} This approach seems to be roughly consistent with a ‘minimum welfare’ approach to the welfare of the child.\textsuperscript{114} The HFEA also reviewed the risk factors that should be taken into account in an assessment about the welfare of the child. The HFEA concluded that risk factors should be limited to those that may cause serious physical, psychological or medical harm and not include social factors.\textsuperscript{115} Finally, the HFEA concluded that clinics should make welfare assessments in accordance with their own professional judgement, based on information collected from patients, instead of being obliged to contact their general practitioner.\textsuperscript{116}

The HFEA announced its new guidance on the welfare of the child to be born on 2 November 2006.\textsuperscript{117} In contrast to the previous guidance, the new guidance contained a ‘presumption to provide treatment, unless there is evidence that the child to be born, or any existing child of the family, is likely to suffer serious medical, physical or psychological harm’.\textsuperscript{118} The current HFEA guidance on the welfare of the child provision has a slightly different formulation. Clinics are now required to refuse treatment where there is a ‘risk of significant harm or neglect’ (emphasis added) to either the child to be born or any existing child of the family.\textsuperscript{119} Clinics are required to make fair and non-discriminatory welfare of the child assessments, based on the wishes of all involved.\textsuperscript{120} A medical history should be obtained by the patient and her partner and centres should seek their consent to obtain any further information from third parties.\textsuperscript{121}

\textsuperscript{112} Ibid, 6.
\textsuperscript{113} Ibid.
\textsuperscript{114} The HFEA’s new approach is also similar to the minimum threshold approach suggested by the STC. However, Elliston has suggested that the retention in the HFE Act 1990 ‘of a specific need to consider “supportive parenting” may be viewed as going beyond this minimum threshold’: Sarah Elliston, ‘The HFE Act 2008 – An End or a Beginning?’ BioNews 16 October 2009 http://www.bionews.org.uk/page_49873.asp.
\textsuperscript{115} Tomorrow’s Children Report, above n 9, 8.
\textsuperscript{116} Ibid, 10-11. Previously, clinics were required to routinely contact a patient’s general practitioner before making assessments about treatment.
\textsuperscript{118} HFEA Chair’s Letter, above n 117. See also HFEA 6th Code, above n 117, [3.1], [3.8].
\textsuperscript{119} HFEA 8\textsuperscript{th} Code, above n 2, [8.15]. See also [8.2], [8.3].
\textsuperscript{120} Ibid [8.7].
\textsuperscript{121} Ibid [8.13].
The two main areas of potential harm for the child to be born as a result of PTT are the physical risks of embryo biopsy, and the physical and psychological risks associated with being born as a donor. I discussed these risks in detail in Chapter 2. As discussed in Part IIIC, HFEA guidance on PTT specifically requires clinics to consider these risks before providing treatment. The current difficulty faced by clinics in assessing the welfare of the child to be born as a result of PTT is the lack of evidence on the potential risks. This has led the HGC to call for further research into the risks to the child to be born as a result of PTT.

In its report on genetic screening technologies, the HGC stated that PGD is a long and complicated process and there is little evidence about the safety of embryo biopsy, particularly in relation to longer-term outcomes. The HGC recommended that patients seeking PGD continue to be offered implications counselling and that regulatory oversight of PGD be improved to ensure more satisfactory and systematic follow-up of all children born as a result of PGD. In addition, the HGC recommended that there should be research into the wellbeing of children born as a result of PTT, given the lack of evidence about the impact of PTT on the child who is born or family relationships.

C Lessons for Australia

The extensive review of the welfare of the child provision in the HFE Act 1990 and its interpretation by the HFEA has highlighted some of the shortcomings of the provision, particularly in its application to PTT. These shortcomings apply equally to the welfare of the child provision in the Victorian ART Act (Vic). In fact, the welfare provision in the ART Act (Vic) is more problematic than its UK counterpart as it requires the interests of the child to be born to be treated as paramount, which is inconsistent with the purpose of PTT.

Part of the problem with the welfare of the child provision in the UK is that its origins do not reveal a clear purpose behind the provision. The inclusion of the welfare of the child provision in the original HFE Act 1990 has been described as ‘a pragmatic regulatory solution which neatly avoids the ethical dilemma of who should gain

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122 Making Babies Report, above n 13, [4.6], [4.13].
123 Ibid, recommendations 25, 26, see also [4.13].
124 Ibid recommendation 28, see also [4.19]-[4.22].
access to treatment, by leaving it to clinics’ discretion.’ Subsequent debate over the welfare provision in the UK highlights the need to reconsider the role of the welfare of the child principle in Australian ART regulation, specifically in the context of PTT. As discussed in Chapter 2, the inclusion of the welfare of the child principle in the ART Act (Vic) was unanimously supported by Parliament, with little consideration about how the provision should be applied in practice.

The decision by the UK Parliament to retain the welfare of the child provision may be described as pragmatic. In replacing ‘the need for a father’ with ‘the need for supportive parenting’, Parliament has removed the discriminatory element of the provision, which was politically unsustainable. However, the other major criticisms levelled at the welfare of the child provision by the STC remain. Significantly, the welfare of the child provision continues to be vague and difficult to apply in the absence of clear legislative guidance. The welfare of the child provision in the ART Act (Vic) is equally vague. Given the lack of clarification of the meaning of the welfare of the child in the context of ART legislation, I have devoted a large part of this thesis to analysing the welfare of the child from ethical principles. I explored the current conceptualisation of the welfare of the child to be born in the context of PTT in Chapter 2 and proposed a revised conceptualisation in Chapter 3 based on the notion of human flourishing.

The review by the HFEA of its policy on the welfare of the child provision has provided some much-needed clarity. The current risk-based approach of the HFEA, with the presumption of treatment unless information suggests there is a ‘risk of significant harm or neglect’, provides clear parameters for clinics to work within. It should also minimise discrimination based on sexuality or marital status under the guise of the welfare provision. The risk-based approach in the UK is similar to the ‘minimum welfare’ approach to the child to be born that I proposed in Chapter 4. Greater clarity and certainty could be achieved in the UK by enshrining a risk-based or ‘minimum welfare’ approach to the child to be born in legislation, particularly as the HFEA guidance is not legally enforceable. There is no clear guidance on how the welfare of the child provision should be interpreted in Victoria, either in the ART Act

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125 Fenton and Dabell, ‘Time for Change (1)’, above n 74, 848.
126 See discussion in Chapter 2, Part IIA.
(Vic) or from VARTA. A ‘minimum welfare’ approach to the child to be born as a result of PTT should be included in legislation in Australia.

Assessments about the welfare of the child to be born as a result of PTT could also be improved in the future once further evidence is available on the potential physical and psychological risks for the child to be born. The recommendations by the HGC to amend the HFE Act 1990 to permit more satisfactory and systematic follow-up of all children born using PGD and to promote research into the wellbeing of children born following PTT have real merit. Current HFEA policy on PTT requires clinics offering PTT to have arrangements in place for inviting patients and their families to take part in long-term medical and psychosocial studies of children born as a result of PTT.127 Welfare of the child assessments for PTT in Australia could equally be improved through a nationally coordinated system of monitoring the effects of PTT children born using the procedure.

V ROLE OF THE STATE IN REGULATING ART

The other major theme that arose out of the reviews of the HFE Act 1990 was the role of the state in regulating assisted reproduction. I begin this Part by exploring the justifications in the UK for state involvement in assisted reproductive decision-making. I then review the current regulatory framework for ART and PTT in the UK, including the recent amendments to the HFE Act 1990. I outline the proposals for reform of the HFE Act 1990, which arose out of the various reviews of the Act, and the responses to them by the UK Government. Finally, I explore some of the advantages and disadvantages of the ‘permissive’ regulatory approach to ART and PTT in the UK. In particular, I consider whether the benefits of a broad and flexible approach to regulating assisted reproduction (under which the HFEA has a wide discretion to formulate policy) are outweighed by the problems associated with this approach.

A Justifications for regulating assisted reproduction

The regulation of assisted reproduction has been justified in the UK on the basis that the state has an interest in restricting reproductive freedom to prevent harm or negative impacts on society. The status of the human embryo lies at the heart of the

127 HFEA 8th Code, above n 2, Guidance Note 10 [10.24].
regulation of assisted reproduction in the UK. In 1984, the Warnock Committee determined that the embryo had a special status, entitling it to ‘some protection in the law’. In its review of the Draft Bill, the Joint Committee echoed this position by stating that ‘the special status of the embryo means regulation of both research and treatment continues to be appropriate and desirable.’

It is not possible in a diverse society to reach a consensus on the status of the embryo and its relationship to the moral principle of the sanctity of human life. There is a range of views on the moral status to be accorded to the embryo. The STC identified the following three principle views:

1. The embryo is a human life, entitled to full human rights;
2. The development of personhood is a gradual process but the embryo is entitled to some protection (gradualist approach); and
3. The embryo is merely a collection of cells, with the potential to develop into a human being.

The Warnock Committee adopted a gradualist approach to the developing moral status of the embryo. According to the STC, this approach ‘provided a firm foundation for legislation’. The STC recognised that the gradualist approach may create difficulties in the drafting of legislation but concluded that ‘it represents the most ethically sound and pragmatic solution and one which permits [IVF]… within certain restraints set out in legislation.’ The gradualist approach enables a balance to be struck between the protection to be afforded to the developing embryo and the interests of potential parents. It achieves this by allowing infertility treatment to be undertaken on the basis that the reasons for the creation and use of embryos in a specific manner are carefully evaluated.

129 Joint Committee Report, above n 18, [105].
130 See, for example: Making Babies Report, above n 13, [22]; STC Report, above n 10, [46].
131 Ibid [24].
132 This approach is generally identified with the Catholic Church, although advocates of this position are not exclusively Catholic: Ibid [25].
133 This approach is favoured by the Church of England and Jewish faith: ibid [26].
134 This approach was discussed in the Warnock Report, above n 5, [11.5].
135 Ibid [11.17].
136 STC Report, above n 10, [28].
137 Ibid.
138 Ibid [29].
The use of embryos in assisted reproduction for implantation in order to establish a pregnancy is generally considered less controversial than the use of embryos in research, as the ultimate aim in assisted reproduction is the birth of a child. In the context of PTT, ‘unsuitable’ embryos may ultimately be destroyed in compliance with the relevant regulatory regime. Those who favour an absolutist approach to the status of the embryo consider any form of embryo selection, including PTT, to be morally wrong. According to a gradualist view of the status of the embryo, however, embryo selection (and destruction) is acceptable provided there are legitimate reasons for the procedure.

Apart from the destruction of the embryo, other concerns have been raised in relation to the potential physical harm to the embryo from the biopsy process, the commodification of the child to be born, and the potential long-term physical and/or psychosocial harms to the child to be born. These concerns, which I discussed in detail in Chapter 2, arise out of the welfare of the child principle. According to the STC, concerns about harm can be adequately addressed with the correct application of the precautionary principle. In the context of assisted reproductive technologies, this means ‘that alleged harms to society or patients need to be demonstrated before forward progress is unduly impeded.’

The STC stated in its report that the promotion of consistent and satisfactory treatment standards provides a further justification for regulating assisted reproductive treatment. The Warnock Report cited the ‘protection of the public’ as ‘the primary objective of regulation’ and recommended the establishment of a statutory licensing authority to regulate infertility services. A regulatory framework that imposes standards and accreditation requirements can promote high standards of treatment and protect patients from some of the health risks associated with ART. I discuss the ways in which regulation can operate as a form of ‘quality control’ in more detail in

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139 Ibid [30].
140 As discussed in Chapter 2, Part VA1, the NHMRC Guidelines on ART state that embryos may either be stored for future treatment, donated, destroyed, or used in research (if they are declared “excess embryos”).
141 STC Report, above n 10, [110].
142 See discussion in Chapter 2, Parts IV and V.
143 STC Report, above n 10, [47].
144 Ibid [317].
145 Warnock Report, above n 5, [13.3].
Chapter 6. In the next section, I critically analyse the current regulatory framework for ART and PTT in the UK.

B Current Regulatory Framework for ART and PTT

1 A ‘permissive’ approach to regulating ART

The HFE Act 1990 regulates assisted reproduction through the licensing of clinics involved in the creation and use of embryos. The Act sets out broad licensing criteria and confers discretionary decision-making powers on the HFEA. As previously discussed, the HFE Act 1990 specifically requires the welfare of the child to be born to be taken into account in relation to treatment services by making it a condition of every licence under the Act, but leaves it to the HFEA to provide guidance on this requirement. The Act has, in the past, been described as essentially ‘permissive’ rather than ‘prescriptive’, subject to constraints applied by the HFEA and the welfare of the child provision.

In creating this regulatory framework, the UK Parliament has effectively devolved decisions about access to reproductive treatment to clinics, subject to the welfare of the child requirement and in accordance with HFEA policy. This is in line with the approach recommended by the Warnock Committee and, as discussed above, was a ‘pragmatic’ response to the question of access to treatment, which Parliament was unable to determine prior to the enactment of the HFE Act 1990. Through its Code of Practice, the HFEA gives guidance to clinics about the proper conduct of licensed activities, including assessments about the welfare of the child to be born. The HFEA can revise the whole or any part of the Code from time to time, in order to keep pace with new developments.

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146 HFE Act 1990, ss 13(1),(5) and 25(1). See Part II.
147 McDonald, Fenton and Dabell, above n 39, 294.
148 See discussion above, Part IVC.
149 The treatment services for which a licence are required include the creation of embryos in vitro, embryo screening and implantation: see para 1(a), (d) and (e) of Schedule 2 of HFE Act 1990. See also s 11(1)(a) of the HFE Act 1990.
150 HFE Act 1990, s25(1); HFEA 8th Code, above n 2.
developments in the law or clinical practice.\textsuperscript{151} The HFEA has effectively been given a wide discretion to develop policy, ‘in recognition of the fact that technological advances in this area require a fast response, unhindered by the machinery of Parliament’.\textsuperscript{152}

The HFEA also has an advisory role as it is required to keep the HFE Act 1990 under review and advise the Secretary of State upon request.\textsuperscript{153} The HFEA therefore functions both as a regulator and an advisory body.\textsuperscript{154} As discussed below, this dual role is problematic.\textsuperscript{155}

2 HFE Act 1990 now specifically sanctions PTT

Prior to its amendment in 2009, the HFE Act 1990 did not specifically mention PTT. As discussed in Part III, this created difficulties for the HFEA as it was required to make swift policy decisions about PTT in response to requests from clinics, which has led to wide criticism and legal challenge. HFEA policy on PTT was heavily influenced by the welfare of the child provision, which the HFEA had difficulty interpreting.

The amendments to the HFE Act 1990 provide greater clarity about the availability of PTT. The HFE Act 1990 now specifically authorises the HFEA to license PTT where the existing sibling ‘suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child’.\textsuperscript{156} However, the tension between flexibility and regulatory certainty remains in the new legislation. Licences for PTT are still granted by the HFEA on a case-by-case basis and must be in accordance with the welfare of the child provision in the HFE Act 1990. As Elliston points out:

In reviewing the new regulatory regime, it is important to remember that much still rests upon the judgement of treatment providers and the interpretation of the legislation made by the HFEA.\textsuperscript{157}

\textsuperscript{151} HFE Act 1990, s 25(4). Licensed centres are notified of changes to HFEA policy by Chair's Letters: HFEA, HFEA Chair’s Letters http://www.hfea.gov.uk/189.html.
\textsuperscript{152} Fenton and Dabell, ‘Time for Change (1)’, above n 74, 848.
\textsuperscript{153} HFE Act 1990, s 8.
\textsuperscript{154} STC Report, above n 10, [208].
\textsuperscript{155} See discussion below, Part VD2.
\textsuperscript{156} HFE Act 1990, Schedule 2, para 1ZA(1)(d).
\textsuperscript{157} Elliston, above n 114.
In particular, the welfare of the child provision remains vague and open to interpretation. Although the current HFEA policy on PTT in its Code of Practice suggests a ‘minimum welfare’ approach to the welfare of the child akin to the ‘minimum threshold’ proposed by the STC, ‘the retention of a specific need to consider ‘supportive parenting’ in the welfare provision of the HFE Act 1990 may be viewed as going beyond this minimum threshold’.  

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C Proposals for Reform

1 STC Proposals for a New Regulatory Approach

In its report on the law on ART, the STC considered the current regulatory regime in the context of alternative legislative and regulatory models and proposed a new regulatory approach to assisted reproduction.

The STC asserted that greater Parliamentary oversight over issues related to assisted reproduction ‘would give the public greater confidence that the big ethical issues of the day are being given adequate attention’.  

\[159\] Whilst recognising the flexibility in conferring a broad policy-making discretion on the HFEA, the STC concluded that Parliamentary scrutiny of contentious bioethical issues was sufficiently important to compromise that flexibility. To this end, the STC recommended the establishment of a new Parliamentary Standing Committee on Bioethics to undertake annual scrutiny of the regulatory authority, make recommendations about legislation, and scrutinise draft legislation before Parliament within its remit.  

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In terms of reproductive decision-making, the STC recommended that any intervention by the state into the reproductive choices of individuals must be based on sound ethical principles and take into account evidence of harm to children or society. To achieve this, the STC proposed that the current regulatory model, in which the HFEA has a large degree of policy-making flexibility, be replaced with a model that devolves clinical decision-making to patients and clinicians while strengthening Parliamentary and ethical oversight.  

\[161\] The STC proposed the creation of a new body – the Human Genetics, Fertility and Tissue Commission – to provide recommendations on significant ethical issues such as those arising in relation to PTT.

\[158\] Ibid.
\[159\] STC Report, above n 10 [356].
\[160\] Ibid [398].
\[161\] Ibid [390].
The new body, which would expand the remit of the current Human Genetics Commission to include the issues currently in the domain of the HFEA, would be informed by public consultation and social science research.162

2 Government Response to STC Report and White Paper

In its White Paper, the Government acknowledged some deficiencies in the current regulation of ART but ultimately proposed relatively minor changes to the regulatory framework for ART. The Government proposed that ‘the current model of regulation, whereby Parliament sets the prohibitions and parameters within which a statutory authority licenses activities, should continue’.163

In its Response to the STC Report, the UK Government agreed that it would be preferable if the parameters for PGD were more clearly set out in law.164 It therefore proposed in its White Paper that explicit rules for new embryo screening technologies, including PTT, be incorporated into legislation.165 The Government specifically sanctioned the use of PTT to identify a tissue match for a sibling suffering from a life-threatening illness.166 The Government proposed that licensing of PTT be undertaken on a case-by-case basis.167 While acknowledging the considerable debate over HFEA decisions about the selection and screening of embryos, the Government confirmed an ongoing role for a regulator ‘in ensuring consistency in practice, and the licensing of screening in accordance with criteria relating to the seriousness of the disorder in question’.168

As part of a broader Government goal to streamline the bureaucracy in providing public services, the Government also proposed that the HFEA be merged with the Human Tissue Authority (HTA) into a new regulatory body, the Regulatory Authority for Tissue and Embryos (RATE).169

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162 Ibid [399]. The new body would not provide clinical guidance, which would remain within the remit of the regulatory authority.
163 White Paper, above n 16, [2.4].
164 Government Response to STC Report, above n 15, [44].
165 White Paper, above n 16, [2.43].
166 Ibid.
167 Ibid [2.44].
168 Ibid.
169 The merger policy arose out of the Department of Health’s review, Reconfiguring the Department of Health’s Arms Length Bodies (July 1994). The HTA regulates the removal, storage, use and disposal of human bodies, organs and tissue from the living and deceased, pursuant to the Human Tissue Act 2004 (UK).
3 Joint Committee Review of Draft Bill

In its report on the Draft Bill in August 2007, the Joint Committee commented on the failure of the Draft Bill to provide both an appropriate ethical and a balanced regulatory framework. It also made specific recommendations in relation to PGD, PTT and the welfare of the child provision, which are set out in Table 2. In particular, it recommended the Draft Bill be amended so that PTT would be available for ‘serious’ as well as ‘life-threatening’ conditions.170

In respect of the ethical framework, the Joint Committee criticised the Draft Bill for lacking explicit ethical principles and guidelines to cater for the regulation of new scientific developments.171 The Joint Committee contended that ‘the draft Bill gives the impression of tinkering with existing legislative provisions rather than going back to first principles and seeking to take an overall view of where to go in the next 15 years or so’.172 The Joint Committee called for the establishment of a specialist parliamentary ethics committee to provide ethical input to the Draft Bill and other legislation raising significant issues in bioethics.173

In addition to establishing a satisfactory ethical framework, the Joint Committee stated that the Draft Bill should also ‘set an appropriate, consistent and workable regulatory architecture which achieves the right balance of responsibilities between Parliament, the regulator, clinicians and individuals.’174 In essence, this requires the Bill to balance legal certainty with the flexibility needed to deal with future scientific and medical developments, changing societal attitudes and individual circumstances. The Joint Committee strongly recommended against the proposed merger of the HFEA and the HTA on the grounds that a single body would have insufficient expertise to deal with two separate and complex areas.175 The Joint Committee was

170 Joint Committee Report, above n 18, [199].
171 This criticism has been echoed in academic debate. See, for example: Anna Smajdor, ‘The Review of the HFE Act: Ethical Expertise or Moral Cowardice?’ Bionews 6 Nov 2007 http://www.bionews.org.uk/page_37959.asp; McDonald, Fenton and Dabell, above n 39, 304.
172 Joint Committee Report, above n 18, [44].
173 The Joint Committee was unable to support proposals for an independent national bioethics committee, stating that ‘[u]ltimately it must be for Parliament to set the ethical framework, taking the widest range of advice’: ibid [48].
174 Ibid [49].
175 Ibid [92].
also unconvinced that a merger would save money or create a more streamlined regulatory process.\textsuperscript{176}

The Joint Committee accepted that regulation of treatment was appropriate and desirable given the special status of the embryo and the fact that regulation provides quality assurance and protection to patients.\textsuperscript{177} However, the Joint Committee did not wish to see the Government or the regulator involved in decisions that can safely and responsibly be devolved to patients and clinicians. The Joint Committee recommended that the Draft Bill ‘be amended to give the regulator statutory power to define areas of exemption from the current regulatory remit where appropriate’.\textsuperscript{178} This approach appears to be in line with public opinion. A public debate held by the Progress Educational Trust following the publication of the Draft Bill, discussed the role of the Government in imposing boundaries on PGD. There was a general consensus that prescriptive legislation in relation to PGD was problematic and that decisions around PGD should be made by affected families in consultation with clinicians.\textsuperscript{179}

\textbf{4 \textit{Government Response to Joint Committee Report}}

In its Response to the Joint Committee Report, the Government recognised the value of debating bioethical issues in Parliament but did not commit to establishing a specialist bioethics parliamentary committee. The Government did, however, abandon its proposal to merge the HFEA and RATE following the Joint Committee’s recommendation that the two regulators remain as separate entities.\textsuperscript{180} It also accepted the Joint Committee recommendation that PTT be extended to help those with ‘serious’ as well as ‘life-threatening’ conditions.\textsuperscript{181}

\textsuperscript{176} Ibid.
\textsuperscript{177} Ibid [105].
\textsuperscript{178} Ibid [105], see also [56].
\textsuperscript{181} Joint Committee Report, above n 18, [41].
The Government rejected the Joint Committee’s recommendation for a framework of devolved regulation on the basis that it would lack accountability and that greater regulatory flexibility would lead to increased scrutiny of the HFEA and legal challenge. The Government did, however, state that it supports a move towards ‘lighter touch’ regulation. In support of this, the Government referred to a clause in the Draft Bill requiring the HFEA ‘to carry out its functions effectively, efficiently and economically’ and with ‘regard to the principles of best regulatory practice.’

The Government introduced the revised Human Fertilisation and Embryology Bill (the HFE Bill) into Parliament on 8 November 2007 and, on 5 February 2008, the Bill was brought from the House of Lords with further amendments. The HFE Act 2008 received royal assent on 13 November 2008. Part 1 of the HFE Act 2008, which amended the HFE Act 1990 to permit PTT where the sibling suffers from a serious medical condition, came into force on 1 October 2009. The section in the HFE Act 2008 dealing with PTT is one of three controversial aspects of the Act for which Labour MPs were allowed a free vote of conscience in the House of Commons.

D Benefits and Disadvantages of Current Regulatory Framework

1 Benefits

There are certain benefits of the current regulatory model for assisted reproductive treatment in the UK, which consists of essentially permissive legislation with a broad policy-making discretion conferred on the HFEA. Such a flexible regulatory framework is better placed to deal with scientific and technological developments, which may not be in existence at the time of drafting the legislation. There are also certain advantages in delegating regulatory power to an arm’s length body like the

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182 Government Response to Joint Committee Report, above n 19, [8]-[13]. See HFE Bill, clause 7 (s 8ZA).
183 Clause 11 of the HFE Bill clarified the reference to ‘other tissue’ in para 1ZA(1)(d) of Schedule 2 of the HFE Act to exclude whole organ donation in para 1ZA(4). Clause 14(2)(b) of the Bill inserted the child’s need for ‘supportive parenting’ in s13(5) of the HFE Act (to replace the reference to the child’s ‘need for a father’, which was to be omitted).
HFEA. Unlike Parliament, the HFEA is ‘insulated against political pressures and vagaries’ and can make changes relatively quickly. 185

Furthermore, the fact that circumstances will vary in each individual case supports an approach to assisted reproduction that allows individual decisions about treatment to be made on a case-by-case basis within the broad parameters set by the law and HFEA policy. The issue of how closely assisted reproduction should be regulated has proven to be highly controversial and not easily determined at a Parliamentary level. This is not to suggest that there should be no regulation of assisted reproduction, but rather that the nature of the regulation should be flexible enough to be applied to different individual circumstances in a manner that is sensitive to the religious and moral values of potential parents.

2 Disadvantages

Some of the criticisms of the UK approach to regulating PTT have been addressed by the recent amendments to the HFE Act 1990. For example, the Act now specifically authorises the HFEA to license PTT, reducing the scope for further legal challenges. However, there are still some problems with the current model for regulating assisted reproduction and, specifically, PTT. In particular, the role of the welfare principle and the development of policy by the HFEA have not been universally endorsed.

As discussed in Part IV, the welfare of the child provision has been criticised for being inconsistent, unfair and discriminatory and has led to widespread criticism of decisions by the HFEA. 186 The Hashmi and Whitaker cases discussed in Part III highlight the difficulties faced by the HFEA in applying the welfare principle to applications for PTT. The STC criticised the approach by the HFEA to the development of policy in relation to PTT as ‘highly unsatisfactory’. 187 The STC argued for the abolition of the welfare requirement in its current form, on the basis that decisions about the welfare of the child are best made by patients in consultation with their doctor, rather than by the HFEA and clinics. 188

The criticism of HFEA policy on PTT leads to the broader question of whether the HFEA should be making policy decisions which directly impact on the reproductive

185 STC Report, above n 10, [356].
186 See, for example, STC Report, above n 10, [251].
187 Ibid [251].
188 Ibid [107].
rights of individuals. The first limb of this question relates to whether or not it is appropriate for a statutory authority to make these types of decisions in the absence of democratic debate. According to the STC, ‘there are no compelling reasons for a statutory authority to make judgements on whether or not a family can seek PTT, provided they fall within parameters set by Parliament’.  189

The second limb to the broader question about the scope of HFEA’s policy-making relates to the ability of the HFEA to exercise its substantial policy-making discretion in a fair and balanced manner. The HFEA’s membership comprises doctors, scientists and a substantial number of lay persons.  190 Some commentators have suggested that the HFEA’s substantial lay membership ‘weakens its expertise’.  191 The STC raised concern about the extent of scientific and clinical expertise of the HFEA but recognised the importance of the principle behind a lay majority where issues of public concern are involved.  192 The HFEA also has an Ethics and Law Group to advise it on ethical issues and it often supplements this group with additional expertise drawn from outside the HFEA to ‘gain a wider ethical input’.  193

A further concern raised in relation to the HFEA is the incompatibility of its dual regulatory and advisory roles. The HFEA’s ‘dual role as both guardians and contesters of the Act’ has been described by the STC as ‘problematic’.  194 The problematic nature of these dual roles came to the fore when the HFEA was faced with an application for a licence for PTT on behalf of the Hashmi family. Although the STC recognised that the HFEA had little choice but to make a licensing decision, it criticised the HFEA for its failure to invite Parliament to clarify the law on PTT until six years later.  195 A similar conflict arises between the HFEA’s regulatory and policy roles, according to the British Fertility Society.  196

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189 STC Report, above n 10, [129].
190 HFE Act, s 5, Schedule 1. This is consistent with recommendation 2 in the Warnock Report [13.4]. The Warnock Committee stated that while the regulating body would need access to scientific and medical expertise, ‘[i]t is concerned essentially with broader matters and with the protection of the public interest’: Warnock Report, above n 5, [13.4].
191 McDonald, Fenton and Dabell, above n 39, 294.
192 STC Report, above n 10, [196] – [198]. The STC suggested that this problem could be resolved by establishing an Authority comprised entirely of lay members but which was informed by a specialist advisory committee with scientific and medical expertise: [200].
193 Joint Committee Report, above n 18, [35].
194 STC Report, above n 10, [208].
195 Ibid [250].
196 STC Report, above n 10, [363].
Despite the flexible nature of regulation under the HFE Act 1990, the ability of the Act to regulate new areas of reproductive technology consistently and fairly has been challenged by the use of PTT to create saviour siblings. The inevitable rate of scientific and technological development necessitated the review of the HFE Act 1990 to deal with new reproductive technologies, such as PTT, that fell outside the scope of the Act. The problems faced by the HFEA in dealing with applications for PTT highlight the fact that even flexible legislative frameworks require review in the face of new technologies that were not envisaged at the time of enactment.

E Lessons for Australia

Victoria has a similar regulatory regime for ART to the permissive regime operating in the UK. It is therefore helpful to draw on the above analysis of the UK regulatory framework when reviewing the regulation of PTT in Australia.

The UK Government has, in one sense, been between a rock and a hard place in relation to the level at which it regulates PTT. As the past has shown, there is a need to specifically legislate on PTT to avoid inconsistency and legal challenge. Legislative guidance can also serve to protect the embryo and the child to be born from unnecessary harm and therefore serve the interests of society more generally. However, the more prescriptive legislation is, the more it encroaches on the reproductive choice of individuals.

Reproductive choice is better preserved by permissive legislation that specifically allows PTT but devolves decisions about PTT to patients, in conjunction with their health care team. As the STC noted, there is no evidence that parents would use PTT for ‘trivial’ reasons to a degree that would harm the child to be born as a result of the procedures. The focus of PTT regulation should therefore be to assist parents in the ethically complex decision-making process. Some independent ethical oversight may also be necessary in relation to decisions involving PTT, to provide a threshold level of protection to the child to be born. I explore the options for regulating PTT in more detail in Chapter 6 when I propose a new regulatory framework for PTT in Australia.

197 STC Report, above n 10, [251].
VI CONCLUSION

The amendments to the HFE Act 1990 have improved the regulation of PTT in the UK. It is now clear that the HFEA has the authority to licence PTT within clearly defined parameters on a case-by-case basis. The HFEA’s Code of Practice also now provides clearer guidance on the welfare of the child provision, with a presumption in favour of treatment unless there is a ‘risk of serious harm or neglect’ to either the child to be born or any existing child of the family. The law and policy on PTT in the UK provides much needed clarity in an ethically complex area that has significant social impact. In contrast to the position in Australia, where the interests of the child are treated as paramount, the approach in the UK to the welfare of the child to be born is easier to apply and more consistent with the primary purpose of PTT (to save the life of an existing child). There is also merit to a permissive approach to PTT where decisions are made on a case-by-case basis, as the circumstances of each case will vary significantly. A flexible regulatory framework can accommodate new information that becomes available on the risks and benefits associated with PTT.

However, the current flexible regulatory scheme in the UK has some drawbacks. The HFEA has a broad discretion to develop policy in relation to the welfare of the child provision, which remains vague and open to interpretation. This raises issues about accountability and consistency in relation to decisions by the HFEA about PTT. The proposal of the STC, to replace the model in which the HFEA has a large degree of policy-making flexibility with a model that devolves clinical decision-making to patients and clinicians while strengthening Parliamentary and ethical oversight, has some real merit. The welfare of the child provision could be replaced with a provision clearly setting out a minimum threshold level of protection for the child to be born. Ethical oversight of individual decisions could be carried out by clinical ethics committees, which are arguably better placed for this task than a statutory body like the HFEA.

I draw from the lessons learnt about regulating PTT in the UK in the next Chapter, where I propose a new approach to regulating PTT in Australia.
CHAPTER 6

REFORMING PTT REGULATION IN AUSTRALIA

I INTRODUCTION

In this Chapter, I outline a regulatory framework for PTT in Australia, based on the relational ethical approach I proposed in Chapter 4. I also draw on the lessons learnt in Chapter 5 about regulating PTT in the UK to inform my proposals for reform. I begin by summarising the problems with the current framework for regulating PTT in Australia raised at the beginning of this thesis and briefly outlining how I intend to address them in this Chapter.

A Recapping problems with PTT regulation in Australia

In Chapter 1, I argued that the regulation of PTT in Australia is fragmented, inconsistent, and lacks a clear ethical foundation. These problems are partly due to the constitutional limitations on the Commonwealth Parliament, which does not have explicit constitutional power to legislate nationally in relation to the provision of ART services. However, as discussed in Chapter 1, the Commonwealth Parliament has on occasion circumvented constitutional limitations to enact federal legislation in areas of state legislative power with corresponding state legislation. For example, the Commonwealth Parliament enacted national legislation on human embryo research and cloning technologies and, after agreement through COAG, the states and territories enacted mirror legislation to achieve consistency across Australia.  

Although federal cooperative arrangements can bring their own challenges, this does not mean that they should not be explored as one option for implementing uniform national regulation in relation to ART.  

In this Chapter, I outline a unified national approach to regulating PTT in Australia based on clear ethical foundations. As discussed in Chapter 1, there have been several calls for a unified national approach to ART in Australia, particularly in relation to the

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1 See: Prohibition of Human Cloning Act 2002 (Cth); Research Involving Human Embryos Act 2002 (Cth).
2 For a discussion of the limitations of Commonwealth-State cooperative schemes as well as other options for enacting uniform national legislation on ART, see Chapter 1, Part IIIA, esp footnotes 44 and 45. An in-depth discussion of the constitutional options and their limitations is beyond the scope of this thesis.

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‘social issues’ raised by controversial genetic testing technologies like PTT.³ To date, Victoria is the only state in Australia to have specifically regulated PTT.⁴ I shall therefore focus on how Victorian law and policy could be improved, in light of both the ethical discussion in Chapters 2 to 4 and the lessons from the UK in Chapter 5. My proposals for reform could then be used as a template for the other states and territories in Australia to form the basis of a cooperative federal scheme for regulating PTT throughout Australia.

A fundamental problem that lies at the core of PTT regulation in Victoria is the emphasis in the Assisted Reproductive Treatment Act 2008 (Vic) (ART Act (Vic)) on the welfare and interests of the child to be born. In Chapter 1, I argued that the paramount importance attributed to the welfare and interests of the child to be born under the ART Act (Vic) is inconsistent with PTT, a procedure motivated by the interests of the parents and the existing ill sibling. This inconsistency is not surprising given the lack of ethical analysis of the application of the welfare of the child principle to PTT by legislators and law-reformers in Australia. My ethical analysis of the welfare of the child in Chapters 2 to 4 supports a relational approach to PTT, whereby the interests of family members are taken into account in connection with the interests of the child to be born. Instead of attributing paramount importance to the welfare and interests of the child to be born, I propose that legislation should confer a minimum threshold level of protection to the child to be born. In this Chapter, I outline a regulatory framework for PTT in accordance with this relational approach.

I propose detailed national policy guidelines for PTT, based on the National Health and Medical Research Council (NHMRC) Guidelines on ART ⁵ and the previous VARTA Conditions on PTT. These Commonwealth and Victorian policies on PTT contain some useful guidance on PTT. In particular, they clarify the circumstances in which PTT is available and the type of support clinics should provide parents. The case-by-case approach to decision-making reflected in these policies is appropriate

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³ See Chapter 1, Part IIIA.
⁴ As discussed in Part IIC of Chapter 1, Victorian policy on PTT is currently being reviewed. For the purposes of this thesis, I refer to the Victorian Assisted Reproductive Treatment Authority (VARTA) Conditions on PTT that were in place up until July 2010: VARTA, Conditions for Use of Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis (February 2010) (previous VARTA Conditions on PTT).
⁵ NHMRC, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004 (as revised in 2007 to take into account the changes in legislation) (June 2007) (NHMRC Guidelines on ART)
given that the circumstances of individual cases will vary considerably. In practice, the current NHMRC Guidelines on ART could be amended to incorporate the detailed national guidelines I propose. However, I highlighted three significant gaps in the current Commonwealth and previous Victorian policies on PTT in Chapter 1. First, there is a lack of ethical guidance for parents seeking PTT. Second, insufficient consideration is given to the legitimate interests of other family members affected by a decision to use PTT. Third, there is no effective monitoring of the short and long-term consequences for children born as a result of PTT. I address these gaps in the regulatory matrix for PTT in this Chapter. My proposed regulatory framework for PTT in Australia is outlined in Table 3.

B Chapter outline

I commence this Chapter by asking, in Part II, whether PTT should be regulated at all. I argue that, applying a relational approach, there is still an important role for the state in regulating PTT. Regulation can improve the decision-making process for PTT and protect the child to be born from exploitation, abuse and neglect. In Part III, I explore the most appropriate regulatory framework for PTT. I discuss the advantages and disadvantages of a permissive as opposed to prescriptive regulatory framework and conclude that a flexible permissive regulatory framework should be applied to PTT. I suggest improvements to the current permissive approach to PTT in Victoria, which should assist parents making decisions about PTT and better protect the welfare of the child to be born.

I outline my detailed proposals for reform of PTT regulation in Australia in Part IV, based on the criteria for a relational approach discussed in Chapter 4. I discuss how the ART Act (Vic) in Victoria could be improved and used as a template for a national coordinated approach. I also draw from the NHMRC Guidelines on ART and the previous VARTA Conditions on PTT in formulating detailed ‘soft law’ guidelines for PTT. I conclude that essentially, day-to-day decisions about PTT should be made by parents in consultation with their health care team. Decisions should be made in accordance with guiding principles laid down by Parliament and detailed national guidelines prepared by a national specialist advisory committee, such as the NHMRC. Decisions should also be subject to ethical oversight by clinical ethical committees to ensure that the welfare of the child is adequately protected.
II SHOULD PTT BE REGULATED?

In Chapter 4, I argued that the child born as a result of PTT should receive a threshold level of protection. I also explained how a relational approach to PTT might assist parents in deciding whether or not to use PTT. In this Part, I build on these findings to argue that PTT should be regulated. First, I argue that PTT regulation can help ensure that patients receive adequate information, counselling and ethical guidance in the decision-making process. Second, I argue that retaining the welfare of the child provision (in a modified form) can protect the child to be born from exploitation, abuse and neglect. As PTT is a form of ART, I begin by exploring the purpose of regulating ART services generally, before concentrating on the regulation of PTT.

A Regulating ART generally

The term ‘regulation’ has a ‘bewildering variety of meanings’ and can denote a vast array of different controls. According to the public interest theory of regulation, regulatory intervention is justified where there is likely to be market failure in achieving public interest goals. In the area of medicine and health care, the vulnerability of patients and information asymmetries justify regulation in some form. Medical practitioners in Australia are generally regulated by self-imposed professional standards, state legislation and common law principles. As I discussed in Chapters 1 and 5, fertility specialists in Victoria and the UK are regulated over and above the legal and ethical restraints on medical practitioners generally. Brazier has observed, with some scepticism, that ‘(r)eproductive medicine is singled out as special, as a part of medicine of such particular social concern and significance that the state should have a direct stake in its evolution.’ In this section, I explore whether the ‘special’ nature of ART justifies regulation beyond that which already applies to the medical profession.

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6 By way of contrast, Jackson argues that the welfare of the child principle is irrelevant to the provision of ART services and should be removed from ART legislation in the UK. Emily Jackson, ‘Conception and the Irrelevance of the Welfare Principle’ (2002) 65(2) Modern Law Review 176. See also Margaret Brazier, “Regulating the Reproduction Business?” (1999) 7 Medical Law Review 166.
8 Ibid, 2-3.
10 Brazier, above n 6, 166.
ART raises a plethora of ethical and legal questions, which cannot be ignored. As Brazier notes, developments in assisted reproductive technologies in recent decades have led to the cry that ‘something must be done’.\(^\text{11}\) According to Brownsword, there is ‘little virtue in leaving genetics to the play of subjective preference and the market’.\(^\text{12}\) However, within Australia and the UK, regulation has focused on a limited sector of reproductive medicine involving in vitro fertilisation (IVF) and related technologies. According to Brazier, ‘(r)elegation of reproductive medicine remains partial and selective.’\(^\text{13}\) Skene similarly points out that in Australia there are many areas of reproductive medicine that are not specifically regulated.\(^\text{14}\) For example, a woman can take contraception to prevent the birth of a child, undergo surgical sterilisation, have a sterilisation reversed, repair her fallopian tubes to assist conception, and artificially inseminate herself with donor sperm, all free of legislative interference.\(^\text{15}\) The position is similar in the UK.\(^\text{16}\)

The selective or random nature of regulation within reproductive medicine is arguably unjustified. In some areas of reproductive medicine there may be stronger reasons for regulation than there are for IVF, based on the prevention of harm. For example, Brazier has observed that ‘do-it-yourself’ artificial insemination (AI) using fresh sperm carries risk to the woman of HIV or other sexually transmitted disease that is not present for IVF.\(^\text{17}\) AI also raises the same concerns associated with IVF treatments involving donor gametes, where the child born may not have a social relationship with his/her biological father (or mother). Inconsistencies within the regulatory landscape for reproductive medicine do not, however, undermine legitimate reasons for regulating ART. The justifications for regulating ART may well support a broader regulatory net over reproductive medicine.\(^\text{18}\)

\(^{11}\) Ibid 168.
\(^{13}\) Brazier, above n 6, 169.
\(^{14}\) Skene points out, however, that ‘whilst these areas are not specifically regulated by legislation, there are laws that regulate them incidentally’: Loane Skene, ‘Why Legislate on Assisted Reproduction?’ in Ian Freckleton and Kerry Petersen (eds), Controversies in Health Law (1999), 266, 267.
\(^{15}\) Ibid.
\(^{16}\) Brazier, above n 6,170.
\(^{17}\) Ibid.
\(^{18}\) The extent to which the state should regulate reproductive medicine generally is beyond the scope of this thesis. Interestingly, Brazier suggests that the licensing of fertility specialists in the UK, which promotes high standards of medical practice, could be extended to all emerging specialties: Brazier, above n 6, 167.
There are limitations on the effectiveness of self-regulation in the medical profession. Self-regulation by medical practitioners lacks transparency, provides limited scope for public debate, and may therefore be viewed suspiciously by the public. There is significant support for state involvement in ART. According to Szoke, the state has an important role in resolving any conflicts which may exist over reproductive technologies and ‘formalising an expression of the public interest.’ Similarly, Cannold and Gillam argue that the state has a legitimate role in regulating ART:

…the state has an obligation to protect the interests of its citizens and regulation is a legitimate method of achieving this. It is possible that ART can be practised in ways that threaten the interests of at least some citizens and so, in principle, it is ethically permissible for the state to regulate in such situations.

Various justifications have been given for regulating ART, reflecting concern for patients, doctors, the embryo, the child to be born, the expenditure of public funds, and general standards of morality. Johnson suggests a narrower role for regulation. He argues that, as a broad principle, ‘regulation should be restricted to the support of those who should be capable of making an informed decision and to the protection of those incapable of protecting themselves’. In the context of ART, regulation should therefore support patients seeking ART and protect those who may be born as a result. Savulescu takes a similar approach to ART regulation when he states that ‘we should consider the vulnerable and consider the children by balancing the risks and benefits’. In the remainder of this section, I outline three broad justifications for regulating ART: (1) quality control; (2) respect for the embryo; and (3) protection of the child to be born. These justifications are consistent with the regulatory parameters for ART proposed by Johnson and Savulescu.

23 Martin H Johnson, ‘The Art of Regulation and the Regulation of ART: The Impact of Regulation on Research and Clinical Practice’ (2002) 9 Journal of Law and Medicine 399, 405. Johnson envisages that the first category would include patients and possibly doctors. He suggests that the second category would include children (desired and existing), the embryo, and gamete donors.
24 STC Report, above n 19 [36].
The first reason for regulating ART is to support patients seeking ART through the ‘quality control’ of ART services. Quality control is integral to public confidence in ART services. An independent report in New Zealand on preimplantation genetic diagnosis stated that:

Ensuring that the health and safety of both the persons accessing fertility services and the embryos produced as a result of assisted reproductive procedures are protected to the highest standard possible is a major factor in gaining public confidence in any regulatory framework.\(^{25}\)

Regulation can ensure high standards of treatment within clinics through inspection and quality assurance requirements.\(^{26}\) A regulatory framework that imposes standards and accreditation requirements can protect patients from some of the health risks associated with ART. According to Brazier, regulation can prevent the exploitation of patients by ‘maverick doctors’ or their abuse by ‘rank amateurs’.\(^{27}\) Quality control can, and should, extend beyond ensuring high technical standards within clinics to establishing a supported decision-making process, with adequate information, counselling and ethical guidance. I discuss this element of quality control in more detail in the next section.

The second justification for regulating ART, respect for the embryo, was a primary reason for regulating ART in the UK.\(^{28}\) As discussed in Chapter 5, the UK Parliament adopted a gradualist approach to the embryo in order to reconcile reproductive liberty with some level of protection for the embryo.\(^{29}\) The gradualist approach allows specific infertility treatment to be undertaken, subject to careful evaluation of the reasons for the creation and use of embryos in respect of the treatment. The House of Commons Science and Technology Committee in the UK (the STC) reaffirmed the


\(^{26}\) STC Report, above n 19 [317-9], Brazier, above n 6, 171. See also Report of the Committee of Inquiry into Human Fertilisation and Embryology Cm 9314 (July 1984) (Warnock Report) [13.3].


\(^{28}\) See, for example, discussion by Brazier, above n 6, 172. Brazier states that the case for ART regulation made by the Warnock Committee was based on a pre-eminent concern for embryos and a focus on regulating standards. In Australia, the status of the embryo has been the focus of detailed discussion in relation to the regulation of embryo research and cloning: Senate Community Affairs Legislation Committee, Report on the Provisions of the Research Involving Embryos and Prohibition of Human Cloning Bill 2002, October 2002, 2-8.


\(^{29}\) See discussion in Chapter 5, Part VA.
gradualist approach in its 2005 Report, concluding that ART remains a legitimate interest of the state. 30

Protecting the welfare of the child to be born is the third justification for regulating ART. The welfare of the child to be born is of paramount concern in ART regulation in Victoria. 31 It is also a key feature in UK legislation. I discussed the role of the welfare principle in relation to ART in detail in Chapter 4. According to a liberal theory of law, ‘legal prohibitions on individual action are justified to prevent harm to others’. 32 This can be traced back to John Stuart Mill who stated that ‘the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others.’ 33 In a liberal democracy, the state is therefore justified in placing limits on reproductive liberty in order to prevent harm to the child to be born, particularly given that the putative child is incapable of protecting him/herself. However, as Gavaghan points out, ‘the concept of ‘harm’ is not as straightforward as Mill… perhaps assumed, and it is especially problematic in relation to ‘genesis’ questions, that is, decisions about who should be born.’ 34 Furthermore, it is possible that the child to be born may be ‘wronged’ even though s/he is not strictly ‘harmed’. Adopting a Kantian approach, state intervention may be justified to ensure that any child to be born as a result of ART is not treated ‘solely as a means’, whether or not the child can be said to be harmed. 35

The dilemma of how far the state should regulate ART to protect the welfare of the child to be born can be approached on the basis that ‘any intervention into reproductive choice must have a sound ethical basis and also take into account evidence of harm to children or to society.’ 36

30 STC Report, above n 19 [46].
31 ART Act (Vic), s 5(a).
34 Colin Gavaghan, Defending the Genetic Supermarket: Law and Ethics of Selecting the Next Generation (Routledge-Cavendish, 2007), 37-8.
36 STC Report, above n 19 [390], [46].
The justifications for regulating ART apply to PTT, which is a form of ART. There are, however, two key reasons for specifically regulating PTT, which arise out of the discussion in Chapter 4.

First, regulation can improve the decision-making process for parents considering PTT. This reason falls within the first justification for ART – ‘quality control’. In Chapter 4, I highlighted the importance of the decision-making process in dealing with the individual and collective interests that exist within a family. I argued that the various interests in relation to PTT within a family should be considered in an open moral space. Clinicians, counsellors and ethicists play key roles in promoting a supporting collaborative and constructive environment in which decisions about PTT can be made. Regulation should outline the various roles of treating health care professionals involved in PTT to ensure that parents receive adequate information, counselling and ethical guidance when making decisions about PTT.

Second, regulation can protect the child to be born from exploitation, abuse and neglect. This reason falls within the third justification for ART – protecting the child to be born. As discussed in Chapter 2, there is a potential risk of physical harm associated with the embryo biopsy process and ART generally. There is also a future risk of harm to the child if peripheral blood or bone marrow donations are required at a later date. Finally, there is also a potential risk of psychosocial harm to a child born as a result of PTT associated with being selected as a donor for an existing child. There is currently no evidence to suggest that either the physical or psychosocial harm that may be caused by PTT is of a level that constitutes exploitation, abuse or neglect. However, further evidence may reveal otherwise. In particular, there are no longitudinal studies of the long term physical and psychosocial impacts on ‘saviour siblings’. Regulation should safeguard the welfare of the child to be born in order to protect the child from any risk that may be revealed in further studies. Moreover, given the lack of evidence in this area, regulation should facilitate further longitudinal research into the long term risks to the child born as a result of PTT. This could be achieved through a nationally coordinated system of monitoring the effects on children born using PTT.
There is also a risk that PTT may involve the exploitation of the child to be born by his/her parents. In Chapter 2, I suggested that it is possible (albeit unlikely) that parents may treat a child conceived through PTT as a commodity, solely as a means to saving the life of their existing child. In the event that a cord blood donation did not cure the existing child, the parents may require the donor child to undergo further, more invasive, treatments until the existing child is cured. This raises an issue as to how far into the future the state should protect the welfare of a child who is born using PTT. I argued in Chapter 4 that the state has some obligation to the future welfare of the child to be born as a result of PTT. Protection against future exploitation is already provided by existing legislation in Australia.\textsuperscript{37} In addition to laws governing tissue donation by minors, the state also protects the welfare of children generally through child protection laws.\textsuperscript{38} A question remains as to whether the protection afforded to a child who is already in existence is sufficient. Arguably the state should safeguard against certain risks before a child is born, if the risks are sufficiently high and imminent. Ordinarily, the state should not ‘second guess’ how parents seeking any form of ART will parent. However, as discussed in Chapter 4, the state has some obligation to protect the basic safety of the child to be born. The state should not assist parents to conceive a child solely as a commodity, if counselling revealed that the parents had no genuine desire to care for their new child.\textsuperscript{39}

C Role of the welfare of the child principle

The welfare of the child principle has been incorporated in Australian\textsuperscript{40} and UK ART legislation to protect the welfare of the child to be born. However, some commentators are cynical about the role of the welfare principle in regulating ART. According to Brazier, the welfare provision in UK legislation has essentially been used to protect the child to be born by restricting access to ART.\textsuperscript{41} Walker suggests that the welfare provision in Victorian legislation is vague and its application has led,

\textsuperscript{37} See discussion in Chapter 2, Part VA2.
\textsuperscript{38} See, for example, \textit{Children Youth and Families Act 2005} (Vic), \textit{Child Wellbeing and Safety Act 2005} (Vic).
\textsuperscript{39} As discussed in Chapter 4, this is an unlikely scenario. However, if counselling revealed that the parents only wanted a child as a source of tissue, the state would be derelict in its duties to allow the parents to proceed with PTT. My proposal is analogous to the current system in Victoria, where there is a presumption against ART where a woman, or her partner, has committed a sexual offence or violent offence, or has had a child protection order made against them: s 14 ART Act (Vic). As with the presumption against treatment, decisions to refuse PTT should be reviewable.
\textsuperscript{40} In ART legislation in Victoria, Western Australia and South Australia.
\textsuperscript{41} Brazier, above n 6, 174.
in some cases, to discrimination. Other commentators have argued that the welfare of the child principle should not be relied on as a justification for interfering with an individual’s reproductive liberty.

In Chapter 3, I argued that the welfare of the child principle should be reconceived to embrace the collective interests a child shares with his/her family as well as the child’s individual interests. Accordingly, the welfare of the child provision should be retained but the focus of regulation should be shifted from ‘gate-keeping’ to one that genuinely assists families as a whole. The relational approach to PTT discussed in Chapter 4 places a strong emphasis on information, counselling and ethical guidance to enable parents seeking PTT to reach an informed decision for the family as a whole, including the child to be born. It is the clinic, rather than Parliament or the offices of a statutory body, in which decisions about the welfare of an individual child within a family should be made. Such decisions ought to be made on a case by case basis, based on clear criteria set down in legislation and policy guidelines.

A relational approach to regulating PTT achieves two distinct regulatory goals. First, it promotes the welfare of the child to be born by providing a safety net to protect the child from exploitation, abuse and neglect. Second, it enhances quality control (in a broad sense) by assisting parents in deciding whether or not to use PTT. In response to the critique by some liberal justice theorists that reproduction is private and no business of the state, a relational approach to regulating PTT (based on a broad conception of the welfare principle) can arguably be seen as enhancing parental choice by supporting parents in the decision-making process. In the next Part, I discuss the most appropriate regulatory framework for achieving a relational approach to PTT.

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42 Walker, above n 32, 131-3.
III WHAT TYPE OF REGULATORY FRAMEWORK IS APPROPRIATE?

A Current confusion over PTT regulation in Victoria

Like the UK, Victoria has opted for a ‘permissive’ or ‘facilitative’ approach to regulating PTT, as opposed to a ‘prescriptive’ or ‘prohibitive’ regime. Decisions about PTT are to be made within the broad legislative framework of the ART Act (Vic) and subject to the presumption against treatment that applies to ART generally. Prior to the new ART Act (Vic) coming into force in Victoria on 1 January 2010, decisions about PTT carried out in conjunction with preimplantation genetic diagnosis (PGD) were made by the Infertility Treatment Authority (ITA) in accordance with the Infertility Treatment Act 1995 (IT Act (Vic)) and ITA policy. It is currently unclear as to who will make decisions about PTT under the new ART Act (Vic) or how they will be made.

The ART Act (Vic) repealed the IT Act (Vic) and replaced the ITA with a new regulatory authority, the Victorian Assisted Reproductive Treatment Authority (VARTA), whose powers are currently unclear. The body responsible for making decisions about PTT appears to vary according to whether or not PTT is carried out in conjunction with PGD. As discussed in Chapter 1, parents are only strictly eligible for PTT under the ART Act (Vic) where it is used in conjunction with PGD to screen for a genetically heritable disease. Although parents are not strictly eligible under the ART Act (Vic) for PTT if the existing child is suffering from a non-heritable disease (and PGD is not required), they can apply to the Patient Review Panel to consider their application for treatment. The Patient Review Panel may determine

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46 The Victorian approach was endorsed by the VLRC: VLRC Report, above n 9, 50. For a comparative discussion about the facilitative regimes for ART in the UK, Victoria and New Zealand and the more restrictive regimes such as in France, the Netherlands and Germany, see: Human Genome Research Project, above n 25, 307. These categorisations are not beyond contention. In the UK, for example, there is divergence in opinion about the ‘permissive’ nature of access to ART. See, for example, discussion by Brazier, above n 6, 176-8.
47 The presumption against ART came into operation in Victoria on 1 January 2010: ART Act (Vic), s 14. See footnote 37.
48 Infertility Treatment Authority, Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis (at January 2004) [2.4]. Applications approved by the ITA were subject to review by an institutional ethics committee. PTT was only available under the IT Act (Vic) in conjunction with PGD to screen for genetic abnormality or disease: IT Act (Vic), s 8(3).
49 VARTA is established under Part 10 of the ART Act (Vic). As discussed in Part IIIC of Chapter 1, the Victorian Department of Health is currently reviewing the scope of VARTA’s authority.
50 ART Act (Vic), s10(1)(b)(i) & (2)(a)(ii). See discussion in Chapter 1, Part IIIB.
51 ART Act (Vic), ss 15(1)(b), 85 (e); Victoria, Parliamentary Debates, Legislative Council, 10 October 2008, 4192 (Gavin Jennings, Minister for Environment and Climate Change).
that there is no barrier to parents undergoing PTT where PGD is not otherwise required.\footnote{ART Act (Vic), s15(2). The parents would thereby become entitled to treatment under s10(1)(b)(ii) ART Act (Vic).}

It is less clear as to who will make decisions about PTT carried out in conjunction with PGD. VARTA imposed conditions on the use of PTT in conjunction with PGD in February 2010 (previous VARTA Conditions on PTT).\footnote{See above, n 4.} These Conditions, which were removed from VARTA’s website in July 2010, required VARTA to approve all applications for PTT in conjunction with PGD.\footnote{Ibid [2.4].} There seems to be some confusion about the jurisdiction of VARTA to make decisions about PGD under the Act, which impacts on the validity of the previous VARTA Conditions on PTT.\footnote{The Chair of the Patient Review Panel stated in a letter to the author that VARTA has no role in relation to matters involving PTT and PGD: Letter from the Hon Susan Morgan to Michelle Taylor-Sands, 9 September 2010.} However, the ART Act (Vic) specifically empowers VARTA to impose conditions of registration on clinics.\footnote{ART Act (Vic), s 75.} The powers conferred on VARTA by the ART Act (Vic) also appear to be quite broad.\footnote{For example, s 100(1)(a) of the ART Act (Vic) enables VARTA to administer the registration system under the Act. Although the second reading speech for the ART Act (Vic) states that Parliament intended VARTA to have a ‘more focused role’, the Act does not clearly limit the powers of VARTA: Victoria, Parliamentary Debates, Legislative Council, 10 October 2008, 4194 (Gavin Jennings, Minister for Environment and Climate Change).} Since July 2010, it is not clear who should make decisions about PTT in conjunction with PGD. However, the ART Act (Vic) suggests that these decisions should be made by clinics.\footnote{ART Act (Vic), s10(3) requires a doctor to be satisfied that the woman is at risk of transmitting a genetic abnormality or disease on the basis of advice from a clinical geneticist or another doctor with specialist qualifications in human genetics. This interpretation of the ART Act (Vic) was reinforced in a telephone conversation between the author and Tracey Petrillo (Policy Officer, VARTA) on 16 July 2010. However, the Chair of the Patient Review Panel has suggested that decisions about PTT in conjunction with PGD shall not be made by clinics: Letter from the Hon Susan Morgan to Michelle Taylor-Sands, 9 September 2010.} Until new policy on PTT is developed, there are also no guidelines on how decisions about PTT will be made.

Whether or not decisions about PTT are made by VARTA, individual clinics or the Patient Review Panel, they must be in accordance with the guiding principles of the ART Act (Vic), the first of which states that the welfare and interests of the child to be born are paramount.\footnote{ART Act (Vic), s5(a), s 91(2). See also previous VARTA Conditions on PTT, above n 4 [2.2], [2.3].} This approach is consistent with the recommendation by the Victorian Law Reform Commission (VLRC) that decisions about PTT should be made ‘on a case-by-case basis, and according to the principle that the welfare and
interests of the child are paramount." In this Part, I argue that PPT regulation should remain permissive, subject to some fine-tuning. I discuss the benefits and disadvantages of a permissive approach before proposing a revised framework for the regulation of PTT in Victoria. I also draw on the lessons learnt from the permissive framework in the UK to suggest improvements to the current Victorian regulatory framework.

B Benefits and disadvantages of a permissive approach to regulating PTT

1 A ‘permissive’ approach within a regulatory continuum

Before I outline the benefits and disadvantages of a permissive approach to regulating PTT, I shall first explain what I mean by ‘permissive’. While the distinction between ‘permissive’ and ‘prohibitive’ regulatory frameworks appears to be obvious – the former permit an activity while the latter prohibit it – this ‘red light/green light’ characterisation is arguably ‘too crude’ in the context of human genetics. Permissive legislation can also be distinguished from prescriptive legislation. In contrast to prescriptive legislation, which provides a detailed regulatory agenda, permissive legislation involves Parliament setting out a broad regulatory framework and devolving regulatory authority and decision-making to another body.

Rather than characterising regulation as either permissive or prohibitive/prescriptive, it is useful to view ART treatments as having ‘a continuum of regulatory options’. Brownsword highlights several ways in which ‘the shading of the regulatory range (for human genetics) needs to be drawn out’, two of which are relevant to the regulation of PTT. First, where regulation permits ART, it may do so subject to certain reservations and/or qualifications. Brownsword describes this approach as ‘permission with negative reservation’. PTT regulation in Victoria is permissive, subject to the negative reservation that the welfare of the child to be born is

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61 Brownsword, above n 12, 16.
62 Szoke, ‘The Nanny State or Responsible Government?’ above n 20, 35. See also Helen Szoke, ‘Australia – A Federated Structure of Statutory Regulation of ART’ in Jennifer Gunning and Helen Szoke (eds), The Regulation of Assisted Reproductive Technology (Ashgate, 2003) 75, 77. For a detailed discussion of three different regulatory ‘models’ that have been adopted in Australia, see Loane Skene, ‘An Overview of Assisted Reproductive Technology Regulation in Australia and New Zealand” (2000) 35(1) Texas International Law Journal 31.
63 Brownsword, above n 12, 16-18.
64 Ibid 16.
 paramount. If the interests of the child to be born were likely to be adversely affected in a particular case, then PTT would be prohibited.65

Second, Brownsword points out that regulation may occur in ‘hard law’ legislation or ‘soft law’ guidelines or codes of practice.66 He argues that, paradoxically, compliance may be improved by soft, as opposed to hard, law. However, because ‘soft law’ regimes lack formal monitoring mechanisms, he suggests that soft law works best when it operates ‘in the shadow of a… harder law regime’.67 As the VLRC pointed out, PTT poses ‘a difficult ethical question’.68 Parents seeking PTT and their health care providers would therefore benefit from detailed guidance in relation to PTT, which may not be easily incorporated in legislation. As discussed in Chapter 4, guidelines outlining the ethical issues arising in relation to PTT and clarifying the roles and duties of parents and health care practitioners in the decision-making process would assist parents in making informed and ethically sound decisions about PTT. Furthermore, guidelines outlining key features of a relational approach to PTT may ultimately enhance compliance with the welfare of the child provision in the legislation.

Any regulatory system has a number of components, each of which may reflect either a permissive or prohibitive approach to regulation. The ‘regulatory tilt’69 in relation to ART in Victoria is, however, predominantly ‘permissive’. In the next section, I discuss some of the advantages and disadvantages of a permissive approach to regulating PTT before proposing some ‘fine-tuning’70 that could improve the regulation of PTT in Victoria.

2 Benefits of a permissive approach

My analysis of the UK in Chapter 5 revealed that a permissive regulatory framework is preferable to a prescriptive one for regulating PTT.71 There is merit to a flexible approach to PTT where decisions are made on a case-by-case basis, as the

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65 Of course, some would argue that ‘it is better to be born than not’ so that the interests of the child to be born are generally served by PTT. For a detailed discussion dismissing this line of reasoning, see Chapter 2, Part VC1.
66 Brownsword, above n 12, 18.
67 Ibid.
68 VLRC Report Summary, above n 60, 8.
69 For a discussion of ‘regulatory tilt’, see: Brownsword, above n 12, 17-18.
70 Brownsword argues that the legitimacy of regulation may not so much lie in its general orientation (prohibitive or permissive) as in its fine-tuning: Brownsword, above n 12, 18.
71 See discussion in Chapter 5, Part VD1, E.
circumstances of each case will vary significantly. A flexible regulatory framework can also accommodate new information and technological developments. For example, as previously discussed, further longitudinal studies are needed on the impacts of PTT on the child who is born. As this information arises, it can be fed into the decision-making process for PTT. Technological advancements in the area of PTT may also impact on the level of harm caused to the embryo during the biopsy process, which may be relevant to the welfare of the child to be born. Brownword points out the inherent risk of detailed regulation being ‘left behind’ where technology is continually advancing:

This implies that regulation needs to incorporate a degree of flexibility or open-endedness; that it should, wherever possible, adopt ‘technologically neutral’ strategies; that it should be interpreted purposively; and that soft-law might sometimes work better than hard or hard-wired confining law.\(^\text{72}\)

A permissive approach to PTT is also in line with public opinion, at least in the UK. In a public debate held by the Progress Educational Trust (PET) in 2008, there was general consensus that prescriptive legislation in relation to PGD (including PTT) is problematic and that decisions around PGD should be made by affected families in consultation with clinicians.\(^\text{73}\) Three expert speakers on PGD contributed to the PET debate, which was attended by around 80 people with an interest in this area, including policy-makers, journalists, patients, academics, clinicians and students.\(^\text{74}\) Removing individual decisions about PTT from the Parliament also insulates essentially private decisions from the politics of the day.

3 Disadvantages of a permissive approach

There are, however, difficulties associated with permissive regulatory frameworks. One major downside of flexibility is a lack of predictability and consistency, which can cause regulatory uncertainty.\(^\text{75}\) The ad hoc development of early policy by the Fertilisation and Embryology Authority (HFEA) on PTT, in response to requests from the Hashmi and Whitaker families in the UK, is an example of the regulatory uncertainty that can arise when a statutory body is required to make decisions within a

\(^{72}\) Brownword, above n 12, 31.
\(^{73}\) PET debate, above n 27, 9.
\(^{74}\) Ibid, 1. The three expert speakers were: Alison Lashwood (Clinical Genetics Department, Guy’s Hospital, UK); John Wyatt (Professor of Neonatal Paediatrics, University College London); and Ann Furedi (Chief Executive, British Pregnancy Advisory Service).
\(^{75}\) Brownword, above n 12, 31.
broad legislative framework. These decisions are made even more difficult when they involve new and controversial reproductive technologies, which may impact on the welfare of the child in different ways to other forms of ART. The legal challenge to the authority of the HFEA to license PTT in the Quintavalle case added further to the regulatory uncertainty surrounding PTT. A related problem with case-by-case decision-making is the time it takes to process applications on an individual basis. As discussed in Chapter 5, the HFEA recently determined that time delay was a primary concern in processing PTT applications on a case-by-case basis. However, given there are relatively few cases involving PTT, the system would not be overburdened by requiring fast responses to individual PTT applications.

The ART Act (Vic) does not specifically sanction PTT. The Act also fails to provide any clear guidance on how the welfare principle should be applied in cases involving PTT. Clinics and statutory bodies in Victoria face similar challenges to those experienced by the HFEA in the Hashmi and Whitaker cases in the UK, given the lack of legislative clarity over PTT and the welfare principle. Insufficiently clear or minimalist legislation can also cause problems when courts are required to interpret the legislation. Legislation should therefore sanction PTT and provide clear guidance on how the welfare of the child principle is to be interpreted in the context of ART, including PTT. Legislation should also set limits on the time taken by a clinical ethics committee (CEC) to reach a decision about PTT to minimise delay.

Another criticism of permissive or minimalist regulation is that it ‘could end up being used in a way that is very different from its original intention’. A permissive framework in which decision-making is devolved must establish a robust decision-making process to ensure that decisions about PTT are made within the spirit of the

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76 See, for example, comments of the Genetic Interest Group (GIG) in the UK in relation to the case-by-case approach to PTT by the Human Fertilisation and Embryology Authority (HFEA): Nick Meade, ‘The Case for Case-by-Case Regulation of PGD: a response to Dr David King’ BioNews 26 January 2010 www.bionews.org.uk/page.asp?print=1&obj_id=53848. Meade (Policy Analyst, GIG) argued that time delay is ‘especially harmful for families with a sick child who could benefit from a sibling donation of cells or tissue’.

77 As discussed in Part III of Chapter 5, the HFEA has been criticised for being inconsistent in its application of the welfare of the child principle and subjected to legal challenge. The previous VARTA Conditions on PTT, above n 4, provided some useful guidance on PTT carried out in conjunction with PGD. However, as discussed in Part IV of Chapter 5, there is a need for clarification by Parliament on these contentious procedures.

78 See, for example, discussion by Brownsword of the Quintavalle case: Roger Brownsword, ‘Reproductive Opportunities and Regulatory Challenges’ (2004) 67(2) The Modern Law Review 304. See also Brownsword, above n 12, 30-37. PET debate, above n 27, 7.

79 PET debate, above n 27, 7.
legislation. Provided the decision-making process preserves the legislative intent, there are advantages in Parliament delegating decisions about PTT to an arm’s length body like VARTA or the Patient Review Panel or to individual clinics. In Chapter 4, I argued that reproductive decisions should be devolved even further – to the parents of the existing child – if a relational approach to PTT is adopted. In the UK, the STC was critical of the Parliament devolving essentially private reproductive decisions to a statutory authority (the HFEA). The STC stated that decisions about the welfare of the child to be born are best made by patients in consultation with their doctor, rather than by the HFEA, but recognised that difficult cases should be resolved by recourse to local ethics committees. As discussed in Chapter 4, a genuine relational approach to decision-making would place decisions about PTT in the hands of parents in consultation with their health care team, subject to oversight by a CEC. Legislation should establish a robust decision-making process for PTT to ensure that decisions reflect the legislative intent.

Finally, non-legislative instruments that frequently supplement permissive legislation are not subject to the rigours of Parliamentary debate. In the UK, the HFEA was criticised for its lack of transparency in developing policy on PTT and the welfare of the child. Concerns were also raised about the HFEA’s expertise and ability to make ethical decisions, given its lay membership. Finally, the HFEA’s dual roles as regulator and policy-maker have been described by some as incompatible and leading to ad hoc decision-making. ‘Soft law’ guidelines should therefore be made in a transparent manner, by a body with sufficient expertise, and with opportunity for input from key stakeholders.

I attempt to resolve some of the problems associated with a permissive regulatory approach in the next section. I argue that an improved permissive approach to PTT in Victoria can better navigate parents through the ethical minefield of PTT, whilst protecting the child to be born.

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80 See discussion in Chapter 5, Part V.
81 STC Report, above n 19 [107].
82 STC Report, above n 19 [129]. See also Human Genome Research Project, above n 24, 333.
Proposals for improved permissive approach

Given the various interests at stake in relation to PTT, I propose that PTT regulation should perform three main functions based on the relational approach proposed in Chapter 4. First, regulation should provide clear guidance on the availability of PTT and the various individual and shared interests within a family that may be affected. Second, regulation should establish a robust decision-making process to manage individual and shared interests within families, which will not necessarily coincide. Third, regulation should provide a threshold level of protection to the child to be born. I propose a combination of ‘hard’ and ‘soft’ law initiatives to achieve these goals.

1 Clear guidance on PTT and the interests at stake

A balance needs to be struck between clarity and flexibility in regulating PTT. To promote greater clarity, the regulatory framework for PTT should be grounded on clear ethical principles laid down by Parliament. It is not the role of Parliament to make definitive statements about opposing ethical theories in a pluralist society. However, Parliament plays a critical role in ‘formalising an expression of the public interest’ in representative democracies. As discussed in Chapter 5, calls have been made in the UK for the legislature to better address the ethical foundations of ART regulation. According to Brazier, there is ‘little conceptual depth’ underpinning UK ART law. The fact that there is ‘no single, coherent, philosophy’ underpinning the Human Fertilisation and Embryology Authority Act 1990 (UK) (HFE Act 1990) has led to the result that ‘again and again, as new medical developments emerge, we debate the same issues in different disguises.’

Given the controversial nature of PTT, a deliberative democratic model should be adopted, involving robust debate and community consultation, in an attempt to define

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85 Szoke, ‘The Nanny State or Responsible Government?’, above n 20, 481. In the UK, the STC stated that ‘a larger role for our democratically accountable Parliament would give the public greater confidence that the big ethical issues of the day are being given adequate attention’: STC Report, above n 19 [356].

86 Brazier, above n 6, 167. See also discussion in Joint Committee Report, above n 84 [32]-[48], esp [44]. The Joint Committee recommended that the UK Parliament establish a specialist parliamentary ethics committee to provide ethical input to ART legislation: [48].

87 Brazier, above n 6, 167; see also: Anna Smajdor, ‘The Review of the HFE Act: Ethical Expertise or Moral Cowardice?’ BioNews 6 November 2007 http://www.bionews.org.uk/page_37959.asp; McDonald, Fenton and Dabell, above n 84, 294. While some debate over new assisted reproductive technologies is inevitable, the debate would become more focused if there was clear legislative guidance on the principles that should be applied.
ethical principles that reflect community concerns.\textsuperscript{88} The legislative process is an important mechanism for addressing technologies that have social implications and identifying and reviewing social priorities.\textsuperscript{89} As Smajdor states, ‘if politicians don’t engage in ethical debate, who will?’\textsuperscript{90} In support of statutory regulation for ART, Waller quotes Sir Ninian Stephen:

\begin{quote}
The passage of a measure through the legislature confers a unique stamp of democratic legitimacy, valuable in a country possessing democratic traditions… An elected legislature as the identified and visible maker of laws can be seen to be responsive to legitimate pressures and to the strongly held views of the community.\textsuperscript{91}
\end{quote}

Currently, the ART Act (Vic) does not specifically mention PTT nor does it give any guidance on whether the interests of family members (other than the child to be born) should be taken into consideration. Past experience in the UK provides a good example of the problems that can arise when a parliament fails to engage fully with the ethical debate over ART. In particular, the Hashmi and Whitaker cases in the UK highlighted a need for the UK Parliament to specifically legislate on PTT to avoid inconsistency and legal challenge. In Chapter 5, I argued that there are compelling reasons for the availability of new and controversial reproductive technologies to be addressed by parliaments through democratic debate rather than by the courts.\textsuperscript{92} The Victorian Parliament should follow the UK Parliament’s lead by expressly sanctioning PTT under the ART Act (Vic). The relational approach to PTT proposed in Chapter 4, which is based on a broad conception of the welfare of the child, should also be endorsed in the ART Act (Vic) through guiding principles. In particular, the Act should clarify the interests of other family members that must be taken into account in connection with the interests of the child to be born. By specifying clear parameters for PTT in legislation, the Parliament can ensure that PTT policy operates

\begin{footnotes}
\textsuperscript{88} Rob Stein, ‘Q&A with Amy Gutmann of Presidential Commission for Study of Bioethical Issues’ \textit{The Washington Post} (Washington) 9 June 2010, B03.
\textsuperscript{89} See discussion by Szoke, ‘The Nanny State or Responsible Government?’ Above n 20, esp 482. See also Joint Committee Report, above n 84 [27], which states that it is Parliament’s role in a representative democracy to make a ‘collective judgement’ about what legislation should say.
\textsuperscript{90} Smajdor, above n 87.
\textsuperscript{92} As discussed in Chapter 5, Brownsword argues that judicial determinations on new assisted reproductive technologies raise problems of incrementalism in the regulation of ART, lack of institutional accountability and regulatory uncertainty. See discussion in Chapter 5, Part IIIB.
\end{footnotes}
‘in the shadow of’ the law. This would avoid the type of ad hoc decision-making for which the HFEA in the UK has been criticised in the past.

In order to retain some flexibility, more detailed guidance on PTT and the nature of interests affected should be contained in non-legislative guidelines. Detailed guidelines can help facilitate understanding, improve decision-making and ultimately boost compliance with the ART Act (Vic). In line with a national approach to PTT, national guidelines should be drafted by an independent specialist committee with both clinical and ethical expertise, such as the NHMRC. In practice, this could involve amendment to the current NHMRC Guidelines on ART. Clinicians, bioethicists and the public should also be given an opportunity to make submissions on proposed guidelines to ensure ‘deliberative democracy’. Public consultation ensures that medical decision-making is not purely based on medical and scientific utility but that it also takes into account the perceived impact of the activity by the public. Under the previous Victorian legislation, the ITA developed detailed policy in relation to PTT, in consultation with its own Ethics Panel and key stakeholders including institutional ethics committees, clinicians and bioethicists. The approach taken by the ITA could inform future attempts to develop guidelines for PTT.

In Part IV, I outline some guiding principles that should be included in the ART Act (Vic) as well as more detailed policy guidelines for PTT. My proposed guidelines should apply to all applications for PTT, whether or not it is to be carried out in conjunction with PGD. The previous VARTA Conditions on PTT distinguished between PTT alone and PTT in conjunction with PGD in Victoria in the same way as the HFEA’s interim policy on PTT distinguished between the Hashmi and Whitaker cases. As discussed in Chapter 5, this distinction is unjustifiable and no longer applies in the UK. The distinction should similarly be removed in Victoria.

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93 Brownsword, above n 12, 18.
94 STC Report, above n 19 [251].
95 For a discussion of this approach, see Szoke, ‘The Nanny State or Responsible Government?’, above n 20, 479.
96 This approach has been adopted in New Zealand: Human Genome Research Project, above n 25, 333.
97 Ibid.
98 Infertility Treatment Authority (ITA), Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis (at January 2004).
Permissive regulation should outline a robust decision-making process for PTT to ensure that decisions are consistent with the legislative intent. In line with the relational approach proposed in Chapter 4, legislation should devolve decisions about PTT to parents in consultation with their health care team, subject to approval by a CEC. This would allow decisions to be made on a case-by-case basis, according to the individual circumstances of each case, while also ensuring that the welfare of the child is adequately protected.

Legislation and policy should therefore focus on establishing a robust relational decision-making process rather than attempting to create a list of cases prescribing when PTT is/is not allowed. This would ensure that the legislative intent is embodied in the decision-making process while enabling regulation to remain responsive to new technological and scientific developments. Regulating the process by which decisions about PTT are made should also enhance the decision-making ability of parents by supporting them in making difficult decisions. As discussed in Chapter 5, the focus of PTT regulation should be to assist parents in the ethically complex decision-making process. Regulation should therefore focus on the ways in which health care professionals can support parents in making decisions about PTT. In particular, regulation can clarify the roles of key participants within the decision-making process, including physicians, counsellors and ethicists. As some commentators have pointed out, the role of either clinicians or statutory bodies as gatekeepers of ART is problematic. Some independent ethical oversight of decisions involving PTT is also necessary to ensure a threshold level of protection to the child to be born.

Finally, PTT regulation should provide a threshold level of protection to the child to be born, who is incapable of protecting him/herself. The current welfare of the child provision in the ART Act (Vic) is vague and difficult to apply, in the absence of clear guidance. More detailed guidance on the welfare principle should therefore be

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100 PET debate, above n 27, 7.
enshrined in the ART Act (Vic) to ensure that the principle is applied consistently and fairly in all cases, including those involving PTT.

In particular, legislation should specify the limits of ART to protect the child to be born from exploitation, abuse and neglect. As discussed in Chapter 4, instead of treating the welfare and interests of the child to be born as paramount, my proposed approach represents a ‘minimum welfare’ approach to the child to be born. The current risk-based approach to the welfare of the child to be born in HFEA policy, outlined in Chapter 5, is an example of a ‘minimum welfare’ approach. The HFEA policy, which contains a presumption of treatment unless information suggests there is a ‘risk of significant harm or neglect’, provides clear parameters for clinics to work within and should minimise unfair discrimination based on sexuality or marital status. I argued in Chapter 5 that greater clarity and certainty could be achieved by enshrining a risk-based or ‘minimum welfare’ approach to the child to be born in legislation rather than in policy.\textsuperscript{102} To ensure that due consideration is given to the welfare of the child to be born, the ART Act (Vic) should also require that applications for PTT be reviewed by a CEC.

More detailed guidance on the application of welfare principle to specific forms of ART (such as PTT) should be contained in policy guidelines. While this thesis has focused on the welfare of the child to be born as a result of PTT, a broader conception of the welfare of the child could be applied to ART generally.\textsuperscript{103} Similarly, the relational approach I propose for PTT could equally be applied to other forms of ART.

\textit{D Summary}

Within legislatively-determined parameters and in accordance with more detailed guidelines, essentially private decisions about PTT should be made by patients in consultation with their health care team rather than by a statutory body like VARTA or the Patient Review Panel.\textsuperscript{104} This approach is in line with the recommendation by the UK Joint Committee that neither the Government nor the regulator should be involved in ART decisions which can safely and responsibly be devolved to patients.

\footnotesize\textsuperscript{102} See Chapter 5, Part IVC.

\footnotesize\textsuperscript{103} The arguments in favour of a broader conception the welfare of the child in Chapter 6 are not necessarily limited to cases involving PTT.

\footnotesize\textsuperscript{104} See discussion above, Part IIIB2, 3. Similar recommendations were made by the STC in the UK: STC Report, above n 19 [107], [129].
and clinicians.\textsuperscript{105} Although not ultimately accepted in the UK, the Joint Committee’s recommendation has merit. As the STC noted, ‘(d)ecisions made at a local level have the advantages of speed and proximity to the clinical setting’.\textsuperscript{106} However, it is worth paying heed to Jayson Whitaker’s comment (based on his personal experience with PTT) that, while clinical decisions should be left to the patient and doctor, ‘there does need to be some voice of reason in there’.\textsuperscript{107}

Legislation can establish clear parameters for ART services, within which more detailed policy on PTT can be developed. Carefully formulated guidelines on PTT can assist parents and clinicians facing difficult decisions about PTT. In addition, CECs are well-placed to provide independent ethical oversight in individual cases. PTT regulation can support parents seeking PTT by clarifying the roles of clinicians, ethics committees and parents in the decision-making process. A permissive regulatory framework along these lines should provide parents with the ‘voice of reason’ needed to make well-informed decisions about PTT. In the next Part, I outline my proposals for reform of PTT regulation in Australia, based on the relational approach discussed in Chapter 4.

IV PROPOSALS FOR REFORM OF PTT REGULATION IN AUSTRALIA

In this Part, I suggest how the current regulatory framework for PTT in Australia, and specifically Victoria, should be fine-tuned to implement the improved permissive approach proposed in Part III. As far as possible, day-to-day decision-making should be delegated to parents in consultation with their health care team, subject to guiding principles and ethical oversight. In particular, clarification of the welfare principle is necessary to promote consistent decision-making in relation to PTT, based on sound ethical principles. Legislation should provide a clear threshold level of protection for the child to be born from abuse, neglect or exploitation.

In Part III, I argued that PTT regulation should be supported by clear ethical principles. As the STC has pointed out, ‘ethical oversight of assisted reproduction…

\textsuperscript{105} Joint Committee Report, above n 84 [105]. See also discussion in Chapter 5, Part VC3. See also PET debate, above n 27, 9.
\textsuperscript{106} STC Report, above n 19 [353].
\textsuperscript{107} Ibid [373].
can take place at several levels." National guidelines can provide more detailed guidance on the operational aspects of specific forms of ART, such as PTT. As discussed in Part III, one major benefit of guidelines is that they can be detailed, flexible and responsive to technological developments and changing community concerns. Finally, clinical ethics consultation can ensure that the ethical implications of each case are considered. I propose two separate stages of clinical ethics consultation. First, a clinical ethicist should provide ethics counselling to assist parents in the decision-making process. Second, a separately constituted CEC should independently review decisions to proceed with PTT to ensure that they comply with the ethical criteria set out in legislation and national guidelines. I discuss how legislation, national guidelines and clinical ethics consultation can regulate PTT in sections B, C and D, respectively. I begin, in section A, by outlining how the general regulatory framework could work in Australia and how it would differ from the current system.

A Outline of Regulatory Framework for PTT in Australia

1 A uniform national approach to PTT

Ideally, PTT regulation should be nationally consistent. As discussed in Chapter 1, the current piecemeal approach to ART regulation in Australia creates gaps, inconsistencies and general confusion for ‘individuals, policy-makers, parents and potential parents’. The absence of uniform ART legislation has also led to ‘reproductive tourism’ within Australia, whereby people who are ineligible for treatment in one state travel to unregulated states to undergo treatment. Uniform national regulation is generally viewed as a ‘positive objective’ in the area of reproductive technology. It not only reduces regulatory duplication but also ensures common clinical and ethical standards in relation to treatment services at a national level. The VLRC received a number of submissions calling for nationally

108 Ibid [329].
110 Ibid 81.
112 VLRC Report, above n 9, 44, 55.
114 See STC Report, above n 19 [378] and [381].
consistent regulation, leading up to its report on ART in 2007. The Australian Health Ethics Committee (AHEC), a Principal Committee of the NHMRC, previously recommended in 1996 that uniform legislation should be enacted throughout Australia on ART, especially on ‘social issues’, such as eligibility and PGD.

The AHEC also noted that uniform regulation of ART is necessary for regulating national data collection and maintaining a centralised database. Harmonising monitoring programs throughout Australia would, in the words of the UK Medical Research Council, provide ‘the maximum statistical power particularly for the analysis of putative adverse events’. This is particularly important for PTT where more information is needed about the long-term impacts of PTT on the welfare of the child to be born. As discussed in Chapter 5, current HFEA policy on PTT requires UK clinics offering PTT to invite patients and their families to take part in long-term medical and psychosocial studies of children born as a result of PTT. At present, Australian ART clinics must monitor and record short and long-term outcomes relating to treatment procedures. However, this information is not reported to the NHMRC (unless it pertains to research conducted by that facility) nor is it recorded in any national registry. In Victoria, VARTA records ART births in their annual reports but there are no follow-up arrangements in place in relation to children born as a result of PTT. Australia should adopt a similar nationally-coordinated system to that in the UK for monitoring the effects of PTT on children born in order to gather more evidence about the risks associated with PTT.

As previously discussed, one way in which uniform regulation of ART might be achieved in Australia is through a cooperative federal agreement under which the

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115 VLRC Report, above n 9, 44.
116 The AHEC, which is established under s 35 of the National Health and Medical Research Council Act 1992, advises the Council on ethical issues relating to health: s 35(3)(a).
117 National Health and Medical Research Council (NHMRC), Ethical Guidelines on Assisted Reproductive Technology (1996) [5]. See also NHMRC Guidelines on ART, above n 5 [1.3].
118 Ibid.
119 Submission by the Medical Research Council to the STC: STC Report, above n 19 [379].
121 NHMRC Guidelines on ART, above n 5 [10.2]. Email from the NHMRC to Michelle Taylor-Sands, 18 June 2010.
122 Email from Tracey Petrillo (Policy Officer, VARTA) to Michelle Taylor-Sands, 13 May 2010.
states implement consistent legislation and confer authority on a national regulatory body to administer the scheme.123

2 Variations to the current regulatory framework for PTT in Victoria

For the purposes of this thesis, I shall focus on the ART Act (Vic) in Victoria, as a starting point for legislative reform. My proposals for reform of the ART Act (Vic) in relation to PTT could provide a model for uniform legislation in all states and territories. I have set out my proposed regulatory framework for PTT in Table 3, which represents a variation of the current system operating in Victoria. Currently, the Reproductive Technology Accreditation Committee (RTAC) conducts annual audits of ART clinics to ensure compliance with statutory and regulatory requirements. I propose a continuing role for the RTAC to ensure that clinics comply with ART legislation and national guidelines. Clinics should therefore have proper recording and reporting systems in place to show that they have complied with the decision-making process for PTT.

As discussed in Chapter 1, the ART Act (Vic) regulates ART services through a new system of ‘deemed registration’ in order to reduce regulatory duplication and burden. Under the Victorian system, clinics accredited nationally by the RTAC are deemed to be registered under the ART Act (Vic). Registered clinics can carry out ART services in Victoria, subject to conditions of registration imposed by VARTA.124 The previous VARTA Conditions on PTT were an example of conditions of registration. The RTAC is responsible for clinical oversight and sets national professional standards in its Code of Practice. Accredited RTAC clinics must also comply with the NHMRC Guidelines on ART. Clinics offering PTT in Victoria are therefore subject to clinical and professional standards imposed by the RTAC as well as ethical guidelines contained in the NHMRC Guidelines on ART and, until recently, the VARTA Conditions on PTT. In Table 3, I propose that the separate national and state ethical guidelines on PTT be replaced with one set of national guidelines to further reduce regulatory duplication. These national guidelines for PTT could be incorporated into the NHMRC Guidelines on ART.

123 See discussion in Part IA and Chapter 1, Part IIIA. Alternatively, the Commonwealth could potentially use one or more of its powers under the Constitution to indirectly legislate in relation to the provision of ART services.
124 ART Act (Vic), s 75(1).
As discussed in Part III, there is a need for clear legislative guidance to underpin the regulation of controversial technologies like PTT.\textsuperscript{125} I propose to retain the current approach in Victoria, whereby the ART Act (Vic) establishes an ethical framework for ART through guiding principles. However, the first guiding principle in the Act, which confers paramount importance on the welfare and interests of the child to be born, should be replaced with guiding principles that reflect a relational approach to PTT. In order to protect the child to be born from exploitation, abuse and neglect, the ART Act (Vic) should place specific restrictions on PTT. This represents a ‘minimum welfare’ approach to the child to be born similar to that currently applied in the UK.

The regulatory framework for PTT in Table 3 also proposes a continuing role for CECs in providing ethical oversight of decisions involving PTT. At present there is no legislative requirement in Victoria for ART clinics to establish CECs. I propose that the establishment of CECs be a condition of registration for all ART clinics under the ART Act (Vic). As discussed in Chapter 1, both the NHMRC Guidelines on ART and the previous VARTA Conditions on PTT require clinics to seek advice from a CEC before offering PTT in individual cases.\textsuperscript{126} However, the role of the CEC differs between the two systems. Under the previous VARTA Conditions on PTT, a CEC could refuse an application for PTT. By way of contrast, the role of a CEC under the NHMRC Guidelines on ART is advisory only and the ultimate decision lies with the clinic.

At the beginning of this Part, I stated that decisions about PTT should, as far as possible, be made by parents in consultation with their health care team rather than by a statutory body, clinic or CEC. However, clinical ethics consultation is an integral part of my proposed approach to PTT. I envisage two separate forms of ethical oversight. First, \textit{ethics counselling} should be provided by a clinical ethicist to assist parents making a decision about PTT. Second, \textit{ethics review} of a decision made by parents to use PTT should be carried out by a separately constituted CEC to ensure that the child to be born is not at risk of exploitation, abuse or neglect. If a CEC finds that the child is at risk, then the clinic should not be permitted to provide treatment.

\textsuperscript{125} See Part IIIC.
\textsuperscript{126} The NHMRC Guidelines on ART require clinics to seek advice from a CEC (or a relevant state or territory regulatory agency): NHMRC Guidelines on ART, above n 5 [12.3]. Previous VARTA Conditions on PTT, above n 4 [2.4].
CECs would therefore have a decision-making capacity, rather than simply acting as advisory bodies.127

Given the grave implications for the existing child of a refusal by a clinic to allow PTT, I propose that the ART Act (Vic) provide a mechanism for parents to obtain independent review of a decision by a CEC to refuse PTT. The new Patient Review Panel, an independent multi-disciplinary review panel established under the ART Act (Vic), currently has the power to review applications for ART that fall outside the eligibility requirements under the Act. This includes applications for PTT that will not be carried out in conjunction with PGD. Under my proposed framework, the Patient Review Panel should be empowered to make determinations about PTT where a CEC has decided that it should not be provided.128 However, individual clinics should not be compelled to perform PTT.129

Unlike the current position in Victoria, where the Patient Review Panel routinely determines all PTT applications involving PGD,130 I propose that the Patient Review Panel only consider PTT applications at the request of parents or clinicians where the application has been rejected by a CEC. As is currently the case, the Patient Review Panel would be required to apply the guiding principles in the ART Act (Vic) and relevant guidelines on PTT. The Patient Review Panel could therefore only uphold a decision by a CEC to refuse treatment where it found that the child to be born was at risk of exploitation, abuse or neglect. Decisions about PTT by the Patient Review Panel should be reviewable by the Supreme Court on points of law but not on their merits ‘because they are decisions made by a group of specialists’.131 This is consistent with the current position under the ART Act (Vic), which allows appeals from the Patient Review Panel to the Victorian Civil and Administration Tribunal (VCAT) but does not allow appeals from decisions about PTT.132

127 The VLRC proposed a similar role for CECs: VLRC Report, above n 9, 63. Currently, most CECs operating in Victorian hospitals act as advisory bodies.
128 The VLRC made a similar recommendation about the role of CECs: VLRC Report, above n 9, 63.
129 This is consistent with the principle of ‘conscientious objection’ in medical practice generally. This principle is reflected in the NHMRC Guidelines on ART, above n 5 [5.9]. See also: VLRC Report, above n 9, 63, 66; Sarah Elliston, The Best Interests of the Child in Healthcare (Routledge-Cavendish, 2007), 42.
130 In cases involving a genetically heritable disease, the parents would satisfy the general requirements for treatment procedures in s 10(2)(a)(iii) of the ART Act (Vic).
131 VLRC Report, above n 9, 66.
132 The ART Act (Vic) specifies categories of Patient Review Panel decisions that are reviewable by VCAT in s 96. The categories do not include decisions about treatment where the applicant does not
In the following sections, I explain in detail how legislation, national guidelines and clinical ethics consultation can improve the decision-making process for PTT and protect the welfare of the child to be born. A critical factor in ensuring these outcomes is the provision of ethical guidance and oversight throughout the decision-making process. The current guiding principles in the ART Act (Vic), the NHMRC Guidelines on ART and the previous VARTA Conditions on PTT provide some ethical guidance on PTT. I propose more detailed ethical guidance on PTT than that which is currently contained in these instruments. This involves revised guiding principles in the ART Act (Vic) as well as more detailed national guidelines on PTT. I also recommend the ethical oversight of individual cases by CECs. I deal with my proposals for the ART Act (Vic), national guidelines and CECs separately.

B ART Act (Vic)

The ART Act (Vic) should provide clear ethical guidance on PTT and the role of the welfare of the child principle. It should prohibit PTT where the child to be born is at risk of abuse, neglect or exploitation. To ensure this prohibition is enforced, the Act should require decisions about PTT to be reviewed by CECs.

1 ART generally

In Chapter 4, I argued that a relational ethical approach should be applied to PTT in order to accommodate the individual and collective interests within a family. Although I have focused specifically on PTT, Chapter 4 revealed that there is increasing support for a relational approach to general medical decision-making. In the context of ART, some common law jurisdictions reflect elements of a relational approach to decision-making.\(^{133}\) For the reasons discussed in Chapter 4, a relational approach should be endorsed by the ART Act (Vic) through the following guiding principles:

(1) An important concern in ART is the welfare of the child to be born, which includes both:

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meet the criteria for treatment: see ss 10(2), 91(1)(e). This is the category into which applications for PTT would fall.

\(^{133}\) For example, the ethics of care is an underlying principle in the New Zealand Human Assisted Reproductive Technology Act 2004 (NZ) (HART Act 2004) and the Canadian Assisted Human Reproduction Act 2004 (Can). See Human Genome Research Project, above n 25, 310.
• the individual interests of the child in nourishment, shelter, protection from harm, and respect; and
• the collective interests the child shares with his/her family in intimacy, love, affection and collective endeavour.

(2) Treatment decisions should involve consideration of:
• the individual interests of the child to be born;
• the individual interests of the parents and any existing siblings; and
• the collective interests of the child’s intimate family. ¹³⁴

(3) The child to be born as a result of ART should be protected from abuse, neglect and exploitation.

(4) The welfare of a child is inextricably connected to the welfare of the intimate collective that is his/her family.

(5) An intimate family is characterised by close and enduring relationships between family members rather than by biological connections or a particular family structure.

(6) The needs, values and beliefs of people from different religious and cultural perspectives in Australian society should be considered and treated with respect.¹³⁵

(7) Good record-keeping and data reporting is vital for tracking the short and long-term consequences for children born as a result of ART and their families.

The first two principles clarify the welfare principle by clearly defining the nature of interests that are relevant to decisions about PTT. The principles reflect a different approach from the first guiding principle in the ART Act (Vic), which confers ‘paramount’ importance to the welfare and interests of the child to be born in relation to treatment decisions.¹³⁶ Rather than focusing primarily on the interests of the child to be born, the first two principles require a broader consideration of interests within

¹³⁴ This requirement is similar to the guiding principle in the former IT Act (Vic), which stated that the interests of the family should be considered: s 5(c). There is no equivalent guiding principle in the current ART Act (Vic).

¹³⁵ A similar statement is included in the guiding principles in the New Zealand HART Act 2004: s 4(f).

¹³⁶ ART Act (Vic), s 5(a).
the putative child’s family. The first principle also attempts to clarify the meaning of the phrase, ‘welfare of the child’, which is not currently defined in the ART Act (Vic). The first principle defines the ‘welfare of the child’ in accordance with the notion of human flourishing discussed in Chapter 3, which includes both the individual interests of the child to be born as well as the collective interests the child shares with his/her family.

The welfare of the child to be born is protected by the third principle, which proposes a ‘minimum threshold’ of protection for the child by stating when treatment should be prohibited. The minimum threshold of protection should be enforced in the Act by a separate provision creating an offence for clinicians to engage in any form of ART where the child to be born is at risk of abuse, neglect or exploitation. In cases where the child to be born as a result of ART does not appear to be at risk of abuse, neglect and exploitation, decisions about treatment should be made by parents in consultation with their health care team in accordance with the guiding principles in the ART Act (Vic) and national guidelines on ART. In difficult cases (such as PTT), ethical oversight is also necessary. Where the minimum threshold is satisfied, parents should not be denied treatment on the basis of the welfare of the child. Walker proposes a similar system for ART based on a presumption of access, subject to specific exclusions:

…in the absence of general community consensus about what makes a good parent, we should adopt a cautious approach that ensures the basic safety of the child but does not involve value judgments about parenting abilities.

The fourth, fifth and sixth principles reflect a flexible approach to the role of family in the decision-making process and the importance given to other family interests. As discussed in Chapter 3, all families are different and it is closeness rather than structure that makes a family intimate. Furthermore, in Chapter 4 I argued that the nature of relationships within a family will impact on the welfare of the child to be born. Cultural identity also plays a significant role in the nature and role of extended

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137 These principles represent a combination of the approaches in WA legislation (which requires consideration to be given to the interests of the parents: Human Reproductive Technology Act 1991 (WA), s 23(e)) and UK legislation (which requires consideration to be given to the interests of other siblings who may be affected: HFE Act 1990, s 13(5)).


139 Walker above n 32, 134.
family. Given the cultural diversity within Australia, it is important to acknowledge the role of extended family in some cultures. 140

The seventh principle reflects a commitment to the improvement of ART services through good record keeping and data-recording. The continued improvement of ART services depends on a nationally coordinated system for monitoring any long-term consequences for children born using ART.

As different forms of ART may involve specific detailed considerations, which may vary over time, the Act should delegate the power to make detailed guidelines on specific forms of ART to a national specialist advisory committee, such as the NHMRC. In relation to PTT, there are some broad matters that should be covered in the Act itself.

2 Specific context of PTT

The Act should endorse a relational approach to PTT by requiring that national guidelines for PTT focus on improving the decision-making process to enable parents to make informed and ethically sound decisions. As far as possible, decisions about PTT should be delegated to parents in consultation with their health care team, subject to the guiding principles in the Act and relevant national guidelines. However, given the ethical complexities involved for PTT, the Act should also require clinics to refer decisions about PTT to CECs for review. The Act should specify a time limit of two weeks for approval by CECs, to avoid undue delay.141

Implementing my approach in Chapter 4 to protect the child to be born from abuse, neglect and exploitation, the ART Act (Vic) should expressly prohibit PTT where:

(1) the parents do not want another child for his/her own sake; or

(2) there is a significant risk of serious harm to the child to be born.

The first limb is intended to protect the child from exploitation or from being treated solely as a means, in contravention of Kant’s categorical imperative. As discussed in

140 For example, New Zealand legislation recognises that it is important for Maori to preserve their genetic inheritance, which requires a balance to be struck between individual and collective rights to the use of PGD: HART Act, s 4(f),(g); Human Genome Research Project, above n 25, 6.

141 In Victoria, the Royal Womens’ Hospital Clinical Ethics Advisory Group (CEAG) and The Royal Childrens’ Hospital Clinical Bioethics Committee (CBC) are generally able to convene within a week’s notice: email from Margaret Coady (Committee Member, CEAG) to Michelle Taylor-Sands, 25 March 2010; CBC, Clinical Ethics Service, The Royal Children’s Hospital Melbourne http://www.rch.org.au/bioethics/clinical.cfm?doc_id=12222
Chapters 2 and 4, the reasons people have for becoming parents are varied, multifactorial, and rarely entirely altruistic. The first limb is not intended to ‘judge’ parents seeking PTT and should not interfere unduly with their reproductive decisional privacy. Rather, it is intended to screen against the remote possibility that parents are seeking PTT to raise a child *solely* as a commodity in order to save the life of an existing child.

The first limb should also not operate as a ‘but for’ test in the sense that parents should be prohibited from using PTT if they would not have had another child but for the fact that they have an ill child in need of a bone marrow donor.\(^\text{142}\) It may be the case that parents of an ill child, who may otherwise not have chosen to have another child, are initially motivated to use PTT by a desire to save their existing child.\(^\text{143}\)

However, provided the parents genuinely want another child for his/her own sake in addition to helping the existing child, then they should be allowed to use PTT. Parental motivation for having a child is complex and often difficult to ascertain. However, as discussed in Chapter 4, at least some attempt should be made to identify parents who do not genuinely desire a child for his/her own sake through family consultation and appropriate counselling.

The second limb is intended to protect the child to be born from significant harm that constitutes either abuse or neglect. The ART Act (Vic) should broadly define the phrase ‘significant risk of serious harm’ but otherwise leave these determinations to clinicians and CECs. As discussed in Chapter 4, significant risk of serious harm might be defined as ‘more than a minor increase over the level of harm that a healthy child normally experiences’.\(^\text{144}\) More detailed guidance for determining acceptable levels of harm, based on current evidence, could be contained in non-legislative guidelines. The guidelines can be reviewed from time to time and are more easily amended than legislation.

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\(^{142}\) See discussion in Chapter 2 in response to Rob Sparrow’s argument that the child to be born as a result of PTT is commodified if the parents would not have had the child but for the fact that their existing child needed a stem cell transplant: Chapter 2, Part IVA.

\(^{143}\) For example, parents seeking PTT in the UK have stated, ‘although we’re desperate in that we want to help (our existing child); we’re not totally desperate in that we’ve not considered what we’re doing.’: Anoushka Shepherd, ‘TV Review (of BBC documentary): Having a Baby to Save my Child’ BioNews 22 February 2010 [http://www.bionews.org.uk/page_54922.asp](http://www.bionews.org.uk/page_54922.asp).

\(^{144}\) This test is based on Ross’ definition of *minor increase over minimal risk of harm*, discussed in Chapter 4, Part IIC1. According to Ross, blood donations involve a minimal risk of harm, bone marrow donations involve a minor increase over minimal risk of harm, and kidney donations involve more than a minor increase over minimal risk of harm.
As discussed at the beginning of this Chapter, the NHMRC Guidelines on ART and the previous VARTA Conditions on PTT contain some helpful guidance on PTT. I have drawn from these and related policies to frame more detailed guidelines for PTT in this section. In line with my proposed national approach to regulating PTT, the guidelines should be prepared by a national specialist ethical advisory committee with appropriate ethical, religious, scientific, legal and clinical medical expertise. Dedicated national advisory committees are sometimes criticised for being ‘talking shops’, expensive bureaucracies or extremely politicised. However, these concerns can be addressed by clearly defining the role of the committee, embedding their policies within the regulatory scheme, and removing political control over appointments.

The AHEC, a Principal Committee of the NHMRC, is a national body with expertise in philosophy, clinical medical practice and nursing, disability, law, religion and health consumer issues. The AHEC developed the NHMRC Guidelines on ART, so is therefore well-placed to prepare more detailed guidelines on PTT. The AHEC could amend the current NHMRC Guidelines on ART to incorporate my proposed national guidelines on PTT. The AHEC should continue to operate as an advisory committee and not become involved with individual cases involving PTT. CECs

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145 I have also drawn from the following policy documents: Australian New Zealand Infertility Counsellors Association (ANZICA), Guidelines on Professional Standards of Practice Infertility Counselling (October 2003) (ANZICA Guidelines); former Infertility Treatment Authority (ITA), Decision-Making under the Infertility Treatment Act 1995: Guidelines for Services, Practitioners and Patients (August 2003); HFEA Code, above n 120; New Zealand National Ethics Committee on Assisted Human Reproduction (NECAHR), Guidelines on Preimplantation Genetic Diagnosis (March 2005); New Zealand Advisory Committee on Assisted Reproductive Technology (ACART), Consultation on Draft Guidelines for the Use of Preimplantation Genetic Diagnosis with Human Leukocyte Antigen Testing (July 2008) (ACART Consultation). I have referenced those aspects of my proposed national guidelines that are based on these other policy documents in footnotes. I have also drawn from recommendations made in the following Victoria, UK and New Zealand reports: VLRC Report, above n 9; STC Report, above n 19; Human Genome Research Project, above n 25, 6.

146 For example, see discussion in STC Report, above n 19 [348]-[352].

147 See study by Slowther et al for discussion of the relationship between CECs and clinical governance: Anne Slowther, et al, ‘Clinical Ethics Support Services in the UK: An Investigation of the Current Provision of Ethics Support to Health Professionals in the UK’ (2001) 27 (Suppl 1) Journal of Medical Ethics 12. The study suggests that CECs need to be seen as ‘functioning with, but not simply as part of, clinical governance’: i7. See also discussion in STC Report, above n 19 [350-351].


149 The NHMRC Guidelines on ART were developed by the AHEC and issued by the CEO of the NHMRC: NHMRC Guidelines on ART, above n 5, 15.

150 The role of the AHEC would be similar to that of the ACART in New Zealand. ACART is responsible for creating policy in accordance with the HART Act: Human Genome Research Project,
should provide ethical input at a local level by reviewing individual applications for PTT. My proposed national guidelines should therefore include guidance on the operation of CECs to ensure that they apply the law and policy on PTT consistently and transparently.\textsuperscript{151} The NHMRC Guidelines currently require clinics to seek advice from a CEC when requested to perform PTT.\textsuperscript{152} I propose a slightly different role for CECs, by requiring them to review cases involving PTT to ensure that the child to be born is protected from exploitation, abuse and neglect.

As with the current NHMRC Guidelines on ART and previous VARTA Conditions on PTT, my proposed national guidelines reflect a case-by-case approach, clarify the circumstances in which PTT is available, and stipulate that clinics must provide parents with information and counselling. Unlike the current Commonwealth and Victorian policies, my proposed guidelines require the provision of ethical guidance to parents seeking PTT, consideration of the interests of family members beyond the child to be born, and a formal system for monitoring long-term consequences for the child to be born as a result of PTT. I propose that the same guidelines apply to all applications for PTT, whether or not PTT is carried out in conjunction with PGD. My proposed guidelines therefore remove the distinction, currently operating in Victoria, between PTT carried out in conjunction with PGD and PTT carried out alone. I do not attempt to draft an exhaustive set of guidelines for PTT in this section. Instead, I elaborate on how the general principles for a relational approach to PTT outlined in Chapter 4 might be implemented in national guidelines. The general principles appear in italics and the guidelines referable to those principles are set out under the relevant principles.

1. \textit{A relational approach to PTT requires consideration of the interests of all family members, not just those of the child to be born.}

Applications for PTT should be dealt with on a case-by-case basis as the circumstances of individual cases will vary. However, national guidelines should identify the following interests at stake in relation to PTT as part of the decision-making process:

\begin{itemize}
  \item above n 25, 309, 313-4. The Ethics Committee on Assisted Reproductive Technology (ECART) approves ART procedures in accordance with the guidelines issued by ACART: Human Genome Research Project, above n 25, 314.
  \item See STC Report, above n 19 [353-4]. This approach is in contrast with the approach recommended by the VLRC that CECs develop their own processes: VLRC Report, above n 9, 63.
  \item NHMRC Guidelines on ART, above n 5 [12.3].
\end{itemize}
• The future interests of the child to be born in respect and protection from harm.
• The interests of the parents in saving the life of their existing child and in having another child.
• The interests of the sick child in receiving a bone marrow transplant and having a sibling.
• The interests of any other siblings who will be affected by the decision.
• The collective interests of the family as a whole in the life and health of each of its members.

In line with the relational approach I proposed in Chapter 4, the interests of the child to be born should be considered in connection with the interests of his/her family rather than in opposition to those interests.

2. A “process model” is preferable to a conflict-based model for managing individual and collective interests within a family.

3. The decision-making process for PTT should openly and respectfully explore the family’s values, beliefs and preferences as these are relevant to the welfare of the child to be born.

To enable parents to make genuinely informed decisions about PTT within a supported environment, national guidelines should outline the following features of the decision-making process:

• Decisions about PTT should be made by parents in consultation with their health care team, which should consist of a PTT physician, counsellor and clinical ethicist.

• Where appropriate, all existing children (not just the child suffering from a life-threatening condition) should be given an opportunity to contribute to the discussion about PTT.

• It is reasonable for parents to make decisions that take account of the needs of all their children.

• Individual and collective family interests should be explored in a supportive environment that promotes the intimate nature of family.
• The values, beliefs and preferences of all family members should be discussed in a non-judgemental manner, within an ‘open moral space’.

• The health care team should provide and discuss information with sensitivity to cultural diversity and religious beliefs.

• Where there is a difference of opinion between family members about PTT, a ‘discourse ethics’ approach should be taken to resolve potential conflicts wherever possible.

• Where there is entrenched conflict between family members, an attempt should be made to settle disputes by mediation, although a decision to use PTT should ultimately be made by the parents.

4. National guidelines should clearly outline the respective roles of parents, the health care team (PTT physician, counsellor and clinical ethicist) and the CEC in the decision-making process.

(a) Role of parents in determining the welfare of the child to be born

• **Parents** seeking PTT should actively contribute to a determination about the welfare of the child to be born.

(b) Role of health care professionals in treating the family as an intimate collective and protecting the welfare of the child to be born

• The **health care team** should assist parents in determining whether or not to proceed with PTT by providing relevant information, counselling and ethical guidance to parents and, where appropriate, existing children within the family.

• Where any member of the health care team is of the opinion that the child to be born as a result of PTT is at risk of exploitation, abuse or neglect, the member should outline his/her concerns in detail to the CEC.

• The **PTT physician** should provide parents and any existing children involved in the decision-making process with relevant information on PTT, including:
  
  o information about the tissue typing tests required;

  o the latest evidence about any risk associated with ART and embryo biopsy;
• The **counsellor** should support parents and any children involved in the decision-making process by:
  
  o exploring the motivation of parents seeking PTT;
  
  o addressing the implications of undergoing PTT treatment for parents, their existing children, and any child born as a result;
  
  o providing personal and emotional support to parents and any existing child who is likely to be affected by a decision to use PTT;
  
  o encouraging parents and existing children to develop realistic expectations about treatment outcomes;\(^{153}\)
  
  o promoting discussion about appropriate coping strategies in the event that PTT is ultimately unsuccessful in curing the existing ill child;\(^{154}\) and
  
  o advising parents about additional services and support networks that are available.

• The **clinical ethicist** should provide ethics counselling throughout the decision-making process by:
  
  o assisting all family members to explore their own preferences, values and beliefs in the context of PTT;
  
  o facilitating moral deliberation and consensus through ‘discourse ethics’; and
  
  o where consensus is not achieved, mediating any disputes that arise.

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\(^{153}\) Based on the ANZICA Guidelines, above n 145 [1.2.1].

\(^{154}\) Based on the ANZICA Guidelines: ibid.
(c) **Role of CECs in ensuring that the welfare of the child to be born has been given due consideration in accordance with the law and policy on PTT**

- The **CEC** at the relevant ART clinic should review decisions to proceed with PTT to ensure that they comply with the ethical criteria in relevant ART legislation and national guidelines on PTT on:
  - the welfare of the child to be born; and
  - the decision-making process for PTT.

- The CEC should determine that PTT should not be provided where:
  - the child to be born is at risk of exploitation, abuse or neglect; or
  - the decision-making process has been so flawed that the parents cannot have made a fully informed decision.

**5. Guidance should be given as to how the welfare of the child to be born is likely to be adversely affected by PTT.**

National guidelines should state that the child to be born as a result of PTT is at risk of abuse, neglect or exploitation in the following two circumstances:

- The parents do not want another child for his/her own sake (commodification).
- There is a significant risk of serious harm to the child to be born (harm).

Specific guidance should be given in relation to the issue of **commodification**:

- Parental motivation for having a child is complex and multifaceted and rarely entirely altruistic.

- How the parents are likely to treat the child once s/he is born is more important than parental motivation for having the child.

Specific guidance should also be given in relation to the risk of **harm**:

- Harm includes physical, psychological and social harm, in particular:
  - possible physical harm associated with ART and embryo biopsy;
  - any likely long-term psychological and social implications; and
  - any intrusive surgery likely to be required in the future.

- Parents regularly expose their children to some risk of harm.
• The intimate nature of family relationships sometimes justifies imposing a greater risk of harm on family members than would otherwise be justified in relation to strangers.

• The nature and intimacy of existing relationships within the family should be taken into account.

• A significant risk of serious harm falls outside the realm of risks to which parents often subject their children.

• A child who is born as a result of PTT may donate bone marrow in the future but should not donate any non-regenerative or whole organs.\textsuperscript{155}

General guidance should also be given about balancing risk and benefit in the context of specific relationships. Relevant factors include:

• The circumstances of the family seeking treatment, including:
  
  o the nature of relationships within the existing family;\textsuperscript{156}
  
  o the demands of ART/PTT treatment on the parents while caring for the existing child;\textsuperscript{157} and
  
  o the extent of social support available within the extended family.\textsuperscript{158}

• The severity of the condition of the existing child, including: \textsuperscript{159}
  
  o the degree of suffering associated with their condition;
  
  o the speed of degeneration in progressive disorders;
  
  o the prognosis, including all treatment options;
  
  o the availability of other sources of tissue; and
  
  o the availability of other effective therapy / alternative treatment options.

\textsuperscript{155} As discussed in Chapter 2, the donation of non-regenerative tissue is generally prohibited in Australia by state legislation. See, for example, \textit{Human Tissue Act 1982} (Vic), s 14(1). The ACT is the exception, in that it expressly permits the donation of non-regenerative tissue from minors under very strict conditions. See \textit{Transplantation and Anatomy Act 1978} (ACT), s 14.

\textsuperscript{156} While it can be difficult to judge the nature of relationships within families, this is effectively what US courts have done in the context of cases involving organ donations by siblings. See discussion by Dwyer and Vig in relation to \textit{Hart v Brown} and \textit{Strunk v Strunk}: James Dwyer and Elizabeth Vig, ‘Rethinking Transplantation between Siblings’ (1995) 25(6) Hastings Center Report 7.

\textsuperscript{157} Based on HFEA Code, HFEA Guidance Note 10, above n 120 [10.21(e)].

\textsuperscript{158} Ibid [10.21(f)].

\textsuperscript{159} Ibid [10.19].
• The likelihood of a successful outcome.

• The consequences of an unsuccessful outcome.

6. Decisions about PTT should be recorded and clinics should attempt to monitor the long-term effects of PTT on children born as a result.

Clinical ethics committees must be satisfied on the basis of medical, counselling and ethical reports that the welfare of the child has been satisfactorily safeguarded in accordance with the relevant ART legislation and national guidelines on PTT.\(^{160}\)

National guidelines should therefore require clinics to keep accurate records to ensure that:

• Due consideration has been given to the welfare of the child to be born.

• The decision-making process for PTT has complied with ART legislation and national guidelines on PTT.

National guidelines should also require clinics to make arrangements for inviting and encouraging patients and their families to take part in long-term follow-up studies of:

• Long-term medical effects on children born as a result of PTT.

• Psychosocial effects on children born as a result of PTT and their families.

The information obtained by clinics in relation to long-term effects of PTT should be reported to the NHMRC and recorded on a national registry to assist further research in this area.

D Clinical Ethics Consultation

Clinical ethics consultation is an integral part of my proposed regulatory framework for PTT. My approach involves two stages of ethical oversight in the decision-making process for PTT.

At the first stage, a clinical ethicist working within the health care team should provide ethics counselling to assist parents in deciding whether to proceed with PTT.

\(^{160}\) Based on the ‘New Zealand Draft Guidelines for the use of PGD with HLA Testing’, ACART Consultation, above n 145, which state that ‘medical and counselling reports satisfy ECART that the health and wellbeing of the resulting child is safeguarded’: 2(a)(iv).

\(^{161}\) Based on HFEA Guidance Note 10, above n 120 [10.24].
Ethics counselling should therefore be mandatory under the ART Act (Vic). Ethics counselling is a new and fledgling area in Australia and is not generally offered in Australian hospitals. Where ethical consultation services are offered, they are generally provided to clinicians rather than parents. Ethics counselling for parents seeking PTT is, however, an essential element of the relational approach that I outlined in Chapter 4. I am proposing that a clinical ethics consultant work alongside the PTT physician and counsellor by helping parents navigate their way through the complex ethical questions that arise in relation to PTT. As discussed in Chapter 4, the clinical ethicist should facilitate moral deliberation and consensus using ‘discourse ethics’ rather than act as an expert moral authority. Where consensus is not achievable, the clinical ethics consultant should assist by mediating any disputes that arise and helping parents, their existing children, and members of the health care team engage meaningfully in the decision-making process.

Once parents have made a decision to proceed with PTT, a second stage of ethics review of the decision should be carried out by a separately constituted CEC. As previously discussed, ART clinics in Victoria are not legally required to establish CECs. While there are no national figures on the number of CECs operating in Australian hospitals, the numbers are probably quite low. Under my proposed framework, all clinics offering ART should have CECs. The CECs should ensure that the welfare of the child is given due consideration in accordance with relevant ART legislation and national guidelines on PTT by routinely reviewing decisions to proceed with PTT. Upon review, a CEC should refuse PTT if it is of the view that the child to be born as a result of PTT is at risk of abuse, neglect or exploitation. A CEC should also remit a decision about PTT back to the clinic for further consideration in

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162 Counselling by an ART counsellor is currently mandatory under s 13 of the ART Act (Vic). This provision could be extended to incorporate ethics counselling as well.
163 For example, the Royal Children’s Hospital in Victoria now has a Clinical Ethics Response Group (CERG), which provides ethical advice to clinicians at their request. While the role of the CERG is still evolving, parents are not generally involved in ethics consultations: information provided by Associate Professor Lynn Gillam, Academic Director, Children’s Bioethics Centre, Royal Children’s Hospital to author on 28 April 2010.
164 See discussion at p 20. However, as discussed, both the previous VARTA Conditions on PTT and the NHMRC Guidelines on ART require ART clinics to seek advice from a CEC before offering PTT in individual cases. Two examples of CECs operating in Victoria are: the Royal Womens’ Hospital Clinical Ethics Advisory Group; and the Royal Children’s Hospital Clinical Bioethics Committee.
165 Lynn Gillam estimates that maybe 10-20% of hospitals in Australia have CECs: presentation by Lynn Gillam, Academic Director, Children’s Bioethics Centre, Royal Children’s Hospital at the Monash Intensive Bioethics Course, Alexandra, on 3 December 2009. Gillam contrasts the position in the US, where all hospitals in the US are required to have a clinical ethics process for accreditation.
cases where, in the opinion of the CEC, the process has been so flawed that the parents cannot have made a fully informed decision. In addition to ethically reviewing decisions about PTT, CECs can also play an educative role by disseminating national guidelines in a manner that can be easily digested and applied by their clinics. As Doyal has pointed out, ‘CECs can play a valuable role in disseminating national guidance, which has been presented in long documents and may not be readily assimilated by busy clinicians.’\textsuperscript{166}

The potential lack of independence by clinicians who feel sympathetic to their patients provides a strong argument for the involvement of CECs in the decision-making process. As Mumford et al state, ‘there is a residual unease amongst doctors’ in assessing the welfare of the child in the context of ART.\textsuperscript{167} This concern has been echoed by the STC in the UK and the VLRC in Australia. For instance, the medical director of a UK infertility clinic submitted to the STC that ‘[i]t is possible for us clinicians in particular to become so “wrapped up” in what we perceive to be best for the couple that we do not see the wider picture.’\textsuperscript{168} Similarly, the VLRC consultation process revealed that clinics encounter cases where they are unsure about a particular risk to a child to be born.\textsuperscript{169} The VLRC recommended that CECs should be more than an advisory body in complex cases and should have a decision-making capacity.\textsuperscript{170}

The ‘external review’ of PTT decisions by local CECs provides ‘a mechanism for determining whether or not to treat the person or couple which is transparent, procedurally fair and allows each case to be evaluated on its own merits’.\textsuperscript{171} A properly constituted CEC should have the appropriate expertise to assess the welfare of the child in the context of PTT.\textsuperscript{172} Review by a CEC is more appropriate than

\textsuperscript{166} Submission by Len Doyal to the STC: STC Report, above n 19 [342]. See also Len Doyal, ‘Clinical Ethics Committees and the Formulation of Health Care Policy’ (2001) 27 (Suppl 1) \textit{Journal of Medical Ethics} i44, i47.


\textsuperscript{168} STC Report, above n 19 [374].

\textsuperscript{169} VLRC Report, above n 9, 62. See also UK study by Slowther et al, above n 147, which provides the following statistics on the perceived need for CECs: 89% in favour; of these, 62% for a CEC, 26% for an individual clinical ethicist and 12% for some other model of clinical ethics service.

\textsuperscript{170} VLRC Report, above n 9, 62-3.

\textsuperscript{171} Ibid 62.

\textsuperscript{172} The VLRC recommended that CECs should generally include a child development expert, a psychologist or psychiatrist with expertise in the prediction of risk of harm to children, and a doctor with experience in ART: ibid Given the ethical and legal aspects of the role I am proposing for CECs, I would add an ethicist and a lawyer to the list.
other types of external review, such as judicial or administrative review, which are more formal, time-consuming, and removed from the clinical setting. A local CEC has benefits over a national ethics committee,173 because it is closer to the clinical setting and able to make decisions that reflect the circumstances of individual cases.174 The value in local CECs lies in their ability to ‘provide support that is responsive and relevant to local circumstances.’175

Two challenges for my proposed system, in which there are multiple CECs interpreting and applying ART legislation and national guidelines on PTT, are cost and consistency in decision-making. The costs involved in establishing a nationally coordinated network of CECs must be justified. Although there are only a small number of cases of PTT in Australia, there is an increasing need for clinical ethics services in light of the complex ethical issues raised by new developments in ART. While this thesis focuses specifically on PTT, the relational approach I have proposed could be applied to ART services more generally. The role of CECs would therefore be broader than simply reviewing applications for PTT and could extend to other ART services. As McLean states, ‘[c]linical ethics committees … are becoming a more common feature on the landscape of health care delivery … around the world’.176

Greater consistency in decision-making could be achieved if CECs operated within a nationally coordinated framework. Although there is considerable infrastructure and guidance on the operation of human research ethics committees (HRECs) in Australia, no such framework exists for CECs.177 Unlike HRECs, CECs are a hospital-driven phenomenon in Australia and are neither established nor overseen by the NHMRC.178 A national framework for CECs should therefore be established, setting out their composition and working practices.179 As far as possible, CECs should rely on the advice of the individual clinical ethicist working within the health care team, as s/he

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173 One example of a national ethics committee is ECART in New Zealand. ECART, a national statutory body, approves ART procedures in New Zealand in accordance with the national guidelines issued by ACART: Human Genome Research Project, above n 25, 232, 314.
174 See STC Report, above n 19 [353].
175 Slowther et al, above n 147, i2.
177 VLRC Report, above n 9, 63.
178 Lynn Gillam, above n 165.
has been directly involved in the decision-making process. The clinical ethicist should provide a detailed report to the CEC, providing the background to and reasons for the decision to proceed with PTT in each case. This report should be supplemented by reports from the PTT and the counsellor involved in the decision-making process. Where the clinical ethicist or any other member of the health care team is concerned that the child to be born as a result of PTT is at risk of exploitation, abuse or neglect, they should provide details of the concerns in their report to the CEC. As previously mentioned, clinics should not be compelled by a CEC to perform PTT.180

V CONCLUSION

There are strong reasons for regulating ART and, specifically, PTT. Regulation is not only important to protect the child to be born from exploitation, abuse and neglect, but it can also improve the decision-making process. Instead of unduly restricting reproductive liberty, a permissive approach to regulating PTT can enhance parental choice by supporting parents in making ethically complex and emotionally charged decisions.

The national regulatory framework for PTT outlined in this Chapter differs from the current regulation of PTT in Victoria in several key ways. First, my proposed legislation requires that the interests of all family members be considered in connection with the interests of the child to be born. Whereas the current approach under the ART Act (Vic) requires the interests of the child to be treated as paramount, I am proposing a relational approach to decision-making based on a broad conception of the welfare of the child to be born. Second, I have attempted to provide clearer ethical guidance on the welfare of the child to be born as a result of PTT in legislation and national guidelines. In particular, my proposed legislation confers a minimum threshold level of protection to the child to be born. This ‘minimum welfare’ principle should be easier to apply than the current formulation of the welfare principle in the ART Act (Vic), which is vague and may lead to discrimination.

180 See discussion above, Part IVA2. This is consistent with the requirement in the NHMRC Guidelines on ART, above n 5, that conscientious objections be respected [5.9].
Third, my framework devolves decisions about PTT to parents, in consultation with their health care team, rather than a statutory body like VARTA or the Patient Review Panel as has previously been the case in Victoria. I have argued that decisions about the welfare of the child to be born are best made by patients in consultation with their health care providers, rather than by a statutory body. My framework more closely resembles the current system in Victoria, in which decisions about PTT in conjunction with PGD are likely to be made by clinics. However, I propose a greater role for parents in the decision-making process. To ensure that decisions about PTT are made within the spirit of the legislation, I have outlined a detailed decision-making process for PTT that should be incorporated in the NHMRC guidelines on ART. The detailed national guidelines I propose are aimed at supporting parents in making ethically sound decisions that are consistent with their value system, while providing a threshold level of protection to the child to be born.

Fourth, a key element of my proposed decision-making process is the provision of ethics counselling to parents making decisions about PTT. Under the current system in Victoria, parents seeking PTT receive detailed information from their physician as well as general counselling from an approved counsellor. Parents do not, however, receive any ethical guidance in relation to PTT. Ethical consideration of PTT applications by a CEC occurs as a separate stage in the approval process, at which parents are not involved. Given that parents are effectively the decision-makers under my framework, it is imperative that they be given ethics counselling to help them navigate the ethical dilemmas posed by PTT. I am also proposing additional and independent ethical oversight of decisions about PTT by a CEC through a system of review.

Finally, my proposed national guidelines require clinics to have systems in place to encourage families to take part in long-term follow-up studies of the medical and psychosocial effects on children born as a result of PTT and their families. I have also proposed that the information obtained by clinics be recorded on a national registry. National reporting and recording requirements for PTT should further promote the welfare of the child to be born by capturing important relevant information about the

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181 As discussed in Part IIIA, it is not entirely clear as to who shall make decisions about PTT in conjunction with PGD in Victoria: esp footnote 58.
long-term risks associated with PTT, which are currently missing from the evidentiary matrix.
CHAPTER 7

CONCLUSION

In this thesis I have proposed a national framework for regulating PTT in Australia. My proposed regulatory framework reflects a relational approach to PTT whereby the interests of the child to be born are considered in connection with the interests of other family members. I have argued that a relational ethical approach is more appropriate for regulating PTT than the current approach in Victoria, which treats the interests of the child to be born as paramount. The child to be born as a result of PTT is clearly in a vulnerable position and regulation should protect his/her welfare. However, the welfare of a child extends beyond the child’s individual interests and includes the collective interests the child shares with his/her family. The very nature of PTT also requires a broader consideration of interests beyond those of the child to be born. PTT is a procedure that affects the whole family and is primarily designed to save the life of an existing child. It would therefore be disingenuous to focus solely on the individual interests of the child to be born when making decisions about PTT.

I conclude my thesis with a summary of arguments in support of my proposed regulatory framework for PTT. I also reflect on the two key issues for PTT that I highlighted at the beginning of the thesis, namely: (1) the welfare of the child to be born; and (2) the role of the state in regulating ART. I then briefly mention some of the benefits and burdens of a relational approach and highlight some areas for further research. One benefit of a relational approach to PTT is that it is more responsive to the individual circumstances of each case than the current approach in Australia. For example, a relational approach would not unnecessarily limit PTT to donations between siblings if a family is sufficiently close to justify donation to another family member, such as a parent. A relational approach should also encourage parents to make well-considered decisions about PTT that serve them into the future. The key drawback of a relational approach is the complexity of the decision-making process. I conclude that this is, to some extent, inevitable. However, I suggest how empirical investigation might lead to improvements in the decision-making process. I finish by suggesting how a relational approach may be applied to other forms of ART and briefly comment on its application to medical decision-making generally.
I SUMMARY OF ARGUMENTS

In Chapter 1, I argued that the current approach to regulating PTT in Australia is fragmented, inconsistent, and lacks a clear ethical foundation. Although the Commonwealth Parliament does not have explicit power to legislate on ART services, I suggested that nationally consistent legislation could be achieved through cooperative federal agreement by COAG. A national approach to ART is desirable, particularly in relation to the ‘social issues’ raised by controversial technologies like PTT. I therefore proposed a framework for regulating PTT involving nationally consistent state legislation and detailed national policy guidelines by the NHMRC.

As Victoria is the only state to have specifically regulated PTT, I have focused my analysis on the law and policy regulating PTT in Victoria. My main criticism of Victorian ART legislation is the paramount importance attributed to the welfare and interests of the child to be born. PTT is a procedure that affects the whole family and is primarily motivated by the interests of the parents and the existing child. However, the guiding principles in the Victorian Assisted Reproductive Treatment Act 2008 (ART Act (Vic)) fail to give due regard to the welfare of other family members directly affected by a decision to use PTT. The ART Act (Vic) also fails to clarify what is meant by ‘welfare and interests of the child’, a phrase which I explored in detail in Chapters 2 and 3.

I also analysed the current Commonwealth and the former Victorian policies on PTT in Chapter 1 and identified useful guidance on PTT as well as three significant gaps. The Commonwealth and Victorian policies require decisions about PTT to be dealt with on a case by case basis. They also clarify the circumstances in which PTT is available and the type of support clinics should provide parents. However, I argued that the policies in both jurisdictions are deficient as they do not require the provision of ethical guidance to parents and they give insufficient weight to the interests of other family members affected by a decision to use PTT. The policies also fail to promote the monitoring of short and long-term consequences of PTT for the child to be born. I addressed these gaps in the new regulatory framework for PTT proposed in Chapter 6.

Given the lack of guidance on the welfare of the child principle in the ART Act (Vic), I explored the nature and role of the welfare of the child principle in regulating PTT in
Chapters 2 and 3. The welfare of the child principle is a central tenet in Australian ART regulation and plays an important role in protecting the child to be born as a result of PTT. However, there is insufficient guidance in Australian ART law and policy on how the welfare principle should be applied in practice. I have used applied ethics to analyse how the welfare of the child to be born is conceptualised in the context of PTT. Adopting an ethical pluralist approach, I examined two key (Kantian and consequentialist) concerns about the welfare of the child to be born that have dominated the debate over PTT. I then introduced relational feminist and communitarian perspectives to broaden the conception of the welfare of the child, by viewing the child within the social context of his/her family.

The two main ethical concerns raised by contemporary Kantian and consequentialist ethicists are that the child to be born will be commodified and/or harmed as a result of PTT. In Chapter 2, I concluded that these two concerns highlight the putative child’s interests in respect, ongoing care and protection from harm. I argued that PTT regulation should ensure that these interests of the child to be born are taken into consideration when decisions about PTT are made. To ensure that this occurs, I recommended that parents seeking PTT receive appropriate counselling in order to protect the putative child’s interests in respect and ongoing care. Further empirical research into the long and short-term impacts of PTT on the child who is born should also be promoted to gain greater insight into the risk of harm to the child.

I argued in Chapter 2 that the ethical concerns about commodification and harm reflect an individualistic approach to the welfare of the child to be born, whose interests are treated as largely separate to and distinct from the interests of other family members. I contended that this narrow approach to the welfare of the child is problematic for two reasons. First, the welfare of the child is inextricably connected with the welfare of his/her family. Second, the very nature of PTT requires a broader consideration of interests beyond those of the child to be born. In particular, the interests of the parents in saving the life of their existing child and the interests of the existing child in leading a healthy life should be taken into account. I briefly explored utilitarianism as one way of balancing the various interests at stake in relation to PTT. However, I concluded that a utilitarian approach may sacrifice the welfare of the child to be born in order to achieve the greatest good. Furthermore, by treating families as
aggregates of individuals, utilitarianism undervalues the moral significance of families and the relationships within them.

In Chapter 3, I proposed a broader approach to the welfare of the child to be born, which includes the child’s individual interests (in respect, care and protection from harm) as well as the collective interests the child shares with his/her family (in intimacy, love and collective endeavour). This broader conception of the welfare principle is based on the notion of human flourishing and draws from relational feminist and communitarian ethics. I argued that intimate families are not only instrumentally valuable to the children they rear by providing them with ‘relational human caring’, but also inherently valuable as a form of collective endeavour that gives life meaning. By recognising that the welfare of a child is inextricably connected to the welfare of the intimate collective that is his/her family, a broader approach to the welfare of the child to be born protects not only the individual child but also the family which is necessary in order for the child to flourish.

It is appropriate to consider the welfare of the family as a whole in the context of PTT because the procedure involves a collective effort by the whole family. The child to be born is integral to the survival of the existing child and the welfare of the family as a whole. The interests of family members are inextricably connected as they engage in a shared journey to save the life of an existing member. However, the welfare of the child is not necessarily synonymous with the welfare of his/her family. PTT raises an important question about how far parents should be allowed to compromise the welfare of an individual child in order to promote the welfare of the family as a whole. Or, to put it another way, how much can parents ask of their children? The answer to this question warrants a detailed analysis of the nature of families and their concomitant obligations.

In Chapter 3, I argued that parents regularly ask their children to do things for the benefit of the family as a whole that are not necessarily in the child’s best interests. I contended that individual compromise by family members (including children) is an essential element of the intimacy that exists within families and is justified on the basis of familial duty. I also argued that the compromise entailed by familial duty need not be voluntary or based on constructive consent because membership alone provides the foundation for moral responsibility to family. Finally, I argued that the duty owed by family members to one another is greater than the duty owed to
strangers because intimate relationships involve a higher level of mutual obligation and reliance than non-intimate relationships. Put simply, we do more and expect more from family members because of the intimate nature of family relationships. A different range of principles should therefore apply to obligations of family membership than the impartial moral principles grounded in modern liberal theory. This does not mean that general moral constraints should not operate within families, raising another question about when the state should intervene to protect children from their families. To follow on from my previous question, how much is too much?

There comes a point at which necessary compromise by an individual family member becomes unacceptable sacrifice. Although there are good reasons to limit state interference in family decision-making, the state should intervene to prevent abuses of parental discretion. In Chapter 4, I argued that state interference is justified to protect children from exploitation, abuse or neglect. In such cases, the nucleus of well-being and well-acting that is essential to intimate relationships within families has broken down. The child to be born as a result of PTT is in a particularly vulnerable position as s/he does not have a ‘voice’ when decisions are made about PTT. Once born, the child may also feel pressure to make further donations to his/her sibling if the initial cord blood donation is unsuccessful. Some protections are therefore needed to protect the child to be born from exploitation, abuse or neglect. Drawing on the ethical analysis in Chapter 2, I recommended that PTT regulation confer a threshold level of respect and protection from harm on the child to be born as a result of PTT. This represents a ‘minimum welfare’ approach to the child to be born as opposed to the current approach in Victoria, which treats the welfare of the child to be born as paramount. In accordance with my proposed approach, PTT should be allowed provided the parents genuinely desire a child for his/her own sake and there is no significant risk of serious harm to the child to be born.

I proposed an ethical approach to regulating PTT in Chapter 4, which recognises and accommodates the individual and collective interests within a family. Drawing on an ‘ethics of intimacy’, I advocated a relational approach to managing the ‘conflict, confluence and confusion’ of interests within families seeking PTT. A fundamental feature of this approach is that the interests of family members are to be considered in connection with (rather than in opposition to) the interests of the child to be born. In order to achieve this goal, I argued that a supported and collaborative decision-making
process is essential. I proposed active roles for families and members of the health care team in the decision-making process and defined and differentiated the roles of parents, physicians, counsellors and ethicists. In particular, I proposed a new role for a clinical ethicist to assist families in navigating the ethical minefield of PTT by facilitating moral deliberation and consensus through ethics counselling and mediating any disputes that arise. I argued that the clinical ethicist should help create an ‘open moral space’ for parents and other family members to explore and attempt to reconcile the various interests at stake in accordance with their individual values, beliefs and preferences. In this sense, the clinical ethicist operates as an ‘architect of moral space’ rather than a ‘moral authority’. Finally, I proposed that a separately constituted clinical ethics committee should review decisions about PTT to ensure that the child to be born is not at risk of exploitation, abuse or neglect.

Having formulated an ethically principled approach to regulating PTT, I addressed some remaining questions of principle and practice by examining, in Chapter 5, the development of law and policy in the UK on both PTT and the welfare of the child principle. As discussed, the UK experience provides valuable insights into questions about: how decisions about PTT should be made, and by whom; whether the welfare of the child principle should be retained in ART law; and, if so, how the welfare principle should be applied to PTT. The extensive governmental review of ART legislation in the UK also addressed the second key issue highlighted in this thesis about the role of the state in regulating PTT. This, in turn, raises broader questions about how far the state should interfere with the reproductive choices of people seeking ART.

I distilled several key lessons from the UK experience that are relevant to PTT regulation in Australia. First, legislation should clearly sanction PTT to prevent future legal challenges. Second, the arbitrary distinction between PTT in conjunction with PGD and PTT should be removed. Third, clear ethical guidance is needed in relation to the welfare of the child principle and its application to PTT. The HFEA has adopted something along the lines of a ‘minimum welfare’ approach, which is more specific and better assists those making decisions about the welfare of the child to be born. Fourth, ongoing research into the short and long-term impacts of PTT on the child to be born could further improve welfare assessments in the future. Finally, as far as possible, decisions about PTT should be made by parents in consultation with
their health care team and the state should not unnecessarily interfere with the reproductive choice of individuals seeking ART.

Drawing on my ethical analysis in Chapters 2 to 4 and the key lessons from the UK in Chapter 5, I formulated a new regulatory framework for PTT in Australia in Chapter 6. As a preliminary matter, I argued that the state should regulate PTT in order to support parents through an emotionally charged and ethically complex process and to protect the child to be born from exploitation, abuse or neglect. A flexible permissive regulatory framework would achieve these goals without unnecessarily restricting reproductive choice. I also recommended that PTT regulation be nationally consistent to reduce regulatory duplication, ensure common clinical and ethical standards, prevent the need for ‘reproductive tourism’ within Australia, and improve national data collection. Finally, I recommended that decisions about PTT should essentially be made on a case-by-case basis by parents in conjunction with their health care team, according to guiding principles laid down by Parliament and detailed national guidelines prepared by the NHMRC.

My proposed regulatory framework for PTT essentially performs three main functions. First, it provides guidance on the various individual and shared interests within a family seeking PTT through guiding principles in legislation. In particular, treatment decisions should involve consideration of the interests of the child to be born, the interests of his/her parents, the interests of any existing siblings and the collective interests of the family as a whole. I proposed that more detailed guidance on the specific nature of these interests in the context of PTT should be contained in NHMRC guidelines. Second, my proposed regulatory framework establishes a robust decision-making process to manage individual and shared interests within families (which will not necessarily coincide). I have recommended that the roles of parents and their health care team in the decision-making process should be clearly outlined in NHMRC guidelines. In particular, parents should be supported in the decision-making process through the provision of information by their physician, counselling by an ART counsellor, and ethical guidance from a clinical ethicist.

Third, my proposed framework for regulating PTT ensures that the child to be born is given a threshold level of protection. Instead of attributing paramount importance to the welfare and interests of the child to be born, I proposed that legislation require that children born as a result of ART are protected from abuse, neglect and exploitation.
The two concerns about commodification and harm of the child to be born as a result of PTT could be specifically addressed by prohibiting treatment where: (1) the parents do not want a child in his/her own right; or (2) there is a serious risk of significant harm to the child. To ensure that due consideration is given to the welfare of the child to be born, my proposed legislation requires that applications for PTT be reviewed by a clinical ethics committee.

In the next section, I briefly describe how a relational approach may lead to a broader scope for PTT and improved decision-making by parents. I also mention one key drawback of a relational approach – the fact that it involves a more complex decision-making process. However, I argue that the decision to use PTT is inevitably a complex one and that regulation should not shy away from the difficult moral questions that biomedical advances produce. I conclude that empirical investigation is needed to learn how a relational approach to PTT might be improved in the future.

II BENEFITS, BURDENS AND FURTHER RESEARCH NEEDED

The relational approach to regulating PTT that I have proposed in this thesis is likely to be more responsive to the individual circumstances of each case than the current approach in Australia. For example, a relational approach would not unnecessarily limit PTT to select a child with compatible tissue for a sibling if the family was sufficiently close to justify a donation by the child to be born to another family member, such as a parent.¹ In this sense, a relational approach would be more consistent with the current approach in Victoria to regenerative tissue donations by minors.² The UK House of Commons Science and Technology Committee (STC) previously criticised the Human Fertilisation and Embryology Authority for

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¹ The NHRMC currently restricts PTT to the selection of a child with compatible tissue for a sibling: NHMRC, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research 2004 (as revised in 2007 to take into account the changes in legislation) (June 2007) (NHMRC Guidelines on ART) [12.3]. The previous VARTA Conditions imposed the same condition: VARTA, Conditions for Use of Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis (February 2010) (previous VARTA Conditions on PTT) [2.2].

² Regenerative tissue can be removed from a child in Victoria for transplantation to either a sibling or a parent, provided the child agrees: Human Tissue Act 1982 (Vic), s 15. The Family Court of Australia has also allowed a child to donate bone marrow under its "welfare jurisdiction" in two separate cases to an aunt and, more recently, a cousin: In the Marriage of GWW and CMW (1997) 21 Fam LR 612; Re Inaya (special medical procedure) [2007] Fam LR 546.
restricting the use of PTT to enable donations between siblings.³ According to the STC, a distinction between siblings and other members of the family would need to be based on evidence that suggests that ‘the psychological impact on the child, and the nature of the family’s relationship, would be different if the recipient of the stem cells were not a sibling.’⁴

In addition to being more responsive to individual cases, a relational approach should canvass issues that will assist parents in making further decisions that may arise in the future. As previously mentioned, the decision to conceive a saviour sibling may be the first in a series of moral dilemmas faced by a family struggling to save the life of one of its members.⁵ The drama that unfolds in the fictional account of a saviour sibling in My Sister’s Keeper⁶ reveals the ongoing state of crisis that may be experienced by a family into which a saviour sibling is born. As Storrow points out:

> Whereas ethics pronouncements present the creation of a saviour sibling as a way to resolve a familial crisis, My Sister’s Keeper demonstrates how the saviour’s presence can actually intensify the crisis.⁷

If the initial cord blood donation does not cure the existing child, parents will need to consider other options such as peripheral blood or bone marrow donations by the saviour sibling. Decisions about additional donations may be a little less difficult if the parents have already explored both the individual and collective family interests at stake in accordance with their own values and preferences through ethics counselling prior to conception. There is arguably scope for applying a relational approach, whereby the interests of the child to be born are considered in connection with the interests of the rest of the family, to decisions about future donations by a saviour sibling.⁸ There is also an argument for ongoing counselling of parents who conceive a child as a result of PTT (and other family members) beyond the birth of the child.

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⁴ Ibid. For a detailed discussion about the inconsistencies surrounding the ‘parental exception’ to PTT, see: Colin Gavaghan, Defending the Genetic Supermarket: Law and Ethics of Selecting the Next Generation (Routledge-Cavendish, 2007)160-2.
⁵ See discussion of My Sister’s Keeper in Chapter 1, Part IID.
⁸ As previously discussed, future donations by saviour siblings are currently covered by legislation governing tissue donation by minors: see Chapter 2, Part VA2. In Victoria, for example, section 15 of the Human Tissue Act 1982 (Vic) sets out the circumstances in which regenerative tissue may be removed from the body of child. The Family Court also has general jurisdiction to make orders.
One pitfall of my proposed relational approach to PTT is that it introduces more variables into the equation about whether PTT should proceed than currently exist in Australian regulation. For instance, it requires consideration of various individual and collective interests within a family and the nature of the relationships within the family. While this presents a difficult task, it is not impossible. Furthermore, these variables already exist whether or not they are openly acknowledged. In addition to being individuals in their own right, family members are ‘relational and interdependent’. Open acknowledgement of the complex interests and dynamics within families is an important first step in reconciling conflicting interests and achieving consensus. The decision to use PTT is complicated and regulation should at least attempt to accommodate the various interests at stake and support parents in the decision-making process. As Held argues, the ‘messy concerns of morality’ cannot be ‘arranged along neat and clean lines’ by being reduced to the categorical imperative or the principle of utility.

My thesis is based on a theoretical analysis of the welfare of the child to be born. Throughout my thesis, I have emphasised that ongoing empirical research into the short and long-term impacts on children born as a result of PTT is needed to gain a better insight into how the welfare of the child is affected by PTT. If a relational approach to PTT were adopted, empirical investigation into the decision-making process could help identify ways in which the process might be improved. One key aspect of my proposed approach – clinical ethics consultation – is a newly developing area in Australia. As discussed in Chapter 6, few Australian hospitals offer ethics counselling and, when they do, it is generally offered to physicians rather than parents. Some hospitals in Australia have clinical ethics committees that provide ethics review of ethically complex decisions. However, clinical ethics committees are still relatively uncommon compared with research ethics committees. I have proposed a general framework for the operation of clinical ethicists and clinical ethics committees in the context of PTT. However, empirical investigation into the

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9. Virginia Held, The Ethics of Care: Personal, Political, and Global (Oxford University Press, 2006), 72. Interestingly, section 5(c) of the previous Infertility Treatment Act 1995 (Vic) required the interests of the family to be considered in relation to treatment decisions.
10. Ibid 73.
11. See discussion in Chapter 6, Part IVD.
operation and effectiveness of existing forms of clinical ethics consultation could further inform and improve my proposals. Clinical ethics consultation is more common in the UK and, particularly, the US. Research into the operation of clinical ethics committees in these jurisdictions could also be used to enlighten reform initiatives in Australia.\(^\text{12}\)

Finally, a relational approach may be applied beyond PTT, to ART more generally. The next section concludes with a few final thoughts about potential further applications of a relational approach.

### III POTENTIAL FOR A RELATIONAL APPROACH BEYOND PTT

A central theme of my thesis is the interconnectedness and interdependence between family members. This makes decision-making within families a complex task. I have argued that, although parents generally promote the welfare of their children, familial decisions are not based solely on the individual or ‘best interests’ of any particular child. Decisions are made within families according to a variety of factors, including: the needs of family members; the capacity of the family to meet those needs; the nature of relationships within a family; and the character and preferences of a particular family. The relational approach I have proposed for PTT is an attempt to reflect the complex basis on which decisions are made within families. I also have proposed a limited role for the state in regulating ART (including PTT), to preserve the reproductive choices of people seeking ART and facilitate decision-making that reflects the individual circumstances and character of particular families.

I have argued that a relational approach is particularly relevant to PTT, as there are clearly other interests at stake that ought to be considered alongside the interests of the child to be born. However, a relational approach is not limited to PTT and could be applied more broadly. As Belinda Bennett states:

> The debate over ‘saviour siblings’ reveals the complexities in contemporary debates over the regulation of biomedical advances in liberal democratic societies. While rights are often conceptualised in individual terms, within the context of contemporary biomedicine rights and

interests are often overlapping, layered and relational, complicating the task of drawing ethical and regulatory boundaries.

... The debate over saviour siblings can therefore be seen not only as a debate over the ethics of creating tissue matched children, but also as a means of illustrating broader regulatory issues about contemporary biomedicine.13

My proposed regulatory framework touches on ART more generally. For example, I have outlined guiding principles that should be included in the ART Act (Vic) that could apply to all ART decisions. These guiding principles require that treatment decisions involve consideration of the individual and collective interests of all family members likely to be affected by a decision to use ART. I have also proposed a guiding principle that reflects a ‘minimum welfare’ approach to children born as a result of ART by requiring them to be protected from exploitation, abuse or neglect. I have suggested that treatment be expressly prohibited under the ART Act (Vic) in two circumstances that are specifically relevant to PTT. The second prohibition – on treatment that involves a significant risk of serious harm to the child to be born – could also relate more generally to all ART treatments.

The benefits of a relational approach (incorporating a ‘minimum welfare’ principle), which I have identified for PTT, are applicable to ART generally. It makes sense to consider not only the individual interests of the child to be born, but also the interests of the child’s parents and any existing siblings that are likely to be affected by a decision to use ART. The welfare of the child should be considered within the social context of the family into which s/he will be born because, for better or worse, that family will be the intimate community within which the child will grow and hopefully flourish. The particular social context within which a child will be born is particularly relevant in relation to controversial genetic screening technologies. Two currently prohibited applications of PGD are selecting a child with a disability and sex-selection for social reasons.14 These controversial treatments have been flagged by the NHMRC for further discussion.15 In particular, the NHMRC has announced that it

14 NHMRC Guidelines on ART [12.2]. See also: VARTA, Conditions for Use of Preimplantation Genetic Diagnosis (February 2010) (previous VARTA Conditions on PGD), which were removed from VARTA’s website in July 2010; ART Act (Vic), s 28. A copy of the previous VARTA Conditions on PGD appears as Appendix B to this thesis.
15 NHMRC Guidelines on ART [11.1], [12.2].
will carry out a review of the issues surrounding sex-selection for social reasons following a five-year moratorium, which expires at the end of 2010.\(^\text{16}\) It would be interesting to consider how a relational approach might apply in these contexts.

As discussed in Chapter 4, some bioethical writers have also begun to argue for a greater role for the family in medical decision-making generally. This movement is an exciting one, as it recognises the moral import of the families that ultimately share the joys and bear the burdens involved in caring for loved ones. However, care must be taken to ensure that power imbalances that exist within families do not compromise the treatment of vulnerable parties. I have argued in this thesis that power imbalance is often a significant feature of intimate relationships, particularly families. In a sense, the protection of vulnerable individuals – the unborn, the young, the elderly and the ill – is the *raison d’être* of families. Returning to the words of Patricia Smith, ‘family living is very probably a necessity for human existence.’\(^\text{17}\) The relational approach proposed in this thesis aims to support the families charged with protecting the child to be born as a result of PTT and promoting the nucleus of well-being that is the touchstone of intimate families.

PTT challenges our assumptions about the role of parents and the nature of family relations. By exploring the ethics of PTT, this thesis raises questions about why people choose to procreate and how much parents can ask of their children. The answers to these questions can be confronting as they reveal that the choices parents make are not necessarily made in the best interests of the child. Decisions are made within families for a multitude of reasons that are often inextricably connected and may affect the interests of more than one family member. Creating a child to save the life of an existing child raises concerns about the use of genetic screening technologies to create ‘designer babies’, which undermine established notions about parental love. However, selecting an embryo that will grow into a healthy child with the capacity to save the life of his/her sibling does not detract from the nucleus of love or well-being within a family. Parents seeking PTT are not involved in eugenics, they


are simply acting on basic parental instincts to care for their children and preserve life. This point is illustrated in the following plea by Anna’s father in *My Sister’s Keeper*:

We didn’t ask for a baby with blue eyes, or one that would grow to be six feet tall, or one that would have an IQ of two hundred. Sure, we asked for specific characteristics — but they’re not anything one would ever consider to be model human traits. They’re just Kate’s traits. We don’t want a superbaby; we just want to save our daughter’s life. ¹⁸

¹⁸ Picoult, above n 6, 103.
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