

Assisted Reproductive Technology: The Aotearoa/New Zealand Policy Context

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Abstract

The focus of this thesis is the current policy situation in relation to assisted reproductive technologies (ART) in Aotearoa/New Zealand. I explore how government policies (and lack of policy) have shaped access to ART. I also explore the policy initiatives of funding agencies, the National Ethics Committee on Assisted Human Reproduction (NECAHR), managers, healthcare professionals, and interest groups.

My investigation into ART policy issues critically examines the various formal mechanisms and policies used to regulate and control ART in Aotearoa/New Zealand. Drawing on my analysis of policy-focused documents and material from in-depth interviews with key actors in the policy debate, I demonstrate how the *ad hoc* and contingent approach to ART developments, practices, funding, and access has contributed to inconsistent and inequitable access to ART services. I argue that the lack of an ART-specific policy organisation contributes to fragmented, and possibly discriminatory, policy decisions.

I examine how the use of restrictive access criteria to manage the increasing demand for publicly funded ART services disadvantages certain groups wishing to use these services. By investigating the influence of rationing strategies on the allocation of resources and regulation of access, I provide some appreciation of the 'messy reality' of policy creation, interpretation, and implementation. I argue that the criteria used to limit access to public ART services obscure the use of social judgements and provider discretion. Likewise, they succeed in limiting publicly funded ART treatments to those who conform most effectively to the normative definition of family.

My analysis of the ART policy discourse identifies silences and gaps in relation to specific ART practices, particularly the use of ART by Māori. I highlight the invisibility and marginalisation of Māori within the ART policy debate. After examining the broader issues concerning Māori access to health services, I explore how these may affect Māori using ART services to overcome infertility. I argue that the gathering of information about the utilisation of ART services is crucial for the accurate identification of the needs of Māori. It is also fundamental for effective monitoring of state health policy decisions and outcomes.

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1

Introduction: Framing the Issues

The question is not whether choices are constructed, but how they are constructed. Society, in its ultimate meaning, may be nothing more and nothing less than the structuring of choices. (Rothman, 1984:32)

1.1 Introduction

...but you chose not to have children!

This comment, made by my sister, triggered intense personal reflection about the nature of choice and the external constraints on choice in relation to reproduction and parenting. Although I have deliberately used methods to prevent conception at different times in my life, I do not perceive my present childless¹ circumstance as a 'choice'. As with many aspects of my life, a multitude of interconnecting 'choices' and decisions have contributed to my current situation. My sister's comment and my reaction to it highlighted, for me, how the language of choice obscures the many social, cultural, political, economic, and historical influences on reproductive outcomes. At the time, I was conducting interviews for an Honours Degree project with couples who had used assisted reproductive technologies (ART)² to overcome the

¹ I use the word 'childless' with reservation as I interpret it as implying a lack or deficiency rather than acceptable difference. Although I have not given birth to or raised children exclusively, I do interact with and care for a number of children in a variety of situations. Therefore, I do not perceive myself (or the many other women I know who are similarly situated) as being 'childless'. Nevertheless, the decision to use this term is a pragmatic one as I identify with Jan Cameron's (1997) dilemma in finding an unproblematic term to describe people without children, especially when reasons for not having children are not always a straightforward matter of choice or no choice.

² See Appendix A, Abbreviations and Definitions, for descriptions of the assisted reproductive technologies and surrogacy techniques referred to in this thesis.

consequences of infertility. At the same time, another research project into aspects of social policy relating to ART highlighted inconsistencies and contradictions in the public funding and access to ART in Aotearoa/New Zealand. I became interested in the way that government policy (or lack of policy) can constrain or enable the reproductive choices of certain groups, principally the choices of those individuals who seek to use ART to conceive children. My own reflections on 'choice' were embedded in a wider set of issues about access to reproductive technologies.

This thesis explores how reproductive choice is constrained or facilitated by the current policy situation in relation to ART in Aotearoa/New Zealand. I focus on three questions: In the absence of specific ART focused legislation, how are ART practices regulated and controlled? How are resources allocated and who has access to them? What are the issues surrounding the use of ART by Māori? These questions shaped my investigation into the policy issues relating to ART in Aotearoa/New Zealand. My research strategy involved a combination of documentary analysis and in-depth interviews, which were used to explore the positions of the key actors in the policy debate and to identify what silences and gaps existed in the policy discourse. Interviews were undertaken with key actors in the provision of ART services and government health policy, as well as interest group representatives and academic commentators. Analysis was carried out on published and unpublished documents produced by both governmental and non-governmental organisations. These included existing legislation, parliamentary bills under consideration at the time, discussion papers, reports, public submissions to various reports and discussion documents, academic papers, service provision contracts, and service specifications.³

Many commentators have observed that the development of social policy relating to ART in Aotearoa/New Zealand has been fragmented, unplanned, and reactive. They have also noted that there has been no considered response by the State to the many requests for a more proactive approach to ART legislation and policy formulation (Blank, 1990; Caldwell & Daniels, 1992; Daniels, 1994a; Daniels & Lewis, 1996b; Daniels & Hargreaves, 1997; Blank, 1998; Daniels, 1998a; Coney & Else, 1999). In this thesis, I investigate the consequences of this *ad hoc* and contingent approach to policy in relation to ART developments, practices, funding, and access. I demonstrate that the policy responses to ART developments and practices in Aotearoa/New Zealand have contributed to inconsistent and inequitable access to assisted

³ See Chapter Two, The Research Process, for a detailed discussion and analysis of my research strategies.

reproduction for some individuals and groups. I also explore how the values and moral judgements underlying ART policy decisions continue to emphasise the dominant culture and normative family structures, thereby marginalising or silencing certain groups within the ART policy debate.

After critically examining the various formal mechanisms and policies used to regulate and control ART in Aotearoa/New Zealand, I argue that the lack of an ART specific policy organisation contributes to fragmented and, possibly, discriminatory policy decisions. The overlapping and related functions of organisations involved in practical and ethical decision-making in relation to ART remain uncoordinated and independent, with no public accountability for their decisions. A delay in legislative and/or organisational action in relation to issues of information retention and access and cultural safety puts the rights of those involved at risk. Similarly, the absence of legislation to prohibit certain potentially unethical ART developments means that these developments could be established in practice, making it difficult to withdraw or limit their use later on. While I acknowledge that there is a need for legislative flexibility to allow the introduction of beneficial ART innovations and practices, I maintain that there is also a need for legislative protection of the rights of those involved in these practices.

The focus on 'top-down' policy initiatives, as described in Chapter Three, provides one influential arena for policy development and formulation. However, it can suggest that the policy process is linear and progressive. An examination of the interaction between 'top-down' and 'bottom-up' aspects of policy formulation and implementation provided insight into the 'messy reality' of the policy process (Colebatch, 1998:59-61; Green & Thorogood, 1998:11). As such, an investigation into the influences and effects of health sector controls on the allocation of resources and regulation of access provides some appreciation of this 'messy reality' and identifies another influential arena in ART policy creation, interpretation, and implementation by government bodies and providers. The funding decisions that underlie public access to ART practices have been based on historical interpretations of need and access. Therefore, the allocation of these resources in response to the growing demand for ART services has resulted in inequitable and inconsistent funding and access throughout the country. Lack of attention to gathering information on the prevalence of infertility, as well as health sector restructuring and the introduction of explicit rationing strategies have further embedded these inconsistencies. Although the provision of additional public funding and the introduction of national access criteria in 2000 were aimed at eliminating regional disparities, I question whether these changes will be effective given that they are based on historically determined inequities in

funding. In light of further health sector restructuring, I argue that there is a possibility that the status quo will be maintained so that access and funding remain inconsistent throughout Aotearoa/New Zealand.

Although restrictive access criteria were introduced to manage the increasing demand and to address the inequalities in funding and access to publicly funded ART services, they disadvantage certain groups wishing to access these services. While these criteria provide an influential arena for 'bottom-up' policy formulation through their interpretation and implementation by providers, they also illustrate how *ad hoc* and reactive policy-making can institutionalise inequitable resource allocation. The access criteria obscure the use of social judgements and provider discretion and succeed in limiting publicly funded ART treatments to those who conform most effectively to the normative definition of family. This definition of family, as prescribed by the Status of Children Amendment Act 1987, is examined later in this chapter.⁴ I acknowledge that the prioritisation of children's rights over those of donors, recipients, surrogates, and intending parents is sometimes necessary in individual cases and may influence some access decisions. However, I argue that marginalising the rights of whole groups of people on the basis of protecting the interests of children can lead to discrimination and the marginalisation of those who do not conform to the normative definition of family.

The invisibility and marginalisation of Māori within the ART policy debate is highlighted and discussed in Chapter Six. There is an implicit assumption by various commentators that Māori do not access ART services because they have more culturally acceptable ways of dealing with infertility, such as *whāngai* (Daniels & Taylor, 1991; Adair & Rogan, 1998; Dyllal, 1999:36-37). This assumption is sustained by the lack of data on the prevalence of infertility or the ethnicity of those accessing ART services. While some Māori may have access to and use *whāngai* to manage infertility, the diversity of values and needs within the Māori population means that others may decide to access ART practices. The lack of quantitative information relating to prevalence and ethnicity means that the historically determined demand for services generated by the needs of the dominant Pakeha group is used to inform policy decisions. Such decisions may ultimately disadvantage Māori who wish to access ART services. I argue that accurate quantitative data about who actually accesses ART services is crucial to identify the needs of

⁴ See Section 1.4, Families & ART, in this chapter for an analysis of the Status of Children Amendment Act 1987 and its influence on the definition of family and *whānau*.

Māori in relation to fertility treatment and to evaluate and monitor state health policy decisions and outcomes.

In the following sections of this chapter, I will set the context for the preceding issues by discussing the developments in ART that have led many countries to attempt to address the rights, responsibilities, and protection of those involved in ART practices. This discussion will include a review of the regulatory approaches undertaken by Britain, Australia, the United States of America, and Canada. As I use the language of rights and choice throughout the thesis, I include a brief review of the literature relating to reproductive rights and choice. Following this, I examine the Status of Children Amendment Act 1987 (SCAA) and its influence on the definition of family in relation to ART policy. I investigate how changes in social acceptance of diverse family arrangements have not yet led to similar changes in legislation or policy with regard to ART practices. Included in this section is a discussion of how the definition of family used by the SCAA conflicts with the Māori concept of whānau. Finally, I provide an outline of the issues addressed in each of the chapters in this thesis.

1.2 Setting the Context

Until recently, adoption and artificial insemination were the only options available to infertile couples who wanted to become parents. The first known birth following the medicalised use of donated semen occurred in the 1880s and by the second half of the 20th century donor insemination (DI) was commonly used to overcome male infertility (Daniels & Lewis, 1996a:1521). On 25 July 1978, the first baby to be conceived using a process called *in vitro* fertilisation (IVF) was born in England. However, the birth of Louise Brown was not the culmination of an isolated scientific 'discovery'. It took place after years of experimentation and research on women's bodies and reproductive capacities (Spallone, 1989:8-9). The first recorded attempts at IVF took place in 1878 on the ova of a mammal and in 1946 and 1948 two American scientists claimed to have successfully fertilised human ova *in vitro* (Fishel, 1986:13). Advances in reproductive biology, cryopreservation of sperm and embryos, culture techniques, endocrinology, embryology, and laparoscopy all contributed to advances in IVF research and, ultimately, the successful conception and birth of Louise Brown (Fishel, 1986:1-16). Following the initial success of IVF with human ova, clinics and research centres expanded into "almost every country that takes part in the western scientific establishment" (Spallone, 1989:10).

According to Daniels (1999:6), medicalised DI has been practised in Aotearoa/New Zealand since the 1940s. In the late 1970s, the National Women's Hospital was storing frozen sperm and, by the early 1980s, university-based donor insemination clinics had been established in Auckland, Wellington, Christchurch, and Dunedin. In Aotearoa/New Zealand, the first IVF programme was established at National Women's Hospital in 1983 and the following year the first child to be conceived through IVF in Aotearoa/New Zealand was born (Coney & Else, 1999:3; Peek, 1999:18). In Chapter Four, I discuss how publicity surrounding this event led to the increased availability of IVF services and subsequent public funding of these services. In Aotearoa/New Zealand, the growth in the development and use of ART coincided with changing social attitudes, law changes that eliminated the distinction between legitimate and illegitimate children, and the introduction of the Domestic Purposes Benefit. These changes facilitated more single women being able to keep their babies and led to a decline in the number of children being made available for adoption (Else, 1995:216; Adair & Rogan, 1998:264). Undoubtedly, increased media attention and availability of ART practices in Aotearoa/New Zealand would also have contributed to increased public expectations and demand for such services (Blank, 1995:14).

Advances in reproductive technology, IVF, and the use of donated gametes have combined to create the potential for new forms of kinship and family relations that challenge conventional notions of who can parent. Consequently, ART has enabled different forms of surrogacy to take place and increased the potential for surrogacy to be used to overcome involuntary childlessness (English, et al., 1997:31).⁵ Surrogacy is often referred to in relation to ART and discussions of surrogacy arrangements are often included in the discourse relating to ART policy and practices. Although it is not within the scope of this thesis to explore the policy issues relating to the use of surrogacy in detail, it should be noted that much of the policy and policy

⁵ The various arrangements known as surrogacy involve a woman who provides the gestation and birth of a child for others. However, this woman may also provide the ova and conception so that she is the genetic mother, as well as the birth mother (Blyth, 1993:248). There are three main types of surrogacy arrangement: 1. Insemination by intercourse with the intending father or a donor. This is usually a private arrangement with no medical involvement; 2. Artificial insemination, using sperm from the intending father or from a donor. This does not technically require the services of an assisted reproductive technology provider but may involve health professionals; 3. Gestational surrogacy, also known as 'full surrogacy' or 'IVF surrogacy'. One or more embryos, created (usually by IVF) from the gametes of the intending parents, one of the intending parents plus a donor, or two donors, are transferred to the womb of a woman who has no genetic connection to the embryos (Else, 1999a:50). See Appendix A: Abbreviations and Definitions for detailed definitions of the various surrogacy arrangements that can take place using ART.

debate associated with ART practices also relates to surrogacy. Definitions of the ART practices referred to and the abbreviations I have used in this thesis are included in Appendix A.

In Chapter Five, I analyse how the conflation of involuntary childlessness with infertility and the emphasis on heterosexual coupledness work to restrict access by lesbian couples and single women to publicly funded ART services. Combined with the continued medical focus on women irrespective of whether the problem is male or female infertility, these issues also contribute to the marginalisation of men in the discourse surrounding infertility and the desire to parent. Albury (1999:176) maintains that representations of 'man' and 'father' remain largely unquestioned in feminist and popular literature about ART. She believes that the male desire to parent is often trivialised, viewed as a form of exploitation of women, or reduced to the legal aspects of paternity and inheritance. Furthermore, she found that there have been few challenges to the belief that fatherhood necessarily implies a biological rather than social relationship. Correspondingly, the diagnosis and treatment of male infertility receives little attention and is often only investigated after the exclusion of female factor infertility (Purdie in Brander, 1991:23). Although statistical analyses vary on the precise figure, the male partner is implicated in 30-50% of all recorded infertility cases world wide (Brander, 1991:9-13; World Health Organisation in Gillett, et al., 1995:14; Cussins, 1998:75; Gupta, 2000:339).⁶ Reproductive scientists suggest that research into the reproductive functions of men has trailed behind research into women's reproductive functions by at least 15 years (Oudshoorn, 1999:335). Although sperm defect/dysfunction is the most common identifiable cause of infertility, it remains the least understood and the least treatable of infertility conditions (Brander, 1991:2). Although men do undergo surgery for infertility, women undergo most of the ultrasounds, inseminations, surgery, and other invasive procedures, as well as taking most of the drugs in relation to treatment (Cussins, 1998:75 & 97 n.23). Problems with sperm are "managed outside the man's body ... and any resultant embryos still need to implant in the woman's uterus, thereby forcing her to become a patient" (Cussins, 1998:97 n.23). Consequently, women's bodies become the focus of attention for ART practices irrespective of the causes of the infertility. The invisibility of men is particularly obvious in relation to the

⁶ Similarly, the incidence of female-factor infertility is estimated to be between 30%-50%. Most estimates suggest that the causes of infertility are equally divided between female problems and male problems, with a approximately 20% of infertility not being attributable to either male or female factors (unexplained) (Brander, 1991:9-13; World Health Organisation in Gillett, et al., 1995:14; Cussins, 1998:75; Gupta, 2000:339).

Clinical Assessment Criteria (CPAC) for treatment of infertility, which focuses almost exclusively on women's bodies and behaviours.⁷

International Approaches to Regulating ART & ART Practices

International responses to the ethical, legal, social, and political issues raised by ART and surrogacy have been varied. They have included a combination of legislation, organisational policies, reports by commissions and committees, and court decisions that collectively create policy and regulate the practices and development of ART and surrogacy (Blank, 1998:139). The Ministerial Committee on Assisted Reproductive Technologies (MCART, 1994:16) argues that these varied approaches to control and regulation make it difficult to envisage any international trends in policy-making. Despite a lack of uniform policy development with regard to issues such as surrogacy, access to information, sex-selection, cloning, or disposal and research on embryos, there has been a general movement towards clarifying the legal status of children born as a result of ART practices (MCART, 1994:16). On the other hand, only a few countries, such as Sweden, Austria, and Australia, have enacted specific legislation that allows adults conceived using donated gametes to access identifying information about their gamete donor (Daniels & Lewis, 1996b:66; Tollemache, 1999b:34). Although other countries, including Aotearoa/New Zealand, have moved towards openness and full disclosure, they have not enacted specific legislation to ensure the availability of such information.

In Britain, extensive regulation of procedures relating to ART has largely arisen out of the Human Fertilisation and Embryology Act 1990. This Act evolved out of the Committee of Inquiry into Human Fertilisation and Embryology and its ensuing report, *A Question of Life* (the Warnock Report) (1985), on the legal and ethical implications surrounding the use of IVF. The Act established the Human Fertilisation and Embryology Authority (HFEA) and required all clinics involved in IVF, DI, ICSI, human embryo research, or the storage of gametes and embryos to be licensed by this authority.⁸ The first statutory body of its type in the world, the HFEA is required to maintain a formal register of information about donors and all licensed treatment cycles and outcomes (Health Canada Online, 2001a). Nevertheless, only non-identifying information about donors can be made available to persons aged 18 or more who

⁷ See Chapter Five, Regulating Access, Section 5.4, The Priority Criteria, for a discussion of the CPAC.

⁸ See Appendix A, Abbreviations and Definitions, for descriptions of the assisted reproductive technologies and surrogacy techniques referred to in this thesis.

were conceived using donated gametes (MCART, 1994:78).⁹ Although liberal in some of its approaches, such as permitting research on embryos until the 14th day, the Act facilitates major state intervention into ART developments and practices. As well as regulating and overseeing the use and development of ART and surrogacy in Britain, the HFEA also promotes public discussion on issues such as sex-selection and the use of foetal tissue (MCART, 1994:24). In December 2000, the British government amended the Human Fertilisation and Embryology Act 1990 to allow the creation for research purposes of stem cells from early-stage cloned embryos. A resolution was also passed requiring that existing legislation be tightened to prevent cloning for human reproductive purposes (Health Canada Online, 2001a). As discussed in Chapter Three, the passing of this Act raises questions about how technologies developed as a result of this research will be used in Aotearoa/New Zealand if proposals to ban cloning are enacted.¹⁰

In contrast to the United Kingdom's national approach to regulating ART and ART practices, the Australian constitution delegates responsibility for health legislation to the various states. Consequently, the separate states have adopted varying approaches to regulating ART. As a leader in international research into reproductive technology, Victoria became the first state to deal with ART through the legislative process by introducing the Infertility (Medical Procedures) Act 1984 to regulate the use of IVF and donated gametes. In 1998, Victoria replaced the 1984 Act with the Infertility Treatment Act 1995. This Act prohibits commercial surrogacy, regulates the use of IVF, DI, and other fertilisation procedures, regulates the use of human gametes, zygotes, and embryos for research, and promotes research into the incidence and causes of infertility (Tollemache, 1999b:30). Access to treatment is confined to married couples or heterosexual couples in *de facto* relationships. Although access in Aotearoa/New Zealand was initially restricted in a similar way, the introduction of the human rights legislation and changing social attitudes have resulted in the removal of overt restrictions on the basis of marital status or sexuality. However, as discussed later in this chapter, the only legislation in Aotearoa/New Zealand that specifically deals with ART practices positions heterosexual couples as the norm

⁹ The Human Fertilisation and Embryology Act 1990 also makes surrogacy arrangements unenforceable in law, extends the Surrogacy Arrangements Act 1985 to cover all forms of surrogacy, and defines the resulting child's parentage (Blyth, 1995b:4). Although commercial surrogacy is illegal and surrogacy arrangements are unenforceable in Britain, surrogacy does occur under the jurisdiction of licensed providers. There are at least two non-profit organisations in the United Kingdom that facilitate meetings between commissioning parents and potential surrogates (Brazier, et al., 1998:ii). In 1997, Health Ministers in the United Kingdom commissioned a review of certain aspects of surrogacy arrangements, which concluded that new legislation was necessary to implement its proposals (Brazier, et al., 1998:ii).

¹⁰ See Chapter Three, Regulating Practices, Section 3.4, Policy Gaps, for a discussion of this issue.

for reproduction and parenthood. In Chapter Five, I explore how this normative definition of family influences access restrictions to ART services in Aotearoa/New Zealand.

The Infertility Treatment Act 1995 established the Infertility Treatments Authority to monitor and control research, storage, record keeping, licensing and approval, and compliance with the Act in relation to all ART. The Act “makes the welfare of the child the first guiding principle and links this to the restrictions on access to infertility services” (Tollemache, 1999:31). Tasmania and Queensland have both passed restrictive surrogacy laws, which apply to both traditional and IVF surrogacy (MCART, 1994:22). South Australia and Western Australia have both introduced legislative controls for ART with varying levels of detail and prohibited practices. These two states have also established statutory bodies to licence and oversee ART services (MCART, 1994:23). Although New South Wales is in the process of reviewing its position on the regulation and control of ART, it currently uses existing legislation to control the activities of ART providers and researchers. There is no specific legislation in the other states (Health Canada Online, 2001a).

The United States of America (USA) also regulates ART and ART practices on a state by state basis. Although few states have taken statutory action to control ART (Tollemache, 1999b:29), about half have legislated in relation to the status of children born as a result of donor insemination (MCART, 1994:20). Some states have also enacted legislation to deal with specific issues such as cloning and surrogacy. However, the overall approach in the USA is to leave the control of ART practices to market forces, in which the courts or consumer and professional bodies deal with contested issues. Although there is a National Advisory Board on Ethics in Reproduction in the USA, this body has no regulatory function or power (MCART, 1994:21). Unlike Australia and the USA, Canada’s federal government has decided to introduce a national level of control over ART practices and to establish a legislative framework that ensures consistency in the regulation of assisted human reproduction throughout the country (Health Canada Online, 2001b). In 1993, Canada’s Royal Commission on New Reproductive Technologies produced the most comprehensive investigation into the social, ethical, medical, political, and legal issues raised by ART developments to date. The two volume report, *Proceed with Care* (1993b), did not result in the proposed legislation or the recommended establishment of the ‘National Reproductive Technologies Commission’ to license, regulate, and oversee ART practices and developments. Although a bill was introduced to the Canadian parliament in 1996, it contained controversial elements in relation to sanctions, payments, and the regulatory structure and lapsed in 1997 because of the federal election (Tollemache, 1999b:33). In May

2001, the Canadian Health Minister presented draft legislation to the Standing Committee on Health for consideration and requested that their report be produced by the end of January 2002. According to Health Canada (2001b), the draft legislation draws significantly on the work of the Royal Commission and is similar to the 1996 bill. However, the newly proposed legislation takes into account recent scientific developments in reproductive technology.

...it should be noted that scientific methods have developed a great deal since the time of the Commission, raising new and complex issues which the draft legislation addresses. Human cloning, for example, seemed only a very distant possibility at the time of the Royal Commission's report. (Health Canada Online, 2001b)

If the proposed legislation is enacted it would “ban cloning and other unacceptable practices, regulate treatments to protect the health and safety of Canadians who seek assistance to conceive a child, and address research in this area” (Health Canada Online, 2001c).

Britain's unitary system of government has enabled the relatively easy establishment of a consistent national policy and a state regulating authority (Tollemache, 1999b:29). According to Blank (1998:148), countries with federal systems of government often have difficulties in establishing consistent national policy for ART services because health policy and licensing is often the responsibility of the separate states or provinces.¹¹ Consequently, in countries such as the USA, Canada, and Australia the fragmentation of power and responsibility between federal and state agencies is likely to obstruct the implementation of nationally consistent standards and regulations. Similarly, decentralisation can exacerbate inconsistencies between national professional association guidelines and state licensing and regulatory policies.

Although federal systems may hamper the introduction and implementation of consistent national ART policies, developments in Australia and Canada demonstrate that national consistency is not impossible under such political systems. Australia's Reproductive Technology Accreditation Committee (RTAC) was established to oversee the practice of IVF nationally and has been voluntarily accepted by clinics throughout Australia. Likewise, Canada's Federal Government has proposed a national legislative framework to regulate and control ART. As I highlight in Chapter Three, the unitary parliamentary system in Aotearoa/New Zealand has not

¹¹ Unitary government systems concentrate political authority in a central government while federal systems divide authority between central government and the states, provinces, or other local government structures. Although central government in unitary systems may allocate certain administrative responsibilities and services to other institutions, ultimate power remains at the national level. Contrastingly, states or provinces in federal systems are allocated constitutionally based authority in areas such as health policy (Blank, 1994:50). See Blank (1994:49-66) for a description of these

advanced the introduction of legislative action or a state appointed authority to control and regulate ART developments and practices. Nor has it always ensured a nationally consistent approach to funding and access to ART practices, as I illustrate in Chapters Four and Five. Caldwell and Daniels (1992:258) suggest that it is extremely difficult to resolve major moral issues such as the control and regulation of ART in a democratic state. They argue, as does Blank (1995:50), that politicians are unlikely to risk their re-election chances by committing themselves to strongly contested moral issues that are likely to divide the community. Undoubtedly, the lack of international consistency in regulatory approaches has also been influenced by the different historical and cultural contexts and the difficulty in establishing universally acceptable limits on reproductive rights and choices (MCART, 1994:26).

1.3 Rights & Choice

Although originally linked to the “struggle for the right to safe, legal abortion and contraception in industrialised countries in the 1970s and 1980s” (Corrêa, 1997), the politics of reproductive rights and choice has been expanded to include the use of ART. Developments in ART have generated demands for other reproductive entitlements including ‘the right to parenthood’ (Tomasevski in Packer, 1996:54). Consequently, the rights debate has been extended to include contestation of the right to reproduce and to question how such a right would be defined in relation to ART (Ruzek, 1991; Rowland, 1992; Cook, 1995; Rowland, 1995; Shanner, 1995; Di Valentino, 1996; Packer, 1996; Blank, 1997; Steinbock, 1998). The language of rights is included in the discourse surrounding the existing legislation and the policy debate over the use and regulation of ART in Aotearoa/New Zealand. The development of human rights instruments and civil rights movements against various forms of discrimination have played a central role in influencing value shifts in society, especially in relation to changes in attitudes to divorce, remarriage, de facto relationships, homosexuality, the extended family, and solo parenting (MCART, 1994:50). Consequently, the Ministerial Committee on Assisted Reproductive Technologies (MCART, 1994:51) asserts that “domestic human rights legislation and international instruments are essential touchstones in the development and evaluation of policy” and that the Human Rights Act 1993 must be the basis for any discussion of

contrasting political systems in relation to Aotearoa/New Zealand and the United States of America, and the effect this has on health policy.

discrimination in the field of assisted reproduction.¹² Similarly, the Aotearoa/New Zealand Family Planning Association (FPA) supports the application of the Aotearoa/New Zealand Bill of Rights Act and the Human Rights Act in relation to ART, arguing that it

...is essential that the regulation of human assisted reproductive technology not be used as an opportunity to legalise discrimination against certain groups such as lesbians, or single women.
(Family Planning Association, 1997:3)

The Human Rights Commission (1994:2-3) recognises that the rights of those involved in ART practices may be in conflict and that attention must be paid to how these rights are balanced and prioritised. Nevertheless, the Commission “considers that fertility treatment services fall clearly within the meaning of goods, facilities or services” referred to in section 44 of the Human Rights Act. However, others argue that human rights legislation in Aotearoa/New Zealand is inadequate in relation to ART because it focuses on the rights of adults and disregards “the rights and best interests of the child” (Coney, 1999c:43). In Chapter Five, I examine how the rights of the child are often used to argue against the use of ART by lesbian couples and single women. Less evident in the policy debate is any discussion on women’s reproductive rights and the right to access ART treatments. In Aotearoa/New Zealand, rights based claims are most obvious in relation to the debate surrounding the interests of children born through ART practices and access to information about donors by those involved in donor ART practices (Atkin, 1995; Else, 1995; Coney, 1999c; Else, 1999b). Issues surrounding the rights of Māori as Tangata Whenua with respect to assisted reproduction are also marginalised in the policy debate and the effect this has on access by Māori to ART services will be addressed in detail in Chapter Six.

The rhetoric and application of rights shift over time. Similarly, social, political, and technological change influences the definition of certain rights and who has a claim to them.

¹² The Human Rights Act 1993 replaced previous human rights and race relations legislation in Aotearoa/New Zealand. It added new grounds of prohibited discrimination and increased the penalties for unlawful discrimination. The Aotearoa/New Zealand Government has agreed to be bound by the United Nations agreements on human rights and the Human Rights Act 1993 is based on these agreements. Nevertheless, the Government exempted itself from complying with the Human Rights Act 1993 in relation to its own legislative policies and practices until 1 January 2000 (Human Rights Commission, 1998). The subsequent passing of the Human Rights Amendment Act 1999 extended the compliance deadline until 31 December 2001. Although international human rights treaties have no legal status in Aotearoa/New Zealand unless written into domestic law, Aotearoa/New Zealand has a political and moral obligation to ensure they are complied with (Coney, 1999c:42). Henaghan (1995:34) argues that the “traditional view that international treaties are not an enforceable part of domestic law unless written into that law” has been weakened by judicial practice in Aotearoa/New Zealand. Recently, family court judges have begun using the language of children’s rights to validate decisions about access and custody. Henaghan (1995:45, n.8) cites for example: *Neho v Duncan* [1994] NZFLR 157; *Tozer v Newcomb* [1992] NZFLR 51; *Stove v Stove* (Family Court, Hastings, 31 May 1990, FP 020/222/88).

Accordingly, the discourse surrounding 'rights' must be understood within the particular social and historical context in which the rights are being claimed (Blank, 1997:283). This has particular relevance when legislative action is taken to fix policy that cannot be easily changed or adapted to accommodate changes in social attitudes and beliefs, as illustrated by the analysis of the Status of Children Amendment Act 1987 later in this chapter. As the language of 'rights' is more frequently applied to individuals, it is likely to exclude any meaningful examination of the "power relations within which the rights are exercised" (Albury, 1999:6). Rights discourse presumes individual autonomy and the ability to make "free" choices. It fails to recognise the various social, economic, and political factors that contribute to and exacerbate constraints on choice. Such discourse often presumes equality between those making choices (Beveridge & Mullally, 1995:242). However, Robyn Rowland claims that there is no such equality, either in the alternatives offered to people as choices or between those who are choosing, as decisions are "constrained and shaped by the forces of economics, social ideology, personal psychology and established power structures" (1995:16).

The conferral of rights has often been dependent on a person's ethnicity, class, age, marital status, sexuality, gender, religion, culture, health, and physical abilities and these categories commonly form the criterion for access to or exclusion from certain benefits, thereby constraining choice. Rowland (1995:16) argues that these constraints are greater for women than for men and that the use of a rights analysis in relation to ART may lead to social decisions that fail to consider issues of relationship and caring. Dion Farquhar (1996:9-10) maintains that the opposing discourses surrounding the use of ART reduce the variety of women's reproductive experiences to the binary of free/constrained. Whether ART are "enabling, constraining, or neither *and* both" is dependant, in part, on the discourses that describe them (Farquhar, 1996:4). Accordingly, Farquhar argues that reproductive technologies are "not one entity, nor do they play one role, nor have only one fixed set of consequences for users, providers, donors, and the larger society" (1996:10). Similarly, Wajcman (1994) argues that

...the emphasis placed on women's right to use these technologies tends to obscure the way in which historical and social relations are built into the fabric of technologies. While recognizing the social shaping of women's choices, few participants in the debate acknowledge that the technologies from which women choose are themselves socially shaped.

The discourse of rights obscures the way in which choices are highly constrained, as well as the manner in which the available technological options are themselves shaped by particular political and economic interests (Mackenzie & Wajcman, 1999:275).

Recently, reproductive choice has been treated as a consumer good rather than a focus for political or moral scrutiny (Albury, 1999:21). The free-market definition of choice represents ART as being “value-neutral, objective high-technology medicine” (Farquhar, 1996:7). It suggests that decisions are limited to choosing one of several comparable outcomes rather than being associated with expressions of personal freedom and complex decision-making (Albury, 1999:21). Despite low success rates and high costs, the availability of a number of fertility treatment options within a market model is celebrated as fostering women’s self-determination. The ability to decide which treatment to use from a plethora of technological options and provider services is viewed as promoting greater autonomy (Lublin, 1998:93). However, as Franklin and McNeil (1988:553) maintain

...many early feminist campaigns for abortion on demand were waged in the name of “a woman’s right to choose.” Recently, more complex understandings of the context of individual decision making about abortion have led to splits between the single-issue abortion campaign and the movement for a broader politics of reproductive rights. ... In short, in all these domains, feminists have learned that more choice does not necessarily guarantee more freedom or control.

As such, working through reproductive problems and living with the outcome of numerous intersecting decisions is often more involved than the language of choice allows (Albury, 1999:21). These decisions, or “reproductive choices”, are influenced by various social, cultural, and historical contexts, as well as previous fertility histories and experiences (Farquhar, 1996:94). Thus, an individualistic focus on reproductive rights and choices can obscure the social, historical, economic, and cultural dimensions of reproduction. Nevertheless, the purpose of modern human rights is to resolve social inequities between the privileged and disadvantaged members of society (Dworkin in Cook, 1995). Steinbock (1998) argues that the most important role of rights is their protective function, through the expression of important principles of fairness, the empowerment of people against discriminatory practices, and the acknowledgment of human dignity and respect for persons. As these notions of protection, fairness, empowerment, and human dignity are so embedded in the language of rights, it may be difficult to express them in any other way (Steinbock, 1998). Therefore, it is with both the obscuring and enabling aspects of rights discourse in mind that I use the language of rights in this thesis.

1.4 Families & ART

As with adoption, ART has enabled biological and social parenthood to be carried out by separate individuals, creating potential for new forms of kinship and family relations and disrupting the roles and relationships that have traditionally constituted parenthood. The United Nations Convention on the Rights of the Child states that the family is “the fundamental

group of society and the natural environment for the growth and well-being of all its members and particularly children" (United Nations General Assembly, 1990). Similarly, the Aotearoa/New Zealand Law Commission (2000:2) claims that the family provides security and a sense of identity for the child. However, the boundaries of families, the roles of individuals within families, the nature of family relationships, and family members' expectations and responsibilities vary according to the historical, social, and cultural context in which they are located. Although there are a diversity of family structures and formations in Aotearoa/New Zealand, the heterosexual nuclear family continues to be promoted as the normative family structure and alternative family structures are often depicted negatively in research and policy studies (Royal Society of New Zealand & Ministry of Research Science and Technology, 1998:5-6). In the past, membership of the nuclear family was established through the practices of marriage and subsequent procreation and was based on assumptions about biogenetic and marital connections. Therefore, post-industrial family life came to be accepted as a 'natural' fact through its connection with the biological fact of procreation (Strathern, 1995:351-353). However, the increasing recognition of a variety of family formations, such as 'reconstituted' families established through divorce, remarriage, death, or sexual preference, has exposed the constructed nature of family relationships by separating parenthood into its biological, legal, and social aspects. Similarly, adoption and the development and use of conceptive technologies have disrupted the connection between marriage and procreation. Birth control methods have separated sexual intercourse from procreation and enabled people to delay or prevent childbirth. Likewise, a combination of ART practices have enabled single women and lesbians to have children and facilitated the separation of the biological aspects of motherhood from the social and legal aspects.

Like most countries that allow the use of ART and donated gametes, Aotearoa/New Zealand has accepted that the interests of children born from using these procedures are paramount and, therefore, has adopted a law that addresses the legal status of these children (Blank, 1998:142). However, ART and surrogacy challenge deeply held values and ideals concerning family and family relationships. As is discussed throughout this thesis, the legislation and policies enacted in Aotearoa/New Zealand in relation to ART practices are concerned with protecting and reinforcing certain kinds of family relationships. Consequently, the Status of Children Amendment Act 1987 (SCAA) is based on the assumption that a 'normal' family consists of a mother, father, and children and positions heterosexual couples as the norm for reproduction and parenthood. The SCAA legitimises the relationship between the child and the parenting (heterosexual) couple by recognising the birth mother and her husband (legal or *de*

facto) as the legal parents. Providing a woman undertakes an assisted reproduction procedure with the consent of her husband, he will be the legal father of any resulting children. The donors of gametes have no rights or responsibilities with respect to the resulting child (Tollemache, 1999a:18). This situation raises concerns in surrogacy arrangements because the SCAA provides that

(1) Where a married woman becomes pregnant as a result of artificial insemination and she has undergone the procedure with the consent of her husband,---

- (a) The husband shall, for all purposes, be the father of any child of the pregnancy, whether born or unborn; and*
- (b) Any man, not being her husband, who produced semen used for the procedure shall, for all purposes, not be the father of any child of the pregnancy, whether born or unborn.*

(Section 5, Status of Children Amendment Act 1987)

Therefore, any husband who consents to his wife using donor gametes to conceive for the purposes of a surrogacy arrangement will become the legal father of the resulting child (Henaghan, 1992:179). Similarly, the woman who becomes pregnant using donor gametes or a donor embryo is considered to be the legal mother irrespective of whether she intends to be the social mother or not.

(3) Where a woman becomes pregnant as a result of a donor ovum or donor embryo implantation procedure,---

- (a) The woman shall, for all purposes, be the mother of any child of the pregnancy, whether born or unborn; and*
- (b) The woman who produced the ovum from which the embryo used in the procedure was derived shall, for all purposes, not be the mother of any child of the pregnancy, whether born or unborn.*

(Section 9, Status of Children Amendment Act 1987)

This situation raises particular concern when the commissioning parents are also the genetic parents.¹³ Under present policy the genetic parents have no legal rights or responsibilities with regard to the child and would be required to adopt the child in order to become its legal parents (Else, 1999a:50-52). They would be treated as “legal strangers” with regard to the child when applying for an adoption order (Caldwell & Daniels, 1992:270). While the sperm donor can become the child’s legal father by marrying the mother, no such provision is made for the egg donor to become the child’s mother if she marries the legal father (Tollemache, 1999a:18). While pregnancy and birth confer maternal status irrespective of genetic or marital status, women who donate their ova are potentially more vulnerable than male donors of sperm in relation to attaining recognition as the resulting child’s parent. Henaghan (1992:187) argues

¹³ Gestational surrogacy involves a woman gestating a child that has been conceived through IVF, using the gametes of the intending social parents. The resulting child may have no genetic connection to the surrogate but would be genetically related to both the intending social parents. See footnote no.5 in this chapter and Appendix A for descriptions of the range of procedures that may be used in a surrogacy arrangement.

that the SCAA is “concerned with giving particular children a legal father and mother and with excluding other people from that legal status”, particularly the donors of gametes, male same-sex couples, and the partners of lesbian women.¹⁴

The use of donated sperm by lesbian couples and single women has also raised issues about the legal status of the parent-child relationships created as a result of such procedures. The SCAA states that

(2) Where a woman becomes pregnant as a result of artificial insemination and that woman is either a woman who is not a married woman or a married woman who has undergone the procedure without the consent of her husband,---

(a) Any child of the pregnancy, whether born or unborn, shall not have, in relation to the man who produced the semen used in the procedure, the rights and liabilities of a child of that man unless at any time that man becomes the husband of the woman;

and

(b) The man who produced the semen used in the procedure shall not have the rights and liabilities of a father of any child of the pregnancy, whether born or unborn, unless at any time that man becomes the husband of the woman.

(Section 5, Status of Children Amendment Act 1987)

As a result, if a lesbian couple uses donor insemination to have a child, one woman will be the biological and legal parent of the child while the other has no legal status. This woman can apply, however, to become an additional guardian (New Zealand Law Commission, 2000:209). The donor is relieved of the legal ‘rights and responsibilities’ of paternity and, while the child cannot make claims on the donor regarding inheritance and financial support, neither can the

¹⁴ At present, in order for male same-sex couples to raise a child genetically related to one of them, they would have to rely upon a woman to undertake a surrogacy arrangement with them in which she would conceive using one partner’s sperm. However, they cannot rely on the SCAA to achieve legal recognition of their status as co-parents of the child, even if the law was amended to be gender neutral (New Zealand Law Commission, 2000:213). Providing the woman was not married, the sperm-donating partner could be identified as the legal father. However, his partner could not be legally recognised as a co-parent. Similarly, adoption under the current Adoption Act 1955 would only recognise one partner as the legal parent. Because only one adoption order may be in force at any moment in time, two single people cannot jointly adopt a child. Nevertheless, single people can apply to adopt a child (irrespective of their sexuality), although a gay male may only adopt a male child (New Zealand Law Commission, 2000:131-133). The Adoption Act 1955 does allow two spouses to apply jointly to adopt a child (New Zealand Law Commission, 2000:131). However, differing opinions amongst Family Court judges has led to doubt over whether ‘spouses’ includes *de facto* as well as married couples. As a result of this uncertainty, adoption is presently confined to married couples and single people, excluding same-sex couples and *de facto* heterosexual couples (New Zealand Law Commission, 2000:129-132). In its review of the Adoption Act 1955, the New Zealand Law Commission recommended that “persons are not disqualified from eligibility to adopt on account of their relationship status – that is, whether they are single, married, in a same-sex, or *de facto* relationship” (2000:129) and that “the prohibition against a single male adopting a female child be removed” (2000:130). They maintained that the ability to parent a child was the important factor when considering “whether adoption by particular applicants is the best means of promoting the interests of a particular child” (New Zealand Law Commission, 2000:129).

donor make any claims on the child. In an interview conducted for this project, Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) maintains that single women and lesbian couples who approach the clinic often have difficulty when it comes to registering the birth of the resulting child.

Does she choose "father unknown" or, with the donor's permission, can she put his name as the father. Will he be exempt from the Inland Revenue? Will he be exempt from paternity issues? (Rodney Bycroft, Interview: 13 September 2000)

He suggests that often 'known donors' are quite happy to be registered as the father of the child but that the women involved do not want them to be financially responsible for the child. Single mothers who seek state benefits can be pressured to name a father on the birth certificate and if they do not comply their benefit may be paid at a reduced rate (Coney, 1999c:45). However, Rodney Bycroft maintains that many of the single women and lesbian couples that the clinic treats are financially independent and do not rely on the state or the donors for financial support.

Lesbians will often say, "Well look, one of us works, what is the problem? You know we are no different than a heterosexual relationship." I mean you cannot argue with that, you cannot argue with the fact that they definitely want this child. ... There are definitely some financial situations that are not ideal but as a private clinic we have seen single women who are self-sufficient, who do not need to work, they have independent income and they ask, "Why can't I have a child?" (Rodney Bycroft, Interview: 13 September 2000)

In support of this argument, a recent magazine article profiled two financially independent single women who had used ART to achieve their desire to parent (Saunders, 2001). Similarly, Mannis' (1999) review of research on women who choose to mother alone revealed that these women often have financial autonomy, social and family support, education, and a strong, long-standing desire to mother. They formed their families without partners and with no expectation of ever having a co-parent. However, in an interview conducted for this project, Sandra Coney (Executive Director, Women's Health Action Trust) has questioned whether it is ethically reprehensible to allow a child to be born without a father.

...children are entitled to have a father in their lives and some do set up situations where they are having the donation from a gay male friend who is involved in their lives. But, I have difficulty with the idea that these men can avoid a lot of their responsibilities towards the child, and do. (Sandra Coney, Interview: 13 July 2000)

By relieving the donor of rights "rights and liabilities of a father", the SCAA does not create fatherless children. The SCAA takes away the 'right' to apply, as the father, to be appointed as guardian of the child and the 'liabilities' of maintenance.¹⁵ The emphasis in the legislation is on

¹⁵ Henaghan (1992:182) contends that the legislation is not clear on whether the liabilities extend as far as making inheritance provisions.

the need for a child to have a legal father. If there is no other person to be considered for the role of the father, then the donor retains the status of father without the rights and liabilities (Henaghan, 1992:182). Although the donor has no *legal* rights and liabilities, this does not preclude individuals involved in donor insemination from negotiating and establishing certain rights and liabilities within the terms of their relationships.¹⁶

Whereas some commentators argue that it is essential to define parenthood by specifying what roles take precedence (Blank, 1990:11), others support the deconstruction of such definitions and the potential for extending understandings of 'family' relationships that ART and surrogacy offer (Millns, 1995; Strathern, 1995; Thomson, 1998). As Strathern (1995) points out, assisted conception may introduce individuals who have no genetic or familial relationship into the process of reproduction and, as a consequence, provide a model of relations that allows for an extended kinship group outside of that offered by the nuclear family model. Likewise, Barbara Katz Rothman (in Thomson, 1998:179) claims that ART practices

...offer us an opportunity to work on our definitions of parenthood, of motherhood, fatherhood and childhood, to rethink and improve our relations with each other in families. Freed from some of the biological constraints, we could evolve better, more egalitarian ways of relating to ourselves and each other in reproduction.

Furthermore, Gibson (1992:65-66) claims that some feminists have welcomed alternative modes of reproduction because they expand the procreative choices of 'non-traditional' families and may help to broaden the societal definition of family. She suggests that a society with a broader concept of family might be more open to alternative methods of reproduction and less inclined to exclude certain groups of people from such methods. Nonetheless, there is a danger that ART also reinforces the linking of femininity with motherhood and motherhood with childbirth, thereby it re-centres 'normative femininity' on the maternal body (Sawicki, 1991:89).¹⁷ The intent of the legislation in Aotearoa/New Zealand has been to protect the 'family' from the intrusion of third parties and to protect gamete donors from claims of parental responsibility. Consequently, the legislation adds to and reinforces the discourse that represents the 'family' as being organised around two co-habiting heterosexual parents with genetically related children. Although there are unquestionable benefits to children being raised within a family consisting of two parents contributing to the welfare of one another and of their children, it should be recognised that many people raise children as single parents and that the

¹⁶ See 'My two mums' (Dickson, 1999) in which a lesbian couple discuss the active role of the sperm donor in the lives of their two children.

¹⁷ Bartky (in Sawicki, 1991:89) defines 'normative femininity' as a set of disciplinary practices regulating the body, its gestures, appetite, shape, size, movement, appearance, and so on.

desire to parent and bring up children extends to those who do not fit the traditional concept of 'parent' (New Zealand Law Commission, 2000:xv).

Haimes (1990:164) argues that some ART procedures are more acceptable than others because they reproduce the ideological, structural, and genetic relationships necessary for the 'normal' family. Techniques that use the intending parents' own gametes reproduce all the elements necessary for a 'normal' family. However, techniques that use donated gametes only satisfy the ideological and structural concepts of such normality. While resulting children may not be genetically linked to one or both parents, the resulting family structure demonstrates and reinforces the value of family life (Haimes, 1990:164). Relationships created by homosexual couples and single women or men accessing ART fail to satisfy traditional concepts of family and, thereby, challenge the norm more than other ART practices. Nevertheless, research reviewed by the Canadian Royal Commission on New Reproductive Technologies (1993a:457) and the New Zealand Law Commission (2000:133-134) suggests that children raised by lesbian couples are at no greater risk of harm than those raised by heterosexual couples.¹⁸

Pool, Jackson, and Dickson (1998:117) argue that, although policy-makers are informed by what is reported to them, the use of this information is also influenced and modified by the dominant discourse on family formation and structure, as well as public policy strategies. As a consequence, "the norms applied to the formulation of policy are those of the majority, from the dominant culture" even though policy-makers come from a variety of family structures and ethnic groups themselves (Pool, et al., 1998:121). This anomaly was substantiated by Theresa Wall's (Senior Analyst, Māori Health Branch, Ministry of Health) explanation of the use of the nuclear family model in policy in an interview conducted for this project. Although she personally recognised and supported the diversity of family formations in society, she suggested that policy focused on the nuclear family model because it was easier to manage.

¹⁸ According to the New Zealand Law Commission (2000:133), most research concerning the experiences of children reared by homosexual parents has focused on children with lesbian parents and there has been little significant research published focusing on the experiences of children brought up by gay men. Consequently, there is little research to "reliably evaluate either positive or negative influences of gay parenting" (New Zealand Law Commission, 2000:133-134). See *Adoption: Options for Reform* (New Zealand Law Commission, 1999) paragraphs 189-197, for a review of the relevant research. See also: Fitzgerald, B., 1999. 'Children of lesbian and gay parents: a review of the literature', *Marriage & Family Review*, Spring, Vol.29, No.1, p.57 (19). This paper reviews the research literature concerning the development of children with gay and lesbian parents. The body of literature generally concludes that children with lesbian and gay parents are developing psychologically, intellectually, behaviourally, and emotionally in positive directions, and that the sexual orientation of parents is not an effective or important predictor of successful child development.

There are a whole lot of social strictures around the notion that you should have a set of parents, a male and a female and your brothers and sisters and you should all live in a house together. That is the way in which society to a large extent has been organised but everybody really knows ... that families are an extremely fluid structure, and they should be because people change. ... [The nuclear family] is just much easier to manage at a policy level, and at an ideological level, if everybody is slotted into very nice little patterns that behave in certain ways. It is when you have the diversity of human relationships and the diversity right across a whole life span that it becomes difficult for an individual to conceptualise. So, I think that there is just a safety in slotting back into what is popularly identified as being the norm. But, everybody really does know that it is not the norm.

(Teresa Wall, Interview: 24 July 2000)

Nevertheless, this acceptance of the hegemonic nuclear family model in relation to social policy contributes to the marginalisation of alternative or non-conforming family formations and fails to recognise public acceptance of diversity in the structure of families.¹⁹

The New Zealand Law Commission (2000:64) points out that there has been an increasing acceptance of “familial institutions other than the nuclear family” over the last 45 years, calling attention to social changes such as the abolition of the status of illegitimacy, the introduction of State financial support for single parents, the increasing use of ART, and the move to open adoption arrangements. Similarly, Fleming and Atkinson (1999:13-14) maintain that since the late 1980s there has been a shift away from an ideology that places value on the nuclear family as the preferred family unit. However, they argue that the ‘blood’ relationship between the parent and child is taking precedence and this is reflected in changes in policy and in family court decisions on custody and access. Correspondingly, the Adult Adoption Information Act 1985 and the move towards open adoptions have reinforced the shift from affinal to biological links in family policy issues. However, the SCAA effectively obscures the relationship of the person born from a donor or surrogate arrangement to his/her parents, supporting a marital definition of family over a biological one (Macklin in Adair & Rogan, 1998:267). The New Zealand Law Commission’s (2000) review of the Adoption Act 1955 was based on the recognition of these and other changes in social attitudes and values. In this review, the Commission recommends changes to the SCAA that acknowledge the diversity and validity of alternatives to the nuclear family model that can be created through the use of ART (2000:209-213). As it stands, the SCAA contributes to the ‘socialisation of procreative behaviour’ by positioning the heterosexual couple as the norm for reproduction and parenting. It works to inhibit access to ART by single people and those individuals who are not heterosexual, as well

¹⁹ Robin Fleming and Toni Atkinson’s (1999) research into families established through remarriage highlights how policy decisions based on the stereotypical nuclear family can have an adverse affect on families that are organised in different ways.

as marginalising ethnic groups whose concept of family differs from the 'norm'. Therefore, the standards and values associated with normality effectively regulate the behaviour of individuals and groups (McNay, 1994:95-99). In Chapter Five I explore how this definition of family and issues surrounding 'worthiness to parent' have influenced access restrictions to both public and private ART services. Henaghan argues that legislation defining family in relation to ART and surrogacy in Aotearoa/New Zealand "seems a very *pakeha* way of addressing the issue" (1992:186, emphasis in original).

Defining Whānau

While the Status of Children Amendment Act 1987 (SCAA) focuses on the definition and maintenance of the nuclear family, Māori recognise a broader concept of family that includes both the nuclear family and whānau (Durie-Hall & Metge, 1992:60; Henaghan, 1992:186). Although the term 'whānau' has a range of meanings that apply in different contexts, the primary meaning is described as

...a group of relatives defined by reference to a recent ancestor (tupuna), comprising several generations, several nuclear families and several households, and having a degree of ongoing corporate life focussed in group symbols such as a name, a land base (tūrangawaewae) and taonga.

(Durie-Hall & Metge, 1992:61)

However, Pihama (1998:195) argues that the contemporary use of the term 'whānau' includes both biological and non-biological relationships. Correspondingly, Cram and Pitama (1998:142) claim that Māori family systems are "vital and dynamic and, as such, definitions of whānau are being revised within the context of contemporary Māori realities."²⁰ While nuclear families may form the basis of some Māori households, individuals remain linked through wider cultural configurations, particularly through whakapapa (genealogy) (Pihama, 1998:189-190). Both whakapapa and whānau incorporate notions of kinship that allow for relationships, responsibilities, and commitment by a range of adult kin in the parenting of Māori children (Pihama, 1998:182). Māori children are an inseparable and fundamental part of the whānau (New Zealand Law Commission, 2000:82) and sharing the control and care of children with other whānau members is generally expected and accepted by parents and caregivers (Durie-Hall & Metge, 1992:64). It is possible that this inclusive concept of whānau, combined with the concept of whāngai, has enabled Māori to address infertility in the past.²¹

²⁰ See Cram and Pitama (1998) for their interpretation and definition of traditional and contemporary whānau systems.

²¹ The concept of whāngai and its relationship to infertility and surrogacy is addressed in Chapter 6, Addressing Difference, Section 6.5, Whāngai & ART.

The SCAA changes the legal status of the child in a similar way to the Adoption Act 1955, and the birth certificate reads as if the legal parents are the biological parents (New Zealand Law Commission, 2000:210). This has significant consequences for Māori, raising issues about the child's right to access information about donors and their genetic background. As membership of whānau, hapū, or iwi is determined by knowledge of whakapapa, which is an integral part of being Māori, it is essential for individuals to know their true whakapapa or genetic connections (Dyall, 1999:35). The use of donated gametes combined with the SCAA undermines an individual's right to knowledge of their whakapapa and their ability to claim access to their cultural heritage and other entitlements (MCART, 1994: Appendix E, p.5). By assuming that the protection of children is guaranteed by ensuring parental legal status and the promotion of the nuclear family, the SCAA implies that the cultural and social values within Aotearoa/New Zealand are homogeneous (Henaghan, 1992:186-187). Issues surrounding the recognition of cultural and social diversity in relation to ART policy are discussed in more detail in Chapter Six.

1.5 Framing the Thesis

This thesis consists of seven chapters. In Chapter Two, The Research Process, I present a detailed discussion of the various research strategies used to identify and locate the discourses that have informed ART policy. I provide a definition of 'policy' as it is used in this thesis and explore the constraints and choices that influenced and guided the selection of and access to documentary evidence and interview participants. My definition and use of a feminist perspective is described and I outline how I reached a 'position' in the ART policy debate. I provide an explanation of both the access and interview strategies and processes, followed by an analysis of the power relations I experienced during the research process. This discussion leads into a consideration of the personal and political conflict I experienced while engaging in cross-cultural research. Finally, I briefly outline the programmes and strategies used to analyse the accumulated documents and interview material.

Chapter Three, Regulating Practices, provides a review of the complex situation regarding the control and regulation of ART in Aotearoa/New Zealand. In this chapter, I describe the 'official' policy responses to ART developments over the last twenty years and present an overview of the organisations directly involved in the regulation and control of ART developments and practices. This chapter analyses the 'formal' policy background that underlies and influences the issues of funding, access, and Māori use of ART that are discussed in the following chapters. I critically review the two bills currently being considered by a parliamentary select

committee and consider the policy gaps that will remain irrespective of either bill being passed in its current form. The following sections examine the roles of the two organisations most obviously involved in the regulation and control of ART practices in Aotearoa/New Zealand. I analyse the National Ethics Committee on Assisted Human Reproduction (NECAHR) in relation to its *de facto* role in formulating ART policy. I consider the contribution of professional self-regulation, through the Reproductive Technology Accreditation Committee of Australia (RTAC), to the control and monitoring of ART practices. Finally, I address issues of public accountability in relation to the fragmentation of *de facto* policy organisations and the lack of an overseeing ART policy body. Throughout this chapter, I comment on the drawbacks of maintaining the status quo and delaying legislative action.

Chapter Four, *Allocating Resources*, outlines the evolution of public funding based on historically determined levels of demand and its influence on regional inconsistencies in funding and access. In this chapter, I explore how resource constraints and health sector restructuring influenced the introduction of access restrictions for ART treatment. I describe the funding changes and national access restrictions that were introduced in 2000, and I consider how recent health sector reforms may affect these attempts at resolving regional inequalities and inconsistencies in access and funding. This chapter sets the context for the analysis of the recently introduced national Clinical Assessment Criteria (CPAC) in Chapter Five.

In Chapter Five, *Regulating Access*, I investigate how access to both public and private ART treatment is restricted. I analyse the values and assumptions that underlie the use of biological infertility, age, sexuality, and marital status as limiting factors in the provision of ART treatment. Included in this chapter is an examination of arguments based on the interests, rights, or welfare of any resulting child. These arguments are frequently used to justify restricting access to ART practices by particular groups of people. This is followed by an analysis of the national Clinical Assessment Criteria (CPAC), which was introduced in 2000 to reduce regional disparities in access for publicly funded ART practices. In this section, I will consider how the various criteria rely on social and moral judgements of who is considered worthy of treatment and highlight how the CPAC works to limit access by single women, lesbian couples, and older women.

Chapter Six, *Addressing Difference: Māori Infertility and ART*, explores the invisibility and marginalisation of Māori within the ART policy debate. I explore the silences surrounding Māori in relation to ART policy and consider the probability of Māori having existing or future needs to

access ART practices. After considering the broader issues concerning Māori access to health services, I explore how these may affect Māori using ART practices to overcome infertility. This is followed by my examination of issues relating to the collection of information about ethnicity and how the absence of such information affects policy decisions, which may ultimately disadvantage Māori who wish to use ART services. Within this discussion, I consider the difficulties associated with defining Māori and using ethnicity as a variable in social research. Following on from this discussion, I consider whether Māori use whāngai as an alternative to accessing ART services. I explore issues surrounding the protection of whakapapa in relation to donated gametes and the retention and availability of culturally relevant information. Finally, I discuss issues arising from the exclusion or marginalisation of Māori in the ART policy debate. Included in this section is a discussion about the necessity for policy to recognise the difference and diversity within the Māori population. Central to this chapter is an awareness of my position as a Pakeha researcher, as discussed in Chapter Two, Section 2.9, Cross-Cultural Research.

Chapter Seven, Policy in Practice, concludes this thesis with a discussion of the implications of the ART policy situation in Aotearoa/New Zealand and how this situation results in limited consideration and analysis of the values and principles underlying any ethical or policy decision-making. I illustrate how *ad hoc* policy development in relation to funding decisions has built on historically determined levels of need and neglects to consider any investigation into actual demand. This section explores how the lack of a considered approach to the public funding of ART services has contributed to inequitable and inconsistent funding outcomes. I then explore how *ad hoc* policy approaches, characterised by contingent, incremental, and fragmented responses to policy issues, have further embedded inequities in relation to access. By failing to consider the values and principles that underlie restricted access to ART, policy-makers have limited the reproductive choices of certain individuals and groups. I discuss the implications of these issues of regulation, funding, and access for Māori in relation to their marginalisation within the policy discourse. Finally, I consider possibilities for future research and proactive policy attention, as well as the implications of this investigation for future policy considerations in Aotearoa/New Zealand.

2

The Research Process

...the critical issue for feminists is not so much the content of women's choices, or even the 'right to choose,' as it is the social and material conditions under which choices are made.
(Petchesky, 1990:11)

2.1 Introduction

The rationale for this research project is to explore how individuals' access to assisted reproductive technologies (ART) has been shaped by the current policy context in Aotearoa/New Zealand. Many commentators (Daniels, 1994a; Daniels & Hargreaves, 1997; Coney, 1999a) have observed that social policy on ART in Aotearoa/New Zealand has been created through a combination of existing legislation, professional self-regulation, health service controls, and consumer demand. They have also noted that the recommendations from various commissions and committees throughout the late 1980s and early 1990s did not result in legislation. Therefore, policy was often created by default, using these recommendations as guidelines. The Status of Children Amendment Act 1987 (SCAA) is the only piece of legislation that specifically addresses ART. In order to appreciate the current policy situation I decided to identify and analyse the discourses that have informed these various 'default' policies. I concentrated on documentary evidence produced in relation to the ART policy debate and conducted in-depth interviews with representatives of organisations that had been involved in producing policy documents or were active in implementing policy.

In this chapter, I will provide a detailed discussion of the research methods and processes used to inform this thesis. Firstly, I will outline the research principles I applied to the research process and provide the definition of 'policy' as used in this research. This will be followed by a discussion of my subject position in the ART policy arena. I will then describe the research methods and the strategies used to select the documents and participating organisations or

individuals. Next, the procedures used to make contact with and gain access to interview participants will be examined, followed by a detailed description of the interview process. An analysis of the power relations encountered during this research will be followed by a discussion of the difficulties I experienced when engaging in cross-cultural research. The chapter will conclude with a brief discussion of the programmes and strategies used to analyse the accumulated documents and interview material.

In undertaking this research project, I recognised and tried to adhere to the five core principles of ethical conduct in social science research; do no harm, voluntary participation, informed consent, avoid deceit, and confidentiality or anonymity (Tolich & Davidson, 1999:69-77). I acknowledge that my own subjectivity and interest in the subject matter are relevant to the research process, from topic selection to dissemination of the findings (Oakley, 1981; Harding, 1987; Bishop, 1996; Tolich & Davidson, 1999). In this chapter, I have attempted to place myself in the research process and provide a detailed account of the methods used, including the rationale for choices made throughout the process. Although I identify myself as a feminist sociologist, I am aware that “there is not one feminism, but many feminisms: feminists across the disciplines work from within a multitude of intellectual paradigms and political positions” (Ray, 1996:36). Therefore, I acknowledge that there is no definitive feminist method and that processes used by feminists are often widely divergent and multi-methodological (Ray, 1996). Reinharz (1992:6-10) relies on feminists' self-definitions of their work because she believes it avoids the danger of applying a one-dimensional definition to all feminist researchers and research and allows for the rapid changes in feminist scholarship. My approach to this research was derived from feminist principles and understandings of how power differentials impact on all aspects of the research process. Consequently, my attempts at reducing the impact of the power differentials that exist between researcher and participant were informed by feminist critiques of research methodology (Oakley, 1981; James, 1986; Cook & Fonow, 1990; Stanley, 1990a; Stanley, 1990b; Stanley & Wise, 1990; Fonow & Cook, 1991; Reinharz, 1992; Ray, 1996; Wyn, et al., 1996; Casper, 1997). While I recognise that the research participants should be actively involved in the research and reciprocity should be encouraged in order to reduce the power differential between the researcher and participants (Oakley, 1981; Wyn, et al., 1996), I discovered this was not always practical or welcomed by some participants.²² Similarly, I recognise that applying feminist ideals to the research process does not automatically ensure that power inequities are eliminated (James, 1986:25). This

²² This issue is discussed later in this chapter; see Section 2.8, “Studying Up” & Discrepancies in Power.

became apparent when attempting to justify the inclusion of Māori focused interviews and documentary information.²³ I was also influenced by the belief that feminist-based research strives to advance the well-being of women by contributing to political changes that improve women's lives (Cook & Fonow, 1990; Stanley & Wise, 1990; Reinharz, 1992; Stanley & Wise, 1993). Although this research is not overtly 'women focused', my interest in this topic has been shaped by an interest in how gender and the politics of reproduction affect women. My decision to undertake 'policy-focused' research was influenced by this interest and the knowledge that policy has a profound effect on the "material conditions under which choices are made", especially choices made by women in relation to reproduction (Petchesky, 1990:11).

In this thesis 'policy' is used in its broadest sense to include both the private and public strategies used to regulate the provision and use of ART. Acts of Parliament, Ministerial edicts, and Government initiated guidelines and strategy documents play a major part in policy formulation and implementation. However, these are not the only contributions to policy. Managers, healthcare professionals, patients, and the wider community also establish policy through interpretation and implementation of these guidelines and strategies. This broad approach to policy was influenced by Green and Thorogood's (1998) position on health policy analysis.

To understand how policy is made, and how it impacts on various groups in the population, it is not enough merely to look at the decisions of government departments. We also need to examine the more local arenas of decision making and action.
(Green & Thorogood, 1998:11)

Therefore, policy analysis in this thesis attends to the positions of various stakeholders, forms of legislation, organisational regulation, and debate about regulation and funding. In the context of this research, 'policy documents' refers to both published and unpublished documentation that has contributed to the policy debate, influenced practices within fertility clinics, or affected consumer engagement with ART practices. Published documents include records that have been published or made available to the public such as parliamentary debates (Hansard), published reports from committees and commissions, discussion documents, submissions on reports and discussion documents, parliamentary bills, academic papers, and service provision contracts. Unpublished documents include records held by organisations or individuals that are not generally available to the public but contribute to the policy arena by outlining individual and organisational practices and the strategies used to implement policy. They may also be specifically written to lobby for official policy changes. They include

²³ This issue is addressed later in this chapter; see Section 2.9, Cross-Cultural Research.

submissions to select committees and government organisations, providers' 'Conditions of Service' and policy documents, personal correspondence, documents generated by consumer and policy orientated lobby groups, service specifications, and clinical access criteria (see Appendix B for a list of the documents consulted for this thesis). Commentary on ART policy was sought from representatives of organisations that were involved in the production of these documents. Individuals who had contributed to or authored such documents were approached for interviews, as well as those who were actively involved in some aspect of the policy debate. As a result, interviewees were located within a variety of organisations including government policy agencies, fertility clinics, consumer representative groups, and health activist groups, as well as academic contexts (see Appendix C for a list of people interviewed).

2.2 Taking Sides

Finch (1986:209) argues that the knowledge created by qualitative policy-orientated research cannot be 'objective' in the sense of being neutral in relation to the political processes of policy-making. She suggests that the nature of the research and the methods used make it likely that the political stance adopted by the researcher will be oppositional with respect to the status quo and that the researcher is also likely to be 'visible' in the research process and its outcome (Finch, 1986:10). Correspondingly, sociology has traditionally positioned itself as an advocate for the least powerful in society (Green & Thorogood, 1998:167). Howard Becker (cited in Green & Thorogood, 1998:167) also argues that sociology has a role in challenging the 'hierarchy of credibility' that affords more legitimacy to elite versions of social reality and, as such, 'taking sides' is inevitable in doing research. However, Annette Lawson (1991:592) questions this assumption and argues that it is not always obvious who the less powerful are in health research. Similarly, Casper (1997:252) found it difficult to identify whose side she was on and discovered that, given her dissimilar field of informants, she had to practice accountability in different ways.

I began this research with the idea that I should perhaps "take sides", but with some ambivalence towards which 'side' I was on. The literature I reviewed presented compelling arguments 'for' and 'against' ART practices. Even though Becker (1998:7) warns that such reviews can seduce "newcomers" to a field into adopting the ideas of the existing "experts" in that field, I was still not completely won over by the petition for unrestricted use of ART or by the argument for prohibition based on the negative consequences of these technologies. I could not decisively position myself within what appeared to be a dichotomous debate. Dion Farquhar's *The Other Machine: Discourse and Reproductive Technologies* (1996) helped me

recognise that this, in itself, was a valid position. Farquhar argues that reproductive technologies are a mixed blessing and there “seems no point in *simply* opposing them, since they are here to stay” (1995:7, emphasis added). As she goes on to point out, not all women experience ART in the same way and, although some women may experience these technologies as exploitative and abusive, others may have empowering and satisfying encounters with them (Farquhar, 1995). While public policies can regulate and control the exploitative and abusive aspects of these technologies, they can also contribute to the exclusion and marginalisation of some women who want to use ART. It is with this in mind that I approached the interviews from an ambivalent subject position. This position became less ambivalent as the research progressed. I discovered that I could position myself as an advocate for those who experience unequal access to publicly funded ART services and for those whose reproductive choices are jeopardised by the lack of adequate social policies and/or regulations to control the potential for abusive use of ART in Aotearoa/New Zealand.

2.3 Research Methods

Research for this project consisted of a literature review, content analysis of a selection of original documents that have contributed to policy surrounding assisted reproductive technologies (ART), and semi-structured in-depth interviews with representatives of organisations involved in the development, interpretation, and implementation of that policy. Literature surrounding infertility, rights and choice, the regulation and control of reproduction, and ethics in relation to ART was accessed from a variety of disciplines. These included sociological, feminist, political science, psychological, biomedical, and ethical perspectives and particularly drew on feminist discussions related to the politics of reproduction (O'Brien, 1981; Petchesky, 1990; Farquhar, 1996; Albury, 1999). This literature informs discussions throughout the thesis, particularly, but not exclusively, in relation to discussions about reproductive rights. As mentioned earlier, Farquhar (1996) provided an excellent starting point for my own positioning in the debate. She argues that the discourses surrounding ART contribute to the construction of “new identities and subjects, along with new expectations, fears, and conflicts” and that “both clients and resisters create new normative categories and new relationships to the technologies that in turn modify them” (Farquhar, 1996:7). O'Brien (1981) and Petchesky (1990) provided comprehensive theoretical analyses of the feminist politics of reproduction, while Albury (1999) explores the different discursive influences on women's fertility decisions and experiences. She investigates what counts as evidence and who is an authorised expert in the political contests surrounding the regulation of fertility (Albury, 1999:2). Her argument “that we need to look beyond the commonsense understandings of motherhood,

heterosexuality and family formation which shape policy debates" (Albury, 1999: back cover) helped shape the focus and structure of this thesis. Consequently, this thesis tries to look beyond these commonsense debates and investigate their influence on access restrictions to ART, the legal recognition of donor-assisted parenthood, and the rights of those involved in the formation of families using ART and donor gametes.

Although policy documents are only part of the discourse that surrounds policy formation and implementation, they are purposefully written to record or to provoke discussion of a social practice. Recognising the importance of policy documents in this context and, because of time and financial constraints, I decided to confine the research for this project to documents specifically produced to influence or establish ART policy. However, documentary evidence only represents formal policies and, as such, the philosophies and practices of the actors who shape policy 'on the ground' could not be accessed solely by an analysis of these documents. Therefore, I chose to use a combination of documentary analysis and in-depth interviews to explore the influences and motivations of the various commentators and formulators of policy in the ART policy debate.

Interviews with state agencies, fertility clinics and health providers, consumer groups, and academic commentators were seen as vital sources of information on ART policy. While I identified the documents as representing the 'public' account of ART policy, I anticipated that in-depth interviews would reveal some of the 'private' rationalisations offered by those who contributed to the policy debate. Appreciating that policy is not only influenced by decisions and documents produced by government organisations, I chose to include the more local areas of policy interpretation and implementation (Green & Thorogood, 1998:11). Therefore, non-governmental documents and interviews with non-governmental actors in the policy debate were also included. State produced documents included reports from ministerial committees, State commissioned discussion documents, and ministerial policy documents and annual reports. Non-governmental documents included submissions to the Parliamentary Health Select Committee, providers' proposals to the Health Funding Authority (HFA), the New Zealand Infertility Society's magazine, professional codes of practice, and privately produced discussion documents such as *Protecting Our Future* (Coney & Else, 1999). Interview participants from State agencies included representatives of the Ministry of Health, Te Puni Kōkiri (Ministry of Māori Development), and the Health Funding Authority (HFA). Actors who were interviewed outside the governmental realm included fertility clinic managers, the New Zealand Infertility

Society (NZIS) Executive Officer, the Family Planning Association (FPA) Medical Training Co-ordinator, health activists, and an academic.

Preliminary analysis of the policy documents had indicated that, while there were explicit agendas influencing the documents, there were also less obvious ideologies influencing some recommendations and guidelines. As Green and Thorogood (1998:157) point out,

Much policy making rests on implicit assumptions, ... and each of these derive from a particular set of beliefs about the world and will influence the type of action (i.e. politics) which are aspired to, if not achieved. Thus ... policies are the result of politics, that is, systematic ideas about how society does (or should) function.

Like Luker (cited in Reinharz, 1992:148), I anticipated that a comparison of 'produced' interview material with 'found' archives and organisational literature would enhance my understanding of the relation between individual understandings and the public discourses of organisations. I hoped that the in-depth interviews would indicate some of the underlying assumptions and beliefs that have contributed to the formulation of ART policy. However, I also anticipated that the interviews would provide an opportunity to gather private and/or unpublished documents that I would not otherwise have had access to, as well as providing me with more insight into how the policy process works 'on the ground'. In addition, I wanted to examine what the differently situated organisations perceived to be the important issues, as well as analysing the silences and gaps in the policy discourse.

2.4 Strategies for Accessing Documents

Initial documents analysed included the Ministerial Committee on Assisted Reproductive Technologies (MCART) report, *Navigating Our Future* (1994), as well as work by Daniels (1994b) and Daniels and Hargreaves (1997). The MCART (1994) report and academic research articles (Daniels, 1994a; Daniels & Hargreaves, 1997) had informed an Honours Degree research project in 1999 and investigating sources mentioned in these documents through library and Internet searches yielded other relevant material. However, these strategies only alerted me to published discussion documents. Interview participants proved invaluable in the search for both published and unpublished literature, including press releases, 'Conditions of Service', and draft policy changes, as well as submissions made in response to reports and discussion documents. Either these documents had been produced by the participants' organisations and were not published or readily accessible through libraries and the Internet, or they were communications between the actors involved in ART policy. Serendipity, as mentioned by Stacey (1991:27), also proved to be a valuable research tool and seemingly chance events helped locate some important documents. Random scanning of the Health

Funding Authority's (HFA) website produced a copy of the funding contract between that organisation and Fertility Associates in Auckland. Similarly, a chance comment to Dianne Yates' (Member of Parliament for Hamilton East) personal assistant led me to the written submissions to the Health Select Committee. These submissions had been 'tabled' the previous day and were only just available to the public. As I was due to leave Wellington the next day, this information was invaluable. However, it would not have been brought to my notice if the personal assistant had understood my original question. These situations cannot be planned for and serve to reinforce the need to pay attention and follow even the most inconspicuous lead when chasing research material. The regulation and control of ART practices has proved to be a fast-changing and dynamic policy arena in which to research. Therefore, documentary data collection has continued throughout the duration of this thesis (see Appendix B for a list of the documents consulted for this thesis).

2.5 Selecting Participant Organisations & Individuals

I began the process for selecting participant organisations in early March 2000 while compiling and refining the research proposal. The selection process was ongoing and covered several months, overlapping with access strategies and the interviews, because selected organisations were not always available or willing to participate. Initially, I developed a flow chart (see Appendix D) to assist in the identification of the major actors involved in the ART policy debate in Aotearoa/New Zealand. This device enabled me to categorise these actors into three broad organisational groups (state, providers, and consumers/commentators) and provided a framework within which to locate selected interview participants. I positioned Government organisations and politicians under 'state', fertility clinics and other health service providers under 'providers', and consumer and political lobby groups, as well as academic researchers and commentators, under 'consumers/commentators'. However, I anticipated that some of these organisations and/or their representatives would belong to more than one category. Likewise, organisations grouped together would not necessarily identify or agree on areas of concern and may even have opposing ideas about the ways in which access to ART is constrained or enabled by existing policy. As I was hoping to ascertain some of the underlying assumptions and beliefs that have contributed to the formulation of ART policy, it made sense to target organisations that were involved in the production of the policy documents. While I acknowledge that specific individuals cannot represent or speak on behalf of all members of a social group (Edwards, 1996:169), the interviewees were accessed as representatives of public and private organisations and, as such, were speaking as named participants on behalf of their organisation. Once again, financial constraints placed limits on the selection of participant

organisations. Travel and accommodation costs influenced the location and number of organisations that could be approached for interviews, as well as affecting the timeframe for the interviews. As most of the targeted organisations were based in Wellington or Auckland and my home base is Christchurch, consolidating interviews in these three locations was my highest priority. Similarly, time constraints meant that not all of the initially targeted participants could be included in this study. For these reasons, people and organisations such as Wayne Gillett,²⁴ the Otago Fertility Service, Paparangi Reid,²⁵ Phillida Bunkle,²⁶ the Human Rights Commission, the New Zealand Medical Association, and the New Zealand Endometriosis Foundation were not approached for in-depth interviews.

Some organisations, such as the New Zealand Infertility Society (NZIS), the Ministry of Health, and fertility clinics, were obvious targets for interviews. I decided to speak to representatives of the Christchurch Fertility Centre because it was geographically accessible and I had already established a working relationship with this organisation. North Shore Fertility was selected because it is a private clinic that does not provide publicly funded treatment and I thought that they might provide a divergent perspective on ART policy from the other clinics. Additional organisations were identified through the previously accessed documentation and the Internet. MCART's (1994) report provided lists of organisations and individuals that had made submissions to the Ministerial Committee and this helped identify organisations that I believed would still have an active interest in ART policy. I added government organisations to this list, such as the Ministry of Women's Affairs, the Ministry of Health, the HFA, and the National Advisory Committee on Health and Disability, because I assumed they would have an interest in ART policy. Individuals who had a high profile in the policy debate and/or had participated in the authorship of policy documents, such as Sandra Coney, Dianne Yates, Ken Daniels, and John Peek, were also included. I continued the selection process while carrying out the interviews in Auckland and Wellington, as participants frequently provided names and contact information of people they considered were important in the ART policy debate and who were likely to make a valuable contribution to the research. Although I tried to contact some of

²⁴ Wayne Gillett is an Associate Professor with the Department of Obstetrics and Gynaecology at the University of Otago and a co-author of *Costs and effectiveness of infertility services in New Zealand: a decision analysis* (Gillett, et al., 1995) and *Access to Infertility services: development of priority criteria* (Gillett & Peek, 1997).

²⁵ Dr Paparangi Reid was a member of the two-person Ministerial Committee on Assisted Reproductive Technologies and co-authored their report, *Navigating Our Future* (MCART, 1994).

²⁶ Phillida Bunkle is a Member of Parliament and a member of the Health Select Committee considering the two bills on ART.

these people, they were often unattainable or unavailable because of time constraints or other commitments.

2.6 Making Contact & Gaining Access

The access process proved to be the most time consuming and, at times, frustrating aspect of the research. I began approaching organisations and individuals in May 2000 to request the contact names and addresses for recipients of introductory letters. In most cases I selected the manager, chief executive, or director of the targeted organisations as the initial contact and possible interviewee. In some cases, however, the organisation and/or representative were selected because of their high profile in the policy debate and/or authorship of policy documents. Once again, the Internet proved to be a valuable resource and I was often able to access names, phone numbers, and addresses via the targeted organisation's website. I identified additional participants by phoning the organisation in question and requesting the name of someone who could be contacted in relation to my research. Occasionally, I was redirected to people in a variety of positions before locating someone who was willing to be identified as a contact and/or was conversant with the topic. Sometimes this course of action would lead nowhere and I would have to begin the process again. On one occasion, I was redirected to the Executive Officer of a consumer organisation who was more than willing to participate in the research, as well as provide additional documentary information. This circumvented sending the introductory letter and I was able to make an interview appointment straight away. Once a contact name was provided or located, this person was sent a letter of introduction or contacted by telephone. Sixteen organisations and two individuals were initially contacted for interviews. Of these initial contacts, twelve organisations and the two individuals agreed to participate in the research project.

On 8 June 2000, I sent fourteen letters to the selected interview participants or institutional contacts in Wellington and Auckland. These letters described the research and asked for the recipients' participation or that of a nominated representative (see Appendix E for a copy of the letter). Potential interview participants in Christchurch were initially contacted by telephone and the first telephone access was made on the 9 June 2000. I used this approach in Christchurch because I had established a previous research relationship with some of the targeted organisations. I also wanted to shorten the access process so that I could commence the local interviews prior to starting those in Wellington or Auckland. These initial interviews helped me refine the interview process and indicated some additional interview topics to include on the

subsequent interview guides.²⁷ However, access to contact names and possible interview participants continued to be a complicated and time-consuming process.

The original strategy was to follow the introductory letters with a telephone call within the ensuing two weeks to establish the recipients' and/or organisations' willingness to participate, and to organise interview times if appropriate. However, one of the targeted recipients contacted me the day he received the letter to arrange an interview date and time. Another emailed me to inform me that she was leaving the organisation and that her position would cease to exist. However, she had passed my letter on to her manager had undertaken to contact me with an alternative representative. The enthusiastic response by these two people was reassuring and I was encouraged to hope that gaining access to interviewees would be easier than I had originally anticipated. This confidence was short-lived and I managed to confirm only three interviews after contacting eleven organisations with the follow-up phone calls on the 14 June 2000. One of the confirmed interviews was with the person who had rung me two weeks earlier and another was with a provider representative who would be overseas when I was intending to be in Auckland. Fortunately, this representative agreed to a telephone interview when he returned to Aotearoa/New Zealand. One contact for a government organisation declined an interview because he felt the organisation did not have anyone currently working in the ART policy arena and, therefore, did not have anything to contribute to the debate. The remaining contacts were not available or had referred my letter to someone else, who had not had an opportunity to read it. I noted the new contacts' names and arranged to make another set of calls the following week.

My first experience of 'gatekeeping' involved the information officer of a government organisation who refused to provide me with a direct contact when I phoned that organisation in May 2000. She suggested that I email the introductory letter directly to her and she would then pass it on to those she thought were appropriate. I had hoped to avoid such tactics by targeting those at top of the 'institutional hierarchy'. Although I recognised that all my contacts were gatekeepers to some degree, I reasoned that it would save time to target those people whom I assumed would have the ultimate responsibility for approving their organisation's participation in the research. This strategy did not work in all cases as personal assistants or secretaries often vetted the recipients' mail and proved to be gatekeepers in their own right. One state organisation, with which I negotiated access through a gatekeeper, refused to

²⁷ See Section 2.7, The Interviews, in this chapter for a discussion of interview strategies.

participate after I had sent the introductory letter to the nominated representative. I had not been able to talk directly to the targeted participant and I was suspicious of this decision, speculating that my request was considered a low priority and I was being 'fobbed off'. This proved to be a valid suspicion when, a month later, the Chief Executive of the organisation contacted me after she finally received my letter. She expressed concern that I had not received a reply. However, she justified the decision not to participate by arguing that her organisation performed an advisory role rather than an active policy-making role and she believed that the organisation would not have anything further to contribute to the debate. I was left with the impression that the outcome may have been different if my letter had reached her desk first and I had been able to talk directly to her when I made the follow-up phone call.

Gatekeeping occurred more frequently in relation to government organisations, where initial contacts appeared to be far more wary about participating in the research than those in non-governmental organisations and private enterprise. Nevertheless, some of the larger private organisations also refused to take part in my research project. Again, my contact with these organisations was with gatekeepers and I suspected that the request had not reached the intended participants. However, this reticence may have been a consequence of the contact's position in a hierarchically structured institution that requires the employee to operate within a context of loyalty and formal procedures (Green & Thorogood, 1998:163).²⁸ Furthermore, it may have reflected the lack of priority given to ART matters by some organisations, as well as institutional resource and time constraints that preclude employees spending time on projects outside their own organisational responsibilities. People were being approached as named commentators and were required to make public statements on behalf of their organisations on a controversial topic and this may have acted as a disincentive to involvement in the project.

In order to establish a timeframe in which to schedule the interviews I verified air travel times and availability before contacting potential participants. As it was necessary to confirm the interviews before finalising travel arrangements, the delay in contacting people meant that the window of opportunity in which to book airfares was closing. Finally, through a combination of repeated phone calls and email messages I confirmed one more Auckland interview and three more Wellington interviews. Consequently, I had scheduled only two face-to-face interviews in Auckland. While this gave me time to follow the additional leads that I had been given while

²⁸ See Section 2.7, The Interviews, in this chapter for a discussion of how the interview participant's position in the organisation may also have affected the interview process.

trying to access participants, these proved fruitless as the people and organisations involved could not see me within the timeframe I had allowed or they were not available. I had managed to arrange five interviews in Wellington over a period of three days. However, this meant doing two interviews a day and left little latitude for changes in schedules. Before leaving for Wellington I had to reschedule two of these interviews because of changes in the participants' schedules. This proved a complicated process as I had allowed little time within which to negotiate changes and I was unable to change flight bookings because of the financial consequences and the availability of seats. There was less urgency in arranging or changing interview times in Christchurch and, although I had arranged and completed two interviews before leaving for Auckland, I continued the access process for these interviews once I returned from the North Island. An additional interview in Dunedin was scheduled when the participant contacted me after being notified of the research project by another contact.

Initially, methodological procedures for gaining access worked well. Nonetheless, it became obvious that accessing participants is time consuming and not as straight forward as my initial success suggested. Difficulties in contacting gatekeepers and their inability to access potential participants meant that timetables were disrupted and access strategies needed to be revised or adjusted. In retrospect, excluding obvious financial and time constraints, the snowball method of gaining potential participants would have worked well in this project. As mentioned earlier, many of the interview participants provided names of organisations and individuals that could have made valuable contributions to the research.²⁹ Although I tried to contact some of the people recommended by other participants, only one responded to my overture and was available for an interview. Furthermore, the tightly constrained interview timeframes in the two North Island locations meant that the interview schedule was somewhat inflexible, particularly in Wellington. Consequently, interview opportunities were missed as information on additional commentators or participants in the ART policy arena could not be followed up and one cancelled interview could not be rescheduled. As with the selection process, access initiatives continued over several months, overlapping with interviews and the transcription process. The final interview participant was confirmed on 11 August 2000, three months after the first contact was initiated. In general, gaining access was far less troublesome with private organisations than with government organisations, where I had to negotiate with gatekeepers and encountered hierarchical decision-making processes. One positive outcome of locating

²⁹ In some cases, potential interviewees were recommended by more than one person and others had already been approached or considered for interviews.

potential participants via a range of intermediate contacts was that I gained information on the structure of the organisations I was trying to access, as well as insights into the policy process 'on the ground'.

2.7 The Interviews

The interviewing process began on 14 June 2000 and the final interview was undertaken on the 31 August 2000. Fourteen interviews were carried out, consisting of twelve face-to-face interviews and two telephone interviews (see Appendix C for a list of the organisations and individuals involved in the interview process). Two of the face-to-face interviews were undertaken in Auckland, five were situated in Wellington, one in Dunedin, and the remaining four took place in Christchurch. Both of the telephone interviewees were located in Auckland. Before each interview commenced, the participant or participants were given an information sheet and asked to complete a consent form (see Appendix F for examples). The information sheet explained the focus of the interviews and reminded the participants that they were being interviewed as representatives of the organisation for which they worked. All of the interviewees were interviewed in their professional capacity as representatives of organisations or as academic researchers/commentators who have made public contributions to the ART policy debate and, as such, it was not considered necessary to offer anonymity. Thirteen of the interviews were audiotaped to allow the interview to be transcribed verbatim and to ensure the information collected was accurate. Although permission to tape the interviews was sought during the access process, I repeated this request before commencing the interviews. Where possible, hand written notes were taken. However, note taking proved difficult when I considered it necessary to concentrate fully on the participant's conversation. This was particularly necessary in two cases when there was significant background noise and the participants were very softly spoken. An interview with Dianne Yates (Member of Parliament for Hamilton East) was so constrained by time that it was not feasible to set up the tape recorder and only hand written notes were taken. Although this severely limited interview did not provide any information I could use in the final analysis, it did provide an unplanned opportunity to access invaluable documentary information in the form of the written submissions to the Health Select Committee.³⁰

³⁰ This serendipitous event is described in Section 2.4, Strategies for Accessing Documents, in this chapter.

Eleven of the face-to-face interviews were conducted in the participants' workplaces and one interview was conducted in the participant's home. The two telephone interviews were conducted at a time the participant nominated. One provider representative consented to material from an interview for an earlier research project being included in this thesis. Consequently, material from both interviews has been used in this thesis and is differentiated by the dates on which the interviews took place. The length of the interviews ranged from 10 minutes to 105 minutes. This variation in length was dependent on the participant's personal and professional involvement in and knowledge of the policy debate, as well as other commitments. All the interviews were undertaken using a semi-structured, in-depth approach. This meant that, although the interviews were focused on ART policy and what the participant perceived to be the enabling or constraining aspects of this policy, standardised questions were not used. This approach allowed the interview participant/s to engage with the topic and address issues they thought were important. However, as I was interested in the policy 'gaps' and the marginalisation of certain groups within current policy discussions, I would introduce these topics if the participant/s had not addressed them during the course of the interview. Accordingly, interview guides were used to help keep the interview focused and to ensure these issues were addressed (see Appendix G for an example of the interview guide). These guides varied between the three categories of participating organisations to allow for the different institutional contexts and perspectives.

On three occasions, considerable prompting and probing were necessary to generate engagement with the topic. This occurred in interviews with representatives of state organisations. Participants in two of these interviews had been nominated by a gatekeeper to represent their organisation and were accompanied by a more senior work colleague. These representatives tended to have little accumulated knowledge of ART practices and policy. Restructuring, changing administration, and staff retrenchment have meant that staff with institutional and historical knowledge of the issues have moved on and those interviewed were new to the area and had a limited work-related knowledge of ART policy issues.³¹ This would have influenced their ability to engage with the topic without prompting and could explain why some individuals and organisations would not agree to an interview. The responses of participants working within government organisations may also have been influenced by their

³¹ See Chapter 3, *Regulating Practices*, Section 3.7, *Accountability*, for a discussion of how the depletion of institutional knowledge and experience within government agencies has affected consumer trust in these policy organisations.

position within an “institutional context of hierarchy, loyalty and formal procedures” (Green & Thorogood, 1998:163). This was sometimes evident when the interviews were completed and the tapes were turned off, as the participants relaxed and were more open about their personal and professional views. Although employees of private organisations may also be influenced by their position within the institutional context, those interviewed within the provider and consumer/commentator categories appeared to be less constrained and guarded in their views and were more inclined to blend their personal and professional opinions. The organisations targeted in these groups were smaller than the state organisations and were represented by a manager, chief executive, or director who had more institutional authority to speak on behalf of their organisation than the state employees did. Their confidence and candour when discussing the issues could have been due to the senior positions they held in their organisations. Furthermore, the provider and consumer/commentator organisations that participated in the research generally specialised within the ART area and were directly affected by the policy debate. Therefore, they may have been more informed and more capable of discussing the issues in depth. However, it was evident that all the interviewees engaged in strategic representation of their organisations and their policy positions.

One state organisation initially declined my request to tape-record the interview and hesitated about signing a consent form. Although the organisation had previously contributed to the ART policy discussion, this input was limited, and those who had been involved in this work were no longer part of the organisation. Understandably, the representatives were wary of discussing something about which they had only limited knowledge. Although an interview strategy was negotiated that enabled the interview to proceed and gave the participants more control over the eventual use of the interview material,³² they were generally very cautious with their responses throughout the interview. Although copies of relevant published information from the organisation were made available, I was informed that I would have to use the Official Secrets Act to gain access to unpublished material related to their policy involvement (this related to submissions, guidelines, and recommendations). Hornsby-Smith (1993:54) argues that some organisations approach participation in research with caution because they “see research as a threat because ... there are fears of exploitation or it may result in damaging disclosures...” Although the organisation did not restrict physical access to the research setting, access to information was restricted through discursive strategies, such as reluctance in responding to questions and an unwillingness to provide access to unpublished documentation.

³² See Section 2.9, Cross-Cultural Research, in this chapter for a discussion of this negotiation process.

These were tightly focused interviews with representatives of public or private organisations reflecting on their organisations' role in the ART policy debate. As such, participants were interviewed in their official capacity and were not required to share personal information or experiences. The more formal nature of the interviews precluded the use of a conversational style and equal sharing to reduce power differentials between the participants, as advocated by Anne Oakley (1981).³³ Although I occasionally employed conversational interaction, I preferred to limit my spoken involvement in the interviews. Rather than positioning myself as distant and impartial, I was attempting to remove any influencing or disrupting elements while maintaining an involved presence. The first transcription made it obvious that even my restrained presence could disrupt the participants' focus or train of thought. My murmured agreement could also prevent the speaker from finishing what they were saying, as they obviously assumed I understood or knew what they intended to say. I tried to be more aware of the impact of my own participation in the subsequent interviews. Although I would intercede to clarify a point, direct the discussion towards certain issues, or answer direct questions, I tried to limit my own participation so that I was not interrupting the participants or preventing them from completing what they were saying. Nevertheless, some interviews were more informal than others and it was not possible to sustain this strategy of limited participation. Increased participation on my part was also necessary in the interviews that required more prompting and consistent follow-up questions. By necessity, the telephone interviews were more focused and formal than the face-to-face interviews. These variations in procedure highlighted the unpredictable nature of interviews and the need for flexibility in interview techniques.

Scheduling five interviews over three days while in Wellington was tiring, with little time to refine and reflect on the process. Ideally, more time between interviews would have enabled me to transcribe and absorb what was discussed in each interview before carrying out the next interview. Although I had allowed five days between the Auckland and Wellington trips to review the interview process, this time was taken up with access issues and reorganising scheduled interviews. Time constraints in Wellington also caused problems when two interview participants needed to reschedule at short notice. My inability to reschedule within the time I had allowed meant that one interview was severely constricted by time and the other had to be carried out with a replacement representative who was less informed than the original

³³ See Section 2.8, 'Studying Up' & Discrepancies in Power, in this chapter for a discussion of the strategies used to diminish power inequities

participant. All the participants agreed to further contact if the transcription and analysis process highlighted any issues or questions that needed clarification. Both telephone interview participants were forwarded consent forms to complete.

2.8 “Studying Up” & Discrepancies in Power

While the more common research relationship involves the subjects of the research having less power than the researcher, this is not always the case. In some research situations, those being studied have considerably more institutional power than the researcher. Monica Casper (1997:245) describes this as “studying up”. She suggests that interviewing people in elite settings and as part of elite social networks has important implications for the nature of the research and “may affect everything from the feelings of the researcher to how we represent ourselves in research sites to issues regarding access” (Casper, 1997:245). During most of the interviews I was aware that I was “studying up” and that certain interview participants had more institutional or reputational ‘power’ than I did as a female student researcher. For the most part the interviewees were managers, directors, or executive officers within the participating organisations and some of the interviewees were medical specialists. Casper (1997:247) suggests that the elite nature of specialised knowledge within medical and techno-scientific settings also contributes to power inequities. Nonetheless, I did not feel intimidated or disadvantaged by this lack of specialised knowledge, even though I often had to ask for clarification of clinical and scientific terms and practices. Like Casper (1997:247), I discovered that the participants’ answers often produced useful information or insights. However, the participants’ institutional knowledge and position were not the only factors influencing the power relationship between researcher and participant. I contributed to the power imbalance by conferring on some participants what Weber called “charismatic authority” (Ritzer, 1996:132). These participants had gained status via their reputations in academia or the popular media and my deference to their experience and knowledge added to my perception of “studying up”. One participant’s seemingly aggressive response to my request for an interview certainly accentuated my own insecurities about the validity of my research and the questions I wanted to ask. I approached this interview with some trepidation, expecting impatience and condescension. Although I was consciously aware of my perceived ‘inferior’ position, the participant’s responsiveness and hospitality during the interview diluted any discomfort and nervousness. This situation revealed how power differentials can be misinterpreted or exaggerated by the researcher’s own subjectivity.

Although I felt it was not appropriate to use the feminist interview techniques advocated by Oakley (1981), I did try to reciprocate or 'give back' during the interviews. While I did not volunteer information about my position in the policy debate, I was willing to answer any questions about this position. However, I was rarely asked where I stood on any of the topics discussed and, in general, the participants showed no curiosity about my political position in relation to ART. On occasion I would 'share' personal information or the motivations behind my research involvement in the ART field with the participants but this was generally during the more informal or less focused discussions towards the end of the interviews and the 'sharing' was usually initiated by me. Jane Ribbens (1989:584) observes that interview participants may interpret the research situation as giving them permission to talk about themselves or their opinions at length. Consequently, they may perceive any unasked for interruptions or contributions by the researcher as a nuisance and not part of the original research agreement. Similarly, Gayle Letherby (Cotterill & Letherby, 1993:6) discovered that her involvement and presence in the interviews was partly structured by her respondents' interest or lack of interest in her personal history. It is likely that the participants made certain assumptions about my position in the ART policy debate. However, only two interviewees articulated their opposing assumptions.

A participant's assumption that I was politically aligned with her organisation, combined with my own feelings that I was obliged to 'give back' in some way, created a situation where I felt unable to refuse a request. Directly after one interview I was asked to "return the favour" by performing a small task at a function the organisation was arranging. I felt obligated to agree and I was left wondering how I would have handled this situation had the request been for something that I was uncomfortable with or opposed to doing. I can only assume I would have negotiated some other way of 'repaying the debt'. This situation accentuated the fact that participants may have expectations about continued involvement and assistance from the researcher and why strategies need to be in place for dealing with such requests. It also re-emphasised the complexities of power in research; the researcher and participants may occupy shifting positions in the relationships of power and this relationship may not be completely one-sided (Cotterill, 1992; Cotterill & Letherby, 1993).

Finch (1986:206-207) argues that discussions of research ethics often distinguish between the relative power of different research subjects. She also suggests that considerations of privacy and protection can be partially suspended in research on the 'powerful'. However, participants in policy research can be officials who themselves are relatively powerless within the setting

being researched and, therefore, ethical issues may not be particularly different from research on less powerful groups (Finch, 1986:206-207). As noted earlier, the participants working within the government organisations I targeted were more likely to have been in this position than the managers and directors of the private organisations. Nevertheless, these participants were in some sense powerful relative to the researcher, as I was reliant on their ability and willingness to provide access to organisational literature and information.

While I experienced power inequities within the access process and research setting, I also had significant power as researcher. I decided what research topic to address, what methods to use, whom to interview, when to probe, as well as how to interpret, analyse, and present the information the participants gave me. Like Bev James (1986:30), I justified such decisions in terms of what she calls “necessary power”. Although those with more institutional power may have the means by which to protect themselves from exploitation, I agreed with Finch’s (1986:207) argument that the ethical issues of doing no harm and maintaining privacy were still valid. In order to reduce the likelihood of doing harm and to ensure that none of the participants felt disempowered by the interview process, consent forms were introduced before the interviews began. As Green & Thorogood (1998:169) suggest, confidentiality is an important ethical consideration within health care settings because “individual professionals may be providing information that could damage their relationships with others if made public, or damage the reputation of their organisation.” For this reason, the consent forms provided the participants with the opportunity to specify how they wished to be represented in the research (see Appendix F). Two organisations also chose to use the consent forms to impose limitations on the use of the information they gave me. However, only one of these interviews was used in the final analysis as the other interview provided little information relevant to the research topic.³⁴

In conjunction with the consent form, the participants were given an information sheet prior to commencing the interview (see Appendix F). As mentioned earlier, the information sheet outlined the research project and reminded the participants that they were being interviewed as

³⁴ This interview was with a women’s health collective, which provided free health related information and advice. Most of their work, at the time of the interview, involved contraceptive advice and pregnancy tests for teenagers. If they were asked for advice on fertility problems their policy was to refer the person on to a doctor or the Family Planning Association. I decided not to transcribe the tape as there was little information I could use directly. However, the interview was the first one I undertook and it provided an opportunity to develop and extend my interview skills.

representatives of the organisation they worked in. It also contained the names of my supervisors and university contact information to allay any concerns they might have about participation in the project. Furthermore, a ten-page summary was offered to their organisation upon request at the completion of the thesis and information on accessing the completed document was provided. Although this provision was made in order to provide some feedback and reciprocity for participation in the project, only two participants requested a copy of the summary for their organisation.

2.9 Cross-Cultural Research

Feminist-based research methods acknowledge the inherent power imbalance between the researcher and the participants, as well as the researcher's subjective influence on research decisions. Such methods seek to address and reduce this power imbalance by actively involving participants in the research process and by informing participants of the results of the research (Wyn, et al., 1996: 166-169). However, these strategies cannot completely eliminate ethical dilemmas within the research process, especially the dilemmas posed by undertaking cross-cultural research.

A Pakeha researcher neither can nor should speak for women of another culture. With her different personal experiences and social position a Pakeha woman must acknowledge her perspective is imbued with assumptions based on her own ethnicity.
(James, 1986:26)

With this in mind, it was with some trepidation that I approached the idea of including Māori and conducting interviews with representatives of Māori focused organisations.³⁵ An awareness of the ethical issues of marginalisation, exploitation, and power inequality surrounding the inclusion of Māori created a twofold tension. If I wanted to examine the policies and practices surrounding ART in Aotearoa/New Zealand, how could I justifiably refrain from addressing these issues in relation to Māori? Conversely, how could I, as a Pākehā researcher, attempt to explore and write about these issues in relation to Māori? Although I ultimately decided to include a chapter focusing on Māori infertility and ART, this complicated and troubling tension continued throughout the research, as well as during the writing stages. It highlighted the ethical responsibilities I had as a feminist researcher. Nevertheless, the most significant reason for including Māori in this research project was based on the unique status that Māori occupy as tangata whenua and as partners to te Tiriti o Waitangi (the Treaty of Waitangi).

³⁵ Even though I recognise that other ethnic and cultural groups may have similar or divergent issues relating to ART, it was beyond the scope of this thesis to address these issues.

The decision to request and carry out interviews with representatives of Māori focused organisations was grounded in an awareness of my own limited knowledge of Māori culture, difficulties with cross-cultural research practices, possible access difficulties, and an unwillingness to exploit Māori perspectives. An appreciation of the basic principles of Kaupapa Māori research and Māori-centred research (Bishop, 1996:11-19; Cunningham, 1998:399-402) added to the personal and political unease I was experiencing. I acknowledge and accept the reasons behind the growing resistance to non-Māori research into the lives of Māori,³⁶ as well as the wishes of groups who believe that “Māori research should be led and undertaken by Māori people only” (Bishop, 1996:17). However, I believe that if I had omitted an analysis of ART policy in relation to Māori I would be contributing to the marginalisation and invisibility that Māori already experience in many areas of Aotearoa/New Zealand society. Correspondingly, I agree with James (1986:26-27), who argues that Pākehā researchers have a responsibility to address ethnicity in relation to their own membership of a powerful cultural group. They should investigate how that group constructs and maintains unequal power relations, as well as acknowledge how their own experiences are influenced by the practice of power and privilege in particular contexts (James, 1986:26-27).³⁷ Consequently, I recognise that within the limitations of this research project I can only offer a Pākehā perspective of ART policy in relation to Māori. However, rather than speak for members of an ethnic and/or cultural group that I do not belong to or attempt to present a Māori perspective, my intention is to present a Pākehā interpretation of the marginalisation of Māori with regard to access to and use of ART.

Given the importance of whakapapa and genealogical knowledge to Māori culture, I wanted to understand how policy relating to ART might have an effect on Māori. The interviews with representatives of Māori organisations were intended to inform me and to offer some insight into what the ART policy issues might be for Māori and how these issues could be addressed in a culturally acceptable way. Nevertheless, I recognised that Māori are not a homogeneous group and specific individuals or organisations cannot represent or speak on behalf of all members of a social group (Edwards, 1996:169). As one interviewee put it,

³⁶ For most of the twentieth century research into Māori lives and society has been dominated by a “Pakeha world-view.” This style of research has often been carried out for the sole benefit of the researcher, who has also decided what to research, controlled the research methods, analysed the results from a Pākehā perspective, and taken control of reporting the outcomes. This process has often “proscribed and belittled certain Māori knowledge gathering and information processing methods and contexts” (Bishop, 1996:15).

³⁷ Although Pākehā currently occupy the dominant social position in New Zealand, I recognise that individuals within this group occupy varied positions in their relationship to power and privilege. Similarly, individual Māori occupy varied subject positions in relation to marginalisation and subordination.

...it is expected in the world of Māori that two, ten, twelve different tribes will have two, ten, twelve different [perspectives]. It is expected by Māori that they do have a different opinion.

(Naida Glavish, Chief Advisor - Tikanga, Māori Health Development Service, Auckland Healthcare Services Limited, Interview: 9 August 2000)

As this thesis focuses on the analysis of policy surrounding ART, it was logical to start with organisations that are involved in Māori policy development. These organisations were selected and approached using the same methods as previously described. Although several other Māori contacts and organisations were approached to participate in the project, those that finally agreed to participate included two state organisations and one provider/consumer organisation. The Māori Health Branch of the Ministry of Health was selected because I felt that, given the Ministry's involvement in the ART policy arena, it would be the most conversant with the issues. Similarly, the role of Te Puni Kōkiri (Ministry of Māori Development) in providing policy advice to the Government and other agencies, as well as providing services to assist Māori achieve their development aims, influenced their selection. As there are no official Māori providers in the ART domain, I contacted the Māori Health Development Service (He Kamaka Oranga) located within Auckland Health Services. This group provides Māori corporate support on policy issues, systems and processes, and supplies information about how to apply aspects of tikanga³⁸ within the organisation.

The two state organisations had no policy *per se* on the use of ART and this significantly affected the final analysis and presentation of the research findings.³⁹ The representative of He Kamaka Oranga was not available while I was in Auckland and was one of the two participants with whom telephone interviews were organised. As she used Māori language to describe certain concepts and relationships, she agreed to edit the transcript to ensure accuracy in spelling and context. Her involvement in this task gave her a chance to veto or change the interview transcript. As mentioned earlier, the representatives of one state organisation initially would not agree to the interview being taped and resisted signing the consent forms. Along with concerns about a lack of institutional knowledge regarding ART policy, one of the interviewees indicated that this wariness was also motivated by the organisation's desire to maintain control over research information so that it was not used to portray Māori in a negative way. We negotiated to proceed with taping the interview and upon completion, if

³⁸ Tikanga can include law, customs, values, traditional behaviour, and philosophy (New Zealand Law Commission, 2000:75 n.247). According to Naida Glavish (Chief Advisor - Tikanga, Māori Health Development Service, Auckland Healthcare Services Limited, Interview: 9 August 2000), "tikanga are the customs and protocols of spirituality that Māori require to be included in the delivery of services."

³⁹ See Chapter 6, Addressing Difference: Māori Infertility and ART.

satisfied with the content, they would then sign the consent forms. If they were not comfortable with the outcome, I agreed to return the tape to them. This strategy worked well and both participants eventually signed the consent forms with the proviso that they (or representatives of their organisation) could review and approve any mention of their organisation in the final analysis. As their participation in the research was conditional on my acceptance of this constraint, I was more than happy to agree. This provision also gave the participants and organisation some control over how their interview material was analysed and presented. In order to give both the organisation and interviewees a chance to review their contribution to the research project in context, I supplied them with a complete chapter on 14 November 2001. As the original interview participants were no longer available, I forwarded the draft chapter to another 'Policy Manager' whose name I had been given by my original contact with the organisation. This person did not respond to my repeated attempts at contact and, in late December 2001, I sent an email suggesting that if I did not hear from her I would assume that the organisation was happy with the inclusion of the interview material and proceed with submission of the thesis.

Having determined that it was important to include interviews with individuals knowledgeable about issues relating to ART and Māori, the question then became "how?" I was hesitant to begin the analysis because I was aware that I had undertaken "Research Involving Māori" (Cunningham, 1998:397). While this style of research includes Māori as participants and subjects and includes secondary sources of Māori knowledge and culture, it does not allow for Māori involvement in all levels of the research process or for the production of Māori knowledge.⁴⁰ Although I attempted to minimise the power differentials by observing the necessary research ethics and employing a feminist methodology, I was conscious of the fact that the analysis and presentation of the information gathered would be mine. While financial and time constraints, my own ethnicity, and the requirements of Master's (MA) thesis research made it impractical to engage in "Māori-centred Research" as described by Cunningham (1998),⁴¹ I have attempted to pay attention to the effects of my ethnic position on my analysis

⁴⁰ Cunningham describes such research as typically "involving Māori as participants, subjects and /or researchers. It may also involve Māori 'data', possibly in written or oral form, such as statistics and interviews. It will frequently refer to secondary sources, such as accounts of traditional knowledge and beliefs. ... It is likely that a mainstream analysis will have been applied. ... This analysis will **not**, however, produce Māori knowledge – it will produce mainstream knowledge of Māori" (1998:397-399; emphasis in original).

⁴¹ In "Māori-centred Research", Māori are involved at all levels of the research process, such as participants, researchers, and analysts. Māori data will be gathered and Māori analysis will be applied so that the resulting knowledge will be Māori knowledge (Cunningham, 1998:399).

of the data collected. I did not want to objectify Māori as the 'other' but hoped to address 'difference' in a positive and informative way. However, I avoided engaging in an analysis of the information collected until late in the writing-up stage. This was partly due to ongoing tensions in relation to being a Pākehā and researching Māori, and a related avoidance of having to decide how to include Māori. Although I originally considered incorporating this information into the existing chapters, it soon became evident that I could not just 'add in' Māori to my analysis of the policy situation surrounding ART. Embedding discussion of Māori issues relating to ART in the other chapters would have contributed to the marginalisation that Māori experience on a daily basis and may have presented issues out of context. The proposed sections eventually evolved into a separate chapter as I considered the inequalities of Māori access to a predominantly Pākehā focused health sector, as well as the conditions that may preclude Māori from experiencing health services, including ART services, in the same way as Pākehā New Zealanders. Nevertheless, some issues relating to Māori use of ART, such as the definition of whānau, have been included in other chapters where I considered it contextually appropriate.⁴²

2.10 Analysis of the Research Material

The first interviews were transcribed verbatim including pauses and interruptions. However, as the transcription process developed, certain shortcuts and abbreviations were employed to hasten the process. Eventually, non-relevant data such as telephone interruptions were excluded and a note was made in the transcription to indicate this. Information was also excluded when informants indicated they were speaking 'off the record', ensuring that such information was not available to tempt me during the coding and writing-up stage. Documents and interviews were analysed to determine common themes, such as what groups are granted authority to speak and whose voice is ignored or erased, as well as to uncover any contradictions that existed within them. The texts and interviews were then compared to ascertain what contradictions existed between them and to highlight the gaps, marginalisations, and resistant strategies that are part of the policy situation surrounding ART practices. Although the portions of the interviews that were included in the thesis were edited as necessary, the meaning was not changed. Only words such as "um" and other peculiarities of spoken narratives were omitted from quotations. Brackets have been used to indicate where a word has been changed or inserted to clarify what the interviewee is talking about.

⁴² See Chapter 1, Introduction: Framing the Issues, Section 1.4, Families & ART.

The 'Non Numerical Unstructured Data Indexing, Searching and Theorizing' (NUDIST) computer programme was used to code, retrieve, and organise the transcribed interviews. The transcripts were studied carefully and recurring themes were noted. A coding framework was developed from the recurring themes and the aims of the research, and the transcripts were coded according to the codes using NUDIST (see Appendix H). During the analysis of the interview material I kept in mind Foucault's claim that silence is not the opposite of discourse but a facet of it and what is excluded or marginalised within the discourse is relevant to what is accepted as legitimate knowledge and truth (in Armstrong, 1997:27). Analysis of the coded interview material allowed for exclusions and marginalisations, as well as inconsistencies and contradictions, to be identified. Although the coding and analysis of the interview material was a laborious and time-consuming task, it facilitated a sound knowledge of the content of the interviews. The small size and tight timeframe of the project undoubtedly prevented me from learning and using the programme to its fullest potential. However, the time taken to code and analyse the data ensured that it was easily accessible and retrievable.

This chapter has outlined an apparent linear progression in research activity, from identifying and accessing participants and documentation to analysing and presenting the interview material. However, the process itself has been one of negotiation and adaptation, emphasising the emergent nature of the research process and the need to be versatile and resourceful. Similarly, the information collection and analysis continued throughout the writing-up stage, highlighting the unfinished nature of policy and policy analysis. The thesis was completed at a time when there was significant and increasing attention being paid to the two bills relating to assisted reproduction. These two bills have been at the select committee stage for more than five years and a report is due 31 May 2002. The decision to conclude discussion and research endeavours at the end of 2001, a seemingly arbitrary point in the policy debate surrounding ART, was shaped by the timeframe for thesis submission rather than any closure in the topic addressed.

3

Regulating Practices

And so, it has been an ad hoc historical thing as opposed to a planned policy moving forward to providing a service.

(Helen Williams, Policy Analyst, Elective Services Project, HFA, Interview: 29 August 2000)

3.1 Introduction

As highlighted in Chapter One, different countries have responded to the ethical, legal, and political issues raised by assisted reproductive technologies (ART) in a wide variety of ways. These have included a combination of legislation, governmental and organisational regulations, court decisions, and reports by government appointed commissions to create policy and regulate the practices and development of ART (Blank, 1998:139). In Aotearoa/New Zealand, public policy surrounding ART and surrogacy has been shaped by an assortment of existing legislation, professional self-regulation, health service controls, and consumer demand and ART practices have been dominated by a medical model of control and regulation (MCART, 1994:11). However, a network of relationships between consumers, providers, and government institutions, as well as cultural and structural factors, have also influenced policy issues surrounding the public funding, access, utilisation, and culture of ART services. These policy issues are debated within a variety of public institutions and arenas, including academic publications, newspapers, magazines, television, radio, Internet, public conferences, and workshops. Those who participate in these debates shape the language, as well as influence the issues that are considered. They also have an effect on the timeframe and manner in which the issues will be resolved (Albury, 1998:130). Although governments are expected to provide the formal policy solutions in relation to ART, there are many other actors and institutions involved in the development and formulation of policy. As Blank (1998:148) acknowledges, it is important that the policy-making process includes an ongoing public

discussion of the goals of ART technologies and the social concerns surrounding the provision of these technologies. Consequently, the ART policy debate should include consideration of issues relating to who has access to ART services, public funding priorities, and the protection of those involved. While this chapter will focus on issues surrounding the regulation and control of ART practices, the following chapter will investigate how public funding provisions for ART have developed in an unplanned and contingent fashion, and how this has influenced the restriction of access to publicly funded ART practices. Chapter Five will explore how the access restrictions imposed on those wanting to use ART practices are used to regulate and control family formation by relying on social judgements of 'worthiness' to parent. The implications for Māori of these issues of regulation, funding, and access are the focus of Chapter Six.

This chapter sets the context for the ART policy issues discussed in the following chapters. I highlight the sometimes arbitrary and fragmented nature of ART policy development and argue that there is a need for a more cohesive oversight and control of both ART practices and policy development. I begin by detailing the 'official' responses to the introduction and expansion of ART practices in Aotearoa/New Zealand. Although presented in a chronological and linear fashion, it is important to note that the 'messy reality'⁴³ of policy-making is far less orderly and systematic, and several policy initiatives may be under consideration at the same time. Similarly, while this analysis of ART policy development focuses primarily on 'top-down' policy initiatives, I acknowledge the need for attention to the 'bottom-up' elements of the policy process, some of which will be discussed in the following chapters. While early reports established a reactive approach to ART developments in Aotearoa/New Zealand, the Ministerial Committee on Assisted Reproductive Technologies (MCART, 1994) proposed a far more proactive response. This report has influenced public debate and commentary relating to ART over the last eight years, particularly the two bills on reproductive technologies currently being considered by the Health Select Committee. I will present a review of these bills, the content of which proposes legislative control and regulation of certain ART practices and research developments. This is followed by an analysis of the gaps in ART policy that are likely to remain, irrespective of either of the bills being passed in their current form. The role of the National Ethics Committee on Assisted Human Reproduction (NECAHR) in relation to ART policy

⁴³ This phrase was used by Martin and Salmond (2001:44), *Policy Making: The 'Messy Reality'*, in their consideration of how history and context affect the policy process in the health sector. They borrowed the phrase from Peter John, *Analysing Public Policy* (1998), London: Printer, p.7.

formulation is then examined and this is followed by an analysis of the use of professional self-regulation to control and monitor ART practices. Finally, I explore issues of accountability in relation to government officials, the fertility clinics, NECAHR, and the Reproductive Technology Accreditation Committee of Australia (RTAC).

3.2 Policy Background

From the mid-1980s to the mid-1990s, several commissions and committees, both public and private, were formed to address issues of regulation and control surrounding ART and surrogacy in Aotearoa/New Zealand. The first child in Aotearoa/New Zealand to be conceived through IVF was born in 1983. In 1984, a group representing the Royal Society of New Zealand, the New Zealand Law Society, the Medical Council of New Zealand, and the New Zealand Medical Association requested that the government appoint a standing committee to consider the legal, moral, and social issues surrounding IVF, artificial insemination, and related problems of biotechnology (Daniels, 1998a:79; Coney & Else, 1999:3). The following year the Law Reform Division of the Department of Justice published *New Birth Technologies: An Issues Paper on AID, IVF, and Surrogate Motherhood* (1985). Although this document was intended to “promote public debate on the issues raised by the new reproductive methods”, it set the precedent for a ‘wait and see’ approach by Government in relation to ART and surrogacy (Department of Justice, 1985:7). One hundred and sixty-four submissions were received in response to the issues paper, a quarter of which referred to the need for a committee to oversee assisted reproduction developments in Aotearoa/New Zealand and ninety-nine of which made reference to surrogacy.

In response to the requests for an overseeing body, the Department of Justice established the Interdepartmental Monitoring Committee on Assisted Reproductive Technologies (IMCART) to collect information, monitor developments, and advise ministers on ART. This committee was comprised of representatives from the Departments of Justice, Health, Women’s Affairs, Social Welfare, Manatu Māori, and Pacific Islands Affairs and it maintained the reactive stance initiated by the Government in dealing with ART issues. In 1987, the only piece of legislation that specifically deals with ART was passed by parliament. The Status of Children Amendment Act 1987 (SCAA) was enacted in order to clarify the status of the children, donors, and legal parents where donated gametes are used. It legitimises the relationship between the child and the parenting couple by recognising the birth mother and her husband (legal or *de facto*) as the legal parents. Providing a woman who undertakes an ART procedure using donated gametes has the consent of her husband, he will be recognised as the legal father of any resulting

children. The SCAA ensures that the donors of gametes have no rights or responsibilities with respect to the resulting child (Tollemache, 1999a:18).⁴⁴

In 1990, several providers of ART in Aotearoa/New Zealand invited the Reproductive Technology Accreditation Committee of Australia (RTAC) to oversee developments and practices of ART within their clinics. This move was motivated by the providers' concern over the lack of a system of accountability and, consequently, RTAC became the accrediting body for Aotearoa/New Zealand clinics (Daniels, 1998a:79-80; Coney & Else, 1999:3-5). Although many commentators have acknowledged the logic of using RTAC as an accrediting body (Helen Williams, Interview, 29 August 2000; John Peek, Interview: 12 July 2000; Rodney Bycroft, Interview: 13 September 2000), others have raised concerns regarding the use of Australian standards to accredit Aotearoa/New Zealand clinics (Sandra Coney, Interview: 13 July 2000; Ken Daniels, Interview: 31 August 2000; Dyall, 1999:37). Although many accept that the local ART industry is too small to warrant the establishment of an independent Aotearoa/New Zealand based accrediting committee, there is some unease concerning the absence of Aotearoa/New Zealand specific guidelines within RTAC's 'Code of Practice',⁴⁵ particularly in relation to cultural safety issues for Māori consumers,⁴⁶ accountability issues, and access to information.

The Medical Council of New Zealand commissioned the University of Otago Bioethics Centre to review the whole area of ART in 1991. The resulting report, *Biotechnology Revisited*, raised concerns about the lack of statutory regulation of infertility services (The Bioethics Research Centre, 1991:3) and concluded "that the field of human reproduction is too sensitive an area to be left to individual initiative or voluntary self-regulation" (The Bioethics Research Centre, 1991:5). It recommended the "establishment of a licensing authority for continued oversight of the practice of reproductive technology and related research in New Zealand", as well as "an expert advisory panel be set up to assist in the drafting of legislation which would take into account the rights of all parties, but in particular the safeguarding of the welfare of all children born by means of assisted reproduction" (The Bioethics Research Centre, 1991:5).

⁴⁴ See Chapter One, Introduction: Framing the Issues, Section 1.4, Families & ART, for an analysis of the SCAA and its impact on family formations produced through the use of ART.

⁴⁵ Section 3.6: Professional Self-Regulation in this chapter addresses the use of RTAC to regulate ART practices in New Zealand.

⁴⁶ See Chapter Six, Addressing Difference: Māori Infertility & ART, for a discussion of these issues, as well as issues relating to access to treatment, whāngai, and protecting whakapapa.

Responding to growing tensions between the legal and medical professions surrounding the regulation and control of ART and surrogacy in Aotearoa/New Zealand, the Minister of Justice established the Ministerial Committee on Assisted Reproductive Technologies (MCART) in 1993. The two-person committee was commissioned to review policy and legislation from overseas that might be adopted in Aotearoa/New Zealand and they published their report, *Assisted Human Reproduction: Navigating Our Future*, in 1994. A majority of the submissions received by MCART supported a licensing process for providers within an Aotearoa/New Zealand-specific framework (Coney & Else, 1999:6). MCART (1994) recommended that a policy focused 'Council on Assisted Human Reproduction' be set up to advise and monitor the field of ART. After regional ethics committees expressed concern over inconsistent decision-making with regard to ART practices, the Minister of Health established the Interim National Ethics Committee on Assisted Reproductive Technologies (INECART) to manage this area on a national basis (Daniels, 1998a:80). In 1995, the Minister of Health reconstituted INECART as the National Ethics Committee on Assisted Human Reproduction (NECAHR) to monitor new and innovative practices (Coney & Else, 1999:7). That same year, the Department of Justice assigned an officials' committee to investigate MCART's proposals and provide advice to the Government. Although the committee supported some of MCART's recommendations, it did not support the establishment of a 'Council on Assisted Human Reproduction' to oversee ART practices and policy. Instead, the officials' committee recommended that the NECAHR undertake some of the suggested tasks of the proposed council, effectively "taking NECAHR beyond the domain of ethics and into the policy arena" (Daniels & Hargreaves, 1997:4).

Dianne Yates introduced the 'Human Assisted Reproductive Technology Bill' as a Private Member's Bill in 1996 (Yates Bill; see Appendix I). After its second Parliamentary reading in April 1997, the bill was sent to the Justice and Law Reform Select Committee for consideration (Hansard, 1997). However, it was moved to the Health Select Committee sometime later. In November 1998 the National-led Coalition Government introduced the 'Assisted Human Reproduction Bill' (Graham Bill; see Appendix J),⁴⁷ which seeks to prohibit certain unethical techniques, provide rights of access to information for gamete donors and children born through donated gametes, and affirm and expand the role of NECAHR. As a consequence of the Graham Bill, it would appear that the National-led Coalition Government made a policy decision (or non-decision) to refrain from 'officially' regulating surrogacy arrangements. The

⁴⁷ This bill was introduced by Sir Douglas Graham, who was the Minister of Justice for the National/New Zealand First Coalition Government in 1998.

Graham Bill mentions surrogacy as part of the interpretation but does not address any of the contentious issues surrounding payment and the rights of those involved in surrogacy arrangements (Else, 1999a:52). In 2000, the New Zealand Law Commission addressed the issue of surrogacy in its report on adoption law reform, *Adoption and Its Alternatives: A Different Approach and a New Framework* (2000:60, 186-207). The Law Commission makes some suggestions about placing surrogacy within its own regulatory framework, but contends that there has not been enough public consultation for their proposals to be considered as firm recommendations (2000:60). The inclusion of surrogacy within the Law Commission's terms of reference for adoption law reform has taken the consideration of issues over the legal status of those involved in such arrangements out of the medical context and placed them in a legal context. However, the issue of restricting access to ART practices that enable some surrogacy arrangements to take place is still within the jurisdiction of NECAHR and the fertility clinics.

Although the Status of Children Amendment Act 1987 (SCAA) remains the only legislation that specifically deals with ART, it is not the only legislation or common law that could be used to resolve any legal issues arising from ART practices. Some of the existing regulations and statutes that could have particular relevance to ART include the Adoption Act 1995, the Adult Adoption Information Act 1985, the Contraception, Sterilisation and Abortion Act 1977, the Human Rights Act 1993, the New Zealand Bill of Rights Act 1990, the Human Tissue Act 1964, and the Privacy Act 1993. Similarly, the current legal framework governing medical practice has an effect on the provision of ART services and the protection of patients' rights, including the following acts and their amendments: the Health and Disability Commissioner Act 1994, the Code of Health and Disability Services Consumers' Rights, the Health Information Privacy Code, the Health Act 1956, the Health (Retention of Health Information) Regulations 1996, the Health and Disabilities Services Act 1993, the Medical Practitioners Act 1995, the Medicines Act 1981, and the Nurses Act 1997-1994 (MCART, 1994:11; Tollemache, 1999a). For example, the Adult Adoption Information Act 1985, the Health Information Privacy Code, the Health Act 1956, and the Health (Retention of Health Information) Regulations 1996 give individuals access to records and information if they exist. However, these Acts do not necessarily require such information to be recorded and access to information in relation to ART procedures is dependent on what records providers are currently obliged to keep according to their RTAC accreditation requirements (Tollemache, 1999a:20). The Human Rights Act 1993 makes it unlawful to discriminate based on characteristics such as sex, disability, marital status, family status, sexual orientation, ethnic or national origins when providing goods, facilities, or services. The Human Rights Commission (HRC) has previously received complaints in relation to the

provision of ART services on the grounds of disability, marital status, and sexual orientation (Hamed, 1997).⁴⁸

Blank argues that existing statutes are often poorly suited to ART practices and frequently require new interpretations in their application to such practices. He maintains that the “divergent and potentially conflicting combination of private and public actions results in ambiguous policy” (1998:147). Over the past twenty years, there have been a profuse and diverse number of government agencies and individual actors involved in ART policy discourse and decision-making in Aotearoa/New Zealand. Combined with the lack of a dominant policy relating to ART or an agency specifically responsible for ART issues, this means that more discretionary power is likely to be given to those involved in implementing the guidelines and controls that do exist (Sabatier, 1986:30-31; Blank, 1994:7).

While policy formulation and implementation is often theorised as progressing through a distinct set of phases,⁴⁹ most analysts acknowledge that the process is not as linear or straightforward as set out by the models. However, they see such normative models as a useful tool in the analysis of the policy process as a whole (Blank, 1994:6; Colebatch, 1998:105). Top-down policy models focus on a central authority which initiates, selects, and then implements policy directives through “the development of rules, regulations and guidelines essential to the carrying out of the decision” (Blank, 1994:7). Such policy models are often criticised for focusing on central decision-makers as the key actors in policy formulation and failing to acknowledge the important initiatives of “street level” groups, workplace managers and workers, as anything other than complicating factors in the policy process (Sabatier, 1986:30; Colebatch, 1998:58). Others argue that the process also works from the ‘bottom-up’ in that the

⁴⁸ A lesbian woman made a complaint under the previous Human Rights Commission Act 1977, when she was denied access to services on the basis of marital status and the HRC supported the woman’s complaint. Since the new Human Rights Act 1993, the HRC has received many enquiries. The most notable complaint has been on the basis of disability. The HRC successfully resolved the situation through a consultative approach, in which the Commission facilitated a meeting between the couple and various specialists in the field, such as fertility practitioners, an ethics committee member, an RHA disability manager, representatives from the Children’s Commissioner, and home help providers (Hamed, 1997). See also Chisholm, D. & L. Umbers, 1994. ‘Scientist quits over Lesbian Ruling’, *The Press*, 29 July 1994, p.2.

⁴⁹ Brewer and deLeon (in Blank, 1994:6-7) outline this process as involving six stages; initiation, estimation, selection, implementation, evaluation, and termination. Similarly, Howlett and Ramesh (in Colebatch, 1998:105) developed “a model of policy as a cycle of applied problem solving” which includes agenda setting, policy formulation, decision-making, policy implementation, and policy evaluation.

...range of grounded practices that arise from day-to-day work in the health care sector constitute policy in themselves: they both contribute to the policy agenda and also mould its operation.
(Green & Thorogood, 1998:11)

While acts of parliament, ministerial edicts, and government initiated guidelines and strategy documents play a major part in policy formulation and implementation, they are not the only contributors to policy. Bottom-up analysts argue that policy develops through a constant interaction between 'top' and 'bottom', as well as insiders and "relevant others" (Colebatch, 1998:61). Accordingly, managers, healthcare professionals, patients, interest groups, and the wider community create and establish health policy through interpretation and implementation of guidelines and strategies. ART providers and consumers of ART practices were crucial in formulating and putting into practice policy initiatives relating to donors being identifiable and the technical oversight of ART practices.⁵⁰ The formulation, interpretation, and implementation of policy from this bottom-up perspective is always more unstable, intuitive, informal, and "messy" than the more normative model would allow, involving a variety of participants with their own distinct understanding and expectations surrounding the issues (Colebatch, 1998:59). Colebatch (1998:60) argues that both perspectives play an important part in the policy process and that the policy process involves a combination of both top-down and bottom-up elements, including both horizontal and vertical dimensions,⁵¹ empirical and normative frameworks, and language that is used as part of the action. Correspondingly, the publicly funded provision of ART services through negotiated purchase agreements and the subsequent allocation and management of public funds by service providers introduces another influential arena for the creation, interpretation, and implementation of policy by government bodies and providers. While the implications of public funding decisions relating to ART will be considered in the next chapter, the following section will consider the 'top-down' initiatives in policy formulation concerning ART and ART practices that have been under consideration in Aotearoa/New Zealand for more than five years.

⁵⁰ As mentioned earlier, concern over the lack of a system of accountability motivated several Aotearoa/New Zealand fertility clinics to invite the Reproductive Technology Accreditation Committee of Australia (RTAC) to oversee developments and practices of ART within Aotearoa/New Zealand clinics by becoming the accrediting body for their clinics (Daniels, 1998a:79-80; Coney & Else, 1999:3-5). Similarly, ART providers and consumer representative bodies have been active in promoting openness between parents and children in relation to donated gametes, as well as collecting and storing donor information.

⁵¹ The vertical dimension is concerned with authority and hierarchy, where policy is seen as being about choice and the pursuit of objectives. The horizontal dimension is concerned with the way the policy process moves outside any particular organisation and includes people who "share an interest in the policy question, but have a distinct perspective on it and whose cooperation cannot be taken for granted" (Colebatch, 1998:61-62). Within the horizontal dimension, the policy 'problem' does not appear automatically but is recognised as the disparate participants introduce their different perspectives.

3.3 Proposed Legislation

As mentioned earlier, social policy surrounding ART and surrogacy in Aotearoa/New Zealand has been created in an *ad hoc* manner, combining and adapting to the interactions between existing legislation, professional self-regulation, health service controls, and consumer demand. The policy development has also been significantly influenced by the reports of various commissions and committees that have been established to address the issues of regulation and control of ART over the last 20 years. The *New Birth Technologies: An Issues Paper on AID, IVF, and Surrogate Motherhood* (Department of Justice, 1985) was intended to promote public debate on the issues surrounding ART and surrogacy. However, it also contributed to the 'wait and see' approach adopted by successive governments (Department of Justice, 1985:7). The Ministerial Committee on Assisted Reproductive Technologies (MCART) report, *Assisted Human Reproduction: Navigating Our Future* (1994), has probably been more influential with respect to public debate and policy matters relating to ART. Consequently, most of the people interviewed for this study mentioned this report as having some influence on organisational policy positions.

The MCART (1994) report has also influenced the instigation of legislative action in the form of the Yates and Graham Bills (see Appendices I & J). While both bills propose bans on certain unethical practices, such as the cloning of humans and the sale of human gametes and embryos, they differ on how ART practices should be regulated and controlled. The Yates Bill follows the recommendations of MCART more closely, setting out to license clinics, establish a central register for children born through ART, and ban commercial surrogacy. This bill also places restrictions on the use of sex selection techniques and mandatory genetic screening. It aims to establish a licensing authority (the Human Assisted Reproductive Technology Authority) to "regulate and ensure proper monitoring of services" (Yates, 1997: see Appendix I). The Graham Bill bans the implantation of animal embryos in humans or the implantation of human embryos in animals. It also bans the use of human cells to develop procedures or techniques for undertaking any of these activities. While the National Ethics Committee on Assisted Human Reproduction (NECAHR) is given statutory recognition and has its role expanded, it appears that it will remain under the control and oversight of the Ministry of Health and its Minister. NECAHR's extended responsibilities remain ambiguous as the Graham Bill states that the committee's functions are dependent on the Minister of Health's discretion. This bill also establishes a legislative requirement for a centralised system that retains and stores information about donors of gametes and embryos, as well as the children born through such donations

(Graham, 1998: see Appendix J). However, the Graham Bill only mentions surrogacy as part of the interpretation and does not address any of the contentious issues surrounding payment and the rights of the parents (Else, 1999a:52). The Graham Bill does not include any mention of the Treaty of Waitangi (te Tiriti o Waitangi) or its provisions for the protection of Māori as Tangata Whenua (Coney, 1999a:26-27; Dyall, 1999:35). Nor does it advocate a separate policy body to oversee and monitor ART practices and to consolidate the fragmented formulation of policy that has occurred in this area. The proposed legislation does not deal directly with access issues and it is unclear whether the functions of the proposed Council in the Yates Bill or the increased jurisdiction of NECAHR proposed by the Graham Bill will address such issues. Therefore, these issues may continue to be shaped by the rationing of publicly funded treatment, the Human Rights Act, and the policies and practices of individual clinics.⁵²

Both bills emphasise the rights of people conceived through ART practices to information about their genetic heritage.⁵³ The Human Assisted Reproductive Technology Bill (Yates Bill) specifically states that the aim of the bill is to

...protect the rights of children, and the rights of women (birth mothers) as well as donors (men and women).
(Yates, 1997: see Appendix I)

Although both bills place legal requirements on the collection and storage of information and provide for a centralised system for recording and storing this information, neither fully addresses what genetic information should be recorded or specifies how it will be collected and stored. All the provider representatives interviewed supported the introduction of legislation

⁵² See Chapter 4, Allocating Resources, and Chapter 5, Regulating Access, for discussions of funding and access issues in relation to ART practices.

⁵³ At present, there is no statutory requirement for the collection and storage of information about gamete and embryo donors, surrogates, and any people born from the use of donated genetic material. Nor is there any provision for these people to access identifying or genetic information about donors or surrogates (Henaghan, 1992:184). Until the early 1990s, it was the policy within clinics to guarantee anonymity to gamete donors. However, New Zealand's position on access to identifying information has been influenced by the Adult Adoption Act 1985, which recognised the need for information by adopted people, and accredited clinics no longer provide the option of anonymity to donors. Although this is not a legal requirement, Aotearoa/New Zealand fertility clinics encourage donors to agree to contact should the person conceived using their gametes wish it (Adair & Rogan, 1998:268-270). RTAC's 'Code of Practice for Centres using Assisted Reproductive Technologies' (1999) ensures that some records are kept by accredited clinics. Accredited clinics are required to keep permanent records of "ART procedures, identifying patients, gamete or embryo donors and recipients, and outcomes of attempted fertilisation and conceptions" and clinics are advised that they "should allow all donors and patients access to their records" (RTAC, 1999). The 'Guidelines for Screening for Gamete Donation' (RTAC, 1999: Attachment J) sets out what information about the donor's social history is "considered to be appropriate" and "which may be of assistance to parents of children at a later date". However, the guidelines do not specify who may have access to what information, and it appears that these issues are decided by the clinics in question. Furthermore, access to any retained information is limited by whether or not the parents tell their children of the circumstances of their conception.

that would formalise the collection and storage of information about gamete and embryo donors, surrogates, and any people conceived using donor gametes. John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) maintains that such a move would only be reinforcing what was already happening within clinics.

...I think in a way any bill that is enacted will just be codifying what is general practice for most people.

(John Peek, Interview: 12 July 2000)

Peek is supportive of the benefits the proposed legislation will have in relation to removing some of the barriers to openness.

...there are some people who still want to maintain secrecy so the bill could make maintaining that secrecy difficult because there would be a register and everybody could look up and see whether they were conceived from donor insemination and be able to contact their donor. And, I think that would be good really.

(John Peek, Interview: 12 July 2000)

Nonetheless, access to this information is limited by whether or not the parents tell their children of the circumstances of their conception. Robyn Scott (Executive Officer, New Zealand Infertility Society [NZIS]) acknowledges the diversity in people's willingness to be open about the circumstances surrounding their child's conception and/or birth.

...we support openness of information. All the NZIS policy statements support openness of information. ... We certainly believe that children are entitled to correct genetic information. That is a stated policy of the NZIS. However, you would find amongst our membership a huge variation in [individuals'] preparedness to implement that policy.

(Robyn Scott, Interview: 26 July 2000)

Similarly, John Peek concedes that there is no guarantee that donors will continue to be available or identifiable even if they initially intend to be.

In New Zealand, we are different from overseas because basically the clinics and the consumers have voluntarily moved towards having identifiable donors. It does not guarantee that a donor is going to be identifiable but they go in with that intention.

(John Peek, Interview: 12 July 2000)

Although generally supportive of legislation that would formalise the information storage and collection process, providers are less inclined to support the establishment of a central donor register that would be controlled and monitored by a body other than the clinics. Mark Leggett (Business Manager, The Fertility Centre, Christchurch) is wary of trusting sensitive information to a central register maintained by a government department.

It is a relationship thing. If we go through a central register, that is not a problem, but ... you have got to have the same trust that you have with the clinic ... and some of the government departments have not generated a whole lot of trust in recent years, in relation to privacy act issues. And, it is a very strong privacy issue.

(Mark Leggett, Interview: 22 September 1999)

Similarly, Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) emphasises privacy issues and the unreliability of public officials in handling sensitive information.

[I support a central donor register] on the condition that it is handled properly. That is going to be the hard one because as soon as you get a social agency involved you end up with the possibility of horrendous mistakes. [Whereas] clinics are under enormous constraint, such as professional pressure, confidentiality issues, and privacy issues to do with preserving the rights of the parents and the child. The bar is not as high for social agencies. ... I do not believe that many mistakes occur at the moment where the clinics have responsibility for that information. ... If that data then goes to Birth, Deaths, and Marriages and you end up with a junior clerk making a [mistake] and sending someone the wrong information ... so I support it but it has to be a system that has very little chance of disaster.
(Rodney Bycroft, Interview: 13 September 2000)

Both Leggett and Bycroft suggest that systems managed by the medical professional are more reliable than government bureaucracies. However, this position fails to take into account the possibility that information may not be retained because of individual clinic discretion or it may be lost when clinics close or merge. Lack of consistency over information retention and individual clinic discretion over what information to disclose and who has access to it may impinge on the rights of donors and those conceived from donated gametes. John Peek points out that it is not just the issue of a central register that is important. The issue of guidelines and rules about the use of and access to the information gathered should also be included in the debate.

[You need] instructions on what to do and not how to do it. To say there is going to be a register in this sort of information is one thing but not to say how you access it and how you look after people in the process is, I think, a very big deficiency. ... But, the whole thing ... at the moment is not about keeping the information but how do you facilitate and look after people using the information. I do not think the Bills address that at all.

(John Peek, Interview: 12 July 2000)

Concerns for the security of information appear to be premised on the idea that increases in the amount of information kept will jeopardise the right to privacy by those individuals undertaking ART treatments.

Given that every extra record of donor or treatment information increases the risk of a breach of security or privacy, couples in treatment programmes have the right to maximum privacy and to control who knows what, and when.

(New Zealand Centre for Reproductive Medicine (The Fertility Centre, 1997:14)

However, protecting the 'couples' right to privacy may restrict and marginalise the rights of donors, as well as the rights of people conceived using donor gametes or surrogacy arrangements to information about their genetic background. The same provider had earlier argued for the primacy of the interests of the children in relation to who has access to ART. The apparent shift in focus highlights how a rights focused debate continually places the interests of those involved in conflict with each other. Considering the rights of all those

involved in ART practices, the donors, recipients, surrogates, intending parents, and those individuals conceived through donated gametes, is particularly important and complex when addressing who should have control and access to information regarding genetic origins.

The Health Select Committee is considering both bills and it is unlikely that any report on either of them will be released before this thesis is submitted. Ministry of Health representatives, Helen Lockyer (Senior Policy Analyst) and Matthew Soeberg (Policy Analyst), suggest that the Yates Bill has been interpreted as too “prescriptive” and support is leaning towards the more “flexible” approach to regulating ART practices and future developments as outlined by the Graham Bill.

We cannot pre-empt what [the] Health Committee will ultimately decide, and what the views of the Ministers of Justice and Health will be, but the bit of analysis that we have done to date, and Justice has done to date, tends to be steering us more towards Sir Doug Graham's bill. Taking into account some of Dianne Yates' ideas as well because some of them are very similar ... and tweaking that. So we are almost merging them together, the merge will in a sense be based primarily on Sir Doug Graham's bill, we think. We cannot pre-empt...

(Helen Lockyer, Interview: 24 July 2000)

Also the submissions that we have had a quick look at have indicated that the Graham Bill is the preferred one rather than the Dianne Yates' one.

(Matthew Soeberg, Interview: 24 July 2000)

This perceived preference might be influenced by the significant power of the biomedical community and the fact that any successful policy must have at least implicit backing by those being regulated (Blank, 1995:178). The continuing and rapid advances in ART innovations and applications, as well as their rapid inclusion into acceptable practice mean that any decision in ART policy is in danger of being outdated and obsolete within a very short timeframe. Therefore, the ART policy-making process is never finished and, according to Blank (1998:135), fixing policy through government legislation may limit the use of technology and inhibit the flexibility needed to adapt to new applications. This view is supported by Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) who advocates a more flexible system of control through which biomedical progress can be accommodated more readily.

Looking at models overseas, I think that an official government appointed body that had the job of reviewing, from time to time, reproductive practices and technology is a far better way of doing it than having tight legislation. That is more to do with the speed of change and the ability to accommodate that change in a timely way that does not actually end up prejudicing and disadvantaging New Zealand citizens. The problem with legislation is that it quite often does not foresee the future and by not foreseeing the future, it then becomes a mammoth exercise to amend it and change it through the parliamentary process.

(Rodney Bycroft, Interview: 13 September 2000)

Similarly, NECAHR's submission to the Health Select Committee on the Assisted Human Reproduction Bill requested that any new legislation allowed for flexibility.

NECAHR is of the view that there is a gap in the law with regard to assisted human reproduction. ... However, NECAHR urges legislation that allows for flexibility in a rapidly developing technological field.
(NECAHR, 2000a:3)

Nevertheless, too little state intervention can expose vulnerable groups and individuals to exploitation and discrimination, especially given the decreasing amount of time between the initial research into a technique and dissemination into widespread use (Blank, 1995:10).⁵⁴

Ministry of Health representatives (Matthew Soeberg and Helen Lockyer, Interview: 24 July 2000) explained the lack of progress on either bill as a consequence of parliamentary progress, procedural issues, and the complexity of reviewing over 150 submissions. However, others interviewed believe the delay is due to the lack of governmental prioritisation and importance placed on ART issues and a belief that the present system of medical control is adequate, as well as the inherent difficulties in resolving moral and ethically contentious issues (Sue Bagshaw, Interview: 21 August 2000; Sandra Coney, Interview: 13 July 2000; Ken Daniels, Interview: 31 August 2000). Blank (1995:50) suggests that elected officials find ART issues politically risky and are therefore hesitant to formulate national policy or specific legislation. He argues that, as public officials are not re-elected based on their efforts to resolve future problems, they refrain from making "hard choices" in politically volatile areas until a crisis is obvious. This argument is supported by Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury)

...the area of assisted human reproduction is like a graveyard for politicians. It is fraught with problems. It is one of those moral issues like abortion and contraception and so on. You have got strongly divided opinions, Parliaments, as a whole, never handle moral issues very well, and this is seen as a moral issue. So, I think there has been some general reluctance to get involved in it.

(Ken Daniels, Interview: 31 August 2000)

Sue Bagshaw (Medical Training Co-ordinator, Family Planning Association, Christchurch) suggests that, while assisted human reproduction is a politically difficult issue to resolve, it is the responsibility of elected officials to make the "hard choices".

...that is why we have parliament and we elect people to make judgements for the good of society.

(Sue Bagshaw, Interview: 21 August 2000)

Although it may appear that successive governments have been reluctant to intervene in what has traditionally been accepted as a matter of individual privacy, there are many statutes within the Aotearoa/New Zealand legal system that do intervene in issues relating to human

⁵⁴ This issue is discussed in more detail later in this chapter; see Section 3.5, NECAHR.

reproduction and parenting, illustrating that past governments have addressed the difficulties associated with legislating moral issues in the past.⁵⁵ While the lack of specific legislation in relation to ART does not mean that these services and practices are completely unregulated, it does contribute to the fragmentation of ART policy and regulation. It also adds to the vulnerability of those involved in ART practices using donated gametes, especially in relation to access to information, and may allow exploitive and socially unacceptable uses of ART to become embedded into practice before the negative consequences can be assessed (Blank, 1994:10-13). Furthermore, by avoiding legislation and delegating decision-making for specific ART related issues (both ethical and policy related) to NECAHR, the Government can effectively evade direct accountability and controversy.

Although the two ART bills being considered by the Health Select Committee address a range of important issues and coincide in banning certain unethical practices, they diverge with respect to the levels of state regulation they prescribe. According to Blank (1995:16), those who support biomedical technologies tend to concentrate exclusively on “clinically indicated applications” (infertility, genetic screening for inheritable diseases, screening for sex-specific inherited diseases) and down-play the possibility of coercive uses, while those who oppose them often give more attention to the potential coercive or abusive aspects of specific techniques (compulsory genetic screening, embryo harvesting, foetal experimentation, eugenics programmes, and sex-selection techniques). This polarisation of attention is reflected in the two bills under discussion. The Graham Bill tends to focus on those issues that already have wide support from health professionals, such as banning cloning, data collection and storage, and access to information by those involved in ART practices using donated gametes, as well as a non-regulatory form of policy review. On the other hand, the Yates Bill takes a more interventionist approach to a wider range of potentially coercive and abusive applications of the technologies and, unlike the Graham Bill, it addresses some aspects of surrogacy. Blank (1995:16) suggests that the ambiguity often encountered in the debate surrounding biomedical technologies is caused by a failure to distinguish between the techniques and the uses to which they are put. Therefore, while the current debate is polarised around these two interpretations of the issues, many social and ethical issues remain unresolved.

⁵⁵ For example: the Contraception, Sterilisation, and Abortion Act 1977 and its subsequent amendments; the Adoption Act 1955 and its subsequent amendments; the Adoption (Intercountry) Act 1997; Guardianship Act and its subsequent amendments; the Births, Deaths, and Marriages Registration Act 1995 and its subsequent amendments.

3.4 Policy Gaps

While there is no specific legislation to control and regulate ART developments and practices, this does not mean that they exist within a policy vacuum or that they are unregulated. As discussed earlier, a combination of Acts, regulations, and professional guidelines controls and regulates the medical profession, as well as specialist ART providers. However, even if the previously discussed Graham or Yates Bills are passed as they currently exist, there will remain several areas of concern where no or very little official policy exists. Surrogacy, sex-selection, embryo donation, embryo experimentation, property rights for genetic material, and stem cell cloning have either been ignored or only partially addressed in either bill. Although it is not within the scope of this thesis to discuss all these issues, it is important to acknowledge that issues surrounding these procedures are likely to intensify in the near future and there is little or no policy to address the introduction and acceptability of these practices in Aotearoa/New Zealand.

All the provider representatives interviewed (Mark Leggett, Interview: 22 June 2000; John Peek, Interview: 12 July 2000; Rodney Bycroft, Interview: 13 September 2000) affirmed that they were considering embryo donation as a strategy for patients who had 'surplus' embryos in storage after completing or ceasing their own treatment. They all saw embryo donation as a natural progression, although they did acknowledge that it required certain 'constraints' and that NECAHR approval would have to be sought before proceeding. All three provider representatives equated embryo donation to the adoption process in some way. Mark Leggett (Business Manager, The Fertility Centre, Christchurch) in particular saw the difference as being a matter of timing. However, he was specific about differentiating between an embryo created from donated gametes and an embryo created for use by a "couple" from their own gametes.

Embryo donation is very similar to adoption, just nine months earlier. You are not donating one gamete ... therefore, one of the parents is at least a biological parent. These are two non-biological parents to a baby that has come from [these people] over here. [A] donor embryo is completely from another couple's gametes. If they had [embryos] replaced and got pregnant ... and then passed the baby on that would be an adoption process. ... I think there should be some connection to recognise what is going on because you are handing over a baby or a potential baby as opposed to just a gamete.

(Mark Leggett, Interview: 22 June 2000)

This quote highlights the difficulties involved for clinics in conceptualising the relationships that are enacted through the use of ART. It appears to be important for this provider to differentiate between embryos created for people who intend to co-parent the resulting child and embryos created from the gametes of donors who do not intend to parent the resulting

child. Similarly, John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) is specific about not creating embryos for donation.

Basically, these are from people who have stored embryos. We would not be creating embryos for donation. They are people who had twins and then another child or whatever and decided they do not want to have any more and who prefer to donate than to discard [the remaining embryos]. ...and we would say that it had to go like adoption. It had to be open and people probably had to meet beforehand.

(John Peek, Interview: 12 July 2000)

However, in cases where donated gametes are used, the resulting embryo is at least partially donated and in a small number of cases may even be completely created from donated gametes. It would appear that the donating 'couple' are conceptualised as the potential parents, whether or not they both have contributed the gametes for the creation of the embryo. The gamete donors are seen only as altruistic gift givers with no future responsibilities or rights. Therefore, it would seem that the relationship of the 'couple' is what differentiates embryo donors from gamete donors. Interestingly, it appears that in relation to embryo donation a woman who receives the embryo and consequently experiences pregnancy and labour, can only be conceptualised by the providers as the 'mother' through the adoption process.⁵⁶ This is in contrast to gamete donation as outlined by the Status of Children Amendment Act 1987 (SCAA),⁵⁷ where the gestating woman and her husband are considered the legal parents regardless of the origin of the gametes.

Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) also sees embryo donation as a logical development. However, his justification is slightly different to that of the providers, as he sees embryo donation as an acceptable and incremental extension of donating gametes, rather than conceptualising it as the donation of a potential child.

I am not surprised that it is going to come and I think it is a logical development. I cannot see how you could say we allow sperm and we allow egg, but we do not allow the combined. A number of people have talked about this as pre-implantation adoption. I think there are some different issues involved that will need to be looked at very carefully. But, I personally, from an ethical point of view, cannot see any ethical objections to it, having gone as far as we have.... I mean if in fact you say no assisted reproduction at all, no donation of gametes, then that is fine but as soon as you start opening it up, you have to say, "Well if we approved that, what is different about this that makes us take a different stand than what we did before?" In other words, we debated the ethical arguments at

⁵⁶ Although marginalised in the discourse surrounding parental, embryonic, and foetal rights, pregnancy and birth is an embodied experience for women and is dependant on a biological relationship between both entities, irrespective of who donates the gametes.

⁵⁷ The Status of Children Amendment Act 1987 is discussed in Chapter One, Introduction: Framing the Issues, Section 1.4, Families & ART.

that time and we approved this, what additional ethical issues emerge from this development. That is the only way the Ethics Committee can really look at it.

(Ken Daniels, Interview: 31 August 2000)

Other commentators (INECART, 1995:21; Brazier, et al., 1998:36) argue that it is questionable whether it is in the interests of children to be born from donor ART or surrogacy arrangements. Sandra Coney (Executive Director, Women's Health Action Trust) also argues against embryo donation because of its potentially negative effect on children.

...I do not agree that some services should be provided at all. I am particularly concerned about the ones involving donation. ... Embryo donation is like egg or sperm donation only a lot worse. I mean it is that couple's completely genetic child. ...the idea that a child would have no genetic connection to the mother that carries them and to the people bringing them up but have genetic connections to somebody else. A whole family that they might really belong to and not be with them ... this is deliberately creating a disjointed, fractured family where the genetic connections are completely severed.

(Sandra Coney, Interview: 13 July 2000)

When arguing against the use of donated gametes and embryos, Coney fails to acknowledge that such circumstances are not particular to donor or surrogacy assisted reproduction and that adoption, death, divorce, abuse, and abandonment can create similar situations (Robertson, 1994:121). Adair (1998:270-271) refers to studies that have investigated the psychological development of children conceived using ART and donor gametes and found no evidence of psychological or emotional disorder.⁵⁸ Similarly, drawing on the experiences of individuals who have been adopted, Baran and Pannor (in Blyth, 1995a:193) propose that more harm is likely to result from past practices of secrecy and anonymity. Societal responses and the stigmatisation of donor and surrogacy arrangements may pose the greatest threat of harm to the child (Blyth, 1987:24). Nevertheless, the impact of such arrangements on children is an important concern and any risk of harm should be minimised. These practices, however, should occur only under conditions that attempt to protect the welfare of *all* those involved, especially those conceived from donated gametes, the donors, recipients, and surrogates. Concerns about the use of donated gametes and embryos also raise issues surrounding the ownership of biological material and the rights of embryos.⁵⁹ The New Zealand Law Commission (2000:188, n.534)

⁵⁸ These studies include: Brewaeys, A., 1996. 'Donor Insemination, the impact on the family and child development', *Journal of Psychosomatic Obstetrics and Gynaecology*, Vol.17, pp.1-13; Golombok, S., A. Brewaeys, R. Cook, M.T. Giavazzi, D. Guerra, A. Mantovani, E. Hall, P.G. Crosignani, & S. Dexu, 1996. 'The European study of assisted reproduction families: Family functioning and child development', *Human Reproduction*, Vol.11, No.10, pp.2324-2331; Golombok, S., R. Cook, A. Bish, & C. Murray, 1995. 'Families created by the new reproductive technologies: Qualities of parenting and social and emotional development of the children', *Child Development*, Vol.66, pp.285-298.

⁵⁹ The framework and language of rights is used within competing discourses to promote and protect the interests of embryos/foetuses, as well as to promote and protect women's rights to reproductive choice. While the conflict between two rights-bearing entities has often been the focus of legal, religious, and ethical discourses in relation to abortion and birth, reproductive technologies have increasingly removed the woman carrying the baby from consideration. The increasing use of foetal imaging

claims that both the Yates and Graham Bills do not sufficiently address the issue of the “rights of the child and of the unborn or yet to be conceived child”, suggesting that these issues will be a continuing source of concern. By focusing solely on the rights and interests of children in the policy debate, the rights and interests of the donors, recipients, surrogates, and intending parents are in danger of being undermined and/or marginalised, especially if these people do not conform to the normative definition of family.⁶⁰ Similarly, such a narrow focus fails to acknowledge that children conceived through ART practices will eventually be adults and, as such, their rights and interests are in danger of being overlooked. Although it is not within the scope of this thesis to discuss all these complex issues in detail, it is important to note that these topics need to be considered within the ART policy framework.

Blank (1995:51) claims that there is increasing evidence in the United States of America (USA) that people are willing to use technologies that offer control over the characteristics of their children. Although he acknowledges that gender preferences are “less clear” in the USA, Blank (1995:45-46) maintains that the availability of sex-selection procedures and the tendency for one or two-child families will combine to create a widespread demand for such procedures. A recent newspaper report indicates that sex-selection techniques are also increasing in demand in the United Kingdom (UK). Despite restrictive legislation in the UK, the report claims that the “procedure is reportedly available at a number of licensed clinics which operate as a result of a loophole in the law” (*The Press*, 5 November 2001, p. 12). Although John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) claims that most sex-selection methods do not work, he does acknowledge that there is an increasing demand in Aotearoa/New Zealand for these techniques to be used for social reasons.

technologies, such as ultrasound, sonogram, and endoscopy, contributes to the illusion that the embryo is disconnected and independent of the woman in whose body it exists (Terry, 1989:22; Shildrick, 1997:201-202). Correspondingly, ART has added to the increasing invisibility of the women in the reproductive process by enabling conception to take place outside the body and dividing the female body into its component parts. By concentrating on the separate roles and functions of these component parts in relation to conception and pregnancy, ART potentially contributes to the effacement of pregnancy as an embodied experience by women. It also obscures the embryos’ dependence on women’s bodies and enhances the ability to identify embryos as individuals with rights. The manifestation of foetal rights positions pregnant women’s rights as competing and therefore, hostile to those of the embryo/foetus they are carrying because the pursuit of women’s rights to choose not to parent are at the expense of the life of the foetus. Furthermore, by assuming that the foetus has equal rights within the mother, the rights of the foetus are effectively prioritised (Terry, 1989:22-23). Accordingly, the interests of the embryo are not necessarily placed in conflict with those of the mother; rather they are given precedence over them.

⁶⁰ See Chapter 5, Regulating Access, Section 5.3, Access & Rights, for a discussion of how focusing solely on the rights of children can impact on those seeking access to ART services.

Well, fortunately none of the sex-selection methods actually work. The only thing that is reliable is sorting sperm and then using IVF, and I think that there is only one clinic in the [USA] that I know of that does that and even then you have only got like a 70% or 80% chance of having a child of the right sex. All the other methods do not work. ... A lot of people ask about sex-selection. I must get one or two calls a week but it is usually European people with one or two children who want a child of the other sex and I [wonder] what the expectations for children are.
(John Peek, Interview: 12 July 2000)

Subsequently, it was reported in March 2001 that Fertility Associates had received limited approval from NECAHR to conduct a feasibility study into Fluorescent In-Situ Hybridisation (FISH) (Philp, 2001). This technique enables the detection of abnormal chromosomes in embryos before they are implanted using IVF. While intended to “reduce miscarriages for women trying to get pregnant through IVF by screening out the weakest embryos”, the technique can also detect chromosome anomalies associated with Down’s Syndrome and Turner’s Syndrome⁶¹ and can be used to determine the sex of an embryo (Philp, 2001:19-20). These capabilities raise questions about the eugenic applications of such techniques and who has the authority to make the decisions and choices associated with them. While the use of sex-selection techniques is often justified in terms of therapeutic use, such as a sex-linked genetic predisposition to a disease, it is often unclear what the definition of ‘therapeutic use’ might include.

My own view is that I have no difficulties with sex-selection where there is a medical reason for it. I would take a lot of persuading, in fact, I am not quite sure that I could be persuaded, I just do not think that for social reasons that it is acceptable.
(Ken Daniels, Interview: 31 August 2000)

ART techniques make a diverse range of clinical and eugenic applications possible, depending upon the motivation of the people using them (Blank, 1995:47). Similarly, the manner in which they are applied can be either enabling or constraining of reproductive choice and rights.

As mentioned earlier, the speed at which ART innovations and applications advance has been used by some commentators as a justification for resisting legislative control. Others stand by the ‘slippery-slope’ argument as defined by Mendeloff (1985:83, emphasis in original); “the principles used to justify current decisions tend also to justify *in advance* future decisions that may be much more troubling.” Sandra Coney (Executive Director, Women’s Health Action Trust) is particularly concerned about the effects such procedures will have on the vulnerable in society. She implies that allowing the use of certain procedures will undoubtedly lead to more questionable procedures in the future.

⁶¹ Turner’s Syndrome can cause infertility, as well as heart and lung problems.

The whole history of scientific experimentation is that things barge ahead without enough consideration of the ethical issues and then you find out a lot later that you have got some ghastly dilemma on your hands. I cannot see any advantage in cloning what so ever ... and I even think that things like sex-selection for genetic [linked disorders] have to be thought about really carefully. I know that some of the groups, [such as] Cystic Fibrosis, are very keen on some of these things, [those] who have got it in their families. You can be very sympathetic to that but that has to be balanced against the effect on the whole of society ... because then the flow on effect of that can be that people who have a child who is imperfect get blamed or will not get social support. So, there are big social effects of going down some of these routes. ... I can see there may be some value of research on embryos that have been miscarried or aborted and people consent to that occurring. I do not at all like the concept of creating embryos for the purpose of research. The reason for that is the same reason as, "If you can do that, what else can you do? Can you create human beings so you can get their kidney?" If you treat human life as objects and as commodities then it is very easy for that approach to just spread.
(Sandra Coney, Interview: 13 July 2000)

Mark Leggett (Business Manager, The Fertility Centre, Christchurch) acknowledges that at present there are no regulatory controls in Aotearoa/New Zealand to stop scientists experimenting with procedures such as cloning. However, he is convinced that scientists in Aotearoa/New Zealand would not participate in such research.

The fear of the people in white coats who will do anything they like if we do not control them. That might happen overseas but I doubt it happens in New Zealand or Australia so much. As I say, someone is bound to be, at the moment, working on human cloning. Simple as that. [There are] plenty of private laboratories around. The technology has existed for a little while now so somebody is doing it. ... Well it could happen in New Zealand, you could do anything you like. ... I do not think we have got the actual technology to do it but theoretically, we could do it. ... There is nothing to stop us doing it because the legislation is not in place yet! So, it could be done, but knowing the industry in New Zealand... we certainly have not done anything with humans. New Zealand is so small you would never get away with it.
(Mark Leggett, Interview: 22 September 1999)

Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) is also convinced that research into as yet unsuccessful procedures will continue and will eventually succeed.

I think we can expect the unexpected in this area of medicine. ... I think you would be naive to think that just because it has not worked right at the beginning it is not going to ever work. You only have to look at the automobile and people who said there that the car would never take off. It is a very naive approach. I think you have to deal with the issue that most things that are theoretically possible will probably become practically possible.
(Rodney Bycroft, Interview: 13 September 2000)

However, he also cautions against what he calls "knee-jerk" reactions and "scare mongering". Like Mark Leggett, he believes that there are enough social controls in Aotearoa/New Zealand to prevent scientists and doctors overstepping social boundaries in relation to genetic experimentation and manipulation.

I subscribe to the view that most scientists are responsible and ethical. Most of the ones I have spoken to are. There might be some nutters out there. There is a popular myth that scientists are all mad. I have not seen that. I have seen

scientists and doctors holding meetings in their own time at their own expense, to explore the social and ethical issues that they are dealing with.

(Rodney Bycroft, Interview: 13 September 2000)

Nevertheless, recent media coverage of claims by Italian scientists that they will be the first to clone a human highlight the fact that there are scientists and doctors who are willing to push boundaries in relation to what is considered socially acceptable scientific and medical practice (McCurdy, *The Press*, 12 March 2001, p.1; Robson, *The Press*, 9 August 2001, p.11; McKie, *The Press*, 14 August 2001, p.5). It also raises questions about the future use of technologies developed overseas as a result of these genetic experimentation and manipulations. As the proposed legislation in Aotearoa/New Zealand bans human cloning, does this mean that any advances in reproductive science generated from such research will not be used here? Would it be ethically or morally appropriate for Aotearoa/New Zealand to ban such experimentation and then benefit from its development in other countries?

While there is currently very little research done into infertility and ART techniques in Aotearoa/New Zealand, clinics do develop and refine techniques developed internationally. John Peek maintains that there is

...developmental work when we start using a technique but [they are] nearly always techniques that already exist overseas. It is just us trying to get them to work locally.

(John Peek, Interview: 12 July 2000)

Although supportive of legislative control over certain practices, Rodney Bycroft is wary of a complete ban on cloning or embryonic research without careful consideration of what the procedures include or how they may benefit society.

I think that there definitely needs to be control over certain practices that people find abhorrent. Cloning humans and human hybrids and things like that. I think the bill is correct there to make some of those processes illegal. ... Experimentation on human embryos is one area that really should be handled intelligently because if we are going to learn more on how to help people to perform safer pregnancies through the technology then certain controlled research needs to be done there. But certainly some things like forming human/ animal hybrids, cloning issues, although you have to be very careful how you define cloning because cells have been cloned for years. ... There are clearly things involved in cloning that could be sensible and ethical and morally defensible and yet there are some things that are clearly unethical.

(Rodney Bycroft, Interview: 13 September 2000)

Similarly, Mark Leggett argues that there needs to be some consideration of the issues involved and a general ban is unrealistic and prohibitive for future advances in reproductive medicine.

It needs to be thought through more. As scientists will tell you, there are aspects of cloning technology that are useful in reproductive medicine. Not that they actually do cloning but that there are parts of it that could be used to assist average couples in reproductive life. While you are not actually doing cloning there are parts of the process that are useful or that could be useful. So, [I] feel that on the whole disallowing cloning all together is a stupid thing to do.

(Mark Leggett, Interview: 22 September 1999)

The nature of fertility clinics' work and their experience and interest in embryology is likely to place them at the forefront of any new developments in genetic manipulation and/or experimentation.

Policy gaps exist in two key areas relating to ART developments and practices; the control and oversight of innovative applications of existing technologies and the rapid expansion of new biomedical technologies that are potentially applicable to human fertility. As it stands, it is NECAHR's role to approve and provide guidelines for any innovative practices or research strategies in the use of ART in Aotearoa/New Zealand.

3.5 NECAHR

There is nobody else making policy decisions though. Who is making policy decisions? Should that be a Ministry of Health area or should policy be enshrined in legislation or should legislation be enacted and then policy developed? What should the process be?

(Robyn Scott, Executive Officer, NZIS, Interview: 26 July 2000)

The National Ethics Committee on Assisted Human Reproduction (NECAHR) was established under section 46 of the Health and Disability Services Act 1993 and reconstituted under section 11 and 16 of the New Zealand Public Health and Disability Act 2000 (NECAHR, 2001b). In April 1993, the Minister of Health established the Interim National Ethics Committee on Assisted Reproductive Technologies (INECART) to provide specialist advice in the area of assisted human reproduction. INECART was established in response to regional ethics committees expressing concern over "proposals and protocols from providers of assisted human reproduction ("AHR") services" (NECAHR, 2001c). In March 1995, INECART was reconstituted as the National Ethics Committee on Assisted Human Reproduction (NECAHR) under section 46 of the Health and Disability Services Act 1993 and, in 2000, was re-established under section 11 of the New Zealand Public Health and Disability Services Act 2000 assuming the same role as it had previously (NECAHR, 2001c).

NECAHR's terms of reference (2001a:1) outline the functions it is required to perform. These functions include the evaluation of new, experimental, or innovative ART applications and research "to ensure that the ethical aspects are considered and that participants in research and innovative treatment are protected" (NECAHR, 2001c). NECAHR is also required to develop protocols and guidelines relating to the ethical issues involved in aspects of assisted human reproduction to assist providers and researchers in their applications for ethical approval. However, in the absence of legislative guidance or a broadly focused policy organisation to

make decisions on the social implications of ART practices and procedures, NECAHR has found itself in this role.

From time to time, it has felt that it has been forced inappropriately to take an ad hoc role in policy formulation in the vacuum that exists. (NECAHR, 2000a:3)

In its submission to the Health Select Committee, NECAHR argues that this gap in the ART legislative or policy framework has compromised its ability to maintain an autonomous role in ethical decision-making.

Accredited ethics committees in New Zealand operate in accordance with the National Standard for Ethics Committees which provides for independence of decisionmaking in regard to ethical review. Currently, NECAHR is more or less autonomous in its application of ethical review. In the absence of a contextual framework NECAHR has, by default, become involved in major decisions with far reaching social implications and also policy formulation in the area of assisted human reproduction. NECAHR has become aware of difficulties in exercising the kind of autonomous role that its current terms of reference seem to imply. (NECAHR, 1999:4)

John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) agrees that the two roles of policy and ethical decision-making should not be handled by one organisation and is critical of the Graham Bill's proposal to extend NECAHR's functions to include policy and monitoring roles.

The alternative also has some weaknesses in that they were going to give all the functions of monitoring what is happening to the ethics committee, the National Ethics Committee on Assisted Human Reproduction. I think you cannot give those two roles to one organisation because the organisation which monitors should also be monitoring the ethical decisions in the way those functions are handled whereas I do not think [NECAHR] can really monitor itself.

(John Peek, Interview: 12 July 2000)

Similarly, Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) sees the role of ethics and policy formulation as complementary but distinct.

...my contention would be that when you develop a policy you take into account a whole lot of factors of which ethics is a very important one. But, if the ethics is determining the policy, then we have got something wrong in the system.

(Ken Daniels, Interview: 31 August 2000)

Beauchamp and Childress (1994:10) argue that policy formation and evaluation "involve more complex forms of judgment than merely invoking ethical principals and rules." Although such principles and rules should provide the moral context for policy decisions, policy formulation requires empirical evidence and attention to relevant fields, such as medicine, economics, law, psychology, and sociology (Beauchamp & Childress, 1994:10). Although NECAHR has made some general policy decisions, such as allowing the practice of altruistic IVF surrogacy, it continues to make decisions about the application of such policies using a case-by-case process.

Rather than taking the reactive stance of NECAHR, John Peek believes that there should be a policy body that is proactive in looking at ART policy issues. He highlights the necessity for

urgent decision-making in some situations and argues that a policy organisation with the role of investigating and consulting on new or unusual developments could give providers some guidance in these circumstances.

At the moment, there is no body that formulates those policies. It is only if somebody thinks of an idea and passes it to an ethics committee. [NECAHR] is taking on a little bit of a role of trying to have some guidelines, policy guidelines, but usually it is reactive. Somebody comes to them and that triggers their mind that perhaps there should be something more uniform. ... I think it should be some [organisation's role] to think about what might be needed and put it up for debate. I think what is coming out of the ethics committee is quite useful. ... [NECAHR] came up with some suggested guidelines about how to approach [using men's sperm after they have died]. ... I think to have some policies along those lines is good because otherwise what happens [is that] the clinics are caught when the pathologist rings up and says, "I am doing an autopsy and the family have mentioned this. What shall we do?" and there is no time to really think about it so you do it and then you have got it in the [sperm] bank and then you have a precedent and what do you do with it? So, to have some policies would be really good.
(John Peek, Interview: 12 July 2000)

However, according to Blank (1994:12-13), the inability to predict the long-term consequences of new technological practices in medicine combined with short-term political pressures concentrates technological assessment on the immediate future. The case-by-case approach to decision-making, as practiced by NECAHR, is easier to manage politically because it focuses on cases in which the benefits and beneficiaries are easily identifiable and avoids having to reach agreement on criteria and principles that may be politically contentious. This approach enables decision-making without having to justify an overarching policy through particular ethical principles or rules and simplifies the search for political resolution. Mendeloff (1985:87) argues that it is easier to obtain group consensus on individual cases than to get agreement on general principles and particular policies. Not having to justify decisions on a general basis also allows policymakers to be flexible in their responses to individual cases (Mendeloff, 1985:83 & 89). The 'muddling through' method of policy-making and ethical decision-making can be rationalised by the need to allow for limited timeframes, information, and reasoning ability (Mendeloff, 1985:85). Although the future impact of technology is difficult to predict because it is reliant on a number of social and practical factors, not just the existence of the technology, inattention to long-term consequences may prove harmful (Blank, 1994:13). The use of certain unethical ART practices may become widespread through the acceptance of practices that individually do not indicate the potential for harm (Blank, 1994:13). Blank (1995:10) suggests that the potentially negative consequences of biomedical technology are not likely to be apparent until the technology has been "frozen" into technical, institutional, and social patterns. Once this has happened he predicts that controls will be both costly and difficult to put into practice.

Those interviewed raised concerns about the absence of a consumer representative on NECAHR. NECAHR's terms of reference state that

NECAHR shall consist of not more than 10 members appointed by the Minister of Health ("the Minister"). NECAHR's membership shall include members with specialist knowledge of and experience in assisted human reproductive procedures. NECAHR shall have at least two Māori members. At any time, at least half the members of NECAHR shall be lay members. For the purposes of appointments to NECAHR, a lay member is defined as anyone who:

- *is not a registered health professional engaged in health care delivery or employed in the provision of health or disability services*
- *is not involved as a researcher in health and disability research in the field of assisted human reproduction*
- *may not be construed by virtue of current or previous employment to have a potential conflict or professional bias in assessing a majority of applications presented to NECAHR for ethical review.*

The Director-General of Health will appoint one person to represent the Ministry of Health. It will be the responsibility of that person to provide NECAHR with information regarding government policy and ministerial views.

(NECAHR, 2001a)

Both consumer and provider representatives believe that the voice of the consumer is marginalised within the policy debate because of their exclusion from NECAHR. MCART (1994:39) recommended that the membership of NECAHR should be carefully chosen and balanced with respect to gender, ethnicity, and professional background. However, Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) claims that the Minister of Health does not see NECAHR as a representative body for interest groups and, expresses his own reservations about having consumer representation on an ethics committee.

Well I actually believe that we need a policy body in New Zealand and I think consumers should be on the policy body. I must admit that I have got some uncertainties, and that is all they are, about the role of consumers in an ethics committee. Now, if we had been a policy committee looking at surrogacy we needed the consumer voice there. But, ethics is a highly specialised area, and people are supposed to be appointed because they have got some knowledge in that area. And I mean I would not want to come out strongly and say one way or the other that there should not be [consumer representation] but I think if we had a different system there would be no question that consumers would be involved in that. ... Various Ministers have made clear on a number of occasions that this is not a representative body. You do not have somebody there to present a particular viewpoint; everybody is focusing on the ethics of the issue. Now I think that is a bit blurry as well. I can see it from both points of view.

(Ken Daniels, Interview: 31 August 2000)

Nevertheless, Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) believes that there should be a consumer representative on NECAHR.

I definitely support the consumer's desire to be represented on NECAHR. Definitely! ...I feel that the voice of the consumer on the Committee is only heard through those people who are working in the industry and most of the Committee will have access to some consumer information if you think about it. Some of the GP's on the committee will have access to their patients. I will have access through my advisory role because I am seeing patients all the time. Ken Daniels knows patients because he has talked to them for years. Rosemary De Luca through her chairpersonship and through her interests in informed consent will

have a view on consumers' interests. So, I think it is probably naive to say that the consumer is not represented. The consumer is not represented directly with a consumer with a particular bandwagon. I guess the issue is that you end up with someone who has a barrow to push but then I believe [the consumer] should be there because it is fair. It just seems fair that [the consumer] voice is heard.

(Rodney Bycroft, 13 September 2000)

Bycroft displays some disquiet over the possibility that a consumer member would have a particular bias with regard to ART practices. He suggests that the 'experts' already represented on the committee would adequately represent consumer concerns but continues to support consumer representation in the interests of fairness. However, while suggesting that a consumer representative may have a "barrow to push", he fails to recognise that the existing NECAHR members may have their own agenda regardless of their professional position and that 'expert' status does not necessarily confer objectivity.

Edwards (1998:154) argues that it is difficult to uphold the separation between 'lay' and 'expert' opinion because members of both categories are "cultural beings" who draw on specific "cultural ideas to order and make sense of social phenomena of which they need not ... have direct experience." As such, both lay and expert representatives on the ethics committee will draw on their own experiences, including their cultural expertise and personal understandings of kinship, to understand and evaluate of new ART practices or techniques (Edwards, 1998:154). Correspondingly, Mendeloff (1985:88) suggests that bioethical committees may under-represent the perspective of society because their membership is often chosen from the educated elites. He speculates that specialist members of bioethical commissions are likely to be more supportive of medical research than other groups. Robyn Scott (Executive Officer, NZIS) argues that academic representation and support for medical research is not enough and that the voice of the consumer is being silenced in relation to decisions that affect their reproductive choices.

We have some reservations about NECAHR. Firstly, there is no consumer representation on the ethics committee that is making decisions on behalf of consumers. ... So, we have a lot of concerns that there are a lot of academic people making decisions on behalf of infertile people in New Zealand with no broad based opinion ever presented to them. ... There is no provider representation and there is no consumer representation. (Robyn Scott, Interview: 26 July 2000)

In 1988, the Cervical Cancer Committee of Inquiry produced guidelines for research involving humans, which recommended that "lay representation on the ethical committee approximates one half of the membership" (Cervical Cancer Committee of Inquiry & Cartwright, 1988:214).⁶²

⁶² The Cervical Cancer Inquiry into questionable research ethics had considerable influence on the establishment of guidelines for all research involving human beings, including social research (Tolich &

By continuing to reject membership nominations from the New Zealand Infertility Society (NZIS),⁶³ the Minister of Health is in danger of subjugating 'lay' knowledges, concerns, and experiences beneath the more dominant 'scientific' or 'expert' discourses represented by the current membership of NECAHR (Lupton, 1997:104).⁶⁴

Until recently there was no provider input on NECAHR. However, a specialist scientific officer nominated by the clinics is now present at NECAHR meetings. This person does not have a voting role but is available for clarification of issues in relation to ART practices and technology.

From time to time, fertility clinics have been critical of the level of specialized scientific expertise on the Committee to inform its discussions. In response to these criticisms, meetings are now attended by a clinic's representative with scientific expertise who has been nominated by the clinics to advise NECAHR on specialized scientific matters. NECAHR also seeks expert advice from time to time.
(NECAHR, 2000a:2-3)

Although John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) perceives the overall composition of NECAHR as flawed, he acknowledges that this development makes the ethics committee more responsive to consumer and provider requirements in terms of timeliness and approachability.

I think it has great holes in it. I think most of the people there are fine except that it has lots of representation from government organisations, from the health profession, although the people on it from the Health profession are generally not very knowledgeable about ART because the field is relatively small. Anybody that has knowledge about ART is likely to be someone submitting stuff to the committee. They have a system now where they rotate expert opinion from each of the clinics, which is a bit of an advantage. So, I think that they lack a lot of information about ART and there is no consumer representation. ... The committee is quite a lot more open than it used to be. ...they welcome people to come along and answer the questions at the time of the committee meeting whereas before they would have the meeting and you would have to wait three months to have an opportunity to answer the questions and then there would be more questions from those questions.
(John Peek, Interview: 12 July 2000)

Expert knowledge in a technical field does not guarantee that the social implications of technology are considered and in some cases, these implications may even be obscured by attention to the technical aspects (Blank, 1998:138). However, successful health policy is dependent on some level of specialised medical knowledge (Blank, 2001:149). Therefore,

Davidson, 1999:83-84). It concluded that ethical standards "must be applied rigorously to research and treatment protocols on behalf of the patients" (Cervical Cancer Committee of Inquiry & Cartwright, 1988:152) and lead to the established of regional ethics committees under Area Health Boards in the late 1980's (NECAHR, 2001c).

⁶³ The New Zealand Infertility Society (NZIS) has repeatedly canvassed the Minister of Health and NECAHR for consumer representation on the committee.

⁶⁴ See Appendix N for a list of the members of NECAHR and their professional and/or academic status.

although the specialised knowledge of experts is not solely adequate to deal with the distinctive ethical and moral issues associated with ART practices, technical experts should be included in the debate over “social priorities” (Blank, 1998:138). Although such experts may initiate and direct public debate on biomedical issues, extensive public involvement is critical if democracy is to be maintained (Blank, 1998:138).

For Sue Bagshaw (Medical Training Co-ordinator, Family Planning Association, Christchurch) the issue of consumer representation is connected to the lack of public consultation undertaken by NECAHR.

NECAHR is not really representative of society and I find that really worrying. ... [They] do not have the time and they are not asked to really. ... If you actually said that NECAHR needs to be representative and put in its constitution that you must go away and consult and you must take into account all these groups' opinions, then at least they would have to try to do that. I mean it is a pretty hard task but at least they would have to try to do that. To me that would be a much more democratic way of deciding what happens.

(Sue Bagshaw, Interview: 21 August 2000)

Although NECAHR acknowledges the importance of public consultation in making its decisions, it argues that the pluralistic nature of society in Aotearoa/New Zealand, the specialised knowledge relating to ART practices, and the “private and personal aspects of most requests for ethical review” often make public consultation difficult (NECAHR, 2000a:2). Consequently, the ethics committee relies on a diverse range of media to keep its members informed of public debate in the area of ART.

When possible, the Committee uses opportunities that offer good investigative journalism to engender public discussion. It also consults about proposed guidelines. For example, the guidelines for non-commercial altruistic surrogacy using IVF as treatment will be distributed shortly for public consultation. NECAHR also informs itself about public debate by reading relevant reports and submissions in the field that have been called for by groups other than itself, and follows media reports, published correspondence and radio ‘talk-back’ programmes. Arrangements are being put in place to make NECAHR's work public via a website.

(NECAHR, 2000a:2)⁶⁵

The avenues of public expression identified above are in themselves specific discourses that give authority to certain voices, controlling what is said, who can speak, and when (Foucault cited in Campbell, 1993). Although useful in the contribution to public debate, some of these avenues for public discussion are arbitrary in their attention to issues relating to ART and should not be a substitute for direct consultation with interested or concerned publics. A wide

⁶⁵ This website is now operational and appears to have been created on the 21 September 2001. It provides online access to NECAHR's annual reports, submissions to the Health Select Committee and the Law Commission, Terms of Reference, membership, and links to other relevant sites (Available: <http://www.newhealth.govt.nz/necahr.htm> [6 November 2001]).

range of interested individuals may be excluded from having their views considered in the debate because they lack the information, social capital, or cultural knowledge to engage in these forums for discussion. While public consultation can be difficult and time consuming, it is a far more inclusive method of gathering information and opinion than relying solely on 'expert' advice or 'popular' media presentations. Blank (2001:148) argues that there is a strong belief in Aotearoa/New Zealand that the public should have a participatory role in deciding 'public policy'. However, he suggests that in recent years Aotearoa/New Zealand has moved away from participatory democracy towards 'thin' democracy in which health care decisions are being primarily made by the health providers and public administrators. Accordingly, there has been a move towards reducing the control of medical professionals and limiting the amount of public consultation in health policy (Blank, 2001:150). Therefore, NECAHR's position as the only government appointed group with direct responsibility for ART policy decisions and guidelines, strengthens the need for it to undertake public consultation in relation to ART developments.

Although providers are required through their professional codes of practice and the Reproductive Technologies Accreditation Committee (RTAC) to submit research and new treatment proposals for ethical review to NECAHR, there is no regulatory framework to enforce NECAHR's findings. However, NECAHR stresses that fertility clinics currently comply with accreditation and ethical requirements despite the lack of regulatory enforcement.

Although the Committee has no legislative powers, fertility clinics currently demonstrate a due regard for and compliance with its ethical review findings. ... There has been an informal undertaking by RTAC to make compliance with NECAHR's guidelines a requirement of accreditation for New Zealand clinics. This undertaking will be pursued when public consultation on the surrogacy guidelines is completed and the guidelines formalised. (NECAHR, 2000a)

Coney (1999a:22) contends that in the past some ART research proposals have not been referred to NECAHR but have been dealt with by university ethics committees. She also speculates that, under NECAHR's terms of reference, practices that have been long established internationally, but are new to Aotearoa/New Zealand, may not need to be submitted for ethical approval. NECAHR also notes that the only incentive for clinics to submit proposals comes from their accreditation commitments.

The RTAC guidelines require accredited clinics to submit research and new treatment proposals for ethical approval before adopting new procedures. This ethical review is undertaken by NECAHR. In the absence of any overarching statutory body, RTAC accreditation provides the only impetus for clinics to submit proposals for review. (NECAHR, 1999:2)

However, Rodney Bycroft argues that the clinics' statutory requirements to comply with RTAC are a sufficient motivation for clinics to comply with NECAHR's findings and judgments.

NECAHR will say that they do not have the authority to compel clinics to do things but the clinics through their registration process are required to do or to act on the advice of their ethics committee. So, for us here at the clinic, we would be stupid to run against the advice and recommendations of NECAHR because it would be in breach of our statutory requirements to be registered and to take notice of [them]. From time to time, some clinics have contested NECAHR's recommendations.

(Rodney Bycroft, Interview: 13 September 2000)

Nevertheless, there are no penalties in place if a clinic does not comply with NECAHR's decision and carries out a procedure that does not have ethical approval.⁶⁶ The Assisted Human Reproduction Bill (Graham Bill) does not make any recommendations regarding this issue.

The Bill is silent on the situation where the ethics committee decides that a procedure should not be given ethical approval. Currently the only mechanism preventing the implementation of such a procedure is the requirement under the RTAC accreditation guidelines.

(NECAHR, 1999:4)

Consequently, NECAHR and RTAC remain the only two organisations in Aotearoa/New Zealand with specific control over ART at present and, as explained in the following section, they remain independent and are not accountable to each other.

3.6 Professional Self-Regulation

Professional self-regulation has a principal role in the control and regulation of ART in Aotearoa/New Zealand.

In 1992, the RNZCOG [Royal New Zealand College of Obstetricians and Gynaecologists] formulated a policy that all providers of ART, including DI services, in New Zealand, be accredited with the Australian Reproductive Technologies Accreditation Committee to set minimum professional standards and allow peer review.

(MCART, 1994:11)

The Australian based Reproductive Technologies Accreditation Committee (RTAC) is one of two bodies with specific control over ART and surrogacy in Aotearoa/New Zealand. RTAC monitors the practical aspects of ART provision and provides procedural guidelines for the professional qualifications of clinic staff, the prevention of diseases, the collection of information, informed consent, the provision of laboratory facilities, ethics and research, and the provision of support services including counselling (MCART, 1994:11; RTAC, 1999). Nevertheless, commentators have expressed concern about the use of an Australian based organisation to oversee Aotearoa/New Zealand clinics.

Standards for recognition or accreditation of ART clinics in New Zealand are currently based on Australian standards. The values and perspectives of Australia, however, are not necessarily appropriate for New Zealand.

(Dyall, 1999:37)

⁶⁶ Clinics may lose their accreditation with RTAC if they do not comply with NECAHR's findings. The consequences of this are discussed in the following section of this chapter.

Similarly, Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) expressed concern about the lack of accountability or sanctions provided by relying on an offshore accreditation committee that has no regulatory obligations to the Government of Aotearoa/New Zealand.

RTAC is in no way answerable to the New Zealand Government. So, there is an accountability issue and if the Government is interested in protecting the interests and welfare of children and of families and so on, how do they actually monitor that? And, there is no process for any input into RTAC standards or for RTAC to report back to anybody in New Zealand. So it is very much a self-regulatory system and while that has quite a lot going for it, it also has weaknesses. How does it actually tie in? I mean if the professional group says, "This is what we are going to do" and the Government does not like it, then what can they do about it?

(Ken Daniels, Interview: 31 August 2000)

Others involved in the policy debate argue that disparate health systems and cultures make it inappropriate for an Australian-based organisation to oversee ART practices in Aotearoa/New Zealand.

It is not appropriate. I do not see how they can. I think there are several issues. One is around differences in the structure of the health system and the other is in cultural differences that they would not be able to deal with and the third is just the practicalities of being able to perform as an accreditation body.

(Sandra Coney, Executive Director, Women's Health Action Trust, Interview: 13 July 2000)

All Aotearoa/New Zealand ART providers are presently accredited through RTAC, as originally required by the RNZCOG (Ministry of Justice & Ministry of Health, 1997). However, there is no legal requirement for the clinics to be accredited. As a self-regulatory organisation, the RNZCOG and, latterly, the RANZCOG⁶⁷ has no power to enforce their members to comply with their standards and guidelines (MCART, 1994:12). Similarly, there are no legal sanctions in place if providers fail to comply with RTAC's guidelines or lose their accreditation.

There are [no sanctions] in New Zealand. It is the stigma really. In Australia if you are not accredited you are not eligible to get the drugs from the federal government which means that your patients would be severely disadvantaged so [they would go somewhere else].

(John Peek, Interview: 12 July 2000)

Mark Leggett (Business Manager, The Fertility Centre, Christchurch) suggests that market forces would ensure that clinics maintained their accreditation, as loss of reputation would be a consequence of not being accredited by RTAC.

Reputation probably more than anything else. No one would recommend you I would think. ... If we do not provide a very good service people would not come back. They will go somewhere else, out of town.

(Mark Leggett, Interview: 22 September 1999)

⁶⁷ In 1998, the Australian and New Zealand Colleges amalgamated to form the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG).

This observation fails to take into account the small number of clinics and geographical limitations that restrict the options available to consumers. MCART (1994:12) argues that those providers who negotiate purchase agreements for publicly funded ART services would be disadvantaged if they did not hold RTAC accreditation. As Helen Williams (Policy Analyst, Elective Services Project, HFA) maintains

If you were not accredited I do not think the HFA would purchase from you.
(Helen Williams, Interview: 29 August 2000)

However, this is only effective as a sanction if the clinic is involved in applying for government contracts. The smallness of the ART community and the role of the NZIS and affiliated regional infertility societies in educating and informing consumers about the standards of services they can expect may work to ensure that non-accredited clinics are disadvantaged. On the other hand, the small number and geographical location of clinics may offset any disadvantages by limiting consumers' options for treatment. Helen Lockyer (Senior Policy Analyst, Ministry of Health) sees the lack of effective sanctions as one of the reasons for making accreditation mandatory.

...that would be one of the advantages of making such accreditation or something similar mandatory and actually having some sanctions. Penalties [is] one of the issues that [is] covered by both of the bills.

(Helen Lockyer, Interview: 24 July 2000)

All of the provider representatives interviewed supported the use of RTAC as their accrediting agency, suggesting that setting up an independent Aotearoa/New Zealand accrediting organisation would be extreme and costly considering the small number of clinics in this country.

RTAC is pretty good. The industry is not so huge and diverse in New Zealand and Australia that people would get away with anything, really.

(Mark Leggett, Interview: 22 June 2000)

Similarly, Helen Williams (Policy Analyst, Elective Services Project, HFA) identifies the size of the Aotearoa/New Zealand ART 'industry' as too small to warrant setting up its own self-regulating organisation.

Because we are too small a country to have a New Zealand based one and that happens with a lot of specialities. I think it is absolutely fine for it to be an Australian based; it has New Zealand input as well.

(Helen Williams, Interview: 29 August 2000)

John Peek agrees that, as far as overseeing the technical aspects of ART practices is concerned, RTAC is a prudent choice. However, he argues that there is a need for local guidelines to be added to RTAC's 'Code of Practice' to take into account the cultural differences between Aotearoa/New Zealand and Australia.

I think that RTAC was mainly to look at technical things and especially at the tradition of counselling and looking after people from that aspect and that you went through ethics committees and all that sort of stuff. So, I think those are similar enough that probably makes no difference. I think it is really good to have an offshore body in one way, in that New Zealand is pretty small, in terms that trying to cobble together something that can look after five or six clinics, whereas in Australia there are 25 or 30. I think is really sensible. ... [There are] definitely New Zealand dimensions that should be looked after. New Zealand cultural things, not just Māori, but New Zealand's culture of openness about donor insemination.... So, I think it should have some New Zealand guidelines. At the moment, it has New Zealand participants in that a member of the local Infertility Society is the local person, counsellors are local, one of the doctors is local, but there are no actual New Zealand guidelines or part to it

(John Peek, Interview: 12 July 2000)

Although there are two Aotearoa/New Zealand representatives on RTAC, a gynaecologist/obstetrician and a consumer (Ministry of Justice & Ministry of Health, 1997), the RTAC 'Code of Practice for Centres Using Assisted Reproductive Technology' (1999) contains no Aotearoa/New Zealand-specific guidelines. In 1994, MCART (1994:37 & 40) acknowledged that accreditation of Aotearoa/New Zealand clinics by RTAC served "a vital purpose in ensuring that appropriate standards are set at an international level". However, they recommended that an Aotearoa/New Zealand supplement to the guidelines be given priority.

MCART (1994:40) recommended that the Royal College of Obstetricians and Gynaecologists (RNZCOG) undertake this task in "consultation with providers, consumers, public officials", and their proposed overseeing body (Council on Assisted Human Reproduction). Although there have been repeated calls for the development of a Aotearoa/New Zealand supplement to the RTAC guidelines, this supplement has not eventuated. While acknowledging the need for such a supplement, Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) suggests the difficulty of the task may have been the reason for the delay.

The job of drawing up that supplement has been pushed from pillar to post. But, it was given to the Royal College of Obstetricians and Gynaecologists to do and, to my knowledge, they have never done it, although they have been pushed by Ministers and they have been pushed by NECAHR. I mean it is a very difficult thing to do; it is an extremely difficult thing to do. ... But, there is still no standard; no specification as to what should be looked at in terms of determining whether New Zealand clinics are operating in an appropriately culturally sensitive way. That supplement is the missing part....

(Ken Daniels, Interview: 31 August 2000)

However, MCART (1994:40) did not foresee the task as being too difficult and claimed that RTAC was willing to include an Aotearoa/New Zealand-specific supplement developed by New Zealanders. It appears that, while it is still the intention of the Ministry of Health to include the proposed supplement, the timing and form that this inclusion takes is dependent on the outcome of the Health Select Committee's consideration of the two bills.

The NZ (sic) supplement to the RTAC guidelines has not been completed. This is primarily because we are awaiting the outcome of the select committee's deliberations on the two assisted human reproduction bills. The legislation may have implications for the content of the guidelines. The Health Select Committee hopes to consider the bills in April or May of this year.

(Personal Communication, 21/01/01)⁶⁸

In the meantime, gamete donors, surrogates, commissioning parents, and individuals conceived with donor gametes are offered few assurances that practices will be monitored and regulated in a way that best suits the historical, cultural, or political environment of Aotearoa/New Zealand. These issues will be discussed in more detail in Chapter Six.

As the sole method of regulation and control, professional self-regulation excludes or marginalises people outside the profession from having any input into the development or enforcement of policies and codes of practice. Medical codes that are generated without public or patient consultation rely on the traditions and judgements of the medical profession and “may do more to protect the profession’s interests than to introduce an impartial and comprehensive moral viewpoint” (Beauchamp & Childress, 1994:8). The Canadian Royal Commission on New Reproductive Technologies (1993a:57) argues that “a self-regulating profession is not necessarily best equipped to assess the social, ethical, and economic implications of the technologies and may be insufficiently accountable to those whose needs they are meant to serve, particularly in the absence of a broader regulatory system.” Correspondingly, Beauchamp and Childress (1994:7-8) argue that professional codes sometimes take too broad a view with regard to ethical requirements or claim to be more comprehensive or authoritative than they are entitled to. This approach often leads professionals to mistakenly assume that, by following the rules of the code, they will satisfy all the moral requirements. Although medical codes pay attention to general principles and rules such as ‘do no harm’ and confidentiality, only a few comprehensively address issues of honesty, openness, autonomy, and justice (Beauchamp & Childress, 1994:8).

Daniels and Taylor (1993:1474) claim that fertility specialists are not resistant to government intervention and “would prefer to operate within a set of clearly specified guidelines determined by a publicly appointed and/or approved body.” However, the preference for guidelines is undoubtedly influenced by an unwillingness to support regulatory interference with their professional autonomy when exercising clinical judgement (Daniels & Taylor, 1993:1474).

⁶⁸ Email communication with Helen Lockyer, Team Leader, Professional Regulation & Quality, Personal & Family Health Directorate, Ministry of Health, 21 January 2001.

While fertility specialists in Aotearoa/New Zealand may be resistant to regulatory controls, they do not appear to be totally opposed to mandatory accreditation or to the establishment of some form of policy body to oversee ART practices and developments. Notably, in the early 1990s Fertility Associates in Auckland requested that the Minister of Justice establish some form of regulatory authority to supervise ART practices in Aotearoa/New Zealand. As mentioned earlier, Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) would prefer to have a government appointed committee to review reproductive practices and technology than controlling legislation.

I guess my personal opinion is that I would like to see a separate body but, in the absence of that, I think somebody has to do it and NECAHR is probably in the best position to do that at the moment. If the Government clearly do not want to set up a body that regulates the industry then NECAHR [is probably the next best thing].
(Rodney Bycroft, Interview: 13 September 2000)

Similarly, John Peek is not opposed to some form of government regulation of ART but is wary of the costs of setting up a specifically ART focused policy organisation being passed on to consumers and providers.

You can have government regulation that does not cost too much. It is just what sort of bureaucracy you put with it. I do not mind having an external thing but ... it should be done very cheaply and ... rely on trying to use existing laws and mechanisms as much as possible. ... You would have some sort of committee just to hold it all together rather than making a new committee to do it all.
(John Peek, Interview: 12 July 2000)

The MCART (1994) report recommended the establishment of a body to oversee and coordinate policy decisions in ART and Ken Daniels supports this model of policy formulation and control.

If you had an umbrella organisation that was responsible for looking at things like ethics, standards, accountability, public education ... I guess those are the main areas. Bill Aitkin and Paparangi Reid [MCART] actually made some comments about that in their report; that there needed to be a group that took a much broader brief.
(Ken Daniels, Interview: 31 August 2000)

As indicated previously, there has been no progress towards establishing a policy body that would take an overseeing and policy formulating role, as well as co-ordinate the intersecting and related functions of NECAHR and RTAC in relation to ART. Consequently, issues of accountability and decision-making transparency are the central concerns for some ART commentators.

3.7 Accountability

According to Blank (1998:135), the relationship between the number of reports by government committees and the paucity of government action in response to them may reflect the political use of *ad hoc* bodies as a deflective mechanism by elected officials. It may also be a recognition that the issues raised by ART are too complex or politically sensitive for decisive

action. As a consequence, Daniels (1998a:80) contends that ethical and professional practice decisions are likely to dominate when there are gaps in public policy. As there is no overseeing body to co-ordinate the contributions of the various groups and organisations already involved in the ART policy arena, Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) defines organisations such as NECAHR, RTAC, and the HFA, as the

...de facto policy groups in New Zealand at the moment because of the policy vacuum and decisions are being made in lots of different areas by different groups.
(Ken Daniels, Interview: 31 August 2000)

As mentioned earlier, he would like to see these groups brought together under the auspices of a body dedicated to formulating policy and overseeing the diverse range of participants in the field. This body would be responsible for making policy within a regulatory framework.

That is where I think there is a role for a policy group. If you had an umbrella organisation that was responsible for looking at things like ethics, standards, accountability, and public education. (Ken Daniels, Interview: 31 August 2000)

Robyn Scott (Executive Officer, NZIS) also sees the current fragmented policy situation as contributing to a lack of accountability on the part of government agencies.

The process of decision-making is not transparent and nobody is held accountable for the decisions they make. The letters that we write, the letters to the Minister, the letters to the HFA, the HFA meetings we have, nobody is ever accountable for anything, never. It is always somebody else's problem and somebody else's fault ... there is no transparency.... (Robyn Scott, Interview: 26 July 2000)

She partly attributes the lack of accountability and transparency within the present policy situation to the depletion of involvement and historical knowledge (of the ART policy debates and developments) within the government sector.⁶⁹ Correspondingly, she sees this as a consequence of high staff turnover and the continuing health sector restructuring.

There is no way of tracking who is [responsible] as somebody who is working in [the field] today might be gone in two months or three months. We are into our fifth Health restructuring in nine years so the system is being restructured all the time as well. There is an awful amount of time, energy, and money that is taken up by that change. So, it is like a constant change process really.
(Robyn Scott, Interview: 26 July 2000)

In 1998, statistics showed there had been large staff turnover levels in forty-six government departments and agencies over the previous five years (Lilley, 1998). The inability to retain an experienced and committed policy skill base within government organisations means that those with the most consistent and historical knowledge of ART policy debates and developments are those people who have been directly or indirectly involved in the provision of services over the

⁶⁹ See Chapter 2, The Research Process, Section 2.7, The Interviews, for how the depletion of institutional knowledge and experience in this area influenced the research process.

past two decades.⁷⁰ Martin and Salmond (2001:55) suggest that the recent integration of the Health Funding Authority (HFA) into the Ministry of Health is highly likely to result in a loss of a “valuable source of specialised and contestable advice to the Minister”, even though the process “was designed to avoid overlapping jurisdictions and to reduce costs”. In contrast, Devlin et al (2001) maintain that a conscious effort is being made “not to lose institutional knowledge and experienced staff during the transition.” Nevertheless, the NZIS’s past experiences with health sector restructuring has contributed to their scepticism regarding the current restructuring process and the loss of institutional knowledge and continuity.

...this is a problem that we have always had, this lack of continuity. The minute we network and make contact with somebody, they are gone, and it changes and it is just this continual process. And, that must be replicated by many areas of Health in New Zealand. (Robyn Scott, Interview: 26 July 2000)

The perceived lack of accountability and transparency in the present system of official policy-making and negotiation means that the NZIS suspects conspiracies within the current arrangement, as they have no way of verifying why and how decisions are made and there is a lack of continuity in official contacts.

Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury, Interview: 31 August 2000) sees accountability as an issue in relation to RTAC and the Aotearoa/New Zealand Government. He believes one of the dangers with self-regulation is its lack of transparency. As explained in the previous section, RTAC is not required to report to the Aotearoa/New Zealand Government and, although there are professional requirements, there are no legal requirements for clinics to belong to RTAC. Ken Daniels does not see the need to establish an independent Aotearoa/New Zealand based accreditation committee, but does believe that RTAC should have some responsibility to an Aotearoa/New Zealand based policy group.

So, I think we need some kind of legislation that sets up a policy group and that that policy group has responsibility for those different areas that I mentioned before [ethics, standards, accountability, and public education]. I do not see it needing to set up a whole lot of regulations. For example, when it came to the issue of standards and accountability, there is no reason why it could not subcontract that to RTAC. But, that RTAC then reported to that group on the visits that it made. At the moment, RTAC comes, makes a visit to [the clinics], who

⁷⁰ According to Robyn Scott (Executive Officer, NZIS, Interview: 26 July 2000) “...many of them have worked in the industry for a long time. It is not an industry where the staff changes a lot. You have still got your original group of Freddie [Graham], Richard [Fisher], Joy Ellis, and John Peek that started up IVF at National Women’s [and] all still work at Fertility Associates and still work in infertility.” See footnote no.73 in Chapter 4, Allocating Resources, Section 4.2, Funding Issues, for a summary of John Peek’s involvement in this area.

knows what goes in those reports? I mean all that is known is, "Is this clinic given a one year extension, a 3 year extension, or what?"

(Ken Daniels, Interview: 31 August 2000)

However, as mentioned earlier, NECAHR is the only government body that has direct responsibility for making decisions in relation to ART. As a result, they have been charged (by default) with making policy decisions on a case-by-case basis. There is no contact between RTAC and NECAHR so clinical and ethical decisions are made in isolation of each other. Moreover, some decisions regarding public education and accountability are not made at all or are left to the initiative of clinics and consumer groups.

Well no, you see we do not have any contact with RTAC. There was an interesting phase when RTAC were over here doing a visit [and] we invited them to come to a NECAHR meeting. We sat down and had a very profitable discussion and lunch together and one of the results of that was that somebody from NECAHR was going to be invited to visit clinics whenever it took place in New Zealand. And, somebody from RTAC, one of the New Zealand representatives, was to be on NECAHR. Well I do not know what happened to that. We certainly were invited ... but I do not think that is happening now but maybe that was because there was a change of personnel in RTAC. ... But, that would have actually facilitated some communication between the two groups. Not that RTAC were responsible to NECAHR or vice versa but we did share certain things in common. For example, our commitment to wanting to provide for the safety and welfare of children meant that we needed to know what clinics were doing, what kinds of forms they were using, etc. But, short of us going and visiting the clinics, which would have been duplicating RTAC's work, there was no way we could really do that efficiently. Therefore, that is the bit that is missing in the total picture, it seems to me.

(Ken Daniels, Interview: 31 August 2000)

Sue Bagshaw (Medical Training Co-ordinator, Family Planning Association, Christchurch) also argues for a national body that would be responsible for overseeing and formulating ART policy, maintaining that such a body would also enable issues of differential access and funding to be addressed. These issues are presently left to individual clinics and consumer groups to canvass the Health Funding Authority.⁷¹

If you had a national body that was a bit more democratic than NECAHR it could look at the ethics of discriminatory access, and I think that should be one of the things that they look at and it should be at a national [level]. ... There needs to be lay input into it definitely. I think there needs to be the influence of people who are sub-fertile because then they understand the pressures that drive the market, if you like, as well as people who are fertile and maybe have a more objective view.

(Sue Bagshaw, Interview: 21 August 2000)

As there is no organisation solely responsible for co-ordinating overlapping interests or concerns, issues regarding future research developments and utilisation are left until they become immediate. Therefore, RTAC continues to focus on the standards and clinical application of procedures, while NECAHR concentrates on making case-by-case decisions with

⁷¹ See Chapter 4, Allocating Resources, and Chapter 5, Regulating Access, for discussions about funding and access to ART practices.

regard to surrogacy, producing guidelines on the use of certain procedures, and responding to applications from providers when they seek approval for new innovations in the use of ART.

3.8 Conclusion

Underlying the discussion in this chapter is the understanding that health policy formulation and implementation is influenced and shaped by the interactions between state controlled funding and policy agencies, managers, healthcare professionals, patients, interest groups, and the wider community. Consequently, elements of both 'top-down' and 'bottom-up' policy development need to be acknowledged in any analysis of the policy process in the field of ART.

ART policy in Aotearoa/New Zealand has been formulated using an *ad hoc*, reactive, and case-by-case approach as new or challenging issues have arisen over ART service provision. Many reports from various committees and commissions have called for public debate and an overseeing organisation to advise and monitor ART practices and developments. However, no such administrative body has been created and the only official bodies involved in the control and regulation of ART practices are the Reproductive Technology Accreditation Committee of Australia (RTAC) and National Ethics Committee on Assisted Human Reproduction (NECAHR). These two committees operate independently and are not accountable to each other. Although the Status of Children Amendment Act 1987 (SCAA) remains the only piece of legislation that explicitly deals with ART, there are many existing regulations and statutes that could be used in relation to legal issues arising from ART practices. These include professional codes of practice and legislation specific to the health and medical sector, as well as legislation relating to adoption and human rights.

During the last five years, two bills have been introduced to Parliament that propose varying degrees of legislative regulation and control over currently practiced assisted reproductive techniques, as well as potentially harmful ART developments. Although these bills have been considered by Parliamentary Select Committees for a combined total of five years, they have had the due date for their report/s extended on numerous occasions and there is no guarantee that they will be tabled before this thesis is submitted.⁷² Delays in reporting on the two bills

⁷² A check of the Office of the Clerk of the House of Representatives' website 'Bills before the Select Committees' (<http://www.gp.co.nz/wooc/npaper/select-committee-bills.html>), prior to submitting this thesis, indicated that the due date has again been extended and the report is now due on the 31 May 2002.

have been explained as systemic and procedural. However, it is more likely that the delays have been influenced by the fact that the issues are politically contentious and involve state interest in matters that are generally considered private. Although issues surrounding the use and development of ART may be politically difficult to resolve, the lack of action by successive political parties and coalitions has meant that the resolution of many social and ethical concerns remain dependent on the attention and discretion of providers, NECAHR, and RTAC. Embryo donation, sex-selection, and surrogacy are all areas that require further public debate and consideration. Controlling the introduction and application of these practices currently remains dependent on providers applying to NECAHR for approval of their use and then complying with NECAHR's decisions.

While both the Yates and Graham Bills propose the banning of certain unethical procedures, they differ over the level and structure of oversight for ART practices. The Yates Bill proposes that fertility clinics be licensed and aims to establish a licensing authority which will control and monitor the provision of ART services. However, the Graham Bill proposes a policy structure similar to the one currently in effect and, although NECAHR is given statutory recognition and its role is expanded, the committee remains under the control of the Minister of Health. The bills differ over the level of attention they give to surrogacy and the recognition they give to the Treaty of Waitangi (te Tiriti o Waitangi). They also reflect the polarisation of issues around the clinical applications and the potentially harmful aspects of specific techniques. Some commentators have expressed concern that prescriptive legislation would restrict the use and development of any technological advances in assisted reproduction. They have suggested that the establishment of a government appointed organisation to oversee and monitor such developments and ART practices would provide a more flexible and timely form of control.

Although not established as an ART policy organisation, NECAHR has taken on this role by default. Consequently, ethical decisions, which should form the basis of policy in conjunction with other fields of knowledge and experience, have become *de facto* policy decisions. The ambiguity in NECAHR's role, combined with difficulties in predicting the future consequences of certain practices, political expediency, limited finances, timeframes, and information, as well as the flexibility offered, have all contributed to a case-by-case decision-making approach, which lacks legislative support. The lack of consumer representation on NECAHR also raises concern over the marginalisation of the experiences of those with fertility problems in the formulation and implementation of policy and ethical decisions. NECAHR has no legislative power to support and enforce their decisions and this has raised concerns with the committee, as well as

other commentators. However, some providers believe accreditation requirements for RTAC are sufficient to ensure compliance. RTAC is an Australian based organisation that is not answerable to any Aotearoa/New Zealand agency or authority and has no statutory ability to enforce its accreditation requirements or sanctions. Although recommended by MCART and supported by many other commentators in the field, a Aotearoa/New Zealand supplement to RTAC's 'Code of Practice' has not eventuated and New Zealander's involved in ART practices have little assurance that these practices will be monitored and regulated in line with local cultural and political values and principles.

Providers do not appear to be resistant to compulsory accreditation or the creation of some form of policy development body that would oversee and coordinate policy initiatives and developments in ART. However, despite repeated calls for such an organisation, it has not eventuated. If the Graham Bill remains the preferred option for legislating ART practices, it is unlikely that such a body will be established in the near future. It is highly likely that NECAHR will be reconstituted to officially recognise the policy-focused role it has undertaken in the last few years. Consequently, the status quo will be maintained and ethical and policy decisions will be combined and implemented using a case-by-case approach. Alternatively, the establishment of an ART focused policy body would offer oversight to the ART arena and provide a sense of accountability and responsibility in relation to policy decisions. Such an organisation could also co-ordinate the interrelated roles and functions of NECAHR and RTAC in relation to ART and could oversee the implementation of policy and ethical decisions in the clinics. It would enable the voice of consumers and providers, as well as other interested publics, organisations, and individuals, to be heard.

While this chapter has focused primarily on the initiatives and implementation of ART policy from a 'top-down' perspective, I do not disregard the consequences and significance of 'bottom-up' policy processes. The interpretation and observance of ART policy protocols and guidelines by providers, consumers, and involved groups and individuals has an influential effect on policy formulation and implementation. The following chapter will investigate how the *ad hoc* development of public funding for ART services has entrenched regional inconsistencies and inequities in funding and access.

4

Allocating Resources

At the moment, what is provided where is really historical accident.
(John Peek, Interview: 12 July 2000)⁷³

4.1 Introduction

As the majority of assisted reproductive technology (ART) services in Aotearoa/New Zealand are provided through the private sector, access is primarily dependent on the ability to pay.⁷⁴ Most health insurance companies do not cover infertility treatment. The medical insurance scheme available to members of the New Zealand Police Force is the only one that provides coverage for infertility in Aotearoa/New Zealand (New Zealand Infertility Society, 2000). Some services are provided by the public health sector and the total public funding for ART treatments in Aotearoa/New Zealand is approximately \$5.8 million (*The Dominion*, 9 August 2000, p.7). However, this figure was arrived at through *ad hoc* policy development based on historical levels of funding, rather than a planned policy to provide publicly funded infertility services. This chapter will explore how access to public resources for ART services evolved out of contingent responses by particular doctors and researchers to the growing demand for services.

⁷³ John Peek is the Scientific Director for the Fertility Associates group of clinics. He supervised the infertility laboratory at National Women's Hospital from 1984 until he joined Fertility Associates in 1987. He is instrumental in overseeing the Fertility Associate group's contracts with the Health Funding Authority (Fertility Associates N.Z., 2001b: <http://www.fertilityassociates.co.nz/staff/index.html>). As John Peek has worked in the ART field for many years, he has had extensive involvement and historical knowledge of the ART policy debates and developments.

⁷⁴ See Chapter Five, Regulating Access, for an analysis of access restrictions to both public and private infertility services.

Initially funded on an *ad hoc* basis through research programs and obstetric and gynaecological services, ART services expanded into the public health system by default. Services were centralised in Auckland and attracted consumers from throughout Aotearoa/New Zealand. Eventually increasing demand led to the opening of private clinics and the establishment of regional ART services. However, regional funding was based on the utilisation of services in Auckland and did not consider regional population requirements.

The decision-making processes and values underlying the public provision of ART services have never been addressed or publicly debated and I argue that the continued 'muddling through' approach to ART funding policies has embedded regional inequities and inconsistencies in funding public ART services. Similarly, the contingent and incremental approach to implementing access restrictions for publicly funded ART services to limit the demand for public resources has further embedded inequities in access. Recent attempts by government funding agencies to address these inequities and inconsistencies have failed to investigate issues relating to the prevalence of infertility in Aotearoa/New Zealand or the regional utilisation of services. Consequently, increased funding continues to be based on historical perceptions of need rather than considered empirical evidence. The *ad hoc* development of funding policies has been exacerbated by recent health sector reforms. This chapter will explore how the disbanding of the Regional Health Authorities and the Health Funding Authority (HFA), and the establishment of 21 District Health Boards could affect the goal of national consistency in the provision of and access to public ART services.

This chapter also provides the background for the following chapter, which will explore how limiting access to ART services has further embedded inequities by using restrictions based on social judgements and the normative concept of family. Firstly, I examine how ART services were incorporated into the public health sector and discuss how historically determined levels of need have contributed to limited and inequitable public access to ART services. I then consider how health sector reforms and the introduction of explicit rationing strategies have influenced the development of access criteria to ration publicly funded ART treatments. This is followed by a discussion of how recent changes to funding levels, the prioritisation of infertility within the public health system, and further health sector reforms may influence the public provision of ART services.

4.2 Funding Issues

John Peek (1999:18) argues that the public funding of infertility treatment in Aotearoa/New Zealand has developed in an informal and unplanned way. Professor Bonham began storing frozen sperm at National Women's Hospital in the late 1970s and by the early 1980s university based donor insemination clinics had been established in Auckland, Wellington, Christchurch, and Dunedin. These clinics used university funds and resources and, consequently, the universities unwittingly provided 'free' treatments.

In Wellington, infertility service was done by John Hutton through the university. He hived off university employees to provide technical services and the technical input was from people on university salaries. The same thing really happened in Christchurch. (John Peek, Interview: 12 July 2000)

In 1983, the first IVF programme was set up at National Women's Hospital using "borrowed staff, borrowed equipment, and borrowed space" (Peek, 1999:18).

Our hospital board did not even know that they had an IVF program until there was a picture of an ultra sound scan of the first baby on the front page of the Herald. That is when the Auckland Hospital Board discovered that there was an IVF program in one of its hospitals. ... So it has had a history of never being funded but sought of a wedge has been stuck in the system somewhere and you slowly try to lever [more money out of it.]

(John Peek, Interview: 12 July 2000)

The Auckland Hospital Board eventually provided funding for staff and diverted additional funds from elsewhere in the hospital system. Eventually the programme incorporated the existing donor insemination and ovulation induction programmes. The IVF programme treated people from throughout Aotearoa/New Zealand and "the inability of this sole public clinic to cope with demand led to the opening of private clinics" (Peek, 1999:18). Blank (1995:14) argues that the public does not create the initial demand for biomedical technology and that scientists initiate medical research and development, based on their own perception of the need. Consequently, scientists create potential needs that require the availability of new resources. Demand for access by medical professionals and patients increases once the innovation invokes media attention. Increased publicity and availability eventually leads to expectations by the consumer public that these innovations will be readily accessible and available for their benefit and, as such, the demand for access increases (Blank, 1995:14).

In 1987, Freddie Graham and Richard Fisher established a private clinic in Auckland called 'Fertility Associates' (2001b: <http://www.fertilityassociates.co.nz/about/index.html>).⁷⁵ By 1993,

⁷⁵ Graham and Fisher had previously overseen the infertility programme at National Women's Hospital.

there were two private clinics in Auckland and IVF programmes in Christchurch and Wellington. According to John Peek, public funding was subsequently distributed throughout the regions based on how many people from these regions had previously been accessing treatment in Auckland.

Public funding for infertility really started in Auckland and, for a few years, Auckland was the only place with an IVF program so that people would come from all over the country. Then when they divided up into regions they just said, "Well how many people have been coming from Wellington to Auckland for treatment?" Of course, that was relatively low and so there was relatively less funding in those areas.
(John Peek, Interview: 12 July 2000)

Infertility programmes outside the Auckland region received less funding because they had previously been a minority source of patients for the National Women's infertility programme. As Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) indicates, this minority status resulted from the geographical location of the initial IVF programme and a lack of resources by potential clients to finance travel and accommodation rather than from any indication of actual demand.

...back in 1984 National Women's Hospital looked at the socio-economic grouping of the people who were seeking IVF. People at that stage had access from all around the country. What that study showed was that disproportionately more people sought treatment from the Auckland region than would be representative on a population basis. Which is a geographical bias and that is because the service was accessible and ... had a higher profile than [for] somebody living in Invercargill. It was also more accessible because it was geographically close and still the socio-economic groupings were above the average for the population. So it was still seen as the domain of those who maybe were well informed.
(Rodney Bycroft, Interview: 13 September 2000)

At the same time as IVF programmes were being established nation-wide, health sector reforms were being initiated in an attempt to establish a quasi-market that would ensure better access and use of resources by separating the roles of purchaser and provider of health services.⁷⁶

When the old hospital boards broke up or were replaced by the Regional Health Authorities they just inherited the budgets for those areas.
(John Peek, Interview: 12 July 2000)

In 1992, the National Advisory Committee on Core Health and Disability Services was set up to establish the "boundary between health services that should reasonably be paid for (in whole or in part) by the state, and services that should be the responsibility of the individual" (Cheyne, et al., 1997:239). While attempting to retain the "principles of universal access to health care", the government decided to restrict the range of publicly funded health services to an explicitly

⁷⁶ Area health boards were reconfigured into Crown Health Enterprises (CHEs) and four Regional Health Authorities (RHAs) (Cheyne, et al., 1997:239). It was the role of the RHAs to purchase health services according to what they perceived to be the health service requirements of their populations.

defined list of 'core' health services that would be revised annually (Hunter, 1997:103; Ashton, 1999: 138).⁷⁷ Coney (1999a:23-24) maintains that infertility services were often used in discussion documents as an example of what services might not be part of the 'core'. However, within seven months of its appointment the Advisory Committee abandoned the concept of a specifically defined 'core'. They took the view that all existing publicly funded services should be regarded as the 'core' and began modifying access to these services. Attention turned towards evidence-based medicine, clinical effectiveness criteria, and the development of guidelines (Hunter, 1997:104; Ashton, 1999:138).

In line with this change of focus, Wayne Gillett, John Peek, and Richard Lilford (1995)⁷⁸ were commissioned to provide a report to the National Health Committee⁷⁹ on the costs and effectiveness of infertility services in Aotearoa/New Zealand. According to the National Health Committee (1996), thirteen of the seventeen submissions they received in response to the report supported public funding.⁸⁰ In response to increasing surgical waiting lists and waiting times between 1993 and 1996, the National-New Zealand First Coalition Government initiated a points-based priority criteria system to determine who was eligible for publicly funded health care (Ashton, 1999:145).⁸¹ The points system has been widely interpreted as another way of cutting health spending and in 1997 "approximately 30000 people were removed from waiting lists because they were not deemed sick enough to be eligible for publicly funded surgery" (*New Zealand Herald*, 21 October 1997 in Ashton, 1999:145). It was within this context that the National Health Committee commissioned the development of access criteria to ascertain who would have "the greatest potential to benefit from receiving publicly funded infertility services" (1996).

⁷⁷ These 'core' services were to be defined by examining the costs, effectiveness, and benefits of each service, as well as through public consultation (Cheyne, et al., 1997:228).

⁷⁸ Wayne Gillett is an academic from Dunedin who had expertise in tubal surgery and IVF; John Peek is the Scientific Director of Fertility Associates, based in Auckland; and Richard Lilford is an English academic with an interest in the epidemiology of infertility (Peek, 1999:18).

⁷⁹ In 1995, the Advisory Committee was renamed the National Advisory Committee on Health and Disability Services (the National Health Committee) to reflect its change of focus and its extended control over public health services (Ashton, 1999:138).

⁸⁰ Five were from individuals, four from health care providers, five from advocacy groups, and one each from the Ministry of Women's Affairs, the General Practitioners Association, and the Royal New Zealand College of General Practitioners (National Health Committee, 1996).

⁸¹ The criteria combine clinical factors, such as the severity of the illness and effectiveness of treatment, with social factors, such as the ability to work and to care for dependants. Higher priority patients acquire a higher point score, which helps clinicians to decide who should be treated and when. The level of funding determines the number of points (the threshold) at which a patient can expect treatment (Hunter, 1997:106-107).

By 1996, the National Health Committee (1996) and its predecessors had received forty submissions on infertility services, “the majority of which were from affected consumers who support public funding of infertility services”. The National Health Committee considered these submissions in conjunction with the submissions received by the Ministerial Committee on Assisted Reproductive Technologies (MCART, 1994)⁸² and concluded that

After considering all the submissions, reports and analyses, the National Health Committee is of the view that infertility services should receive public funding. However, the extent of those publicly funded infertility services and the terms of access have yet to be determined. (National Health Committee, 1996)

The Committee did not explain how or why it had come to this decision, given that it had previously acknowledged that many of the submissions to MCART had rejected public funding. Blank (1994:12) suggests that policymakers will retain the support of the public as long as they talk in general terms with regard to rationing or discontinuing health care expenditures. However, as soon as they are specific about what services they are intending to cut they tend to face opposition from actual and potential stakeholders. As a consequence, policymakers are unlikely to accept any technology assessment that recommends that a procedure should not be funded (Blank, 1994:12).

Those involved in both the provision and funding of services have raised questions about the public funding of ART practices.

One of the key [questions] is do we purchase infertility services [at all]? And, you would be aware that fertility services have been [funded] in a haphazard, inequitable way. My view is that it has not been a funded service. So, we could never really say that we did provide a publicly funded service because it was so infinitesimal that you could not actually provide a system. ... So, I think that is one thing about it, is deciding whether we are going to provide it full stop, and if we are going to provide it, if fertility as a service is a publicly funded service, then there has to be some policy stuff around that. The policy, I suppose the additional funding has come about in that the HFA decided that it would in fact purchase infertility services as a part of the core services and that has just happened with this new money. For the first time in New Zealand has fertility services been considered to be part of the core.

(Helen Williams, Interview: 29 August 2000)

Helen Williams (Policy Analyst, Elective Services Project, HFA)⁸³ implies that the question of

⁸² In 1994, the MCART had received almost one hundred submissions in relation to its consideration of ART practices in New Zealand. The National Health Committee (1996) noted that “MCART supported public funding, even though many submissions to that committee did not”.

⁸³ A change in government in 1996 led to further changes in the health system and on 1 July 1997, the RHAs were officially combined into the Health Funding Authority (HFA). The HFA's responsibilities included determining health care needs and developing, implementing, and managing contracts with providers.

funding infertility services in Aotearoa/New Zealand has been answered by the provision of more money and the incorporation of the services within the 'core' public health services. However, as with the National Health Committee, she fails to explain what decision-making processes and values were used to reach this decision. The failure of policy-makers to provide reasons for their decisions in relation to ART practices is typical of a 'muddling through' policy process.⁸⁴ The time, information, and reasoning constraints associated with biomedical developments contribute to an incremental approach to policy-making, which often involves limited analysis and ignores many values and alternatives (Mendeloff, 1985:82-85). Consequently, this process simplifies the search for political solutions by avoiding having to justify decisions by reference to general ethical principles that may be used to appeal later decisions. Therefore, unjustified decisions allow policymakers greater flexibility in their responses to individual cases. John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland), who operates within the public/private field of infertility treatment, echoes Helen Williams funding concerns.

I think that either you should have a generous amount of public funding or no public funding. At the moment, there is so little that the rationing is so severe and so illogical.
(John Peek, Interview: 12 July 2000)

Given that the task of matching supply and demand is the responsibility of the providers, they frequently face the difficult undertaking of refusing people treatment because of a lack of resources. It may be that providers would prefer not to have to make decisions on the allocation of such scarce resources and would prefer the government to make a unilateral decision to cease funding entirely rather than maintain an ineffectual system of rationing a severely constrained budget.

The National Health Committee (1996) claimed that it had "established a working group to develop the cost effectiveness report into access guidelines". The 'working group' consisted of two of the authors of the original costs and effectiveness report (Gillett, Peek, & Lilford, 1995), both of whom worked in the provision of ART services.⁸⁵ They were directed to develop criteria to that could be used to determine who has the greatest probability of benefiting from publicly funded infertility services and to provide advice "on the type of infertility services that should be purchased to ensure the most effective use of public funds" (National Health Committee, 1996).

⁸⁴ Lindbolm (in Green & Thorogood, 1998:12) describes the policy process as an incremental process of 'muddling through' rather than one of rational planning.

⁸⁵ At the time of publication Wayne Gillett was an Associate Professor with the Department of Obstetrics and Gynaecology at the University of Otago. John Peek was the Scientific Director of a private fertility clinic (Fertility Associates) in Auckland.

Wayne Gillett and John Peek produced *Access to Infertility Services: development of priority criteria* (1997),⁸⁶ which was intended to help frame the Committee's "formal recommendation to the Minister of Health" (National Health Committee, 1996). The proposed priority criteria were intended to introduce a nationalised system for establishing treatment eligibility and were based on the "possibility of a successful outcome" (a resulting pregnancy), as well as certain social criteria (Coney, 1999a:24). However, the planned recommendations to the Minister on the level of funding never eventuated (Peek, 1999:19).

Basically, the National Health Committee and its predecessors recognised that infertility was something that they could chip off around the edges. ... The Core Health Services Committee really looked around the periphery at health to see what little things [they could] chip off and they looked at human reproductive technology and fertility and commissioned Wayne [Gillett] and I to do those studies. But, there really was no mechanism once those studies were done, to actually make it happen in the Health system. They presented it to the corporate services committee and then it was supposed to be up to the Minister to decide how they were going to implement it. I do not think that was ever done.

(John Peek, Interview: 12 July 2000)

The National Health Committee's reticence in making recommendations to the Minister of Health and inaction with regard to the access criteria, combined with contract negotiations based on historically inequitable funding practices, contributed to nation-wide inconsistencies in funding, service provision, and access criteria across the different health funding regions throughout Aotearoa/New Zealand. By maintaining the status quo in relation to ART funding, there is no consciously made decision to deliver less and health professionals and consumers in some regions are conditioned over long periods of time to expect and demand less service than is offered in other regions (Klein, et al., 1996:68). This supports Klein, Day, and Redmayne's (1996:67) claim "that non-decisions are as important as decisions." So, services are rationed by allowing the "the lottery of history" to determine who gets what and, as a consequence, the lack of supply creates its own lack of demand (Klein, et al., 1996:68).

In 1999, John Peek identified continuing funding inequities between the four health regions in Aotearoa/New Zealand.

Public spending on infertility treatments ranges from \$0.71-\$0.75 per head in the Northern and Southern regions, to only \$0.27 in the Midland region. IVF patients in Midland and Central still have to pay for drugs (typically between \$1500 to \$2000 per cycle) unless they have a Community Services Card. The eligibility for IVF treatment varied between regions.

(Peek, 1999:19)

⁸⁶ This document forms the basis of the rationing strategies and access restrictions to publicly funded infertility treatments. It is discussed in Chapter 5, Regulating Access, Section 5.4, The Priority Criteria.

Gillett and Peek (1997:35) argued that the \$4.5 million that was being spent on infertility investigations and treatments at the time could not be fairly distributed using any priority criteria. Moreover, certain aspects of the criteria met with disapproval from infertility societies and the Human Rights Commission (HRC) (Coney, 1999a:24). Nevertheless, some providers adopted the criteria or modified versions of these guidelines in order to access money from the Government's waiting list fund. Although there were some variations in the way the criteria were administered, all four Regional Health Authority contracts used them in some form to limit access to publicly funded treatment. The Northern, Midland, and Central funding regions used 'all or nothing' thresholds for each variable, so that people needed to be eligible at every point in the access criteria to gain access to treatment. The thresholds were similar but not equal in these three regions. The Southern funding region had adopted the draft priority scoring system as developed by Gillett and Peek (1997), applying a threshold of 40 points to the total score (Mark Leggett, Business Manager, The Fertility Centre, Christchurch; Interview: 22 September 1999). Consequently, those seeking to access publicly funded ART treatment were subject to varying restrictions, which were dependent on geographical location.⁸⁷

Disparities also existed in the waiting times for treatment between the four funding regions.

In the Northern region the wait for IVF treatment is 9-12 months with only one IVF cycle offered, while elsewhere up to two cycles are offered but the wait is much longer. Only the Northern region offers an appreciable amounts (sic) of non-IVF treatment, such as DI, AIH or ovulation induction. (Peek, 1999:19)

As Helen Williams (Policy Analyst, Elective Services Project, HFA) points out, there have never been planned policy objectives relating to the provision and funding of infertility services in Aotearoa/New Zealand.

Well, it was purchased by the Regional Health Authorities before the HFA. So, that was why it was regionally variable. My understanding is ... some of it was being purchased through gynaecology and some of it obstetrics and eventually it got filtered out to being infertility. So, it has been an ad hoc historical thing as opposed to a planned policy moving forward to providing a service. ... Now we have moved for the first time to looking [at whether] we should be providing the service at all. I am not aware of any major consumer consultation occurring other than what occurred around the National Health Committee document.

(Helen Williams, Interview: 29 August 2000)

⁸⁷ If those seeking public funding in the Northern, Midland, or Central funding regions failed to reach the threshold for any one of the criteria they were refused access. In the Southern region, the scores for each of the criteria were combined and a formula was used to calculate the final score. Consequently, those seeking funding in this region did not have to pass every one of the criteria to gain access to publicly funded ART treatment.

Correspondingly, John Peek acknowledges the dependence of clinics and consumers on individual interest within the HFA rather than coherent policy guidelines in relation to funding infertility services.

...it has really [involved] people pressing the HFA to say we should be doing something and interested people within the HFA. And, there are one or two people within the HFA that are interested and are trying to tidy up infertility. ... It is usually [people] in the HFA who get responsibility for a certain area and say, "This does not look right. There are huge geographical inequalities and the rules do not make sense" and I guess it is up to people like that to say, "I think I will do something about that." Whereas some other manager might think that it is just too much small funding and anomaly, [and] they will let [it] sit.

(John Peek, Interview: 12 July 2000)

As with ART policy formulation in general, ART funding policies have developed and been implemented in an *ad hoc* and reactive fashion. Levels of public funding for ART have been based on historically determined need, as defined by the numbers accessing the original IVF services in Auckland rather than national population requirements. Until recently, access criteria were negotiated as part of the Health Funding Authority (HFA) contracts. However, additional funding and changes to access restrictions were introduced in 2000 in an effort to reduce existing inequalities.

4.3 Changes in 2000

In August 2000, the HFA implemented changes to the funding and provision of public infertility services in an attempt to resolve existing inconsistencies in funding and access. In addition to allocating an additional \$3.7 million in funding to tertiary infertility treatments, the organisation amended the services specifications for infertility treatment contract holders and introduced the national referral guidelines and the Clinical Assessment Criteria (CPAC) for treatment of infertility (Health Funding Authority, 2000a). However, existing disparities in funding and access criteria had been created through a lack of attention to national population requirements and the changes have been based on these existing inequities. Policy decisions regarding the allocation of resources for the management and treatment of infertility should be based on accurate prevalence data (Brander, 1991:9). However, there has been little investigation into the prevalence of infertility or into the utilisation of ART services in Aotearoa/New Zealand.⁸⁸ Information on the prevalence of infertility used to guide policy formulation has been obtained from international studies (Gillett, et al., 1995:13), literature reviews (Brander, 1991:9-13), and

⁸⁸ I address the consequences of this for Māori in Chapter Six, Addressing Difference: Māori Infertility & ART.

a local survey into the contraceptive practice of 1000 women aged between 25-44 years of age (Paul, et al., 1988:812).⁸⁹ According to Gillett, Peek, and Lilford (1995:37), the only comprehensive information on the treatment and outcomes of infertility in Aotearoa/New Zealand is from the Dunedin Database.⁹⁰ However, Helen Williams (Policy Analyst, Elective Services Project, HFA) suggests that the collection of information on the use of infertility services may improve with the changes initiated by the HFA to the services specifications for public infertility treatment.

We have had even less information on infertility ... we do not collect it on the National Data System because it is an outpatient service. We have a quarterly report where we collect data for elective services ...on who is waiting for the quarter and for the year and all that stuff. We have not been collecting infertility data in that but we are just going to start. ... So, we are changing the service specifications and getting them to national consistency. We are actually putting in a whole lot of reporting requirements, which will be national. But [the clinics] report and are accredited by RTAC so it would be [foolish] for us to duplicate that so we may very well use some of RTAC's information.

(Helen Williams, Interview: 29 August 2000)

Nevertheless, it is too soon to tell whether these changes will provide accurate information on the use of infertility services in Aotearoa/New Zealand. As Helen Williams suggests, information collected by the Reproductive Technologies Accreditation Committee (RTAC) may be used and it

⁸⁹ The results of the Aotearoa/New Zealand study suggest that 3% of married women between the ages of 25-24 years could be classified as infertile. However, the authors noted that the definition they used for infertility might have resulted in an underestimation of prevalence (Paul, et al., 1988). However, Brander (1991:1) claims that the "most recent reliable estimates of prevalence suggest an infertility rate of at least 14% for industrially developed nations." MCART (1994:5) claims that most estimates of prevalence of infertility for Aotearoa/New Zealand and other western societies have ranged between 10%-20%. Increases in the supply and demand for services are assumed to relate to delayed childbearing, aging populations, increasing treatment options, and increasing service consultations, rather than increases in the overall incidence of infertility (Brander, 1991:1). Nevertheless, it is estimated that only 50% of women with primary infertility consult services for advice and/or treatment (Brander, 1991:3). The definition of infertility and methods of measurement have a significant effect on estimates of prevalence. Although the World Health Organisation (in MCART, 1994:4) referred to infertility as the failure to conceive after 2 years of "exposure to pregnancy", Gillett, Peek and Lilford (1995:13) define infertility as "the inability to conceive after 1 year of trying for a pregnancy." However, they note that this definition is arbitrary and that using a 2-year definition would "reduce the resources required for the assessment and treatment" (Gillett, et al., 1995:13). Moreover, the motivation for determining the incidence of infertility has an effect on the method of measurement. In countries where infertility is perceived to be a health problem and publicly funded, a focus on the numbers presenting and requiring treatment will be relevant as estimates based on service utilisation undoubtedly result in an underestimation of prevalence (Brander, 1991:12-13). However, if the aim of the measurement is to "assist population projections or interpret patterns of fertility, a focus on the numbers who have been unable to conceive after a year or more of unprotected intercourse" will provide a more accurate measurement of infertility (Brander, 1991:12).

⁹⁰ This database was established in 1986 as a joint clinical and research tool to assess diagnosis and outcome of infertility treatment. It is based on referrals for infertility to the Dunedin Hospital clinic from the Otago region and does not include IVF referrals until 1994 when IVF Otago and the Dunedin Hospital clinic were merged to form the Otago Fertility Service (Gillett, et al., 1995:37).

is unclear whether this data will be presented as country-specific or amalgamated with Australian data, as with the success rate information collected by RTAC. Although statistical information cannot illustrate how social inequities are produced or how policy can address these inequities, they are a useful device for documenting and monitoring of policy outcomes (Green & Thorogood, 1998:79-81; Reid, 1999b:84).⁹¹

Perhaps the most influential move so far, in relation to reducing geographical inequalities in access, has been the re-classification by the HFA of public infertility treatment as a 'core' health service.⁹²

Fertility is now seen as part of the core services ... [that] means that DHBs will be obliged to provide services.

(Helen Williams, Interview: 29 August 2000)

According to Helen Williams, this re-classification means that regional health and disability service providers can no longer choose not to purchase tertiary infertility services. The changes are aimed at extending the coverage of ART services, reducing waiting list periods to a maximum of six months, and eliminating inequalities in the services provided throughout Aotearoa/New Zealand. However, what will happen in practice is still uncertain as the District Health Boards (DHBs)⁹³ take up their responsibilities and the Ministry of Health absorbs some aspects of HFA policy work.

...all I can see with the DHBs is that it is going to fragment this process. That we will not have national consistency and it should not depend on where you live. You should be able to access the public health system.

(Helen Williams, Interview: 29 August 2000)

Sue Bagshaw (Medical Training Co-ordinator, Family Planning Association, Christchurch) expressed similar concerns in relation to national consistency in access criteria.

...with DHBs there is a possibility of that getting even worse. ... You can just see 21 different funding criteria, different access criteria evolving. ... But, the worry is that because there are so many of them we will not get any national consistency.

(Sue Bagshaw, Interview: 21 August 2000)

Devlin, Maynard, and Mays (2001) question the effectiveness of establishing 21 health districts, some of which have small scattered populations. They suggest that smaller districts may find it

⁹¹ See Chapter Six, Addressing Difference: Māori Infertility & ART, Section 6.4, Being Counted, for a discussion of the consequences, for Māori, of not collecting information on service utilisation and the prevalence of infertility in Aotearoa/New Zealand.

⁹² Although the establishment of specifically defined core services was 'officially' dropped, it is apparent that the HFA still works within certain parameters of this concept.

⁹³ District Health Boards have a majority elected membership, as well as Government appointed members to complement those elected. From the enactment of legislation in 2000 until elections in 2001, the Government appointed Transitional District Health Boards (Ministry of Health, 2000).

difficult to manage their population-based financial resources in an equitable and justifiable manner. The kind and amount of secondary and/or tertiary infertility services provided by the individual districts may be prioritised according to how the DHBs interpret their populations' past use of such services rather than on evidence-based needs.⁹⁴ Such prioritising will further undermine the goal of national consistency in access to infertility and ART services. Publicly funded ART services are currently provided by a small number of specialised provider clinics and, while the DHBs may provide ART services by contracting to existing providers, concern has been raised that preference may be given to public providers rather than private clinics (Ken Daniels, Interview: 31 August 2000). In addition, private providers may have to apply for public funds and negotiate contracts with potential competitors.⁹⁵ Services may also be centralised within the districts, effectively maintaining the status quo and limiting access by geographical location. Consequently, patients will still have to travel to access treatment that can sometimes involve staying for several days, adding accommodation costs to travel costs. Although the travel and accommodation allowances previously available on application to the HFA will no doubt still be available, the added burden of applying for such benefits may deter consumers from accessing such benefits. Therefore, the inequalities in the provision of services may be replicated and/or exacerbated under the new system.

What we do not know is ... how far the money is going to go ... so we have set the threshold at 65 provisionally. We have said we will review it in 3 months time. I suspect that 3 months is probably going to be a bit soon. We may well end up reviewing it at 6 months.
(Helen Williams, Interview: 29 August 2000)

It is too early to predict how effective the additional money and changes in access criteria will be in improving inequities in funding and access, or in reducing waiting lists.

By raising the point threshold (in some regions) some people who had previously been 'approved' for public funding will no longer qualify. With the introduction of the national CPAC, those who were admitted to the Christchurch waiting list prior to the 30 June 1998 were assured treatment. However, those admitted after 1 July 1998 have to undergo reassessment using the new threshold (Personal Communication, December 2000).⁹⁶ In Christchurch, where the threshold was 40 points, this may eventually mean a reduction in those who make it onto

⁹⁴ As discussed earlier in relation to the initial funding decisions for regionally based IVF programmes.

⁹⁵ Since the existing infrastructure of hospital management is being used as the initial basis of the DHBs and the population that each board will be responsible for approximates the local catchment of its hospital, the funders (DHBs) will also be involved in the provision of some competitive services (Devlin, et al., 2001).

⁹⁶ Telephone conversation with the waiting list manager of The Fertility Centre, Christchurch, December 2000.

the waiting list. However, in December 2000, there was a 2½-year waiting list in Christchurch for publicly funded access and a recent newspaper report stated that the waiting time in Christchurch has actually increased and people now face a three to five year wait for publicly funded treatments (Watson, 2001:3). In Auckland and other regions that previously administered 'all or nothing' access criteria (100 points), the introduction of the national CPAC will possibly lead to increased waiting lists as more people will be eligible under the new threshold of 65 points. Nevertheless, recent reports suggest that there has been a reduction in the waiting time for IVF treatment.⁹⁷ Even if people do access the waiting list they are likely to become discouraged by the delay and either pay for the treatment themselves, if possible, or withdraw completely. John Peek supports Ashton's (1999:145) argument that the waiting lists work as an implicit form of rationing, in that the presence of the waiting list deters people from applying for treatment.

We used to have a 3 to 4 year waiting list of which 30-40% of people used to drop out on the waiting list because they would seek private treatment. They got sick of waiting, looked at other options, or just got lost. You can get away with any amount of rationing if your waiting list is long enough because people drop off or get too old or whatever in the process.

(John Peek, Interview: 12 July 2000)

Mechanic (1995) maintains that restricting the resources available in any health area and imposing access controls through waiting lists is easier and less controversial than imposing explicit exclusions. Even with the increased funding, it is evident that the waiting lists continue to affect access to publicly funded ART treatments.

Although the amended service specifications (Health Funding Authority, 2000b: see Appendix L) standardise the types of services that can be publicly accessed and remove co-payments for drugs, they also specify a limit of one IVF cycle,⁹⁸ or other clinically appropriate treatments to the same value, for those who meet certain points within the CPAC (Health Funding Authority, 2000a). Robyn Scott (Executive Officer, New Zealand Infertility Society (NZIS), Interview: 26 July 2000) suggests that one IVF cycle would be ineffective for most women as the only way of perfecting individual responses to drug levels and treatments is through repeated cycles.

⁹⁷ In June 2001, Fertility Associates' Newsletter reported reduced waiting time for IVF treatment in all regions of the North Island and claimed that the "level of funding should allow treatment within 6 months of enrolment, once the initial backlog has been cleared" (Fertility Associates N.Z., 2001a).

⁹⁸ IVF is a 'cycle' of treatment involving several discrete stages, all or some of which may be repeated at varying intervals. These treatments include drug-induced ovulation, egg retrieval, insemination, fertilisation, embryo culture, and embryo transfer (Farquhar, 1996:134).

However, she acknowledges that “one fully funded cycle is still a diagnostic tool.”⁹⁹ Similarly, Mark Leggett (Business Manager, The Fertility Centre, Christchurch, Interview: 22 September 1999) argues that “your best results [are] over 3 [IVF] cycles.” Scott believes that reducing the number of IVF cycles per funded treatment is a way of redistributing the available money and reducing the waiting lists.

I think national criteria will give more people a chance to access treatment, which is why it has to be funded differently. But, then we are going to reduce the amount of treatment that is available to people who qualify so we “rob Peter and pay Paul”, the usual story.
(Robyn Scott, Interview: 26 July 2000)

Klein, Day, and Redmayne (1996:12) describe this as rationing by dilution, whereby offering a reduced scale or ‘depth’ of service decreases demand. Although there will be an increase in overall availability, the amount of treatment for those who qualify for public funding will be reduced. As a consequence of restricting the publicly funded IVF treatments to one cycle, it is likely that clinics will be more willing to support and enforce access restrictions that ensure only those with the highest chances of success are treated within the public system. Clinics’ reputations attract private consumers and these reputations are primarily based on the number of successful conceptions and pregnancies. As most of the clinics also operate within the private sector, they are dependent on reputation and success for their survival in a competitive market, as well as when competing for public contracts.

Reputation is everything in the industry. Well, success and reputation, particularly in a competitive environment like in Auckland where you have three or four centres. Reputation and results are key. Branding is important.
(Mark Leggett, Interview: 22 June 2000)

The results from publicly funded treatments are incorporated into the clinics’ overall results and the restriction on repeated cycles imposed by the changes to funding will mean that the clinics will want to ensure that their chances of success are as high as possible for each publicly funded treatment.

In New Zealand, we report our results, along with all the Australian clinics, to the National peri-natal statistics unit in Sydney but they are all anonymous so they are just abc’s. You can usually work out a few of them.
(John Peek, Interview: 12 July 2000)

⁹⁹ Cussins (1998:76) argues that all fertility clinics base their predictions of success on statistics, and that such predictions legitimate doing the same thing again in the face of failure because the statistical probability of never succeeding reduces as the number of attempts increases. To support this rationale for continuing treatment, each attempt must be exactly the same as the one preceding it. However, each cycle is often “fine-tuned” to allow for individual hormone responses to drugs or poor oocyte maturation. Consequently, practitioners have no way of knowing if the failure to conceive is a statistical “dry run” or an indication that the procedure has been changed in a relevant and detrimental way. Therefore, cycles can be disregarded as “crucially not the same and so not counted” (Cussins, 1998:76). Therefore, slight alterations in drug levels, procedures, and timing provide a reason for proclaiming every failed attempt as a diagnostic tool.

Although the results from Aotearoa/New Zealand clinics are amalgamated and supposedly anonymous when published, the size of the ART community, combined with word of mouth or clinic self-promotion, will ensure that the clinics' success rates are easily attainable or deducible.¹⁰⁰

The NZIS Executive Officer sees the restriction to one fully funded IVF treatment as effectively setting the providers and the consumers against each other and breaking down a traditional coalition of support.

One cycle is much easier for the clinic to administer. The clinics are not totally opposed; I mean they are not opposed to it at all.

(Robyn Scott, Interview: 26 July 2000)

She also expressed concern over how increasing private business, through the efforts by providers to attract international clients, may affect this alliance. Although supportive of the necessity for providers to sustain and build their businesses, she expressed some apprehension over the possibility that such moves may also affect the levels of support they have previously shown public consumers.

...it has never been an issue in the past. The people who laid the foundation stones for the infertility industry have always been such huge supporters of the consumers that I really do not know! Certainly there are some indicators now that perhaps the business ethic, where the private work is worth a lot more than the public work, that maybe that will become more of an influence. And, I think that is a shame.

(Robyn Scott, Interview: 26 July 2000)

Past funding decisions or 'non-decisions' are also seen as placing people with infertility problems in opposition to people who have unlimited access to publicly funded maternity and reproductive health services.¹⁰¹

I can understand the HFA. The Health dollar does not stretch to infinity. However, I really take umbrage with the fact that reproductive health in terms of infertility is completely singled out. We do not ration antenatal services, we do not say you can have 1.9 children [and] after that, you start paying for your own maternity care. We do not ration family planning services and we certainly do not ration terminations! Now when you have unlimited access to those services you

¹⁰⁰ For example, see *Information on Assisted Reproductive Technology: Treatment procedures, risks and outcomes* (Otago Fertility Service, 1997), *Assisted Reproductive Technologies* (Serono Colloquia Australasia, 1997a), and *In-vitro Fertilisation & Associated Procedures: Success Rates with IVF* (New Zealand Centre for Reproductive Medicine Ltd, 2001).

¹⁰¹ According to Peek (1999:20), the total public funding spent on elective reproductive services is approximately \$300 million annually. At the time of the interviews for this thesis, approximately \$4.5 million was spent directly on ART services. Much of that money was spent on investigations and only \$1.5 million was spent on ART treatments. Elective reproductive services include antenatal care, obstetrics, postnatal care, family planning, and abortion services. Therefore, it should be noted that individuals with fertility problems also have access to reproductive health services, such as the Family Planning Association and maternity service funding, if pregnancy is achieved. In addition, not all those diagnosed as 'infertile' will seek ART treatment in order to overcome the problem.

do have a lot of choices. When you are infertile you have [severely constrained] choices!
(Robyn Scott, Interview: 26 July 2000)

Consequently, consumer representative groups may face an undermining of their ability to influence policy decisions. Consumers are not represented on NECAHR and have limited representation on RTAC. If their coalition with the providers is strained or fractured, they may find it more difficult to be heard and influence policy decisions, particularly funding decisions.

At the time of writing, it is too early to tell whether additional funding to tertiary infertility treatments, changes to access restrictions, the reduction of services, and the reclassification of infertility treatment as a 'core' service, combined with the effects of the health service reforms, will help to reduce or simply exacerbate the existing inequalities.

4.4 Conclusion

As discussed in the previous chapter, ART policy in Aotearoa/New Zealand has developed in an *ad hoc* and reactive manner. Likewise, the introduction and maintenance of public funding for ART treatments has been informal and unplanned. The provision of ART services within the public health system began as part of a research strategy at National Women's Hospital in the early 1980s and, as interest and demand grew, services were extended to other regions. Although funding for the Auckland service was initially provided by default through the provision of staff and facilities, the Auckland Hospital Board eventually incorporated an IVF programme into its funded services and treated people from throughout Aotearoa/New Zealand. With the development of IVF programmes in other regions, funding was re-distributed based on the number of people from these regions who had been accessing treatment in Auckland. Consequently, there has been little detailed consideration given to the population requirements for such services and no coherent discussion of what funds would be required to provide an equitable service throughout Aotearoa/New Zealand. The geographic and financial constraints that affected the level of access by people from outside Auckland were not taken into account and, by the early 1990s, inequitable provision of services and public funding had evolved throughout Aotearoa/New Zealand.

In response to health sector reforms and the introduction of explicit rationing strategies, the National Health Committee commissioned an investigation into the costs and effectiveness of infertility treatment in Aotearoa/New Zealand. Based on this report (Gillett, et al., 1995) and in response to supportive submissions between 1993 and 1996, the National Health Committee decided to continue funding ART services. The introduction of points-based priority criteria to

reduce waiting times and waiting lists in 1996 prompted the National Health Committee to commission the consultation document, *Access to Infertility Services: development of priority criteria* (Gillett & Peek, 1997). This document was intended to provide a framework for funding recommendations to the Minister of Health, as well as provide a structure for the introduction of access criteria on a national basis. Nevertheless, the National Health Committee failed to make funding recommendations to the Minister of Health or to introduce the national access criteria for publicly funded ART treatment. Consequently, nation-wide inconsistencies in funding, service provision, and access restrictions prevailed and these inequities were exacerbated by disparities in the waiting times for treatment between the four health funding regions. By failing to make decisions regarding the inequalities in the level of funding, the National Health Committee maintained the status quo and did not have to justify any increase or reduction of funding in relation to ART treatments. Individual clinics and consumer groups were left to canvass these issues with the Health Funding Authority, relying on the personal interest of administrators rather than consistent policy guidelines to overcome the deep-seated inequalities in access to and funding of public ART services. Funding authorities and service providers face considerable difficulties in allocating severely constrained resources and both providers and administrators have raised questions about the continued funding of such services. Invariably, a decision by government to cease funding completely would reduce the strain of trying to match supply and demand, as well as the face-to-face burden clinicians encounter when having to refuse people treatment for financial reasons.

In August 2000, the HFA increased funding, incorporated ART treatment into the 'core' services provided in each region, amended service specifications, and introduced national referral guidelines for ART treatment and Clinical Assessment Criteria (CPAC) (see Appendix K). These changes were aimed at extending the coverage of ART services, reducing waiting list times, and eliminating the regional inequalities. However, these changes were not based on information regarding the prevalence of infertility or utilisation of ART services in Aotearoa/New Zealand. Therefore, additional funding appears to have resulted as a contingent response to lobbying by consumers and providers and has built on existing inequitable funding decisions. The changes to the public provision of ART services occurred in an environment of further health sector reforms, which included the disbanding of the four Regional Health Authorities and the HFA and the establishment of 21 District Health Boards (DHBs). As part of the funding reforms, the points threshold for the priority criteria was standardised across regions and funding was limited to one IVF cycle or equivalent-value treatment. Consequently, the HFA has increased the overall availability of services but diluted the amount of treatment available to those who

qualify for public funding. Provider support for these changes and consumer resistance to the dilution of services may affect the long-standing alliance between providers and consumer support groups, thus undermining consumers' ability to influence the policy debate. Funding decisions have been based on historical perceptions of need, as indicated by the initial demand for services and recent attempts at addressing regional inconsistencies in funding have not taken into account actual levels of infertility in Aotearoa/New Zealand nor considered regional population requirements. Uncertainty remains about the effectiveness of the changes, as the newly introduced DHBs may maintain the centralised location of services and funding and access may continue to be prioritised according to historical use of services by their populations. At the time of writing, the increased funding, national CPAC, and health sector reforms have not been operational long enough to evaluate the effect of the changes.

The rationing of publicly funded ART treatment combines both implicit and explicit approaches, including restricted funding, waiting lists, a reduction of services offered, and the introduction of the CPAC. Funding decisions based on historical interpretations of need have combined with the normative definitions of family that underlie the Status of Children Amendment Act 1987 (SCAA) to influence the restriction of access to ART practices. In the next chapter, I will discuss how access to ART treatment is regulated by social judgements about the 'worthiness' to parent and the implications of this situation for individuals and couples who wish to use ART services.

5

Regulating Access

Reproductive technologies serve as a litmus test for concerns about contemporary relations to nature and children, about who can and should parent, about what families can and should look like.
(Farquhar, 1996:10)

5.1 Introduction

Access to assisted reproductive technology (ART) services in Aotearoa/New Zealand has always been restricted in some way. Initially, these restrictions were not solely related to resource constraints, and marital status and sexuality were used to limit access to ART treatments. Although providers have relaxed these access restrictions in relation to private treatment, access to publicly funded treatment is dependent on meeting tightly constrained criteria, which have been influenced by the values that motivated the original access restrictions. As described in the previous chapter, health sector reforms and resource constraints influenced the development of explicit rationing strategies in the form of the Clinical Assessment Criteria (CPAC) to limit demands for ART services in Aotearoa/New Zealand. Although explicit in the sense that they provide guidelines for decision-making, I argue that little or no attention was paid to the values that underlie the inclusion of several social factors in the development of the criteria. As a consequence, the CPAC rely heavily on social judgements of 'worthiness' to parent.

Although the problem of allocating scarce health care resources has always existed (Hunter, 1997:17), demographic changes, advances in medical science and technology, and rising public expectations of availability and standards of service means that these resources will continue to be constrained (Klein, et al., 1996:vii-viii). Consequently, it will not be possible to meet all health care needs and demands now or in the future. As Klein, Day, and Redmayne (1996:139) argue, there will never be a perfect solution for deciding who should receive treatment when

resources are severely constrained. Therefore, setting priorities and deciding how to distribute limited resources will continue to be a political and managerial necessity (Hunter, 1997:17). However, relying on explicit guidelines may only mask the fact that clinical decisions are based on value judgements (Hunter, 1997:28). Therefore, I argue that attention should be paid to who sets these priorities and establishes the guidelines and, if social judgements are used to assist in the prioritisation of access, then the judgements that are included should be clearly identified and openly debated.

In this chapter, I investigate how attempts to limit demands for ART services and ration existing resources have privileged certain individuals and groups over others. I examine how access restrictions for both public and private ART treatments have been shaped by the normative definition of family, discriminating against and marginalising individuals who do not conform to certain norms of parenthood. To begin with, I analyse the concept of 'biological infertility' and explore how this concept has been used to justify the exclusion of single women and lesbian couples from access to public funds. I also consider the use of women's age as a limiting factor for access to ART treatment. Following this, I explore how the prioritisation of rights is used to justify limitations on access, while the human rights legislation has been used to expand access limitations. Finally, I analyse the national Clinical Assessment Criteria (CPAC) (Health Funding Authority, 2000a; see Appendix K). I maintain that the CPAC obscures the use of moral and social judgements and relies heavily on social rather than clinical considerations of the ability to benefit from treatment. Although ostensibly used to ration scarce financial resources, I argue that the CPAC effectively regulate who is considered 'worthy' to parent.

5.2 Restricting Access

As discussed in Chapter One, the definition of family as comprising of two heterosexual parents and their children is implicit within the Status of Children Amendment Act 1987 (SCAA) and contributes to the marginalisation of more diverse concepts of family, particularly those recognised by Māori.¹⁰² The dominance of this definition of family has influenced who has access to ART treatments and has been implicit in the formulation of access criteria for publicly funded ART treatment. In the past, only married couples were considered eligible for treatment and de facto couples, single women, and lesbians were excluded. Eventually de facto

¹⁰² See Chapter 1, Introduction, Section 1.4, Families & ART, for a discussion of how the SCAA reinforces the heterosexual, two-parent family as the norm in relation to ART practices.

heterosexual couples in stable relationships were admitted to some programmes (Department of Justice, 1985:13). The Human Rights Commission Act 1977 made it illegal to discriminate on the grounds of sex, marital status, religious belief, ethical belief, colour, race, and ethnic or national origins. The subsequent Human Rights Act 1993 added the new grounds of disability, age, political opinion, employment status, family status, and/or sexual orientation when providing goods and services (Human Rights Commission, 2001). Consequently, moves by certain clinics to prevent a lesbian woman and a couple with disabilities from accessing treatment have been challenged under these Acts and ART providers have gradually relaxed their access criteria (Hamed, 1997).¹⁰³ Although post-menopausal women, single women, and lesbian couples do seek assistance from ART providers to conceive, the majority of people who use ART services are heterosexual couples (Daniels & Burn, 1997:79) and debate has continued over the issue of access by those who do not fit the normative categorisation of 'worthy' parents.

As mentioned earlier, in August 2000 the HFA implemented updated service specifications (Health Funding Authority, 2000b; see Appendix L) and the national CPAC (Health Funding Authority, 2000a; see Appendix K) for the provision of publicly funded ART services. Previous versions of the service specifications assumed heterosexual coupledness throughout. The modified service specifications and referral guidelines endeavour to reduce exclusive language by substituting "individual/couple" where the term "couple" had appeared in earlier versions. While lesbian and gay couples and single men and women are not obviously excluded, the eligibility requirements assume heterosexuality and the availability and/or willingness of a sexual partner of the opposite sex.

*...the services should be available to all people with **biological infertility**, including those whose fertility is or will be impaired by cancer treatment or injury*
(Health Funding Authority, 2000b:1, emphasis added)

The HFA also defines 'eligible' service users as those who are heterosexual and have a physiological impediment that prevents them having children.

*...those who are unable to achieve pregnancy after at least one year of unprotected **intercourse** of attempting (sic), or have **biological circumstances** which prevent them from attempting, or are unable to carry pregnancy to term.*
(Health Funding Authority, 2000b:2, emphasis added)

¹⁰³ See footnote no.48 in Chapter 3, Regulating Practices, Section 3.2, Policy Background.

Similarly, existing contracts are titled "Medical Treatment for Biological Infertility" (see Appendix M) and are interpreted by John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) as referring to heterosexual couples.¹⁰⁴

...the public contract only really covers people with biological infertility so that means only couples, heterosexual couples get treated. Single women, people in lesbian relationships can have private treatment but they are not eligible for public funding.

(John Peek, Interview: 12 July 2000)

By positioning infertility as a biological condition of those in heterosexual relationships, those who do not fit the normative concept of the heterosexual nuclear family are rendered "invisible within the terms of consideration" (Shildrick, 1997:185).

...the current service specifications do not delineate them out. They just say that you have to have a biological infertility so the partner who is receiving the treatment has to have a biological infertility. Social infertility does not count.

(Mark Leggett, Interview: 22 June 2000)

Consequently, it is unlikely that those outside the definition of eligibility, as assessed by the service providers, will gain access to public funds.

The Ministerial Committee on Assisted Reproductive Technologies (MCART, 1994) also differentiates between 'social' and 'biological' infertility, claiming that single women and lesbian couples "while not physiologically infertile are socially infertile" (MCART, 1994:14).

The stated aim of many providers has been to treat the physiologically infertile, and in particular, DI is said to be used for the treatment of male infertility. Because of these aims, most providers to date have only treated couples in stable heterosexual relationships of at least two years duration.

(MCART, 1994:14)

MCART failed to recognise the involvement of fertile women in treatment of male infertility, assuming that infertility is a condition of heterosexual relationships rather than a physiological condition of one individual. This is also evident in the HFA's new service specifications where it is stated that

...each couple will be treated as a unit.

(Health Funding Authority, 2000b:1)

By treating the couple as a unit, different subject positions are collapsed into one category, 'the

¹⁰⁴ Given organisational changes in the health sector it is uncertain whether contracts will be renegotiated with existing providers or whether the biological emphasis will remain. However, it is assumed existing contracts will continue until their expiry date. A personal communication with the Christchurch Fertility Centre (December 2000) suggests that clinics have had no guidelines on how to interpret the new access criteria and therefore will continue to use their existing interpretations until they are instructed otherwise. The use of such discretionary methods could undermine the purpose of the nationally implemented CPAC to create national consistency in referral and access to publicly funded ART treatments.

infertile', making invisible or marginalising those who cannot or do not want to conceive without the assistance of ART because of genetically inheritable conditions, physical disabilities, sexual orientation, or their single status. It also obscures the fact that many of the heterosexual women and men who use ART are fertile. For example, a woman may be able to conceive and carry a pregnancy to term and yet be involuntarily childless because of her relationship with an infertile man. Shildrick (1997:200) claims that male infertility is often 'treated' by undertaking ART interventions and techniques on women's bodies while barely acknowledging that the women have any subject identity. Consequently, the treatment and pregnancy becomes an attribute of the heterosexual couple rather than the individual (Kirejczck in Shildrick, 1997:200). Although infertility and involuntary childlessness can be related issues, the latter is a social condition which can be attributed to a fertile individual's relationship with an infertile partner, sexuality, and/or an individual's single status. Recognising that publicly funded ART is often used to resolve involuntary childlessness rather than infertility for many individuals in heterosexual relationships highlights the discriminatory practices sustained by ART funding policies and the access criteria.¹⁰⁵

In their submission to the Ministerial Committee on Assisted Reproductive Technologies the Women's Health Action Trust (1994) acknowledges the parallel between single women and lesbians and fertile 'involuntarily childless' married women. However, they question whether ART treatment can be justified for any form of social infertility.

Single women, lesbians and fertile married women do have the option of getting pregnant the regular way with a fertile man. While this might be considered distasteful by the individuals concerned, it is possible for them to have a child without medical intervention. It is arguable whether medical resources should be provided in such circumstances.
(Women's Health Action Trust, 1994)

Arguments that claim single women, lesbians, and post-menopausal women (at some point in their lives) are fertile individuals if they "undertake sexual intercourse with a fertile man" (Daniels & Burn, 1997:79) reinforce the distinction between 'social' and 'biological' infertility. However, they disregard the social and moral constraints that prevent people from engaging in casual or temporary sexual encounters, as well as the possible health risks involved. They also seem to place the desire to parent in competition with bodily and sexual integrity and freedom of choice. Conversely, MCART (1994:14) argues that the provision of ART services to lesbian couples and single women may reduce the risk of infection because ART services are "especially designed to minimise the spread of infectious diseases like HIV/AIDS and hepatitis". They also

¹⁰⁵ The access criteria are discussed in Section 5.4, The Priority Criteria, in this chapter.

argue that by allowing these groups access to ART and "the policies which regulate it, the offspring may well have the best chance for obtaining information about his or her genetic origins in future years" (MCART, 1994:14). Nevertheless, the Women's Health Action Trust offers a counter argument.

...people who do not want to conceive by normal sexual intercourse might come to private arrangements in the case of access to sperm. The argument has been put forward that these people run risks of catching infectious diseases where the arrangements are informal. We are not aware that sperm from men informally donating it is any more likely to be infectious than sperm deposited during normal sexual intercourse. Screening for HIV/AIDS and hepatitis is available, so this is a matter of public education for all people. We believe that informal donation of sperm will in any case continue even if the services are provided through clinics, as they are now. Some people do not want to or cannot pay for what is essentially a simple service.
(Women's Health Action Trust, 1994)

While opposed to gamete donation in general, the Women's Health Action Trust appears to support what they call "informal arrangements", arguing that these will continue irrespective of medical intervention. They defend their opposition to donated gametes by arguing that

...the more human the relationships between people, the better the outcome will be.
(Women's Health Action Trust, 1994: emphasis removed)

This argument rests on the assumption that heterosexual intercourse and reproduction are essential to humanness and does not acknowledge that relationships based on this 'essential' ingredient are not always positive or in the best interests of those involved.

Coney (1999a:23-24) argues that restrictions to access apply only to publicly funded services and that those who can pay can access a full range of services in the private sector. However, those making the decisions about who is worthy of treatment in the public sector are generally the same practitioners who treat patients in the private sector and occasionally patients are being treated within both systems.¹⁰⁶ As those who make the decisions about who can access ART are also the people who design and implement the procedures and decide the criteria for eligibility, their personal values and beliefs will be inherent in their decisions (Ministry of Women's Affairs in Henaghan, 1992:198, no.59). Mark Leggett (Business Manager, The Fertility Centre, Christchurch) acknowledged that the clinic enforces its own age restrictions in relation to private treatment.

We will not treat people over 50. They have to be clinically appropriate to treat. We will not replace more embryos than two or three if they are over 40. So, we have our own limits in that sense.
(Mark Leggett, Interview: 22 June 2000)

¹⁰⁶ "Often the patients who go on the public waiting list, they've got two to two and a half years to wait, will pay for a treatment while they're waiting" (Mark Leggett, Interview: 22 September 1999).

Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) maintains that there are no limitations on privately funded ART treatments.

No, none at all. Other than those restrictions that are biological and that are partly related to maternal age. In other words, if somebody comes to us at the age of 50 and they are almost menopausal and the chances of tertiary treatment are so low that it would be ridiculous to keep going then we would discourage them from spending their money on it. However, they still have the right to do silly things.

(Rodney Bycroft, Interview: 13 September 2000)

However, both Leggett and Bycroft indicate that there are some restrictions on private access irrespective of the ability to pay, and that these restrictions are partly based on the social judgements of the ART provider about what age is appropriate for a woman to parent. Another provider representative acknowledged that, while there are no restrictions on private access other than biological considerations that affect the likelihood of a successful outcome, this did not mean that the clinics willingly treated all those who could afford treatment.

There are lots of people the doctors would prefer not to treat. And, there are lots of people our doctors tell to "go away" ... because the doctor thinks the chances are low and tells people the chances are low. We have had one or two cases where we have thought it was crazy treating people.

(John Peek, Interview: 12 July 2000)

John Peek argues that there should be limits imposed on both publicly funded and private ART provision and maintains these limits should follow the biological limits of death for men¹⁰⁷ and menopause for women.

I think there are some limits we should impose and they would be biological limits. I think there are some exceptional circumstances but I prefer that people did not father children after they are dead because I think that is a good biological limit to fertility (laughs). ... I personally think that having children beyond menopause, goes beyond what the human species biological inheritance [is] if you like. But, on the other hand, the Human Rights Commission has told us that donor egg is very liberating for women because it gives them the same chance of having a pregnancy when they are older as men do. Men do not suffer the menopause so they have interpreted in the sort of feminist way that donor egg is liberating women from the constraints of their biology.

(John Peek, Interview: 12 July 2000)

While John Peek sees the Human Rights Commission (HRC) argument as a feminist strategy to override 'nature', he fails to recognise that many medical interventions into the human body override the constraints of the patients' biology. Heart, kidney, lung, and cornea transplants are all used to liberate both men and women from the limitations imposed by a physiological condition and to overcome biological boundaries, such as death and illness. Nor does he

¹⁰⁷ Recent media debate has highlighted controversy surrounding the use of frozen sperm after the donor has died (*Sunday Star Times*, 28 March 1999; *The Press*, 14 June 2000, p.3; McLeod, *The Press*, 17 June 1999, p.4; Dekker, *The Press*, 24 June 2000, p.3; Coney, *Sunday Star Times*, 29 June 1999). This controversy motivated NECAHR (2000b) to issue *Guidelines for the Storage, Use, and Disposal of Sperm from a Deceased Man*.

acknowledge that menopause is not solely related to older age in women. Just as some older women may conceive without medical intervention (Stein & Susser, 2000:1682), some younger women may be infertile because they have experienced early menopause and, for this reason, may require ART treatment. Farquhar (1996:87) contends that by continually emphasising infertility as an affliction of “delayed childbearers” and equating women’s biological lifespan with their reproductive lifespan, the discourse surrounding ART re-establishes the connection between maternity and biology that ART practices, such as embryo donation, surrogacy, and egg donation, have destabilised.

The HRC (1994:8) maintains that there are no grounds for discriminating against older women in the provision of ART services, particularly as the “medical technology exists to make post-menopausal pregnancy relatively safe for mother and child” and they note that men do not experience discrimination by private providers based on age. The age of an intending father is not questioned within the policy discourse,¹⁰⁸ however, recent research suggests that the age of the male gamete provider can have an effect on the ability to conceive (Ford, et al., 2000),¹⁰⁹ and it has been known for some time that certain inherited genetic disorders are more common in the children of older fathers (Stein & Susser, 2000). Using hormones to assist uterine responsiveness and the donation of oocytes greatly increases the chances of older women, including post-menopausal women, to successfully gestate and give birth to a child.¹¹⁰ The Canadian Royal Commission on New Reproductive Technologies (1993a:260-261) examined pregnancy and birth outcomes in their evaluation of the effects of aging on female fertility and found that, although studies over the last forty years suggest that older women have increased risk of experiencing adverse pregnancy related outcomes, the absolute level of risk remained low when combined with good obstetrical care and monitoring. Similarly, Stein and Susse’s (2000:1681-1682) review of research into the risks of having children later in life suggests that although “the higher relative risk for older women persists, their absolute risk has been greatly

¹⁰⁸ See Chapter One, Introduction: Framing the Issues, Section 1.2, Setting the Context, for a discussion of the marginalisation and invisibility of men in relation to ART practices and policy.

¹⁰⁹ Other studies acknowledge that male fecundity declines with age. However, they place less emphasis on its importance and suggest that effects are “less dramatic and only become significant in the late forties and early fifties” (Fox, 2000).

¹¹⁰ Gosden and Rutherford (1995) claim that “remarkably high pregnancy rates can be achieved when eggs are transferred from younger to older women, and successful pregnancy long after the normal age of menopause shows that the egg rather than the uterus is the Achilles’ heel of human reproduction.” Similarly, Stein and Susser (2000:1682) maintain that there is no difference in embryo implantation between women older than 40 and younger women when using IVF with donor oocytes and “in which the uterus is hormonally prepared”.

reduced" with advances in obstetrics and prenatal screening. They argue that the biological disadvantages that older mothers may face can be balanced against the social advantages of more knowledge and experience, and better economic circumstances (2000:1682). Similarly, Millns (1995:92-93) suggests that

...an older woman, with a wealth of experience and time to devote to bringing up a child, is not necessarily incapable of doing so simply because of her age.

Consequently, limiting access to ART treatment based on age can no longer be solely justified by equating older age with menopause and using it as a 'natural' benchmark for fertility. ART developments that enable women to extend their reproductive lifespan highlight the normative judgements and expectations surrounding the suitability of older mothers.¹¹¹ In the following section, I investigate how the expression of rights is used in arguments for both limiting and expanding access to ART services.

5.3 Access & Rights

Although clinics do treat lesbian couples and single women in the private sector, it is clearly more difficult for them to access publicly funded treatment given the emphasis placed on biological infertility. By granting itself a partial exemption from complying with the Human Rights Act 1993,¹¹² the Aotearoa/New Zealand Government has been able to limit public funding to 'biological' infertility and implement criteria that disadvantage lesbian couples and single women. Consequently, the government appears to be implying that some groups have more legitimate rights than others to publicly provided financial and biological resources in relation to ART practices. According to MCART (1994:58), the exemption also appears to create an inconsistency between the public and private health sectors in the application of anti-discrimination laws. MCART's report, *Assisted Human Reproduction: Navigating Our Future*, dealt with access issues under the chapter entitled "Discrimination", addressing topics raised by the Human Rights Act 1993 (1994:50-61). The chapter addressed changes in social values and challenges to the restriction of access on the grounds of age, sexual orientation, disability, marital status, and ethnicity. While the committee recommended the establishment of an

¹¹¹ See Parks (1999) for a feminist analysis of the exclusion of post-menopausal women from access to ART treatments.

¹¹² The New Zealand Government exempted itself from complying with the Human Rights Act 1993 in relation to its own legislative policies and practices until 1 January 2000 (Human Rights Commission, 1998). The subsequent passing of the Human Rights Amendment Act 1999 extended the compliance deadline until 31 December 2001. From 1 January 2002 the Government became liable for discrimination in the public sector and will only be able to discriminate if the enactment or practice in question can be "demonstrably justified in a free and democratic society" (Human Rights Commission, 2002).

advisory and overseeing body consisting of a diverse range of representatives from various interest groups, it was unclear whether they intended this body to oversee or facilitate access decisions.

MCART outlined the functions of the proposed 'Council on Assisted Human Reproduction' and stated that it

...could act as an advisory body to Ministers, and it could prepare or assist in the preparation of codes of practice and guidelines. ... It would liaise with the variety of different agencies which play a role in the work of ART. It could have a powerful influence on future policy formation, in safeguarding competing interests and in overseeing assisted reproduction generally. (MCART, 1994:44)

The committee's principal recommendation in relation to access issues was that ART providers "review their practices and policies and make alterations to comply with the law" (MCART, 1994:61). The subsequent officials' committee report, *Assisted Human Reproduction: A Commentary on the Report of the Ministerial Committee on Assisted Reproductive Technologies* (Department of Justice, 1995), endorsed this recommendation. However, the committee did not support the development of general guidelines by the Human Rights Commission or a 'Council on Assisted Reproduction', suggesting that "providers would need to have sufficient discretion to decide each case on an individual basis taking into account all relevant circumstances" (Department of Justice, 1995:12). The officials' committee also suggested that it would "not be unlawful discrimination for a provider to refuse treatment to persons where it is in the interests of the potential offspring to do so" (Department of Justice, 1995:12). While it is unclear what measures or standards would be used to decide what was in the best interests of the child and who would make the decision on whose interests to prioritise, the implication is that the medical profession would continue to decide who is eligible to receive ART treatment and that any complaints could be addressed through procedures set up by the Human Rights Commission under the Human Rights Act 1993 (MCART, 1994:61).

The Fertility Centre also prioritises the rights of the child in its 'Conditions of Service'.

The aim of the Fertility Centre is to help couples achieve a wanted pregnancy and child. At times there is conflict between those involved. In these circumstances the Fertility Centre staff act primarily in the interest of any potential child conceived.

(New Zealand Centre for Reproductive Medicine (The Fertility Centre), 1997)

While it is again unclear what values and methods would be used to define the best interests of the child, the HRC claims that the 'rights' and the 'welfare' of the child are often used when arguing for the restriction of ART services to those who fit the ideal nuclear family (Hamed, 1997). The subjective nature of decisions based on the interests of the child is acknowledged by Robyn Scott (Executive Officer, NZIS).

We feel that the rights of the children over-ride all rights but I would have to say that is a very loose bandied around term and can be used by any group with an interest, a vested interest, in this area. What exactly does that mean? What exactly (is meant) by the rights of the children.

(Robyn Scott, Interview: 26 July 2000)

The Women's Health Action Trust (1994) states that they agree in general that there should be no discrimination on the grounds of disability, age, family status, sex, religious belief, sexual orientation, ethical belief, ethnic origins, national origins, or race in access to infertility services. However, their submission to MCART states,

We have some difficulty with the prospect of people with some (particularly mental) disabilities having access to ART procedures. We believe that the rights of the child need to be balanced here against the rights of adults to access services.

(Women's Health Action Trust, 1994)

This statement places a condition the earlier declaration of support for non-discriminatory access by singling out people with mental disabilities as in need of special consideration. There is an inference that people with mental disabilities are less likely to be good parents and, consequentially, will be detrimental to the interests of any children they intend to parent. This statement brings into focus the Human Rights Commission's (Hamed, 1997) claim that arguments concerning rights and interests of children are often used to mask certain assumptions and expectations about what "the best type" of parent or families should be like.

The concept of the interests of the child is subjective and often carries a myriad of unexamined assumptions with it. Such ideas are usually defined according to the speaker's own interests and beliefs.

(Hamed, 1997)

Similarly, Zipper and Sevenhuijsen (1987:132) suggest that the dominant political actors in relation to ART often define the 'interests of the child' in terms of growing up in a two parent heterosexual family.

Few rights are unconditional, however, and the HRC recognises that it may be necessary to balance the rights of "nondiscriminatory treatment and other competing human rights" (1994:12). While discrimination in order to protect a child may be necessary in particular circumstances, assessing individual cases is very different from excluding a whole group in society from access to services (MCART, 1994:12). MCART was opposed to ART providers formulating blanket rules denying single women, lesbian couples, and post-menopausal women access to ART services and suggested that "some wider consultation and the production of guidelines is called for, to ensure that there is proper balancing of interests within the structure provided for by the Human Rights Act" in relation to deciding access issues (1994:59). This position is supported by the HRC.

Blanket rules in this area are not helpful. They not only fail to give due regard to the individual circumstances and merits of each person or couple wishing to use the service but are denying them their right to be treated fairly and with human dignity. (Hamed, 1997)

It is the ART providers' responsibility to show lawful grounds for discrimination or to seek an exemption under section 97 of the Human Rights Act 1993 to support a decision not to treat somebody. However, in order for people to challenge any such decisions they must be knowledgeable about their entitlements and rights, as well as being aware that they are being discriminated against. If the clinicians' decision-making processes are not transparent, it is unlikely many potential users of these technologies will be able to challenge decisions not to treat.

In the *Access to Infertility Services: development of priority criteria* consultation document, Gillett and Peek (1997:24) suggest that "because of the Human Rights Act, access to treatment by single and lesbian women will need to be covered by this criterion." This quote implies that if this law was not in place these groups would not be considered for publicly funded assisted reproduction and individual commentators have reinforced this assumption.

...well the point is that it is illegal to ... the whole point is not really whether we would support it or not but the fact that it is illegal to discriminate against people like that so there is not much point in us not supporting that because it would be illegal. (Robyn Scott, Executive Officer, NZIS, Interview: 26 July 2000)

Similarly, Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) acknowledges the influence of the Human Rights legislation.

Yes, we are obliged to do that. Human Rights' legislation was amended to make it unlawful to discriminate on the basis of gender and sexual orientation. (Rodney Bycroft, Interview: 13 September 2000)

John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) discusses how the legislation has affected medical practice in relation to making non-medical decisions on whom to treat. However, he suggests that the Human Rights Act does not sufficiently protect the interests of the children because of its focus on preventing discrimination in the provision of services.

There have been a few people that we wanted to refuse treatment but we went to the Human Rights Commission and we were told we had to treat them. ...they acknowledged our concerns for the child but there is no law in New Zealand that says that you have to take the child's interests into account. There is the Human Rights Act and that takes precedence. We also did not want to treat single women and lesbians, initially, on the grounds that we were an infertility clinic and we thought that was outside our scope. The Human Rights Commission said that we provide goods and services and therefore we cannot distinguish. So, for something like donor insemination if someone just says, "I want it" then we have to provide it even if they are not infertile. (John Peek, Interview: 12 July 2000)

While the implication is that the Human Rights' legislation conflicts with the welfare of the child by allowing lesbian couples and single women to access ART, the distinction between biological and social infertility is used to justify the clinic's unwillingness to treat such groups.

Some commentators oppose public funding of ART for lesbian couples on the grounds that there are limited resources available to treat heterosexual couples.

I think also, there are some practical problems for the clinics in treating those groups, in that there are insufficient donors for couples with biological infertility and I think it poses a lot of logistical problem for clinics in that they do not have sufficient donors in the first place.

(Robyn Scott, Executive Officer, NZIS, Interview: 26 July 2000)

There is an implicit assumption that heterosexual couples have an overriding right to both financial and biological resources, reinforcing the notion that the nuclear family is the norm for reproduction and parenthood. Cook (1995) argues that it is usually the marginalised and vulnerable in society who have to invoke the principles of human rights to protect and promote their interests. In contrast, those who have benefited from occupying a dominant social position and its inherent protection of their rights, often resist challenges to their position. While those in positions of power will often be supportive of rights that advance their own privileged position, they may "resist service to rights that requires them to yield or share their privilege, observe duties related to rights, or support action that would reduce their privilege to no more than the rights that are shared by all others" (Cook, 1995).

The two bills before the Health Select Committee do not directly address the regulation or control of access to ART, nor do they address the issue of resource allocation. As discussed in Chapter Three, the focus of both bills is on the control of certain practices and the regulation of access to information by donors, recipients, and people conceived using donor gametes. At present, access to ART services is mediated by the ability to pay, clinic location, and/or being able to fit the narrow access criteria for public funding, thus there is no automatic entitlement to the use of reproductive technologies. The New Zealand Infertility Society (NZIS) (1995) defines infertility as a disability and argues for access to ART services on the grounds that those with infertility or sub-fertility have a right to adequate health care, which may enable them to found a family.

The greatest benefit of treatment is to enable people to fulfil a basic human right – to found a family. (New Zealand Infertility Society, 1995; emphasis removed)

They argue for this right under the International Declaration of Human Rights and such conventions that recognise "the right to found a family", "the right to adequate health care", and "the right to share in scientific advancement and its benefits" (New Zealand Infertility

Society, 1995). Likewise, the Family Planning Association's (FPA) policy on the use of ART advocates for

...the right of women and men to have access to the fertility treatment services of their choice, including assisted human reproductive technology. FPA believe that the human rights of those seeking fertility treatment should be upheld. In particular, fertility treatment AHRT [Assisted Human Reproductive Technologies] should not be denied on the grounds of disability except where the disability is such to significantly reduce the chances of the treatments effectiveness. Nor should it be denied on the grounds of relationship status or sexual orientation.

(Family Planning Association, 1999a)

However, others argue that 'the right to found a family' does not apply to the use of medical treatment to create a child as such rights were "formulated to address the situation of people in extreme situations" (Coney, 1999c:42). Coney (1999c:42) interprets 'the right to a family' as a negative right, and does not believe people have a positive right to assistance or resources to fulfil the desire to found a family.¹¹³

We do not believe that any person or couple has a 'right to a child'. In our society, rights are always conditional, and the rights of society and of others affected by the actions of individuals have to be balanced against the rights of individuals to do as they please.

(Women's Health Action Trust, 1994: emphasis removed)

Conversely, the Family Planning Association (FPA) interprets the use of ART to reproduce as a positive right. However, they recognise that this right must be mediated by the medical likelihood of success, as well as limited resources.

FPA acknowledges that fertility treatment services are unlikely to be offered in cases where there is expected to be a poor outcome from the treatment, or where there are limited resources. In this regard, FPA believes that women and men have the right to be informed of the imposed criteria in being considered for fertility treatment.

(Family Planning Association, 1999b)

Limitations on the right to reproduce require the consideration of other rights and responsibilities. It is the specific responsibility of the government to ensure that the clinical criteria used to ration funds and limit access are based on sound scientific and medical research, and that the acceptance of social criteria and practitioner discretion to assist in the prioritisation of access is clearly identified and openly debated.

There are limited resources available for the public provision of healthcare and rapid advances in technology, growing professional and public expectations, and changing demographics (aging and rising populations) continually increase demand (Ministry of Health, 1998b). Consequently,

¹¹³ See Bonnie Steinbock's *Rethinking the Right to Reproduce* (1998) for a comprehensive discussion of the distinction between moral and legal rights, as well as positive and negative rights, in relation to reproduction and ART.

some strategy for rationing the available resources is undoubtedly necessary.¹¹⁴ As discussed in the previous chapter, inequitable and limited funding for public access to ART treatment has resulted from funding decisions based on historical need. Moreover, health sector reforms and rationing strategies have led to the introduction of the national CPAC to restrict access to the available public funding. Although Adair (1998:265) claims that the imposition of access restrictions on publicly funded ART treatment is solely due to the lack of resources, I argue in the next section that the criteria used to restrict access to public funding have been influenced by a normative definition of family and social judgements surrounding what the appropriate age is for women to experience pregnancy and parenting. Consequently, normative assumptions about who is 'worthy' to conceive, gestate, and parent work to exclude those who do not fit the perceived ideal for parental or family arrangements.

5.4 The Priority Criteria

As a result of the Aotearoa/New Zealand Government's history of non-intervention in ART, certain medical professionals have almost total unregulated power to make social, moral, and legal judgements with regard to who can use ART (Henaghan, 1992:172). Although there is no explicit legislation or prohibition restricting access to treatment in Aotearoa/New Zealand, access to ART practices are most obviously controlled through the rationing of publicly funded treatment. As mentioned earlier, providers holding contracts to provide public treatment are required to restrict access through the application of the Clinical Assessment Criteria (CPAC) and the imposition of a point threshold. Consequently, the Health Funding Authority's (HFA) service specifications and the CPAC are the most influential documents in relation to the control and regulation of clinics that compete for public funding. Nevertheless, the interpretation and implementation of the policies outlined in these documents remain the responsibility of the individual clinicians. Health professionals also control and regulate the recruitment and selection of gamete donors, as well as deciding who will have access to the donated gametes and what information will be collected (Daniels & Lewis, 1996a:1525). As the ART provider is customarily the only link between all of the parties involved, and the only person with access to relevant information about the use of gametes and the identity of donors, they hold a powerful position in deciding what happens to that information (Else, 1999b:57). As a consequence, they regulate the relationships that can exist between these parties (Daniels & Lewis,

¹¹⁴ The terms 'priority-setting' and 'rationing' are often used interchangeably when considering the allocation of resources.

1996a:1525). Although there are certain biomedical considerations regarding the ultimate success of any ART procedure that must be taken into account, the issue of restricted access based on social rather than clinical factors places non-medical decisions about who are appropriate parents in the hands of the clinicians. According to Henaghan (1992:177), the power to decide who can use ART “is really the power to decide who has the right to have children.” However, as discussed in Chapter Three,¹¹⁵ this is not a power that some health professionals necessarily want.

There are social issues that have to be discussed, where you have got values issues, like the single women and the lesbians, those things I do not really mind either way, because I would prefer not to have to make that decision, I will manage the policy. You make the policy; I will manage it.

(Mark Leggett, Interview: 22 June 2000)

The newly implemented CPAC is based on the National Health Committee’s consultation document, *Access to Infertility Services: development of priority criteria* (Gillett & Peek, 1997). This document was commissioned in response to the health sector reforms and the rationalisation of public services and funds mentioned earlier. It proposed a set of guidelines that were “intended to standardise diagnosis of infertility for *any couple* presenting to a primary, secondary or tertiary infertility service” (Gillett & Peek, 1997:6, emphasis added). However, its main aim was to present criteria for access to publicly funded infertility services and to provide a model for more explicit rationing. The CPAC require service providers to identify exclusion factors and modifying factors, and to allocate points to objective and social factors. Exclusion factors for access to treatment are based on situations that the providers consider would compromise the safety of the couple or a child (Health Funding Authority, 2000a:28). The referral guidelines do not specify how such risks will be assessed and who will be considered able to make such judgements. Although it is acknowledged that “no factor may be used that is unlawful and that might breach the Human Rights Act or the Bill of Rights Act”, it is also stated that “ultimately it will be the doctor, practising at a primary, secondary or tertiary level, who will decide – and that doctor would need to defend this decision” (Health Funding Authority, 2000a:28). However, Hunter (1997:28) argues that the debate surrounding whether health service rationing should be explicit or remain implicit arises from a “growing perception” that doctors are always the most adept at making rationing decisions. As stated earlier, this is not necessarily a function that ART providers wish to have control over.

¹¹⁵ See Chapter 3, Regulating Practices, Section 3.6, Professional Self-Regulation, for further discussion of this issue.

Modifying factors for access to treatment are identified as body weight and medical factors that can be alleviated by surgery or treatment. Although it is stated in the consultation document that extremes in body weight can affect ovulation and ovarian stimulation, body weight is not used as a deciding factor (Gillett & Peek, 1997:21). It would appear that this factor has been included in the document to encourage self-surveillance and monitoring by those who wish to access ART and to provide the clinicians with more discretionary power. Shildrick (1997:49) suggests that the capillary processes of power multiply the norms of function/dysfunction and the subject is "made responsible, and thus all the more cautious and manageable, for her own success in obtaining state benefit". According to Mark Leggett (Business Manager, The Fertility Centre, Christchurch, Interview: 22 June 2000), weight can be used to delay treatment and ensure conformity to the standardised weight range. Women seeking publicly funded ART treatment who are outside the body mass index (BMI) range of 18-32 will be placed on the waiting list but have to demonstrate they are committed to treatment by losing weight. Although body weight is not 'officially' a deciding factor, it would appear that it does influence how providers interpret a client's commitment to treatment and their eventual 'worthiness' for accessing treatment. This discretionary power is reinforced by the referral guidelines.

There are factors that limit the success of weight improvement, and in this circumstance it is reasonable to proceed with treatment providing the ovarian response is closely monitored. Treatment should only continue if the response is satisfactory.
(Health Funding Authority, 2000a:28)

Although not inevitable, extremes in body weight can have adverse effects on reproduction. However, recent research suggests that some of these problems can be overcome by ART treatment. Wang, Davies, and Norman (2000) maintain that "there is no conclusive evidence that extremes of weight are associated with a low rate of pregnancy in women receiving assisted reproduction treatment." Although some weight loss or gain may increase the chances of 'natural' conception in women with weight related infertility, their ability to lose or gain weight may have been the reason they sought ART treatment in the first place. Although it is claimed that body weight is an influencing factor and not a determining factor in granting access, it would appear that it has been included in the CPAC to further limit the numbers that would qualify for higher points under the "prognosis of conceiving without treatment" criteria.

Coney (1999a:24) claims that restrictive criteria on weight effectively excludes women from certain ethnic groups from accessing publicly funded ART procedures because of the tendency for such women to exceed the recommended body mass index (BMI). Similarly, the Human Rights Commission (HRC) argues that

...the factor of body weight could have some implications in relation to indirect discrimination on the basis of race and ethnic origins. Certain ethnic groups in New Zealand have a propensity for either higher or lower than average body weight to height ratios (BMI, body mass index).

(Human Rights Commission, 1997:3)

However, as the CPAC do not use the BMI as a deciding factor for access, it is unlikely that claims of indirect discrimination on the basis of race would be able to be made (Human Rights Commission, 1997:3). John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) suggests that the weight range is necessary because it eliminates those who have a reduced likelihood of responding 'efficiently' to ART treatments. Nevertheless, he recognises that the weight range effectively excludes many Māori and Pacific Island people.

...Māori tend to be a lot heavier and therefore they need more drugs to respond and [they are] more likely not to respond to stimulation IVF and at the moment the emphasis is on making the service efficient so we only treat the people who are going to get the highest chance of pregnancy which are the people who are going to respond the most to the drugs. So, you have got a weight range - a BMI of 18-32 which excludes a lot of Māori and then a lot of Māori and Pacific Islanders who fall into that are at the top end and they do not respond so well to the drugs.

(John Peek, Interview: 12 July 2000)

Peek claims that it is not "about equity of access but about biological differences that somehow you have to work out" and argued that the resolution would be to provide more funding so that "Māori people having an IVF cycle should be allowed to spend more on drugs for instance or not have such strict ... weight related restrictions" (John Peek, Interview: 12 July 2000). However, Teresa Wall (Senior Analyst, Māori Health Branch, Ministry of Health, Interview: 24 July 2000) suggests that asking for more money to treat Māori or Pacific Island people obscures the fact that the criteria are discriminatory. Similarly, Grant Allen (Senior Policy Analyst, Te Puni Kōkiri) suggests the use of the BMI scale, even as a modifying factor, implicitly discriminates against Māori and Pacific Island peoples.

Unfortunately, the BMI is based upon a western profile. ... There have been studies that have shown that the density of a Pacific Island person's body is heavier in general than Europeans. So you may have those problems, I mean the criteria itself is probably a profile for the type of people going through, middle-class, white middle class?

(Grant Allen, Interview: 25 July 2000)

Universally formulated policies are blind to differences of race, culture, gender, age, or disability and often maintain rather than challenge social inequality. Such policies often accept the capabilities, values, behaviours, and physiology of the dominant group as the standard or norm and assess all those applying for social assistance against these norms (Young, 1990:173-174). Accordingly, Young (1990:174) maintains that social equality can only be accomplished through the development of certain "group-conscious" policies, which acknowledge the group's

distinctiveness.¹¹⁶ She argues that the “oppressions of cultural imperialism that stereotype a group and simultaneously render its own experience invisible can be remedied only by explicit attention to and expression of the group’s specificity” (Young, 1990:174). Consequently, it may be necessary to acknowledge this difference in relation to body weight and establish distinct access criteria for some ethnic groups.¹¹⁷

The ‘objective’ factors are scored on a points system and they include age of the female partner, prognosis of conceiving without treatment, hormone levels, and a history of current smoking in the female partner. In their submission on the consultation document, the HRC claim that the inclusion of age and the “heavy weighting through a relatively narrow range of age bands” appeared to be subjective (1997:4). Gillett and Peek (1997:21) admit that “the rate at which fertility falls with age seems to vary between studies performed in different countries, and on different population groups within large countries such as the United States of America”. While they acknowledge that older women may have a greater need than younger women because of age related infertility (Gillett & Peek, 1997:22), they disregard this argument and go on to state twice in the document that “women who wish to embark on parenthood need to consider their priorities well before 35 years of age” (Gillett & Peek, 1997:6 & 38). This statement appears to be based on a moral judgement by the authors rather than ‘objective’ fact. Similarly, John Peek discusses the emphasis on age in the education kits that Fertility Associates provide to schools.

...the big message we are trying to get across is “Try to plan your family as much as you plan your career ...and be aware of the fact that once you are in your late thirties your chance of pregnancy really reduces.”

(John Peek, Interview: 12 July 2000)

The emphasis on women prioritising and planning their reproductive ‘careers’ fails to allow for demographic changes in Aotearoa/New Zealand and life events that may preclude having a family any sooner. Such arguments do not acknowledge that pressure to conform to male orientated career paths and inadequate childcare facilities may impact on decisions about when to have children (Woliver, 1991:486). Similarly, a partner may have some influence on the decision when to have a child or some women may not have access to a willing male sexual partner.

¹¹⁶ Young defines ‘social equality’ as the “full participation and inclusion of everyone in a society’s major institutions, and the socially supported substantive opportunity for all to develop and exercise their capacities and to realize their choices” (1990:173).

¹¹⁷ See Chapter 6, Addressing Difference: Māori Infertility and ART, for a discussion of the constraints facing Māori in relation to accessing ART.

Sandra Coney (Executive Director, Women's Health Action Trust) suggests that focusing on personal choice and 'career planning' in relation to having a family disregards the influence of social and economic conditions on women's reproductive choices.

...the other thing we could do is actually provide better social and economic conditions so that women can have children when they are younger. ... I think that is discrimination because the way the work force has changed quite rapidly in recent years means that it is very difficult for women to take time out to have children. ...to think that somehow women should be thinking at the age of 25 "Oh, if I leave it too much longer I might you know not have enough points when I..." is just bizarre. So, I think there are a lot of things that could be done in social and economic policy to support women in having children when they may prefer to have them at a younger age. (Sandra Coney, Interview: 13 July 2000)

Fertility in women does reduce with age and by the age 45 is almost half that of a 20 year old (Serono Colloquia Australasia, 1997b:6-7). However, these statistics are based on averages and do not take into account the individuality of women's fertility. Klein, Day, and Redmayne (1996:87) argue that applying information about groups to individuals and using it as criteria for allocating resources can lead to discriminatory and inequitable decisions. They contend that using age as a rationing strategy could lead to an older person with a good prognosis being denied treatment while a younger person with a poor prognosis is offered treatment. The HRC (1997:4) argue that the 'age of the female partner' and 'prognosis of conceiving without treatment' criteria and the scores associated with them are contradictory, given that age could be a contributing factor to the inability to conceive without treatment. The objective factors give higher points to women who have a poor chance of pregnancy without treatment. Although the consultation document allows that the "chance of pregnancy per month falls as the woman's age increases" (Gillett & Peek, 1997:21), the CPAC scores reduce as the woman's age increases and effectively eliminate anyone over the age of 39 from achieving access to publicly funded ART treatment.¹¹⁸ As mentioned earlier, the use of donor oocytes can improve the likelihood of older women benefiting from ART treatments.

The inclusion of 'a history of current smoking in the female partner' in the objective criteria implies that its effect on the ability to conceive is supported by clinical evidence. However, the consultation document states that smoking "seems" to reduce the likelihood of conception and offers no conclusive evidence (Gillett & Peek, 1997:22-23). As the HRC point out, the desire to

¹¹⁸ The current point threshold to access publicly funded ART is 65 points. Using this threshold no woman over the age of 39 would qualify for public funding, even if she scored the maximum points on the remaining criteria.

eliminate smoking and its harmful effects is commendable but it should be made explicit that this is a social factor based on a moral judgement of a social behaviour rather than evidence-based.

It is recognised that the elimination of smoking is an admirable public health goal. However, factors such as this should be justified on clinical grounds. The language of the report is somewhat hesitant as to the actual known effect of smoking on fertility. Without sound reasoning being provided for the exclusion of smokers it could seem that this is a moral judgment of individuals' social behaviour rather than a logical medical reason such as protecting a child in utero from risks to its health and safety. Perhaps this factor could be better grouped among the social criteria.
(Human Rights Commission, 1997)

Although the inclusion of smoking as a restrictive criteria appears to be based on the 'capacity to benefit' principle (Klein, et al., 1996:88), it has also been interpreted by one provider as an indication of how deserving of treatment the individual is. Mark Leggett (Business Manager, The Fertility Centre, Christchurch) sees smokers as less deserving of public funds because their habit may be contributing to the condition for which they are seeking treatment.

You could not say if you are a smoker, you cannot get service. That would be stupid. But, if you are a smoker, it reduces the amount of service you can get. Because we can only afford so much and why would we give it to someone who is going to minimise their chances deliberately? So, that makes sense.
(Mark Leggett, Interview: 22 June 2000)

Gillett and Peek (1997:23) argue that smoking does not "significantly impair sperm quality or reduce fertility" in men. However, the American Society for Reproductive Medicine (2001) claims that heavy smoking can increase abnormalities in sperm mobility and shape and may combine with other factors to reduce fertility. The consultation document does not include any acknowledgment of the effect of passive smoke inhalation by female partners of male smokers, which may also contribute to "abnormalities of reproductive function" (American Society for Reproductive Medicine, 2001). This omission highlights the CPAC's focus on the women's bodies and behaviour, and emphasises the invisibility of men in both the reproductive process and the disciplinary techniques used to control and normalise procreative behaviour.¹¹⁹

The purpose of the consultation document was to "develop criteria based on a couple's measurable need and their opportunity to benefit" (Gillett & Peek, 1997:36). According to

¹¹⁹ Disciplinary power operates to control and regulate certain populations through the use of disciplining techniques. Modern medicine provides an important system of knowledge and related practices, which enable the body to be understood and experienced. Knowledge gained through the 'clinical gaze' of medical practitioners and the 'confessions' of their patients is used to inform discourses and practices that construct the body and its various parts. Disciplinary power operates within the medical encounter by providing guidelines for how patients should understand, regulate, and experience their bodies. By subjecting patients to examination, observation, and measurement, bodily norms are established and individuals can be compared and categorised (Lupton, 1997:101).

Klein, Day, and Redmayne (1996:25) an idea of equity underlies most rationing strategies and is often defined as allocation according to need. However, problems arise when trying to establish operational definitions of the concepts of 'equity' and 'need' as a way of comparing the relative needs of one individual or group against those of another (Klein, et al., 1996:29). Gillett and Peek acknowledge the difficulties in judging need with respect to older women as opposed to younger women in relation to the age criterion.

It may be argued that older women, who may have a greater need, should have a higher priority than younger women. The difficulty here is that although the need might be greater (and how do we judge that?) there is no doubt that the effectiveness is lower.
(Gillett & Peek, 1997:22)

From the final weighting of points given to older women it must be assumed that desire for efficiency and cost-effectiveness finally outweighed any perceived need by older women (Health Funding Authority, 2000a:30). Along with need, a variety of other principles are often used, either implicitly or explicitly, when making resource allocation decisions. Some of these principles focus on the characteristics of the individuals concerned and include concepts of desert and merit (Klein, et al., 1996:30). Others, however, are concerned with considerations about the use of resources for the good of society and include the argument that "resources should go ... to whoever is likely to benefit most as a result of treatment" (Klein, et al., 1996:31). The social priority criteria are presented as reflecting "opinion as to the worthiness of access to treatment" (Gillett & Peek, 1997:7), a concept that is obviously based on the principles of need, merit, and desert. As they stand, the social priority criteria establish the level of 'worthiness' in relation to the duration of infertility, number of children in the current relationship, and previous sterilisation. All three criteria are based on a perceived 'need' for treatment and contain elements that require a degree of discretionary input by the service provider. Klein et al (1996:29) argue that "discretion ... is a function of ambiguity" and its use by service providers is a reasonable response to decision-making criteria that are not sufficiently specific or able to be applied to all possible circumstances. Although the CPAC appear to limit the discretionary element in the decision-making process and provide consistency in access throughout the country, John Peek acknowledges that the points system provides areas of ambiguity in deciding 'worthiness' of treatment.

Well there are some advantages [in the 'all or nothing' access criteria] because it is easy to say yes or no. ... With the points system some of the criteria [or] components to the points are a little bit more subjective and you grade for severity of infertility ... and that I guess could be challenged. You are also asking your patients to self-report on the length of infertility and I am sure that would be generously interpreted in the future. ... But, we try to keep the grey areas to a minimum because there is no boundary to a grey area.

(John Peek, Interview: 12 July 2000)

The 'all or nothing' system for deciding access is interpreted as being easier to administer, as there are no 'grey areas' in the decision-making process that need to be negotiated by the provider. The subjectivity inherent in making non-medical decisions is also acknowledged as presenting grounds for the providers' decisions to be challenged. Discretion in the interpretation of guidelines, codes of practice, and rules is characteristic of all systems of service delivery (Klein, et al., 1996:138) and is a necessary aspect of some clinically based decisions (Mechanic, 1995). However, Mechanic (1995) suggests that problems arise when doctors make assumptions about benefit of treatment based on social judgements "about intelligence, family circumstances, personality traits, and the like" rather than "subjective judgements of medical necessity."

Although Gillett and Peek (1997:24 & 27) approached health professionals and consumers to indicate what factors they thought should be regarded in priority setting, only forty-eight responded.¹²⁰

The respondents were asked to list up to 10 factors that they deemed important and were asked to rank them from 10 (the most important) to 1 (the least important).
(Gillett & Peek, 1997:17)

From these responses, the authors selected the four top ranking factors for inclusion in the priority criteria: length of infertility, prognosis without treatment, female age, and number of living children (Gillett & Peek, 1997:18). However, they disregarded other high-ranking factors and, although they give some reasons for excluding these, they are not explicit about why all these factors were excluded (Gillett & Peek, 1997:18). It is unclear from the consultation document how many people included the top four criteria in their selection as the final ranking was based on cumulative points. Therefore, some respondents may have selected the criteria but given them relatively low ranking in importance compared to other respondents. Neither is it specified in the document, which groups of people selected each of the criteria or the rankings each respondent gave the criteria that they did select. A further three criteria (follicle stimulating hormone [FSH] levels, smoking, and previous sterilisation) were selected by the authors but they do not specify why they selected these factors over others, especially as all three factors had low response rates and/or low rankings.¹²¹ Furthermore, only twenty-eight people responded to the exercise to determine what 'values' would be allocated to categories

¹²⁰ These included 19 consumers, 26 health professionals (mainly from IVF units) and 3 health administrators (Gillett & Peek, 1997:17).

¹²¹ FSH levels were selected by nine respondents with a mean ranking of seven, smoking was selected by four respondents with a mean ranking of 3.5, and sterilisation reversal was selected by eight respondents with a mean ranking of 2.3.

within the individual criteria. The authors acknowledge that there are limitations to the 'values' chosen to represent the various levels of worthiness within the social criteria because of the limited number of responses. Despite this, they rationalise the inclusion of these values because "there are no other data available" (Gillett & Peek, 1997:24). They maintained that "refinement of these scores can be made by seeking the views of a wider group of people" once the priority criteria had been established in clinical practice (Gillett & Peek, 1997:24). Although the draft criteria were "tested in a least 2 NZ (sic) tertiary centres", they were introduced as the national CPAC with only minor changes in August 2000 (Health Funding Authority, 2000a:24). There is no clear indication that any further public consultation has been carried out in relation to defining the criteria for need assessment and the opinions of an undefined number of people (a maximum of forty-eight) have been institutionalised as definitive of what social categories of people are 'worthy' of ART treatment.

Gillett and Peek (1997) suggest that the implementation of the CPAC would empower infertile couples seeking public access.

The present model puts some power into the hands of the infertile couple – all doctors should be able to calculate the same score in the same circumstances. The opinion of the individual doctor about whether treatment is worthwhile will be replaced by objective scoring.
(Gillett & Peek, 1997:38)

An analysis of the criteria listed indicates that the only 'power' conferred on those hoping to access ART procedures is self-surveillance and modification of their own bodies. The only factors that the potential women patients have any direct control over are body weight and smoking habits. By taking the authors' advice and considering their priorities "well before 35 years of age" (Gillett & Peek, 1997:6 & 38), women may have some control over the age factor. However, there is no guarantee that their efforts will be rewarded, as it is ultimately the medical profession's definition of the norms that these characteristics will be measured against. Gillett and Peek (1997:7) suggest that the model based on these criteria will improve "the standards of care in Aotearoa/New Zealand, allowing greater and fairer access to treatment programmes and giving the opportunity to *couples, who are most in need and most likely to benefit*, to attain their life goal of having a family" (emphasis added). It is clear from this statement who is considered to be the most deserving of treatment. At present, the public provision of ART services benefits and reinforces the 'normal' heterosexual nuclear family (Shildrick, 1997:186). Nevertheless, the consultation document takes a contradictory stance from its earlier couple focused treatment criteria when it claims, "to achieve a fertile status will require individuals to be aware of the issues that prevent them from being parents" (Gillett & Peek, 1997:39). Farquhar (1996:42) and Sawicki (1991:84) claim that focusing attention on the individuals' responsibility depoliticises the causes of infertility by deflecting attention and energy away from

addressing the environmental,¹²² iatrogenic,¹²³ or idiopathic¹²⁴ causes, as well as the social and economic issues that restrict access to adequate health care and nutrition.

The referral guidelines and CPAC provide doctors and ART providers with criteria for good practice in the distribution of public funds and, undoubtedly make the decision-making processes for allocating resources more visible and explicit (Klein, et al., 1996:137). Nevertheless, the preceding analysis of the CPAC highlights how the decision-making processes surrounding access to publicly funded ART include judgments about complex issues that cannot be resolved solely by appealing to medical knowledge and science (Klein, et al., 1996:62). The technical nature of medicine means that successful health policy will always be reliant on the specialised knowledge of the medical and associated professions to some degree (Blank, 2001:149).¹²⁵ However, the emphasis on explicit clinical decision-making as promoted by the CPAC (*Clinical Assessment Criteria*) obscures what are in effect decisions made on social and moral grounds about the degree of 'worthiness' or 'need' exhibited by those applying for public funding of ART treatment (Hunter, 1997:28). Limited resources and increasing demand necessitates constraints on access to publicly funded ART treatment and clinical grounds may not always be adequate for deciding who should receive treatment when resources are severely

¹²² Recent studies have demonstrated links between environmental pollution, including toxic work environments, and human reproductive system dysfunction (Gupta, 2000:340-343). Higher rates of infertility have been observed in women whose employment has exposed them to nitrous oxide, glycol ethers, and organic solvents. Similarly, pesticides have been connected with the low sperm counts of men, male infertility, and other unfavourable reproductive outcomes (Fidler & Bernstein, 1999).

¹²³ Symptoms or illness unintentionally caused by medical intervention.

¹²⁴ Used to describe a disease or disorder that has no known or identifiable cause.

¹²⁵ Traditionally, the medical profession has had a high level of autonomy that has protected it from control by the state or other professional groups (Davis & Ashton, 2001a:12). This autonomy has been challenged and eroded over recent years, both internationally and locally. Throughout the 1980s and 1990s, health sector reforms in New Zealand shifted health care decisions to managers and administrators (Blank, 2001:148 & 150). However, the medical profession still plays a major role in health policy agenda (Hunter in Davis & Ashton, 2001a:12) and are ultimately responsible for implementing any health policy decisions, such as determining the allocation of resources to individual patients (Klein, et al., 1996:136). While limited resources mean that judgements must be made about what treatments are funded and who has access to them, debate continues over the suitability of using implicit or explicit strategies in allocating and rationing resources. See for example, Blank, R.H., 1994. *New Zealand Health Policy: A Comparative Study*. Auckland: Oxford University Press; Feek, C.M., et al., 1999. 'Experience with rationing health care in New Zealand', *British Medical Journal* [Online], Vol.318, No.7194, pp.1346-1348, Available: <http://www.bmj.com> [29 November 2001]; Hunter, D.J., 1997. *Desperately Seeking Solutions: Rationing Health Care*. London & New York: Longman; Klein, R., P. Day & S. Redmayne, 1996. *Managing Scarcity: Priority Setting and Rationing in the National Health Service*. Buckingham: Open University Press; Mechanic, D., 1995. 'Dilemmas in rationing health care services: the case for implicit rationing', *British Medical Journal* [Online], Vol.310, No.6995, pp.1655-1659, Available: <http://www.bmj.com> [2 December 2001].

constrained (Hunter, 1997:24). Additionally, any form of rationing will disadvantage some people and be interpreted by some as unfair no matter how explicit it is (Hunter, 1997:32).

The notion that there is some 'ultimate solution', waiting to be discovered, is illusory. Decisions about managing scarce resources ... involve trying to reconcile competing values, interests and concepts of the good. The balance struck at any one point in time will inevitably shift in the light of experience and changing social expectations. Neither science nor economics will resolve the pain of choice. The best we can hope for is to strive to improve the process by which we reach the decisions.
(Klein, et al., 1996:139)

Blank (1995:183) also argues that the most appropriate question is not whether rationing should be done but who should be responsible for establishing procedures and guidelines that are non-discriminatory and reasonable. To ensure that health policy is fair and publicly acceptable, any decision-making about the content and implementation of such policy should only occur after considerable public consultation and input has taken place (Blank, 2001:157; Davis & Ashton, 2001b:275). Similarly, health researchers and health professionals should be frequently consulted about current and potential developments in medical technology, as well as the implications of these for health policy (Davis & Ashton, 2001b:276). It may inevitably be necessary to limit access to publicly funded ART treatments on more than clinical grounds. However, if it is necessary to restrict access by using criteria such as the age of the women, social behaviours, weight, number of children, and previous sterilisation, it should be clear how and why these social criteria are arrived at. Moreover, the clinicians and health care professionals who have been given the authority to make rationing decisions should be publicly accountable for the way in which they make these decisions, and those applying for public funding should be fully informed of the nature of the criteria on which they are being judged.

5.5 Conclusion

ART treatment was initially restricted to married couples, but access restrictions were eventually eased to allow *de facto* heterosexual couples in stable relationships into some programmes. In 1987, the Status of Children Amendment Act (SCAA) institutionalised the definition of family in relation to ART practices as comprising of two co-habiting heterosexual parents with (ideally) genetically related children. The legislation reinforced the idea that only heterosexual couples were appropriate candidates for ART treatment and effectively marginalised the more diverse concept of family acknowledged by Māori. Nevertheless, attempts by clinics to restrict access by lesbians and people with disabilities were challenged under the Human Rights Commission Act 1977 and the Human Rights Act 1993. Consequently, providers have gradually relaxed their access restrictions in relation to private ART treatment and currently treat single women and lesbian couples. Regardless, debate has continued over the issue of access to ART treatment

by those who do not fit the traditional concept of 'parent'. Some commentators have implied that the welfare of the child and the rights of heterosexual couples should take precedence over the rights of single women, lesbian couples, and post-menopausal women who wish to access ART practices. Such arguments are often based on assumptions about who should parent and how families should be constructed. While acknowledging that individual rights need to be considered in relation to each other, others have debated that blanket rules denying access to ART by certain groups fail to allow for individual circumstances. Although not overtly excluded from publicly funded access to ART, lesbian couples and single women are marginalised within the terms of eligibility. The Health Funding Authority's (HFA) recently modified service specifications no longer include exclusive references to 'couples', but eligibility requirements continue to assume heterosexuality. By confining eligibility to biological infertility and defining this as a physiological problem experienced by one member of a heterosexual couple, lesbians and single women are outside the interpretation of eligibility. The distinction between biological and social infertility is founded on treating the heterosexual couple as a unit and regarding the individual's infertility as a condition of the relationship. This distinction obscures the fact that many of the heterosexual women and men who access publicly funded ART services as members of a couple are socially infertile.

Age is also used to restrict access to ART services in both the private and public sector. However, it is only used to restrict the access of older women. There are no limits on the age of men applying to use ART services and death is considered the only limit to male fertility. The national Clinical Assessment Criteria (CPAC) use age to restrict access on the grounds that women's fertility declines with age. There is no concession allowed for age being a contributing factor in the need to access ART services. Age-related declining fertility, menopause as women's 'natural' fertility limit, and the risks of pregnancy associated with older women are all used to justify limiting older women's access to both public and private ART services. However, the possibility of using donated oocytes has removed the barrier of menopause. Likewise, pregnancy complications are not inevitable and medical advances in obstetrics have eliminated or reduced many of the risks encountered by later pregnancy. Older women, single women, and lesbian couples are not incapable of raising children nor are the children necessarily disadvantaged by the structure of their family. Therefore, I argue that social judgements on the value and ability of such mothers should not be used to exclude them from accessing ART.

As well as making the decision-making processes for the allocation of scarce resources more visible, the CPAC also highlight the incorporation of non-medical judgements about the social

issues of 'worthiness' and 'need'. Although the name of the national *Clinical Assessment Criteria* (CPAC) implies that priority decisions will be made on explicit clinical grounds, the CPAC include moral and social judgements, as well as some medical ones. The CPAC is explicit about the inclusion and use of some social factors to limit access to publicly funded ART services. Nevertheless, other factors that are based on 'worthiness' or 'deservedness' of treatment are less obvious and the non-medical basis of their inclusion is concealed by references to inconclusive evidence of their detrimental effects on reproduction. Both the weight and smoking related criteria are partly based on whether the applicant 'deserves' treatment, given that their weight or behaviour may be causing their condition. The emphasis on explicit clinical decision-making also obscures the discretionary judgements that service providers are required to undertake in relation to the criteria. The limited public consultation and the subsequent lack of responses in relation to selecting the access criteria and the allocation of 'values', undermines the validity of the CPAC and calls into question how reflective of the wider community's social values the criteria are.

Limited resources and increasing demand will continue to place pressure on the provision of publicly funded ART services. Similarly, medical professionals will necessarily continue to play an important role in the formulation and implementation of any access restrictions, particularly in relation to the clinical applications of ART. While it may be necessary to include social, moral, and value judgements in the limitation of access to severely constrained ART services, it should be made clear why these judgements have been included and what groups or individuals have contributed to their inclusion. Given that any form of rationing will disadvantage some members of society and be interpreted by some as unfair, it should be anticipated that any criteria for limiting access to ART services will be subject to challenges by those who feel themselves to be disadvantaged. Therefore, every effort should be made to ensure that any access criteria are as fair and non-discriminatory as possible and that procedures are in place to facilitate the public accountability of those who implement them.

Both implicit and explicit access restrictions for ART services have been influenced by the normative definition of family underlying the Status of Children Amendment Act 1987 (SCAA). The document that underlies the CPAC, *Access to Infertility Services: development of priority criteria* (Gillett & Peek, 1997), reinforces the 'normal' heterosexual nuclear family and marginalises alternative family formations by making assumptions about ideal child-rearing arrangements and family structures. Consequently, limited funding and restrictive access criteria combine to disadvantage single women, lesbian couples, and older women, as well as

ethnic groups that recognise a broader concept of family than the two parent nuclear model. The following chapter will explore how Māori are marginalised within the wider health sector and how the *ad hoc* development of ART policy may affect their ability to access ART services.

6

Addressing Difference: Māori Infertility & ART

The politics of difference ... aims for an understanding of group difference as indeed ambiguous, relational, shifting, without clear boundaries that keep people straight – as entailing neither amorphous unity nor pure individuality. ... Difference now comes to mean not otherness, exclusive opposition, but specificity, variation, heterogeneity. ... Difference no longer implies that groups lie outside one another. To say that there are differences among groups does not imply that there are not overlapping experiences, or that two groups have nothing in common.
(Young, 1990:171)

6.1 Introduction

Social policy affects the lives of all New Zealanders but not necessarily equally. For most of Aotearoa/New Zealand's colonised history, social policy has developed from a Pākehā perspective, which has often marginalised and sometimes discriminated against Māori. Early state policies enabled the acquisition and confiscation of Māori land in the face of Māori opposition, as well as encouraging assimilation through education (Consedine & Consedine, 2001:89-95).¹²⁶ Likewise, state policies aimed at assisting Māori were often assimilatory and paternalistic in nature and have contributed to the marginalisation of Māori values and perspectives and a loss of traditional knowledge (Cunningham, 1998:396; Consedine & Consedine, 2001:20). However, public sector agencies are "now required to be responsive to the needs of Māori in carrying out their business" (Cunningham, 1998:397). Nevertheless, ART policy continues to assume homogeneity among those accessing ART services, failing to

¹²⁶ See Consedine and Consedine (2001: 76-118) for an overview of some of these policies and their effect on Māori culture and society.

acknowledge or accommodate social diversity in relation to family structure,¹²⁷ let alone cultural diversity. The lack of adequate data on the prevalence of infertility within groups and the ethnic and socio-economic backgrounds of those accessing ART services contributes to the formulation of policy on access that may be discriminatory in effect, if not in intention. It is not within the scope of this chapter to address all the policy issues surrounding infertility and ART in relation to Māori. Nevertheless, I will attempt to highlight some issues that may contribute to and/or exacerbate inequalities in access to ART by Māori, as well as highlight areas that require more research and public policy consideration.

Although the focus of this chapter is on issues surrounding the use of ART by Māori, I recognise that other ethnic and cultural groups may have similar or divergent issues relating to ART. However, I have focussed on Māori because of their unique status as tangata whenua and as partners to te Tiriti o Waitangi (the Treaty of Waitangi). Te Tiriti o Waitangi is Aotearoa/New Zealand's founding document and, as such, recognises the partnership between the "two sovereign peoples", Māori and Pākehā (Manatu Māori in MCART, 1994: Appendix E, p.2). This relationship necessitates that the drafting, implementation, and monitoring of policy incorporates and acknowledges the "values and norms inherent within Māori society", such as the importance of whakapapa in Māori culture (Manatu Māori in MCART, 1994: Appendix E, p.2).¹²⁸ Accordingly, Dyall (1999:35) maintains that the Treaty embodies a number of fundamental principles that provide a framework for determining the rights and responsibilities of the different actors involved in determining and implementing ART and surrogacy policy in relation to ensuring cultural safety.

The decision to include a Māori focussed chapter was fraught with personal and political difficulties.¹²⁹ However, I considered that such a chapter was necessary if I was to avoid contributing to the marginalisation and invisibility already experienced by Māori in this area.

¹²⁷ See Chapter One, Introduction, Section 1.4, Families & ART, for a discussion of this issue.

¹²⁸ There is ongoing debate about the relevance and necessity of including the Treaty in social legislation. See *Te Kawenata o Waitangi: The Application of the Treaty of Waitangi to Health* (Durie, 1998:81-97), *Te pupuri I te ao o te tangata whenua* (Reid, 1999a:56-59), and *Why treaty has no place in social law* (Graham, 2000) for discussions relating to this debate. Both the Te Puni Kōkiri and Ministry of Health representatives, who were interviewed in relation to issues Māori may have regarding ART policy, claimed that changes in government (administration) had significantly influenced the nature of the debate. They maintained that the change in 1999 from a National-led Coalition Government to a Labour-led Coalition Government had resulted in the debate focusing on how to incorporate the Treaty in social legislation, rather than whether to incorporate it at all.

¹²⁹ For a discussion of these difficulties see Chapter Two, The Research Process, Section 2.9, Cross-Cultural Research.

While the overall focus of this project was to discover how ART policy constrained or enabled reproductive choice in Aotearoa/New Zealand, I discovered little Māori-specific information or policy in relation to ART practices. The most comprehensive discussion I could find on ART policy issues for Māori was produced by Manatu Māori (Ministry of Māori Affairs), which provided a seven-page submission to the Ministerial Committee on Assisted Reproductive Technologies (MCART, 1994: Appendix E) in the mid-1990s. The submission raised some specific areas of concern for Manatu Māori in relation to the provision and use of ART. These included

...the protection of whakapapa and informed choice and consent, as well as ensuring that across all technologies the processes involved are culturally supportive and safe. In addition, it is the view of this working group that there is a need to promote the prevention of infertility within the context of today's health risks.
(MCART, 1994, Appendix E: 3)

In spite of these concerns, there has been no discussion or research into whether these issues are relevant or have been dealt with appropriately. Although many commentators and researchers mention Māori in relation to ART practices, it is often with regard to access to information, the relationship between whāngai and surrogacy, or the shortage of Māori gamete donors. Similarly, those interviewed as representatives of Māori focused organisations, could offer little or no insight into Māori policy responses to ART practices. Although there are generic strategies in place that are designed to minimise the inequalities of access and treatment that Māori experience within the health sector, these are not specific to ART practices and do not appear to be enforced in this area. Consequently, I discovered silences in ART policy in relation to Māori and turned my attention to addressing the questions and issues raised during the interviews that are believed to contribute to these silences.

As issues such as the definition of whānau and family formation have been discussed in an earlier chapter,¹³⁰ this chapter will start by looking at whether there is a current or future need for ART services among Māori. In this section, I examine the various health issues and lifestyle changes that may influence future fertility rates for Māori. Next, I discuss the issue of Māori access to health services and how this may impact on Māori using ART. Recognising that the wider issues of disparity in health care and socio-economic status will impact on Māori accessing and using ART services, the following section examines how the collection of data on ethnicity impacts on policy formulation. I have included in this section a discussion of the

¹³⁰ See Chapter One, Introduction, Section 1.4, Families & ART, for a discussion surrounding the influence of the Status of Children Amendment Act 1987 (SCAA) on the definition family and whānau in relation to ART.

difficulties in defining Māori and the use of ethnicity as a variable in social research. This is followed by consideration of the use of the traditional practice of whāngai as an alternative to ART for those experiencing infertility. I then explore the issue of protecting whakapapa in relation to the use of ART and donated gametes. Finally, I look at issues surrounding diversity and difference within the Māori population and the need to acknowledge heterogeneity within groups as a policy strategy.

6.2 Is there a need?

The question really is what degree do problems with fertility exist in the Māori population?

(Teresa Wall, Senior Analyst, Māori Health Branch, Ministry of Health, Interview: 24 July 2000)

The desire and ability to have children is no less important for Māori than it is for any other group of people (Dyall, 1999:35). Both Lorna Dyall (Hui Whai Maramatanga Whai Oranga & Ministry of Māori Development, 1995:29; Dyall, 1999:37) and Chris Cunningham (Hui Whai Maramatanga Whai Oranga & Ministry of Māori Development, 1995:33) have suggested that the prevalence of infertility in the Māori population of Aotearoa/New Zealand may be increasing. While there is a small amount of data available on the prevalence of infertility in the general population of Aotearoa/New Zealand, there is no ethnic-specific data on the incidence of infertility.¹³¹ Information on access and utilisation of ART services by Māori is also non-existent and the information collected during this research was mainly anecdotal. However, in 1993 Te Puni Kōkiri (cited in Durie, 1998:129) found that Māori women were 1.4 times more likely to be at risk of reproductive system disorders than non-Māori women. Similarly, recent research into the prevalence of sexually transmitted infections (STI) (McNicholas, et al., 2001) found that chlamydia was the second most commonly diagnosed STI in Aotearoa/New Zealand in 1998 and approximately two-thirds of the diagnoses were in people aged less than 25 years. Rates of chlamydia and gonorrhoea infection were found to be disproportionately high among Māori and Pacific Island people. Chlamydia and gonorrhoea are recognised as significant causes of tubal infertility, and research by Peek (1990:64) found that there was “a high incidence of chlamydia in Aotearoa/New Zealand women being treated with IVF for tubal disease.” Consequently, there may be a growing demand for ART services among Māori women in the near future.

¹³¹ See Chapter Four, Allocating Resources, Section 4.2, Funding Issues, for comments on the prevalence of infertility in Aotearoa/New Zealand.

...recent research showed that chlamydia and gonorrhoea were very high in the Māori population ... [so] this is going to become more important in the future.

(Grant Allan, Interview: 25 July 2000)

Although ART issues may not be designated a high priority within Te Puni Kōkiri's (Ministry of Māori Development) mandate at present, Grant Allan (Senior Policy Analyst, Te Puni Kōkiri) acknowledges that these issues may become more important in the future.

Penny Ehrhardt (Policy Analyst, Te Puni Kōkiri) suggests that changing childbearing trends by Māori women may affect future demands for ART services.

There is also the issue of the changing demographics in society, so for Pākehā population the age of giving birth has increased dramatically and it has subsequently done that among the Māori population. ... So, although there is a group of Māori women who have children very young..., there are a lot more Māori women waiting until they finish their education, careers, etc., etc, just the same as non-Māori women. I know that people working in the fertility areas would say that is an issue because when women do look to start their families they may find that they are less fertile than they had been or they assumed that it was just something to avoid for all those years.

(Penny Ehrhardt, Interview: 25 July 2000)

Although the Māori population has a slightly higher rate of natural increase than the non-Māori population, there has been a substantial decline in Māori fertility over the last 40 years. According to Pomare, Keefe-Ormsby, Ormsby, Pearce, Reid, Robson, and Watene-Haydon (1995) this decline has been "one of the most rapid ever documented in the world and it is the result of a number of factors including reducing Māori mortality over the previous decades; rapid urbanisation; the availability of contraception, and fuller participation in education and employment, especially for women." Conversely, there remains a widespread belief that Māori have large families even though the 1996 census shows that empirically this is not the case. This census showed that there was little difference in the fertility rates of Māori and non-Māori women; an average 2.1 children were born to Māori women aged 15 years and over, while non-Māori women in the same age group gave birth to an average of 1.9 children (Ministry of Health, 1998a:27). However, Māori women tend to have their children at a younger age than non-Māori. Māori women in the 15 to 24 age group are three times more likely to have at least one child than non-Māori women in the same age group (Ministry of Health, 1997:22; Ministry of Health, 1998a:27). While Māori women tend to start and finish having their children at a younger age than non-Māori, there is "evidence that Māori women's childbearing patterns are becoming similar to that of non-Māori women" (Ministry of Health, 1997:22). If this is the case, then it is probable that an increasing number of Māori women will experience fecundity problems associated with declining fertility in relation to age. However, Māori women and men may encounter more barriers to accessing ART services than non-Māori women and men.

6.3 Access Issues

Te Puni Kōkiri's second report in the *Closing the Gaps* (2000) series¹³² shows that Māori "experience poorer health status, lower income levels, higher unemployment, higher rates of prosecution and conviction, lower educational status, and lower rates of living in owned homes than non-Māori" (Te Puni Kōkiri, 2000a:10). There can be little doubt that these structural conditions influence Māori health status and access to health care services.

Accessibility is one of the biggest [problems] in terms of rural and local [Māori] but that is not to say that just because you live outside the doors of the hospital you have accessibility. That is another issue.

(Naida Glavish, Chief Advisor-Tikanga, Māori Health Development Service, Auckland Healthcare Services Limited, Interview: 9 August 2000)

There has been a great deal of work done on the influence of socio-economic status and ethnicity in relation to health care access and outcomes. This work has highlighted the barriers that exist for Māori in relation to costs (services, childcare, transport, and lost wages), location, and lack of cultural comfort and safety within many mainstream health services (Pomare, et al., 1995; Ministry of Health, 1998a; Baxter, 2000; Tobias & Howden-Chapman, 2000; Tobias, 2001). Teresa Wall (Senior Analyst, Māori Health Branch, Ministry of Health) argued that these barriers are also likely to impact on Māori accessing ART services.

...there are lots of barriers to Māori getting into services. A lot of it is to do with the costs, the transport, where the service is, all those sorts of things.

(Teresa Wall, Interview: 24 July 2000)

As all the specialist fertility clinics are located in the main urban centres, geographic access remains limited for people living outside these centres. However, some clinics provide blood tests and diagnostic services in outlying areas in order to reduce travel and financial costs for their out-of-town clients.

We send one of the doctors up to Nelson on a six weekly basis to run clinics so that patients do not have to come here for a first visit... We try to make sure that they get all their blood tests done and their scans and things done up there.... So, they get out of the need to pay for the trip down and ... the number of times they have to visit here is minimised. They have to come here for the actual end point treatment anyway but we get done what we can.

(Mark Leggett, Business Manager, The Fertility Centre, Christchurch, Interview: 22 June 2000)

¹³² Te Puni Kōkiri published the first *Progress Towards Closing the Social and Economic Gaps Between Māori and non-Māori: A report to the minister of Māori Affairs* in 1998. The purpose of this report was to provide a benchmark against which progress towards closing gaps between Māori and non-Māori achievements in education, labour force participation, housing, and health could be measured (Te Puni Kōkiri, 2000a).

John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) also discussed strategies his clinic had initiated to overcome the problems experienced by those without a fertility clinic in their city or town.

...that is why we set up clinics in Hamilton and Wellington. So that people will not have to travel and we do consultations in most small cities in the North Island. So, it is easier to access. We tried to address them indirectly I guess. ... We have clinics in Whangarei and we have gone a long way to try to make blood tests easy by people sending it by courier or by doing it locally. So, I guess we have tried to address some of the access issues that Māori face...

(John Peek, Interview: 12 July 2000)

However, patients still have to travel to the clinics for treatment that may involve staying for several days, adding accommodation costs to travel costs.¹³³ Although travel and accommodation allowances are available on application from the Health Funding Authority (HFA), Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) suggests that those experiencing fertility problems may find applying for such benefits an added burden.

If you live in Timaru and you can get assistance to get to Christchurch for treatment in the public health system..., if in fact you are using it, a whole lot more people become aware. Say you are in a [small town] and you have to apply [for a benefit] to somebody [you know] ... or somebody is dealing with your file that you do not particularly want to know [about it].

(Ken Daniels, Interview: 31 August 2000)

Boston and St John (1999:102) outline the various factors that can contribute to low take-up rates for such benefits. These include a lack of awareness of entitlement, a desire to avoid being stigmatised, a need to maintain privacy, abatement rates that reduce entitlements to negligible amounts, time-consuming procedures, and complex forms to fill in.

Although geographic and financial access remain important barriers for many Māori, Teresa Wall argues that these obstacles are only part of the problem and suggests that institutional racism plays some part in limiting access by Māori to health services.

Then conversely, there are professional assumptions made about whether Māori will be good patients, whether they will comply with treatments and, if they think that they do not comply, then there is no point in really referring them on. So, there are all those sort of issues about primary care. Whether [GPs] have these assumptions and whether they actually refer them on to secondary care. If they do have these assumptions, [how do they] affect the way in which they treat [people]? [Do] they give them the best treatment or the best available treatment? I think that there are some that are fine [however,] ... I think there is still a huge

¹³³ IVF, in particular, involves 'cycles' of treatment that can entail several stages, repeated at varying intervals. These treatments include drug induced ovulation, egg retrieval, insemination, fertilisation, embryo culture, and embryo transfer.

amount of organisational or institutional racism. There are a lot of presumptions about Māori and Pacific people and that affects the treatment that they get.

(Teresa Wall, Interview: 24 July 2000)

This claim is supported by Baxter (2000:XII) who maintains, “institutional racism likely contributes to ... poor outcome from health services.” Services are developed without considering the full extent of Māori needs, and discrimination is likely to manifest itself in individual and institutional attitudes to Māori “through lower levels of expectation of outcomes, negative stereotypes of Māori and potentially through lack of access by Māori to services” (Baxter, 2000:XII). Howden-Chapman, Wilson, and Blakely (2000:162) also suggest that the “institutional arrangements and disrespectful attitudes” within the medical profession contribute to differentials in access to health care. Citing American research, Bhopal (1998) has also claimed that socio-economic status (SES) is not the only explanation for ethnic disparities in health outcomes. Escarce et al (in Bhopal, 1998) found that health care services received by ‘black’ patients were influenced by differences in disease patterns, levels of doctor-patient contact (particularly specialist contact), patients’ preferences, and doctors’ management of their patients on the basis of ethnicity, as well as economic and organisational barriers. Similar factors may influence the referral of Māori women and men with fertility problems by primary health care providers to specialists or fertility clinics for secondary or tertiary care. Furthermore, information about treatment options and funding entitlements may be less accessible by Māori for similar reasons. However, these issues require further research in Aotearoa/New Zealand.

ART services are expensive and, at present, appear to be mainly utilised by those who can afford to pay for them. When asked about the demographic composition of his clinic’s clients, Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland)¹³⁴ claimed that they were generally well off.

In general, private IVF is the domain of the well to do and that disadvantages a significant section of society. ... Definitely white middle to upper class. I mean to say, if you are realistically thinking of having somewhere between 10 and 20 thousand dollars of disposable income that you could allocate to having a child you are not talking about three-quarters of the Auckland population which is unfortunately the case. (Rodney Bycroft, Interview: 13 September 2000)

The majority (approximately 60%) of the Christchurch Fertility Centre’s clients are private patients. However, some of those who enter as public patients can access money to pay for private treatment.

¹³⁴ As a private clinic, Artemis does not hold a public contract for the provision of fertility services. Consequently, all those accessing treatment at the clinic are fee-paying patients/clients.

Often the patients who go on the public waiting list, they've got two to two and a half years to wait, will pay for a treatment while they are waiting.

(Mark Leggett, Interview: 22 September 1999)

Rodney Bycroft acknowledges that socio-economic status influences those seeking treatment, specifically through lack of knowledge of treatment options and the cost involved.

So if you were ... [to] take someone who has not got a really good education, who does not have access to information with respect to Internet, newspapers, or TV, and doesn't really know much about IVF, then it is unlikely that even if they have a problem that they would end up seeking treatment. So they are disadvantaged geographically, they are disadvantaged quite often because of race and ethnicity, and certainly disadvantaged from income.

(Rodney Bycroft, Interview: 13 September 2000)

The inability to pay for treatment may also be viewed as affecting the patients' commitment to the treatment. In their proposal to the HFA on how to achieve national consistency in publicly funded treatment, two clinics suggested that co-payments for drugs in relation to fertility treatment "would tally with some providers' comments that patients tend to show more commitment to treatment if they have to pay for some of it themselves" (Leggett & Peek, 1999). Cussins' (1998:73 & 96 n.15) ethnographic research into the practices of infertility clinics in the United States of America revealed that some physicians equated their levels of job satisfaction with the kinds of patients they were able to work with; white middle-class or higher. Similarly, Ken Daniels (Associate Professor, Department of Social Work, University of Canterbury) suggests that paying clients may be accorded a higher status in the eyes of the providers.

If you are going for private treatment, you get it much faster and maybe there are some other subtle influences too. If you are seen to have important status in the eyes of the people who are providing the service....

(Ken Daniels, Interview: 31 August 2000)

Consequently, it would be unrealistic to assume that inequalities in relation to overall health status and differentials in access and utilisation of services between Māori and non-Māori based on the ability to pay would not be replicated within this narrower field of inquiry. Furthermore, the factors that affect the take-up rate of targeted benefits may also deter those experiencing fertility problems from seeking medical help.¹³⁵

Mark Leggett (Business Manager, The Fertility Centre, Christchurch) suggested that a lack of information and knowledge about entitlement contributes to the paucity of people in lower socio-economic groups accessing treatment.

¹³⁵ MCART (1994:7) cites a study in the United Kingdom that estimates that less than 50% of all 'couples' experiencing infertility present to health services.

Some people do not know that it can be free.

(Mark Leggett, Interview: 22 June 2000)

However, the limited resources and extended waiting lists mean that the clinic is hesitant to advertise the fact that treatment is publicly funded.

We really do not want to advertise it as being free because we just cannot cope with the demand and the waiting list would just expand out. I've got no problem with having more people on the waiting list but it doesn't do our patients any favours, they wait longer so ... if there was funding, complete funding I would be advertising left right and centre that you could get it free.

(Mark Leggett, Interview: 22 June 2000)

This service provider engages in a form of implicit rationing in an attempt to balance supply and demand. Methods of rationing that deflect or deter people from making demands on services cause rationing to be less visible, lessen political costs, and assist those who are involved in avoiding having to make difficult decisions as to how resources should be allocated (Klein, et al., 1996:16 & 25). By not actively advertising the fact that infertility treatment is publicly funded, the clinic contributes to the rationing process by limiting the number of people who will approach the clinic directly. The clinic manager sees this as a way of helping to limit the number of people on the waiting list. While this approach may help those already in the system by reducing the potential demand on public funding and keeping waiting list times down, it is more likely to impact negatively on those who do not have access to the information from other sources. As Māori are less likely to utilise primary healthcare services (Pomare, et al., 1995), they are less likely to be informed of their options with regard to publicly funded infertility treatment. Policy in relation to ART continues to be based on the perceived needs of the historically dominant Pākehā culture and applied without investigation into the actual prevalence of infertility or the demand for ART services by Māori.

That is kind of across the board. That is a major issue that Te Puni Kōkiri has with the social services across the board - the lack of accurate data to make these kinds of decisions.

(Grant Allan, Senior Policy Analyst, Te Puni Kōkiri, Interview: 25 July 2000)

6.4 Being Counted

...I suspect that even the number of people who front up to [fertility clinics], their ethnicity would not be collected. Ethnicity collection across the whole of the health sector is very poor.

(Teresa Wall, Senior Analyst, Māori Health Branch, Ministry of Health, Interview: 24 July 2000)

According to Reid (1999b:84), the collection of quantitative data is “an acknowledgement of being valued” and is vital to the effective monitoring of state policy outcomes and evaluating the fulfilment of guarantees made in te Tiriti o Waitangi. Subsequently, the lack of adequate data means that it is impossible to answer the questions raised by Teresa Wall.

You have to come back further and ask if fertility or problems with fertility are problems that Māori exhibit at the moment? ... Is there a need in the Māori community for fertility services? Is there behaviour at the moment, which may lead to fertility problems in the future and, if there is, what should we be doing about it?
(Teresa Wall, Interview: 24 July 2000)

Although contracts for the provision of publicly funded ART require clinics to implement certain policies with regard to the collection of data on ethnicity (Health Funding Authority, 2000a: 10, see Appendix K; Health Funding Authority, 2000b:18, see Appendix L), John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) argues that in the past the HFA has not collected this information.¹³⁶

The trouble with the HFA and Māori things is that they do not implement it. They put all these requirements for Māori, have Māori policies, in the contract that say what you should do, but they never bother implementing it. We have to report every month on things but, although our contract has reporting requirements, they do not ask us to report on those. ... I mean it doesn't mean to say we don't think they are important and try to do something about it, but what the HFA requires in its contracts and what it actually expects the provider to do on a day-to-day practical basis, I think are a bit different at the moment.

(John Peek, Interview: 12 July 2000)

Helen Williams (Policy Analyst, Elective Services Project, Health Funding Authority) confirms this claim.

I know we have not even collected [data on] ethnicity. So, we do not even know who's been fronting up. [Some people] have been collecting that data on their own accord but the HFA has never asked for it. And, all contracts now have the generic overview section on Māori. ... Sometimes this is more relevant than others and often there is no data to put into that section anyway because we do not collect it.
(Helen Williams, Interview: 29 August 2000)

Te Puni Kōkiri's (2000b:29) review of the Health Funding Authority found "the collection of ethnicity data is not well enforced, particularly in the case of hospitals." Consequently, health service priorities may be generated by historic demands without taking the issues for Māori into consideration (Te Puni Kōkiri, 2000b:30). Heitman and Schlachtenhaufen (1996:191) warn that the assumptions underlying the collection of demographic data on infertility may be based on the needs and interests of the population already seeking treatment, a population that appears to be disproportionately white and middle-class.

Helen Williams argues that there is a lot of work taking place to address these inadequacies and that reclassifying infertility services as part of the core services will help in the collection of data.

¹³⁶ All new HFA contracts with both Māori and mainstream providers include standard clauses that establish contractual requirements for providers to be attentive to the needs of Māori (Te Puni Kōkiri, 2000b:31).

...we have not been collecting infertility data but we are just going to start. ... So, we are changing the service specifications and getting them to National consistency. We are actually putting in a whole lot of reporting requirements, which will be national.
(Helen Williams, Interview: 29 August 2000)

Current changes to the health sector structure have not had time to take effect and it is uncertain whether the reclassification of infertility services will improve the situation in relation to data collection or the implementation of other Māori-specific requirements. Nevertheless, the lack of adequate data in relation to ART is not specific to Māori and would appear to be the situation for ART services in general.

...as far as planning, we are not even asked at the moment to plan for European. At the moment, we do not even know what the infertility needs in epidemiology¹³⁷ are, let alone planning for them. I think that is what we need to do.

(John Peek, Interview: 12 July 2000)

However, while there is a need for research into the prevalence of infertility and the demand for ART services in general, a Pākehā perspective remains dominant within the policy discourse surrounding ART and influences how policy is formulated and whose needs are attended to. Unless challenged by alternative perspectives on social relations and interaction, as well as different values and language, this perspective will continue to be asserted as universal and the interests of Māori will be assumed to correspond with those of the dominant group (Young, 1990:185-186). Young (1990:185) suggests that those in a privileged social position are less inclined to protect or advance the interests of marginalised groups "partly because their social position prevents them from understanding those interests, and partly because to some degree their privilege depends on the continued oppression of others." This is particularly relevant to publicly funded ART services as they are constrained by limited funding and biological resources, creating increased competition for these resources among potential consumers. While this competition adds to the necessity for restrictive access criteria, it also has an effect on the continued marginalisation or exclusion of groups who do not have the material or social resources to campaign for or even be aware of their entitlements. Likewise, while data on ethnicity may be collected, its analysis and use may not be relevant or adequate for informing policy with regard to the access to and utilisation of services by Māori. Consequently, the lack of information collected in relation to Māori infertility and access to ART services will affect the ability of Māori to access these services in the future, as policies will continue to be made

¹³⁷ Epidemiology is the study of the distribution and determinants of disease. According to Bhopal and Senior (1994), the main method of epidemiological study, when investigating the causes of disease, is to compare populations with different risks of disease and, increasingly, ethnicity is used as a variable to define these populations.

without adequate consideration of the issues for Māori. Of particular relevance to data collection is the way in which ethnicity is defined and recorded.

Central to being able to generate statistics on Māori infertility and use of ART are issues relating to how to define Māori. As Pomare et al (1995) point out, the Māori population is dynamic and constantly changing, and problems with defining Māori have contributed to difficulties in monitoring this population. Although statutory definitions of Māori have changed over time,¹³⁸ from 1860 to 1986 Government definitions of Māori were based on biological concepts of race (Reid, 1999b:84).¹³⁹ Since the mid-1970s the concepts of 'ethnicity' or 'culture' have replaced the biologically based concept of race, and in 1986, the Aotearoa/New Zealand census form dropped the term 'race' in favour of 'ethnicity' and self-identification became the method used to determine ethnic identity (Durie, 1998:124). Accordingly, the preferred definition of Māori became "a person who has Māori ancestry and who chooses to identify as Māori" (Pomare, et al., 1995:30). The most recent official definition of an ethnic group used by Statistics New Zealand is a social group whose members share a common origin, claim a common and distinctive history and destiny, possess one or more dimensions of collective cultural individuality,¹⁴⁰ and feel a sense of unique collective solidarity. Using this definition, ethnicity can be differentiated from the related concepts of ancestry,¹⁴¹ natality,¹⁴² and nationality.¹⁴³ However, ethnicity is not purely a matter of personal choice or preference. It is a fluid and dynamic concept that allows individuals to identify with more than one ethnic group and to move between ethnic groups over time (Tobias, 2001:2).

Many analysts have addressed the difficulties surrounding the use of ethnicity as a variable in social research, especially in relation to health (Senior & Bhopal, 1994; Pomare, et al., 1995; Heitman & Schlachtenhaufen, 1996; Bhopal, 1997; Bhopal, 1998; Durie, 1998; Green & Thorogood, 1998; Reid, 1999b; Mckenzie & Crowcroft, 2001; Tobias, 2001). These difficulties

¹³⁸ See Durie (1998:123-126) and Reid (1999b) for explanations of these changes.

¹³⁹ During the 19th century, differences between races were assumed to be biological and were used to support the perceived superiority of 'white' races and to justify the continued subordination of 'coloured' groups (Bhopal, 1998). However, modern genetics have weakened the biological concept of race, proving there is more genetic variation within racial groups than between them. Moreover, the genes responsible for physical features that are often used as the basis of racial differentiation are "few, atypical, and not associated with genes responsible for disease" (Senior & Bhopal, 1994).

¹⁴⁰ Tobias (2001:2) defines this concept as "a unique language, religion, customs, mythology, or folklore."

¹⁴¹ Origin or descent.

¹⁴² Birthplace or country of origin.

¹⁴³ Country of permanent residence or citizenship.

include inconsistent definitions of ethnicity used in data sets such as the national census, hospital admissions, live births records, and mortality and morbidity rates. Although there has been widespread progress in relation to defining ethnicity through cultural affiliation and self-identification, there remains some variation between government departments (Durie, 1998:125-126). These inconsistencies mean that accurate comparisons cannot be made across government data sets or between the same data set over time. Pomare et al (1995:31) define the three current options for estimates of the Māori population as 'Māori Ancestry',¹⁴⁴ 'Māori Ethnic Group',¹⁴⁵ and 'Sole Māori'.¹⁴⁶ Questions regarding ethnicity have changed over four consecutive censuses and the change in 1996 led to a large decrease in the size of the 'Sole Māori' population and an increase in the size of the 'Māori Ethnic Group' population (Te Puni Kōkiri, 2000a:51).¹⁴⁷ Each data set has its own meaning and policy advice will differ depending on the data set used to inform particular studies or policy issues. Therefore, consideration should be given to "which population should be used for which occasion" (Pomare, et al., 1995:31) as the outcomes may determine how Māori roles and needs are defined for many years.¹⁴⁸ According to Tobias (2001:21), difficulties in measuring ethnicity are also compounded by a lack of understanding or acceptance by the general population who continue to interpret ethnicity as biological race, natality, or nationality. Senior and Bhopal (1994) suggest that the terms ethnicity and race are often used interchangeably in health research and that this infers that differences in the incidence of certain diseases between ethnic groups is partly due to genetic variations. Consequently, they argue that it is important for researchers to be clear about the differences between the two terms.

¹⁴⁴ Those who identified Māori ancestry.

¹⁴⁵ Those who identified Māori as one of their ethnic groups.

¹⁴⁶ Those who identified Māori as their only ethnic group

¹⁴⁷ Between the 1991 and 1996 censuses, the 'Sole Māori' population "unexpectedly decreased by 16% ... while the Māori ethnic group increased by 20%" (Te Puni Kōkiri, 2000a:51). These changes cannot be explained by the demographic processes of births, deaths, and migration (Statistics NZ in Te Puni Kōkiri, 2000a:51). Instead they reflect changes in the wording of the ethnicity question between the 1991 and 1996 censuses. ACNeilsen (in Te Puni Kōkiri, 2000a:51) argues that wording that encouraged people to tick more than one ethnic group category precipitated the accidental capture of information on ancestry, rather than ethnicity. Consequently, Statistics New Zealand (in Tobias, 2001:9) reverted to the 1991 wording of the ethnicity question for the 2001 census in the hope that the results will enable better comparative analysis with the 1991 census. According to Tobias (2001:10), Statistics New Zealand is undertaking a major review of ethnicity measurement, which may result in changes to the ethnicity questions for future censuses.

¹⁴⁸ Reid (1999b:86) highlights the difference in outcomes that can be achieved by using the 'Sole Māori' population in contrast to the 'Māori Ethnic Group' population when comparing the first admission rates for Māori and non-Māori women with psychiatric disorders between the years 1991-93. Using the 'Sole Māori' population as the denominator reveals considerable disparity between Māori and non-Māori. However, when the 'Māori Ethnic Group' population is used as the denominator this disparity is considerably reduced.

Although the HFA does not enforce the collection of ethnicity data by ART providers, some clinics do attempt to collect this information.

We actually give them ethnicity of treatments and stuff but that is the only demographic stuff we are required to provide... and within the clinic, the information gathering on treatment is really good... But, as far as IVF, we have got databases and we know lots of stuff about every single treatment cycle that we do.
(John Peek, Interview: 12 July 2000)

A lack of incentive and guidance may mean that the information collected is not consistent between clinics or in a form that can inform policy with regard to the prevalence, access, or utilisation issues for Māori. While the new service specifications (Health Funding Authority, 2000b:10, see Appendix L) for publicly funded ART treatments provide a chart for recording patients' ethnicity, they do not set out guidelines for the collection of the data. Neither do they appear to provide a definition for any of the ethnic groupings shown on the form. The accuracy of the data is also dependent on the method used to complete this section of the form.

We are supposed to be identifying the ethnic groups of all our patients but that is not an easy task. And I would say you could probably count on two hands the number of patients that would call themselves Māori or are recognisable as Māori off the names on the list, you know looking for a Māori surname and things like that.
(Mark Leggett, Interview: 22 June 2000)

While some researchers (in Senior & Bhopal, 1994) have maintained that names analysis is "sensitive and specific" in identifying ethnic group status, such methods do not take into account ethnic intermarriage and the adoption of a spouse's name. Embarrassment by clinic staff may prevent direct questioning and speculation about ethnicity based on physical appearances is highly inaccurate (Kilgour & Keefe in Durie, 1998:125). According to Heitman and Schlachtenhaufen (1996:192), direct questioning or filling out forms may result in respondents refusing to provide the information or providing inaccurate information. Such responses may be motivated by suspicions about how the information will be used and mistrust in a health system that they perceive to have excluded them or worked against their interests in the past.

Traditionally, Māori health and illness statistics have been presented in comparison to non-Māori statistics (Durie, 1998:127). Such comparative approaches inevitably use the dominant population as the norm (Bhopal, 1997) and are based on the assumption that health outcomes should be the same, imposing a "common concept of health on all ethnic groups" (Tobias, 2001:22). Consequently, they are in danger of supporting assimilative aims and goals (Durie in Reid, 1999b:89). However, highlighting the disparity in health needs and outcomes between Māori and non-Māori can also portray Māori health as being less than or inferior to non-Māori. Green and Thorogood (1998:78) point out that there has been substantial criticism of

explanatory methods that use cultural practices to explain differences in health outcomes. Such methods look to explain differences in health outcomes in the behaviour of the disadvantaged groups and emphasise a 'victim blaming' approach. Bhopal (2001) acknowledges this dilemma when using ethnicity as a variable in health research. While conceding that ethnocentrism can only be challenged by an analysis based on the examination of differences and accepting that such an analysis requires data on ethnicity, he argues that such analyses also perpetuate the use of ethnicity to accentuate differences and provide the potential for abuse. It is this potential for abuse that concerns Grant Allan (Senior Policy Analyst, Te Puni Kōkiri) in relation to the use of Māori specific statistics. He argues that such statistics may be used to negatively portray Māori¹⁴⁹ and he uses Māori teenage pregnancy rates¹⁵⁰ as an example.

...they actually use our pregnancy as an indicator for something, which is negative, when it could be interpreted as a positive. It is difficult to take.

(Grant Allan, Interview: 25 July 2000)

Likewise, Penny Ehrhardt (Policy Analyst, Te Puni Kōkiri) questions the use of comparative statistics and ethnocentric analysis in relation to teenage pregnancy.¹⁵¹

It is a very interesting issue for Māori because, of course, there is a lot of government policy and a lot of public comment concerned about teenage pregnancy rates and young people having children. So, there is a lot of emphasis on that and traditionally, say 30 or 40 years ago, Māori have had children younger than non-Māori and that has been publicly perceived as a bad thing. [Contributing to] poor health outcomes and linked to the mother being young when she has her first child. There is some debate as to whether that is a culturally biased way of looking at our family formation.

(Penny Ehrhardt, Interview: 25 July 2000)

¹⁴⁹ Bishop (1996:14-15) highlights reasons why Māori are growing increasingly resistant to research into their lives by non-Māori researchers. He argues that traditional research has misrepresented Māori knowledge for the "consumption" and benefit of "the colonisers". Consequently, the voice and authority of the "expert" researcher has subjugated Māori experiences and knowledges. Furthermore, he argues that Māori cultural practices and meanings have been misinterpreted and misrepresented by non-Māori researchers, and have been used to further subordinate Māori culture (Bishop, 1996:14-15).

¹⁵⁰ There is some debate over the consequences of Māori teenage pregnancy. The Ministry of Health (1997:21 & 24) maintains that unplanned pregnancy is an important issue for Māori, and that teenage pregnancy is associated with and perpetuates disadvantage. While Chris Cunningham (Hui Whai Maramatanga Whai Oranga & Ministry of Māori Development, 1995) acknowledges that teenage childbearing may disadvantage both mother and child, he argues that the measure of "unplanned pregnancy" (the number of births to both teenage mothers and unpartnered women) disadvantages Māori because of their 'natural' pattern of fertility. Te Puni Kōkiri's stated position (in Ministry of Health, 1997:21) is "that for Māori no pregnancy or baby, whether intended or not, is unwanted or a problem if adequate support exists." Accordingly, they claim many Māori support a pro-Māori childbearing position as a means of continuing to increase the Māori population.

¹⁵¹ Ginsburg and Rapp claim that Western industrial societies have an obsession with classifying teenage sexuality and pregnancy as a "social problem." Cross-cultural comparison suggests that such societies construct the problem in relation to their own understanding of adolescence, "reduced value placed on fertility, and lack of cultural and social supports, all of which are differentially mediated by considerations of age, class, race, ethnicity, sexual preference, and marital status" (Ginsburg & Rapp, 1991:320).

Although the collection of routine statistics alone does little to identify the means by which “social inequalities are reproduced as health inequalities, or how policy could usefully address them” (Green & Thorogood, 1998:81) and may negatively impact on some groups, they are fundamental for documenting and monitoring inequities in health policy and service outcomes, as well as for evaluating the achievement of guarantees made in te Tiriti o Waitangi.

6.5 Whāngai & ART

Several of those interviewed suggested that the use of ART might not be an issue for Māori as they could possibly use more culturally acceptable ways of dealing with infertility, such as the practice of whāngai.

Māori may have ways of dealing with it that do not require IVF, as with respect to whāngai children of families. (Teresa Wall, Interview: 24 July 2000)

This suggestion has been echoed in the available documentation and literature. The New Zealand Law Commission (2000:75 n.246) maintains that “infertility was often used as a reason why a child was offered as a whāngai to a relative.” Similarly, Dyll (1999:36-37) argues that the traditional practice of whāngai has enabled Māori to address infertility (social and biological), as it facilitates the sharing of children within kin groups. Whāngai has also been used as a means to heal conflict and create or strengthen relationships between whānau, hapū, and iwi.¹⁵² Māori use the concept of whāngai (feed/nurture) to describe situations where adults other than the birth parents and grandparents assume primary care of a child for any significant period (Durie-Hall & Metge, 1992:71). Integral to this concept is the belief that children are not the exclusive possession of their parents, but that they belong to the whānau, hapū, and iwi. “They are ‘ā tātou tamariki’ (the children of us many) as well as ‘ā tāua tamariki’ (the children of us two)” (Durie-Hall & Metge, 1992:63-64). The concept of whāngai is supported by principles of openness, placement within the whānau, whakapapa (genealogy), and “the centrality of relationships to the Māori way of life” (whanaungatanga) (New Zealand Law Commission, 2000). Therefore, unlike traditional Pākehā adoption practices, whāngai does not involve secrecy and the children grow up with knowledge of their whakapapa and why their care has been shared (Dyll, 1999:37). Consequently, the concept of whāngai encourages the continuation of relationships between the child and both birth and social parents. Whāngai has had varying levels of legal endorsement and, although it is no longer legally recognised, Māori

¹⁵² Whāngai placements were generally arranged between members of the same hapū or iwi, although relatives by marriage would occasionally be considered as caregivers. Consequently, land rights did not become diffused and remained concentrated within the tribe (New Zealand Law Commission, 2000:75).

continue to practise whāngai placement as a means of caring for children (New Zealand Law Commission, 2000:73 & 85).¹⁵³

Some commentators (Daniels & Taylor, 1991; Adair & Rogan, 1998) have equated the concept of whāngai to surrogacy. Similarly, some submissions by public bodies to MCART (1994:107) endorsed certain forms of surrogacy on the grounds that it could be compared to both Māori and Pākehā traditional practices. However, the various arrangements known as surrogacy centre on the involvement of a woman who provides gestation and the birth of a child with the intention that others will raise the child.¹⁵⁴ While there is no empirical evidence that whānau members have conceived children for the sole purpose of whāngai, there is some anecdotal evidence that this has occurred. One of those interviewed had been told of a child that had been deliberately conceived in order to be raised by another family member.

...her daughter was infertile so somebody else in their whānau had a baby for her.
(Robyn Scott, Interview: 26 July 2000)

Correspondingly, the only submissions to MCART (1994, Appendix C, p.27) that “actively supported surrogacy came from Māori who discussed the whāngai concept...” Father Henare Tate (in New Zealand Law Commission, 2000:75) maintains that the tikanga associated with the concept of whāngai can vary between iwi.¹⁵⁵ Accordingly, there were differing opinions among those interviewed on the appropriateness of equating whāngai to surrogacy. Naida Glavish (Chief Advisor - Tikanga, Māori Health Development Service, Auckland Healthcare Services Limited) argues that it is not appropriate to compare the concept of whāngai with surrogacy.

¹⁵³ See *Adoption and Its Alternatives: A Different Approach and a New Framework* (New Zealand Law Commission, 2000:73-92) for a discussion of the varying degrees of legal recognition placed on Māori customary adoption practices, as well as a discussion of the succession and inheritance issues surrounding whāngai. See *A Question of Adoption* (Else, 1991:172-196) for a brief account of the impact of the Pākehā system of adoption on the Māori practice of whāngai.

¹⁵⁴ The various arrangements known as surrogacy involve a woman who provides the gestation and birth of a child for others. However, this woman may also provide the ova and conception so that she is the genetic mother, as well as the birth mother (Blyth, 1993:248). There are three main types of surrogacy arrangement: 1. Insemination by intercourse with the intending father or a donor. This is usually a private arrangement with no medical involvement; 2. Artificial insemination, using sperm from the intending father or from a donor. This does not technically require the services of an assisted reproductive technology provider but may involve health professionals; 3. Gestational surrogacy, also known as ‘full surrogacy’ or ‘IVF surrogacy’. One or more embryos, created (usually by IVF) from the gametes of the intending parents, one of the intending parents plus a donor, or two donors, are transferred to the womb of a woman who has no genetic connection to the embryos (Else, 1999a:50). See Appendix A for a more detailed description of the various surrogacy arrangements that can occur by using of ART.

¹⁵⁵ Tikanga can include law, customs, values, traditional behaviour, and philosophy (New Zealand Law Commission, 2000:75 n.247). According to Naida Glavish (Chief Advisor - Tikanga, Māori Health Development Service, Auckland Healthcare Services Limited, Interview: 9 August 2000), “tikanga are the customs and protocols of spirituality that Māori require to be included in the delivery of services.”

...in some instances the whāngai are in actual fact "gifted" children. ... They are given out, whāngai out, for specific purposes and they are special, very special. But, there are instances when the whāngai is one who the whānau, the mother or the father, just cannot cope and the baby is given away. So, there are positive and negative in the terminology of whāngai. But, surrogacy, whāngai does not enter into the surrogacy world. (Naida Glavish, Interview: 9 August 2000)

While not opposed to non-commercial surrogacy, Naida Glavish argues that it is the deliberate conception of a baby to be raised by someone else that differentiates surrogacy from whāngai.

Usually with whāngai, it is not decided before the baby is even conceived that there is going to be a baby conceived to whāngai out. And so, surrogacy in one sense, whereby the womb has got a "for sale" sign on it ... violates the tapū of the womb, the tapū of the wharetangata. But surrogacy, agreeing to have the baby out of the goodness of your heart because you feel for your best mate who cannot have children, well that is a different issue all together.

(Naida Glavish, Interview: 9 August 2000)

As discussed earlier, both whakapapa and whānau presuppose relationships, responsibilities, and obligations that allow a range of adult kin to take parenting roles in the lives of Māori children (Pihama, 1998:182). Parents are expected and expect to share care and control of their children with other whānau members (Durie-Hall & Metge, 1992:64). Māori children are regarded as an integral part of the whānau, rather than individuals divisible from the whānau (New Zealand Law Commission, 2000:82). It is in relation to this concept of shared care that one commentator sees the parallel between surrogacy and whāngai, as well as the possible acceptance of surrogacy by Māori as an alternative to other ART practices.

Non-Māori [attitudes to the] ownership of children is an issue that is at odds with how Māori might see or view children. So, surrogacy may well be a reproductive solution that Māori might find more acceptable than [other ART practices]. ... I do not know whether people would have had babies for somebody else so much, but certainly, it is not uncommon for people to have a baby and someone ask them for it.

(Teresa Wall, Interview: 24 July 2000)

As whāngai facilitates the sharing of children within kin groups, ensuring that the children grow up with knowledge of their whakapapa and why their care has been shared, it would be more appropriate to compare whāngai to the Pākehā concept of fostering or guardianship where the biological parents remain the legal parents and the child is fully aware of its genetic and familial origins. The concept of whāngai is consistent with an increasing commitment to 'open adoption' in which the birth parents retain social connections with both the adoptive parents and the child. These practices challenge traditionally dominant definitions of family and resist the prevailing legal principle of severing relationships between birth and social parents that has existed within traditional Pākehā adoption practices.¹⁵⁶

¹⁵⁶ An emphasis upon secrecy has pervaded adoption law since 1955 (New Zealand Law Commission, 2000:3). Although New Zealand adoption policy has encouraged 'open' adoptions since the 1980's, there

While acknowledging that whāngai and fostering may be used as an option for addressing infertility, Penny Ehrhardt (Policy Analyst, Te Puni Kōkiri) recognises that it was difficult to predict whether the use of traditional practices would mean there is less demand for ART services among Māori.

It may be worth looking at the concepts of fostering and whāngai in terms of family formation. [They may be] options that Māori are more likely to pursue if they do not have biological children of their own. [It is not clear] whether those [options] are supported by policy and government strategies and whether that does mean there is less demand. (Penny Ehrhardt, Interview: 25 July 2000)

Indeed, in their submission to MCART (1994, Appendix E, p.3), Manatu Māori (Ministry of Māori Affairs) argued that the “need for fertility clinics to devise and implement culturally supportive and safe processes in respect of ART arises from the recognition that this technology is being sought by Māori recipients and donors.” The inclusive concept of whānau combined with the concept of whāngai may have enabled some Māori to address infertility without using ART. Nevertheless, Māori do seek out and use ART services to overcome infertility problems.

...the number of people coming for consultations, Māori and Pacific Islanders, in the Northland health area is about the same as the population so I think we are reaching people relatively well. (John Peek, Interview: 12 July 2000)

Therefore, while whāngai may be an appropriate alternative to ART treatment for some Māori, there may be many reasons why it is not considered appropriate or feasible by others. For those who choose to use ART to address their fertility problems it is necessary to ensure that issues surrounding the protection of whakapapa are attended to.

6.6 Protecting Whakapapa

...there are the things about whakapapa, and children of Māori parentage being able to track their whakapapa. So there is the matter of donors giving over that information, it being stored, and some way in which the child is given that information.

(Teresa Wall, Senior Analyst, Māori Health Branch, Ministry of Health, Interview: 24 July 2000)

It is the knowledge of whakapapa (genealogy) rather than the extent of an individual's Māori 'blood descent' that determines membership to a whānau, hapū, or iwi and, as such, this knowledge is an integral part of being Māori (Dyall, 1999:35). Knowledge of ancestry is also

is no legislative control to ensure that such arrangements continue. See *Adoption and Its Alternatives: A Different Approach and a New Framework* (New Zealand Law Commission, 2000) for a comprehensive review of the law of adoption, and the Law Commission's recommendations on how the legal framework should be changed to better address contemporary social needs.

important in relation to exercising certain constitutional rights, particularly the right to take claims to the Waitangi Tribunal, to register on the Māori electoral roll, to access scholarships, and to own and sell Māori land (Dyall, 1999:35; Reid, 1999b:86; New Zealand Law Commission, 2000:83). Consequently, as the use of ART sometimes involves the use of donated gametes, the collection of and access to information regarding gamete donors and genetic background is particularly relevant to Māori. The traditional culture of secrecy surrounding donor insemination practices,¹⁵⁷ as well as restrictions on access to information about donors and birth parents, can create difficulties for Māori conceived using donated gametes who wish to trace whakapapa and access entitlements (New Zealand Law Commission, 2000:83). The movement in Aotearoa/New Zealand towards information openness in adoption and gamete donation has been strongly influenced by Māori culture and its emphasis on knowing one's whakapapa (Daniels, 1998b:94).¹⁵⁸ Consequently, secrecy in relation to adoption and donor insemination is no longer the accepted practice. Nevertheless, openness is not a legal requirement and access to any information is limited by whether or not the parents tell their children of the circumstances of their conception and whether the clinic or general practitioner involved had overturned its policy of secrecy and anonymity or kept records of those involved. Although accredited clinics no longer provide the option of anonymity to donors, the legislation still upholds this practice by legitimating the provision of a 'false' birth certificate and, consequently, the suppression of the genetic origins of individuals' conceived through the use of donor gametes.

The Status of Children Amendment Act 1987 (SCAA)¹⁵⁹ changes the legal status of the child in a similar way to the Adoption Act 1955. However, unlike adoption, there is only one birth certificate and it reads as if the legal parents are the biological parents (New Zealand Law

¹⁵⁷ Daniels (1999:6) maintains that donor insemination has been practised in New Zealand for at least 55 years and until the early 1990s it was the policy within clinics to guarantee anonymity to gamete donors. The culture of secrecy and anonymity that has surrounded the practise of donor insemination has led to an unknown number of children being born in New Zealand who will have no access to either identifying or non-identifying information about the donor.

¹⁵⁸ It should be noted that this was not the only influence on the move to open adoption. Other factors influential in initiating the practice of 'open adoption' include changes in social values in relation to single motherhood, the feminist movement, active campaigning by adopted adults, birth parents, and adoptive parents for an individual's 'right to know' about their genetic connections, and changes in nursing home policies (Else, 1991:169; Else, 1999b:57).

¹⁵⁹ See Chapter One, Introduction, Section 1.4, Families & ART, for a discussion of the Status of Children Amendment Act 1987 and how it affects the legal status of parents and children who have been conceived through the use of donor gametes.

Commission, 2000:210).¹⁶⁰ So, as Else (1995:217) points out, the SCAA “ensures that, unlike adoption, sperm and egg donation leave no legal traces, because no legal process is required to establish parenthood.” This has significant consequences for Māori and raises issues about an individual's rights to access information about donors and their genetic background.¹⁶¹ The use of donated gametes together with the SCAA can inhibit an individual's access to knowledge of their whakapapa and, consequently, their access to their cultural heritage and entitlements. According to Else (1995:218), “the key to making openness effective, whether in adoption or in birth through ART, is the free availability to the offspring of full and honest birth certificates.” Although official records can only hold a limited amount of information and cannot provide “the fullest possible knowledge of the genetic and/or birth connection” afforded by personal contact, they can provide a starting point for contact (Else, 1999b:60). Even though openness can be encouraged, it would be impossible to legislate for compulsory disclosure or to enforce such a law without infringing on individuals' right to privacy. Therefore, the issue of secrecy or disclosure will no doubt be left to the parents to resolve. However, without legislation or specific guidelines that ensure the collection of culturally relevant identifying information, as

¹⁶⁰ Upon adoption, a child's birth record is sealed and a new birth certificate, showing only the names of the adoptive parents and their ages at the birth of the child, is issued. By concealing the child's genetic and (in some cases) cultural background, the ‘culture of secrecy’ was further embedded into Pākehā adoption practices. However, this ‘culture of secrecy’ has been partly undermined by the Adult Adoption Information Act 1985 (New Zealand Law Commission, 2000:19). This act makes it possible for adopted people aged 20 years or over to obtain their original birth certificate and the birth parents may obtain the adopted persons name, subject to the adopted person's consent. However, either party may place a veto on the release of identifying information concerning them (Griffith, 1991:154). As birth fathers are not often named on the birth certificate, adopted people are currently dependent on the birth mother for information about the birth father. Similarly, the Adult Adoption Information Act 1985 does not provide access to information about siblings, half-siblings, grandparents, and other extended family members (Iwanek, 1998).

¹⁶¹ Although New Zealand culture places a strong emphasis on individual's right to know their genetic origins, there is no statutory requirement for the collection and storage of information about gamete and embryo donors, surrogates, and any people born from the use of donated genetic material. Nor is there any provision for these people to access identifying or genetic information about donors or surrogates (Henaghan, 1992:184). Until the early 1990s, it was the policy within clinics to guarantee anonymity to gamete donors. However, New Zealand's position on access to identifying information has been influenced by the Adult Adoption Act 1985, which recognised the need for information by adopted people, and accredited clinics no longer provide the option of anonymity to donors. Although this is not a legal requirement, New Zealand fertility clinics encourage donors to agree to contact should the person conceived using their gametes wish it (Adair & Rogan, 1998:268-270). RTAC's ‘Code of Practice for Centres using Assisted Reproductive Technologies’ (RTAC, 1999) ensures that accredited clinics keep permanent records of “ART procedures, identifying patients, gamete or embryo donors and recipients, and outcomes of attempted fertilisation and conceptions.” Clinics are advised that they “should allow all donors and patients access to their records” (RTAC, 1999). The ‘Guidelines for Screening for Gamete Donation’ (RTAC, 1999: Attachment J) sets out what information about the donor's social history is “considered to be appropriate” and “which may be of assistance to parents of children at a later date”. However, the guidelines do not specify who may have access to what information, and it appears that

well as the permanent availability of such information, the individuals involved in donor ART practices remain vulnerable to the inconsistencies of location, clinical discretion, and clinic closure in relation to information being available when they need it.

According to MCART (1994:70), secrecy about genetic origins “is antithetical to Māori values and could be said to conflict with the principles of the Treaty of Waitangi.” Although the Assisted Human Reproduction Bill (Graham Bill; see Appendix J) stresses a policy of openness, proposing the establishment of a centralised system of information gathering and giving those involved in ART extensive information rights, it fails to include any mention of te Tiriti o Waitangi or its provisions for the protection of Māori as tangata whenua (Coney, 1999a:25; Dyll, 1999:35).¹⁶² In contrast, the Human Assisted Reproductive Technology Bill (Yates Bill; see Appendix I, p.2) establishes the Treaty as one of the guiding principles of the bill. However, neither bill fully addresses what genetic information should be recorded or how it will be collected and stored. Alternatively, the New Zealand Law Commission’s (2000:73) review of the legal framework surrounding adoption in Aotearoa/New Zealand acknowledges the “unique status that Māori occupy as tangata whenua and as partners to the Treaty of Waitangi” when considering Māori views on adoption and recommends that there should be

...unrestricted access to information by those in the adoption triangle. This should alleviate the concerns of Māori and other cultural groups regarding access to whakapapa/genealogical information. (New Zealand Law Commission, 2000:91)

This review also recommends unrestricted access to information about donors and individuals conceived using donor gametes for “persons born as a result of assisted human reproductive technology/donor insemination, their parents and the donor” and that “access to such information by other persons would be limited in the same way as for adoption information” (New Zealand Law Commission, 2000:228). However, while outlining two options for recording and storing donor information, it falls short of recommending which option should be implemented. Until either bill is enacted (in its original form or as an amended/combined version) or the adoption laws are amended to include ART practices involving donor gametes, the recording and maintaining of information is limited, voluntary, and dependent on the requirements of the Australian Reproductive Technology Accreditation Committee (RTAC).

these issues will be decided by the clinics in question. Moreover, access to this information is limited by whether or not the parents tell their children of the circumstances of their conception.

¹⁶² Sir Douglas Graham (2000), who introduced this bill, has since argued that the Treaty of Waitangi has no place in legislation relating to health, education, housing, and the social services in general. He maintains, “there are many areas where the treaty is simply irrelevant. The provision of health services is one of them.”

The 'Code of Practice for Centres using Assisted Reproductive Technologies' (RTAC, 1999) ensures that some records are kept by accredited clinics. However, there is no legal requirement for Aotearoa/New Zealand clinics to be accredited and much of the information is retained according to the clinics' discretion. Other concerns include the lack of accountability by RTAC to the Aotearoa/New Zealand Government and the absence of an Aotearoa/New Zealand supplement in the 'Code of Practice' that would recognise and protect Māori involvement in ART practices.¹⁶³ Although there have been repeated calls for the development of a Aotearoa/New Zealand-specific supplement to the RTAC guidelines, this supplement has not eventuated and now appears to be dependent on the outcome of the Health Select Committee's consideration of the two bills on ART. These two bills have been under consideration since 1996 and 1998, and at the time of writing, a combined report was due in May 2002. However, this deadline had been revised several times since the beginning of this thesis and there is no guarantee that this is a definite date for the publication of the report. Some protection may be afforded those who access publicly funded ART treatment as the Health Funding Authority (2000b:5) now requires clinics that hold public contracts to "be cognisant of Māori requirements around guardianship of personal information and practise these rigorously." However, there is no guarantee that this requirement will be enforced or monitored and it is too early to tell whether recent changes to the service specifications for infertility services will improve the situation in relation to the implementation of Māori specific requirements. In the meantime, Māori gamete donors, surrogates, commissioning parents, and individuals conceived with donor gametes are offered little protection that the information they may seek will be permanently available, accurate, or culturally relevant.¹⁶⁴

¹⁶³ See Chapter Three, Regulating Practices, Section 3.6, Professional Self-Regulation, for a discussion of RTAC's role in the regulation of New Zealand fertility clinics.

¹⁶⁴ As highlighted in Section 5.2: Is there a need?, there is a possibility that the use of ART by Māori will increase as a result of female reproductive disorders caused by STD's. However, it should be acknowledged that there are differences in the practices surrounding sperm donation and ovum donation. While it is traditionally acceptable for recipients experiencing male-factor infertility to use sperm from unknown donors, recipients experiencing female-factor infertility are encouraged to use ova donated by a family member and to engage in face-to-face contact with the donor. For these reasons, ova donation may lead to fewer problems in relation to future access to genetic information by any children conceived from these gametes. Therefore, the practices surrounding ova donation may be more culturally acceptable to Māori than the traditional practices surrounding sperm donation.

6.7 Policy Issues

Chris Cunningham (Hui Whai Maramatanga Whai Oranga & Ministry of Māori Development, 1995:28) argues that the sharp drop-off in fertility rates for Māori women should be of concern and may lead to increased demand for ART services by Māori. However, Teresa Wall (Senior Analyst, Māori Health Branch, Ministry of Health) questions the need for public investment in high cost technologies at the expense of preventative measures.

Preventing the problem at the outset or putting in place high cost technologies? For Māori it should be identifying whether there is going to be a problem in the future and I suspect that there will be, because of the reports that we are getting now about the higher chlamydia rates. We need to be combating that as opposed to putting in place high cost technologies, which may not be [effective]. Māori will have problems getting [access to] them irrespective, because of targeting and because its perception that it is not an issue.

(Teresa Wall, Interview: 24 July 2000)

Similarly, Penny Ehrhardt, (Policy Analyst, Te Puni Kōkiri) stressed the need to focus on preventative approaches to reduce the need for ART in the future.

The need to protect fertility ... seems more of a priority because of [sexually transmitted infections] etcetera, are high and the recent research that has come out that they seem particularly high among young Māori women, and therefore issues of infertility may become greater issues in the future. The hope is to take a preventative approach at this stage rather than focus on down the track helping a lesser number if possible.

(Penny Ehrhardt, Interview: 25 July 2000)

Most of those interviewed argued for improved educational programs that would inform young people on how they could best avoid exposure to fertility risks. Similarly, Blank and Merrick (1995:221-222) suggest that more resources spent on preventative measures for the known causes of infertility and research into the causes of unknown infertility would better assist marginal groups than increased spending on ART innovations. However, those young Māori women who have already been exposed to fertility threatening STI's are likely to face the barriers mentioned to accessing ART services in the near future and prevention focused policies will not assist them. Regardless of resources devoted to preventing infertility, there is a need to examine how ART services can better assist Māori people who are already experiencing fertility problems.

The exclusion or marginalisation of Māori within the policy discourse surrounding ART practices is not necessarily a deliberate strategy implemented by policy-makers, providers, and consumers. According to Iris Marion Young (1990:185), "policy issues are often defined by the assumptions and priorities of the privileged." Groups with social and economic privilege have the "material, personal, and organisational resources" that facilitate their ability to express their needs and priorities so that they are seriously considered (Young, 1990:185). As such, and

without specific information on the use of ART by Māori, ART policy continues to be based on the perceived needs of the culturally dominant Pākehā group. This is not to say that providers are unaware of the barriers to services that Māori face. Some are already trying to accommodate cultural diversity and improve their services for Māori.

It is very hard because there is not a Māori voice to go to you know. We have used Māori people and we have used particular feedback from patients to try to be more sensitive and to try to think and deliver a better way...

(John Peek, Interview: 12 July 2000)

Similarly, Rodney Bycroft (Scientific Director/Manager, Artemis North Shore Fertility, Auckland) acknowledges the need for cultural sensitivity in relation to ART practices.

...the relationship we have with other cultural groups needs to be recognised. I would say that would include, in Auckland because it is such a cosmopolitan city now, Chinese, Asian, Korean, Indian, Pacific Island, you name it. That means that we have to have access to interpreters, we have to be culturally sensitive to their requirements, and the specific issues of whānau and iwi and consultation with hapū and their elders. ... And, I believe that that consultation process is vital to some of the specific issues of [certain] ethnic groups.

(Rodney Bycroft, Interview: 13 September 2000)

While these clinics have indicated a willingness to consult with Māori about how they can better improve their services and make them culturally safe, as stipulated in the service specifications (Health Funding Authority, 2000b:2, see Appendix L), it appears that there are no sanctions implemented regarding non-compliance. The conditions imposed by the service specifications for publicly funded ART require clinics to implement a Māori health policy that recognises “that Māori health is a specifically identified health gain priority area” and to “identify how these services will be measured to ascertain what benefit is evident and any other additional opportunities that may exist for furthering Māori health gain” (Health Funding Authority, 2000b:2, see Appendix L). However, there are no specific procedures outlined to assist clinics in developing and implementing this policy and, although providers are required to submit their plan within three months of the implementation of the service specifications, there is no guarantee that the Ministry of Health will follow up or enforce these plans anymore than the HFA implemented the data collection requirements of the previous contracts.¹⁶⁵

Young's (1990:158) politics of difference promotes “equality as the participation and inclusion of all groups” and argues that, as such, “it sometimes requires different treatment for oppressed or disadvantaged groups.” Accordingly, social policy should recognise that certain groups have particular needs and should target these groups for specific treatment. While the Ministry of

¹⁶⁵ In January 2001, the HFA's functions were integrated into the Ministry of Health and District Health Boards.

Health recognises that Māori are particularly disadvantaged in the health arena and address this issue through the inclusion of Māori focused policies, the inequalities in access appear to have low priority in relation to ART. This is perhaps influenced by the perception of ART and infertility treatment as a “niche” area, mainly utilised by the white middle classes. However, some Māori do use ART and, although the policy discourse that does exist in relation to the use of ART by Māori articulates a need for ART practices to be culturally safe, what these requirements might be are not explicitly laid out. The formulation of adequate policy in relation to Māori and the use of ART must start with the collection of information, addressing issues such as whether technological solutions to infertility are appropriate or acceptable for Māori and what issues need to be addressed to make ART practices culturally safe. As John Peek (Clinical Manager/Group Operations Manager, Fertility Associates Auckland) acknowledges,

...we still do not know what proportion of Māori feel comfortable using ART as an approach to infertility and what proportion [are uncomfortable with it].

(John Peek, Interview: 12 July 2000)

This raises a point made by Penny Ehrhardt (Policy Analyst, Te Puni Kōkiri) in relation to finding out what Māori see as the main issues regarding the use of ART.

The other point to make in terms of Māori input, if [the Ministry of] Health or anyone was going to do a look at ART [or the] guidelines, we feel it is important that they actually go and ask Māori what they see as their priority. ... Not necessarily door knocking, maybe going to Māori organisations. Te Puni Kōkiri does not speak for Māori.

(Penny Ehrhardt, Interview: 25 July 2000)

Reid (1999b: 89) argues that it is important to recognise that “Māori are a diverse population, expressing ethnicity across a spectrum of realities, from conservative to modern and tribal and urban.” There is no one Māori voice to articulate the needs of Māori; nor is there one Māori reality. As Durie (1998:215) and others (Cunningham & Kiro, 2001:68) have pointed out, Māori inhabit varied cultural worlds. Tobias (2001:21) argues that the “ethnic experience is different for males and females, for people living in different parts of the country..., for people of different birth cohorts ageing through different periods..., and for people belonging to different social classes.” Similarly, Dame Joan Metge (in New Zealand Law Commission, 2000:84) contends that “many urban Māori are alienated from their cultural heritage and may be more comfortable with Pākehā views and practices.” Accordingly, those interviewed in relation to Māori infertility and the use of ART (Glavish, Wall, Peek, Ehrhardt, and Allan) emphasised or reiterated the point made by Grant Allan (Senior Policy Analyst, Te Puni Kōkiri).

You cannot just generalise the opinion of one Māori to another.

(Grant Allan, Interview: 25 July 2000)

Although Crown objectives concentrate on reducing inequalities between ethnic groups, Cunningham and Kiro (2001:68) argue that the increasing disparity within the Māori population

is of equal importance and that health policy must allow for heterogeneity in relation to cultural experience, health status, and expectations with regard to outcomes. However, Naida Glavish (Chief Advisor - Tikanga, Māori Health Development Service, Auckland Healthcare Services Limited) argues that at present all health services

...are basically homogenous and are ill equipped, bordering on incompetent, to deal with the heterogeneous and accepting difference. All the structures are designed for that homogenous psyche basically.

(Naida Glavish, Interview: 9 August 2000)

Recognising that Māori are a diverse group of people whose needs and values are varied and complex highlights the difficulties surrounding policy formation. Teresa Wall (Senior Analyst, Māori Health Branch, Ministry of Health, Interview: 24 July 2000) argues that investment in the notion, if not the belief, of a homogeneous population was a way of simplifying policy formulation. She maintains that catering for the diversity of human relationships within the policy framework is too difficult and that a uniform a notion of family is easier to manage at a policy level.¹⁶⁶ Young (1990:174) argues that affirming 'difference' may produce stigma and exclusion and highlights past strategies where "group-conscious policies were used to separate those defined as different and exclude them from access to the rights and privileges enjoyed by dominant groups." However, the assumption of homogeneity within groups as a policy strategy will also continue to disadvantage those who do not fit the accepted norms and standards associated with that group. The marginalisation of Māori in the existing ART policy discourse appears to be based on the belief that "...Māori don't access it" (Helen Williams, Policy Analyst, Elective Services Project, Health Funding Authority, Interview: 29 August 2000) and that Māori may have other ways of dealing with infertility. These assumptions are direct results of the lack of information available about the prevalence of infertility and the ethnic composition of those already accessing ART treatments.

6.8 Conclusion

While exploring ART policy and its impact on reproductive choice in Aotearoa/New Zealand, I was unable to locate any significant documentation or policy initiatives relating to Māori use of ART. Specific concerns had been raised by Manatu Māori (Ministry of Māori Affairs) (MCART, 1994: Appendix E) about the protection of whakapapa and the use of culturally supportive and safe ART practices. However, there appeared to be no research into whether these concerns

¹⁶⁶ See Chapter One, Introduction, Section 1.4, Families & ART, for a detailed discussion about this in relation to the definition of family.

continue to be of relevance. In general, interviewees offered little insight into Māori specific policy responses to ART practices. Consequently, the focus of this chapter became the silences in the ART policy discourse in relation to Māori, as well as the issues raised by the interviewees about the prevalence of infertility in the Māori population, the barriers Māori encounter to accessing health services, and the collection of information on ethnicity within the health system.

There is no data available with regard to the prevalence of infertility in the Māori population of Aotearoa/New Zealand. Neither is there any quantitative information about the utilisation and access of ART services by Māori. However, high rates of reproductive system disorders and exposure to sexually transmitted infections by young Māori women, as well as changing characteristics in relation to Māori women's childbearing patterns indicate that there may be an increasing demand for ART services by Māori women in the near future. As Māori women and men generally hold lower socio-economic status than non-Māori women and men, they are more likely to encounter barriers to accessing ART services. These access barriers include financial costs and geographic location, as well as experiencing cultural insensitivity and discomfort in mainstream health services. Similarly, obstacles experienced in relation to the take-up rates of other social assistance schemes may also influence the take-up rate of publicly funded ART treatment. Lack of entitlement awareness, stigmatisation, privacy issues, abatement rates, and the time costs may all contribute to the inability or unwillingness to access publicly funded treatment.

Until accurate quantitative data is available in relation to who actually accesses ART services, it will be impossible to accurately identify the needs of Māori in relation to infertility treatment or to effectively evaluate and monitor the State's health policy outcomes. Although HFA contracts require fertility clinics providing publicly funded fertility treatment to retain information on the ethnic composition of ART consumers, this requirement is not enforced and, as yet, there is no evidence that the newly instigated health sector restructuring will alter this situation. Difficulties in defining Māori and the use of ethnicity as a variable in social research further complicate the collection and generation of statistics in relation to Māori infertility and access to ART services. Inconsistencies in defining ethnicity and the inability to make comparisons across data sets, as well as the use of statistics to engage in negative comparisons of Māori and non-Māori, have all contributed to a distrust of data collection in relation to Māori by some commentators. Nevertheless, until accurate statistical data are available, ART related policy will continue to be based on historic demands and influenced by the perceived needs and welfare of

the culturally dominant Pākehā population. As such, those who do not have the social or material resources to compete for scarce resources in this area will continue to be marginalised.

Several commentators have suggested that the use of whāngai is a culturally acceptable alternative to ART treatment for infertility and others have equated whāngai to surrogacy. Although it is possible that surrogacy is more acceptable to Māori than other ART practices because it shares some characteristics with whāngai, there is no empirical evidence to support either of these suppositions. While there is undoubtedly a diverse range of definitions associated with the practice of whāngai within Māoridom, it is perhaps more suitable to associate whāngai with the Pākehā concept of fostering or guardianship or the increasingly acceptable concept of 'open adoption'. Although whāngai may be an appropriate alternative to ART for some Māori, it cannot be presumed that it is an acceptable or even feasible solution to infertility for all Māori. Māori men and women do currently use ART services and this raises important issues in relation to the protection of whakapapa. Even though there has been a move towards a culture of openness in relation to donor insemination and adoption in Aotearoa/New Zealand, this is not a legal requirement. Access to information is dependent on parental openness about the circumstances of their children's birth and the availability of accurate information. Legislation continues to promote secrecy through the provision of a 'false' birth certificate and, although RTAC requires that some records be kept by accredited clinics, they are an Australian based committee that, as yet, does not include an Aotearoa/New Zealand-specific supplement to their 'Code of Practice'. Therefore, the lack of legislation to promote and guide the collection of ethnically relevant information means that Māori involved in donor ART practices must continue to rely on clinical discretion to ensure that knowledge of whakapapa will be permanently available.

Rather than speak for members of another ethnic and/or cultural group, my intention was to highlight what I perceive to be the silences surrounding the use of ART by Māori in relation to policy issues. ART innovations and applications will continue to advance and, as highlighted earlier, there may be an increasing demand for ART practices by Māori people. However, the ability of Māori to access ART will continue to be severely constrained by the lack of information about the prevalence of infertility experienced by Māori and the continued policy emphasis on the needs of the dominant cultural group in Aotearoa/New Zealand. By positioning infertility as a white middle class problem and contending that ART is not an option considered by Māori people with fertility problems, policy-makers and commentators ignore barriers to access that may effect take-up rates by Māori and low-income groups. Consequently, the take-up rate is

presumed to be a reflection of the need rather than a symptom of inequality in access and policy. However, increasing recognition of Māori as a diverse group of people with varied needs and values will continue to undermine the homogeneous focus of most policy initiatives and may accentuate the need for Māori-specific access policies to overcome the inequalities and barriers they experience in relation to the health system. This chapter does not presume to recommend how Māori might wish to address policy issues surrounding access to and the provision of ART services for Māori. Nonetheless, it does highlight a need for more research into the barriers Māori experience in relation to accessing ART treatment for infertility. It also emphasises the need for more information gathering in relation to the use of ART practices by Māori so that future policy can accurately provide for the needs and interests of Māori individuals without assuming that they correspond with the needs and interests of the equally diverse dominant Pākehā group.

7

Policy in Practice

7.1 The 'Messy Reality'

This thesis has explored how access to assisted reproductive technologies (ART) has been shaped by the current policy context in Aotearoa/New Zealand. At first glance, it would appear that the absence of specific legislation to control and regulate ART practices has left the regulation of ART practices in a policy vacuum. However, although the Status of Children Amendment Act 1987 (SCAA) is currently the only piece of legislation that explicitly deals with ART, there are many existing regulations and statutes that could be used in relation to legal issues arising from ART practices. These include professional codes of practice and legislation specific to the health and medical sector, as well as legislation relating to adoption and human rights. However, policy is not only developed and instigated through Acts of Parliament, ministerial edicts, and government initiated guidelines and strategy documents. Although these procedures play a major part in policy development, they are not the only approaches available for formulating policy. By examining how ART is regulated and controlled in Aotearoa/New Zealand, I have demonstrated that policy formulation and implementation does not always occur through the ordered, linear, and progressive models prescribed by some policy theorists. The 'messy reality' of the *ad hoc* approach to ART policy formulation provides an excellent case study of how the complex interactions, relationships, and policy initiatives of a variety of social actors work together to shape policy and, as a consequence, the reproductive choices of some individuals and groups in Aotearoa/New Zealand. As seen in Chapter Three, ART policy has been influenced and shaped by the interactions and relationships between state controlled policy and funding agencies, the National Ethics Committee on Assisted Human Reproduction (NECAHR), managers, healthcare professionals, patients, interest groups, and the wider community, as well as contingent responses to ART developments and health sector changes.

I acknowledge that this process of 'muddling through' may have provided a practical solution to developing policy in an area where there are difficulties in predicting the future consequences of certain biomedical developments and practices, as well as limited financial resources, timeframes, and information. However, *ad hoc* policy responses to ART developments and practices have often involved limited analysis and resulted in the marginalisation of alternative values and options. This is particularly evident in the lack of attention or action taken to incorporate an Aotearoa/New Zealand supplement to the Reproductive Technologies Accreditation Committee's (RTAC) 'Code of Practice'. Subsequently, the cultural and political values and principles of Aotearoa/New Zealand are marginalised in the monitoring and regulation of clinic practices. The deflective capacity of such policy-making strategies has also allowed various governments to avoid direct responsibility for decision-making in relation to ART. Consequently, the potentially controversial and contentious issues have been dealt with by the National Ethics Committee on Assisted Human Reproduction (NECAHR). Successive governments have avoided making politically unfavourable decisions and instigating overt state involvement in matters that are generally considered private. Undoubtedly, the flexibility and political expediency offered by a case-by-case decision-making approach have influenced the State's continued reliance on contingent and incremental policy-making. Nevertheless, delays in taking a more proactive approach to ART policy through legislative action and the complete avoidance of establishing a policy focused body to oversee ART developments and practices has placed the rights of those involved at risk and marginalised concerns about information access and retention, cultural safety, and the protection of whakapapa.

The lack of a considered and consistent approach to ART policy formulation means that the resolution of any social and ethical concerns remains dependent on the interest and attention of providers, NECAHR, and RTAC. At present, NECAHR's dual role as an ethics committee and *de facto* policy body places it in an ambiguous position, which compromises its ability to maintain an independent position in ethical decision-making. Although professional self-regulation is provided by RTAC, accreditation only ensures the control and regulation of the practical aspects of ART procedures. Accreditation remains voluntary, although providers do not appear to be resistant to compulsory certification. Neither NECAHR nor RTAC has any statutory power to ensure that providers comply with decisions made by NECAHR and, as an offshore accrediting body, RTAC is not accountable to the Aotearoa/New Zealand Government. While non-compliance with either NECAHR's decisions or RTAC's regulations would undoubtedly result in a loss of accreditation, the effectiveness of this as a sanction is questionable. The limited

consumer input into NECAHR and RTAC raises concerns about the marginalisation of those who experience infertility problems in relation to the formulation of policy and/or ethical decision-making. As a consequence of this marginalisation, any policy decisions (or non-decisions) may not consider the interests of those most affected and alternative solutions may be ignored. While ethical and practical considerations should form the basis of ART policy, input from other fields of interest, knowledge, and experience is necessary to ensure a balanced and considered approach is taken to such policy formulation.

Advances in ART and ART practices continue to be rapidly included into acceptable practice and any ART policy decisions are threatened with being out of date and invalid within a very short timeframe. While this necessitates careful consideration before enacting prescriptive legislation that cannot be easily changed or adapted, it also requires considered attention to the negative consequences of relying on *ad hoc* policy responses to ART innovations and applications. Predicting the possible effects of biotechnology may be difficult and the rapid nature of such advances may create time and information constraints that limit the ability of policy-makers to take a proactive stance. Nevertheless, *ad hoc* policy responses may allow incremental advances or changes in ART practices to become cemented into common practice before the negative consequences are apparent. Fast moving ART developments impose time constraints for the formulation and implementation of policy and this means that policy is likely to be made without the collection of necessary empirical evidence. Similarly, the pressure to develop and implement rapid policy responses could mean that the values underlying any decisions are not questioned and alternative solutions are in danger of being disregarded or overlooked. Consequently, the rights and interests of certain individuals and groups may be marginalised while attention is given to those groups that can better articulate their needs and interests.

7.2 'Muddling Through'

In Chapter Four, I examined the contingent responses by ART providers and state funding agencies to the increasing demands for ART services. My investigation illustrates that the maintenance of an *ad hoc* policy approach has established and maintained inequities and discriminatory practices in relation to the public provision of ART services. The initial use of research facilities and resources to fund and develop IVF programs resulted in providers expanding into the public health arena and infertility treatments being publicly funded by default. Growing demands, generated through increased availability and publicity, led to public funds for ART services being distributed throughout Aotearoa/New Zealand on a regional basis. However, the regional allocation of resources was based on the numbers of individuals from the

various regions that had accessed ART in Auckland rather than detailed consideration of the incidence of infertility in Aotearoa/New Zealand or population based requirements. Consequently, government funding agencies have entrenched regional inequalities and disparities in funding and access policies. Given the highly constrained health budget, questions have occasionally been raised about the rationale for continuing to publicly fund ART services. Nevertheless, there has not been a thorough examination of the underlying principles for providing such services and funding has continued at historically established levels. Political expediency makes it unlikely that funding for these services will be completely withdrawn. Nevertheless, rationing strategies have depleted availability and entitlement to such services.

The introduction of explicit rationing strategies and an investigation into the costs and effectiveness of infertility treatment did not lead to equitably funded ART services or nationally consistent access restrictions. These health sector strategies have resulted in incremental policy changes rather than consistent guidelines to help overcome the deep-seated inequalities in the access to and funding of publicly resourced ART services. By avoiding in-depth analysis of principles underlying ART funding decisions (or non-decisions), policy-makers do not have to justify any politically contentious decisions and inequities do not have to be publicly addressed. Campaigning by individual clinics and consumer organisations and the forbearance of some administrators in the Health Funding Authority (HFA) has resulted in some policy changes. However, the introduction of increased funding, national referral guidelines, and the Clinical Assessment Criteria (CPAC) appear to be a contingent response to increasing demand, rising costs, and growing waiting lists. Additional funding has been based on historically established funding levels and the reduction of publicly funded IVF cycles available to individuals under the new funding package dilutes the available services and reduces visible demand rather than actual demand. Moreover, health sector reforms have created uncertainty over the effectiveness of these changes. The creation of 21 health districts and administrative boards to allocate resources may exacerbate and further embed regional inequities and inconsistencies in ART funding. The fragmentation of funding decisions may also undermine the goal of national consistency in access to ART services. However, it is too early to evaluate what the combined effect of the increased funding, national use of the CPAC, and health sector reforms on funding and access will be. The formulation and implementation of the CPAC may further entrench inequalities in access based on 'worthiness' to parent and conformity to the normative definition of family.

7.3 Limiting Entitlement

Rapid advances in technology, mounting professional and public expectations, and changing demographics have all contributed to increased demands for the limited resources available for publicly funded healthcare. Consequently, the allocation of the available resources has become more dependent on explicit rationing strategies. Nevertheless, access to publicly funded ART services is rationed through a combination of both implicit and explicit approaches, including restricted funding, waiting lists, a reduction of services offered, and the use of the Clinical Assessment Criteria (CPAC). Although it has become increasingly necessary to limit access to publicly resourced ART services, access has not always been restricted on the basis of constrained public funds. In the past, access has been limited by marital status and sexuality, as well as geographical location. Originally restricted to married couples, access was eventually extended to *de facto* heterosexual couples in stable relationships. Thus, the definition of family that underlies the Status of Children Amendment Act 1987 (SCAA) has also influenced the restriction of access to ART services. Access restrictions were relaxed to include single women and lesbian couples only after clinics were challenged under the human rights legislation. While it would appear that there are no longer any obvious value-based limitations on access to private ART treatment, menopause as a 'natural' constraint on women's reproductive lifespan is used to justify age limits on private ART treatment. This remains a contentious issue given that the use of donated oocytes overcomes the 'natural' constraint of menopause and medical supervision reduces the physical risks often associated with older childbearing women.

The debate has continued over the issue of access to ART services by those who do not fit the normative definition of 'worthy' parents. In recent changes to the service specifications and referral guidelines for publicly funded ART treatment, the HFA has attempted to eliminate exclusionary language that emphasised heterosexual coupledness as the norm for access. However, changing the language has not addressed the underlying principles that originally governed the use of this language and the distinction between biological and social infertility remains a deciding factor for granting access to public ART treatment. As I have argued in Chapter Five, this distinction rests on a definition of infertility that conflates heterosexual relationships and involuntary childlessness. I claim that access to publicly funded ART services is still considerably more difficult for single women and lesbian couples than for those individuals who conform to the normative concept of an ideal family arrangement. This is because the underlying principles that were originally used to exclude single women and lesbian couples remain uncontested and unresolved.

As the most obvious method of rationing ART treatments and restricting access, the government initiated CPAC have been influenced by normative assumptions about who is 'worthy' to conceive, gestate, and parent and have added to the invisibility of men in the policy debate surrounding these issues. The Aotearoa/New Zealand Government granted itself partial immunity from complying with the Human Rights Act 1993 until December 2001 and, debatably, this has had an impact on its ability to introduce access criteria that disadvantage lesbian couples and single women. In contrast, the human rights legislation has influenced the practices of ART providers in relation to making non-medical decisions about access. Consequently, single women and lesbian couples are no longer excluded from gaining access to private ART treatment. Nevertheless, there is an ongoing policy debate relating to the prioritisation of children's rights over the rights of would-be parents whose personal circumstances do not conform to the normative definition of family. Irrespective of whether there is an ultimate 'right' to use ART to assist in the creation of a family, I maintain that the individual rights of all those involved in ART practices should be considered in relation to each other. As I have argued previously, the rights and interests of the donors, recipients, surrogates, and intending parents, as well as the rights of adults conceived using ART practices, are in danger of being overlooked or marginalised if the rights and interests of children are the sole focus of the policy debate.

Although the CPAC outwardly make the decision-making process for the allocation of scarce resources more visible, they effectively obscure the use of non-medical and discretionary judgements by providers to establish entitlement to publicly funded ART services. I maintain that the CPAC have been influenced by a normative definition of family and social judgements surrounding what the appropriate age is for women to experience pregnancy and parenting and that the emphasis on clinical assessment obscures the use of these judgements to restrict access to ART. While the use of social judgements to establish 'worthiness' or 'need' may be necessary to limit access to tightly constrained public resources, I contend that the limited consultation and ill-defined methods used to decide what criteria would be used to limit access to publicly funded ART services undermine the validity of the CPAC. There has been little or no analysis of the values and principles that underlie the selected criteria. Therefore, the CPAC further embed inequities in the distribution of limited resources by marginalising or excluding those who do not fit the perceived ideal for parental or family arrangements. Any form of rationing will disadvantage some individuals or groups and changing social values and expectations may call into question any criteria used to determine entitlement. Nevertheless,

adequate public consultation, a system of accountability, and transparency in the decision-making processes would reduce the possible discriminatory effects of limiting access.

7.4 Considering Difference

Although the Tiriti o Waitangi (the Treaty of Waitangi) creates a relationship between Māori and Pākehā that necessitates that policy formulation, implementation, and monitoring recognises and encompasses the values and principles of Māori society, there is considerable silence surrounding the use of ART by Māori in the ART policy discourse. Concerns have been raised by Manatu Māori (Ministry of Māori Affairs) in relation to the protection of whakapapa, informed choice and consent, and cultural safety. Nevertheless, specific attention to these concerns has not been forthcoming and ART policy continues to be influenced by the perceived needs and interests of the culturally dominant Pākehā population. This is highlighted in Chapter One by my analysis of the SCAA, which has institutionalised a definition of family that fails to recognise or accommodate social diversity in relation to family structure, especially the more diverse concept of whānau acknowledged by Māori. Similarly, the CPAC contain standards of acceptable weight that are based on a western profile. The homogenous focus of ART policy is exacerbated by the contingent and incremental approach used to develop and implement any policy initiatives or changes. As mentioned earlier, this approach does not allow for in-depth analysis of the values and principles that underlie ART policy formulation. As I argue in Chapter Six, if Māori perspectives on social relations and interaction, as well as their values and language, are not considered and acknowledged during the policy-making process, the dominant values and perspective will continue to be upheld as universal. As a result, the interests and needs of Māori in relation to ART treatment will be assumed to correspond with those of the dominant Pākehā group.

The marginalisation of Māori in the ART policy debate is aggravated by the lack of quantitative data on the prevalence of infertility in the Māori population and information on the utilisation of ART services. The availability of such information would assist in the formulation of policy that accurately identified the needs of Māori in relation to infertility treatment and would enable interested publics to effectively evaluate and monitor future ART policy initiatives. I acknowledge that there are difficulties in collecting and analysing accurate or useful quantitative data, especially in relation to ethnicity. The collection of data on ethnicity may be limited by inconsistencies in defining Māori, the ability to make comparisons across data sets, and the use of statistics to undertake negative comparisons between Māori and non-Māori. Inadequate or irrelevant analysis of such information may further hinder its usefulness for informing policy.

Nevertheless, without accurate information relating to Māori infertility and access to ART services, policy decisions will continue to be made without sufficient attention to the issues for Māori and the ability of Māori to access these services in the future will be affected. This is particularly relevant as available information on reproductive health issues for Māori women, as well as changing demographics in relation to Māori women's childbearing patterns, indicate that there may be an increasing demand for ART services by Māori women in the near future.

The prediction of increased demand is not definite and other commentators have suggested that Māori may use whāngai as an alternative to ART practices in dealing with infertility. However, there is no empirical evidence to support this assumption. Although there is a diverse range of definitions associated with the practice of whāngai in Māoridom and it may be used by some Māori as an alternative to ART, I would suggest that this concept is more accurately equated to the Pākehā concepts of fostering, guardianship, or 'open' adoption. Consequently, whāngai should not be used to justify lack of policy attention to the use of ART by Māori. Māori men and women do currently use ART services and this raises important issues in relation to the protection of whakapapa and the retention of culturally appropriate information. Although access to information is ultimately dependent on parental openness about the circumstances of their children's birth, existing legislation continues to promote secrecy through the provision of a 'false' birth certificate. Furthermore, the lack of legislation to ensure the collection of ethnically relevant information means that Māori involved in donor ART practices must currently rely on clinical discretion to ensure that knowledge of whakapapa will be permanently available.

The diversity of the Māori population, as of any population, makes it difficult to establish policies that equitably address all the issues. Nonetheless, attention to the diverse nature of the Māori population will destabilise the universal focus of ART policy initiatives and highlight the availability of alternative values and options. Although there has been some attention to Māori specific policies to overcome existing inequalities and inconsistencies in access to the wider health system, there is a need for more research into the barriers Māori experience in relation to accessing ART treatment for infertility. Similarly, the collection of accurate information in relation to the use of ART practices by Māori and the consideration of Māori values and principles are necessary if future ART policy is to be accurate in its attention to the needs and interests of Māori individuals without marginalising them in relation to the needs and interests of the dominant Pākehā group.

7.5 Future Considerations

The complexity of the technologies involved in assisted reproduction and the relationships these technologies make possible require a more complex set of policy responses than has previously been instigated. Given the speed of biomedical innovation and implementation, incremental and contingent policy approaches will continue to play a necessary role in regulating and controlling ART development and practices. However, developing ART policy solely as a contingent and/or incremental response to the financial, ethical, and medical dimensions of service provision will potentially marginalise or exclude the consideration of other issues. The fragmented organisational responsibility and time constraints inherent in such *ad hoc* policy responses has already resulted in a lack of consideration of the principles influencing funding and access decisions, as well as the marginalisation of alternative values and interests in relation to family formation. As I argued earlier, the establishment of an ART focused policy body would offer regulatory oversight of ART practices and provide a system of accountability and responsibility in relation to ethical and policy decision-making. Such an organisation could also co-ordinate the interconnected functions of NECAHR and RTAC and could oversee the implementation of policy and ethical decisions by providers. Moreover, it could facilitate the development of proactive and carefully considered ART policy that incorporates the values and concerns of consumers and providers, as well as other interested publics, organisations, and individuals, while enhancing the decision-making process through the inclusion of a more diverse range of knowledges and experiences. Consequently, those currently marginalised and silenced within the ART policy discourse would gain greater voice and visibility.

It is necessary to consider what areas of concern require legislative control, as well as the consequences of implementing proscriptive laws. Although some areas of concern are currently being addressed by the Health Select Committee considering the two proposed bills on ART, issues such as the use of sex-selection techniques and embryo donation have not been addressed and may be introduced into practice before adequate consideration is given to the consequences of their use. Similarly, protracted delays in legislative action have left the rights of those conceived using donated gametes unprotected in relation to information retention, storage, and access. The proposed banning of some unethical practices, such as the cloning of humans, raises questions about how the use of technologies developed overseas through such processes will be dealt with in Aotearoa/New Zealand. Similarly, banning the sale of human gametes and embryos highlights concerns surrounding the ownership of biological material and the rights of embryos. ART policy decisions relating to funding and access need to be informed by accurate quantitative data on the incidence of infertility in Aotearoa/New Zealand. Attention

to who is using ART services and what access barriers individuals experience is crucial to policy formulation. Consequently, more research into these issues is required, as well as research into how policies that distribute resources and limit access are interpreted, implemented, and managed by providers.

By exploring the *ad hoc* policy process and fragmented organisational responsibilities in relation to the regulation and control of ART practices in Aotearoa/New Zealand, as well as the resulting inequities in funding and access to publicly funded ART services and the marginalisation of Māori in the policy debate, I have shown that some individuals and groups have their reproductive choices constrained by the present ART policy situation in Aotearoa/New Zealand. Although government initiatives and decisions are central to the instigation and formulation of formal policy in relation to ART, there are many individuals and non-governmental organisations involved in the development and formulation of policy. By contributing to the ART policy debate, different actors influence the language used and the issues that are considered, as well as having an impact on how and when the issues will be addressed and resolved. Accordingly, this thesis is part of the policy debate and discourse relating to ART developments and practices. I hope that it will contribute to and have a positive effect on the policy-making process and the necessary public discussion of the principles and values underlying ART practices, as well as highlight issues of concern relating to the inequitable public provision of these technologies.

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Appendix A:

Abbreviations & Definitions

Abbreviations:

CPAC: Clinical Assessment Criteria

HFA: Health Funding Authority

HRC: Human Rights Commission

MCART: Ministerial Committee on Assisted Reproductive Technologies

NECAHR: National Ethics Committee on Assisted Human Reproduction

NZIS: New Zealand Infertility Society

RTAC: Reproductive Technology Accreditation Committee

SCAA: Status of Children Amendment Act 1987

Definitions:

ART: assisted reproductive technologies

Assisted reproductive technologies refer to those reproductive technologies that aid or achieve conception. These include, but are not limited to, ovulation induction, IVF, DI, AIH, IUI, GIFT, ICSI, ZIFT, frozen embryo transfer, cryopreservation of gametes, and assisted hatching. See below for definitions of these terms, as well as definitions of amniocentesis, ultrasound imaging, PGD, and FISH, which are associated with ART procedures.

AIH: assisted insemination homologous

Term for assisted insemination when the sperm from the woman's husband or partner is used. Also known as 'assisted insemination by husband'. AIH is used for unexplained infertility, mild or moderate male factor infertility, or endometriosis.

Amniocentesis:

A procedure in which a needle is used to withdraw a small amount of amniotic fluid that surrounds the foetus in the uterus. The fluid can be tested for chromosomal abnormalities and genetic disorders.

Assisted Hatching:

This is an option in IVF or ICSI. A small hole is made in the soft shell of the embryo before it is replaced in the uterus. There is some evidence that assisted hatching can improve pregnancy rates in some groups of IVF patients, mainly those who are older or who have had several IVF cycles without success.

Cryopreservation: preservation through freezing with liquid nitrogen.

Embryos can be frozen through cryopreservation. Frozen embryos can be 'thawed' and used at a later time. Once embryos are frozen and stored, most will remain unchanged for long periods of time. About two thirds of embryos will survive the process of freezing and thawing.

DI: donor insemination

Sperm from a donor is inseminated close to the time of ovulation. The time of ovulation can be identified from blood tests, or urinary tests done at home. Traditionally DI has been used when men have no sperm or poor quality sperm, but it is also an option for single women and women in a lesbian relationship.

Donor Egg:

A donor (sometimes a friend or family member) starts an IVF cycle but donates the eggs to the recipient. The recipient receives hormonal treatment so that her uterus is synchronised with the embryo's development. Donor eggs can be used for women who do not produce oocytes of their own.

Embryo:

In humans, this term usually refers to the early stages of growth after fertilisation, from two weeks through the eighth week after fertilisation.

Foetus:

The developing entity from eight weeks after fertilisation until birth. The two earlier stages of development are zygote (fertilisation to two weeks) and embryo (two weeks until eight weeks).

FISH: Fluorescence in-situ hybridisation

FISH utilises fluorescent probes, which are specific for a given chromosome. A mix of several probes of different colours is added to the cell nucleus. The probes attach to their target chromosomes showing up as coloured spots, which can be counted to ensure the embryo has the correct number. (Fertility Associates Auckland has permission from NECAHR to develop the technique but do not have approval to use the technique.)

Frozen Embryo Transfer:

In the majority of Assisted Conception cycles, stimulation with hormonal medications results in the production of several follicles and the retrieval of multiple oocytes. While an attempt is usually made to fertilize all available oocytes, not all resulting embryos are immediately transferred. When the 'optimal' number (as defined by your clinic) of embryos for transfer is exceeded, the 'extras' can be cryopreserved for use at a later time. When embryos are to be thawed, the woman's menstrual cycle is monitored with blood tests to make sure the embryos are replaced at the right time of the menstrual cycle.

FSH: Follicle stimulating hormone

FSH is the hormone secreted by the pituitary gland, which stimulates follicles to develop in the ovary. As the follicles grow, they make the hormone oestrogen, which in turn reduces the amount of FSH secreted. If the ovary does not make any or much oestrogen, then the pituitary makes more FSH to compensate. A high FSH level means the pituitary is working harder to stimulate the ovaries. It is believed that this is often associated with the ovary having fewer or poor quality eggs left to stimulate. There is evidence that high FSH levels are associated with a much lower chance of pregnancy. As women get close to the menopause, the number of eggs in their ovaries falls, and their FSH levels rise. For this reason, some people look at FSH levels as a marker of ovarian age, as distinct from biological age.

Gamete:

The mature male or female reproductive cell, which contains half the normal number of chromosomes (23) that unites with another cell of the opposite sex in the process of sexual reproduction. Ova and spermatozoa are gametes that unite to produce a cell (zygote) that may develop into an embryo.

GIFT: gamete intra-fallopian transfer

GIFT is used when the woman has undamaged fallopian tubes, and when a good rate of fertilisation is expected. After the eggs are removed from the ovaries, two or three eggs and some sperm are put directly into the Fallopian tubes.

ICSI: intracytoplasmic sperm injection

ICSI is a variation of IVF, where instead of the sperm and eggs being mixed in a test tube, a single sperm is injected into each mature egg. ICSI is used when sperm quality is too poor for conventional IVF to work. The female partner will undergo ovarian stimulation and egg recovery in preparation for micromanipulation and embryo transfer.

IUI: intrauterine insemination

A form of donor insemination in which sperm are placed directly into the uterine cavity. It may be used to overcome barriers to natural insemination, such as incompatibility between sperm and cervical mucus, impotence, or vaginismus.

IVF: *in vitro* fertilisation.

IVF usually has several steps. Firstly, hormonal drugs are used to increase the number of eggs developing in the cycle from one to around 5-15. Progress is monitored by blood tests and ultrasound scans. Maturation of the eggs is stimulated by another drug, and the eggs are sucked out of the ovary using a needle guided by ultrasound. Sperm and eggs are placed in a test tube together to allow fertilisation. Fertilisation is checked the day after adding the sperm, usually two embryos are replaced in the uterus 1-4 days later.

Laparoscopy:

A procedure, requiring general anaesthetic, in which the reproductive organs are viewed through a narrow, light-transmitting instrument (laparoscope) inserted near the naval after the abdomen has been inflated with carbon dioxide. It is used to investigate for adhesions, endometriosis, and pelvic inflammatory disease.

Micromanipulation:

Performance of surgery, injections, dissection with attachments to a microscope, which allows magnified visualisation.

Oocyte: a cell that develops into a female reproductive cell

Ova: a female egg or oocyte, formed in an ovary

Ovulation induction:

Drug treatment to induce ovulation in women with irregular or absent cycles. Ovulation induction can involve taking pills, or subcutaneous injections of drugs (the way diabetics give insulin). It nearly always involves blood tests and ultrasound scans to monitor progress, both to time intercourse and to reduce the chance of multiple pregnancy. Usually the couple has intercourse when ovulation is predicted or triggered, but artificial insemination using partner's sperm can be used, especially if the drugs affect the ability of sperm to make their way through the woman's cervix.

PGD: preimplantation genetic diagnosis

One or two cells are removed from an 8-cell zygote on day 3 after fertilisation and the genetic material analysed using a technique called FISH (fluorescence in-situ hybridisation). The cells are typically screened for the five or six chromosomes most commonly associated with pregnancy loss using and only embryos showing a normal number of chromosomes are transferred. The rapid advance in genetics is starting to allow testing for a particular genetic make-up rather than counting chromosomes. At the moment detecting an abnormal gene, such as for cystic fibrosis, is a lot harder than counting the number of chromosomes, but already more than 100 children around the world have been born from IVF embryos screened for major gene defects before they were transferred.

Spermatozoa (sperm): male reproductive cells**Ultrasound:**

Scanning procedure using high frequency sound waves, which are focussed on the body and reflected to provide a video image of internal organs, tissues, and structures. Often used for in utero examinations of a developing foetus, for guidance of the needle in amniocentesis, for the evaluation of the development of ovarian follicles (fluid filled structure in the ovary that contains the developing egg), and for guided retrieval of eggs for IVF and its alternatives.

ZIFT: zygote intrafallopian transfer

A form of assisted reproduction in which a zygote obtained by IVF is transferred to the fallopian tube, usually by a catheter (small tube) through the uterus under ultrasound guidance. This technique is also known as PROST (pronuclear oocyte salpingo transfer) and TEST (tubal embryo stage transfer).

Zygote:

The fertilised egg until approximately 14 days of development; from 2 weeks to eight weeks of development the developing entity is termed an embryo; from eight weeks to birth it is termed a foetus.

The above definitions have been adapted from:

The New Zealand Centre for Reproductive Medicine Ltd website (<http://www.nzcrm.co.nz/>);
 Fertility Associates N.Z. website (<http://www.fertilityassociates.co.nz/>);
 Xtra Health, Ask an Expert website (<http://www.xtra.co.nz/health/0,,212-615828,00.html>);
 Encarta World English Dictionary, North American Edition website (<http://dictionary.msn.com>);
 Royal Commission on New Reproductive Technologies Canada, 1993. *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies*. Vol. 2 of 2. Ottawa: Canada Communications Group, pages 1147-1174;
 Coney, S. & A. Else (eds.), 1999. *Protecting Our Future*. Auckland: Women's Health Action Trust, page 13.

Surrogacy:

The various arrangements known as surrogacy centre on the involvement of a woman who gives birth to a child for others by providing gestation and birth. She may also provide the ovum and conception, so that she is the genetic and birth mother. It is this woman who is referred to as the 'surrogate mother'. There are three main types of surrogacy arrangement:

1. Traditional surrogacy - insemination by intercourse with the intending father or a sperm donor. This is usually a private arrangement with no provider involvement. The surrogate is the genetic and birth mother.
2. Assisted surrogacy - assisted insemination, using sperm from the intending father or from a donor. This does not technically require the services of an assisted reproductive technology provider. The surrogate is the genetic and birth mother.
3. Gestational surrogacy – one or more embryos, created (usually by IVF) from the gametes of the intending parents, or two donors, are transferred to the womb of a woman. The woman is the birth mother but has no genetic connection to the embryos unless she is related to the intending parents.

Adapted from Else, A., 1999. 'Surrogacy' in *Protecting Our Future*. S. Coney & A. Else (eds.). Auckland: Women's Health Action Trust, page 50.

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Appendix C:

Interview Participants

State:

Helen Lockyer, Senior Policy Analyst, Ministry of Health, Wellington.
Matthew Soeberg, Policy Analyst, Ministry of Health, Wellington.
Interview: 24 July 2000

The Ministry of Health develops policy advice for the Government on health and disability issues, administers health regulations and legislation, funds health and disability support services, plans and maintains nationwide frameworks and specifications of services, monitors sector performance, and provides information to the wider health and disability sector and the public. Recently, the enactment of the New Zealand Public Health and Disability Act 2000 has allowed for the functions of the Ministry of Health and Health Funding Authority to be combined and for District Health Boards to be established.

Adapted from:

<http://www.moh.govt.nz/moh.nsf/e00eda991ab5e3704c256670004079ba/58579029ccf1fb73cc256abd0003449a?OpenDocument>

Teresa Wall, Senior Analyst, Māori Health Branch, Ministry of Health, Wellington.
Interview: 24 July 2000

The Māori Health Directorate is headed by the Deputy Director-General Māori Health, and currently includes a Māori health policy advice section, Te Kete Hauora, a Chief Advisor Māori Health, Special Projects Manager, Manager Māori Health Policy and Strategy, Manager Service Development, Senior Locality Manager Māori Development, and Manager, Treaty and Iwi Relationships. The role of the Māori Health Directorate is to provide policy advice on the overall strategy for achieving the government's objective for Māori health which is to reduce disparities in health status for Māori; to work with other branches, sections and teams within the Ministry to enable them to incorporate Māori issues into their policy advice and increase their understanding and responsiveness to the needs and aspirations of Māori; to develop relationships with the key organisations and agencies which contribute to a health and disability sector which works for Māori.

Adapted from: <http://www.moh.govt.nz/moh.nsf/>

Grant Allan, Senior Policy Analyst, Te Puni Kōkiri, Wellington.
Penny Ehrhardt, Policy Analyst, Te Puni Kōkiri, Wellington.
Interview: 25 July 2000

The Ministry of Māori Development Act 1991 established Te Puni Kōkiri, the Ministry of Māori Development in 1992. Currently, Te Puni Kōkiri's work focuses on providing high quality policy advice to Government and other agencies on the Crown's relationship with iwi, hapu, and Māori, and the Government's objectives, interests and obligations relating to Māori. Te Puni Kōkiri's key functions (under the Ministry of Māori Development Act 1991) include promoting higher achievement by Māori in the areas of education, training and employment, health, and economic resource development. Te Puni Kōkiri also has a role in monitoring and liaising with each department and agency that provides, or has a responsibility to provide, services to or for Māori to ensure the adequacy of those services. In 2000, Government broadened the policy focus of Te Puni Kōkiri to include some direct provision of services to Māori.

Adapted from: <http://www.tpk.govt.nz/about/role/default.htm>

Diane Yates, Member of Parliament (Hamilton East), Wellington.
Interview: 25 July 2000

Dianne Yates was the Labour MP for Hamilton East and is currently a Labour Party List Member of Parliament. Dianne Yates introduced the Human Assisted Reproductive Technology Bill as a Private Member's Bill in 1996 (Yates Bill; see Appendix I).

Adapted from: <http://www.labour.org.nz/yates/index.html>

Helen Williams, Policy Analyst, Elective Services Project, Health Funding Authority, Dunedin.
Interview: 29 August 2000

The Health Funding Authority (HFA) was established on 1 July 1997. The HFA's responsibilities included buying or funding health and disability services on behalf of the National Advisory Committee on Health and Disability. It assessed healthcare needs, consulted with communities over priorities, and decided where to spend the money made available through Vote Health. One of its roles was to provide detailed information on the level of service it could buy with available funding and to identify where there were shortfalls and what it would cost to fill the gaps. The HFA paid providers for contracted services and it was responsible for developing, implementing, and managing the contracts with providers. In November 2000, the HFA was disbanded and its functions were integrated into the Ministry of Health and District Health Boards.

Adapted from:

National Advisory Committee on Health and Disability, 1997. *The Best of Health 3: Are we doing the right things and are we doing those things right?* (Online). Wellington: National Advisory Committee on Health and Disability. Available:

<http://www.nhc.govt.nz/pub/bestofhealth3/index.htm> [21 February 2002].

Providers:

Mark Leggett, Business Manager, The Fertility Centre, Christchurch.

Interviews: 22 September 1999 & 22 June 2000

The Fertility Centre is the trading name of the New Zealand Centre for Reproductive Medicine Ltd, a joint venture set up between Healthlink South and the University of Otago. The Fertility Centre is located at Hiatt Chambers, St George's Medical Centre Christchurch and provides both private and public infertility services. At the time of the interview, the Fertility Centre held the contract for the Southern Funding Region, as well as a portion of the Central contract that covered the Nelson/Marlborough region.

Adapted from: <http://www.nzcrm.co.nz/>

John Peek, Clinical Manager/Group Operations Manager, Fertility Associates, Auckland.

Interview: 12 July 2000

Fertility Associates was founded in 1987 by Freddie Graham and Richard Fisher, who had previously introduced in vitro fertilisation (IVF) to New Zealand while they ran the infertility programme at National Women's Hospital. Fertility Associates is the provider of publicly-funded tertiary infertility services in the North Island and is the largest fertility clinic in New Zealand, with clinics in Auckland, Wellington, and Hamilton. Fertility Associates is also a partner of Fertility Associates North Shore, which offers fertility services on Auckland's North Shore.

John Peek is the Scientific Director for the Fertility Associates group of clinics. He supervised the infertility laboratory at National Women's Hospital from 1984 until he joined Fertility Associates in 1987. He is instrumental in overseeing the Fertility Associate group's contracts with the Health Funding Authority. As John Peek has worked in the ART field for many years, he has had extensive involvement and historical knowledge of the ART policy debates and developments. He is co-author of *Costs and effectiveness of infertility services in New Zealand: a decision analysis. A Report to the National Advisory Committee on Core Health and Disability Support Services* (Gillett, Peek, & Lilford, 1995) and *Access to Infertility Services: development of priority criteria* (Gillett, & Peek, 1997).

Adapted from: <http://www.fertilityassociates.co.nz/staff/index.html>

Naida Glavish, Chief Advisor - Tikanga, Māori Health Development Service, Auckland Healthcare Services Limited, Auckland.

Telephone Interview: 9 August 2000

In 1994, Auckland Healthcare was one of the first Hospital and Health Services in New Zealand to establish a Māori Health team to focus on Māori health issues within the organisation's environment. Auckland Healthcare's partnership with Māori continues to promote values and qualities unique to Māori. He Kamaka Oranga (Māori Health Development) is involved in key projects within Auckland Healthcare.

Adapted from: <http://www.adhb.govt.nz/akhealth/Intro-Human.html>

Rodney Bycroft, Scientific Director/Manager, Artemis North Shore Fertility, Auckland.

Telephone Interview: 13 September 2000

At the time of the interview, Artemis North Shore Fertility was a private fertility clinic. The clinic did not provide public ART services. However, in February 2001 the doctors of North Shore Fertility, Fertility Associates, and Shore Women merged to form a new company called Fertility Associates North Shore. Rodney Bycroft left the company in December 2000.

Adapted from: <http://www.fertilityassociates.co.nz/news/index.html> and email communication with Fertility Associates North Shore, 20 February 2002.

Consumers/Commentators:

Cindy Carmichael, Health Worker, The Health Alternatives for Women (THAW), Christchurch.

Aline Medland, Health Worker, The Health Alternatives for Women (THAW), Christchurch.

Interview: 14 June 2000

THAW is a health information and resource centre. The centre offers free pregnancy testing and information, free condoms, abortion information and referral, safe sex information, health information, and referrals to other groups, individuals, or practitioners. THAW works in a political way to change the health practices that damage women's health.

Adapted from: <http://www.cmrf.org.nz/chr/thaw.htm> and THAW information pamphlet.

Sandra Coney, Executive Director, Women's Health Action Trust, Auckland.

Interview: 13 July 2000

Women's Health Action is a charitable trust with the aims of providing women with high quality information and education services to enable them to maintain their health and make informed choices about their health care. The Trust has a health promotion and disease prevention focus, with a special interest in screening and approach health within a holistic framework of the whole of women's lives, rather than from a narrowly medical perspective. Since 1984 Women's Health Action has been at the forefront of women's health in New Zealand. Founded by health activists Phillida Bunkle and Sandra Coney, the group came to national prominence when it broke the story of 'the unfortunate experiment' at National Women's Hospital in Auckland. As advocates the Trust lobbies health officials and politicians, makes submissions and contributes to the policy development processes, makes media statements Act as consumer representatives on government and other health sector committees, publishes reports, books, and discussion papers, and networks with other community groups and health professionals.

Sandra Coney is the Executive Director of Women's Health Action. She is the co-editor of *Protecting Our Future* (Coney & Else, 1999). *Protecting Our Future* is a discussion document, which was produced by the Women's Health Action Trust "to assist the debate around ART" (Coney & Else, 1999:iii).

Adapted from: <http://www.womens-health.org.nz/>

**Robyn Scott, Executive Officer, New Zealand Infertility Society, Wellington.
Interview: 26 July 2000**

The New Zealand Infertility Society (NZIS) is New Zealand's National Infertility Network. It was formed in 1989 and actively encourages links between all those involved in the treatment and support of infertility. The NZIS is a non-profit consumer-based organisation committed to promoting the well being and welfare of all people with fertility problems through national representation in the general community, medical arena, and scientific arena. Its main three objectives are Support and Networking, Information, and Advocacy. The NZIS sees its role as advocate for people with fertility problems as involving the promotion of public awareness through national representation in the political arena; ensuring that the views and wishes of those in the infertility area are represented to decision makers; consumer representation on RTAC; accreditation of all clinics working in infertility; and promoting the views of the Society's members with respect to Public funding of infertility services, medical insurance coverage of infertility, and legislation affecting the area of infertility.

Adapted from: <http://www.nzinfertility.org.nz/about.htm>

**Sue Bagshaw, Medical Training Co-ordinator, Family Planning Association, Christchurch.
Interview: 21 August 2000**

The Family Planning Association (FPA) provides sexual and reproductive health information, clinical services, education, training, and research. Services include- contraception, STD/STI checks, menopause, talking to your children about sexuality, vasectomy, PMS, adolescent sexuality, pregnancy and many other topics. The Association is a not for profit charitable organisation working to promote a positive view of sexuality. They aim to help people make informed choices about their sexual and reproductive health.

Sue Bagshaw is now the Manager, Medical Services, Southern Region, Family Planning Association. She has been involved in a number of research projects on chlamydia.

Adapted from:

<http://www.theword.org.nz/> and <http://www.fpanz.org.nz/default.asp>

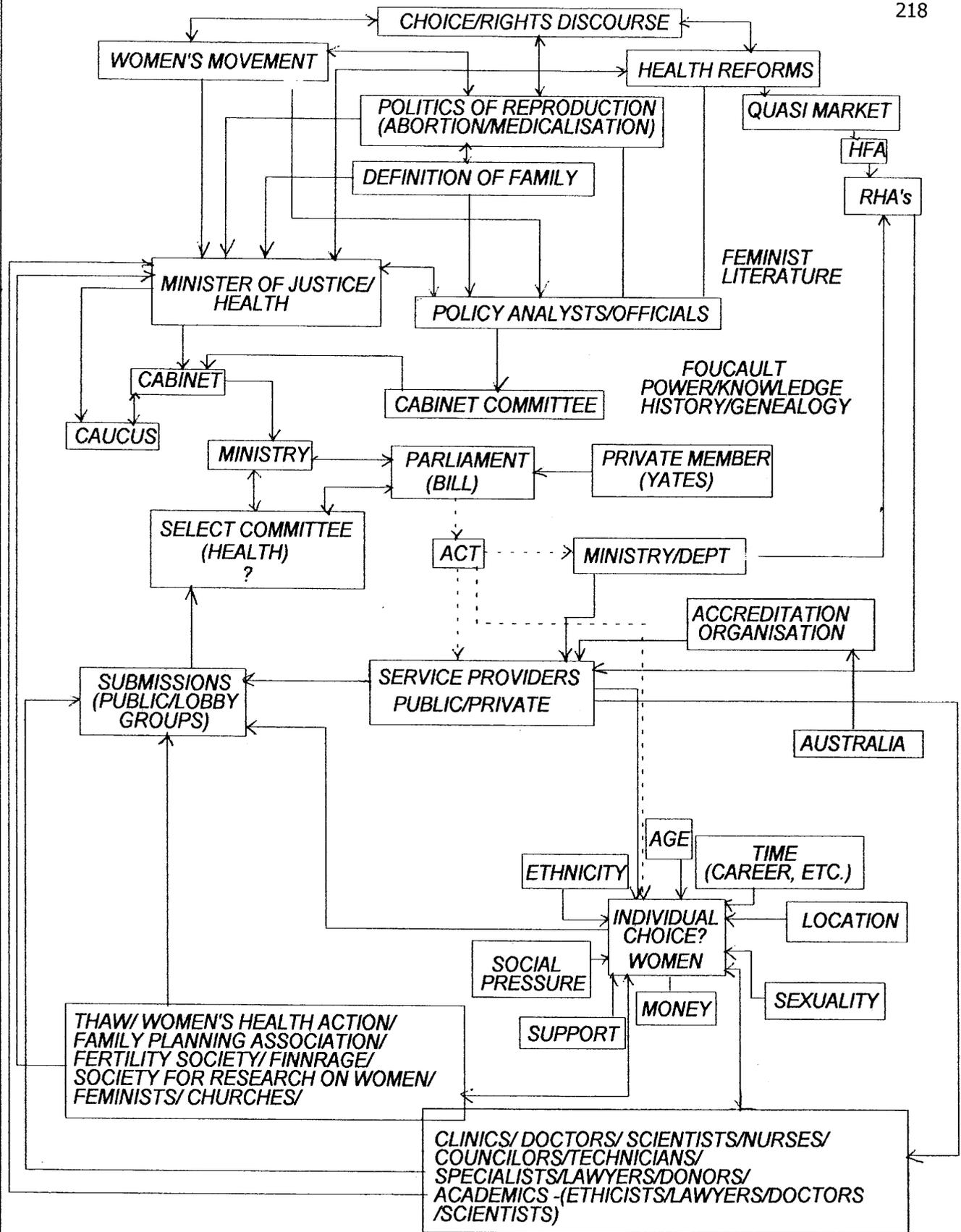
**Ken Daniels, Associate Professor, Department of Social Work, University of Canterbury, Christchurch.
Interview: 31 August 2000**

Ken Daniels is an Associate Professor in Social Work at the University of Canterbury. He teaches values and ethics and has taken advanced studies in bioethics. He has been researching and writing in the field of assisted human reproduction for twenty four years and has published over 100 papers, chapters, and books on this issue. He is currently involved in research in Sweden, Germany, the United Kingdom, Singapore, Argentina, and New Zealand.

Adapted from: <http://www.sowk.canterbury.ac.nz/> and <http://www.newhealth.govt.nz/necahr/membership.htm>

Appendix D:

**Flow Chart of the
ART Policy Process**



HOW IS WOMEN'S REPRODUCTIVE 'CHOICE' CONSTRAINED OR ENABLED BY THE EXISTING ART POLICY SITUATION?

Appendix E:

Introductory Letter

1 June 2000

«Title»
«Branch»
«Building_Name»
«Organisation»
«PO_Box»
«Street_Address»
«Suburb»
«City»

Attention: «Attention»

Dear «Attention»

SUBJECT: SOCIAL POLICY AND ASSISTED REPRODUCTIVE TECHNOLOGY.

I am a post-graduate student in the Department of Sociology at the University of Canterbury. In order to complete my Master's degree, I am carrying out a research project on policy issues surrounding the use of assisted reproductive technology. In this research project I intend to focus on what those involved in the policy discussion (politicians, providers, and consumer representatives) consider to be the constraining and/or empowering aspects of the present policy situation in New Zealand.

I would appreciate the «Organisation»'s participation in this study. Involvement would require a one hour semi-structured interview with yourself or a nominated representative of your «OrgMin». During the interview we would discuss current policy issues regarding control, regulation, funding, research, and access to assisted reproductive technologies, as well as the influence of the proposed legislation should it be enacted. I will follow this letter with a telephone call within the next two weeks to ascertain your «OrgMin»'s willingness to participate and to arrange the interview time and location. At this stage I am anticipating being in «City» during early July.

The project is being carried out under the supervision of Dr Jane Higgins and Ms Rosemary Du Plessis. Both can be contacted at the Department of Sociology, University of Canterbury, phone (03) 3667001. They are willing to discuss any concerns you may have about participation in the project. Should you be interested in the results of this project a ten-page summary will be available to your «OrgMin» upon request at the completion of the thesis. The completed document will also be available for reading in the University of Canterbury library.

Yours sincerely,

Lynne Batty
Ph: (03) *****
Email: l.batty@soci.canterbury.ac.nz

Appendix F:

**Information Sheet &
Consent Form**

University of Canterbury
Department of Sociology

Information Sheet

Social Policy and Assisted Reproductive Technology.

I am Lynne Batty, a post-graduate student in the Department of Sociology at the University of Canterbury. My Master's thesis involves research on policy issues surrounding the use of assisted reproductive technology. I intend to focus what those involved in policy discussion about assisted reproduction (politicians, providers, and consumer representatives) consider to be the constraining and/or empowering aspects of present policy in New Zealand.

During this interview we will discuss current policy issues regarding control, regulation, funding, research, and access to assisted reproductive technologies, as well as the influence of the proposed legislation should it be enacted. You will be asked to reflect on your organisation's role in policy discussion and any changes or inclusions to the current policy situation it would support.

The project is being carried out under the supervision of Dr Jane Higgins and Ms Rosemary Du Plessis. Both can be contacted at the Department of Sociology, University of Canterbury, phone (03) 3667001. They are willing to discuss any concerns you may have about participation in the project. Should you be interested in the results of this project a ten-page summary will be available to your organisation upon request at the completion of the thesis. The completed document will also be available for reading in the University of Canterbury library.

Lynne Batty
Ph: (03) *****
Email: l.batty@soci.canterbury.ac.nz

Consent Form

Social Policy and Assisted Reproductive Technology.

I have read and understood the description of the above-named project. On this basis I agree to participate in the project in my professional capacity, and I consent to the results of the interview being used in Lynne Patricia Batty's Master's thesis.

Please tick the appropriate boxes:

I agree to the use of my name in the above project.

I agree to the use of my position in the above project.

I agree to the use of my organisation's name in the above project.

Name

Position

Organisation

Signed: _____

Date: _____

Appendix G:

Interview Guide

Topics Covered in Interviews

Services & Access Restrictions

- Services provided by clinics
- Percentage of publicly funded services versus private services
- Access restrictions on private services
- Connecting with consumers
- Access mediated by geographic location
- Advertising overseas and “off-shore” clients
- The proposed national priority access criteria
- Surrogacy

Information Collection & Storage

- Record keeping and storage of information on donors, recipients, and children
- Access to information on donors, recipients, and children
- Organisations position on the proposed centralised data collection agency

Funding

- Public funding issues
- Allocation of funding
- Contract negotiation
- Changes to funding

Consumers

- Ethnic diversity of consumers
- Availability and/or demand for different ethnicity in donors, recipients, etc
- Treatment of single people and lesbian or de facto couples
- Barriers to people using your services – other than funding
- Who are most affected by these barriers?
- Information on the demographics of your consumers
- Public awareness of infertility and its causes

Policy Issues

- Organisations role in the ART policy discussion and/or formulation of policy
- Constraining/empowering aspects of the current policy situation
- Reaction to the two bills before the Health Select Committee
- Changes or inclusions the organisation would like to see in the current policy situation
- The affect of the proposed legislation on current practices
- Consultation and/or information sharing between clinics, the NZIS, and government agencies involved in formulating policy in New Zealand
- Research – causes of infertility, ART techniques, cloning, genetics, sex-selection, embryo research
- Embryo donation and sex-selection
- Documentary evidence - submissions, etc.

Regulation & Control

- Professional self-regulation or external regulation
- The Australian Reproductive Technology Accreditation Committee (RTAC)
- Sanctions for not belonging to or complying with RTAC
- A New Zealand based overseeing organisation
- The National Ethics Committee on Assisted Human Reproduction (NECAHR) as a “de facto policy maker”
- Representation and membership of NECAHR
- Changes to NECAHR’s responsibilities proposed under the Graham bill
- Tighter regulation and control over ART practices

Appendix H: NUDIST Codes

NVivo revision 1.2.142 Licensee: Sociology Department
 Project: ART & Policy User: Lynne Batty Date: 31/10/01 - 15:27:27
 NODE LISTING

Nodes in Set: All Tree Nodes
 Created: 04/09/00 - 17:33:23
 Modified: 04/09/00 - 17:33:23
 Number of Nodes: 54

1	(1)	/Access	28	(16)	/Policy
2	(1 1)	/Access/Priority Criteria	29	(17 1)	/Policy/History
3	(1 2)	/Access/Points Threshold	30	(18 2)	/Policy/TPK
4	(1 3)	/Access/Location	31	(19)	/Research
5	(1 4)	/Access/International	32	(19 1)	/Research/Sex-Selection
6	(2)	/Awareness	33	(19 2)	/Research/Cloning
7	(2 1)	/Awareness/Education	34	(19 3)	/Research/Embryos
8	(2 2)	/Awareness/Entitlement	35	(19 4)	/Research/Genetics
9	(3)	/Bills	36	(20)	/Rights
10	(3 1)	/Bills /Yates	37	(20 1)	/Rights/Choice
11	(3 2)	/Bills /Graham	38	(20 2)	/Rights/Human Rights Act
12	(4)	/Commercialisation	39	(20 3)	/Rights/Children
13	(5)	/Contracts_Service Specs	40	(20 4)	/Rights/Others
14	(6)	/Control_Regulation	41	(21)	/Self-Regulation
15	(7)	/Family	42	(21 1)	/Self-Regulation/Sanctions
16	(8)	/Funding	43	(22)	/Surrogacy
17	(8 1)	/Funding/History	44	(22 1)	/Surrogacy/Whangai
18	(10)	/Gender	45	(23)	/Statistics_Demographics
19	(10 1)	/Gender/Differences	46	(24)	/Social Aspects
20	(11)	/Information	47	(25)	/General
21	(12)	/Language	48	(25 1)	/General/State
22	(13)	/Maori	49	(25 2)	/General/Providers
23	(14)	/Marginal Groups	50	(25 3)	/General/Consumers
24	(14 1)	/Marginal Groups/Single	51	(26)	/Ethics
25	(14 2)	/Marginal Groups/Lesbian	52	(27)	/Treaty of Waitangi
26	(14 3)	/Marginal Groups/Older	53	(28)	/Prevention
27	(15)	/NECAHR	54	(29)	/Accountability

Appendix I: Yates Bill

Access to this document is available from: <http://www.knowledge-basket.co.nz/gpprint/acts>

Appendix J: Graham Bill

Access to this document is available from: <http://www.knowledge-basket.co.nz/gpprint/acts>

Appendix K:

Clinical Assessment Criteria (CPAC)

GYNAECOLOGY

National Referral Guidelines

SPECIFIC GYNAECOLOGY REFERRAL LETTER GUIDELINES

- Referrals can be accepted from registered Medical Practitioners, smear takers and midwives.
- Referrals should include GP diagnosis and categorisation with reference to National Gynaecology ACA.

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY

Diagnosis	Evaluation	Management Options	Referral Guidelines																																				
<p>Gynaecology problems are addressed under the following headings:</p> <table border="0"> <thead> <tr> <th></th> <th>Page No.</th> </tr> </thead> <tbody> <tr><td>• Amenorrhoea</td><td>2</td></tr> <tr><td>• Cervical Dysplasia (CIN)</td><td>2</td></tr> <tr><td>• Dysmenorrhoea</td><td>6</td></tr> <tr><td>• Ectopic Pregnancy</td><td>6</td></tr> <tr><td>• Infertility</td><td>8</td></tr> <tr><td>• Miscarriage</td><td>9</td></tr> <tr><td>• Menorrhagia</td><td>9</td></tr> <tr><td>• Ovarian cysts</td><td>15</td></tr> <tr><td>• Pelvic pain</td><td>15</td></tr> <tr><td>• Pelvic inflammatory disease</td><td>16</td></tr> <tr><td>• Postcoital bleeding</td><td>16</td></tr> <tr><td>• Postmenopausal bleeding</td><td>16</td></tr> <tr><td>• Postpartum bleeding</td><td>17</td></tr> <tr><td>• Prolapse</td><td>17</td></tr> <tr><td>• Urinary symptoms</td><td>17</td></tr> <tr><td>• Vaginal discharge</td><td>18</td></tr> <tr><td>• Vulval disease</td><td>18</td></tr> </tbody> </table>		Page No.	• Amenorrhoea	2	• Cervical Dysplasia (CIN)	2	• Dysmenorrhoea	6	• Ectopic Pregnancy	6	• Infertility	8	• Miscarriage	9	• Menorrhagia	9	• Ovarian cysts	15	• Pelvic pain	15	• Pelvic inflammatory disease	16	• Postcoital bleeding	16	• Postmenopausal bleeding	16	• Postpartum bleeding	17	• Prolapse	17	• Urinary symptoms	17	• Vaginal discharge	18	• Vulval disease	18	<p>A thorough history and examination is required to determine a specific diagnosis and its degree of urgency. Some appropriate investigation by the referrer will facilitate the referral process.</p>	<p>Specific treatments – see relevant sections.</p>	<p>These guidelines are provided (below) to give greater clarity in situations of the primary/secondary interface of care.</p> <p>Local communication requirements may be annotated here:-</p>
	Page No.																																						
• Amenorrhoea	2																																						
• Cervical Dysplasia (CIN)	2																																						
• Dysmenorrhoea	6																																						
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• Postpartum bleeding	17																																						
• Prolapse	17																																						
• Urinary symptoms	17																																						
• Vaginal discharge	18																																						
• Vulval disease	18																																						

Note: These national referral recommendations have been prepared to provide guidelines for referral to specialist gynaecology services. They should be regarded as examples or guidelines for referring health professionals and are not an exhaustive list. The referring health professional should ensure that in using these national referral recommendations generally accepted clinical practice should be properly taken into account. If there is a conflict between the national referral recommendations and generally accepted clinical practice, then generally accepted practice should prevail.

GYNAECOLOGY

Summary of the revised Bethesda System (1991) (TBS)¹⁵

APPENDIX 1

Adequacy of the Specimen

- Satisfactory for evaluation
- Satisfactory for evaluation but limited by.... (specify reason)
- Unsatisfactory for evaluation.... (specify reason)

General Categorisation

- Within normal limits
- Benign cellular changes : See descriptive diagnosis
- Epithelial cell abnormality : See descriptive diagnosis

Descriptive Diagnosis

Benign cellular changes

Infection

- Trichomonas vaginalis
- Fungal organisms morphologically consistent with Candida
- Predominance of coccobacilli consistent with shift in vaginal flora
- Bacteria morphologically consistent with Actinomyces
- Cellular changes associated with Herpes simplex virus
- Other

Reactive epithelial changes

- Inflammation (includes typical repair)
- Atrophy with inflammation ("atrophic vaginitis")
- Radiation
- Intrauterine contraceptive device
- Other

Epithelial cell abnormalities

Squamous cell

- Atypical squamous of undetermined significance (ASCUS)
Qualify: favour reactive or favour premalignant/malignant process
- Low grade squamous intraepithelial lesion (LSIL):
encompassing CIN 1 and/or human papillomavirus (HPV)
- High grade squamous intraepithelial lesion (HSIL):
encompassing moderate and severe dysplasia, CIN 2 and CIN 3/Carcinoma in situ (CIS)
- Squamous cell carcinoma

Glandular cell

- Endometrial cells in a post menopausal woman who is not on hormone replacement therapy
- Atypical glandular cells of undetermined significance (AGUS)
Qualify: favour reactive or favour premalignant/malignant process
- Endocervical adenocarcinoma in situ (AIS*)
- Endocervical adenocarcinoma
- Endometrial adenocarcinoma
- Extrauterine adenocarcinoma
- Adenocarcinoma, not otherwise specified

Other malignant neoplasms: Specify

- * NZ addition to TBS

GYNAECOLOGY

Action Plan for Cervical Smear Results

1. NORMAL OR BENIGN/REACTIVE CHANGES

Smear Result	Smear History	Action
Satisfactory	Previous normal smears	Smear in 3 years
	First smear, or more than 5 years since last smear	Smear in 1 year
	Previous abnormal smears	Refer to flow chart
Satisfactory but limited *	Previous normal smears	Smear in 1 year
	First smear, or more than five years since last smear	Smear in 1 year
	Abnormal smear in last five years	Smear in 6 months
Unsatisfactory Smear		Smear in 1-3 months

* Except absent endocervical/metaplastic cells – in which case; If the cervix has been visualised and adequately sampled and there is no other indication to repeat the smear earlier, repeat the smear in three years.

2. ABNORMAL

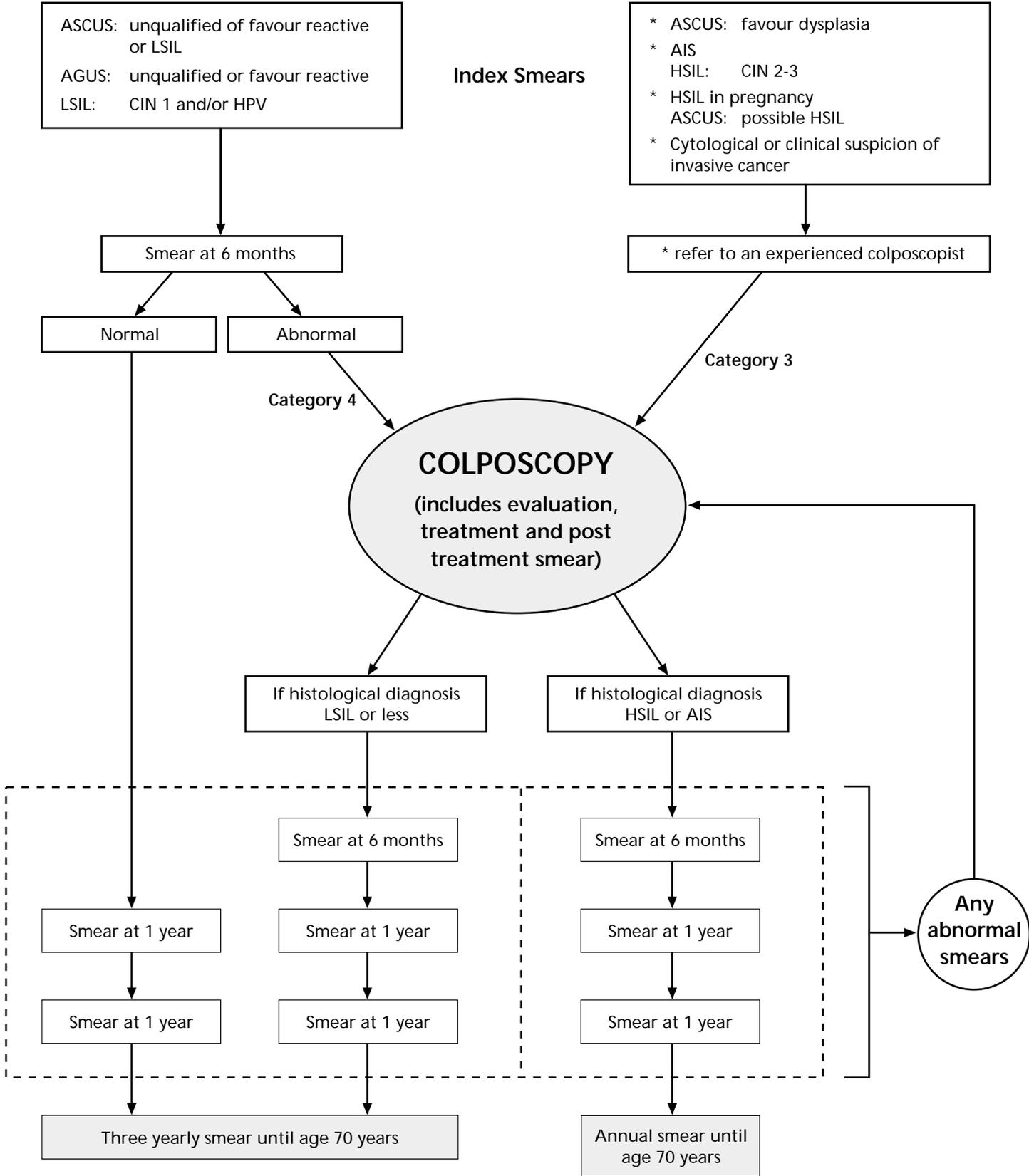
Smear Result	Smear History	Action
Ascus: unqualified or favour reactive or LSIL AGUS: unqualified or favour reactive LSIL: CIN 1 and/or HPV	Previous normal Smears	Smear in 6 months
	Previous abnormal smear	Refer to flow chart
* AGUS: favour dysplasia * AIS HSIL: CIN 2-3 * HSIL in pregnancy ASCUS: possible HSIL * Suspicious or diagnostic of invasive carcinoma		

* Refer to an experienced colposcopist

* See Appendix 1 for glossary (page 3)

GYNAECOLOGY

Management of the Abnormal Smear

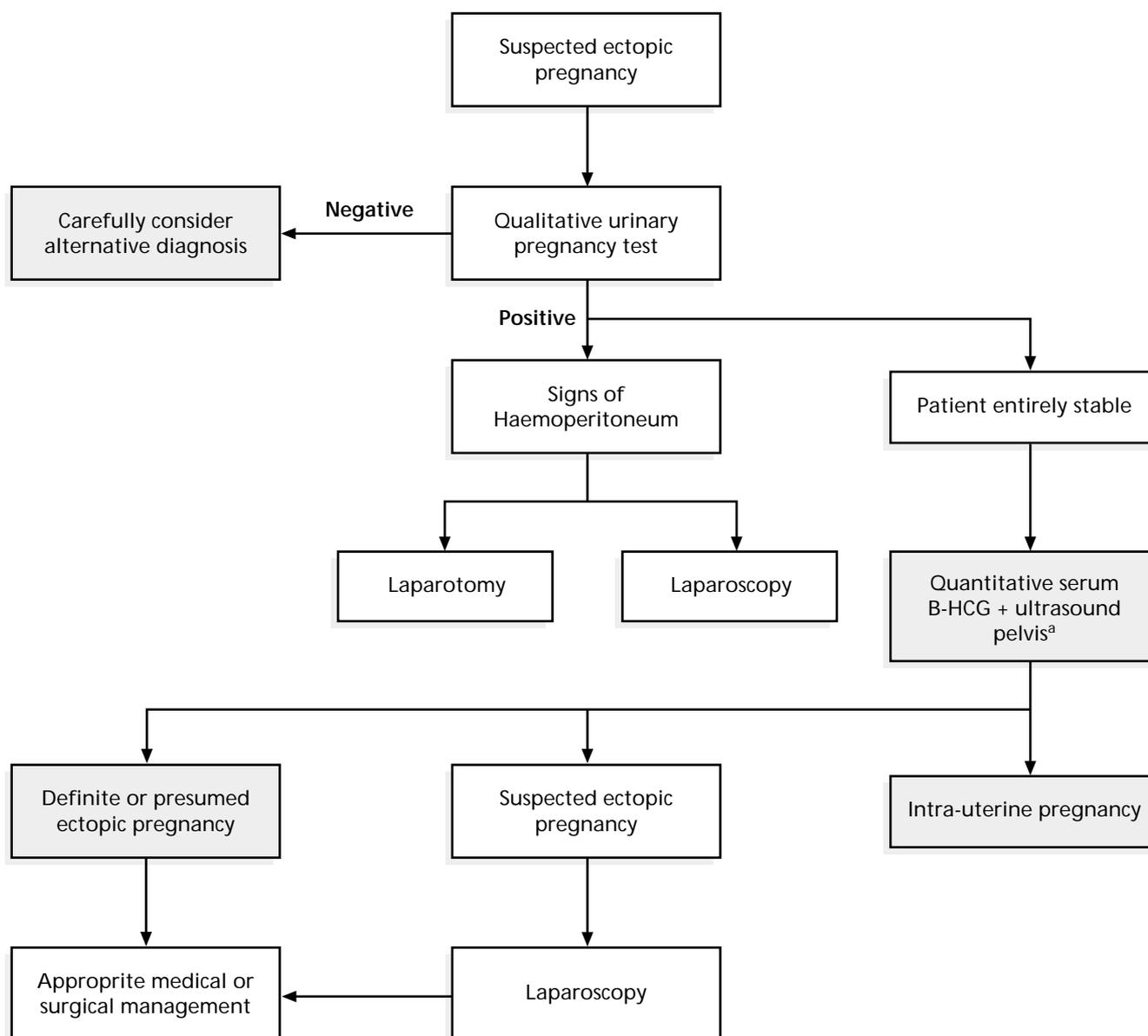


NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY

Diagnosis	Evaluation	Management Options	Referral Guidelines
DYSMENORRHOEA	<ul style="list-style-type: none"> • Pain (suspect Endometriosis), • Fever • Vomiting • Associated discharge • Deep dyspareunia • Pain with bowel movement • Fainting • Time off activities <p>EXAMINATION:</p> <ul style="list-style-type: none"> • Pelvic mass • Cervical excitation <p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> • If PID suspected (see below). • Ultrasound if pelvic mass suspected. 	<p>1. The key to adequate pain control is to treat at first hint of pain/period. Symptomatic analgesia. NSAIDs – Any short acting NSAID O.K.</p> <p>Response to NSAID can be idiosyncratic. The addition of paracetamol may be helpful.</p> <p>Ponstan for refractory cases may be tried.</p> <p>2. COCPs with appropriate warnings re VTE</p> <p>3. Depo Provera</p>	<ul style="list-style-type: none"> • Unresponsive to treatment (no improvement in 90 days) – category 4. • If symptoms severe – category 3. • Evidence of mass or endometriomas - category 3.
ECTOPIC PREGNANCY	<ul style="list-style-type: none"> • Diagnosis relies heavily on suspicion radiological and biochemical evidence • Non-acute - Quantitative serum HCG • Ultrasound 	<ul style="list-style-type: none"> • An intrauterine pregnancy should be visible on transvaginal scan if the HCG >1000 mIU/ml • If not, and the patient is >6 weeks pregnant, there is a 95% chance of ectopic – D/W O & G specialist. • If <6 weeks, and no intrauterine or ectopic pregnancy is seen, the HCG should be repeated in 2 days (provided the patients condition is stable) • HCG should increase by at least 80% every 2 days in established pregnancy • If the repeat HCG has increased >80%: re-scan in 10 days • If the repeat HCG has fallen, or increased by <80%: D/W O & G specialist 	<p>Acute – refer category 1</p> <p>Refer</p> <p>Refer</p>

GYNAECOLOGY

Investigation of a patient with suspected Ectopic Pregnancy



^a An intra-uterine gestational sac should be seen with abdominal ultrasound when the B-HCG level is above 2000 mIU/ml. If a transvaginal probe is used, a gestational sac should be seen if the level is above 1000 mIU/ml.

Abbreviation: HCG - Human chorionic gonadotrophin

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY

Diagnosis	Evaluation	Management Options	Referral Guidelines
INFERTILITY	<p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> • History and examination of both partners includes assessment of fertility awareness¹ • Health screening tests for the female partner – rubella immunology, VDRL, hepatitis B antigen, blood group antibodies² • Routine semen analysis, repeated in 4-6 weeks if abnormal³ • Assessment of menstrual cycle including³ <ul style="list-style-type: none"> - a plasma progesterone timed for 5-9 days before the next expected period. If cycle is long to be repeated at weekly intervals until next period - plasma FSH, LH, prolactin, thyroid function if the cycle is prolonged and/or irregular. FSH (day 2-5 cycle) for older women (is measure of biological age of ovary). - Ultrasound of pelvis in some cases⁴ 	<p>* Early Management</p> <ul style="list-style-type: none"> - Fertility awareness - Both partners should be advised to give up smoking and limit alcohol intake - A supervised weight improving programme is advised outside of the BMI range 18-32 - GPs should advise women presenting with infertility to take 0.4 mg folic acid as a supplement and during the first 12 weeks of a pregnancy. - Counseling and grief support - Plan for ongoing support in primary care after referral <p>The fertile phase is a 5 day period preceding ovulation and ending on last day of ovulation. There is no evidence that the use of temperature charts and LH detection kits to time intercourse improves outcome and their use should be discouraged. Couples should be advised to have regular intercourse throughout the cycle.</p>	<ul style="list-style-type: none"> • Refer if any abnormality in history, examination or investigation <ul style="list-style-type: none"> - Refer if unexplained infertility > 18 months duration BUT • Early referral if: <ul style="list-style-type: none"> - female age ≥ 35 - a female history of any pelvic surgery, STDs, PID, severe cyclical pain - male history of genital pathology, urogenital surgery, STD <p style="text-align: center;">Category 4</p>

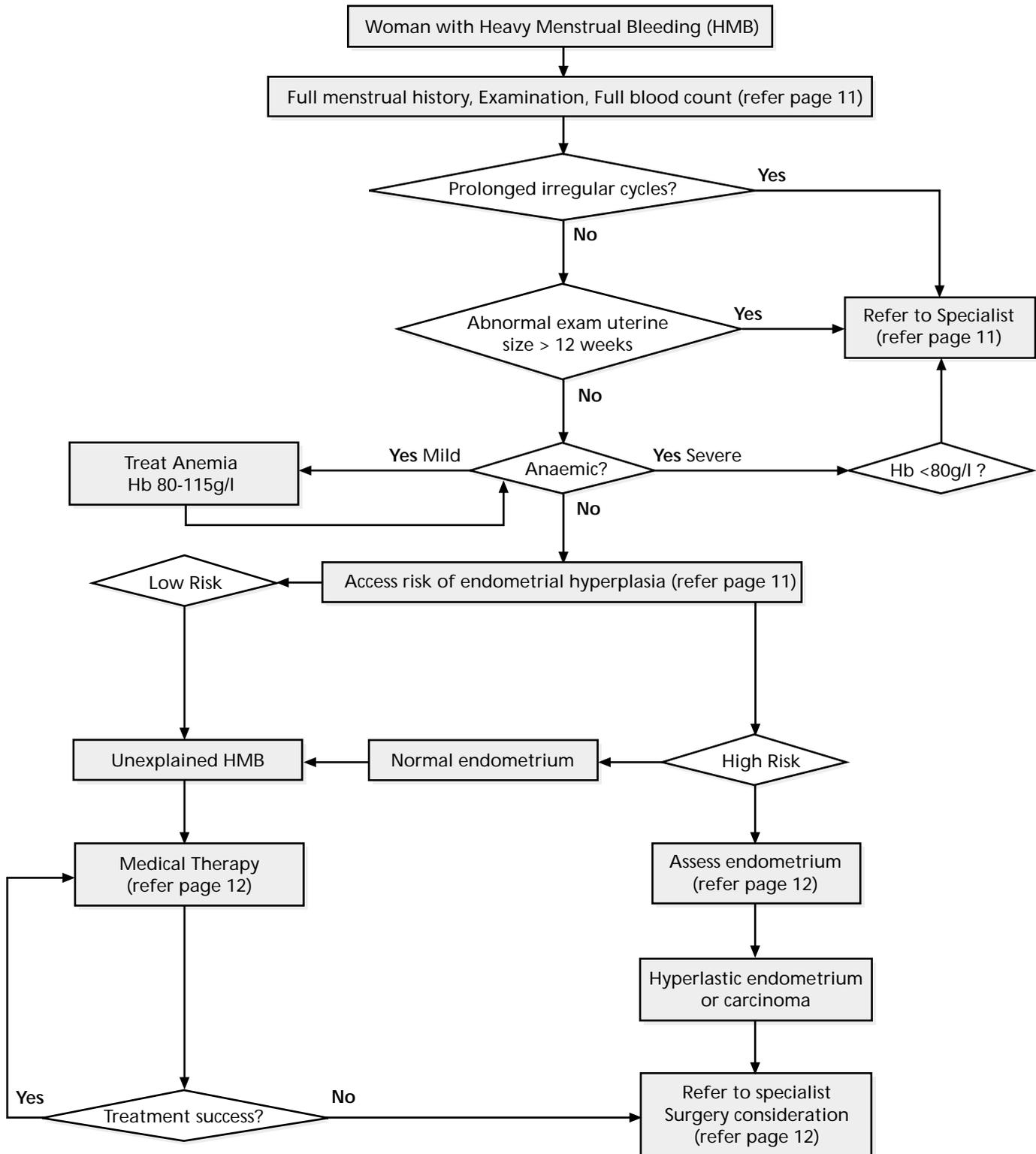
Notes:

1. These will establish predictive factors for various disease processes. Awareness of the fertile time may not only facilitate rapid resolution of their infertility, but improve the response to treatment programmes.
2. Tests that should be performed early. Treatments should be withheld until pregnancy risk factors and their prevention are addressed. (Note HIV and Hep C tests for both partners are also recommended if the couple go onto assisted reproductive procedures).
3. To be completed early in the evaluation.
4. To be completed early in the evaluation if there is a menstrual or ovulation disorder or for assessment of pain. Its predictive values for menstrual disorders are outstandingly high. It is also useful for the definition of ovarian disorders, including the PCOS and endometriomas.

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY			
Diagnosis	Evaluation	Management Options	Referral Guidelines
MISCARRIAGE	<ul style="list-style-type: none"> • Most pregnancies failing in the first 8 weeks are likely to completely abort • After 8 weeks an incomplete abortion is more likely. • Assess for cardiovascular shock, degree of pain, amount of bleeding, and social circumstances • Vaginal examination is mandatory: if the cervical os is open there is no need for ultrasound scanning; if closed, a scan is indicated to distinguish <ul style="list-style-type: none"> - threatened abortion - ongoing pregnancy - missed abortion - incomplete abortion - ectopic pregnancy 	<ul style="list-style-type: none"> • When clinical assessment suggests a simple, uncomplicated miscarriage, and when social circumstances permit, events can be allowed to run their course without admission to hospital • Reassessment for any worsening of symptoms or signs, or persistence of bleeding beyond 36 hrs • Note: Remember anti-D (within 72 hrs) for any bleeding or trauma in pregnancy if patient is Rh-ve 	<ul style="list-style-type: none"> • Refer acute category 1 • Non acute category 2 - the next available operating list
MENORRHAGIA	<ul style="list-style-type: none"> • Menstruation associated with flooding and/or hourly pad changes. • Consider pictorial bleeding chart (see appendix 2) • Pelvic examination • Investigations: <ul style="list-style-type: none"> - FBC - Ultrasound scan - Pipelle if experienced in technique (If endometrial thickness >12mm or if patients weight > 90 kg or if patients age > 45 years) 	<p>Medical Treatment:</p> <ul style="list-style-type: none"> • NSAIDs • Tranexamic Acid (with Consultant approval) • OCP • Levonorgestrel Intrauterine System (Mirena) <p>See NHC Guidelines</p>	<ul style="list-style-type: none"> • Abnormal ultrasound scan • Failed medical treatment • To access pipelle sampling • Category 3-4 <p>See NHC Guidelines</p>

GYNAECOLOGY

National Guidelines for Management of Heavy Menstrual Bleeding Algorithm



NOTE : NHC Guidelines Website: http://www.nzgg.org.nz/library/gl_complete/gynae_hmb/index.htm

GYNAECOLOGY

Explanation of Grading Evidence: The working party accepted a grading of evidence recommended by the Department of Health, UK and endorsed by the National Health Service Executive, UK (Mann 1996).

Grade A - based on randomised controlled trials*

Grade B - based on robust experimental or observational studies

Grade C - based on more limited evidence but the advice relies on expert opinion and has the endorsement of respected authorities

* in diagnostic testing comparative cross sectional studies with a gold standard are Grade 'A'. A gold standard test is defined as best available test.

Full menstrual history, Examination, Full blood count

- Of women who present with HMB, only 50% have menstrual blood loss >80 mls/cycle (**Evidence Grade B**).
- In women <20 years old pelvic examination is unlikely to contribute to management of heavy bleeding and the likelihood of pathology is small (**Evidence Grade C**).
- Increased likelihood (70%) of heavy menstrual blood loss .80 mls/cycle if Hb ,120 g/l (**Evidence Grade A**).
- Consider pictorial blood loss assessment charts (appendix 6.5) for women with normal Hb (**Evidence Grade A**).

Refer to Specialist

The following women are recommended to see a specialist at the initial consultation because of increased likelihood of pathology: (it is beyond the scope of this guideline to provide recommendations for management in these instances).

- Women with erratic menstrual cycles (regardless of loss) (**Evidence Grade B**).
- Women with an abnormal pelvic examination (confirmed by transvaginal ultrasound if possible) (**Evidence Grade C**).
- Perimenopausal women with less frequent cycles but normal blood loss do not require referral (**Evidence Grade C**).
- Women with severe anemia (**Evidence Grade C**).

It is estimated that approximately 15% of all women with HMB will require specialist referral at the initial consultation.

Assess risk of endometrial hyperplasia

Risk of endometrial hyperplasia or carcinoma in women with heavy menstrual bleeding:

All women	4.1%
<45 years old & <90 kg	2.3%
90 kg	10.0%
45 years old	6.0%

Other risk factors for endometrial hyperplasia (**Evidence Grade B**):

- Infertility + nulliparity
- Exposure to unopposed endogenous or exogenous estrogen / tamoxifen
- Family history of endometrial and colonic cancer (**Evidence Grade C**).

Endometrial hyperplasia with atypia may progress (if untreated) to endometrial carcinoma in 20%-75% of cases over a 13 year period (**Evidence Grade B**).

It is estimated that 20% of women with regular HMB will require endometrial assessment because of increased risk factors.

GYNAECOLOGY

Assess endometrium

- Transvaginal ultrasound is recommended as first option for endometrial assessment but if not possible then an endometrial sample should be taken **(Evidence Grade A)**.
- If endometrial thickness on transvaginal ultrasound > 12 mm then an endometrial sample should be taken **(Evidence Grade A)**.
- Consider specialist referral if abnormal transvaginal ultrasound suggestive of submucous fibroids **(Evidence Grade B)**.
- Fifty percent of women >90 kg, who have an endometrial thickness >12 mm on TVS, have endometrial hyperplasia **(Evidence Grade A)**.
- Less than 1% of women >90 kg, who have an endometrial thickness <12 mm have endometrial hyperplasia **(Evidence Grade A)**.
- The number of endometrial samples needed to detect 1 case of endometrial hyperplasia overall is 23. In women > 90 kg the number needed to detect 1 case is 8 **(Evidence Grade B)**.

Medical Therapy

- Comparative Table of Medical Therapy
- The Choice of Medical Therapy
- Decision Analysis of Medical Therapy

Comparative Table of Medical Therapy for the Treatment of Heavy Menstrual Bleeding				
Drug	Mean Reduction in Blood Loss	Women Benefiting*	Specific Benefits	Adverse Effects
Levonorgestrel IUS	94 %	100 %	Contraception No requirement to take tablets	Menstrual cramps Expulsion of system (5%) Intermenstrual bleeding (27%)
Oral Progesterone (days 5-25)**	87 %	86 %	Cycle regularity	Bloating, Mood swings, PMS
Tranexamic Acid	47 %	56 %	None	Nausea, Diarrhoea
NSAIDs	29 %	51 %	Relief of dysmenorrhoea, Headaches	Nausea, Diarrhoea, Headaches
OC pill	43 %	50 %	Contraception Relief of dysmenorrhoea, PMS	Nausea, Breast tenderness, Headache
Danazol	50 %	76 %	None	Weight gain, Acne
Oral Progesterone (luteal phase)	-4 %	18 %	Cycle regularity	Hot flushes, Bloating, Mood swings, PMS

* Proportion with MBL <80 ml/cycle

** Based on only one randomised controlled trial.

GYNAECOLOGY

The Choice of Medical Therapy

The Choice of Medical Therapy will be dependent on individual patient requirements. For example:

Does the patient require contraception ?

Consider:

- LNG-IUS
- OC pill

Does the patient have painful menstruation ?

Consider:

- LNG-IUS
- NSAIDs
- OC pill

Is the patient unable to tolerate hormone treatments ?

Consider:

- NSAIDs
- Tranexamic Acid
- LNG-IUS

See decision analysis at the following table

Some women who have completed their family may decline medical therapy and choose surgery as a first option.

Decision Analysis of Medical Therapy	
Medical Therapy*	Ranking According to Decision Analysis** (Evidence Grade A)
Levonorgestrel IUS	1
Tranexamic acid	2
NSAIDs	2
OC pill	3
Norethisterone (D5-25 15 mg daily)	3
Danazol	4

* More than one therapy can be considered

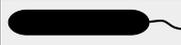
** Based on efficacy, side effect profile and acceptability to women over 12 months (Lethaby et al, 1998) (see appendix 6.5 for full description)

GYNAECOLOGY

Pictorial Bleeding Assessment Chart

EXAMPLE OF COMPLETED CHART

Name: _____

	TOWEL	1	2	3	4	5	6	7	8
1		//				//			
5			###		//				
20			//	//					
	TAMPON	1	2	3	4	5	6	7	8
1									
5			//		//				
10			###						
DAILY SCORE		2	137	101	21	3	1		
TOTAL SCORE =		265							

SAMPLE

Name: _____ Date: _____

	TOWEL	1	2	3	4	5	6	7	8
1									
5									
20									
	TAMPON	1	2	3	4	5	6	7	8
1									
5									
10									
DAILY SCORE									
TOTAL SCORE =		_____							

If score of > 185 then likelihood of menstrual blood loss ≥80 mls/cycle is increased.

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY			
Diagnosis	Evaluation	Management Options	Referral Guidelines
OVARIAN CYST <i>1 CA 125 is associated with epithelial irritation of the ovary so may also be raised in benign conditions such as endometriosis etc</i>	HISTORY <ul style="list-style-type: none"> • Cyclical symptoms • Pain • Dyspareunia • Irregular cycle • Gastrointestinal <p><i>Note: ovarian pathology (e.g. torsion or carcinoma) may present with gastrointestinal symptoms.</i></p> <ul style="list-style-type: none"> • Risk of malignancy greater pre-pubertally and with increasing age to 70+. EXAMINATION: <ul style="list-style-type: none"> • Abdominal • Pelvic INVESTIGATIONS: <ul style="list-style-type: none"> • Ultrasound scan • CA 125¹ in post menopausal women and all cysts >5cm 	<ul style="list-style-type: none"> • If 5 cms and larger refer. • If less than 5 cms repeat scan after a menstrual period when applicable (can exclude corpus luteal cysts). 	<ul style="list-style-type: none"> • Refer torsion – category 1. • Refer others– category 2.
PELVIC PAIN	HISTORY <ul style="list-style-type: none"> • Severity and duration – pain on at least 14 days each month x3 months • Pain calendar (relative to menstruation) • GI function • GU function • Dyspareunia • Dysmenorrhoea • Sexual history/PID/Surgery • ? Sexual abuse in the past • Time off activities EXAMINATION <ul style="list-style-type: none"> • Swabs/smear – current • Bimanual examination • Rectal examination INVESTIGATIONS <ul style="list-style-type: none"> • HVS/Endo Cx swabs • MSU • Ultrasound 	<ul style="list-style-type: none"> • Symptomatic analgesia • COCPs • Psychological support 	<ul style="list-style-type: none"> • Unresponsive to treatment refer Category 4 • If symptoms severe category 3

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY			
Diagnosis	Evaluation	Management Options	Referral Guidelines
PELVIC INFLAMMATORY DISEASE Acute (c.f. Sexual Health Referral Recommendations)	<ul style="list-style-type: none"> Pain, discharge, pyrexia Recent sexual history <p>EXAMINATION:</p> <ul style="list-style-type: none"> Pelvic tenderness Adnexal masses Discharge <p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> FBC/ESR Endocx/urethral swabs(consider rectal & throat swabs) for culture & sensitivity Pregnancy test Smear if due 	<ol style="list-style-type: none"> Link and liaise with STD clinic as appropriate for contact tracing etc. All cases of resistant gonorrhoea should be referred to STD Antibiotics: Augmentin 500mg 8 hrly p.o. for 14 days Plus Doxycycline 100mg p.o. 12 hourly for 14 days, Antibiotics used should be determined by local sensitivities. Note: In pregnancy: Augmentin as above Plus Erythromycin ethyl succinate (EES) 400mg 6 hrly p.o. for 14 days. Ceftriaxone 1 gram can be used as stat doses in the treatment of gonorrhoea Ciprafloracin 500 mg (needs specialist recommendation) 	Acutely unwell, pelvic mass, unresponsive to treatment (24 hours). Refer category 1. If septic abortion is suspected refer to category 1 Unresponsive to treatment - refer category 1.
Chronic	Chronic pain, discharge, erratic bleeding, recurrent episodes of acute PID, dyspareunia <p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> See acute Ultrasound scan for pelvic mass 	<ol style="list-style-type: none"> May require prolonged course of antibiotics: Augumentin; or Amoxil and metronidazole instead of augmentin 	Unresponsive to treatment - refer category 1.
POSTCOITAL BLEEDING	<ul style="list-style-type: none"> Examine Smear HVS/endocervical swab 	<ul style="list-style-type: none"> Small endocervical polyps (less 2cm) in premenopausal woman with normal smear can be avulsed and sent for histology Ectropion with normal smear – Rx silver nitrate 	<ol style="list-style-type: none"> Refer if recurrent – category 2 If polyps are large, broad based or the base is not visible refer – category 3
POSTMENOPAUSAL BLEEDING (6 months from last menstrual period)	<ul style="list-style-type: none"> Drug history. (Contraception, HRT) Evidence of any genital tract abnormalities e.g. cervical polyps¹/atrophic change or abdominal mass Sexual/PID history <p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> Smear HVS/endocervical swab Pipelle (if experienced in technique²) Pelvic transvaginal ultrasound³ Pregnancy Test (unnecessary > 55 years) 	Treatment options for atrophic vaginitis include short term local oestriol, or longer term combination HRT therapy ⁴ (only if ultrasound exam is normal) If PMB is a single event, the ultrasound is normal and no other cause is suspected then repeat ultrasound in 3 months to exclude proliferative endometrium. If bleeding recurs then refer for specialist assessment	<ol style="list-style-type: none"> Refer to specialist service - category 2 Irregular bleeding on HRT⁴ – category 2 If patient on tamoxifen and has post menopausal bleeding refer for specialist opinion- category 3

Notes:

- Cervical polyps are almost always a benign condition, but referral indicated if associated with post menopausal bleeding, to exclude other serious causes.
- If pipelle fails to sample sufficient tissue ultrasound or referral is necessary
- Endometrial thickness (ET) double thickness measurements are highly predictive of endometrial carcinoma. If ≤ 5 mm then carcinoma is unlikely
- It is felt that HRT, its risk assessment and management is the domain of the General Practitioner but referral of women with abnormal bleeding on HRT after 6 months of therapy is recommended.

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY			
Diagnosis	Evaluation	Management Options	Referral Guidelines
POSTPARTUM BLEEDING (within 6 weeks) Notes: Ultrasound scan can be confusing in postpartum bleeding and has little value in aiding diagnosis.	<ul style="list-style-type: none"> • Drug history incl. contraception • Delivery history • Pain, fever. <p>EXAMINATION:</p> <ul style="list-style-type: none"> • Uterine size, tenderness, temperature <p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> • Endocervical swab • Chlamydia test • Hb 	<ul style="list-style-type: none"> • Treat with Augmentin 500mg TDS 5 to 7 days (dependent on local sensitivities) 	<ol style="list-style-type: none"> 1. Heavy bleeding or pain. Refer – category 1 2. No response to treatment – refer – category 2
PROLAPSE (Pelvic anatomical relaxation)	<p>HISTORY:</p> <ul style="list-style-type: none"> • Swelling/Lump • Interference with micturition/defaecation • Dyspareunia • Oestrogen deficiency (includes post partum, depo provera) <p>EXAMINATION:</p> <ul style="list-style-type: none"> • Grade prolapse <p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> • MSU • FBC 	<ol style="list-style-type: none"> 1. If post menopausal, symptoms of prolapse without signs may resolve on treatment with local oestriol which is worth a try before referral (i.e., 3 months) 2. Consider ring pessary. 	Symptomatic prolapse - category 4.
URINARY SYMPTOMS	<p>UROLOGICAL HISTORY:</p> <ul style="list-style-type: none"> - stress, urge incontinence - frequency, nocturia, enuresis - Voiding difficulty (hesitancy) - Haematuria dysuria <p>GYNAECOLOGICAL HISTORY (Prolapse Symptoms)</p> <ul style="list-style-type: none"> • Medical/Drug History • Previous Gynaecological/ Obstetric History • Abdominal/Pelvic/ Neurological Exam <p>INVESTIGATIONS:</p> <ul style="list-style-type: none"> • MSU/Urinalysis (if infected treat and reassess) • Urinary diary • Assess post void residual • (physical exam/ catheterization/ ultrasound 	<ol style="list-style-type: none"> 1. Lifestyle Interventions (decrease caffeine, weight and smoking; treat constipation; appropriate fluid intake) 2. Pelvic Floor Muscle Training (PFMT) and Bladder retaining by trained continence therapist for 3/12 3. Topical vaginal oestriol /HRT if postmenopausal unless contraindicated. 4. Trial of Bladder Relaxants if presumed overactive bladder (and no significant post void residual) 	Referral to Gynaecological or Urological Service in the following circumstances: <ul style="list-style-type: none"> • Failed conservative treatment (PFMT and Bladder retraining) • Complex History e.g. <ul style="list-style-type: none"> - Recurrent incontinence - Incontinence associated with: <ul style="list-style-type: none"> • Pain • Haematuria • Recurrent Infection • Voiding symptoms • Pelvic irradiation • Radical pelvic surgery • Suspected fistula • Significant Post Void Residual • Significant Pelvic Organ Prolapse

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY			
Diagnosis	Evaluation	Management Options	Referral Guidelines
VAGINAL DISCHARGE (C.F. Sexual Health referral recommendations)	1. Sexual and PID history 2. Characteristics - odour, quantity, irritation, blood staining. INVESTIGATIONS: <ul style="list-style-type: none"> • Smear • Swab, HVS, Chlamydia, Viral (if indicated by vesicles) • Blood Glucose (if recurrent candida) 	1. STD's - treat patient and partner. If GP unable to arrange contact tracing and counselling referral to STD clinic. 2. Candida: Topical Azole e.g. Clotrimazole. Recurrent candida: Topical Azole course premenstrually for 3 months or oral medications e.g. Fluconazole or Itraconazole 3. Vaginal antiseptic Aci-Jel 4. Physiological – counselling and education.	1. Refer those women with copious physiological discharge and a wide ectropion for cryotherapy. 2. Unexplained post menopausal discharge – category 2 3. Recurrent or failure to respond to therapy – category 4
VULVAL DISEASE	HISTORY: <ul style="list-style-type: none"> • pain, swelling, pruritus, dyspareunia, localised lesions (pigmented or non-pigmented lesions) • Current treatment to date • Systemic dermatological problems. INVESTIGATIONS: <ul style="list-style-type: none"> • Consider swabs/scrapings • Consider biopsy for a generalised skin condition 	1. Antibiotic treatment of Bartholins abscess is of little value. Acute referral for drainage recommended. 2. The older the patient and/or the more localised the lesion of the vulva, the more urgent the assessment. 3. Topical treatment appropriate to diagnosis.	<ul style="list-style-type: none"> • Bartholins abscess/ category 1. • Bartholins cyst refer category 4. • Persisting symptoms despite treatment – category 2.

GYNAECOLOGY

National Access Criteria for First Assessment [ACA]

Category Definitions : These are recommended guidelines for hospital specialists prioritizing referrals from primary care.

- | | |
|----------------|--|
| 1. Immediate | - <i>acute admission to be arranged</i> |
| 2. Urgent | - <i>to be seen at next available clinic or within 2 weeks</i> |
| 3. Semi-urgent | - <i>within 4 weeks</i> |
| 4. Routine | - <i>within 16 weeks</i> |

Immediate and Urgent cases must be discussed with the Specialist or Registrar in order to get appropriate prioritisation and then a referral letter sent with the patient, faxed or e-mailed (there may be local variety to this). The times to assessment may vary depending on size and staffing of the hospital department.

NATIONAL REFERRAL GUIDELINES : GYNAECOLOGY		
Category	Criteria	Examples (not an exhaustive list)
2. Urgent	<ul style="list-style-type: none"> Diagnosed or suspected malignancy 	<ul style="list-style-type: none"> highly abnormal cervical smear with cervical lesion post menopausal bleeding gestational trophoblastic disease genital lesions or pelvic masses highly suspicious of cancer
	<ul style="list-style-type: none"> Major functional disturbance 	<ul style="list-style-type: none"> large masses causing symptoms heavy vaginal bleeding with severe anaemia
	<ul style="list-style-type: none"> Pain requiring narcotic or high levels of analgesia 	
3. Semi - Urgent	<ul style="list-style-type: none"> Pelvic masses with low risk of malignancy 	<ul style="list-style-type: none"> Ovarian cysts > 5cms
	<ul style="list-style-type: none"> HGSIL of cervix 	
	<ul style="list-style-type: none"> Vulval abnormalities 	<ul style="list-style-type: none"> Pruritus vulvae
	<ul style="list-style-type: none"> Anaemia 	
	<ul style="list-style-type: none"> Moderate functional impairment 	<ul style="list-style-type: none"> Procidentia
	<ul style="list-style-type: none"> Chronic PID 	
4. Routine	<ul style="list-style-type: none"> Gynaecological disorders with limited functional impairment 	<ul style="list-style-type: none"> Dysmenorrhoea Premenstrual symptoms Genital prolapse Abnormal uterine bleeding
	<ul style="list-style-type: none"> Fertility 	<ul style="list-style-type: none"> Infertility
	<ul style="list-style-type: none"> Endocrine dysfunction 	<ul style="list-style-type: none"> Amenorrhoea Hirsutism P.C.O. Endometriosis
	<ul style="list-style-type: none"> Other non urgent problems 	<ul style="list-style-type: none"> Congenital abnormalities
	<ul style="list-style-type: none"> LGSIL of cervix 	

GYNAECOLOGY

National Access Criteria for Specialist Clinical Priority Assessment

General comments and directions

- These criteria do not apply to acute admissions, nor to surgery directly purchased by ACC.
- All sections of the form should be completed including particulars of diagnosis, procedure intended and the outcome of the assessment.
- Select one score only from each category from the options provided.
- The score should be calculated during the consultation, and the patient informed of their eligibility or otherwise for publicly funded treatment. This may occur during the first consultation or it may be in a follow-up consultation after investigations have assisted with establishing a diagnosis (eg CT scans).
- If there is a conflict between generally accepted clinical practice and the decision made by comparing a patient's criteria score to the threshold, then generally accepted clinical practice should prevail. Do not adjust the total score but make comment in the box provided as to the reasons why the clinician considers that this patient is an exception. This must be clear so that hospital administrative staff are aware that the clinician has over-riden the threshold score and will book the patient in for surgery. It is expected that the number of exceptions will be very small and these exceptions may be audited from time to time.

More than one procedure

Where two or more related procedures are contemplated at the same session (for example, under the same anaesthetic) then the score should relate to the most significant procedure. If the procedures are unrelated then a separate score should be determined for each procedure.

Staged procedures

A treatment procedure may be staged over several months or years. For the purposes of the priority access scoring a related series of treatments should be considered as one event. Repeat scoring is not required.

Diagnostic investigations or procedures

Unless there is a specific scoring category that is relevant (for example 'suspicious of malignancy but unproven'), diagnostic investigations or diagnostic procedures should be scored as if the investigation will lead to the most likely unfavourable diagnosis. The patient will be scored again following diagnosis and before being booked for the definitive procedure.

SPECIFIC COMMENTS

Exclusions:

- These criteria only apply to elective and arranged admissions but not to acute admissions nor ACC purchased surgery.
- These criteria exclude standard operative investigations or treatment for infertility unless the surgery is required to enhance physical health (e.g. ovarian cysts, endometriosis – see separate criteria) undertaken at the secondary care level but excludes tertiary infertility services (including tertiary-level infertility investigations) (separate criteria).
- Sterilisations are excluded (separate criteria).
- Planned terminations of pregnancy are excluded, as various requirements and processes are prescribed by the Contraception, Sterilisation and Abortion Act 1977.

Clinician judgement for scoring, not patient self-scoring

Scoring should be based on the considered view of the clinician taking into account the patient's history, examination, results of investigations and the clinician's experience in treating like patients. This is particularly with respect to the scoring categories of 'degree of pain', 'functional impairment' and 'social participation'. It is not appropriate for patients to be asked to complete these scores, as the differentiation between patients can only occur from the clinician's experience of this patient compared to other patients in general, and so that the clinician can ensure that patient-reported pain levels, etc are consistent with the history and examination findings.

"Current Pathology" section

'No pathology' means conditions where surgery might be indicated although no pathological process is present. 'Benign' pathology and the other scoring options within this section mean abnormal function or structure. 'Premalignancy' includes CIN I - CIN III.

"Natural history" section

'Window of opportunity': For some conditions there is an optimum time of treatment. If treatment is delayed the benefits of the procedure will substantially diminish or be lost altogether, or the potential for malignancy or another major complication is greatly increased. It is felt that such clinical situations should be afforded a higher priority.

"Degree of pain" section

(Refer 'clinician judgement' above.)

"Functional impairment" section

(Refer 'clinician judgement' above.)

Where relevant, this may include the impact on parents, guardians or caregivers of children and dependent patients.

"Social participation" section

This should be taken from the perspective of both the individual patient's situation and ability as well as what is relevant to the patient's age, gender, etc. Wide consideration may be given to the patient's situation, including, for example, the ability to work or carry out usual activities, live independently, undertake recreational activities, give care to dependents. For children, it is important that this should include the ability to participate in appropriate educational activities. (Refer 'clinician judgement' above.)

"Effectiveness of procedure/investigation" section

Diagnostic procedures/investigations are assumed to be fully effective. The effectiveness of therapeutic procedures should be based on the usual effectiveness of that procedure taking into account anything of direct relevance to the particular patient that would increase or reduce that effectiveness.

GYNAECOLOGY

National Clinical Priority Assessment Criteria (CPAC) for Treatment

GENERAL GYNAECOLOGY

Patient ID: Complete patient details or place patient sticker here

Nat. Hospital No.: _____

Consultant: _____

Name: _____ D.O.B. ___/___/___

Address: _____

Name of Assessor:

Date of Assessment: ___/___/___

Diagnosis:

Procedure:

Current pathology

Malignancy proven	40
Suspicious of malignancy, but unproven	35
Premalignancy	30
Benign	10
No pathology	0

Natural history of the potential/actual problem

Likely to progress to major complication/ window of opportunity	15
Likely to continue to deteriorate	10
Likely to remain stable	5
Likely to improve in the short term	0

Degree of Pain

Severe (dominates life and regularly interferes with sleep)	10
Moderate (persistent pain causing modification to aspects of daily living)	6
Intermittent	4
Minimal or no pain	0

Functional impairment - disturbance in patient's life including sexual function

Major disturbance	15
Moderate disturbance	10
Minor disturbance	5
No disturbance	0

Social participation

Immediately threatened	10
Threatened but not immediately	6
Not threatened but more difficult	4
Not threatened or difficult	0

Effectiveness of therapeutic procedure/ diagnostic investigation

Diagnostic investigation or very effective therapeutic procedure	10
Moderately effective therapeutic procedure	5
Therapeutic procedure of low effectiveness	0

COMMENTS

TOTAL

GYNAECOLOGY

National Clinical Priority Assessment Criteria (CPAC) Sterilisation Procedures

Patient ID: Complete patient details or place patient sticker here

Nat. Hospital No.: _____

Consultant: _____

Name: _____ D.O.B. ___/___/___

Address: _____

Name of Assessor:

Date of Assessment: ___/___/___

Age of female

30 years or younger	5
31 -35 years	10
36 years or older	15

Number of live children

0	0
1 - 3	5
More than 3	10

Unplanned pregnancies

Nil	0
1	10
2	15
3 or more	20

User contraception

No contraception difficulty	0
User contraception difficult (irrespective of cause)	25

Medical History: Health risk impact due to potential pregnancy

No identified health risk	0
Health problems that increase health risk during pregnancy	
(mild)	10
(moderate)	20
(severe)	30

COMMENTS

TOTAL



GYNAECOLOGY

National Guidelines for using the National Sterilisation Clinical Priority Assessment Criteria (CPAC)

General comments and directions

- These sterilisation criteria apply to both female and male sterilization. In the case of male sterilisation the female partners age, user contraception and medical history are to be considered.
- All sections of the form should be completed including particulars of diagnosis, procedure intended and the outcome of the assessment.
- Select one score only from each category from the options provided.
- The score should be calculated during the consultation, and the patient informed of their eligibility or otherwise for publicly funded treatment.
- If there is a conflict between generally accepted clinical practice and the decision made by comparing a patient's criteria score to the threshold, then generally accepted clinical practice should prevail. Do not adjust the total score but make comment in the box provided as to the reasons why the clinician considers that this patient is an exception. This must be clear so that CHE administrative staff are aware that the clinician has over-ridden the threshold score and will book the patient in for surgery. It is expected that the number of exceptions will be very small and these exceptions may be audited from time to time.

More than one procedure

Where two or more *related* procedures are contemplated at the same session (for example, under the same anaesthetic) then the score should relate to the most significant procedure. If the procedures are unrelated then a separate score should be determined for each procedure.

“User contraception” section

User contraception difficulty is irrespective of cause and may, for example, relate to:

- either the woman or her partner
- inability to use other forms of contraception
- unsuitability of other forms of contraception
- adverse reactions or allergies

GYNAECOLOGY / INFERTILITY

National Specialist Guidelines for Investigation of Infertility.

Priority Criteria for Access to Public Funding of Infertility Treatment

In 1997/98 the publication of the National Health Committee's consultation document "Access to infertility services: development of priority criteria" received numerous public and professional submissions, almost all being in favour of the general principles that fair and equitable access to publicly funded could be achieved by these criteria. These criteria have been tested in at least 2 NZ tertiary centres and with minor modifications the original proposal is being presented to the HFA to introduce to the NZ Health system.

This document is not about directing therapy. It is about guiding the evaluation of the infertile couple to achieve a standardised diagnosis and then providing a rationing basis for public access for treatment, especially using the assisted reproductive techniques. It is intended to benefit those who are most in need for therapy, but balanced by a system that will ensure maximum benefit. The actual level of access will be dictated by the proportion of public funds available for treating infertility. Evaluation of the pilot application of these criteria for IVF funding have, however, confirmed the view that infertility services are severely underfunded. We see these criteria as an essential step in establishing the level of funding needed for infertility treatment and request that Health Practitioners, working with them, use the criteria with diligence and honesty. Already the HFA have declared its support by providing significant funding to assist in clearing the waiting lists for Assisted Reproduction.

We emphasize that the application of the criteria and their weighting is just the beginning. These criteria need to be validated by ongoing research and public discussion.

Wayne R Gillett, John Peek, July 1999

GYNAECOLOGY / INFERTILITY

SECTION 1

Investigation and Diagnosis – a Standardised Approach

Investigation in Primary Care

Refer to National Referral Recommendations: Gynaecology; Infertility

Investigation in Secondary Care

As for primary care. In addition:

- A post-coital test may be used in the early investigation of a referred couple, but the results should be interpreted with caution. Performance of this test is not essential to complete the diagnostic categorisation of the couple (see diagnostic categories).
- Screening for antisperm antibodies is not a routine test, but is suggested when there is a history of testicular trauma or vasectomy reversal. Performance of this test is not essential to complete the diagnostic categorisation of the couple.
- Sperm function tests and sperm assessment procedures (e.g. swim-up tests) should not be used in secondary care practice. They may be of value in helping a couple choose an appropriate ART in a tertiary level service.
- A hysterosalpingogram may be used to test tubal patency. Laparoscopy is the gold standard test for tubo-peritoneal disease and is the preferred method, especially when evaluation of the pelvis is required. If there is a severe semen defect (score of 6, see next page) then there is no need for laparoscopy unless indicated for other gynaecological reasons (or following failed DI treatment). Furthermore for ovarian defects, a trial of therapy is indicated before laparoscopy is considered. Otherwise laparoscopy should be booked within 6 months in the following circumstances:
 1. severe cyclical pain or suspected pelvic pathology
 2. infertility of 18 months duration and where there is a female history of any pelvic surgery, STDs or PID
 3. infertility of 18 months duration and a female age \geq 30 years of age
 4. otherwise unexplained infertility \geq 3 years duration
 5. failed DI or ovulation induction (3-6 cycles of treatment)

Diagnostic categories – to be completed at the secondary (specialist) level

The diagnostic model given here recognises the importance of the severity of a diagnosis and a combination of infertility factors on the probability of a successful outcome without treatment. To define the prognosis calculate the points for each diagnostic category 1,2,3,4,5 and 6.

GYNAECOLOGY / INFERTILITY

Patient ID: Complete patient details or place patient sticker here _____

Nat. Hospital No.: _____

Consultant: _____

Name: _____ D.O.B. ____/____/____

Address: _____

Name of Assessor: _____

Date of Assessment: ____/____/____

Initial Assessment

(1) Ovulation Defects	Categories	
From history, including <ul style="list-style-type: none"> a plasma progesterone timed for 5-9 days before the next expected period. If cycle is long to be repeated at weekly intervals until next period plasma FSH, LH, prolactin, thyroid function if the cycle is prolonged and/or irregular. FSH (day 2-5 cycle) for older women (is measure of biological age of ovary). 	amenorrhoea - any cause	6
	oligomenorrhoea from any cause / luteal defect	3
	anovulation with normal menstrual cycle	2
	intermittent anovular cycles	1
	no ovulation defect	0
	SCORE 1	

(2) Semen Defects	Categories	
Semen sample collected after 2-3 days abstinence. To be repeated in 4-6 weeks if abnormal. The measurement of antisperm antibodies, post coital test or other sperm function tests are not essential for this category, but may be included as indicated	<1 million motile sperm/ml / severe ejaculatory dysfunction / severe sperm antibodies	6
	1 < 5 million motile sperm /ml / moderate antibodies / repeat negative PCT or sperm function abnormality	3
	5-10 million motile sperm/ml	2
	Any other semen defect	1
	No semen defect	0
	SCORE 2	

To be completed following laparoscopy

(3) Endometriosis	Categories	
The American Fertility Society Classification (American Society for Reproductive Medicine 1997). This requires direct visualization by laparoscopy. Surgical treatment at the time of diagnosis will be at the discretion of the gynaecologist conducting the procedure, depending on the common practice of the clinic.	stage IV AFS classification	6
	stage III AFS classification	3
	stage II AFS classification	2
	stage I AFS classification	1
	No endometriosis	0
	SCORE 3	

(4) Other Tubo-peritoneal Disease	Categories	
<p>Although classification can be based on experience of examining specialist, we encourage the use of the American Fertility Society classification of adnexal adhesions (1988). In many cases the pathology may be different on each side. The adnexa with the least pathology should be used (best side).</p> <p>Surgical treatment at the time of diagnosis will be at the discretion of the gynaecologist conducting the procedure, depending on the common practice of the clinic.</p>	Proximal or distal (complete or partial) occlusion on best-side / severe encapsulating tubal or ovarian adhesions on best-side, / missing tubes / or unsuccessful proximal or distal surgery after 12 months	6
	Moderate encapsulating tubal or ovarian adhesions on best-side adnexa / unsuccessful surgery after 6 months	3
	tubal polyps / mild encapsulating adhesions on best-side or / normal tube on best-side with tubal occlusion on the other-side or uterine adhesions	2
	minimal tubal or ovarian adhesions on best-side adnexa	1
	No tubo-peritoneal pathology	0
	SCORE 4	<input type="text"/>

(5) Other Factors	Categories	
<p>These should be classified at discretion of specialist, e.g.</p> <ul style="list-style-type: none"> psycho-sexual disorders fibroids intrauterine pathology 	severe	6
	moderate	3
	mild	2
	minimal	1
	absent	0
	SCORE 5	<input type="text"/>

No diagnosis abnormality identified, i.e. unexplained infertility

(6) Unexplained Infertility	Categories	
<p>If no diagnostic abnormality then define the duration of the unexplained infertility</p>	Unexplained infertility \geq 5 years	6
	Unexplained infertility \geq 4 < 5 years	3
	Unexplained infertility \geq 3 years < 4 years	2
	Unexplained infertility < 3 years	1
	SCORE 6	<input type="text"/>

Final Score for Diagnosis

Add scores 1,2,3,4,5,6 = Score D

SECTION 2

Access to Publicly Funded Treatment

A General Principles:

1. Provision of basic support and guidance at the primary level should be subject to normal primary care charging
2. Simple ovulation induction may be managed by the GP in consultation with a specialist service.
3. Simple conditions requiring medical or psychological therapy should be provided within the primary or secondary services without need for access criteria
3. Conditions with organic disease requiring surgery to enhance physical health (e.g. ovarian cysts, endometriosis) should be subject to the same criteria as for Gynaecology access criteria
4. Conditions that can be managed equally as well with ART or surgery (e.g. tubal occlusion) should be subject to access criteria for infertility. These treatments include AIH, IVF, IVF and ICSI, DI, ovulation induction using gonadotrophins (\pm AIH). The treatment available per individual couple should be directed by the specialist in charge of the individual / couples infertility and in consultation with that individual / couple. The cumulative amount of treatment available to people will depend on public funding available.

B Steps in defining access criteria

1. Exclusion factors for access to treatment

The first is absolute - with access refused if there are situations that compromise the safety of the couple or a child. However no factor may be used that is unlawful and that might breach the Human Rights Act or the Bill of Rights Act. Ultimately it will be the doctor, practicing at a primary, secondary or tertiary level, who will decide - and that doctor would need to defend this decision.

2. Modifying factors for access to treatment

These are conditions that can be modified to improve the chance of conception:

- Hydrosalpinges

Complete distal tubal occlusion, or the hydrosalpinx, accumulates tubal fluid that may drain into the uterine cavity giving a detrimental effect on pregnancy rates with IVF. Depending on the severity of the tubal disease, either salpingostomy or salpingectomy should be performed in women planning entry into an IVF programme. The surgery should be performed by specialists trained in microsurgery or laparoscopic surgery. Each main centre in New Zealand has such specialists.

- Body weight

Weight improvement programmes should be instituted before beginning treatment in women who are outside the BMI range of 18-32. There are factors that limit the success of weight improvement, and in this circumstance it is reasonable to proceed with treatment providing the ovarian response is closely monitored. Treatment should only continue if the response is satisfactory.

GYNAECOLOGY / INFERTILITY

3. Calculation of the Priority Score

Each of the following criteria should be recorded following diagnosis and request for therapy, and modified on an annual basis. For example, June 1 of each year may be regarded as the 'annual' date of revision, since new HFA funding rounds follow on July 1. Simple spreadsheet programmes are available that can recalculate a priority score, simply by adding a new date. Copy of programme available from Wayne Gillett, Dept. O&G PO Box 913.

The final score is the product of a group of objective factors (O1 – O4) and a group of social (subjective) factors (S1 – S3). Points for each of the objective factors are directly proportional to the pregnancy rate. Points for the subjective factors were derived from the results of questionnaires returned by health professionals and consumers.

- The age of the female partner

The weighting of the points reflects the probability of conceiving with therapy.

- The prognosis of conceiving without treatment

See section I for calculation of diagnostic scores.

If Score D = 6 then prognosis < 5% probability of conception in 1 year

If score D = 3 < 6 then prognosis 6 - 20 % probability of conception in 1 year

If Score D = 2 < 3 then prognosis 21-50% probability of conception in 1 year

If Score D < 2 then prognosis >50% probability of conception in 1 year

The weighting of these points reflect the inverse relationship of the likelihood of conceiving

- **The basal plasma FSH**

Ovarian reserve is commonly measured by basal FSH levels between days 2-5 of the menstrual cycle. The normal range will depend on the local assay. The weighting of points reflect the chance of conceiving. If donor oocytes are used in an IVF programme, the donor's FSH level should be measured. FSH should be measured within 6 months before the first planned ART cycle, and repeated at least every 6 months. The normal value be ≤ 12 IU; borderline be $>12 \leq 15$; and abnormal be >15 .

- **A history of current smoking in female partner**

The point system reflects the relative risk on pregnancy outcome of smoking.

Although this will become a priority factor we envisage most women, by stopping smoking, will increase their priority points after 6 months and improve their eligibility depending on the threshold for access to treatment. We believe every effort should be made by women seeking any form of fertility treatment to give up smoking. Duration of smoke free to be three months and no cigarettes at all.

- **Duration of infertility**

The points given here relate to how people feel about the burden of the duration of infertility, rather than how it affects the chance of pregnancy. The duration of infertility to cumulative of previous and current relationships. For single women or lesbians it will be on the basis of either biological infertility or in the case of unexplained infertility to be confirmed by 12 cycles of DI of which 6 should be within an accredited RTAC unit.

- **Number of children**

A child may include an adopted child. These are children currently living with the couple or person.

- **Previous sterilisation**

The points given here recognise the burden of some people never having had children, or the burden of having lost a child (children) by death.

GYNAECOLOGY / INFERTILITY

National Clinical Assessment Criteria (CPAC) for Treatment of Infertility

Patient ID: Complete patient details or place patient sticker here

Nat. Hospital No.: _____

Consultant: _____

Name: _____ D.O.B. ___/___/___

Address: _____

Name of Assessor: _____

Date of Assessment: ___/___/___

Calculation of priority criteria points for publicly-funded infertility treatment

Criteria symbol	Points awarded	Criteria and their categories	Points available
01	<input type="text"/>	Chance of pregnancy without treatment	≤ 5% 10
			6-20% 7
			21-50% 4
			>50% 2
02	<input type="text"/>	Woman's age	≤ 39 years 10
			40-41 5
			42+ 1
03	<input type="text"/>	Basal FSH, day 2-5 cycle, with respect to reference range	always within 10
			sometimes above 8
			mostly/always above 2
04	<input type="text"/>	Woman's smoking	non smoker 10
			smoker 6
Multiply O1 x O2 x O3 x O4 = OC (points from objective criteria)			
=	<input type="text" value="OC"/>	Now divide OC by 10000 = Revised OC (ROC)	<input type="text" value="ROC"/>
S1	<input type="text"/>	Duration of infertility	< 1 year 5
			1<3 year 20
			3<5 years 40
			≥ 5 years 50
S2	<input type="text"/>	Number of children	None 30
			1 by current relationship 10
			> 1 by current relationship 5
			≥ 1 child by prev relationship 8
S3	<input type="text"/>	Sterilisation reference range	neither partner sterilised 20
			death of child 20
			one partner sterilised 10
Sum S1 + S2 + S3 = SC (points from social criteria)			= <input type="text" value="SC"/>
Multiply ROC x SC = Priority Score (PS)			= <input type="text" value="PS"/>

Appendix L:

Health Funding Authority

Service Specifications

SERVICE SPECIFICATION

SERVICE CODE : ASSISTED OR ARTIFICIAL REPRODUCTIVE TECHNOLOGY SERVICE

1. DEFINITION

The Service will provide a range of **tertiary** treatment services for people experiencing infertility. You will also provide advice and information services and best practice guidelines on fertility issues for primary and secondary services.

The service you provide covers Assisted Reproductive Technologies (ART) including:

- In Vitro Fertilisation (IVF)
- Intrauterine Insemination (IUI) including hyperstimulation
- Intracytoplasmic Sperm Injection (ICSI) including the sperm retrieval techniques of
 - Percutaneous Epididymal Sperm Aspiration (PESA)
 - Testicular Sperm Extraction (TESE)
 - Microsurgical Epididymal Sperm Aspiration (MESA)
- Donor Insemination (DI)
- Ovulation Induction with gonadotrophins
- First and follow-up consultations tertiary consultation
- Tertiary level investigations for diagnosis e.g. tests of sperm function to decide between IVF and ICSI.
- Social work & counselling
- Long term storage of gametes for oncology

Indication for Assisted Reproductive Technologies (ART) will be guided by the clinical priority assessment criteria (CPAC) access threshold

This service is closely related to but distinct from:

Gynaecology services including secondary fertility services
 Sexual health services
 Urology services
 Surgical services
 Endocrinology services
 Genetic services

which are covered by separate service specifications.

2. SERVICE OBJECTIVES

2.1 *General*

You will adhere to the guidelines for infertility services:

- a) the ART services you provide are the most appropriate treatment for the person.
- b) each couple will be treated as a unit
- c) the services should be available to all people with biological infertility, including those whose fertility is or will be impaired by cancer treatment or injury

2.2 Maori Health

The Treaty of Waitangi establishes the unique and special relationship between Iwi, Maori and the Crown. As a Crown agency, the health Funding authority considers the Treaty of Waitangi's principles of partnership, proactive protection of Maori health interests, co-operation and utmost good faith, to be implicit conditions of the nature in which the internal organisation of the Health Funding Authority responds to Maori health issues.

You agree that Maori health is a specifically identified health gain priority area. You must therefore establish and implement a Maori health policy that reflects that fact. In developing this policy, and without limitation, you must take into account our strategic direction for Maori health in terms of minimum requirements for Maori health based on the Treaty of Waitangi, Crown objectives for Maori health and specific requirements negotiated from time to time with us.

You must specify how you intend to implement this policy. In particular, you will identify how these services will be measured to ascertain what benefit is evident and any other additional opportunities that may exist for furthering Maori health gain.

The plan will be available within 3 months of the implementation of the service specifications

3. SERVICE USERS

Eligible people are those who are unable to achieve pregnancy after at least one year of unprotected intercourse of attempting, or have biological circumstances which prevent them from attempting, or are unable to carry a pregnancy to term..

4. ACCESS

4.1 Entry and Exit Criteria

You will provide this service in accordance to the referral guidelines (RG's), access criteria for first specialist assessment (ACA) and clinical priority assessment criteria (CPAC)

4.1.1 Boundaries to treatment

You will apply the following boundaries to the service:

- a) treatment should normally be commenced within 6 months of it being offered.
- b) treatment must normally be completed within 18 months of starting first cycle
- c) frozen embryos should normally be used where practical from the first OPU cycle to commencing a second OPU cycle. Couples will be expected to pay for storage after 18 months of first storage
- d) further IVF funded by the provider can be declined if ovarian response was poor – namely if when using 300 IU gonadotrophin per day there were three follicles or fewer or the maximum blood estradiol level was less than 3000 pmol/l -
- e) IVF treatments will be available for a maximum of one cancelled and/or incomplete cycle and one completed cycle¹ per couple

4.1.2 Co-payments

You will not charge a co-payment for any public services provided under this service specification except for 4.1.c above or where a couple elect to have services beyond those covered by this contract.

¹ A completed cycle is defined as one that goes to embryo transfer and/or freeze transfer
A cancelled or incomplete cycle is one that does not result in a transfer

4.2 DISTANCE

Patients shall be eligible for transport and accommodation expenses as per the current HFA guidelines.

5. SERVICE COMPONENTS OF TERTIARY INFERTILITY

SERVICE COMPONENT	DESCRIPTION
Initial assessment by an appropriately qualified clinician and development of a treatment plan	<p>This includes:</p> <ol style="list-style-type: none"> 1. Initial assessment by the specialist 2. Confirmation that the patients meet the access criteria and are suitable for ART treatment 3. Referral of patients who do not meet criteria or are unsuitable back to the referring clinician and explanation of the reasons to the patients/whanau 4. Primary and secondary investigations have been completed as per national referral guidelines. 5. Discussion of ART treatment and management plan with patients/family/whanau as appropriate, including expectation, possible risks, after care arrangements, expected waiting time to receive treatment (essential information to be supplied in writing) 6. Written consent obtained for treatment procedures and anaesthesia 7. (If appropriate) pre-operative referral to the appropriate anaesthetist for anaesthetic management during treatment and respiratory and pain management post treatment
Peri-treatment care	<p>This includes:</p> <ol style="list-style-type: none"> 1. Preparation and treatment of the women for ART procedures, including preparation counselling 2. The service in this phase includes all counselling by medical, nursing, social work and scientific staff, including laboratory tests and radiology services 3. Pharmaceuticals required to be administered at the time of each

	<p>treatment</p> <ol style="list-style-type: none"> 4. All necessary ultrasound scans and blood tests after instituting this service phase 5. Oocyte pick up 6. Insemination and Embryo replacement 7. Embryo freezing per cycle (as appropriate) 8. Immediate post treatment recovery including medical, nursing and other technical services as required
Post-treatment care	<p>Managed care including:</p> <ol style="list-style-type: none"> 1. Immediate response to emergencies 2. Pain control 3. Prevention and management of post-treatment complications 4. Professional clinical services including medical, nursing, counselling and other professional and technical support services as required 5. Discharge as soon as it is appropriate and with a written discharge summary and care plan to be provided to the patient, specialist and general practitioner 6. Patients are familiar with their current medication and can address any concerns before leaving clinic/hospital or arrangements are made with the patient's general practitioner for this to occur
Provision of consumable supplies while in clinic/hospital	<p>This includes, but is not limited to anaesthetic agents and other pharmaceuticals and disposable equipment</p>
Clinical follow-up	<p>This includes:</p> <ol style="list-style-type: none"> 1. Specialist assessment of treatment effects and further treatment requirements 2. One follow-up appointment or more if clinically required 3. Review clinic 3-4 months post ART or as indicated. 4. Early pregnancy assessment (ante-natally up to 12 weeks, then referred on)
Consultation and education services	<ol style="list-style-type: none"> 1. Educative services are provided

	<p>to general practitioners and other specialists concerning appropriate referral protocols and indications for ART</p> <p>2. Consultation and advisory services are provided to general practitioners and other specialists concerning the condition and ongoing management of the referred couples</p>
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5.3 Settings

The place where the service is provided will be an inpatient or day case setting.

5.4 Service Levels

You will provide this service at a tertiary level

5.5 Equipment

You will have access to equipment appropriate to operate a Reproductive Technology Accreditation Committee (RTAC) accredited laboratory

5.6 Support Services

You will provide the following support services;

5.6.1 Clinical support services – You will provide or have access to the following services as clinically required:

- operating theatre and anaesthetic services
- laboratory
- pharmacy
- radiology - ultrasound
- sterile supply

5.6.2. Consumer registration service

You will maintain complete and accurate records identifying consumers, donors and recipients of all gametes involved in fertilisation and embryo formation and detailing the use or disposal of all gametes and embryos.

You will maintain an information system which allows for consumer follow-up and confidentiality within accepted guidelines and lawful requirements. You will be cognisant of Maori requirements around guardianship of personal information and practise these rigorously.

5.6.3. You will provide a specialised scientific and laboratory services including storage, analysis and programme implementation.

5.7 Facilities

You will provide commercial support services including:

- inpatient and outpatient facilities, including furnishings, fittings, equipment, lighting, heating and other amenities
- laundry services
- catering
- cleaning

5.8 Key Inputs

Counselling

You will provide a counselling service to address the social and psychological effects of undergoing infertility treatments as well as other options such as adoption or living without children to all eligible couples. You will ensure that, where appropriate, the special needs of Maori will be accommodated. This may include involvement of whanau in counselling sessions.

You will ensure that you have access to cultural advice including that received from Maori advocates, Maori providers, and Kaumatua support where that is identified by the client/whanau.

6. SERVICE LINKAGES

Associated Services

You should provide the following support services in providing infertility services:

- a) pathology services
- b) radiology services
- c) operating services
- d) anaesthetic services
- e) pharmacy services

You will ensure links are established and maintained with:

- a) primary health services, including health education
- b) general practitioners
- c) secondary and tertiary medical services
- d) general surgical services
- e) community support groups including NZ Infertility Society
- f) Maori health providers

You are to have effective links and continuity of care with the following services:

- Community groups including the Infertility Society
- Research units
- Ethics Committees

And continuity of care with:

- Primary health services including General Practice, Family Planning Association, New Zealand Association of Natural Family Planning, Sexual Health Clinics, Maori and Pacific Island providers, maternity providers
- Secondary medical and surgical services, especially gynaecology and urology

7. EXCLUSIONS

- You will follow the CPAC guidelines and any further changes

- ACC claimants

8. QUALITY REQUIREMENTS

All specialists undertaking the procedures are registered as medical specialists in the relevant medical or surgical discipline and have specialised training and experience in ART.

The service has current accreditation by the Reproductive Technology Accreditation Committee (RTAC).

All anaesthetists undertaking the procedures are registered as specialist anaesthetists.

All other professional staff providing the service must hold a current practising certificate applicable to their profession.

Health professionals holding current practising certificates will supervise all health professionals under training programmes, who do not yet hold current practising certificates.

Laboratory services (or as applicable, individual pathology departments) are registered or working towards registration with IANZ or an equivalent accreditation programme.

Ethical review and advice is obtained from an accredited Ethics Committee of the Health Funding Authority for research and experimental treatments, in accordance with the national standards for Ethics Committees.

8.1 General

You will aim to minimise complications of treatment, including hyperstimulation syndrome, infections, multiple pregnancy and babies needing neonatal intensive care. This means careful consideration of the number of embryos transferred in IVF and of the degree of ovarian stimulation in all treatments.

8.2 Access

You will provide General Practitioners and relevant Specialists with information about the services provided in this contract, including eligibility. You will be available to answer queries about the service from doctors and the public.

Once referred for consultation, you will see new patients within a specified time, to be agreed on between the provider and the HFA.

You will identify and remedy any barriers to access by Maori, and obtain Maori opinion about the service.

8.3 Acceptability

- a) You will undertake customers surveys, and change the delivery of the service according to the feedback received.
- b) You will ensure Maori views are heard, and that Maori participate in planning, delivery and monitoring the service.
- c) You will provide a private and confidential service, and have a named privacy officer to monitor performance and answer any complaints. Privacy issues include those of gamete and embryo donors, and children conceived using donated gametes and embryos.

- d) You will ensure all patients understand the diagnosis and treatment they are undertaking through the provision of written and verbal information in plain language, and the availability of interpreters.
- e) You will ensure informed consent is obtained before any treatment or investigation is started, and that all consent for treatments involving gametes and embryos is written.
- f) You will ensure that all services are co-ordinated from the perspective of the patient. You will help patients accept their infertility when treatment is not available, not chosen, or does not lead to pregnancy. Patients should feel they have achieved the best outcome in the circumstances.
- g) You will promote awareness of infertility, its prevention, and the minimisation of its impact among the general public.

8.4 Efficiency

You will ensure that the services in this contract are delivered within the contract price and that services are equally distributed over each individual year.

8.5 Safety

- a) You will ensure that the clinic is accredited by the Reproductive Technology Accreditation Committee of Australia.
- b) You will comply with all relevant legislation, regulations, statutory requirements, and guidelines from professional bodies.
- c) You will have risk management procedures in place, including for infection control, medical emergencies, and failure of key equipment.
- d) You will have procedures in place to report incidents, accidents, and error, and procedures to remedy these.
- e) You will ensure staff have training and experience in ART, and registration, occupation licenses or certificates appropriate to their job. Staff who do not have registration or certification will be supervised by staff who do.
- f) Laboratory services will be registered, or working towards registration, with IANZ or an equivalent accreditation programme.
- g) You will ensure ethical review and advice for new treatment and for research is obtained from the National Ethics Committee on Assisted Reproductive Technology, or its successor.
- h) You will have written policies outlining the storage, usage and disposal of all body tissues during and after procedures, and policies relating to ethical considerations for the use of donor ovum and sperm. This will include culturally appropriate policies which addresses the needs of Maori
- i) You will have quality improvement systems for clinical practice.
- j) You will ensure that referring doctors provide sufficient information about the patients being referred.

You will endeavour to maximise the chance of pregnancy, while controlling the incidence of untoward consequences.

8.6 Facilities

- a) Your facilities are accessible to consumer irrespective of age, physical or mental disability or any other factor. Facilities for clients with a disability are clearly sign posted.
- b) A family/whanau room is provided within your facility for the family/whanau of clients.
- c) Facilities are maintained in hygienic and orderly condition suited to their purpose.
- d) All reasonable steps are taken to ensure that all buildings and equipment are secure, waste management programmes are implemented, and the safety of patients/couples, staff and visitors is assured.

9 PURCHASE UNITS

9.1 Tertiary Consultancy and Assessment of new couples

Service Category	Purchase Unit	Pricing Unit
First Specialist Assessment	Capacity	Consultation

9.2 Purchase Units and Reporting Requirements

The following table indicates the reporting requirements you will forward to us.

Service Category	Pricing Unit \$
First Specialist Assessment	175
IVF Programme	4,600
ISCI addition	954
IUI	779
DI	677
AIH simple	385
AIH + stimulation	779
Donor egg addition	1,208
Frozen embryo replacement	600
Ovulation induction	1,453
Surgical retrieval of sperm	500
Sperm freezing	100
Annual storage of sperm	115
Cancelled cycle	1,566
Incomplete cycle	4,300

Definition:

Cancelled cycle - terminated prior to gonadotrophins – day 7

Incomplete cycle – no embryo transfer – usually failed fertilisation

8 REPORTING REQUIREMENTS

The following information is to be reported **quarterly** to us:

Service Category	Age < 37 years	Age 38-39 years	Age >40 years	Ethnicity Other	Maori	Pacific Island	Asian	NZ European	Other European
First Specialist Assessment									
IVF Programme									
ISCI addition									
IUI									
DI									
AIH simple									
AIH + stimulation									
Donor egg addition									
Frozen embryo replacement									
Ovulation induction									
unknown donor oocyte									
Surgical retrieval of sperm									
Sperm freezing									
Annual storage of sperm									
Cancelled cycle									
Incomplete cycle									

Annually you should report to us

- as per the RTAC report for services under this contract:
- Organisational plan for Maori including:
 - Maori consumer satisfaction
 - Services meet the needs of Maori
 - Maori participation
 - Quality plan
 - Support for Maori
 - Strategies to recruit and train Maori.
 - A narrative report outlining any issues potential service changes
- Supply data as requested for evaluation of the Fertility Referral & Assessment guidelines

And any other reports as requested.

10.2 Purchase Units

As per table above

10.2 Quality Measures

Clinical indicators

- In 100 consecutive cycles that no cycle is in a woman greater than 35 years of age, that third or more cycles are excluded. Using these guidelines a 15 % live birth rate per OPU is the minimum standard
- Embryo survival or live birth rate of frozen/thawed embryos
- Quality measures for IUI, DIUI,DI programmes
- Minimum targets for the clinic are live birth rates, in women aged 37 years or younger, of 15% per oocyte collection in IVF, 15% per insemination cycle in DI, 10% per insemination cycle in AIH with ovarian stimulation.

10.3 Service Planning Information

You will provide us, on request, the following information:

1. Summary of client characteristics
2. Waiting Times information

Appendix M: Contract

Variation to Agreement

between

Health Funding Authority

229 Moray Place
PO Box 5849
Dunedin
Ph: (03) 477 4222
Fax: (03) 474 0080

650 Great South Road
Private Bag 92-522, Wellesley St.
Auckland
Ph: (09) 580 9000
Fax: (09) 580 9001

Contact:

Tim Wood

and

FERTILITY ASSOCIATES LTD

MEDICAL TREATMENT FOR BIOLOGICAL INFERTILITY

Ascot Integrated Hospital
90 Greenlane Road
Private Bag 28910
Auckland

Ph: 09-520 9520 and Fax: 09-520 9521

Contact:

CONTENTS OF THIS AGREEMENT

Section A Summary

Section B Provider Specific Terms and Conditions

A : SUMMARY

A1 Definitions

- a) "we", "us", "our" means the Health Funding Authority (HFA)
- b) "you", "your" means Fertility Associates Ltd
- c) "either of us" means either we or you
- d) "both of us" means both we and you

A2 Existing Variation

In 1999 both of us entered into Variation 244574 / 156209/01 "the existing variation". This existing variation commenced on 01-Jul-1999 and ended on 30-Sep-1999. Any associated alternate Contract numbers are also listed 02240/00.

A3 This Variation

This Variation (244574 / 156209/02) extends the term and changes the price specified in the existing Variation (156209/01). This Variation begins on 01-Oct-1999 and ends on 30-Sep-2002.

A4 Section B

The attached Section B includes all of the adjustments to this Agreement as a result of this variation.

A5 Remainder of Agreement

The remaining terms and conditions of the Agreement are confirmed in all respects except for the variations as set out in this document.

A6 Signatures

Please confirm your acceptance of the Agreement by signing where indicated below.

For **Health Funding Authority:**

For **Fertility Associates Ltd:**

Name:

Name:

Position:

Position:

Date:

Date:

B : PROVIDER SPECIFIC TERMS AND CONDITIONS

B1 It is agreed that the following details apply to this Variation

Legal Entity Name	Fertility Associates Limited
Legal Entity Number	244574
Contract Number	F244574/156209-02
Variation Commencement Date	01-Oct-1999
Variation End Date	30-Sept-2002

B2 Details of all purchase units which apply to this Variation

Purchase Unit (PU ID)	Total Price excl. GST	GST Rate (%)	Payment Type
N-Fertil Fertility Services	\$3,160,227.00	12.5	SSSG
Total price for the Service Schedule	\$3,160,227.00		

B3 Payment Schedule

Payments will be made by us on these dates:	On invoices received by us on or before:	For services supplied in the period:	Amount (excl GST)
22 November 1999	31 October 1999	October 1999	\$87,784.08
20 December 1999	30 November 1999	November 1999	\$87,784.08
20 January 2000	31 December 1999	December 1999	\$87,784.08
21 February 2000	31 January 2000	January 2000	\$87,784.08
20 March 2000	29 February 2000	February 2000	\$87,784.08
20 April 2000	31 March 2000	March 2000	\$87,784.08
22 May 2000	30 April 2000	April 2000	\$87,784.08
20 June 2000	31 May 2000	May 2000	\$87,784.08
20 July 2000	30 June 2000	June 2000	\$87,784.08
21 August 2000	31 July 2000	July 2000	\$87,784.08
20 September 2000	31 August 2000	August 2000	\$87,784.08
20 October 2000	30 September 2000	September 2000	\$87,784.08
20 November 2000	31 October 2000	October 2000	\$87,784.08
20 December 2000	30 November 2000	November 2000	\$87,784.08
22 January 2001	31 December 2000	December 2000	\$87,784.08
20 February 2001	31 January 2001	January 2001	\$87,784.08
20 march 2001	28 February 2001	February 2001	\$87,784.08
20 april 2001	31 March 2001	March 2001	\$87,784.08
21 May 2001	30 April 2001	April 2001	\$87,784.08
20 June 2001	31 May 2001	May 2001	\$87,784.08
20 July 2001	30 June 2001	June 2001	\$87,784.08
20 August 2001	31 July 2001	July 2001	\$87,784.08
20 September 2001	31 August 2001	August 2001	\$87,784.08
22 October 2001	30 September 2001	September 2001	\$87,784.08
20 November 2001	31 October 2001	October 2001	\$87,784.08
20 December 2001	30 November 2001	November 2001	\$87,784.08
21 January 2002	31 December 2001	December 2001	\$87,784.08
20 February 2002	31 January 2002	January 2002	\$87,784.08
20 march 2002	28 February 2002	February 2002	\$87,784.08
22 April 2002	31 March 2002	March 2002	\$87,784.08
20 May 2002	30 April 2002	April 2002	\$87,784.08
20 June 2002	31 May 2002	May 2002	\$87,784.08
22 July 2002	30 June 2002	June 2002	\$87,784.08
20 August 2002	31 July 2002	July 2002	\$87,784.08
20 September 2002	31 August 2002	August 2002	\$87,784.08
21 October 2002	30 September 2002	September 2002	\$87,784.20
TOTAL			\$3,160,227.00

B4 SERVICE SPECIFICATION

SERVICE SPECIFICATION

SERVICE CODE ARTIFICIAL REPRODUCTIVE TECHNOLOGY SERVICE

1. The Service

You will provide a range of tertiary treatment services for couples experiencing infertility. You will also provide advice and information services and best practice guidelines on fertility issues for primary and secondary services.

The service you provide covers Artificial Reproductive Technologies (ART) including:

- In Vitro Fertilisation (IVF)
- Interuterine Insemination (IUI) including hyperstimulation
- Gamete Intrafallopian Transfer (GIFT)
- Intracytoplasmic Sperm Injection (ICSI) including the sperm retrieval techniques of
 - Percutaneous Epididymal Sperm Aspiration (PESA)
 - Testicular Sperm Extraction (TESE)
 - Microsurgical Epididymal Sperm Aspiration (MESA)
- Donor Insemination (DI)
- Any new techniques which we may approve
- First and follow-up consultations for tertiary infertility
- Tertiary level investigations for diagnosis
- Social work & counselling as part of consultation and treatment
- Distribution of Authorised Pharmaceuticals.

Indications for Artificial Reproductive Technologies (ART) include:

- Tubal damage (not consequent on tubal ligation)
- Male infertility (not consequent on vasectomy)
- Unexplained infertility (more than three years duration)
- Ovulatory disorders

This service is closely related to but distinct from:

- Gynaecology services
- Sexual health services
- Urology services
- Surgical services
- Endocrinology services
- Genetic services

which are covered by separate service specifications.

2. Service Objectives

2.1 General

You will provide infertility services to the levels specified in section 9.

You will adhere to the guidelines for infertility services:

- a) the ART services you provide are the most appropriate treatment for the couple.
- b) each couple will be treated as a unit
- c) the services should be available to all people with biological infertility, including those whose fertility is or will be impaired by cancer treatment or injury.

2.2 Maori Health

The Treaty of Waitangi establishes the unique and special relationship between Iwi, Maori and the Crown. As a Crown agency, the Health Funding Authority considers the Treaty of Waitangi's principles of partnership, proactive protection of Maori health interests, co-operation and utmost good faith, to be implicit conditions of the nature in which the internal organisation of the Health Funding Authority responds to Maori health issues.

You agree that Maori health is a specifically identified health gain priority area. You must therefore establish and implement a Maori health policy that reflects that fact. In developing this policy, and without limitation, you must take into account our strategic direction for Maori health in terms of minimum requirements for Maori health based on the Treaty of Waitangi, Crown objectives for Maori health and specific requirements negotiated from time to time with us.

You must specify how you intend to implement this policy. In particular, you will identify how these services will be measured to ascertain what benefit is evident and any other additional opportunities that may exist for furthering Maori health gain.

3. SERVICE USERS

Eligible people are those who are unable to achieve pregnancy after at least one year of trying, or have biological circumstances which prevent them from trying, or are unable to carry a pregnancy to term. Earlier referral is appropriate when the preliminary investigations show absolute or very severe factors, such as azoospermia or bilateral tubal disease.

4. Access

4.1 Entry and Exit Criteria

You will provide this service in accordance to the referral guidelines (RG's), access criteria for first specialist assessment (ACA) and clinical priority assessment criteria (CPAC) for treatment.

You will provide this service in accordance with any nationally agreed criteria, when such criteria are supplied to you by the HFA.

You will distribute Authorised Pharmaceuticals in accordance with the eligibility criteria issued by Pharmac .

4.1.1 Boundaries to treatment:

You will apply the following boundaries to the service:

- a) treatment should normally be taken up within 12 months of it being offered, or within three months if the women are 37 years or older
- b) treatment must normally be completed within 18 months of starting first cycle
- c) frozen embryos should normally be used within nine months of the last IVF cycle. Couples may be expected to pay for storage or any further treatment privately outside these limits or following an ongoing pregnancy
- d) further IVF funded by the provider can be declined if ovarian response was poor – namely if when using 225 IU gonadotrophin per day there were three eggs or fewer or the maximum blood estradiol level was less than 4000 umol/l
- e) IVF treatments will be available for a maximum of one cycle per couple

4.1.2 Co-payments

You will not charge a co-payment for any public services provided under this service specification except for 4.1.c above or where a couple elect to have services beyond those covered by this contract.

4.2 Distance

Patients shall be eligible for transport and accommodation expenses using the current HFA guidelines, with expenses to be paid from this contract.

5. SERVICE COMPONENTS

5.1

SERVICE COMPONENT	DESCRIPTION
5.1.1 Initial assessment by an appropriately qualified clinician and development of a treatment plan	This includes: <ol style="list-style-type: none"> 1. Initial assessment by the specialist 2. Confirmation that the patients meet the access criteria and are suitable for ART treatment 3. Referral of patients who do not meet criteria or are unsuitable back to the referring clinician and explanation of the reasons to the patients/whanau 4. Discussion of ART treatment and management plan with patients/family/whanau as appropriate, including expectation, possible risks, after care arrangements, expected waiting time to receive treatment (essential information to be supplied in writing) 5. Written consent obtained for treatment procedures and anaesthesia 6. (If appropriate) pre-operative referral to the appropriate anaesthetist for anaesthetic management during treatment and respiratory and pain management post treatment
5.1.2 Peri-treatment care	This includes: <ol style="list-style-type: none"> 1. Preparation and treatment of the women for ART procedures, including preparation counselling 2. The service in this phase includes all counselling by medical, nursing, social work and scientific staff, including laboratory tests and radiology services

	<ol style="list-style-type: none"> 3. Pharmaceuticals required to be administered at the time of each treatment 4. All necessary ultrasound scans and blood tests after instituting this service phase 5. Oocyte pick up 6. Insemination and Embryo replacement 7. Embryo freezing per cycle (as appropriate) 8. Immediate post treatment recovery including medical, nursing and other technical services as required
<p>5.1.3 Post-treatment care</p>	<p>Managed care including:</p> <ol style="list-style-type: none"> 1. Immediate response to emergencies 2. Pain control 3. Prevention and management of post-treatment complications 4. Professional clinical services including medical, nursing, counselling and other professional and technical support services as required 5. Discharge as soon as it is appropriate and with a written discharge summary and care plan to be provided to the patient, specialist and general practitioner 6. Patients are familiar with their current medication and can address any concerns before leaving clinic/hospital or arrangements are made with the patient's general practitioner for this to occur
<p>5.1.4 Provision of consumable supplies while in clinic/hospital</p>	<p>This includes, but is not limited to anaesthetic agents and other pharmaceuticals and disposable equipment</p>
<p>5.1.6 Clinical follow-up</p>	<p>This includes:</p> <ol style="list-style-type: none"> 1. Specialist assessment of treatment effects and further treatment

	<p>requirements</p> <ol style="list-style-type: none"> 2. One follow-up appointment or more if clinically required 3. Review clinic within 6 months post ART 4. Early pregnancy monitoring and care to 12 weeks, or when referred for obstetric care.
<p>5.1.6 Specialist support for other providers [was: Consultation and education services]</p>	<ol style="list-style-type: none"> 1. Educative services are provided to general practitioners and other specialists concerning appropriate referral protocols and indications for ART 2. Consultation and advisory services are provided to general practitioners and other specialists concerning the condition and ongoing management of the referred couples
<p>5.1.7 Distribution of Authorised Pharmaceuticals</p>	<ol style="list-style-type: none"> 1. Protocols for the use of human gonadotrophins for ovulation induction and eligibility criteria for their use are provided to potential prescribing doctors. 2. Pharmaceuticals are distributed in response to requests from prescribers 3. Information is gathered on the use and outcome of pharmaceuticals that have been distributed.

5.2.1 Management of Pharmaceutical Budget

You will hold the budget and control overall expenditure on authorised pharmaceuticals [specified in Section 9.5] when supplied in connection with ovulation induction, both to consumers accepted under this contract for Treatment of Biological Infertility (referred to as "public consumers") and to other eligible consumers resident in the Northern Region (referred to as "private consumers").

You will meet with other providers, within the Northern Region, of services for biological infertility to private consumers and will develop with them an agreed protocol for treatment and you will endeavour to ensure that expenditure of the budget is programmed evenly over each whole year.

You are to ensure that consumers receive authorised pharmaceuticals [specified in Section 9.5] only upon presentation of an application from an authorised prescriber. An authorised

prescriber is a gynaecologist or an endocrinologist who is associated with an Reproductive Technology Accreditation Committee (RTAC) accredited clinic, or who has agreed to comply with treatment protocols and guidelines issued by an RTAC accredited clinic.

You will keep a register and notify the HFA annually throughout the contract term of the names of all authorised prescribers

You will collect monthly data recording utilisation, by public and private consumers of fertility services, of authorised pharmaceuticals specified in Section 9.5, and will forward such information to the HFA (which will in turn notify Health Benefits Limited).

5.3 Settings

The place where the service is provided will be an inpatient or day case setting.

5.4 Service Levels

You will provide this service at a tertiary level.

5.5 Equipment

You will have access to whatever equipment is needed to deliver the services described in this contract.

5.6 Support Services

You will provide the following support services:

5.6.1 Clinical support services

You will provide or have access to the following services as clinically required:

- operating theatre and anaesthetic services
- laboratory
- pharmacy
- sterile supply.

5.6.2 Consumer registration service

You will maintain complete and accurate records identifying consumers, donors and recipients of all gametes involved in fertilisation and embryo formation and detailing the use or disposal of all gametes and embryos.

You will maintain an information system which allows for consumer follow-up and confidentiality within accepted guidelines and lawful requirements.

5.6.3 Specialised services

You will provide a specialised scientific and laboratory services including storage, analysis and programme implementation.

5.6.4 Register of prescribers

You will provide a register of all prescribers requesting Authorised Pharmaceuticals.

5.7 Facilities

You will provide commercial support services including:

- inpatient and outpatient facilities, including furnishings, fittings, equipment, lighting, heating and other amenities
- laundry services
- catering
- cleaning.

5.8 Counseling

You will provide a counseling service to address the social and psychological effects of undergoing infertility treatments as well as other options such as adoption or living without children to all eligible couples.

6. SERVICE LINKAGES

6.1 Associated Services

The following support services should be provided by you in providing infertility services:

- a) pathology services
- b) radiology services

- c) operating services
- d) anaesthetic services
- e) pharmacy services.

You will ensure links are established and maintained with:

- a) primary health services, including health education
- b) general practitioners
- c) secondary and tertiary medical services, including in vitro fertilisation
- d) general surgical services
- e) community support groups including NZ Infertility Society
- f) Maori health groups.

You are to have effective links and continuity of care with the following services:

- Community groups including the Infertility Society
- Research units
- Ethics Committees.

And continuity of care with:

- Primary health services including General Practice, Family Planning Association, New Zealand Association of Natural Family Planning, Sexual Health Clinics, Maori and Pacific Island providers, maternity providers
- Secondary medical and surgical services, especially gynaecology and urology.

7. EXCLUSIONS

You will follow the CPAC guidelines and any further changes.

8. QUALITY REQUIREMENTS

8.1 General

You will aim to minimise complications of treatment, including ovarian hyperstimulation syndrome, infections, multiple pregnancy, and babies needing neonatal intensive care. This means careful consideration of the number of embryos transferred in IVF, and of the degree of ovarian stimulation in all treatments.

8.2 Access

You will provide General Practitioners and relevant Specialists with information about the services provided in this contract, including eligibility. You will be available to answer queries about the service from doctors and the public.

Once referred for consultation, you will see new patients within a specified time, to be agreed on between the provider and the HFA.

You will identify and remedy any barriers to access by Maori, and obtain Maori opinion about the service.

8.3 Acceptability

You will undertake customer surveys, and change the delivery of the service according to the feedback received.

You will ensure Maori views are heard, and that Maori participate in planning, delivery and monitoring the service..

You will provide a private and confidential service, and have a named privacy officer to monitor performance and answer any complaints. Privacy issues include those of gamete and embryo donors, and children conceived using donated gametes and embryos.

You will ensure all patients understand the diagnosis and treatment they are undertaking through the provision of written and verbal information in plain language, and the availability of interpreters.

You will ensure informed consent is obtained before any treatment or investigation is started, and that all consent for treatments involving gametes and embryos is written.

You will ensure that all services are coordinated from the perspective of the patient.

8.4 Effectiveness

You will ensure that referring doctors provide sufficient information about the patients being referred.

You will endeavour to maximise the chance of pregnancy, while controlling the incidence of untoward consequences. Minimum targets for the clinic are live birth rates, in women aged 37 years or younger, of 15% per oocyte collection in IVF, 15% per insemination cycle in DI, 10% per insemination cycle in AIH with ovarian stimulation.

You will help patients accept their infertility when treatment is not available, not chosen, or does not lead to pregnancy. Patients should feel they have achieved the best outcome in the circumstances.

You will promote awareness of infertility, its prevention, and the minimisation of its impact among the general public.

8.5 Efficiency

You will ensure that the services in this contract are delivered within the contract price and that services are equally distributed over each individual year.

8.6 Safety

You will ensure that the clinic is accredited by the Reproductive Technology Accreditation Committee of Australia.

You will comply with all relevant legislation, regulations, statutory requirements, and guidelines from professional bodies.

You will have risk management procedures in place, including for infection control, medical emergencies, and failure of key equipment.

You will have procedures in place to report incidents, accidents, and errors, and procedures to remedy these.

You will ensure staff have training and experience in ART, and registration, occupation licenses or certificates appropriate to their job. Staff who do not have registration or certification will be supervised by staff who do.

Laboratory services will be registered, or working towards registration, with TELARC or an equivalent accreditation programme.

You will ensure ethical review and advice for new treatment and for research is obtained from the National Ethics Committee on Assisted Reproductive Technology, or its successor.

You will have written policies outlining the storage, usage and disposal of all body tissues during and after procedures, and policies relating to ethical considerations for the use of donor ovum and sperm.

You will have quality improvement systems for clinical practice.

You will have a cultural safety programme which addresses the needs of Maori, and people of other non-European cultures.

8.7 Facilities

Your facilities are accessible to consumer irrespective of age, physical or mental disability or any other factor. Facilities for clients with a disability are clearly sign-posted.

A family/whanau room is provided within your facility for the family/whanau of clients.

Facilities are maintained in hygienic and orderly condition suited to their purpose.

All reasonable steps are taken to ensure that all buildings and equipment are secure, waste management programmes are implemented, and the safety of patients/couples, staff and visitors is assured.

9. PURCHASE UNITS

The total contract price is \$1,053,409 per annum exclusive of GST.

9.1 Specialist support for other providers

\$42,500 per annum exclusive of GST.

Service category	Purchase Unit	Pricing Unit
Specialist support	Capacity	

9.2 Consultancy and assessment of new couples

\$81,600 per annum exclusive of GST for 320 first patient attendances.

Service category	Purchase Unit	Pricing Unit
First specialist assessment	Capacity	Consultation

9.3 Treatments

\$840,809 exclusive of GST per annum, as set out below:

Service Category ID	Service category	Price Per unit (\$)	Indicative number of units per year
	DI	621	80
	AIH simple	385	10
	AIH + stimulation	721	145
	IVF	4233	120
	ICSI addition	954	55
	Donor egg addition	1208	3
	Frozen embryo replacement	525	64
	Ovulation induction	421	25
	Microsurgery	3265	11
	Testicular biopsy	410	10
	Sperm freezing	81	120
	Annual storage of sperm	73	340

The average number of IVF cycles shall average at least 120 per annum over the duration of the contract. For the other treatments, the numbers are indicative outputs and it is permissible for the provider to vary these in order to meet demand, providing that in no circumstances is the total cost of treatment to exceed the total price.

9.4 Support for consultation and treatment

\$17,000 exclusive of GST per annum for administration.

\$6,500 exclusive of GST per annum for travel and accommodation support, and for interpreting services.

9.5 Authorised Pharmaceuticals

\$65,000 exclusive of GST per annum.

The provider will purchase only the brands and strengths of pharmaceuticals set out below, at the lowest price.

Pharmaceutical	Brand names	Strengths
Human Chorionic Gonadotrophin	Pregnyl	1500 iu, 5000 iu
Human Follicle Stimulating Hormone	Profasi	2000 iu, 5000 iu
	Gonal F	38 iu, 75 iu, 150 iu
	Puregon	50 iu, 100 iu, 150 iu, 200 iu
Buserelin acetate	Suprafact	Injection, 1 mg/ml, 5.5 ml

10. REPORTING REQUIREMENTS

The following information is to be reported **quarterly** to us:

In the reporting period;

- The number of first patient attendances.
- Ethnicity of patients (clients are allowed to indicate more than one ethnicity) as per the Ministry of Health standard:
 - NZ Maori
 - NZ European or Pakeha
 - Other European
 - Samoan
 - Cook Island Maori
 - Tongan
 - Niuean
 - Chinese
 - Indian
 - Other
- The number of units for of each treatment, and the cumulative value of all treatments.
- Number of couples under treatment
- Number of couples who have completed treatment
- Number of treatments that took place later than the booked date advised – with those changed because of patient postponement or clinical factors noted
- Assessment of final outcome of treatment (number of clinical pregnancies and number of live births per treatment)
- Progress with re-assessment of couples on your waiting list assessment against priority access criteria

- The number of patients booked for each type of treatment.
- The number of patients waiting, unbooked, for each type of treatment
- The cumulative value of travel and accommodation support, and of interpreting services used.
- For the distribution of Authorised Pharmaceuticals, the cumulative number of:
 - Cycles treated
 - Patients treated
 - Cycles to ovulation
 - Cycles discontinued
 - Adverse events
 - Pregnancies
- The current price paid for each Authorised Pharmaceutical, and the cumulative value of Authorised Pharmaceuticals distributed.

The following information should be reported **annually** to us:

- Medical complications from treatment, and how the rate compares internationally
- Multiple pregnancy rates for the key treatment programmes
- Incident reporting and action taken
- Analysis of the ethnicity of users of the service
- Emerging issues and how they will be dealt with
- The number of staff by type (Maori, total)
- Level of patient satisfaction with the service and its aspects
- Organisational plan for Maori including:
 - Maori consumer satisfaction
 - Services meet the needs of Maori
 - Maori participation
 - Quality plan
 - Support for Maori
 - Strategies to recruit and train Maori.

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Appendix N:

NECAHR Membership

Rosemary De Luca (Chair)

Rosemary De Luca is a Senior Lecturer in the Department of Arts and Language Education at the University of Waikato. She was until recently the Chair of the Waikato Ethics Committee and was also a member of the Working Group revising the National Standard for Health and Disability Ethics Committees. She has twelve years' experience in health sector ethics, and teaches and has published widely in this field. Her current research interests include the language and procedures associated with informed consent to medical treatment in hospitals.

Associate Professor Ken Daniels

Ken Daniels is an Associate Professor in Social Work at the University of Canterbury. He teaches values and ethics and has taken advanced studies in bioethics. He has been researching and writing in the field of assisted human reproduction for twenty four years and has published over 100 paper, chapters and books on this issue. He is currently involved in research in Sweden, Germany, the United Kingdom, Singapore, Argentina and New Zealand.

Alison Douglass

Alison Douglass is a partner in the law firm Tripe Matthews and Feist, specialising in civil litigation and health law. She is former Chairperson of the Wellington Ethics Committee and a member of the medical misadventure advisory panel to ACC. She has a Masters degree in Bioethics.

Dr Alastair Gunn

Alastair Gunn is an Associate Professor in the Department of Philosophy at the University of Waikato. He was a member of the Waikato Ethics Committee for a number of years. He has an interest in health ethics, in particular issues relating to assisted human reproduction.

Dr Audrey Jarvis

Dr Jarvis is a microbial geneticist, having retired from the position of Principal Scientist at the New Zealand Dairy Research Institute, Palmerston North. She has served on national and international scientific committees, and received New Zealand and international awards in recognition of her scientific achievements. She has been active on health ethics committees and at regional and national level, and is currently Chairperson of the Interchurch Commission on Genetic Engineering.

Dr Arlene Smyth

Arlene Smyth is a general practitioner working at the Island Bay Medical Centre in Wellington. Her main interests are in the area of women's and children's health and she is a practicing GPO (General Practitioner Obstetrician). She is involved in undergraduate teaching for the University of Otago, regularly tutoring medical students in her general practice and also in the Department of Obstetrics at Wellington Women's Hospital. She is also involved in the Wellington Doctors for Sexual Abuse Cases (DSAC) and is on the Quality Assurance Committee for MATPRO (the Wellington Maternity Project).

Rose Smith

Rose Smith is a registered general and obstetrics nurse and is currently employed as the senior staff nurse, General Surgical and Urology Unit, Health Waikato. She has been a Maori member on the Waikato Ethics Committee, and also serves on a number of other local marae and community committees.

Dr Anne Robertson

Anne Robertson is a consultant obstetrician and gynaecologist. She has an extensive background in obstetrics, gynaecology, sexual health, and ethics. As a health professional member of the Manawatu-Whanganui Ethics Committee since 1996 she has developed significant experience in and knowledge of the area of ethical review in the health sector.

Dr Barbara Nicholas - Director-General of Health's Representative

Barbara Nicholas is currently employed as Senior Advisor (Services Research), Health Services Policy and is located in the Christchurch office of the Ministry. She holds a PhD in bioethics. Her experience in the field of bioethics includes lecturing at the Otago Medical School in this subject, and research in the area of ethics and genetics.

- Adapted from <http://www.newhealth.govt.nz/necahr/membership.htm> [18 February 2002]