

**Understandings and experiences of embryo donation in New
Zealand - a discursive analysis**

Sonja Goedeke

PhD

2014

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**Understandings and experiences of embryo donation in New
Zealand – a discursive analysis**

Sonja Goedeke

**A thesis submitted to Auckland University of Technology in
fulfilment of the requirements for the degree of Doctor of
Philosophy (PhD)**

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Department of Psychology

School of Public Health and Psychosocial Studies

Abstract

Embryo donation (ED) is the donation by a couple who have surplus embryos following in vitro fertilisation to another infertile couple or person. The aim of this research was to address the paucity of knowledge on how ED is understood and experienced by donors and recipients. The research, the first on ED in New Zealand, is particularly relevant due to the newness of ED in the country and the unique guidelines: Registration of donor identity, mandatory individual and joint counselling for donors and recipients, and case-by-case application to an ethics committee.

A discursive analytic approach was adopted, drawing on elements of both discursive psychology and Foucauldian discourse analysis. This took into account the potential influence of extra-discursive factors including embodiment, personal-social biographies and material conditions. Analysis focused on identifying discourses available in New Zealand society and how individuals invested in these discourses, and the implications for donor and recipient experiences and the resulting kinship structures. To facilitate a comprehensive and holistic understanding, the analysis was conducted across a range of sites: The academic literature, New Zealand's legislative frameworks, policy guidelines, and ethics committee applications and decision-making. Further, interviews were conducted with 9 ED counsellors, 22 donors (10 couples, 2 individuals) and 15 recipients (5 couples, 5 individuals).

A central discourse identified was the genetic discourse. Genetic connections were constructed as bestowing immutable kinship ties between donors and offspring. Donors constructed the children as still partly theirs, making ED a difficult choice, and conveying responsibility for the child's welfare. Recipients constructed knowledge about genetic background as significant for their child's identity and health. Disclosure of donor conception and access to the donors was thus assumed as a necessary, albeit challenging, part of being a parent through ED.

Donors and recipients managed the significance of genetics through drawing on a number of further discourses: An adoption discourse (constructing ED as adoption, offering a familiar framework for this form of family-building, and making transparent rights and responsibilities), a gestational discourse (valuing the role of gestation in attachment), gifting and reciprocal exchange discourses (constructing the donation as a gift from donors to recipients, versus a mutually beneficial practice) and a discourse of ED as building extended families. The latter discourse enabled donors to maintain an interest as extended family, allowed recipients to assume parental authority but

accommodate and manage the role of donors, and recognised sibling relationships. Donors and recipients were able to strategically appropriate genetic, gestational, and social elements of reproduction and parenting in a way that did not destabilise family relationships and boundaries. These new kinship forms were constructed as complex and novel however, creating anxiety and ambivalence amongst donors, recipients, and counsellors.

Recommendations suggested for ED policy and practice include strategies to assist donor offspring to gain greater awareness and access to information on their genetic background, and the development of longer-term support structures to assist in the promotion of positive long-term outcomes for all parties involved in ED.

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I hereby declare that this submission is my own work, and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

A handwritten signature in black ink, appearing to read "S. Gredelke". The signature is written in a cursive style with a large, stylized initial "S" that loops back.

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Chapter 1: Introduction

Infertility is estimated to affect one in five couples (Fertility Associates, 2014), and is frequently described in the literature as being emotionally stressful, as involving significant grief, and as having negative effects on identity (Greil, McQuillan, & Slauson Blevins, 2011). A range of assisted reproductive technologies (ARTs), including in vitro fertilisation (IVF), have been developed since the late 1970s to assist individuals in having children. These technologies have advanced rapidly, at times ahead of research into their potential psychosocial consequences, and leading to new social and moral dilemmas. One such dilemma is the fate of cryopreserved embryos that remain following in-vitro fertilisation (IVF), and which may be regarded as ‘surplus’ to requirements once a couple completes their family.

The numbers of embryos in storage are reported to be high, with an estimated 92,540 embryos in storage across Australia and New Zealand in 2010 (Stiel, McMahon, Elwyn, & Boivin, 2010). The estimated number of embryos in storage for New Zealand’s largest clinic, Fertility Associates, is approximately 6,500 embryos over 23 years of practice (J. Peek, personal communication, September 2010). Since many of these embryos may be in storage not for couples’ own reproductive use, they represent a potential ‘problem’ for both clinics and patients (Bankowski, Lyerly, Faden & Wallach, 2005; Brzyski, Binkley, Pierce & Eddy, 2000; de Lacey, 2007b; N. D. Johnson, 2003; Lyerly et al., 2010, McMahon et al., 2000; O’Brien, 2010; Saunders, Bowman, Grierson & Garner, 1995). ‘Disposal’ options for embryos across jurisdictions vary, but may include:

- Discarding
- Embryo donation to research, and
- Embryo donation (ED) to others, which involves donating one or more of the frozen embryos to another individual or couple to gestate. The child born to the recipients as a result of ED is thus genetically unrelated to the recipients.

Disposal decisions are frequently reported to be complex and difficult (de Lacey, 2007a, 2007b; Hoffman et al., 2003; Lyerly et al, 2010; Oghoetuoma, McKeating, Horne, Brison & Liebermann, 2000) and restricted by the availability of options. For example ED to research is prohibited in many jurisdictions, including in New Zealand. Most countries that allow cryopreservation, however, have specified time limits for storage of embryos, implying that after a set time, disposal decisions have to be made.

In New Zealand, as of 2004, embryos may be stored for a maximum of 10 years, after which decisions have to be made as to their fate (Human Assisted Reproductive Technology [HART] Act, 2004).

At the time of writing, ED to others is permitted in Australia, Canada, England, Finland, France, New Zealand, Spain, and the United States. In other countries, including Austria, Denmark, Brazil, Israel, Norway, Sweden, Switzerland, Turkey, Taiwan, Italy and Germany, it is prohibited or restricted (Blyth, Frith, Paul, & Berger, 2011; de Lacey, 2007b; Frith, Blyth, Paul, & Berger, 2011; Lee & Yap, 2003; Mohler-Kuo et al., 2009; Paul, Berger, Blyth & Frith, 2010; Takahashi et al., 2012; Urman & Yakin, 2010, Wanggren, Prag & Skoog Svanberg, 2013). In New Zealand ED has only been available since 2005 (Advisory Committee on Assisted Reproductive Technology [ACART], 2008) and the uptake has been low, with only 53 applications processed by the Ethics Committee for Assisted Reproductive Technologies (ECART), the body responsible for decision-making regarding various ARTs in New Zealand, between 2006 and mid-2012 (ECART, 2012).

Even in countries with longer histories of ED, the practice is described as controversial. Concerns have been expressed around issues such as the uncertainty of long-term psychological outcomes, the effects and possibility of unknown consanguinity where donation is anonymous, and the payment of donors (Applegarth, 2006; Blyth et al., 2011; Borrero, 2002; Eydoux et al., 2004; Guichon et al., 2010; Janssens, 2009; Kovacs, Breheny & Dear, 2003; Lee & Yapp, 2003; MacCallum, 2009; Marcus & Marcus, 1999; Melamed et al., 2009). Much of the research has been quantitative, focusing on identifying factors that affect donation such as disclosure of donor identity, views on parental bonding, the status of the embryo, responsibility to the child, and whether ED is seen as parallel to adoption (Bangsbøll, Pinborg, Andersen & Andersen, 2004; de Lacey 2005, 2007a, 2007b; Hug, 2008; Kirkman, 2003a; Laruelle & Englert, 1995; Lyerly, Brelsford, Bankowski, Faden & Wallach, 2004, Lyerly et al., 2006, Lyerly et al., 2010; McMahon & Saunders, 2007; Mohler-Kuo et al., 2009; Nachtigall, Becker, Friese, Butler & MacDougall, 2005; Newton, McDermid, Tekpetey & Tummon, 2003; Provoost et al., 2010; Söderström-Anttila, Foudila, Ripatti & Sieberg, 2001). Much of the research has also been limited by small sample sizes, low response rates, sampling difficulties, and failure to adequately consider the cultural context in which disposal decisions are made (de Lacey, 2007a; Lyerly et al., 2010).

In contrast, little research has focused on the way in which donors and recipients construct, understand and experience ED, or on longer-term implications for offspring

and families (Blyth et al., 2011; Frith et al., 2011; Lyerly et al., 2010; Newton et al., 2003; MacCallum, Golombok & Brinsden, 2007; Paul et al., 2010). Even less attention has been given to the constructions of those working with, or possibly shaping, the decision-making of donors and recipients. In addition, research that has attempted to explore experiences has occurred in jurisdictions with very different policy and legislative frameworks than the unique policies adopted in New Zealand, thereby limiting the relevance of such research endeavours to the New Zealand context.

In New Zealand, ED practice is highly regulated under the Human Assisted Reproductive Technology Act 2004 (hereafter referred to as HART Act); must follow specific guidelines set by the Advisory Committee for Assisted Reproductive Technology (ACART); and be approved on a case-by-case basis through application to ECART. Guidelines for ED include that the embryos must have been formed from the couples' own gametes, that they must be 'surplus' to requirements and remain after couples have completed their families, and that they may be used to create full genetic siblings in no more than two families. Further, guidelines stipulate donor identity registration and recommend disclosure, so that donor-conceived offspring may have access to their genetic background. Counselling, both separate and joint (where donors and recipients and their families meet), is mandatory and involves full implications counselling. It considers both current and future issues that may arise for the donor-conceived children, and the donor and recipient families. Information-sharing and communication is encouraged between donor and recipient families, similar to the practice of open adoption that has been adopted in New Zealand (Lovelock, 2010).

My interest in the subject area developed after my own experience of miscarriage, and subsequent secondary infertility. Up until that point in time, I had assumed that having children would be a natural and 'easy' part of my life trajectory. Confronted with the experience of trying, unsuccessfully, to become pregnant, I began to understand on a more personal level some of the issues and stressors potentially associated with infertility, and to appreciate the influence of a prevailing motherhood narrative for women as discussed by Kirkman (2003b). While I had one child already, the desire to have more children was stronger than I could have imagined. Given my background as a clinical psychologist, I was curious about my own reactions, and those of others who alternatively offered me sympathy or positioned me as ungrateful by virtue of having a child already. I reflected on the meanings and constructions of motherhood and family available in contemporary society, and I began to consider the various ARTs and options that were available. At that time, ED was not yet available in

New Zealand, but was under consideration. I began to reflect both on what my husband and I would do in the event that we pursued IVF and had surplus embryos, or if we would consider ED as an option for us to have more children. Neither of these situations eventuated, however, and we went on to have two more children, but my interest in the field had been stimulated.

I was fascinated by the language around ED and metaphors used to describe it, including as organ or blood donation or as adoption. Similarly, I was curious as to the status ascribed to embryos and how this could affect decision-making. Could they be described as cells, as life already, as both, or as siblings to existing children? Given that ACART was reviewing the possibility of ED at that time, I was aware of the multiplicity of viewpoints and controversy that surrounded ED, and was conscious of the fact that ED policy and practice varied substantially across jurisdictions, and is prohibited in some. I was interested in the possible implications of these various discourses and discursive practices, how they would affect the ability to proceed with ED either as a donor or as a recipient, and how donation would play out in the longer term for all parties: for the donors, recipients, the donor-conceived offspring, and their families. Given the increasing variations in family formation in the twenty-first century, and that in ED the genetic, gestational and social domains of parenting and family formation are differentiated (Taylor, 2005), I was interested in the implications of ED for constructions of kinship and relatedness.

Thus, I was motivated to research the discourses of ED in the New Zealand context with its unique legislative and policy requirements, and to explore the implications of these constructions. My aims were to:

- Identify the discourses and practices surrounding ED in contemporary New Zealand culture;
- Analyse how these construct embryos and ED, and with what consequences: asking what subject positions these discourses offer and the implications of these for donor and recipient experience;
- Explore some of the conditions (e.g. historical, social and cultural) that accommodate the discourses; and
- Explore how donors and recipients may take up these discourses and assume subject positions, and how factors related to embodiment, personal social

biographies and material conditions provide a context for their investment in particular discourses.

A discourse-analytic approach was adopted given its acknowledgement of the constructive power of language and practice, and that embryos and ED have been framed in a multiplicity of ways in the literature and across jurisdictions. Discourse analysis, grounded in social constructionism, highlights that phenomena, such as ED, may be constructed in varying ways, and with varying implications (Burr, 2003; Willig, 2010).

The methodology I adopted was somewhat unconventional, in that I drew on elements of both macro and micro approaches to discourse analysis. I considered both how the discourses available in contemporary society make available particular action possibilities for donors and recipients and offer particular subject positions (a macro approach), and how donors and recipients locate themselves within these discourses and take up particular positions (a micro approach). The approach adopted in this research was also informed by a critical realist ontology, suggesting that while there may be a multiplicity of ways of knowing this world, there is in fact an external world that can be known (Parker, 2002; Pujol & Montenegro, 1999), and that these ways may be shaped by a range of ‘extra-discursive’ factors, including embodiment, personal social biographies, and material conditions (Burr, 2003; Cromby & Nightingale, 1999; Parker, 2005; Sims-Schouten, Riley & Willig, 2007; Willig, 2010). In so doing, I situated my research within a systemic framework, attempting to explore and bring together some of the multiple influences on the constructions of ED and investment in these discourses, and considering the implications for experiences, donor–recipient relationships, and the types of kinship and family-building that are enabled. I drew on a range of authors to inform my approach, including Cromby (2005, 2011), Nightingale and Cromby (1999), Parker (2002, 2005), Parker and the Bolton Discourse Network (1999), Sims-Schouten (2004), Sims-Schouten, Willig and Riley (2007), and Willig (1999, 2010).

My goals were thus ambitious and aimed at identifying both the discursive economy available and the discursive resources that donors and recipients made use of, and how these were affected by a range of factors. In order to achieve this, the approach to discursive analysis described above was adopted across a variety of sites, including:

- The academic literature
- New Zealand legal frameworks (The HART Act), policy and practice guidelines, (including the ACART guidelines of 2005 and 2008, Australian and New Zealand

(In)fertility Counsellors' Association (ANZICA) and counselling guidelines), and minutes from ECART meetings where ED applications are considered.

Analysis across these sites facilitated what Foucault has termed an archaeological and genealogical analysis (McHoul & Grace, 1997; Mills, 2004) of discourses of ED. Further, a discursive analysis was conducted of transcribed data from:

- Interviews with donors and recipients and their families;
- Interviews with those that had considered ED and elected not to proceed; and
- Interviews with counsellors.

Klitzman (2012) has suggested that social science research needs to explore how different groups of stakeholders and the various parties involved in reproductive donation (e.g. recipients, donors, offspring, siblings and providers) each view (construct) and experience the issues that may arise in a variety of cultural contexts, thus providing insights into how these individuals comprehend and address complex choices. I hoped that analysis across the various sites of my research would offer a comprehensive and holistic understanding of ED, teasing out the discourses available and assumed, and the implications of such discourses.

In November 2014, the 10-year storage limit imposed under the HART Act comes into effect, thereby compelling decision-making for those with embryos reaching their storage deadline. As this deadline approaches, ACART is in the process of reviewing ED guidelines. It was thus appropriate and timely to explore the understandings and experiences of those considering, undertaking and facilitating ED. I hoped to be able to provide information that could assist people in their decision-making about surplus embryos, and in pursuing family-building in this manner. Further, I hoped that my research would highlight issues relevant to the review of policy, and assist counsellors and other healthcare professionals in supporting their clients/patients as they make decisions about embryos and family-building options.

The remainder of this thesis is structured as follows:

Chapter 2: Methodology

In this chapter, I introduce the theoretical underpinnings and ideological stance of this study. I explain how my methodology draws on a critical realist approach to social constructionism, and employs an analytic approach which is grounded in elements of both micro and macro forms of discourse analysis. I describe the relevant key features and challenges of both forms of discourse analysis, and suggest that a solution lies in

drawing on elements of both, allowing consideration of both how discourses may enable or restrict particular action possibilities and subject positions, and how these may be drawn on strategically to position participants in particular ways. Further, I argue for the inclusion of extra-discursive factors, including embodiment, personal social biographies, and material conditions, which may help explain individuals' investment in some discourses and not others. Finally, I outline the dialectical and systemic approach adopted.

Chapter 3: Method

Chapter 3 presents the aims and research procedures of the study. I describe the sites selected for analysis, provide detail on participant recruitment, explain the interview structure, and outline the approach to data analysis. In addition, criteria to assess the rigour of the research are considered and the relevant ethical issues are addressed.

Chapter 4: Literature analysis

In this chapter I review the literature relevant to ED in order to provide a context for the present study. I adopt a discourse-analytic approach, which rather than evaluating and presenting the major 'findings', foregrounds and explicates the discourses available, explores their historical and social context, and analyses the possibilities and subject positions enabled and constrained by discourses. I explore some of the extra-discursive factors that may provide the context for individuals drawing on discourses. My analysis includes commentary and empirical studies of ED and embryo disposal options, and debates around ED policy and practice.

Chapter 5: Results - Legislation, policy, guidelines and ED approval analysis

Chapter 5 begins with an overview of the key legislative frameworks for ED, including the HART Act and the ACART guidelines for ED, initially written in 2005 and revised in 2008. The functions of ACART and ECART in relation to ED are also outlined. In addition, given the central role accorded counselling in ED, this chapter sets out the professional guidelines for fertility counselling in general, and for ED in particular, and includes the ANZICA position paper on ED released in 2006. Key aspects of ECART decision-making related to ED as noted in meeting minutes recorded between 2006 and June 2012 are presented. Following this, I explore the discursive constructions that may be identified in these texts, and discuss their potential implications for ED and the

positions donors and recipients may assume. Finally, I consider factors that may contribute to ED policy and practice in New Zealand.

Chapter 6: Results - Donors and recipients

Transcribed data from interviews with donors and recipients who have undergone ED is analysed in this chapter. In the first section I identify discourses related to the embryo and the donor-conceived child with reference to actions and positions that are made possible through drawing on these discourses. I reflect on how these discourses sit alongside a related discourse of the welfare of the child, with further implications for action possibilities and subject positions that donors and recipients can assume. Next, I identify discourses related to ED as a practice, including ED as ‘donation’, ‘adoption’ and ‘gifting’. I explore how these may position donors and recipients, particularly in relation to each other; how they invest in and resist these discourses; and the implications of this for their experiences. I briefly analyse how donors and recipients construct the role of ECART and of counselling, as these constructions may affect how they are able draw on particular discourses, with further implications for relationships. Finally, I identify particular extra-discursive factors that may contribute to donors’ and recipients’ investment in particular discourses.

Chapter 7: Results - Counsellors

Given counsellors’ central role in facilitating ED, in this chapter I analyse the data from the interviews with counsellors. I identify how counsellors construct ED; consider how their discourses and the discursive practices they engage in potentially shape ED practice; and explore the implications for donors and recipients.

Chapter 8: Discussion and conclusion

In the final chapter, I integrate my analysis from across the various sites of analysis. I discuss the effects of the various discourses of ED for donors and recipients; how these discourses may affect the nature of donor–recipient relationships; and the forms of kinship and relatedness that may be built. I also consider the implications for ED as a solution for surplus embryos, and as a means of family-building. I reflect on the challenges of the research process and suggest areas for future research.

Following the references are appendices that include a glossary of terms related to ARTs as well as Māori vocabulary, the guidelines for ED, and the various Participant Information Sheets, consent forms and interview schedules.

Chapter 2: Methodology

There are times in life when the question of knowing if one can think differently than one thinks, and perceive differently than one sees, is absolutely necessary if one is to go on looking and reflecting at all. (Foucault, 1984, p. 15)

The best research does not allow itself to be defined by its methodology alone, and innovation often proceeds by asking searching questions of one approach from the vantage of others. (Parker, 2005, p. 11)

2.1 Introduction

This chapter introduces the theoretical underpinnings and ideological stance of this study. I explain how my approach draws on a critical realist ontological perspective, positing that there is an external world out there that can be known. However, I argue that this knowledge is not and can never be an objective, unmediated reflection of reality, and that instead there may be multiple ways of knowing this world, each shaped by a range of factors. In this way, my approach is social constructionist in its epistemology. Drawing on the work of a range of authors (including Burr, 2003; Cromby, 2005, 2011; Nightingale & Cromby, 1999; Parker, 1994a, 1999a, 1999b, 2002, 2005; Sims-Schouten, Riley & Willig, 2007; Willig, 1999, 2010), I suggest that an analytic approach which is grounded in some of the elements of both micro and macro approaches to discourse analysis and which allows for the influence of extra-discursive factors aligns well with such a position. I discuss how this provides an appropriate framework to identify discourses of ED and explore how these may either enable or constrain action possibilities and subject positions, as well as the implications for experience, and how individuals may invest in some and not other discourses.

The chapter is structured as follows: I begin with an overview of the tenets of social constructionism, followed by a description of two main types of discourse analysis and their key features as they relate to this study. Thereafter I raise some of the ‘unanswered questions’ with respect to these types of discourse analysis. I suggest that a potential solution lies in an approach that is critical realist, that blends the forms of discourse analysis, and that draws on psychosocial methods that take into account extra-discursive factors such as material conditions, personal-social biographies, and embodiment.

2.2 Social constructionism

This study falls under the umbrella of social constructionist psychology (e.g. Nightingale & Cromby, 1999). The social constructionist movement in psychology, often dated to Gergen (1985), stands in contrast to positivist models, which adopt a realist ontology and epistemology and hold that there is one reality that can be assessed, and that the route to discovering this reality is through objective, unbiased perception and description of the phenomena that make up the world (Tuffin, 2006; Willig, 2010).

There is no single definition of what constitutes a social constructionist approach and no one type of social constructionist research; the term encompasses a range of different approaches which are united only by what Burr (2003) terms “a family resemblance” (p. 2). Nevertheless, social constructionist approaches acknowledge:

- Firstly, that knowledge may be constructed and relative, derived from looking at the world from one of many ways (Burr, 2003; Gergen, 1985; Willig, 2010). Social constructionists postulate that what we perceive and experience may not be a direct reflection of the world, but must be understood in terms of how we ‘read’ these conditions and how our readings are affected by a range of factors, including social and historical ones (Willig, 2010). In this way, social constructionism highlights how knowledge is derived from looking at the world from one ‘perspective’ or another, and that each way may only be one among many ways of seeing the world (Burr, 2003; Willig, 2010). This ties in neatly with feminist critiques of established epistemologies in psychology which argue that it is impossible to have a “God’s eye view” of the world (Nicholson, 1990, pp. 2-3); that we regard the world from *somewhere* (Haraway, 1991); and that the process of creating knowledge is always a process of construction (Gergen, 1985).
- Secondly, social constructionist approaches posit that knowledge is culturally and historically specific (Burr, 2003; Cromby & Nightingale, 1999; Willig, 2010). In other words, we cannot assume that there are universal laws that apply to all people across time and culture. Phenomena are constructed and are mediated by cultural, social and historical factors; they do not exist in and of themselves as is posited by essentialism. Social constructionist research then, is concerned with “identifying the various ways of constructing social reality that are available in a culture, to explore the conditions of their use and to trace their implications for human experience and social practice” (Willig, 2010, p. 7). Note that social constructionists do not assume that one way of understanding is necessarily any better than another, or nearer in terms of being the ‘truth’ as regards people and social life (Burr, 2003). In contrast, social

constructionist research focuses attention on the “historical study of the emergence of current norms of psychological and social life and to the social practices by which they are created” (Burr, 2003, p. 7). Social constructionism also does not assume that it is simply our constructions of the world that are different, but that these constructions in themselves will allow for particular subjectivities that will vary according to culture and time (Cromby & Nightingale, 1999). Social constructionism can thus be regarded as a form of critical psychology in that it encourages us to view psychological ‘wisdoms’ as “temporary social constructions which bear the mark of the assumptions and concerns of their society of origin” (Burr, 1999, p. 114).

- Thirdly, social constructionist approaches propose that knowledge and experiences are the products of social processes through which various versions of knowledge are constructed (Burr, 2003; Cromby & Nightingale, 1999). The individual is not born into a vacuum but into a network of social relationships and as part of wider social structures such as the economy, or institutions such as family and education systems (Burr, 2003). It is through these relationships that versions of knowledge are constructed. Social constructionists thus regard the social as a critical site of explanation (Burr, 2003; Cromby & Nightingale, 1999).
- Fourthly, social constructionists argue that knowledge and action go together. Numerous constructions of a phenomenon may be possible, each creating ‘truth’ and carrying implications for actions enabled or constrained. Constructions are bound up with power relations as they are more than representations, and become determinants or social practices (Cromby & Nightingale, 1999).
- Finally, social constructionist approaches focus on the role of language in knowledge construction. Language is not a passive, neutral medium for reflecting reality but the currency through which we transact, negotiate and plan social events, and a part of the constitution of objects and events, and thus our experiences (Burr, 1999, 2003; Tuffin, 2006). Language predates our existence and we have no choice but to come to understand ourselves in terms of the concepts language makes available (Burr, 2003). With its emphasis on variability, the social constructionist approach to language disputes the notion of individuals as unified, coherent and rational (Burr, 1995; Parker, 2005). Meaning is negotiated, and research needs to address how constructions are produced, change over time and across cultures, and shape people’s experiences in different ways (Burr, 2003; Willig, 2010). We need to look to the linguistic space that individuals occupy to understand them (Burr, 2003).

Social constructionism, then, provides a view of the individual as a social, relational being that is embedded in language and discursive practices of culturally and historically situated communities (Pauw, 2009).

While there are many different ways of doing social constructionist research, most rely on qualitative methods of enquiry as these lend themselves more easily to gathering linguistic and textual data, and are less likely to present decontextualised accounts of individuals' experiences (Burr, 2003). One such method is discourse analysis, which fits well with a social constructionist framework in its shift from representation to signification.

2.3 The 'turn to discourse' and discourse analysis

Within psychology, the recognition of language in knowledge construction has been termed the 'turn to language' or the 'discursive turn' (Parker, 1999a, 2005; Tuffin, 2006). Influential forces in this 'turn' include ideas from microsociology, ethnomethodology, analytic philosophy and writers such as Austin (speech act theory) and Foucault (historical studies) (Parker, 2002; Willig, 2010). While the uptake of these ideas was initially slow, in the 1970s psychologists began increasingly to challenge psychology's cognitivism (Gergen, 1994) and in the 1980s the turn to language gained a more serious foothold (Willig, 2010). Potter and Wetherell's 1987 text *Discourse and Social Psychology* and Gergen's 1985 article 'The Social Constructionist Movement in Modern Psychology' are regarded as important texts in the development of discourse analysis in psychology.

Discourse analysis has emerged as a practice that seeks to identify the discourses that we construct and that construct us, studying the ways texts are constructed, the functions language and constructions serve, the contradictions that run through texts, and their implications (Burr, 2003; Parker, 1992, 2002). The term 'discourse' has no single agreed upon definition, and its meaning may depend on the particular approach to discourse analysis that is adopted, with the term being variously aligned to a linguistic interpretation, a sociological interpretation, or even to a mixture of the two (Mills, 2004; Parker, 2002). 'Discourse' has thus been variously defined; the following two definitions are instructive for our present purposes:

- "A system of statements which construct an object" (Parker, 2002, p. 145).

- “A set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events” (Burr, 2003, p. 64).

These definitions have some commonality with the concept of ‘interpretive repertoires’ put forward by Potter & Wetherell (1987), who define interpretive repertoires as “recurrently used systems of terms used for characterising and evaluating actions, events and other phenomena... a limited range of terms used in particular stylistic and grammatical constructions ... organised around specific metaphors and figures of speech” (p. 149). Yet while the term ‘discourse’ can be used to describe collections of sentences and utterances that have some type of coherent meaning, Foucault, for example, defined ‘discourse’ more widely, regarding it as embedded in practices that include patterns of meaning that have been organised into systems and institutions which he terms ‘discursive practices’. Likewise Parker’s (1992, 2002) definition extends beyond the linguistic, in that he considers ‘all tissues of meaning as texts’. According to him, discourses can be applied beyond interaction and written texts. For example, discourses can be identified in forms of ‘text’ that include architecture, fashion, uniforms, the use of physical space, and so on (Burr, 2003; Parker 2002, 2005). This way of defining discourse has sometimes led to the statement that discourse may be studied wherever there is meaning (Parker, 1999b).

What these definitions share is the concept that surrounding any one event there may be a range of discourses, each of which represents the event differently (Burr, 2003). The discourses do not simply describe the world, but categorise it, bringing certain phenomena into focus (Parker, 1992, 2002) and carrying connotations, allusions and implications for the way in which we construct our world. They “delimit what can be said, whilst providing the spaces – the concepts, metaphors, models and analogies – for making new statements within any specific discourse” (Henriques, Hollway, Urwin Venn & Walkerdine, 2005, p. 104). They address us in particular ways, calling to us to take up a position (subject position) in relation to them, thereby conveying a particular subjectivity (Burr, 2003). This fits in with Althusser’s (1971) explanation of how ideology may hail us, shouting, “hey you there!” commanding our attention (as cited in Parker, 2002, p. 152). Discourse analysis thus suggests that texts play a role in “generating, enabling and limiting empowered/disempowered subject positions” (Hook, 2001, p. 528).

Finally, Parker (2002) points out how discourses may be contradictory, involving and relating to other discourses. As Henriques et al. (2005) suggest, “The systematic character of a discourse includes its systematic articulation with other discourses” (p. 104).

While different definitions of ‘discourse’ exist and different types of discourse analysis emerge, these notions of discourse constructing objects, and having effects on our identity and experience, are common features. When we seek to identify discourses, we look for the different meanings at work in a text – we look for contradiction, and different pictures of the world (Parker, 1999b). We examine how these discourses construct meanings, and what effects these discourses may have on us. This focus on identifying discourses and paying attention to contradiction, construction and practice leads us to what has been termed “critical text work”, which may involve various applications of discourse analysis (Parker, 1999b, p. 7).

While there are many varieties of discourse analysis (Parker, 1999b), two main types have been identified (Cromby & Nightingale, 1999; Parker, 2002; Tuffin, 2006; Willig, 2010) which can be mapped onto two different types of social constructionist psychology that identify with different intellectual traditions (Willig, 2010). The first has been referred to as a ‘light’ or ‘micro’ version, and maps onto the type of discourse analysis that has come to be known as discursive psychology (Burr, 2003; Cromby & Nightingale, 1999; Parker, 2002; Tuffin, 2006; Willig, 2010). The second has been described as a dark version or ‘macro’ approach, which maps onto what has been termed Foucauldian discourse analysis (Burr, 2003; Cromby & Nightingale, 1999; Parker, 2002; Tuffin, 2006; Willig, 2010). These approaches differ in terms of the traditions that inform them, the site of analysis, their interpretation of the role of language, power and subjectivity, their conception of agency, and their relation to relativism and realism. While in practice researchers often draw on aspects of both (Cromby & Nightingale, 1999), either explicitly or implicitly and depending on moral, political and pragmatic issues (Michael, 1999), it is instructive to describe their main tenets to provide a background for the analytic approach I adopt in this research.

2.4 Types of social constructionist research

2.4.1 ‘Light’/micro social constructionism and discursive psychology

This approach has its roots in speech act therapy, conversation analysis, and ethnomethodology (Cromby & Nightingale, 1999; Willig, 2010) and came to the fore in psychology through the work of Potter and Wetherell (1987). Discursive psychology

attends to the minutiae of discourse and social process (Cromby & Nightingale, 1999), or how meaning is negotiated in everyday, interpersonal contexts. It is interested in the interactive features of talk and studies what people do with language, emphasising the performative quality or action-oriented nature of discourse (Burr, 2003; Tuffin, 2006).

Discursive psychology examines how people put their linguistic skills to use in order to build specific accounts of events, accounts which may then have powerful implications for them (Burr, 2003; Cromby & Nightingale, 1999; Tuffin, 2006; Willig, 2010). It considers activities such as justification, rationalisation, categorisation, attribution, naming and blaming: how people manage their interests or reach their own social and interpersonal objectives through use of these practices (Willig, 2010); and how people provide accounts that attend to questions of responsibility and accountability, allowing them to excuse or validate their behaviour, fend off criticism, or allow for a credible stance (Burr, 2003; Tuffin, 2006; Willig, 2010). It thus examines “situated language use” (Burr, 2003, p. 57) and frames the individual as a sophisticated language user, manipulating discourses to achieve specific outcomes and relationships (Parker, 2005). In this sense, individuals are granted agency and are active in constructing their worlds (Burr, 2003).

Psychological concepts, such as identity, become things that people ‘do’ rather than ‘are’. The action orientation of the text takes centre stage in analysing the ways in which speakers manage issues of stake and interest (Willig, 2010). Data is ideally collected in naturally occurring text, and interrogated in terms of questions such as:

- What is this discourse doing?
- What features produce this reading?
- What is the intention of speaking in this way? (Willig, 2010)

The researcher looks at how the text constructs objects and subjects, how such constructions vary across contexts, and with what consequences they are used. Close attention is paid to the choice of terminology, stylistics and grammatical features and preferred metaphors and figures of speech, all the time staying close to the text. Potter and Wetherell (1987) termed these ‘interpretive repertoires’, with different repertoires being deployed for particular effects in social interaction.

The text takes paramount importance. Willig (2010) proposes that in discursive psychology knowledge about the participants in terms of their demographics and background is not necessary, for this type of analysis is concerned with exploring the

way in which reality is constructed within particular contexts through language, and not how these relate to pre-existing categories. As the approach centres on the ongoing construction of meaning that occurs in everyday dialogues between individuals (Gergen, 1994), it has been referred to as a ‘bottom-up’ approach (Gough & McFadden, 2001).

Before moving on to address some of the criticisms of discursive psychology, I outline the central tenets of a ‘dark’ or macro discursive approach below.

2.4.2 ‘Dark’ social constructionism and Foucauldian discourse analysis

Social constructionism was influenced in the 1970s and 1980s by the French historian, philosopher and psychologist Michel Foucault (Willig, 2010). His ideas have spawned a range of approaches that have been termed Foucauldian discourse analysis (FDA), ‘dark’ deconstructionism, and macro social constructionism (Burr, 2003). While FDA approaches are not uniform, Foucault himself did not aim to provide a definitive theory of anything, but rather aimed at challenging common conceptions, and to inform interrogative, socio-historical practice (McHoul & Grace, 1997; Sawicki, 1991).

In ‘dark’ deconstructionism or macro social constructionism meaning extends beyond the text and the immediate context in which language is used between speakers (Burr, 2003). Analysis concerns itself with how discourses construct objects and subjects, and offer subject positions through structures of language, social structure, practices and social institutions (Burr, 2003). A macro orientation or ‘top-down’ approach (Gough & McFadden, 2001) is thus adopted in that it examines the positions of people within historical and cultural contexts and the works of key institutions, such as the education, legal and medical systems (Tuffin, 2006).

FDA researchers examine the discourses available to people within a particular culture or society: a ‘discursive economy’, and then how these emerge, operate and change in a society (Kendall & Wickham, 1999; Willig, 2010). The implications of these discourses for how people think or feel (subjectivity), what they may do, and the material conditions within they may take place (Willig, 2010) are explored. In this way FDA focuses on the relations of power between discourse, institutional practices, and the ways people are enabled and constrained by discourses. It also examines their attempts to resist discourses (Parker, 2002; Semp, 2006). FDA explores the constructive power of discourses and how they work to legitimise ideologies and power relationships within society (Tuffin, 2006). The aim of such research is frequently deconstruction and to challenge the established discourses operating in society (Willig, 2010).

The criticisms of FDA will be discussed later in this chapter, but for now I wish to elaborate a little further some of the key concepts of Foucauldian approaches that I will draw on in my study of ED in New Zealand. This discussion is by necessity brief as Foucault's work is extensive and complex. Note that just like there is no one single way of doing discourse analysis, no Foucauldian method exists per se either (Hook, 2001). The appeal of using approaches derived from Foucault's work is his openness to researchers employing and applying aspects of his work to exploring other areas of social life. As Foucault (1974) states, "I would like my books to be a kind of toolbox which others can rummage through to find a tool which they can use however they wish in their own area"(p. 523).

2.4.2.1 Discourse

While 'discourse' has been defined above, I now expand a little on how it is defined by Foucault, although Foucault (1972) himself acknowledged that he may have added to the fluctuating meaning of the word by treating it sometimes as the general domain of all statements, and sometimes as regulated practices that account for statements (as cited in Mills, 2004). But in general, in FDA, discourses "are not simply groupings of utterances, grouped around a theme or issue, nor are they simply sets of utterance which emanate from a particular institutional setting, but discourses are highly regulated groupings of utterances or statements with internal rules which are specific to discourse itself" (Mills, 2004, p. 43). They are productive (Kendall & Wickham, 1999); practices that "systematically form the objects of which they speak" (Foucault, 1969, p. 49, as cited in Parker, 1999b, p. 3). Discourses, for example medical or physical discourses, can produce certain types of objects (e.g. madness, ill health) and offer subject positions (the mentally ill person, the 'sick' patient) in relation to objects (Kendall & Wickham, 1999; Mills, 2004). They delimit or circumscribe not only what can be said but also what cannot be said (Kendall & Wickham, 1999; Mills, 2004). They both enable and constrain ways of understanding phenomena and possibilities for action; they have the potential to activate, even 'call into existence' an object and to narrow the field of vision to exclude phenomena from being considered worthy of attention (Mills, 2004).

Foucault regards discourses as not just constructing objects in our reality, but also as constructing events and sequences of events in such a way that they come to be regarded by a culture as real, important, or "the true" (as cited in Hook, 2001, p. 525). Foucault (1981) emphasises how the world does not "turn towards us a legible face which we have only to decipher" (p. 67); instead order is imposed on it through discourse.

This is not to suggest however that discourses are closed. Mills (2004) comments that Foucault is concerned with the way in which “discourses inform the extent to which we can think and act only within certain parameters at each historical juncture” (p. 46). Discourses are further regulated not just in terms of their internal rules, but also in relation to other discourses (Kendall & Wickham, 1999; Mills, 2004). Discourses rely on, relate to, or differ from other discourses in ways that make possible the production of possible statements.

Discussing Foucault, Henriques et al. (1984) assert that

Every discourse (is) the result of a practice of production which is at once material, discursive and complex, always inscribed in relation to other practices of production of discourse. Every discourse is part of a discursive complex; it is locked in an intricate web of practices, bearing in mind that every practice is by definition both discursive and material. (as cited in Mills, 2004, p. 44)

Mills (2004) suggests that what Foucault is referring to is the “materiality of discursive structures” (p. 46); that the only way we can apprehend our world is through discourse and discursive structures and these structures lend a solidity that becomes difficult to think outside of. Kendall and Wickham (1999) however, in their delineation of steps to employ FDA, also point to the idea that Foucault’s notion of discourse requires consideration of ‘things’ as well as ‘words’. Through attempting to identify the rules of production of statements, rules that delimit the sayable and create spaces for new statements, Kendall and Wickham (1999) explain how we need to examine the operation of apparatuses, institutions and public aspects of life (e.g. schooling, church rituals). More on this notion of the material versus discursive later.

2.4.2.2 Knowledge/Power

If discourses and discursive practices regulate our knowledge of the world, make it difficult to think outside of them, and shape our social practices, then it becomes apparent that there is a close connection between discourse, knowledge, and power (Burr, 2003; Pauw, 2009). Indeed, for Foucault knowledge and/or the views of the world prevailing at any one particular time are intimately tied to power; power is part of knowledge in such a way that Foucault sees them as inseparable, as existing in a power/knowledge couplet (Burr, 2003; Kendall & Wickham, 1999). Burr (2003) argues that what we call knowledge refers to those constructions of phenomena that have received a ‘stamp of truth’ to them in our society, and what is possible to do or say is given by the version of events currently taken as knowledge in that society.

Yet it is important to understand that Foucault does not regard power as sitting in the possession of individuals, to be wielded by one over another (McHoul & Grace,

1997). Power resides in a web of relationships between discourses, which are also implicated in institutional practices and social structures (Burkitt, 1999; McHoul & Grace, 1997). Discourse can be seen as something that is “both constituted by, and ensures the reproduction of, the social system” (Hook, 2001, p. 522). Power is thus something that is exercised, not possessed; that exists in a relational model (Sawicki, 1991); or, as McHoul and Grace (1997) explain, “for the subject which power has constituted becomes part of the mechanism of power” (p. 22). Kendall and Wickham (1999) argue that power in Foucauldian terms could more rightly be regarded as ‘energy sources’ that ‘keep things going’, and it is thus the ‘field of power’ and not authors of power that are the subject of investigation (McHoul & Grace, 1997). Power from this perspective is also not necessarily repressive, but productive (Sawicki, 1991).

Mills (2004) suggests that discourses are kept in circulation (power) through a range of internal and external mechanisms. Internal mechanisms refer to operations such as commentary, e.g. academic commentary, where discourses are commented upon by others, keeping texts in circulation. Discourses that are sanctioned or embedded in institutions and social practices may be seen as external mechanisms. And a further mechanism is what Foucault refers to as “disciplinary power” (Burr, 2003, p. 69).

According to Foucault, over the last 150 years a number of institutional and cultural practices have arisen that have constituted the individual of contemporary Western society (Burr, 2003). For example, according to Foucault, population increases, and the moves from agricultural to industrial economies, brought with them social practices which allowed for certain discourses or knowledges of the person to be brought into effect. Ways of categorising and controlling the population developed that gave rise to classifications and divisions involving a move toward surveillance and examination (Burr, 2003; Pauw, 2009). Foucault highlights how medicine, psychiatry, criminology and their corresponding institutions such as hospitals, asylums and prisons employed disciplinary practices that divided people up into categories and created particular types of people or subjects through techniques of individualisation (Sawicki, 1991). And so the divisions of healthy/ill, sane/mad and legal/delinquent came into being. Of particular interest for this study is Foucault’s (1976) concept of biopower, of how the body, and in particular sexuality, became a site of power relations:

At the heart of this economic and political problem of population was sex; it was necessary to analyse the birth rate, the age of marriage, the legitimate and illegitimate births, the precocity and frequency of sexual relations, the ways of making the fertile or sterile, the effects of unmarried life or of the prohibitions... Things went from ritual lamenting over the unfruitful debauchery of the rich, bachelors and libertines to a discourse in which the sexual conduct of the

population was taken both as an object of analysis and a target of intervention. (as cited in Burr, 2003, p. 70)

Foucault draws on Bentham's description of the panopticon to illustrate how the power of surveillance operates as a method of social control. The panopticon was an architectural concept for a circular-shaped prison which allowed for the separation of prisoners whilst they were simultaneously under the continual surveillance of the prison guards, who themselves were positioned so that they would all be within the view of the prison governor (Payne, 2002). The effect of the panopticon was to make it unnecessary to use force in prisoner control, as the prisoners came to realise that they were under constant surveillance, and would as a result begin to self-regulate or comply with the expected norms. Foucault asserts that various forms of practice in contemporary society can come to operate as similar mechanisms of surveillance through which people then come to control and regulate their own behaviour according to prevailing standards (McHoul & Grace, 1997). For Foucault, this constitutes a move away in Western societies from 'sovereign power', where the sovereign controlled the populace, to 'disciplinary power' where individuals are managed and regulated by willingly subjecting themselves to the scrutiny of others, to experts (Burr, 2003). Cheek (2000) has argued that healthcare is one example where practice moves from the patient being cared for by a health professional, to the patient managing his or her own health, to "the control of whole population in the name of public health, and in the quest to normalise such populations" (p. 30).

It is important to note though that Foucault (1976) sees much of this disciplinary power as invisible, in the sense that he claims that "power is tolerable, only on condition that it masks a substantial part of itself. Its success is proportional to its ability to hide its own mechanism" (as cited in Burr, 2003, p. 73) Parker (2005) argues that the discipline of psychology can be seen to function as part of such surveillance, acting as a disciplinary technology of power/knowledge and playing a central role of the regulation of people in contemporary society. More on this later.

2.4.2.3 Resistance

The Foucauldian concept of power is not an absolute one, and discourses in themselves are not deterministic as there is always the possibility of resistance and indeterminacy (Arribas-Ayllon & Walkerdine, 2008). According to Foucault, power and resistance go hand in hand. Prevailing discourses are constantly under threat from contradictory, alternative discourses which can serve to unsettle and dislodge them from their position as truth (Burr, 2003). It is by setting the contrasting discourses against one another that

resistance can be identified. The possibility of resistance is already contained within the notion of power (Mills, 2004). “Forces have a capacity for resistance, such that power is only exercised in relation to a resistance, each force having the power to affect and be affected by other forces” (Kendall & Wickham, 1999, p. 50). Essentially then, resistance to power is part of the exercise of power; power is enmeshed within discourse (Hook, 2001).

Foucault emphasises that discourse is what both constrains and enables writing, thinking and speaking – it is thus inhibitive *and* productive (Hook, 2001). Resistance is a difficult construct however, in that it seems that it can only ever take place within predetermined boundaries, within existing discursive structures. As Cromby and Standen (1999) suggest, Foucault wanted to leave room for resistance and change in his construct of power, but it is difficult to understand how “a subjectivity forged through power can bite the hand that made it and fight back” (1999, p. 146). Burr (2003), however, writes that power and resistance are two sides of the same coin as the power in one discourse is only “apparent from the resistance implicit in another” (p. 69).

2.4.2.4 Archaeology and genealogy

Kendall and Wickham (1999) maintain that archaeology, genealogy and discourse are the tools Foucault uses to give order to history. The analysis of discursive structures, their formation, transformation and correlation, is what is meant by ‘archaeology’ and this constitutes the first ‘ordering tool’ (Kendall & Wickham, 1999; McHoul & Grace, 1997; Mills, 2004). The rules of formation are the conditions which make possible in the first place the objects and concepts of a discourse. The rules of transformation are the limits of its capacities to transform itself, the ‘threshold’ from which it can bring new rules ‘into play’. The rules of correlation are “the ensemble of relations which a discourse has with other discourses at a given time and with the ‘non-discursive context’ within which it finds itself” (McHoul & Grace, 1997, p. 44).

Foucault (1972) writes of archaeology:

It does not imply the search for a beginning; it does not relate to geological excavation. It designates the general theme of a description that questions the already-said at the level of its existence, or the enunciative function that operates within it, of the discursive formation and the general archive stem to which it belongs. Archaeology describes discourses as practises specified in the element of the archive. (as cited in Mills, 2004, p. 44)

Archaeology can therefore be regarded as the process of investigating the archives of discourse (Kendall & Wickham, 1999). The archive can be seen as a discursive structure, a set of rules that govern what can be said, in what form, and what

is counted as worth knowing at any particular time period and for a given society (Mills, 2004). Thus archaeology is conducted not to uncover truth, but to discover support mechanisms that keep discourses in place, both intrinsically and in relation to other discourses and to the extra-discursive in the sociocultural sense (Mills, 2004).

Kendall and Wickham (1999) explain how Foucault's genealogy can in many ways be seen as an extension of archaeology, as a kind of successor. It maintains many of the elements of archaeology, including the examination of bodies of statements in the archive. What sets it apart however is that Foucault at this point adds a new concern with power to the analysis, a concern which according to Kendall and Wickham (1999) "manifests itself in the 'history of the present'" (p. 29). They comment that "Genealogy makes the older guests at the table of intellectual analysis feel decidedly uncomfortable by pointing out things about their origins and functions that they would rather remain hidden" (ibid.). It is a tool that is meant to make us see beyond the contingencies that have made us what we are, so that we may appreciate what we have *not* thought, and *not* been.

In this way Kendall and Wickham (1999) argue that genealogy is essentially a way of putting the method of archaeology to work or the "strategic development of archaeological research". For Nikolas Rose (1984) genealogy concerns itself with "disreputable origins and unpalatable functions" (Introduction, no page number given); it is a way of using archaeology to answer problems about the present.

Note that Foucault's approach to history and use of historical methods is, most importantly, about problematisation – it does not close off an analysis having revealed allegiances and affiliations, but it reminds us "not to let history stop, not to let us settle on a patch of sensibleness in a field of strangeness" (Kendall & Wickham, 1999, p. 23). McHoul and Grace (1997) point out how Foucault regards his genealogical research as opening up debate, providing 'propositions' or 'game openings' and not dogmatic assertions. They are "philosophical fragments put to work in a historical field of problems" (Foucault, 1981, as cited in McHoul & Grace, 1997, p. 85).

2.4.2.5 Subjectivity

For Foucault, the formation of subjects is part and parcel of the productivity of power (Kendall & Wickham, 1999). Subjects are the products of discourse in that discourses contain a range of subject positions which enable or contain experience and practice, or contain 'specifications for subjectivity' (Parker 1994a; Willig, 1999). Davies and Harre (1990) suggest that "once having taken up a particular position as one's own, a person inevitably sees the world from the vantage point of that position and in terms of the

particular images, metaphors, storylines and concepts which are made relevant within the particular discursive practice in which they are positioned” (p. 46). The subject position also brings with it certain rights and obligations. Thus the focus is on what can be thought, felt, done and experienced in terms of the discourses within which subjects are located and the positions offered. Willig (2010) provides the example of the biomedical discourse, where those who are ill are positioned as ‘patients’ – this subject position locates such people as passive recipients of expert care (the doctor or specialist). The body of the patient becomes of interest to doctors and the subject may be treated as part of the practice of medicine and its institutions.

Foucault shifted attention away from the notion of a unitary rational subject as he focused on the contradictory discourses which shape us (Semp, 2006). The subject is an effect of power, and Foucault’s analysis concentrates on the process by which subjectivity is produced at a particular juncture (Kendall & Wickham, 1999). Mills (2004) however notes that some regard Foucault as charting ‘the death of the subject’, since Foucault (1980) commented, “One has to dispense with the constituent subject, to get rid of the subject itself, that’s to say, to arrive at an analysis which can account for the constitution of the subject within historical framework” (p. 117).

Foucauldian concepts have much to offer in that they can lay bare the discourses that shape experience and practice, and offer an analysis of social, cultural and historical issues related to these. Foucault’s accounts of power and surveillance are useful tools to understand the effect of a discursive economy. Nonetheless, there remain some unanswered questions, which are related to the debates discussed below.

2.5 Unanswered questions and debates

There are unanswered questions and overlapping debates in both the light and dark approaches to discourse analysis (Burr, 2003; Cromby, 2011; Willig, 2010), as will be outlined briefly below. It is important to note that these debates are being applied generally, since there exist many forms of discursive psychology and many forms of analysis that lay claim to being FDA. Further, as Hook (2001) has commented, Foucault’s thinking in relation to the concept and methodology of discourse was “complex, difficult, nuanced and, at times, flawed and contradictory” (p. 543).

2.5.1 Relativism versus realism; discourse versus materiality

There are disagreements as to what extent there is a ‘world out there’ independent of constructions. Realism asserts that there is an external world that exists independently of our representations of it; that there are underlying structures that can be described (Burr, 2003; Cromby & Nightingale, 1999; Parker, 1994b). Our representations are underpinned by this reality and even if accurate representations cannot be obtained, knowledge may be gained (Burr, 2003). Relativism in contrast, proposes that since any such world is inaccessible both in principle and practice, it need not be postulated (Cromby & Nightingale, 1999). All that is available are various (equally valid) constructions of the world, and these cannot be judged against a reality to determine truthfulness (Burr, 1995, 2003).

Micro approaches tend to be relativist, which can be useful in critiquing ‘truth claims’ and drawing attention to the constructed nature of phenomena. On the other hand, this makes it problematic to assume a critical position (Burr, 2003; Cromby & Nightingale, 1999; Hook, 2001; Parker, 2002). As Burman (1990) asserts, “It dissolves all solutions as remorselessly as they dissolve the problems from which they arise” (as cited in Cromby & Nightingale, 1999, p. 8). Hook (2001) argues that discursive psychology reduces discourse to narratives, representation or language, thereby prioritising textual forms of data at the cost of material forms and paying insufficient attention to the historical and socio-political circumstances which may give rise to, and are a part of, the order of discourse. (Hook does acknowledge that the later work of Potter and Wetherell [1992] includes more of a material focus.)

FDA may adopt a somewhat different approach, holding that while all social constructions are relative, they are not arbitrary but the products of social process shaped by material resources and power relationships (Cromby & Nightingale, 1999). Thus while ‘things’ are still constructed, they are linked with material practices, and the only way we can apprehend our world is through discourse and discursive structures, with these structures lending a solidity that becomes difficult to think outside of. Burr (2003) proposes that discourses are thus intimately connected to institutional and social practices that have a profound effect on our lives, on what we can do and say, and what can be done to us. These social structures and practices in turn are either enforced, embedded in, or encouraged by law and other forms of state control. It is this intimate connection that provides a context for some discourses or versions of representing phenomena or individuals to become seen as truth, and others as fiction (Burr, 2003). Materiality then, is intrinsic to a Foucauldian analysis, but Kendall and Wickham

(1999) argue that for Foucault, the non-discursive is always within the ambit of discourse. There is contradiction here however, as on the other hand Hook (2001) asserts that Foucault's priority is not that of 'reading' or textuality, but of materiality, conditions of possibility and historical circumstance. Hook (2001) therefore argues that Foucault's analysis could thus be seen as fundamentally based on the extra-discursive!

Willig (2010) takes another stance, maintaining that while FDA pays attention to the relationship between discourses and institutions, it still does not make assumptions about the nature of the world. It does not, for her, sufficiently address whether reality can be seen as separate from, or outside of, discourse, and to what extent reality can be said to constrain discourses. Mills (2004) explains that Foucault never defined 'the real' because he maintained that we have access only to discursive structures which determine our perceptions of the real. So while Foucault's theory draws on materiality, it does not, for some (Cromby & Nightingale, 1999; Sims-Schouten et al., 2007), give enough credence to the extra-discursive (material, economic, institutional conditions and practices). I would argue that while Foucault's method does allow for consideration of materiality, it may be strategic to explicitly recognise the role of extra-discursive factors, and to adopt the critical realist approach developed by Burr (1999, 2003), Cromby and Nightingale (1999), Parker (2002), Sims-Schouten et al. (2007), and Willig (2010), which is described later in the chapter.

2.5.2 Structure/determinism versus agency; social versus individual

The various forms of discourse analysis accord different degrees of agency to the individual. In micro forms, where the emphasis is on the manipulation and use of language to achieve interpersonal effects, the emphasis is on the ability of the individual to construct particular versions of accounts, and so individuals are endowed with some degree of agency even if this is 'performed' in interpersonal contexts (Burr, 2003). Yet while discursive psychology sees the person as capable of manipulating language, the basis of this ability is left unclear (Burr, 2003; Willig, 2010), thereby reinforcing a "one-sided individualistic emphasis on the rhetorical strategies of speaker" (Fairclough, 2006, p. 25). Discursive psychology does not necessarily dispute the existence of a subject with emotional states, but suggests that these need to be 'bracketed off', and that subjectivity and emotion is 'performed' in interpersonal contexts. Researchers do not see the person as possessing an essential nature either biologically pre-programmed or acquired, but the form of subjectivity we live out and experience relies on the stories of humanity that are found embedded in our language (Burr 2003). Willig (2010)

comments that in this way discursive psychology “brackets, and yet relies upon, a notion of motivation or desire, which it is incapable of theorising” (p. 107).

Parker (2002) further criticises this approach for its restriction to a particular text, rather than locating the text within wider discursive practices which may regulate people’s understanding of themselves. This ‘light’ approach may overlook the contexts within which relations themselves are located (Burkitt, 1999). In this way Parker (2002) argues that discursive psychology fails to adequately address issues of power and politics. Where power is referred to, it is seen as an effect of discourse, an effect of being able to ‘warrant voice’ in interaction (Gergen, 1989, as cited in Burr, 2003).

In macro approaches, the individual, or subjectivity, is regarded as the effect of discursive structures and the subject positions these invite (Blackman, Cromby, Hook, Papadopoulos & Walkerdine, 2008). Individuals may thus have no capacity to bring about change independent of the conditions in which they find themselves (Burr, 2003). Individuals become the product of the society they are born into and their decisions explained in terms of societal structures and discourses. Foucault, for example, focuses on how we are constrained by our position in discursive limits (Mills, 2004), which may give the impression that we are “eternally trapped in constantly respun webs of power and domination, from which there is no historical escape” (Burkitt, 1999, p. 70). Some authors have suggested that this is akin to discourse determinism and power essentialism (Blackman et al., 2008; Burr, 1999, 2003; Kendall & Wickham, 1999), thus leading to the ‘death of the subject’ in which individuals have no capacity to bring about change independent of the conditions in which they find themselves (Burr, 2003; Mills, 2004). Indeed, various authors (Blackman et al., 2008; Burr, 2003; Butt, 1999; Cromby & Standen, 1999; Parker, 2002) argue that macro approaches may risk reproducing the very dualism (individual versus social) that mainstream psychology has fallen prey to, but instead of privileging the individual the social is over-privileged, with too much credence given to an analysis of historical foundations and social structures. Instead, Adorno (1967) comments that “both (individuals and social) are torn halves of an integral freedom, to which however they do not add up” (as cited in Parker, 2002, p. 2). Individual and society cannot be split or separately considered (Henriques et al., 2005).

Willig (1999) points out that Foucault claimed only to have described systems of discursive ground rules, and he himself said that these still needed to be accounted for. Fox (1997) has similarly maintained that Foucault did not have time to fully address his later concern with the way in which discursive subjects became persons – that is, “the

history of how an individual acts upon himself, in the technology of the self” (Foucault, 1988, p. 19). Willig (1999) thus argues that while FDA allows us to understand changes in discourses and their implications for subjectivity, it does not allow us to account of the emergence and maintenance of the subject and of how people take on or invest in particular discourse positions, and thus does not help us fully understand the dynamics of the self.

It is interesting though to note that Foucault did give attention to how the individual is constituted in contemporary Western society, to how we have come to see ourselves as individuals with subjective experiences (Mills, 2004). Cromby and Standen (1999) thus disagree with the criticism that has been levelled at Foucault that he was denying the subject, and instead regard his work as a sustained effort to understand the ways in which individuals become subjects within particular constructions. They maintain that his work encourages us to challenge and critique particular constructions of self and society that the dominant order imposes.

2.5.3 Investment in or taking up discourses

Parker (2002) argues that we are not “written through discourse” (p. 195) and that discourse does not just “wash through us” (p. 135). Instead, Cromby and Standen (1999) suggest that we need to engage in study that recognises the “thoroughly intertwined continuation of self and society” (p. 147), or, to paraphrase Burr (2003) and Willig (2010), that recognises how people make emotional investments in particular discursive positions. Cromby and Standen (1999) suggest that what social constructionism has not allowed us to do is account for continuity and variability in people’s accounts.

Both micro and macro approaches do acknowledge that a concept of the individual emerges dependent upon ways of accounting for oneself available within a culture (Burr, 2003). Foucault concentrated on describing the type of subject that that could be constituted within contemporary Western society – how we come to see ourselves as individuals, to recognise our “specificity of the self” in relation to historically variable social and institutional practices (including psychiatry and psychology) (Cromby & Standen, 1999, p. 143). Rose (1996, 1999), drawing on Foucault, has argued that psychoanalysis has infused modern culture in ways that shape people’s conceptions of themselves, and Parker (2002, 2005) suggests that we therefore describe and constitute ourselves in terms of psychoanalytic concepts; the social sciences become social principles (Pauw, 2009). For example, the concepts of defences,

the unconscious and past experience are all parts of popular representations of what psychology is, and Parker (2005) maintains that people talk about themselves as if these things were true, to the extent that they become true in a 'psychoanalytic culture'. Butt (1999) comments that people in today's society talk about emotions more frequently than previous generations and have an extended emotional vocabulary – psychology and psychoanalysis as disciplines have been instrumental in this development. Rose (1996, 1999) refers to this notion as the 'psy complex', meaning the

network of theory and practices that comprise academic, professional and popular psychology, cover(ing) the different ways in which people in modern western culture are categorised, observed and regulated by psychology as well as the ways they live out psychological models in their own talk and experience. (Parker, 2002, p. 126)

So our everyday accounts are given in terms of theories which trickle back from the discipline and into the explanations people give of themselves (Parker, 1994b).

Parker (2002, 2005) and Hollway (1989) thus argue that we need to take psychoanalytic explanations seriously, which has led to a 'psychosocial approach' (Frosch & Baraitser, 2008; Frosch, Phoenix & Pattman, 2003; Gough & McFadden, 2001; Hollway 1989, 2008; Parker, 2002, 2005) within which psychoanalysis and discourse analysis are combined to explain how subjects invest in particular positions in discourse. In this approach, Lacan is frequently drawn on to explain how subjects invest in positions guided by intrapsychic processes or defence mechanisms that allow the subject to ward off anxiety and protect vulnerable aspects of the self (Hollway & Jefferson, 2004). Frosch et al. (2003) suggest that such an approach will 'thicken' the discursive reading by drawing on biographical information and the observations of the researcher to understand how participants come to invest in particular discourses.

Parker (2002) reminds us, however, that psychoanalysis is in itself a particular discourse that is culturally and historically located, and that it must be used with the awareness that it operates as a particular form of knowledge. He suggests that the issue is not whether psychoanalysis is true or not, but how it circulates through culture, how it constitutes the subject, and how it can be drawn upon to link the personal and the political. Many contemporary introductory psychology textbooks frame psychoanalysis as 'non-scientific', and there has been a somewhat dismissive stance in some academic psychology circles towards psychoanalysis (Shedler, 2010). Authors such as Shedler (2010), however, present strong arguments for the efficacy of therapies based on psychodynamic principles. Nonetheless, it is possible that with developments of and resistance to psychoanalytic traditions, and the emergence of alternative traditions in

psychology (such as narrative, systems, and cognitive behaviour therapy) other forms of psychological discourse are shaping subjectivity in contemporary culture. As Parker (2005) has pointed out, the discipline of psychology is very different in different cultures and at different points in history. Perhaps it is to these variations that we can turn to understand more fully how individuals draw on particular discourses.

2.5.4 Embodiment

Some authors (e.g. Burr, 1999, 2003; Cromby, 2005; Harre, 1999) take issue with the lack of awareness of the body, or embodiment in social constructionist research. Cromby (2005), and Cromby and Standen (1999) argue that to facilitate *critical* social constructionist work we need to engage in research of embodied activity in the context of a material world. They argue that taking embodiment more explicitly into account is especially important if we are considering those people for whom their embodied nature is an issue. For these people, they propose that their disability or impairment constitute defining factors in relationships with others and in their experiences – while their illness or disability may be socially constructed and sustained by social practices (Burr, 2003), they are not just matters of discourse or language, but enter into and influence the practices and interactions of which they are a part.

Indeed, Cromby (2005) Cromby and Standen (1999) suggest that the body is a biological machine that provides the material preconditions for subjectivity. It provides the substrata for understandings and each body interacts in different ways with socially obtained discourses. The body is not a pure metaphor or text, and social constructionism may downplay the significance of its functional, physiological, hormonal, anatomical and phenomenological aspects. They argue that bodies are not so similar to each other and malleable by discourse that they may as well not be there!

FDA has demonstrated how the body can be understood as a site of power, and shown how those bodily processes which concern us are implicated in a wider process of social control. FDA can highlight how discourse can produce bodily experience, and give it meaning. But Burr (1999) suggests that bodily experience is not only contingent on discourse practices and positioning, confined to its social construction through discourse. Likewise Sampson (1998) emphasises that we must take into account “the embodied nature of discourse itself” (p. 24) or as Durrheim and Dixon (2005) have suggested, regard language and bodily practices as being in a dialectical relationship. Cromby and Nightingale (1999) suggest that “bringing in the body will create problems, but we emphasise that leaving it out has already done so” (p. 11).

2.6 Summary and solution

In examining the various approaches to social constructions and discourse analysis, I have been struck both by the potential for analysis each approach offers and by the debates they generate and questions that remain unaddressed. My solution for the purposes of the present study is thus to engage in discourse analysis that:

- incorporates elements of both approaches, acknowledging both the interpersonal nature of accounts, and the wider social structures and institutional practices within which they are located;
- takes into account extra-discursive factors in an attempt to more fully explain how individuals may invest in particular discourses; and
- adopts a critical realist stance, and a dialectic, systems approach.

I elaborate on this solution below.

2.6.1 Blending the two approaches, and the extra-discursive

Burr (2003) and Burkitt (1999) argue that micro and macro approaches need not be seen as mutually exclusive and can be synthesised to give credence to the interpersonal nature of accounts and the wider social structures and institutional practices within which they are located. Some authors (e.g. Burkitt, 1999; Burr, 2003; Butt, 1999; Davies & Harre, 1990; Fairclough, 2010) have attempted versions of this, and Parker (2002) notes that in practice researchers often borrow ideas and move between these theoretical frameworks, even when they are engaging in ‘honourable fudges’ (Michael, 1999) or blurring genres (Gergen, 1994).

What is needed, then, is a social constructionist approach that can account for materiality and institutions, address the relationship between the individual and the social, and encompass a notion of the human subject (Nightingale & Cromby, 1999; Parker, 2002). In other words, a dialectical critique which can acknowledge that life is “irreducibly multidimensional” (Burkitt, 1999, p. 80).

This study attempts to offer an analysis closer to what Alvesson and Karreman (2000) describe as a meso analysis, which combines sensitivity to language and how it is used in interpersonal contexts (micro approach) with an awareness of broader patterns of meaning, discourse and materiality (macro approach). It thus allows a view of individuals as authors of their own history, but also as authoring under conditions given by historical and material conditions (Burkitt, 1999). It draws on discourse as being both ‘social action and interaction’, both text and context, both inside and outside the text (Fairclough, 1993, as cited in Hook, 2001). It tries to see discourse as an effect of

power as well as an instrument of power (Hook, 2001). It is a critical discourse analysis in that it aims to provide “an account of intricate relationships between text, talk, social cognition, power, society and culture” (Alvesson & Kärreman, 2000, p. 1).

Willig (1999) argues that every discursive practice offers more than one possible way of relating to it, and it thus follows that subjectivities are not determined but accommodated by the material and personal conditions in which they arise – in other words, discursive practices offer ‘potentialities’ that can be accommodated by their present. Research thus needs to be able to account for how individuals invest in or draw upon particular discourses available within society (Burr, 2003; Sims-Schouten et al., 2007; Willig, 1999, 2010). We need to take account of the situated nature of accounts as well as the practices and social structures within which they are constituted (Wetherell, 1998); of how the “social becomes personal without denying the activity and contribution of either social or personal domains” (Dodds, Lawrence & Valsiner, 1997 as cited in Burr, 2003, p. 192). Cromby and Nightingale (1999) suggest that the way forward is to ground analyses with reference to interpersonal and material factors *and* personal-social histories that constrain identities and subject positions and influence what we do and say and how and why we draw upon certain discourses, so that we may “explain the world, in all its extra-discursive intransigence and mess” (p. 10). Young (1998) similarly writes that “we need a way of situating the production of knowledge, and that often means situating it in such a way that we connect biography with history” (as cited in Parker, 2002, p. 3).

Personal social histories include relevant aspects of the subjects’ personal background, biographical events and experiences. Hollway and Jefferson (2004) argue for an approach that positions research subjects as people “whose inner worlds cannot be understood without knowledge of their experiences in the world, and whose experiences of the world cannot be understood without knowledge of the way in which their inner worlds allow them to experience the outer world” (p. 4). We need to look at their particular biographies and how these lead people to draw on discourses in interpersonal contexts (Hollway & Jefferson, 2004). Parker (2002) suggests that in this way we are calling for a ‘complex subject’. He argues that we need to be aware how “all choices are conditioned by local sets of circumstances that it might be possible to move in and out of, and perhaps even to control, and these sets of circumstances are also woven into cultural-political environments that constitute where it is possible for us to move, and what it is possible for us to think” (p. 4). To achieve this, Parker argues that we need to both ‘map the ground-plan’ as well as the psyche, considering the

intentions and desire of the individual and the operation of social structures and discursive forms.

Sims-Schouten (2004) and Sims-Schouten et al. (2007) in their studies explain how aspects of participants' social and personal history and background are relevant for better understanding uptake of discourses. In their exploration of women's uptake of various childcare options in the United Kingdom, they not only explore the discourses and discursive practices surrounding childcare, the working mother, and motherhood, and how these may locate women by offering them various subject positions, but also provide examples of how personal and social issues, in addition to material conditions, create conditions where individuals use particular discourses to explain choices, and invest in particular discourses that have implications for subjective experience. For example, they asked questions of their participants around age, income, type of job, number of children, availability and desirability of childcare facilities, type of childcare options and relationships to these, to offer a fuller analysis. The overall approach, according to Sims-Schouten et al. (2007), is based on three dimensions that include aspects of FDA, elements of interpersonal discursive practice (in exploring the discourses participants use to achieve their desired outcomes), and personal-social-material factors. In this type of approach, the concern is with why individuals draw on certain discourses rather than others, and the roles of factors such as material conditions, personal history, and background in explaining these.

My research draws on the above authors, and is psychosocial in that I attempt to connect the personal social backgrounds, including aspects of the subjects' personal background, with their biographical events and experiences, embodiment and material conditions, and explore how these lead people to draw on particular discourses in interpersonal contexts. In this approach, as Willig (1999) expresses it, "meanings are afforded by discourse, accommodated by social structures and changed by human actors" (p. 44)

2.6.2 Critical realism

This study takes a critical realist position, holding that there are enduring structures and mechanisms that underlie and produce observable phenomena (Bhaksar, 1989; Parker, 1994a, 2002). While critical realism may subscribe to ontological realism, it draws on epistemological relativism to acknowledge that the knowledge we have of 'the world out there' is always provisional and open to construction (Parker, 2002; Pujol & Montenegro, 1999). Critical realism embraces epistemological relativism insofar as it

acknowledges “the impossibility of knowing objects except under particular descriptions” (Bhaksar, 1978, p. 249; Pujol & Montenegro, 1999; Willig, 1999). But in the type of critical realism put forward by Parker (2002), the notion of truth as an entirely discursive effect is resisted, instead a reality beyond this is asserted in order to be able to assume a strong political position (Hook, 2001). Material practices are given an ontological status apart from, but related to, discursive practices, and these material practices are held to accommodate, not simply determine, discourses that may arise. The analysis thus examines the historical, social and economic conditions that make possible and constrain the use of discourses and discursive practices, and then traces their psychosocial effects to help us understand the dynamics of the self (Sims-Schouten et al., 2007; Willig, 1999). Critical realism offers the possibility of arguing for particular ways of understanding and doing things, of why people use some discourses and not others. It thus “offers an alternative to naïve versions of realism and totalizing versions of relativism” (Sims-Schouten et al., 2007).

2.6.3 Dialectical science and a systems framework

A dialectical approach offers a way of understanding reality as dynamic, and of understanding how change is characterised by contradictions (Parker, 2002). Dialectical thinking encourages a move away from dualism towards synthesis. It requires a move away from a reductionist analytical method and towards one that adopts a systemic analysis understanding parts in relation with a whole system (Willig, 1999).

Levins and Lewontin (1985) have argued that reductionist science is inappropriate for the study of complex phenomena because it inappropriately tries to isolate parts and their relative contributions and cannot conceptualise of complex wholes. A dialectical approach allows for interconnectedness and sees parts of the system as intimately connected, and can thus hold the proposition that social life can form the material basis of human experience, but also that social conditions do not determine human experience. It enables a focus on potentialities offered by the environments and our abilities to adopt these. Burr (2003) has proposed a systems model drawing on Sampson (1989) and Bateson (1972). She claims that a systems model offers theoretical constructs that may be capable of bridging the gap between individual and society, structure and agency, the material and the constructed.

Systems theory proposes that individuals need to be understood within their contexts and that to understand a whole organism or phenomenon, not only the elements that make up the organism or system must be studied, but also the relationships among

them. Individual behaviour can thus be understood only by regarding it as situated in the complex and reciprocal interaction between individuals and the systems they live in, including historic and cultural contexts. “The individual, the social practices in which they are engaged, the social structure within which they move, and the discourses which frame their thought and experience, become aspects of a single phenomenon” (Burr, 2003, p. 187–188).

Berger and Luckman (1966, as cited in Burr, 2003) likewise regard the relationship between individual and society as working in both directions, with each affecting the other through a process that involves externalisation (assigning symbols and thus meaning to events), objectification (allowing for constructs to assume an existence independent of human activity) and internalisation (whereby through socialisation we take on constructions and thus interact with others in meaningful ways). This approach allows us to think of persons as being both agentive, actively constructing the world, and constrained by society (to the extent that we live within this world and its constraints and possibilities). As Michael (1999) comments, this is also a heterogeneous approach, characterised by a both/and rather than an either/or approach, giving credence to the ‘real’ *and* the constructed, the material *and* semiotic. The implications for discourse analysis are numerous: Discourses can be seen as products of social structure *and* of individuals, and can be seen to influence and be influenced by these factors. We are essentially claiming back the possibility of a personal and psychological space as a site of enquiry, and if these are regarded as a single system or part of the same entity, then the issue of agency is less fraught (Burr, 1998, 2003). Individuals are both shaped by discourses and draw on discourses (not necessarily unconsciously, as in psychoanalysis [Hollway & Jefferson, 2004]) to justify positions. The discourse analysis is thus multi-level, (Riley, 2002) offering distinct advantages in that allows an appreciation of how people may understand themselves “both in terms of the discourses available in their social milieu and the conditions within which they find themselves, and which offer a range of possible ways of being” (Sims-Schouten et al., 2007)

It is interesting to reflect on Foucault’s notion of power in relation to a systems framework. As previously described, Foucault regarded power as akin to what could be described as an ‘energy source’, not as something to be wielded. Kendall and Wickham (1999) further urge us not to regard Foucauldian methods as arguing for cause and effect relationships, but as advocating for considerations of interrelationship, and not

closing off 'systems'. In this way, a Foucauldian model may sit relatively comfortably alongside a systems framework.

The approach I have outlined above may not be without its difficulties, but it is an approach that tries to do what Wetherell (2012) reflects is important:

... to develop a way of thinking and a line of argument that might flow from psychobiology through to social analysis [where it is possible] to put together integrated readings of the somatic, discursive, situated, historical, social, psychological and cultural bases" of human experience (p. 4), and "how these patterns interrupt, cancel, contradict, modulate, build and interweave with each other. (p. 14)

I further draw reassurance from Gergen's (1994) reflection that "the value of psychological discourse lies not in its capacity to reflect truth but in its capacity to carry out relationships" (p. 70).

In the next chapter, I set out how these ideological foundations translate into practice in this study.

Chapter 3: Method

As to those, in short, for whom to work in the midst of uncertainty and apprehension is tantamount to failure, all I can say is that clearly we are not from the same planet (Foucault, 1984, p. 7)

Having outlined the theoretical underpinnings and methodological assumptions in the preceding chapter, in this chapter I present the method adopted in this research. I describe the aims of my study, the various sites for data analysis, the recruitment of participants, and provide details on data analysis. I also reflect on the criteria for assessing the research rigour of this study and consider relevant ethical issues.

3.1 Study aims

In this study my aims were to:

- identify the discourses and practices surrounding embryo and ED in contemporary New Zealand culture;
- explore how these construct embryo, ED and offer subject positions
- explore the implications of these for subjectivity and experience; and
- explore how individuals take up these various discourses to motivate their understandings and decisions in relation to ED.

3.2 Selection of texts and sites

Parker (1992) suggests that discourses are realised in texts and according to Willig (2010), whenever a researcher is exploring a topic on which there may be ‘public’ and ‘expert’ discourses it is necessary to use multiple texts. The various ‘texts’ that formed the basis of my analysis are discussed in the following subsections.

3.2.1 Academic literature in the field of ED

I analysed the academic literature relevant to ED, including empirical studies of ED and embryo disposal options, and debates and commentary on ED terminology, policy and practice. My purpose in conducting the academic literature review was twofold. Firstly, the review would provide a context for my study and an overview of the academic debates and issues in relation to ED. Secondly, and more critically, the review constituted part of the analytic process in that I engaged in a discourse-analytic reading,

and identified extra-discursive factors related to embodiment, social personal factors and material conditions.

3.2.2 Legislation, policy and practices – HART Act, ACART guidelines, ECART decisions, counselling guidelines and position documents

Assisted reproductive technologies in New Zealand are regulated through the Human Assisted Reproductive Technology Act 2004 (hereafter cited as HART Act) which stipulates guiding principles that are to be considered in the use of any assisted reproductive technology. The Advisory Committee for Assisted Reproductive Technologies (ACART) was set up by the government under the HART Act with the brief to provide recommendations to the Ministry of Health, and draw up guidelines for practice as regards assisted reproductive technologies, including ED. In the case of ED, ACART (reconstituted from NECAHR – National Ethics Committee for Assisted Human Reproduction) recommended guidelines for practice in 2005. These were revised in 2008, and clinics are expected to follow the guidelines. These serve as more than guidelines however, as in order for clinics to be able to offer ED, and for donors and participants to proceed, ethical approval for each case is required by the Ethics Committee on Assisted Reproductive Technologies (ECART), with approval dependent on following the guidelines. Given the critical role played by ACART and ECART in the enactment of ED, it was important to me to analyse the legislation, policies and guidelines, as well as the decisions of ECART (as reflected in their online meeting minutes). Further, since counselling is given a central role in ED, with both individual and joint counselling required before an application can be made, I also engaged in a discourse-analytic reading of the counselling guidelines that (in)fertility counsellors in New Zealand (and Australia) base their practice on, and of a position document on ED released by the Australian and New Zealand (In)fertility Counsellors' Association (ANZICA) in 2006.

3.2.3 Institutional practices – Counsellor interviews

Since counsellors play a central role in the ED process in New Zealand, I interviewed counsellors employed in both public and private fertility services as to their understandings of and their practice in relation to ED. My aim was to analyse their discourses of both ED and their role, and consider how these and the discursive practices they engaged in potentially shaped ED practice, with implications for the

subject positions to which donors and recipients may be called. As Rawlinson (1987) notes, discourses become evident in practices: “Any discourse is intertwined at every point with the technologies and the practices of the disciplines and professions in which it is spoken” (p. 375).

3.2.4 Donor and recipient interviews

I interviewed people who had experienced ED either as donors or as recipients, exploring the discourses they drew on in relation to ED and what subject positions and subjectivities these discourses offered. The outcome of donation (whether the donation was successful or not) was not specified. This was a pragmatic decision since at the time of data collection very few children had been born in New Zealand as a result of ED. Instead, selection criteria included needing to have successfully filed an application with ECART for ED to proceed (implying that all requirements, including counselling and joint meeting, had been met). Since I wanted to avoid the ethical complications of becoming involved in the ED process itself, however, I included only those individuals who had successfully completed their applications to ECART.

I had planned to interview those who had seriously considered ED and had undergone counselling, but had then declined to continue. As discussed further below, I interviewed only one set of donors who met these criteria. I had wanted to explore the discourses of these individuals, thinking that perhaps they might draw on different discourses or deploy discourses in different ways.

Further, in keeping with a systemic perspective, in following culturally safe practice in New Zealand, and in acknowledging that policy makes provision for the inclusion of whānau (Māori language word for family or extended family), I offered the opportunity for donors and recipients to invite their families to participate.

3.3 Recruitment and participant details

3.3.1 Number of participants

Qualitative research does not depend on large numbers, but aims for data saturation. Kvale (2007) suggests that as many subjects as necessary to find out what is needed should be interviewed. In other words, interview sufficient numbers of subjects until ‘completeness’ or saturation is reached; that point when it appears that no new information is being constructed (Holloway, 1997). In this study, where the number of

potential donors and recipients available for recruitment was small, I aimed to interview approximately 5 sets of donors and 5 recipients, along with their elected family members and friends. I also intended to recruit 3 potential donors and 3 potential recipients who had elected not to proceed with ED, and the maximum possible number of counsellors out of a total of 9. I anticipated that I would be conducting between 30 and 35 interviews.

3.3.2 Embryo donors and recipients

In New Zealand, fertility clinics have to retain data about the procedures they undertake. In order to recruit embryo donors and recipients, the two main fertility clinics (with branches in the five main centres of New Zealand) were approached and asked to consider participating in the study by contacting embryo donors and recipients. A formal application was submitted to the clinics detailing the research aims and procedures, and the ethical approval process. Further, I consulted with Māori¹ researchers, elders, and a Māori counsellor, and made a presentation to the AUT School of Health Care Practice's Kawa Whakaruruhau Committee² regarding the research, in which I also described the recruitment method. Following the support of Māori and the initial agreement of clinics, a detailed application was submitted to the Central Regional Ethics Committee (Health and Disability Ethics Committee). Following ethics approval (February 2012, Number CEN/11/12/07/071AM02), clinic staff were asked to review their files for records of (a) those patients who had proceeded with ED either as donors or as recipients, and (b) those patients who had undertaken both individual and joint counselling, and thereafter (prior to ECART application) had elected not to proceed with ED. Clinic counsellors were asked to make contact with these patients, sending them the Participant Information Sheet (PIS; reproduced in Appendixes D and E). The PIS outlined the aims and methods of the study, the costs and benefits associated, any ethical concerns, time needed to participate, information about how to make contact with the researcher, and timeframes within which to do so.

An accompanying letter was sent to make it clear that participation was voluntary, and that counsellors and clinic staff would not have access to information as to who had participated in the study. It is important to note that since all potential participants had completed the ED process and counselling, most were no longer

¹ Māori are the indigenous people of New Zealand.

² The Kawa Whakaruruhau Committee is a committee within the School of Health Care Practice which provides assessment and consultation on research in terms of cultural safety, and adherence to the principles of the Treaty of Waitangi.

patients of the clinics. Provision was made in the ethics application for counsellors to send a follow-up letter 2 weeks following the sending out of the PIS, reminding patients that if they had not already expressed an interest in participating, and wished to do so, they should contact the researcher.

Interested participants were invited to contact me directly, either by phone or by email. Whenever I received a phone call or email, I would follow up, further explaining the nature of the study and its aims, and providing opportunity for any questions or concerns to be addressed. Consent forms (reproduced in Appendix H) were drawn up and copies of these were sent to interested participants prior to setting up an interview time. Once potential participants agreed to participate, a time was set for an interview.

While I invited both members of the donating couple (and where relevant) both members of the recipient couple to participate, on advice of the Kawa Whakaruruhau Committee, the choice of whether to participate as an individual or as couples was left up to the participants. Where both members of the couple wished to participate, they could choose whether to be interviewed separately or together.

All participants had to give signed consent prior to the interview. Note that the consent forms stipulated that participants had the right to withdraw consent at any time prior to and during the interview. The participants also had the rights to review the transcripts generated from the interview, to withdraw parts of the transcript or the transcript in its entirety, and to suggest amendments and additions.

As the number of applications for ED had been relatively low (54 applications up to June 2012), I had some concerns about recruiting a sufficient number of participants. However, recruitment was very successful: 22 donors (10 couples, 2 individuals) participated in the study. Twelve (6 couples) had 'successfully' donated, i.e. their ED had resulted in births (7 children). Fifteen recipients (5 couples, 5 individuals) participated in the study. Of these, 8 (3 couples, 2 individuals) had had children through ED (7 children at the close of data collection; a further two born after). Of the five individual participants, two were single women.

Only two (1 couple) donors who had seriously contemplated ED, had undertaken joint counselling, and then had elected not to proceed with ED, took part in the study. No recipient 'contemplators' were recruited for the study. In interviews with counsellors, it became apparent that they had experienced very few cases of donors and recipients withdrawing from ED following the joint counselling process, and that potential donors and recipients were more likely to withdraw after individual counselling. This explains the low numbers recruited in this instance. Analysis of data

from the interview with the one ‘contemplator’ donor couple has been included with the analysis of donors’ talk, as from my analysis similar discourses appeared to inhabit the talk of this couple.

Since the number of participants in this category was low, I accepted a higher number of actual donors and recipients into the study. Given the small number of people who have made applications for ED in New Zealand, I was surprised by the response rate and interest in the study. Two expressions of interest were received after data collection had ceased. The good response rate may reflect the investment that donors and recipients have in sharing their stories, and having an opportunity to reflect on their stories. For some, the interview process was an opportunity to provide input that could potentially help, or in some cases caution, other couples contemplating ED as an option. Many participants expressed an interest in hearing of others’ experiences, as they had had little or no contact with other donors or recipients. For some, the research interview appeared to provide an opportunity to debrief about their experiences in a safe environment (more on this in the section 3.7 below).

Something that surprised me, given my previous research efforts in the field and the experience of many colleagues, was the level of participation and interest from male participants, particularly donors. Two of the male donors explained their participation with reference to their attachment to their embryos in their capacity as their parents, as ‘fathers’ (as discussed later in chapter 6):

Roy: I suppose it’s the male protective role of looking after my family, and I suppose I’m very strong on that.

Brian: I tell you, men are attached to the embryos more than you ever realise.

Donors and recipients varied in age from the early thirties to the mid-fifties, and were represented by a range of educational levels and socioeconomic backgrounds. Donors and recipients were predominantly European (two donors were Asian). No Māori were recruited for this study. While participants were recruited through the main clinics in New Zealand (with centres in Auckland, Hamilton, Wellington and Christchurch), interviews took place throughout New Zealand. Participants came from both the public and private sectors.

While I had initially planned on giving a more detailed description of these factors, a number of the participants asked for specific details such as educational level, age, occupation, clinic where treatment occurred, or home town/city not to be included in the study. Some participants also asked that the sex of their child/children would not be specified. While these participants were eager to share their stories, and also spoke of

their willingness to disclose their history of ED to others, they constructed this on a ‘need-to-know’ basis, and as personal information. Many participants also spoke of the fact that in sharing their stories they were also sharing the stories of another family, as well as other children. They were mindful of needing to respect the privacy of all parties involved. This is discussed further in Chapter 6.

Thus, as is standard practice, potentially identifying information was disguised as much as possible or deleted. Pseudonyms (either self-selected or randomly allocated) were used, and gender-neutral terms were used with reference to children. Transcripts of interviews have not been represented anywhere in their entirety. I have not provided detailed demographics, or given full individual profile descriptions. Rather, extra-discursive factors are discussed as aggregates in the results section for each group of participants.

3.3.3 Family members/whānau

The PIS sent out by counsellors included information about the potential for involvement of family members/whānau (aged 18 years and over). As it was felt important to respect the privacy of the donors and recipients, the PIS mentioned that extended family members could be included in the research by invitation of the donors/recipients only. Family members could be part of the interviews with donors and recipients or offered separate interviews. Note that offering the potential for whānau involvement was a requirement of the Kawa Whakaruruhau Committee.

The PIS stipulated that the involvement of family could be discussed with the researcher either when contact was made to arrange participation, or at the time of the interview. Separate PISs and consent forms were drawn up for family members (reproduced in Appendixes F and I).

Where the interview with the donor or participant was planned to involve family members, then the family members received the PIS prior to the interview, allowing for adequate time to decide on participation. Signed consent forms also had to be obtained prior to the interview. Where the involvement of family members was considered at the time of interviewing, PISs were left with the donors and recipients to pass on to family members. Family members were asked to make contact with the researcher to indicate their willingness to participate.

Recruitment of family members proved problematic. In only two interviews were family members included as part of the interview, and these were with donors, and

not recipients. As is discussed in the results chapters, the low numbers reflected constructions of ED as being a personal decision, and one that was made as a couple or nuclear family unit. Donors' decisions to undertake ED usually included discussion with their children (on an age-appropriate basis), but for the purposes of this study, children of participants were not included. This was partly a pragmatic decision, as in most instances the children of donors or recipients were minors. Due to the low numbers of family participants, I elected not to include this data in the analysis for this research.

3.3.4 Counsellors

There are 11 counsellors across the various fertility clinics in New Zealand, and all were invited to participate, with the proviso that they must have had experience in counselling either donors or recipients with respect to ED. Counsellors were provided with a PIS about the study (reproduced in Appendix G), and details about the timeframe and ways of making contact with the researcher. Again, signed consent was obtained from counsellors preceding the interviews, and consent agreements stipulated that transcripts of interviews would be provided allowing for comment, change, amendment or withdrawal (Appendix J).

Nine counsellors met the eligibility requirements and all agreed to participate. Counsellors from fertility clinics across New Zealand participated, including Fertility Plus (Auckland) and Fertility Associates (Auckland, Hamilton, Wellington and Christchurch). All counsellors had qualifications in mental health fields, including counselling or social work.

3.4 Interviews

I interviewed participants in a venue of their choosing as I wanted to recognise participants' autonomy (Hague & Mullender, 2005) and respect the privacy of participants, given that for many I suspected this would be an emotionally laden topic. All counsellors elected to be interviewed at their place of work, and all but one set of donors and all recipients elected to be interviewed in their own home. In the latter case, I drew up a researcher safety protocol, which included ensuring that I checked in before and after the interview with a colleague. One set of donors was interviewed in a meeting room at a conference facility.

My interviews were semi-structured in nature, following a set of questions drawn from the literature, but also attempting to leave sufficient space for issues to emerge. Topics for donors and recipients included their background of infertility, understandings and experiences of the embryo and ED, ED practice and policy, and factors influencing choices. Topics for counsellors included understandings of ED practice and policy, experiences of counselling, and any concerns. In addition to this, I asked donors and recipients for details regarding age, socioeconomic group, marital status, occupation, educational level. These factors were drawn from Sims-Schouten et al.'s (2007) study. Other factors that have been identified as potentially relevant to ED were also included, such as number of children, religious affiliation, type of infertility, number of treatment attempts (and for donors) number of embryos in storage (Hug, 2008; McMahon, 2000). Interview schedules are reproduced in Appendix K.

In the interviews I used questions and comments as the interviews progressed to assist interaction, develop rapport, and maintain the flow of conversation. These included questions and strategies as suggested by Kvale (2007) such as follow-up questions that prompt for more response; probing questions such as 'Can you say more about that?'; silences that allowed for reflection and processing; and rephrasing, clarifying and summarising, or what Hill (2009) terms 'minimal encouragers'.

Interviews are commonly used in qualitative research and are regarded as a way of giving voice to participants (Willig, 2010). However, it is important to recognise that in a social constructionist approach interviews are seen as co-productions (Burr, 2003; Parker, 2005; Semp, 2006). Guiding the interviewer's questions and interviewee's responses are assumptions and the data produced are not "uncontaminated by human interaction" (Burr, 2003, p. 152) but will follow on from the relationship between interviewer and interviewee. The product should be seen as a 'text in process' (Kvale, 2007; Parker, 2005). Kvale (2007) describes this type of interviewing as 'travelling interviewing', where the interviewer and interviewee travel together through the landscape of the research topic and together explore the different parts – this journey not only co-constructs knowledge but can also change the travellers (Kvale, 2007).

It was thus crucial to build a good rapport with participants, which I attempted to do through the method of questioning explained above; through approaching my participants with respect and empathy; and where appropriate, through sharing a little of my own background. While I had planned on interviews lasting about 90 minutes, I adopted a degree of flexibility. Most authors (e.g. Burr, 2003; Parker, 2005; Hollway & Jefferson, 2004) recommend a focus on reflexivity and critical reflection to maintain

awareness on the role the researcher plays in the co-construction of the data. In this study, I attempted to do this by mindful reflection on each interview, talking through issues in supervision, and keeping an ‘audit trail’ – this is discussed further later in the chapter. I also sought to obtain participants’ input by providing them with the transcripts of their interviews, and offering the opportunity for any amendments or additions.

3.5 Transcription

Parker (1999b) highlights that transcription can be a process of analysis since a way of reading and representing what has been said is offered. Transcription produces something different – another text, and it is this translation which is subject to discourse analysis. There are various transcription conventions including those based more on micro approaches, which tend to use ‘naturalistic transcription conventions’ to attempt to capture in detail every speech utterance and stay as close as possible to verbatim. This approach is closely aligned to conversation analysis (Oliver, Serovich & Mason, 2005). In the macro approaches, where the emphasis is more on meaning as it constructs realities (rather than trying to lay bare the ‘real’ world), the transcription tends to be ‘denaturalised’ in that it provides a verbatim depiction of content without focusing in detail on speech acts (Oliver et al., 2005). In this study, while I was not concerned with the detail of conversational analytic approaches, I nonetheless wanted to ensure that I captured some of the subtleties in participants’ language use as they constructed accounts motivating their choices. At the same time I wanted to locate my analysis in the broader social and cultural contexts in which they occurred and I was therefore interested in meaning, rather than linguistic convention. I have drawn on Parker’s (2005) guidelines for transcription, which focus on providing verbatim accounts as far as possible, and indicating only main speech features such as pauses (denoted with a series of dots), emphases (bold font), silences (noted as ‘silence’), and emotional indicators (e.g. laughing, crying).

Transcripts of the interviews were sent to all participants for comment and amendment. Participants were free to withdraw any part of the transcript, or the transcript as a whole. Some participants took a significant period of time (up to 2 months) to return transcripts. I was mindful to provide participants with the space and time to read through their interview material, given that for many the topic was an emotional one. Two participants commented on this, making reference to the emotions expressed in the interview and how they appreciated having had time to read through

the material again. They also stated it had been a valuable process for them. Some participants mentioned that they were planning to keep their transcripts as a memento for themselves, or to pass on to their children so that they would understand what they as parents had gone through.

3.6 Analysis

There is no standardised way to do a discourse analysis informed by a critical realist perspective, or meso discourse analysis, in spite of calls to develop such a standard (Cromby & Nightingale, 1999, 2002; Sims-Schouten et al., 2007). Those drawing on Foucauldian discourse analysis (FDA) generally engage in the following dimensions, as outlined by Willig (1999, 2010) and Parker (1992, 1999b, 2002, 2005):

- Identify, and then engage in a comprehensive description of discourses available.
- Analyse how these discourses are deployed and with what consequences, asking what subject positions these discourses offer and how these relate to subjectivity. Note that the concept of power is central here.
- Explore the conditions – historical, social and economic – that accommodate these discourses, but not in a reductionist, deterministic manner but in the sense of ‘potentialities’.

Engaging in a micro analysis further involves comment on how individuals may strategically deploy and draw on various discourses for interpersonal effect and to motivate and justify their decisions. Authors such as Sims-Schouten (2004), Sims-Schouten et al. (2007) and Willig (1999) further supplement these approaches with an analysis of how and why particular discourses are taken up by individuals. They encourage researchers to explore the personal, social, material conditions that create ‘potentialities’ for individuals to invest in particular discourses and not others. I provide more detail on how I achieved this below.

Following the approach suggested by Willig (2010) and Sims-Schouten (2004), I approached the texts from my various data sources (the literature, policy/counselling/legislative documents and interviews) by first immersing myself in the data. I read and reread the various texts, and in my reading made notes and wrote down associations that the text generated for me. I highlighted words and phrases that stood out for me. The next step involved using the question list that I had drawn up (see Table 1 on p.50) with which to approach the data, e.g. how is the discursive object

constructed, what discourses are drawn upon, and what is their relationship to one another? I was reading for all the ways in which the object was constructed in the text, and all the references, both implicit and explicit, were highlighted. This in turn generated further notes and questions. These then allowed me to name and identify (construct?) particular discourses and discursive objects as they emerged for me in the text.

Next I moved on to exploring the potential effects of these discourses, asking what the constructions achieved, what was to be gained by deploying them, and what action possibilities were either enabled or constrained by them. I paid close attention to variability and contradiction in the construction of objects and how the discourses related to other meanings and activities, keeping notes throughout (Parker, 1999b, 2002, 2005; Willig, 2010).

Following this I asked what subject positions were made available by these constructions, and what it was potentially possible to do, feel and experience from these positions (Parker, 2005). I also made notes on the personal, material, social and embodied factors mentioned in each site of analysis, and in the answers to the questions I had asked related to background factors. Again, I made notes as to possible conditions these factors 'created'. In the policy/legislation/guideline analysis, I paid attention to factors that I identified as having a role to play in the development and maintenance of these discourses. In the interviews, I paid attention to material conditions, personal and social factors and embodiment issues that participants oriented to and that could help explain what enabled individuals to draw on particular discourses. In the analysis of counsellor interviews, I focused on aspects contributing to the discourses that counsellors drew on. While I recognise that each of these factors in turn could themselves be discursively constructed, for the purposes of the analysis, these factors were labelled as 'extra discursive' as they in a sense sat outside the discursive objects under consideration, and constituted conditions and potentialities for the emergence, maintenance and transformation of these discourses. They structured the experiences; and participants oriented towards these (Sims-Schouten et al., 2007).

I followed the above process for each text, document and interview separately, although each reading was inevitably informed by the previous reading. For example, I began to use the same coloured highlighters to mark what I saw as similar discourses, action possibilities and subject positions.

In the next stage, I attempted to read across the various texts within each site. For example, in the legislation and policy section I first analysed each text separately, analysing the legislation, the ED guidelines, the counselling documents, and the ECART minutes. In the interviews of donors, I first read through each interview separately, and then read across the various donor interviews. In this reading, I looked for similarities and differences in the types of discourses, discursive objects and subject positions that emerged, and for the ways in which these were used and to what effect. At the same time I looked for similarities and differences in aspects of the individuals' 'conditions' or personal social histories; in potentialities for the various discourses.

While the process of analysis for the counsellors' interviews followed the same pattern, the emphasis was slightly different, in that here I concentrated on two aspects: firstly, how counsellors themselves constructed ED, and secondly how they constructed their roles in relation to ED practice. Since counsellors assume such a central role in the ED process, I wanted to explore their constructions as I felt that this would provide a critical context for the discourses available to donors and recipients, and for the subsequent action possibilities and subject positions available. Again I explored factors that could be constructed as creating conditions for counsellors' investments in discourses.

Finally, I wanted to explore the conditions, historical, social and economic, that accommodated the various discourses – not in a reductionist, deterministic manner but in the sense of them as 'potentialities'. My analysis in this regard concentrated on the academic literature, as well as the policy/legislation/counselling texts, and to some extent the counselling interviews. I considered how discourses emerged and were maintained historically and culturally, tracing the discourses' history, the 'conditions of their emergence', their relation to other discourses, and changes over time (Parker, 2002; Willig, 2010). Thus, for example, in the literature analysis I discussed cultural and historical developments in related fields, such as adoption practice, that in a way 'set the scene' for development in third party-assisted reproduction. I also explored how discourses were implicated in, and reinforced by, the structure of institutions and institutional practices (such as government, counselling associations, clinic practices, counselling practice, etc.) (Parker, 1999b, 2002; Willig, 1999). Thus this constituted a type of archaeological and genealogical analysis, asking what could be said and what could not be said at that time and place, and how and when the various discourses in relation to ED emerged.

In my analysis of the extra-discursive factors for these texts, I explored what the “world must be like for those ideas and activities to be possible” (Bhaksar, 1979 as cited in Willig, 1999, p. 48). Thus in this section I read the texts looking for material conditions that ranged from economic conditions, population size, institutional setup, as well as personal-social factors and embodiment – conditions that provided a context in which certain discursive constructions were more easily enabled or disabled than alternatives (Sims-Schouten et al., 2007).

I analysed the literature, legislation and policy documents, and transcripts from the interviews with donors/recipients and counsellors separately. My aim was to identify the available discourses in the literature and in policy, and then to see if and how my participants articulated these. While it is clearly never possible to read each site free from the impressions gained from the other sites (Parker, 2005), I wanted as far as was possible to read and analyse the voices of my participants away from the literature and policy, and then to reflect on overlaps and contradictions. I was aware that the New Zealand context differed from other jurisdictions, and thus wanted to develop an overview of the wider discursive economy before moving to New Zealand legislative frameworks and policies, and the voices of my participants.

Since social constructionism holds that objectivity is impossible, as each of us approaches the world from different perspectives (Burr, 2003; Parker, 1994a, 1999a), I also wanted to make explicit my own position and background, and how this could potentially affect the discourse identified. I discuss this further in the subsections 3.8.3.1–2 below.

Finally, in chapter 8, I synthesised the analysis across the various sites, exploring interrelationships and how they reinforced particular discourses, action possibilities and subject positions. As Parker (2002) observes, meanings we study need to be considered in terms of how they are produced in the relationship of texts. I compiled the various texts into a systemic framework for understanding ED.

The table on the next page summarises my analytical process. The questions and corresponding analytic stages were adapted from Willig (2010) and Vingoe (2008). The areas highlighted were supplemental items for inclusion based on Sims-Schouten (2004), Sims-Schouten et al. (2007) and my own intentions, and the third column (sites of analysis) was added to illustrate to which sites questions were applied.

Table 1: Questions, analytic stage, and site of analysis

Key questions	Analytic stage	Site of analysis
How is the discursive object constructed through language? What type of object is being constructed? What discourses are drawn upon? What is their relationship to one another?	Stage 1: Discursive constructions and discourses	Academic literature Policy, legislation and guidelines <ul style="list-style-type: none"> • HART Act • ACART policy guidelines • Counselling guidelines • ANZICA position document • ECART minutes
What do the constructions achieve? What is gained from deploying them here? What are their functions? What possibilities for action are mapped out by these constructions?	Stage 2: Action orientation and practice	Counsellor interviews
What subject positions are made available by these constructions? What can be said and done from within these subject positions? What can potentially be felt, thought and experienced from the available subject positions?	Stage 3: Positioning and subjectivity	Donor and recipient interviews (Family/friend interviews)
What material conditions, personal and social factors can be identified that may be relevant?	Stage 4: Investment/ Individual location	
What role has the researcher played in the construction of discourses	Reflexivity and critical reflection	Researcher background and standpoint

3.7 Ethical considerations

As the study involved participants that were to be recruited via clinic files, and in some cases participants could still be patients of these clinics, ethical approval was necessary from the Central Regional Ethics Committee (Health and Disability Ethics Committee). Approval was granted February 2012 (with minor amendments approved 05/03/2012; Number CEN/11/12/07/071AM02)

Several ethical issues (Willig, 2010) are relevant to this study and these are discussed in the following subsections.

3.7.1 Informed consent

I addressed informed consent in a number of ways. Firstly, all participants had been sent a PIS (reproduced in Appendices D-G) that clearly detailed study aims and process, the anticipated benefits and risks, and explained that the study formed part of a PhD. Participants had to make contact with me either by phone or email to express interest in participating. At this initial contact, I reiterated the study aims and design, and provided

opportunity for clarification and questions. Once they had agreed that they wished to take part, participants were sent a consent form (reproduced in Appendices H-J) that had to be signed prior to the interview. The consent process was reiterated before I began each interview, and I again provided the opportunity for any issues to be addressed (including ones discussed below).

3.7.2 Confidentiality

With small-scale qualitative research, there is a chance that participants' stories may be recognised by those that know them. This was outlined to participants before they agreed to participate and was also included in the PISs. Individuals' right to privacy and anonymity was respected by disguising identifying details in the transcript. At the request of some of the participants, details such as occupation, sex of their child/ren, or location was also disguised. These participants wanted to share their stories, but were mindful that in doing so they were also sharing the stories of another family linked to them by virtue of ED. One participant asked for clarification as to who would have access to the transcript, and I reiterated that transcripts would not appear anywhere in full, and offered the opportunity for further amendment or withdrawal (which was declined). Participants were given the opportunity to choose a pseudonym by which they would be known in the research. Only one participant elected to choose a pseudonym, and I randomly assigned pseudonyms to the rest. I made use of one assistant to help me with the transcription of interviews, and she signed a confidentiality agreement.

As was the case for some of my participants, I too was aware that participants were sharing not just their experiences, but those of another family (either the donor or recipient family), and potential children. Both within the interviews and later, during the data analysis, I was mindful of the need for confidentiality; to tread carefully and cautiously; and to ensure that I respected as much as possible the integrity of each participant's story while bearing in mind the wellbeing of another family and potential children. Taking a step back from this process and thinking critically, it is possible that my anxiety around managing the stories I heard reflected the complexity of relationships developed through ED. As discussed in the results chapters, these relationships were constructed as enduring, and needing to be maintained and managed for the wellbeing of the donor-conceived child and siblings. My own anxiety in many

ways was thus a reflection of participants' anxiety about how relationships would unfold, and participants' perceptions of the need to 'tread carefully'.

3.7.3 Participation and right to withdraw

Participation was voluntary, with participants contacting the researcher if they wished to participate. Participants retained the right to withdraw from the research before, during or after the interviews, and were sent transcripts of their interviews providing the opportunity to make amendments, including withdrawing some of or their entire transcript. Participants were not expected to give any reason in this event. No participants elected to withdraw from the study, although some requested minor amendments to their transcripts, and the further disguise of identifying information.

3.7.4 Safety and debriefing

Infertility is considered a stressful experience (van den Broeck, D'Hooge & Enzlin, 2010) and I thus anticipated that talking about their experiences could be difficult for some participants. As a psychologist, I have experience in supporting people as they talk about emotionally difficult issues and so I felt confident that I would be able to offer an appropriate level of support, and ensure that the conversation stayed 'safe' for participants. Prior to the interviews I also reminded participants that they need share only those issues they were comfortable talking about; that the interview could be suspended at any stage; and that they would have the opportunity to review and amend any aspects of their transcripts. I had also arranged that participants (without the need to inform me) would be able to access free counselling (face-to-face, by phone or via email) from AUT's Health & Counselling Services and the details for this were provided in the PIS. It was not anticipated that the counsellors interviewed for the study would require counselling, but their PIS included a reminder of the ability to access support through their supervisory mechanisms and counselling body.

In conducting the interviews with donors and recipients, I had the sense that for some, the interview provided an opportunity to debrief about their experiences in a safe environment, and I cultivated an attitude of respect and empathy (Hollway & Jefferson, 2004). Indeed, one of the counsellors made reference to this in relation to donor/recipient participation:

Ingrid: I truly think there's an element of, 'Oh I'd love to talk to someone in confidence who isn't the person that I talked to before, and where I said all these things.'

Donors and recipients likewise spoke of the value of having an opportunity to reflect on their experiences:

Nathan: It's been good, because we don't stop and talk about it now. So it's been good to have a conversation. It will still be just as tender in the years ahead; still just as close to our hearts...

Brenda: Then I thought, 'Gosh I feel quite emotional,' because when you go through IVF, there's lots of emotion. 'Gosh it's going to be another one of those evenings', because you don't know how it's going to hit you! You know, you think it's all blocked out, gone and past and dealt with... but then. But it's not something we really talk about...

For some, unresolved issues, including grief, anger and frustration, appeared to remain. This is discussed more in chapter 6; however it is important to reflect here that the level of emotion was indeed frequently quite high during the interviews. My background as a psychologist helped me in this regard as I worked hard at containing emotions and providing as safe an environment as possible. I was mindful that the interview could be a cathartic process for participants, but at the same time did not constitute therapy. Subsequent to each interview I followed up with participants via email, thanking them for their time, and checking to see if they had any concerns or questions. I provided reminders that free counselling sessions with AUT were available should the need arise. Several participants sent messages expressing their appreciation at being able to participate and talk about their experiences.

3.7.5 Cultural safety

Part of the planning for this study and obtaining ethics approval was to ensure that in my study aims, design and method I ensured culturally safe practice, meeting the obligations under New Zealand's Treaty of Waitangi. Historically the number of Māori accessing fertility services in general and ED specifically has been low, but ECART minutes between 2006 and mid-June 2012 make note of a small number of ED cases where either the donor or recipient identified as Māori. While the chance of including Māori was thus very low, I hoped that I would nevertheless be able to recruit some Māori participants. I consulted with Māori researchers, an elder and a counsellor who provided useful feedback on my study and offered ongoing support. I presented to the

AUT School of Health Care Practice's Kawa Whakaruruhau Committee, who reviewed this research, provided guidance around method (in particular recruitment and interview processes), and provided their endorsement. Throughout I attempted to follow the principles outlined in Te Ara Tika - guidelines for Māori research ethics as published by the Health Research Council of New Zealand (The Pūtaiora Writing Group) in order to ensure that tikanga (protocol, customs or ethical behaviour guidelines associated with Māori values, beliefs and worldview) and cultural concepts were appropriately acknowledged, and that the Treaty of Waitangi obligations of partnership, protection and participation were honoured. Further, I reviewed relevant research related to Māori viewpoints on ARTs, and considered Māori practices related to infertility and family-building.

3.8 Criteria for assessing research rigour

The relevant criteria for judging rigour in social constructionist research are discussed in the following subsections.

3.8.1 Credibility and coherence

Social constructionism holds that constructions differ, and emphasise phenomena as co-created (Elliott, 2005). As Elliott (2005) asserts, "There is now awareness that the process of research itself does not simply produce descriptions of reality but should also be understood in some senses to construct reality" (p. 154). Thus one cannot really aim for a description that matches 'what is out there', since even in a critical realist approach to social constructionism the aim is not to identify objective facts or make truth claims (Burr, 2003). We are aiming instead at providing accounts that make sense to people; that have credibility or can be regarded as 'trustworthy' (Alvesson, 2002); that are seen to be viable and coherent (Parker, 2004, 2005); and that are well grounded and supportable (Polkinghorne, 1988).

As suggested by Pujol and Montenegro (1999), I attempted to achieve this by reflecting on my reasons for constructing the research in the way I did (epistemological reflexivity), and by systemically detailing the process of analysis. This allows the research process as a whole to be scrutinised, to be open to reason and analysis. Drawing on Gilmour's (2001) strategy, I also chose to include sizeable amounts of excerpts from interviews, and details of legislation, policy and counselling documents. Smythe (1998) has called this process 'show and tell' in that data is presented and followed by analysis, allowing the reader to follow and examine the work. I engaged in

personal reflexivity, considering the influence of my own background (Burr, 2003), and, as detailed further below, to enhance the rigour of my study.

Finally, following Crossley's (2000) recommendations, I attempted to ensure, by reading and rereading and checking, that the interpretations and arguments I put forward stemmed from and were consistent with the data, and were theoretically grounded.

Throughout the process of my research, I shared and reflected on my analysis with a range of people, including my supervisors, my mentor in the field of third party reproduction, and colleagues. I presented aspects of my findings at conference groups consisting of colleagues, fellow students, researchers, practitioners and consumers.

At the same time, I was cautious in claiming the truthfulness of my findings, as I was aware that in identifying discourses I was contributing to, or creating discourses. I was reminded of Parker's (2005) comments: "The question is not whether or not a particular argument is correct or incorrect, but whether it is a plausible argument that makes sense in relation to the material and the chosen theoretical framework" (p. 10).

3.8.2 Representativeness

Qualitative research, relying on small numbers of participants, and concerned with studying a phenomenon in greater detail, is not as concerned with reliability as quantitative research, but nonetheless where the aim of the study is to explore a phenomenon that is relevant to more than the study's participants, then the issue of representativeness needs to be considered (Willig, 2010). In other words, the participants should be representative of the population to whom findings intend to apply. This is a debatable issue however. Haug (1987, as cited in Willig, 2010) claims that even though we do not know how many people share a particular experience once we have identified it, through our research we know is it available within that particular culture: "If a given experience is possible, it is also subject to universalisation" (Haug, 1987, p. 44 as cited in Willig, 2010, p. 17). If we assume that our participants are engaged in social construction of phenomena, and we relate these to discursive, social and institutional practices, then the accounts presented may be open to generalisation (Willig, 2010). Further, in the case of the present study, ED has had a low uptake, and so there was a greater likelihood of this study's representativeness.

3.8.3 Reflexivity

According to social constructionism objectivity is impossible, as “what we find and the sense we make of it are always a function of what we thought we would find and the position we try and make sense of it from” (Parker, 2005, p. 28). Similarly, as Haraway (1991) notes, our view of the world is always “from somewhere” (p. 195), which implies that we cannot be fully present or available to ourselves, aware of our own biases and viewpoints that may colour interpretations and constructions. Inevitably, as Pauw (2009) points out, it is not just the research participant that is constrained by the culture in which he or she finds herself but also the researcher. The questions asked in research will thus arise from assumptions, and may shape research (Burr, 2003). And as Parker (1992) argues, to identify a discourse is already to take a position. As a consequence, we need to work with the intrinsic involvement we have in the research process (Burr, 2003; Nightingale & Cromby, 1999; Parker, 2004) and consider the contribution of the researcher to the construction of meaning (reflexivity). At the same time, we need to acknowledge that reflexivity is itself bound: it is not just that our observations are affected by us as observers, but that we share the same complex backdrop as do the people we research (Parker, 2005), meaning that it is impossible for us to remain ‘outside of one’s subject matter’ (Willig, 2010).

According to Willig (2010) two types of reflexivity are called for:

1. Epistemological reflexivity –awareness of how the questions asked and methods used can give rise to particular understandings or constructions of the topic (Willig, 2010). This calls for keeping a clear audit trail of the research process, outlining what process was followed to promote understanding of how the project was created and conclusions were reached (Willig, 2010). This has been described above and reproduced in Table 1. The term ‘critical text work’ is sometimes used to refer to the process of attending both to the construction of accounts by people, combined with attention to the role of the researcher (Parker, 1999b).
2. Personal reflexivity – where the researcher explicitly reflects on the role of his or her values, expectations, interests, beliefs, wider aims in life, social identity and relevant personal and historical background may have on the research, as well as reflects on how the research may have affected her as a researcher (Willig, 2010). Coffey (2002)’s approach is similar and argues not for

‘confessional tales’ but making the author’s position visible to enhance the credibility of the research. It involves a self-consciously and deliberately assumed position (Parker, 2005).

3.8.3.1 Epistemological reflexivity

I have addressed epistemological reflexivity above, and attempted to achieve this in this study by clear reflection on my ontological and epistemological positions in the previous chapter and a clear exposition of my method in this chapter. A few further comments are however in order here. One of the approaches to discourse analysis I had initially considered, given my interest in how and why individuals invest in some of the available discourses and not others, was to adopt a psychosocial approach (e.g. Hollway & Jefferson, 2004), as it is currently practised. In this form of analysis, individuals’ defence mechanisms and anxieties are explored through a detailed analysis of personal-social biographies and researcher reflections. I opted, however, to instead adopt an approach that could connect personal social backgrounds (including material conditions and embodiment) to discursive resources and practices, but within a systems framework.

As I engaged with the participants, I felt again and again that my decision had been the right one. In much of the academic research I had read that adopted a psychosocial approach, in-depth psychoanalytical interpretations were made of the participant interviews. Firstly, I felt poorly qualified to conduct such an analysis of research data, having limited training in psychoanalysis. Secondly, as I spoke with each participant and realised the complexity of their stories, and the interrelationship of their stories with those of other families and children, it seemed to me that it would be problematic to make in-depth interpretations of their individual anxieties and situations.

I felt far more comfortable with the approach that I had adopted as it seemed more respectful, adopting a wide lens to consider how discourses emerged, and describing extra-discursive factors that could help explain investment in or resistance to them. Given some of the participants’ particular requests for privacy, this seemed even more important to me. Further, rather than locating individuals’ choices and investments in particular discourses in terms of individual, intrapsychic processes, as is the case in psychoanalysis (Burr, 2003; Parker, 2002, 2005), the approach I adopted resisted such essentialist arguments. It included a consideration of the material and social, of

interaction and social practice, and aligned well with a systemic model of understanding.

Next I turn to personal reflexivity, and comment on my situatedness as researcher and the role I may have played in terms of the questions asked, the method adopted, and the interpretation of results.

3.8.3.2 Personal reflexivity

In chapter 1, I outlined my background and how my interest in assisted reproductive technologies developed after the experience of secondary infertility. While I did not volunteer my personal background in interviews, several participants asked specifically if I had children ‘of my own’, and if I had any experience of infertility. I responded to these questions when asked, and was frequently met with the response ‘so you know a bit of what it is like’, with the participants then elaborating on their experiences. My sense was that they spoke in more depth and detail than they may have done had they not had a sense of shared experiences, and of being heard from a position of empathy. I was aware throughout the interview process, however, that my own experiences could both deepen my understandings of my participants’ stories and generate rapport, and influence the way in which I understood and constructed the participants’ stories. I was mindful to listen/hear, as much as I was able, to participants’ stories and perspectives, and cognisant of how these could overlap or differ from my own experiences. I attempted to reflect critically on each interview, in a way that Parker (1999a) has described as an active rebellious exercise. Following each interview, I made notes about the interview process and my reflections, and these formed part of my analytic process.

Further, participants were aware (as it was specified in the PISs) that I was a registered clinical psychologist. Both my qualifications and research background were cited by a number of participants as factors that contributed to their willingness to engage in the research project. Brenda, for example, stated specifically:

To be honest, I checked you out! Only reason being because it told me what an amazing profile you have, and I thought, this is genuine. I just wanted to know if this person was a bit of a freak out there, coming and wanting to suss it out! It could just be any university person or for whatever reason... But I thought, she’s got some profile, yes we’ll do it.

For some, my identity as a PhD student further constructed the research as a ‘serious research effort’. Participating in this research was both a way to (eventually) be able to hear of others’ experiences and contribute their own. In sum, I believe that my personal experiences and background helped facilitate the research process, making me

more sensitive to people's stories and creating the conditions for people to talk with me. At the same time I acknowledge my situatedness as a researcher, and have attempted in my analysis to both draw on and step back from these experiences as far as is possible. Nonetheless, I form part of the system of this research study.

3.9 Conclusion

My aim in this chapter was to make explicit the method that I followed in the research, outlining the various sites of analysis and data collection methods used, and my approach to data analysis. Further, I reflected on some of the ways to promote rigour in this type of research approach, and the ethical considerations that arose in the conducting of the interviews. I attempted to locate the research both from my own epistemological assumptions, as well as my personal background. In the next four chapters, I analyse the discourses identified in the texts collected and generated for the purpose of my study. In the following chapter, I analyse the academic literature in relation to embryos and ED.

Chapter 4: Literature analysis

In this chapter, I analyse the academic literature relevant to ED, including empirical studies of ED and embryo disposal options, and debates around ED policy and practice. As described in the previous chapter, I adopt a discursive analytic approach, which rather than evaluating and presenting the major research ‘findings’, foregrounds and explicates the discourses available, explores their historical and social contexts, and analyses the action possibilities and subject positions enabled and constrained by discourses. I also identify and explore some of the ‘extra-discursive’ factors that may help explain individuals’ investment in particular discourses.

In the first section of the chapter, I sketch the context of ED by identifying discourses in relation to infertility, assisted reproductive technologies (ARTs), and cryopreservation, and by exploring how these may already enable and restrict possibilities for those experiencing infertility and position them in particular ways. Next, I give an overview of the ‘disposal’ options available to those with ‘surplus’ embryos. I identify different ways of constructing these options and different discourses in relation to the disposal decision, and I discuss these along with their potential implications for ED. Since much of the research into ED has focused on how ‘conceptualisations’ of the embryo will influence the decision to donate, in the fourth section I discuss the discourses of the embryo and associated action possibilities and subject positions. Following this, I outline some of the extra-discursive factors (related to personal-social biographies, material conditions, and embodiment) that may influence the uptake of discourses. I then provide an overview of gamete donation and adoption policy and practice, and their sociohistorical context, analysing how discursive constructions in these areas provide a context for ED. Finally, I identify and explore the two main ways in which ED has been constructed in the literature: either as donation, or as embryo adoption (EA). I discuss the potential implications of these discourses for what can be said, done and felt from subject positions enabled through an investment in these discourses.

In each section, I analyse the literature to identify discourses that can be seen to inhabit the findings of the research, and the way in which authors write about the particular object or phenomenon in question. The language I use will vary: I use discursive terms (e.g. constructions, discourses) where I refer to my analysis, and non-discursive language (e.g. conceptualisations, perceptions, views) where research findings are described. While some of the discourses I discuss may have been already

identified and named in the literature, particularly in narrative or discursive research, the discourses presented here represent my analysis of the research. In this way, and as suggested by Smythe and Spence (2012), my literature review is congruent with my methodology; the literature is approached as a rich, complex array of representations and my analysis sets out not only to present a pre-articulated knowledge, but also to open up and explore such knowledge.

4.1 Background

ED takes place within a context of infertility and the use of ARTs, including IVF and cryopreservation of embryos. How these experiences and practices are constructed may affect those contemplating ED, offering particular action possibilities and subject positions. I discuss these briefly below.

4.1.1 Infertility – the person with infertility as ‘mad, bad or sad’

Infertility is reported to affect up to 1 in 6 couples of reproductive age (Fertility Society of Australia, 2013). The experience of infertility is frequently described in the literature as emotionally challenging, stressful, as involving significant loss and grief, and as having negative effects on identity, particularly in the context of a pronatalist society (Boivin, 2006; Cousineau & Domar, 2007; Greil et al., 2011; Kirkman, 2001, 2003b; D. C. Parry, 2005; Ulrich & Weatherall, 2000; Van Den Broeck, D’Hooge, & Enzlin, 2010; Verhaak et al., 2007). Some researchers suggest that these experiences and their resolution may be an ongoing process, even following parenthood (Hammarberg, Fisher, & Winter, 2008; McMahon, Ungerer, Beaurepaire, Tennant & Saunders, 1997; McMahon et al., 2000). In this way, a discourse of infertility as ongoing challenge may be identified, which positions those with infertility as emotionally fragile and vulnerable. Indeed, they may be described as desperate and willing to go to extraordinary, sometimes irrational lengths in their quest to have children (Collard & Kashmeri, 2011; Daniluk, 2001; Kirkman, 2001; Ulrich & Weatherall, 2000). At times, especially if they are older at the time of seeking to have a family, or if sexually transmitted diseases are the cause of the fertility problem, individuals with fertility difficulties are represented in the media as having engaged in lifestyle choices that affected their fertility; the ‘fault’ is assigned to them (Bunting & Boivin, 2008; Payne & Goedeke, 2009). In this way, those with fertility issues may be positioned as ‘mad, bad or sad’ (McLeod & Ponesse, 2008; Payne & Goedeke, 2009).

This may have implications for donors and recipients, as by virtue of their experiences they are already positioned as emotionally vulnerable, even irrational. For example, in writing about recipients' choices to proceed with ED in cases where embryo quality was under debate, de Lacey and Norman (2004) suggest that recipients may be construed as "having faulty capacity for judgment by virtue of their infertility" (p. 1066). While de Lacey and Norman suggest that the construction of those who are infertile as desperate is now viewed as patronising, such discourses call into question their rational decision-making ability for example, in relation to ED.

4.1.2 ART and IVF – normal and viable, or unnatural, risky, immoral, oppressive?

In 1978 the first successful IVF was achieved in the United Kingdom, resulting in the birth of Louise Brown (Edwards & Steptoe, 1978). ARTs developed rapidly, and now include a range of possible treatments including intra-uterine insemination, IVF, donor insemination, intracytoplasmic sperm injection (ICSI), and surrogacy. In 2012, at the annual European Society of Human Reproduction and Embryology (ESHRE) conference, it was reported that over 5 million children had been born as a result of IVF (ESHRE, 2012). This was described as "a remarkable milestone" and "a clear demonstration that IVF and ICSI are now an essential part of normalized and standardized therapies" (Velga, as cited in ESHRE, 2012). Thus, IVF is constructed as a successful, viable and positive solution to the 'problem' of infertility.

With increasing coverage in media, a changing moral climate, government initiatives related to reproduction, and research efforts that report that IVF children have no long-term negative physical or psychological effects, several authors (Hammarberg, Johnson, & Petrillo, 2011; Payne & Goedeke, 2009; Silva & Machado, 2011) have suggested that ARTs have become commonplace and accepted within society. They have become normalised, more familiar, and less 'new', to the extent that these 'technical fixes' become enabled as standard conception options (Lovelock, 2010; MacCallum & Widdows, 2012). Such discourses of 'normal practice' or 'valid treatment' serve to make ART acceptable, or even promote the use of ARTs, positioning those seeking ART as treatment for infertility as 'normal' and rational (Silva & Machado, 2011). It may however also position them as obligated or compelled to try these treatments (McMahon et al., 2000), even if discourses of treatment as stressful can be identified in the literature, where it is frequently described as physically,

emotionally and mentally challenging, akin to an ‘emotional rollercoaster’ and cited as one of the main reasons for discontinuing treatment (Devroey et al., 2009). The discourses of IVF as valid solution may also situate those who elect not to proceed with treatment as ‘abnormal’, selfish, or as lacking commitment to pursue family-building options (Letherby, 1999; McQuillan, Greil, White & Jacob, 2003). It is interesting that Payne and Goedeke (2009) identified that in popular media, some individuals were constructed as pursuing treatment for ‘too long’, positioning them as irrational and emotionally unstable. This potentially places those making choices about ART options in a ‘damned if you do, damned if you don’t’ position – either ‘not trying hard enough’ or ‘trying too long’ (Daniluk, 2001; de Lacey, 2002; Payne & Goedeke, 2009).

While a discourse of ARTs as valid and normal can be identified, a discourse of ARTs as unnatural, unsafe and even immoral can also be detected, especially in some of the earlier literature, and in the writings referencing cultural groups with strong religious and cultural beliefs around fertility (Richards, Pennings & Appleby, 2012). Substantial stigma has been cited in the literature with regard to fertility treatment and having conceived through IVF (McQuillan et al., 2003). Indeed, initial concerns cited relate to the health and long-term physical wellbeing of children born as a result IVF/ART; the artificial, possibly unnatural nature of the process; and the unification of egg and sperm outside the human body as being ‘dehumanising’ and interfering with nature, a couple’s relationship, and God’s will (Gleicher, 2005; Richards et al., 2012). To some, IVF represented the start of a ‘slippery slope’ (Gleicher, 2005). Feminist authors also engaged in critique of ARTs, and a discourse of ARTs as oppressive can be identified in some of this literature, where ARTs are constructed as representing patriarchal manoeuvres to assign a motherhood imperative to women (C. Thompson, 2005). Other feminist authors draw on alternative discourses of ARTs as empowering, pointing to the potentially liberating role of ARTs in offering women greater choice and control over their reproductive lives (Harwood, 2007). Those that pursue ARTs then, may be positioned as rational or foolish, even immoral. Again, these discourses enable ambivalent positions for those contemplating and undertaking ED.

4.1.3 Cryopreservation - Normal and logical, or risky and controversial?

Up until 1983, embryos created through IVF were transferred ‘fresh’, and more than one embryo was frequently transferred at a time. Multiple births were relatively common as a consequence (Adamson & Baker, 2004). The development of

cryotechnology however changed this practice, allowing those embryos that aren't used fresh to be frozen and stored for subsequent use and attempts to achieve pregnancy. Single embryo transfer (SET), or restricting the number of embryos transferred fresh, has become recommended practice in many countries (de Lacey et al., 2012). The first pregnancy from an embryo that had been frozen and then thawed and transferred was reported in 1983 (de Lacey, 2007b; MacCallum & Widdows, 2012), with the first human birth from embryo cryopreservation announced in March 1984 (Blyth et al., 2011).

Cryopreservation is positively described or constructed in the literature in that it:

- increases the likelihood of SET uptake and thereby reduces the incidence of multiple pregnancies (which may be associated with higher degrees of risk);
- reduces the need for couples to engage in further rounds of IVF treatment as they can use their frozen embryos; thus the need for repeated cycles of ovarian stimulation (and the risk of ovarian hyper-stimulation) is reduced, as is the 'burden' of fertility treatment (with its associated financial costs and physical and emotional burden);
- allows a measure of control over the timing of pregnancy; and
- has preserved embryos created through IVF (Bankowski et al., 2005; de Lacey, 2007b; Gorny, 2004; Hill & Freeman, 2011)

In such a way cryopreservation is constructed as scientific progress, beneficial, improving success rates, and as offering a 'safety net' or another chance to those attempting to conceive. In short, it is constructed as 'a logical choice' (O'Brien, 2010).

Cryopreservation has become commonplace in many countries (Bankowski et al., 2005), such as the United States, the United Kingdom, Australia and New Zealand, where it is constructed as acceptable and sensible practice. For example, Provoost et al. (2010) report that many patients¹ view cryopreservation as simply part of standard, routine procedure, and most US clinics surveyed by Gurmankin, Sisti and Caplan (2004) were willing to create and cryopreserve embryos. de Lacey (2007a) reports that

¹ The term 'patient/s' has been used throughout this chapter as it is used in the literature cited. The author however draws attention to the medical discourse supported by this term, and the way in which individuals may be positioned as medical objects.

most patients consent to freezing their embryos with the intent to use them for further treatment, with only 0.4–2% of patients declining freezing.

Yet in its earlier days, anxiety was expressed about the potential harm in suspending human life (Bankowski et al., 2005; de Lacey, 2007b) and creating “non specialised, non-temporalised, non-corporalised beings” (Pasteur Dumas/Hedon et al., 1986 cited in Lornage, Chorier, Boulieu, Mathieu, & Czyba, 1995, p. 2610). Whereas the research to date suggests that there are no negative effects on the embryo or the child, it appears that some patients may still have anxiety around the effects of freezing (Bankowski et al., 2005; Svanberg, Boivin, & Bergh, 2001). M. H. Johnson (2012) suggests that it may not be cryopreservation that presents risk but where there is genetic disparity between mother and foetus, the likelihood of disorders of pregnancy including miscarriage, pre-eclampsia and foetal growth restriction increase. Thus a ‘risk’ discourse can still be identified. This relates also to the social implications of cryopreservation, which Bankowski et al. (2005) suggest have as yet been incompletely explored. The practice continues to be described as “a source of public concern” (de Lacey, 2007b, p. 102), and as having “sparked controversy” (Gorny, 2004, p. 460). Gurmankin et al. (2004) note that “consensus on policies for the creation, use and disposal of human embryos [is] seemingly impossible” (p. 4). It is interesting to note that the practice is prohibited in some countries (such as Italy) and in others restrictions are set on the numbers of embryos that may be frozen, usually a number that it is deemed the couple can realistically use in their *own* reproductive projects (N. D. Johnson, 2003; Larijani & Zahedi, 2007; Mohler-Kuo et al., 2009). Such practices may underscore discourses of cryopreservation as risky, undesirable or controversial.

At the same time as cryopreservation has become routine practice, the increasing number of embryos in storage across the world is described as problematic (Gurmankin et al., 2004; Hoffman et al., 2003; N. D. Johnson, 2003; Melamed et al., 2009; O'Brien, 2010; Oghoetuoma et al., 2000). In 2004, 400,000 embryos were estimated to be in storage in the United States (Gurmankin et al., 2004). In 2010, there were an estimated 92,540 embryos in storage across Australia and New Zealand (Stiel et al., 2010), with estimates for New Zealand’s largest clinic, Fertility Associates, being approximately 6,500 embryos over 23 years of practice (J. Peek, personal communication, September, 2010). A ‘burden’ discourse can be identified (Brzyski et al., 2000; N. D. Johnson, 2003; Klock, Sheinin & Kazer, 2001; Lysterly et al., 2010; Melamed et al., 2009; O'Brien, 2010), especially as there are indications from research that a significant proportion of these are ‘surplus’ to the couples’ own reproductive needs (Hill &

Freeman, 2011; Lyerly et al., 2010; Nachtigall, MacDougall, Lee, Harrington & Becker, 2010; Provoost et al., 2011). This is described as problematic not only for patients, but also presenting clinics with practical, administrative and financial dilemmas, as well as ethical and legal ramifications (Bankowski et al., 2005; Brzyski et al., 2000; de Lacey, 2007b; N. D. Johnson, 2003; Lyerly et al., 2010, McMahon et al., 2000; O'Brien, 2010; Saunders et al., 1995). This is the case particularly where patients have not specified options, the clinic has lost contact with patients, or the clinic has unclear protocols around the management of embryos (for example in situations of death of spouse or divorce).

Thus, while cryopreservation has been framed as beneficial, it is also constructed as a controversial, even risky technology, creating dilemmas and situating patients in a difficult place, depending on their context and culture. If they proceed with this option, they may simultaneously be constructed as rational (increasing their chances of success), inviting controversy, or foolish (ignoring the later consequences of surplus embryos that may become a burden). Embryo donors may thus already occupy some of these positions by virtue of having frozen their embryos during treatment.

Those with embryos remaining after IVF have to choose among a number of options for their embryos, which may include:

- Continued storage (most jurisdictions impose a maximum time limit)
- Discarding
- Donation to research
- Donation to others (ED, or reproductive donation)

4.2 Options for embryos

In this section, I describe the options available for those with surplus embryos, outline their development and uptake, and reflect on the main discourses that can be identified. The decision to undertake ED, as suggested by de Lacey (2007b), may in part be related to how the other available options: discarding, donating to research, or continued storage are seen (constructed), and thus it is necessary to discuss these options. In relation to storage, I also explore how the disposal decision itself is constructed, and how this offers particular action possibilities and subject positions.

4.2.1 Continued storage: Sensible and rational, or foolish and irrational, creating burdens? Disposal decision as avoided, delayed, complex, changing and restricted

According to some researchers most patients store their embryos for their own future use (Hill & Freeman, 2011; Hoffman et al., 2003; Lornage et al., 1995; Van Voorhis, Grinstead, Sparks, Gerard & Weir, 1999), and as discussed in the subsection on cryopreservation, this is constructed as sensible, and positions patients as rational. This may also be the case for those who store their embryos in the event that something happens to their children or their plans change. For example, 50% of those with embryos in storage in Provoost et al.'s (2011) study were storing to 'keep their options open', with the embryos being a type of 'reproductive reserve' or 'insurance policy', and others have suggested that embryos may be seen as potential replacements for children, or as providing some benefit to existing children in the future (e.g. medical benefit) (Bankowski et al., 2005; McMahon et al., 2000; Nachtigall et al., 2005). However, those embryos that remain in storage and that appear not be destined for the couples' use are typically referred to in the literature as 'surplus', 'supernumerary', 'spare', 'excess', 'presumed redundant' or 'extra' (Jain & Missmer, 2008; N. D. Johnson, 2003; Lysterly et al., 2006; McMahon et al., 2000; Saunders et al., 1995; Widdows & MacCallum, 2002). Constructing these embryos as 'surplus' and 'extra' offers certain action possibilities: the couple who created them does not need them, and by implication continued storage may be constructed as unnecessary, even irrational, selfish and wasteful (McMahon et al., 2003; Oghoetuoma et al., 2000).

Storage limits have been introduced in most jurisdictions and range from 1 to 10 years (de Lacey, 2005; 2007b; Frith et al., 2011; Hammarberg & Tinney, 2006; Hammarberg et al., 2011; Paul et al., 2010; Provoost et al., 2011), although the exception is the United States, where there is neither legislation nor regulation restricting time limits for storage of frozen embryos (Frith et al., 2011). Beyond these timeframes, most jurisdictions either require that application is sought for continued storage, or have put processes in place allowing for the legal discarding of embryos (following 'diligent' attempts to contact the couples) (de Lacey, 2007b; MacCallum & Widdows, 2012). In Denmark, 2,500 embryos are disposed of annually as a consequence of the legislative limit of the storage limit being reached (Bangsbøll et al., 2004). In New Zealand, a maximum time period of 10 years was set for storing embryos in 2004 (Advisory Committee on Assisted Reproductive Technology [ACART], 2008),

with the implication that in November 2014 that those patients who have embryos that have reached their 10-year limit will be compelled to specify their directives, or clinics may need to consider disposal (Akoorie, 2014).

Therapeutically, embryos could be stored indefinitely and the time restrictions appear somewhat arbitrary, with some suggesting that one year allows for insufficient time to make decisions regarding family size, future attempts at pregnancy and disposal options, and that 10 years is unnecessarily long, arguably also leading to greater social problems (Svanberg et al., 2001; de Lacey, 2007b). Lornage et al. (1995) suggest timeframes ranging from 1 to 5 years, allowing decisions to be made in the context of a couple's parental plan, respect for the "natural course of procreation", and to ensure that there is no risk of "generational interference" (p. 2610). In this way, storage for a specified time may be constructed as rational, however it also appears that storing embryos beyond a certain timeframe or in the context of no further parental plan is constructed as problematic, both in terms of placing a 'burden' on patients, as well as on clinics (Brzyski et al., 2000; N. D. Johnson, 2003; Lyerly et al., 2010; Melamed et al., 2009). This positions those with embryos in storage as obligated to make decisions.

In some cases embryos may remain in storage because couples do not return to the clinic to use their embryos or to specify directives (Bangsbøll et al., 2004; Brzyski, 1998; Cattoli, Borini, & Bonu, 2004; Lornage et al., 1995; Luna et al., 2009; Newton et al., 2007; Oghoetuoma et al., 2000; Provoost, Pennings, de Sutter, Van de Velde & Dhont, 2012; Saunders et al., 1995). Within this context, a discourse of the decision as avoided or delayed can be identified in many of the texts, with the embryos described as 'unclaimed', 'abandoned', and 'unattended' (Bankowski et al., 2005; Brzyski, 1998; Brzyski et al., 2000; de Lacey, 2007b; O'Brien, 2010; Stiel et al., 2010; Svanberg et al., 2001; Walsh et al., 2010); attempts by the clinic to contact patients as being 'ignored'; and the number of patients who decline to respond as 'disturbing' (Brzyski, 1998). Concern is expressed regarding the 'destiny' or 'fate' of the embryos (Lornage et al., 1995; Walsh et al., 2010). These descriptions evoke emotive images and may position couples as irresponsible, neglectful and shirking their duty. Indeed, they are described as engaging in "passive relinquishment" (Bankowski et al., 2005, p. 829), or as avoiding taking moral responsibility for their embryos (Cattoli et al., 2004; Svanberg et al., 2001), thereby placing the clinic in a "perpetual guardianship relationship" over embryos and creating a "vexing problem" (Walsh et al., 2010, p. 1).

But the disposal decision has also been constructed as complex and fraught, with those who delay the decision reported to do so for reasons including the difficulty of

making a decision, worry about the irreversible implications, and concern about anticipated regret (de Lacey, 2007a; Hammarberg & Tinney, 2006; Janssens, 2009; Lyerly et al., 2010; McMahon et al., 2000; McMahon & Saunders, 2007; Nachtigall et al., 2005; Provoost et al., 2011; Svanberg et al., 2001; Takahashi et al., 2012, Victorian Assisted Reproductive Treatment Authority [VARTA]). The decision has been portrayed as: ‘complex’, ‘morally difficult’ ‘disagreeable’, ‘unpalatable’, ‘negative’ and involving ‘emotional cost’ (de Lacey, 2005, 2007a; Frith et al., 2011; Fuscaldo, Russell & Gillam, 2007; Hammarberg & Tinney, 2006; Klock et al., 2001; Lyerly et al., 2006; Nachtigall et al., 2005; Newton et al., 2007; McMahon et al., 2000; Paul et al., 2010; Provoost et al., 2011; Svanberg et al., 2001). Those with stored embryos are further described as needing to work through various stages in their decision-making, with the process evolving gradually and requiring “philosophical thought, discussion and moral reasoning”, and occurring in the context of cultural factors, changing public policy and debate (de Lacey, 2007a, p. 1752). Crockin’s (2005a) representation of the issues involved as ‘embryo wars’ at the epicentre of science, law, religion and politics underscores the complexity of the decision-making process. Lyerly et al. (2010) and Lornage et al. (1995) suggest that time is needed to allow couples to achieve or alter reproductive goals, recover from stressors, and work through life issues. For those that store in the context of treatment failure, Cattoli et al. (2004) hypothesise that patients fear repeated failure to such an extent that they elect not to use the embryos, ignore their existence, or allow clinics to discard them. On the other hand, Takahashi et al. (2012) suggest that Japanese women may hold on to their embryos to avoid acceptance of their infertility status (even if they have had a child). By constructing the decision as complex, fraught and needing time, those with embryos in storage may be positioned as vulnerable and conflicted. Indeed, patients are described as not being able to make up their minds, or as being uncertain even years after giving birth (Lyerly et al., 2004; McMahon et al., 2000; Nachtigall et al., 2005; Nachtigall et al., 2010; Newton et al., 2007).

Constructing the decision as complex and fraught may also underscore the importance of the need for counselling and information to assist in decision-making and consider the legal, social and psychological implications (de Lacey, 2013; Hammarberg et al., 2011; Hammarberg & Tinney, 2006; Janssens, 2009; Kovacs et al., 2003, Lyerly et al., 2006; McMahon et al., 2003; Nachtigall et al., 2010; Paul et al., 2010; Svanberg et al., 2001; VARTA, 2014). Some research has suggested that there is an insufficiently defined infrastructure at clinics to support decision-making (Fuscaldo et al., 2007;

Lyerly et al., 2006; Nachtigall et al., 2010; Paul et al., 2010), and other studies suggest that while most patients reported sufficient information to make a decision (e.g. Provoost, Pennings, De Sutter & Dhont, 2012a), they had talked to family and friends rather than staff and regarded decisions as private. Yet Hammarberg and Tinney (2006) comment that they do not believe that “apart from thoroughly exploring these issues before cryopreservation, there are any effective strategies to prevent that some will experience significant distress when they are faced with the need to make a decision about embryos” (p. 90). Paul et al. (2010) further comment that it is a challenge helping couples address their present difficulties whilst simultaneously attempting to prepare them for future phases and decisions. Lyerly et al. (2006) write that “while managing the strain of infertility, some participants were not in a suitable affective state to meet the cognitive demand of carefully considering the eventuality of spare embryos” (p. 1629). The decision is thus framed as a complex one, for which support may be needed, but which is also difficult to make within the context of current circumstances. Potential donors’ vulnerable position is thus reinforced, and their decision-making ability may be called into question.

Many of the studies reviewed have been of disposal intentions and attitudes, with far fewer studies reporting on actual decisions made. But it is routinely reported that couples frequently change their minds and elect a different disposal option than the one first indicated (Bankowski et al., 2005; Blyth et al., 2011; de Lacey, 2005; Klock et al., 2001; Lornage et al., 1995; Newton et al., 2007). Such changes are constructed in the literature as confusing and inconsistent, described in terms such as ‘contradictory’, ‘frustrating’ and ‘curious’ (Blyth et al., 2011; Darlington & Matson, 1999; de Lacey, 2005); ‘puzzling’ (de Lacey 2007a); and “at odds with rational decision-making” (de Lacey, 2007a, 1752). Such discourses of the inconsistent decision may further position those with embryos in storage as uncertain and confused, and again as incapable of rational decision-making, particularly prior to treatment. Indeed, some have questioned the utility of advance directives (Pennings, 2002).

Finally, a discourse of the decision as restricted (as involving no choice) may also be identified, and helps explain continued storage. Several researchers, for example, have reflected that decision-making may not be about an active decision in favour of a particular option, but about the rejection of another option (de Lacey 2007a; Frith et al., 2011; Lyerly et al., 2006; Lyerly et al., 2010; Paul et al., 2010). Lyerly et al. (2010) write that those with embryos in storage face “a choice among unappealing disposition options” (p. 506). In their study, nearly half of those with embryos stored

were storing their embryos because ‘good’ alternatives for embryo disposition were lacking (note that in this study, research donation was not available as an option). In de Lacey’s (2007a) study, discarding embryos was not framed as an active decision to destroy embryos, but rather as the unavoidable consequence of a decision not to donate to another couple. de Lacey comments that the decision is driven by “what patients find morally abhorrent rather than choice of the most attractive option” (2007a, p. 1757), with the ultimate decision thus presenting little more than an ‘illusion of choice’ (2007b). In some cases, couples ultimately have to choose between donation or destruction, and in the case of medical research, they are actually choosing both (de Lacey 2007a; Melamed et al., 2009). The same applies to ED in New Zealand, where ED may involve discarding (as policy prohibits donation resulting in genetic children in more than two families) (ACART, 2008).

Decisions also need to be evaluated within the context of what is possible (de Lacey, 2007b; Lyerly et al., 2010). Not all clinics offer all the options discussed, and public policy and practice may constrain the availability of some options. In New Zealand, decision-making is constrained through the unavailability of research as an option. A discourse of the decision as ‘restricted’ or ‘constrained’ may thus be identified, which while it positions those with stored embryos more sympathetically, yet again positions them as vulnerable and potentially conflicted. From within such subject positions the possibility of regret and ambivalence about the decision emerges, which may have longer-term consequences for all parties involved.

In sum, storage for a specified time is framed as positive, and positions those with stored embryos as rational. Those who delay their decisions however and continue storage beyond a certain point, are positioned either as confused or conflicted, and as potentially incapable of making rational decisions, or as irresponsible in avoiding or delaying the decision. It is against this backdrop that the constructions and experiences of those undertaking ED must be evaluated. The possibility that decisions may be enforced, fraught, and made reluctantly positions potential donors as vulnerable; may undermine their rational decision-making ability; and may evoke the possibility of future ambivalence and regret – this in turn may affect how ED is constructed and experienced, both by donors and recipients. Nonetheless, the disposal decision is one that will eventually need to be made, and I discuss these options next.

4.2.2 Discarding: Stressful and achieving closure, or wasteful and selfish?

A number of studies report that many, or possibly the majority of, patients will ultimately elect to discard embryos (Cattoli et al., 2004: 24.4%; Cooper, Laruelle & Englert, 1995; Darlington & Matson, 1999: 18.8%; Hill & Freeman, 2011: 68%; Hounshell & Chetkowski, 1996; Jin et al., 2013: 58.8%; Klock et al., 2001: 33%; Kovacs et al., 2003: 89.5%; Lanzendorf, Ratts, Keller & Odem., 2010: 38%; Newton et al., 2007: 42%; Oke, Hammarberg & Blood, 1998; Tinney, Hammarberg, Breheny & Leeton, 2002; Van Voorhis et al., 1999: 34%). On the other hand, several studies cite a reluctance to discard, with discarding described as difficult, involving sorrow and guilt, and accompanied by concerns about destroying 'life' or anticipated regret (Hammarberg & Tinney, 2006; Laruelle & Englert, 1995; Lysterly et al., 2010; Provoost et al., 2011).

Discarding is thus constructed as difficult and stressful. This may be underscored by clinic practices such as including couples in disposal processes, the use of ceremonies, or inviting couples to take embryos home for their own disposal (Gurmankin et al., 2004; Richards et al., 2012). Some clinics may offer 'compassionate transfer', where the embryos are transferred to the woman at a time in her cycle when she would be extremely unlikely to conceive (J. Ellis, personal communication, September, 2010; Lysterly et al., 2010). While clinics might offer such practices to make the process more natural and respectful, they may also serve to construct the embryo in ways that give the embryo special status, and even if inadvertently, communicate that embryos should not be discarded (Gurmankin et al., 2004).

Indeed, discarding has been described in media as 'throwing away' embryos, wasting, and rejection (Mail Online, 31 December 2012; Oghoetuoma et al., 2000), constructs which may be reinforced through use of the term 'surplus' to describe embryos that remain in storage. Discourses of discarding as challenging, as akin to destroying life, and as wasteful, may constrain discarding as an option and place patients in a difficult position in which they are seen as irresponsible and selfish (e.g. de Lacey, 2005; Takahashi et al., 2012), and they may experience guilt and sadness. Patients may however choose to discard for practical reasons: they might not have enough time to make reasoned decisions; may have completed their families; may have achieved a sense of closure and an end to their responsibility; or they may have a desire to avoid concerns about offspring that could result (Provoost et al., 2011; Svanberg et al., 2001; Takahashi et al., 2012).

4.2.3 Donating to research: Viable, practical and altruistic or immoral and unnatural?

Reports of numbers of patients willing to donate their embryos to research vary, with some suggesting that interest in and willingness to engage in research donation is very low (e.g. Baylis, Beagan, Johnston & Ram, 2003: 2%; Hill & Freeman, 2011: 11%; McMahon et al., 2003: 10%). Others report higher interest (e.g. Bangsbøll et al., 2004: 60% would be willing to consider; Bjuresten & Hovatta, 2003: 92%; Burton & Sanders, 2004: approximately 30% of those with embryos in storage would donate to research, if available; Hammarberg & Tinney, 2006: 42%; Luna et al., 2009: 30% of those specifying directives; Lyerly et al., 2010: 21% said they would be ‘likely’ to donate to research, and of those who were certain that they did not want another baby, 41% considered research donation likely; Nachtigall et al., 2010: 39%; Newton et al., 2007: 44%; Wanggren et al., 2013: 51% in favour). In contrast to several earlier studies (see above) that indicated that disposal was ultimately the most preferred option, some have suggested that donation to research has become more popular (Hammarberg & Tinney, 2006; Lanzendorf et al., 2010: 59%; Provoost et al., 2012: 40.8% vs. 37.8%). Interest is hard to ascertain however given that donation to research is not allowed in all jurisdictions and most studies have explored intentions, and not actions. In sum, it appears that donation to research, where available, is chosen more frequently than ED to others.

A discourse of donation as viable, practical and altruistic can be identified in the literature. Research donation has been described as offering potential for research into the treatment of infertility, therapeutic use and stem cell research which arguably may have substantial implications for regenerative medicine (de Lacey, 2007b; Hug, 2008; N. D. Johnson, 2003). Gorny (2004) argues that donation to research could provide “enormous therapeutic potential that could potentially improve the life of another human being” (p. 473) and N. D. Johnson (2003) describes donation as “logical and desirable” (p. 872). Where patients agree to donation, reasons cited include not wanting to ‘waste’ the embryos, a desire to help others, and a desire to advance science (de Lacey 2007b; Fuscaldo et al., 2007; Hammarberg & Tinney, 2006; Nachtigall et al., 2010). In this way, donation to research may be constructed as an attractive and viable option, making effective use of the by-products of IVF treatment and transforming “waste to health” (Svendsen, 2007, p. 25). Research donation can also be constructed as altruistic, allowing patients to give back (Fuscaldo et al., 2007) and “practice civil

responsibility and express mutual relatedness with the public health care system” (Svendsen, 2007, p. 28). Such discourses offer morally comfortable positions to potential donors.

Yet internationally donation to research has also been the subject of controversy, with concern expressed about the “deliberate creation and deliberate destruction” of embryos (de Lacey, 2007b, p. 105) and arguments that “it represents a further step on the instrumentalisation of human life” (The European Group on Ethics in Science and New Technologies, as cited in Hug, 2008, p. 264). Further, some suggest that donation is experienced as difficult, with some donors feeling that the embryos could still experience pain and that donation is thus ‘callous’ (Fuscaldo et al., 2007; McMahon et al., 2000), and that it constitutes experimentation on human life or could involve a misapplication of technology (Choudhary, Haimes, Herbert, Stojkovic & Murdoch, 2004; Fuscaldo et al., 2007; McMahon et al., 2000; McMahon et al., 2003; Nachtigall et al., 2010; S. Parry, 2006). Donation to research may thus be constructed as problematic, even immoral, placing donors in a difficult position.

It is also interesting to note that donating embryos to research is prohibited or restricted in some countries, such as Germany, Switzerland, and Austria (Mohler-Kuo et al., 2009). In New Zealand in 2010, ACART (2011) engaged in extensive public consultation, and recommended that donation to research become available as an option. The Ministry of Health and New Zealand government have as yet not responded to these recommendations nor given reasons for the delay. However, by prohibiting this practice, a discourse of research donation as problematic is underscored, placing potential research donors in an uncomfortable and conflicted position. Again, a decision to donate to others must be evaluated against this option, where available.

4.2.4 Donating to another couple: Viable, practical and altruistic, or problematic, uncertain, last option and controversial?

As a practice, ED was first reported in 1983 (Trounsen, Leeton, Besanka, Wood, & Conti, 1983). For donors, ED has been described as offering a solution to the ‘problem’ of surplus embryos and an opportunity to use (and thus ‘value’) the embryos, giving them ‘a chance at life’. It is promoted as allowing donors to help others who have similarly experienced difficulties with infertility, as assisting those who have been denied motherhood, and as a way of expressing reciprocity towards the clinic that assisted them in having children (de Lacey, 2005, 2007b; N. D. Johnson, 2003;

Kirkman, 2003a; Lyerly et al., 2010; Svendsen, 2007). In this way, ED is constructed as a moral and altruistic act, which may offer comfortable positions for donors.

For recipients, ED offers a chance of having a child with the advantages of experiencing pregnancy, childbirth and the parenting of a young child, and without the disadvantages of going through IVF and its associated expense and physical intrusion (Blyth et al., 2011; Brzyski, 1998; Check, Wilson, Krotec, Choe & Nazari, 2004; Eisenberg & Schenker, 1998; Hill & Freeman, 2011; N. D. Johnson, 2003; Keenan, Gissler, & Finger, 2012; Manning, 2004). ED has been described as “one of the most efficacious methods of ART” (Eisenberg & Schenker, 1998, p. 52), as “technically straight-forward” (Janssens, 2009, p. 502), and as “very successful” and “cost effective” (Hill & Freeman, 2011, p. 942; Lindheim & Sauer, 1999). It is described as less risky, less expensive, and possibly offering better chances of pregnancy than other options, particularly for those with ‘untreatable’ fertility issues, recurrent pregnancy loss, hereditary disorders, and older women whose eggs may not be viable (Anderson, 2006; Eisenberg & Schenker, 1998). Keenan et al.’s (2012) review of live birth rates suggests that ED yields pregnancy outcomes comparable to autologous procedures, making it an ‘attractive’ and ‘viable’ family-building option. Thus, a medical discourse can be identified that constructs ED as a viable and practical option for donors (making use of embryos) and recipients (opportunity for pregnancy), and positions them as rational in pursuing ED. As Widdows and MacCallum (2002) point to, ED may be driven by a technological imperative – that scientific progress is good in itself and should be pursued and that there exists a ready supply of embryos that could be used.

However, despite these positive discourses that can be identified, legislation around ED varies considerably, with some countries such as Austria, Denmark, Brazil, Japan, Israel, Norway, Sweden, Switzerland, Turkey, Taiwan, Italy and Germany restricting or prohibiting practices such as ED (Blyth et al., 2011; de Lacey, 2007b; Frith et al., 2011; Lee & Yap, 2003; Mohler-Kuo et al., 2009; Paul et al., 2010; Takahashi et al., 2012; Urman & Yakin, 2010; Wanggren et al., 2013). ED is legal in Australia, Canada, England, Finland, France, New Zealand, Spain, and the United States (Wanggren et al., 2013). ED practices, where permitted, can also vary substantially, ranging from anonymous donation (which has historically been the most common form of donation) to varying degrees of open donation. In traditional anonymous donation, donors do not have a role in specifying the selection of recipients, and do not have access to the identity of or contact with the recipients and the donor-conceived offspring. Recipients and offspring may have some access to non-identifying

information about the donors, but this is generally limited to the physical characteristics and the health status of the donor (Frith et al., 2011). Many countries, including Denmark, Greece, Portugal, Bulgaria, Spain, South Africa, the Czech Republic and India, allow anonymous donation (Garcia-Ruiz & Guerra-Diaz, 2012). In directed (conditional) anonymous donation, which is possible in some states of Australia, donors can specify desired characteristics of recipients, such as their age, marital status, ethnicity, socioeconomic class or sexual orientation (de Lacey, Rogers & Richards, 2010; Frith & Blyth, 2013; Frith et al., 2011).

In conditional, known donation, varying degrees of openness and information-sharing may be negotiated, and require donor registration of identity and access of child to identifying information, usually at the age of majority (de Lacey et al., 2010; Frith et al., 2011). Canada, the United Kingdom (since 2005), Sweden, Norway, Netherlands, New Zealand and some states in Australia allow donation in the context of registration of donor identity and access by donor-conceived children to their genetic information (Garcia-Ruiz & Guerra-Diaz, 2012; Hammarberg et al., 2011). ED in New Zealand includes donor registration, information-sharing, and mandatory individual and joint counselling for donors and recipients and their families (discussed further in Chapter 5). Such varying legislation, policies and restrictions however may in themselves construct ED as problematic and uncertain, and as a practice about which there is no agreement about its moral implications. Further, as discussed later in the chapter, they may serve to construct ED in different ways, which may influence the uptake of ED.

Indeed, while the prevalence of ED is difficult to ascertain, given that in some regions it proceeds anonymously and is not rigorously reported, the numbers undertaking ED generally appear low (Blyth et al., 2011). In the United Kingdom, approximately 35 children a year have been born from ED over the past decade (MacCallum & Golombok, 2007). Further, while many clinics may offer services (Blyth et al., 2011; Gurmankin et al., 2004; Hammond, Steinkampf & Cataldo, 2009), they may not actually be providing it, or the numbers performed are low (Hurwitz, Lederman, Jindal, Lieman & Santaro, 2005; Kingsberg, Applegarth & Janata, 2000). In New Zealand, the uptake of ED, in spite of the significant number of embryos in cryopreservation (J. Peek, personal communication, 2010), has been relatively low, with 55 applications processed by ECART between 2006 and mid-2012 (ECART, 2012).

Many researchers have reported that patients may often indicate willingness to donate their embryos as an initial preferred disposal option, with *interest* ranging from 2% to 52% (Bangsbøll et al., 2004: 29%; Brzyski, 1998: 9%; Burton & Sanders, 2004:

15%; Cattoli et al., 2004: 6%; Darlington & Matson, 1999: 5.9% in Western Australia; Hammarberg & Tinney, 2006: 16% in Australia; Hill & Freeman, 2011: 21%; Lanzendorf et al., 2010: 3%; Laruelle & Englert, 1995: 39%; Lyerly et al., 2010: 16%; Mohler-Kuo et al., 2009: 52%; Nachtigall et al., 2010: 7%; Newton et al., 2007: 8%; Newton et al., 2003: 12%). However, it appears that it remains more often contemplated than performed (Burton & Sanders, 2004; de Lacey, 2005, 2007b; Frith et al., 2011; Kingsberg et al., 2000; Saunders et al., 1995); and many potential donors, if not the majority, change their minds, with consistently lower numbers of patients finally donating when faced with making an actual, rather than an abstract or theoretical, decision (Blyth et al., 2011; Brinsden, Avery, Marcus, & MacNamee, 1995; Darlington & Matson, 1999; de Lacey, 2005; Elford, Lawrence & Leader, 2004; Hammarberg & Tinney, 2006; Klock et al., 2001; Lornage et al., 1995; Lyerly et al., 2006; Zweifel et al., 2006). The initial choice to donate in de Lacey's (2005) research is described as an idealistic plan, rather than a purposeful decision. Furthermore, in some of the studies exploring desired disposal options, ED was not an option available at the time (e.g. Mohler-Kuo et al., 2009).

Blyth et al. (2011) comment that in the end fewer than 10% go ahead to donate to others so, in sum, it appears that relinquishment to others is frequently the least favoured disposition option; is uncommon; and is chosen by a small number only (Blyth et al., 2011; Hammarberg et al., 2011; Lee & Yap, 2003; McMahon & Saunders, 2007; Melamed et al., 2009; Nachtigall, et al., 2010; Newton et al., 2007). The relatively low availability and uptake of ED, and the frequency of changes in intentions to donate, may reinforce the discourse of ED as uncertain and problematic.

Further, studies have suggested that where ED is chosen by donors, it is often chosen not as an ideal option, but the "least bad among a range of unattractive options" (Frith et al., 2011, p. 3334); or as "the lesser of all evils" (Paul et al., 2010, p. 263). Paul et al. (2010) suggest that decisions are thus guided by negative, rather than positive motivations, and decisions to donate are reached by a process of elimination. This context has already been described in subsection 4.2.1 above, but its reiteration here highlights a discourse of an enforced, restricted decision, and ED as a 'last option', which may position donors as potentially uncomfortable with their decisions, and evoke the possibility of future regret. This may create concern and anxiety for potential recipients.

It is important to note that research has tended to focus on the decision-making of potential donors, rather than recipients, and despite assertions that clinics are

receiving “a large number of requests” (Hurwitz et al., 2011, S235); that there is a “substantial shortage of embryos available” (Hammarberg et al., 2011, p. 180); and that “demand exceeds supply” (Kovacs et al., 2003, p. 128), this does not necessarily appear to be the case. In New Zealand, clinics report that the anticipated interest by recipients has not materialised, and that they do not have significant numbers of patients on their waiting lists (Ellis, 2012, personal communication). Low demand may partly be as a result of couples’ desire to use their *own* gametes, as it appears that using gametes from others, or by extension embryos, constitutes a last resort when there is no or little chance of a couple having their ‘own’ child using their own gametes (MacCallum, 2009; MacCallum & Golombok, 2007; Richards et al., 2012). Also, as MacCallum (2009) points out, ED tends to be recommended only when both members of the couple are infertile or when previous IVF attempts using the couples’ own gametes have failed. Again then, such low uptake may underscore a discourse of ED as potentially problematic and a ‘last resort’, and may make available positions of uncertainty.

On the other hand, there is little systematic evidence available regarding ED’s outcomes (Blyth et al., 2011; Frith et al., 2011; MacCallum et al., 2007). This stems partly from a lack of accurate recording and inability to engage in follow-up study, as well as the range of ways in which ED is practised and the novelty of the practice. Available research on ED tends to focus on donors’ decision-making regarding their embryos, and factors that influenced their decision-making. Only a handful of studies have explored the development of families formed through ED (e.g. Frith et al., 2011; MacCallum & Golombok, 2007; MacCallum et al., 2007; MacCallum & Keeley, 2008, 2012; Paul et al., 2010; Söderström-Anttila et al., 2001). In MacCallum et al.’s (2007) study of 21 ED families, the children (aged between 2 and 5 years) were reported to be doing well, although parents tended towards higher emotional involvement and more defensive responding than adoptive parents. MacCallum and Keeley’s (2008, 2012) follow-up studies of the children in middle childhood supported these findings. These studies were conducted in the context of anonymity however, and most parents had not or were not planning to disclose to their children, and thus, as the authors acknowledge, the longer-term implications may yet be uncertain.

Yet concerns are expressed about ED in terms of the longer-term unknown implications: Janssens (2009), for example, comments that there is “still much to be learned” (p. 502); Eydoux et al. (2004) that “too many questions remain unsolved” (p. 1685), and Melamed et al. (2009) that the “future societal consequences are not well understood” (p. 189). Caution is frequently recommended, and couples are ‘warned’

that they should be aware of the long-term uncertainty regarding psychological and developmental outcomes (Borrero, 2002). ED is described as one of the more complex and contentious forms of collaborative reproduction, raising significant psychological, ethical, moral and legal dilemmas (American Society for Reproductive Medicine, 2013; Applegarth, 2006; Blyth et al., 2011; N. D. Johnson, 2003; Lee & Yap, 2003). Guichon et al. (2010) go as far as asserting that ED in Canada constitutes an “experiment” on the health and wellbeing of children, and “there is no one to stop it, or at least, to slow it down by asking difficult questions” (p. 1). In contrast however, Pennings (2012) suggests that whilst reproductive donation (including ED) may constitute social experiments, we should not be frightened of these but rather gather data on them, and analyse and interpret them to ensure improved practice. However, such cautions may be dissuasive.

In sum, ED is constructed in the literature as an uncommon and controversial practice that may have unknown implications. It is constructed as a ‘last resort’ by both donors and recipients, and a practice that is more often intended than performed. Further, it is prohibited in some jurisdictions, with practices varying around the world. On the other hand, ED is also positively constructed: as offering solutions to donors and recipients and as a medically viable and successful ‘new’ procedure. These discourses offer contrasting subject positions: one is that of the pioneer, willing to pursue the latest medical advances, which may create some uncertainty and anxiety. On the other hand, donors and recipients may also be positioned as ambivalent, or even foolish, engaging in a practice with unknown implications that may be harmful. Further discourses of ED are discussed in section 4.5, but first I discuss discourses of the embryo and how these may both enable and restrict particular action possibilities.

4.3 Constructions of the embryo

A number of researchers have highlighted how conceptualisations of the embryo may affect disposal choices (Anderson, 2006; Blyth et al., 2011; Brinsden et al., 1995; Cooper & Glazer, 1994; de Lacey, 2005, 2007a, 2007b; Frith et al., 2011; Gorny, 2004; Klitzman, 2012; Lyerly et al., 2006; Nachtigall et al., 2005; Newton et al., 2003; Saunders et al., 1995; Provoost et al., 2009; Provoost et al., 2011). These conceptualisations are described as dynamic and altering over the course of treatment (Kato & Sleebom-Faulkner, 2011). As highlighted previously, much of the literature focuses on those contemplating rather than proceeding with various options, and it is

possible that the embryo may be seen in different ways before and after a decision is made. Further, the emphasis has been on potential donors' conceptualisations, rather than on how recipients may regard embryos and how this affects their choices and experiences. This near-silence in the literature may be indicative of a perceived irrelevance of constructions of the embryo in recipient decision-making, and may possibly serve to construct ED for recipients as a 'common sense' or uncomplicated decision in contrast to the decision that needs to be made by potential donors. It may position recipients as logical and sensible in pursuing this option, or, alternatively, by minimising the significance of constructs of the embryo, it may position them as 'willing to try anything'. In this section I identify discourses in the literature that may inhabit the findings described in research, as well as the ways in which authors write about the embryo. I analyse how these discourses may relate to action possibilities and disposal options, both those that I can identify in the research findings and those that I propose follow on from discursive constructions. Further, I consider subject positions that may be enabled for donors, as well as, where relevant, for the recipients of ED.

4.3.1 Biomedical discourse: The embryo as collection of cells or seeding material

A biomedical discourse may be identified in several research efforts and commentaries that have suggested that patients may regard embryos as collections of cells, seeding material, or as IVF by-products (de Lacey, 2007a; Eisenberg & Schenker, 1998; Gorny, 2004; Nachtigall et al., 2005; Provoost et al., 2009; Provoost et al., 2011). Gorny (2004) describes the embryo as an "eight-celled being that may never come into existence" (p. 476), a view that may be reinforced by medical professionals in their emphasis on the specific properties of the embryo, its development and its quality (Gorny, 2004; Parry, 2006). Such a biomedical discourse allows embryos to be constructed as a useful resource, similar to other biological material such as organs or tissues. Donating embryos to others or for research can then be constructed as reasonable and practical, offering an opportunity to either couples or society as whole, while discarding may be framed as 'wasteful'. In de Lacey's (2007a) study, donors were able to define the embryos as seeding material or 'base material' for further development by the recipients, which enabled their donation, in spite of their acknowledging the potential of the embryo to become a child. Similarly, Söderström-Anttila et al. (2001) report that some donors regarded the practice as akin to blood or organ donation.

However, a discourse of the embryo as cells may also enable options such as discarding, as the discourse allows patients to create a distance from the embryos and protect themselves from emotional attachments and moral responsibilities (Provoost et al., 2009). Further, those that see the embryo as biological material may assume that embryos have ‘expiry dates’ beyond which they are no longer useful, and so no decision can be made or is required (Blyth et al., 2011; Provoost et al., 2010). This may explain patient failure to specify final disposal decisions (Blyth et al., 2011).

From a recipient’s perspective, the biomedical discourse may make the receipt of donated embryos appear less complex and less ethically fraught. Embryos can be constructed as seeding material without specific ties to their progenitors, and thus with fewer longer-term responsibilities and implications for them and their family life.

4.3.2 Life discourse: The embryo as human life

Researchers have also suggested that patients may regard their embryos as children, or as human life already (Brinsden et al., 1995; Collard & Kashmeri, 2011; de Lacey, 2005, 2007a; Frith et al., 2011; Kato & Sleebom-Faulkner, 2011; Laruelle & Englert, 1995; Nachtigall et al., 2005; O’Brien, 2010; Söderström-Anttila et al., 2001; Svanberg et al., 2001). Brinsden et al. (1995), for example, suggest that patients consider the embryo as a ‘tiny baby’; in Melamed et al.’s (2009) study, 77.3% of the participants saw the embryos as life although some were unsure as to when life had begun. Participants in Frith et al.’s (2011) study expressed a belief that life begins at conception (note that participants were recruited through a Christian embryo relinquishment programme) and the Snowflakes Embryo Adoption Program² considers embryos to be ‘preborn children’ (Collard & Kashmeri, 2011). Kato and Sleebom-Faulkner (2011) report that in Japan embryos are referred to as ‘lost children’ and decisions are made with reference to what participants believe their embryos would be ‘satisfied’ with. For many, it seems, having a child through IVF serves as an example of what the embryo could become, and thus the embryo is more likely to be regarded as human life (Elford et al., 2004; McMahon et al., 2000). Indeed, some U.S. states recognise the embryo as a person, as reflected in former president George W. Bush’s assertion, when talking in opposition to stem cell research, that “real human lives are involved... the lives of embryos that will be destroyed” (Coxon, 2005, no page). In Ireland, Medical Council guidelines prohibit the deliberate and intentional destruction of what is regarded as ‘in

² The Snowflakes Embryo Adoption Program was set up by Nightlight Christian Adoption agency, California, in 1997 as an ED and adoption programme.

vitro life' (Walsh et al., 2010); even references in the literature to 'abandoned' or 'orphaned' embryos (Walsh et al., 2010) serve to personify the embryos, or give them life-like status.

By drawing on a discourse of the embryos as life, it is possible that the embryo may be regarded as having the same constitutional rights and dignities accorded a human being, and even that disposition should follow the same procedures used to establish custody rights for abandoned infants (Frith et al., 2011; Gorny, 2004; Mohler-Kuo et al., 2009; Walsh et al., 2010). Walsh et al. (2010) comment that "the tragedy of embryo abandonment comes to be viewed today as the corollary to the baby on the doorstep dilemma from generations past" (p. 2). This positions those with embryos in storage as having 'guardianship' over their embryos (Eisenberg & Schenker, 1998; Walsh et al., 2010), with implications for which options become constructed as desirable or undesirable. If the embryos are constructed as human life, it may become difficult to consider discarding/destroying the embryos, as it implies destroying life (de Lacey, 2007a; Fuscaldo et al., 2007; O'Brien, 2010; Söderström-Anttila et al., 2001; Svanberg et al., 2001), and may even position those who discard as 'murderers'.

Indeed, for patients in de Lacey's (2007a) 'donate' (to others) group, discarding was framed as akin to murder or termination, and even those in the 'discard' group expressed a sense of "killing children" (p. 1756). Likewise, Gorny (2004) describes how some see discarding as the "callous, heartless murder of unborn children", with references to allowing embryos to thaw to "live out their last days" (p. 470).

Some authors (Frith et al., 2011; Manning, 2004) have commented on how the termination metaphor has parallels with how pro-lifers draw on discourses of the embryo as life to justify anti-abortion sentiments. Manning (2004) writes that pro-life advocates may deliberately use emotionally charged terms such as 'embryo adoption' and 'embryo rescue', because such terms emphasise that all embryos are potential children. The Snowflakes programme's mandate is to save potential lives (Collard & Kashmeri, 2011). De Lacey and Norman (2004), however, raise the question of whether an embryo has an absolute right to life (p. 1066) and as Gleicher (2005) points out that while when human life begins may still be regarded as a contentious matter, the U.S. Supreme Court ruling in connection with *Roe v. Wade* (1973) implies that until a foetus reaches potential viability outside of its mother's womb, it cannot be regarded as life with concomitant constitutional protection against death.

Nonetheless, constructing the embryo as life may also lead to postponing disposal decisions, and negative views towards discarding and research donation

(McMahon et al., 2003), as the embryo may be framed as having the capacity to experience discomfort and even suffering (Nachtigall et al., 2005). ED on the other hand has been hailed by some as offering a ‘morally preferable alternative’ to destruction for donors, and as constituting an act of rescue for recipients (Nathaniel Centre³ submission to ACART, as cited in Helm, 2008). Studies of those who had donated their embryos through a Christian EA programme frequently cited their construction of the embryo as life already as influential in their decision to donate to others (Frith et al., 2011; Paul et al., 2010). Svendsen (2007) suggests that donating embryos from within a ‘life ethics’ framework amounts to a demonstration of civil responsibility, contributing to the collective good and balancing one’s own interests with those of the collective. By donating then, donors may be offered a ‘moral’ subject position in which they value life, and the good of society.

On the other hand, in de Lacey’s (2007a) study, the group who ultimately elected to discard also constructed their embryos as ‘children already’. As de Lacey points out, there is a paradox here in that an option is authorised which results in the embryo’s destruction, in spite of the embryo being assigned a childlike persona, and in spite of, I suggest, the potentially negative subject positions that donors may be assigned. Likewise Bangsboell et al. (2004) have suggested that research/discarding options are selected in preference to others. It is possible that decisions are made by drawing on this discourse in relation to others, for example, the genetics discourse, which is described below in section 4.3.4.

4.3.3 Limbo discourse: The embryo as having interim status

The situation may not be as simplistic as a narrow construction of the embryo as either life/a child, or as cells. Both the participants in de Lacey’s (2007a) ‘donate’ and ‘discard’ group could see the embryos’ *potential* as children, yet those in the ‘donate group’ chose to emphasise a view of their embryos as cellular and as ‘seeding’, rather than as ‘childlike’ (p. 1755). De Lacey suggests that the latter view was a more objective one, focusing on the *potential*, the interim and not fully-formed-as-child status of the embryo. The participants in de Lacey’s (2005) study, who all elected to discard after having originally intended to donate, also drew on less absolute views, ascribing a

³ The Nathaniel Centre – the New Zealand Catholic Bioethics Centre – was established on 1 May 1999 as an agency of the New Zealand Catholic Bishops’ Conference.

‘virtual personhood’ status to their embryos – they had a personhood that lacked physical presence but contained biology and spirituality (p. 1665), and for these participants this gave a degree of comfort about discarding. The definition of ‘embryo’ by the Ethics Committee of the American Society for Reproductive Medicine (ASRM) likewise assigns an interim status:

The (pre)embryo is due greater respect than other human tissue because of its potential to become a person and because of its symbolic meaning for many people. Yet, it should not be treated as a person, because it has not yet developed the features of personhood, it is not yet established as developmentally individual, and it may never realize its biologic potential. (Ethics Committee of the ASRM, 2009, p. 1818)

As evident in the quote above, the interim status discourse opens up the action possibility that the embryo should be afforded *some* dignity and rights (Kato & Sleebom-Faulkner, 2011; Mohler-Kuo et al., 2009). However, because the embryo’s status is ‘ambivalent’ (Helm, 2008), a compromise position is enabled (Gorny, 2004; N. D. Johnson, 2003): the embryo does not have the same rights as a person but is also not the same as other human cells and cannot be reduced to the status of a commodity (Eisenberg & Schenker, 1998; Kato & Sleebom-Faulkner, 2011). Frith and Blyth (2013), however, suggest that while the embryo’s current status and interests are weak, actions that damage the embryo’s future interests need to be recognised; that is, the future interests of the person the embryo will become. They argue that it is these rights and interests that need to be protected. What these rights are, however, are difficult to establish, particularly in view of the lack of follow-up studies (Frith & Blyth, 2013).

Some have suggested that as the embryo is not life, contractual law may be drawn upon. This raises questions about donor rights and responsibilities, informed consent, and the right to vary agreements. In New Zealand, Helm (2008) notes that ACART guidelines are based on the 1996 Code of Health and Disability Services Consumers’ Rights Regulations, which stipulate that “no body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved or used otherwise than with the informed consent of the consumer” (Right 7(10) in Helm, 2008, p. 28). However Helm argues that it is debatable whether the embryo can be regarded as a bodily ‘part’ or ‘substance’; neither is it ‘removed’, and it is questionable if it can be asserted that the embryos were ‘obtained’. It is also difficult to assign consumer status to the donors who have completed fertility treatment. In this way, Helm (2008) suggests that the interim discourse may constrain donors’ ability to give consent. In the United Kingdom and New Zealand, guidelines stipulate donor right to withdraw consent until implantation, but this is not the case in organ donation. In

Canada, once recipients have confirmed in writing that they have received the embryos for their own use, the donors can no longer withdraw consent, and the use of, and subsequent disposal of, embryos becomes the responsibility of the recipients, similar to a property transfer. Robertson (cited in N. D. Johnson, 2003) writes that “the notion of special respect will seem like empty rhetoric if it leads to no limits at all on what may be done with the embryos” (p. 871). This discourse thus creates ambivalent subject positions for donors and recipients, as the rights and responsibilities each party carries may be unclear. On the other hand, O’Brien (2010) regards this ambivalence as beneficial, as it provides for flexibility, even a “double benefit”, in allowing society, legislatures and courts to apply the rights of both property and life (p. 2010).

So in sum, paradoxically, those who see the embryo as life or child may draw on this discourse for motivation both to donate embryos and not to donate them (Hammarberg & Tinney, 2006). De Lacey (2005) and McMahon et al. (2000) suggest that this may be because potential donors could not conceive of *their* genetic children being raised within another family, not knowing them, or having them turn up unexpectedly. In my reading of these reflections, it seems to me that it is the construction of the embryo as *my* child rather than *a* child (more abstract and less personal) that comes into play, and that potential donors draw on what I have termed the ‘genetic and kinship discourse’ in their decision-making. This idea is reinforced by Roberts (cited in Svendsen, 2007), who argues that donating embryos to others or to research draws on constructs of the embryo that relate to ‘life ethics’ (potential child or life) rather than ‘kin ethics’. He suggests that drawing on ‘life ethics’ means that the embryos are “stripped of social ties”, and thus “they may circulate to other families or to research and become valuable either way” (cited in Svendsen 2007, p. 31). Constructing the embryos as kin may make it problematic to donate however, as discussed below.

4.3.4 Genetic or kinship discourse: The embryo as my/our child/a family member, and the welfare of the child and family

Several researchers have reported that embryos may be seen as genetic children or replicating existing children (Blyth et al., 2011; de Lacey, 2005; 2007a; Kato & Sleeboom-Faulkner, 2011; Kirkman, 2003a; Laruelle & Englert, 1995; McMahon et al., 2000, 2003; Melamed et al., 2009; Nachtigall et al., 2005; Parry, 2006; Paul et al., 2010; Provoost et al., 2009; Stiel et al., 2010). In Kato and Sleeboom-Faulkner’s (2011) study

in Japan, some participants regarded themselves as ‘mothers’, and the embryos as their children who “had not yet taken on the shape of a human being” (p. 439). McMahon et al. (2000) report that 90% of their participants regarded their embryos as potential siblings to their existing children, and in Paul et al.’s (2010) study, donors referred to the embryos as their children’s full brother or sisters, with one donor commenting that “I felt like I was giving away *my* children” (p. 264). In other words, as N. D. Johnson (2003) has argued, patients may view the embryos not only as potential life, but as *their* potential children and siblings to their children. Participants in de Lacey’s (2005) study went one step further, emphasising the status of the embryo as ‘from the same batch’ as their existing children, thus not merely full genetic siblings, but ‘twin siblings’ (p. 1666), or, as in Collard and Kashmeri’s (2011) study, ‘batch siblings’. Embryos, unlike gametes, are thus perceived as full relatives, as ‘belonging’ to the family (Frith et al., 2011; Fuscaldo et al., 2007) and as “cognitively incorporated into family structure” (Nachtigall et al., 2005, p. 433), and their status thus “needs to be defined within discourses of family relationships” (de Lacey, 2005, p. 1667).

Such a discourse has implications for the action possibilities enabled and the subject positions that may be assumed, with research suggesting that both discarding and donating may be difficult (Elford et al., 2004; N. D. Johnson, 2003; McMahon et al., 2000; Melamed et al., 2009; Paul et al., 2010; Provoost et al., 2009; Söderström-Anttila et al., 2001). Through seeing the embryo as “another of their children” (de Lacey, 2005, p. 1667), donation may be seen as akin to as giving up their child (Melamed et al., 2009), and of separating their own children from their genetic siblings (Blyth et al., 2011). Svendsen (2007) suggests that to donate to research couples have to sever connections between themselves and their embryos that were created in the hope of kinship. It may be hard to acknowledge that the embryos are “unwanted, biological descendants” (Cattoli et al., 2004, p. s17). Donors may worry how being ‘donor-conceived’ may be interpreted as being ‘given away’ and having full siblings growing up in another family with their mutual genetic parents. They may also struggle with the idea of others raising their genetic child or with ‘delegating’ this task to others. In the context of anonymous donation, donors may struggle with not knowing of the existence or wellbeing of their genetic child; may hold fears about unknown consanguinity; and may worry about the child ‘knocking at their door one day’ (Allan, 2010; Bangsbøll et al., 2004; Blyth et al., 2011; Borrero, 2002; de Lacey, 2005; Kovacs et al., 2003; McMahon et al., 2000; McMahon & Saunders, 2007; Nachtigall et al., 2005; Nachtigall et al., 2010).

Investment in a genetic and kinship discourse raises questions as to how the donor-conceived child's wellbeing can be promoted (Kirkman, 2003a; Manning, 2004; Provoost et al., 2009). In other words, a 'wellbeing of the child' discourse is enabled and runs alongside the genetic discourse. Research findings describe donors as feeling responsible for 'their' child's wellbeing even though they have no parenting authority (de Lacey 2005, 2007a; N. D. Johnson, 2003; Kirkman, 2003a; Lysterly et al., 2010, Mohler-Kuo et al., 2009; Paul et al., 2010; Söderström-Anttila et al., 2001). Paul et al. (2010), in their study of families that had donated through a Christian adoption programme, report that donors were seeking to find stable homes for 'their' children to "avoid negative outcomes for the baby" (p. 264). Participants in Kato and Sleebom-Faulkner's (2011) study in Japan made reference to making decisions in relation to "what should be the responsible attitude as a mother to a child?", and one commented that "I have treated my children differently. I feel that I am a bad mother" (p. 443).

This subject position of responsible parent can also be identified in the practice of specifying conditions for donation or expressing interest in doing so (Frith et al., 2011; Fuscaldo et al., 2007; McMahon & Saunders, 2007; Paul et al., 2010; Wanggren et al., 2013). In Paul et al.'s (2010) study, finding the 'right match' with their family, often a family that closely resembled the donors' family in terms of shared values and experiences (the "same profile as me to raise my children" [p. 264]), was important, and framed as in the best interests of the potential child, with one participant commenting that "The child's best interest trumps all other party's rights" (p. 264). Collard and Kashmeri (2011) describe how Snowflakes donors were looking for families comparable to themselves in terms of religion or spirituality, marriage and family values, education, income and race. In Wanggren et al.'s (2013) study, participants wanted requirements around age, criminal background, alcohol use, and partnership status/sexual orientation. For participants in Frith et al.'s (2011) study, being able to play an active role in choosing recipients helped them to feel as if they were ensuring an adequate home for the children and acting as "responsible parents to their embryos" (p. 3336). Similarly, both Fuscaldo et al.'s (2007) and McMahon and Saunders' (2007) studies suggest that many supported the idea of conditional donation allowing them control over the characteristics of recipients. They wanted to ensure a stable and loving home with people who had the means to support the children (Fuscaldo et al., 2007) and control over the caretaking environment (McMahon & Saunders, 2007). In Collard and Kashmeri's (2011) study, donors also had a preference for their embryos to be donated to couples who would have more than one child from their embryos. They appeared to

reason that the children's shared genetic link would enable them to offer each other support in terms of shared experiences. Furthermore, Collard and Kashmeri suggest that donors may believe that by creating more than one child, the donor-conceived children's ongoing relationships with siblings in the donor family may be promoted.

Kato and Sleetom-Faulkner (2011) argue that Japanese patients make their decisions based on 'motherhood ethics', which they contrast with Euro-American societies where, they claim, decisions about embryos are made primarily based on what the embryo means ethically in terms of the development of life. The above analysis suggests otherwise, and that the genetic relationship is constructed as bestowing an emotional tie between genetic donor and child, and between siblings, with subsequent concerns about the child's future welfare and how the child would be raised.

Conditional donation may increase the numbers of patients willing to donate to others as "some families are so worried about putting their embryos in the wrong family" that they do not donate (de Lacey et al., 2010; McMahon & Saunders, 2007). Kaye (2007, as cited in de Lacey et al., 2010, p. 6) asserts, however, that to suggest that any type of social criteria can make for better parenting skims over the surface of the parenting question, and that conditional donation may not guarantee a child good parenting. Concern about discrimination was also expressed by some participants in Provoost et al.'s (2009) study. On the other hand, Frith and Blyth (2013) suggest that what conditional programmes do is promote more open donations, which has been argued to better meet the needs of donor-conceived persons.

Nonetheless, the genetic and kinship discourse appears to enable a concern for the child's welfare and aligns donors with the need to act as responsible parents. Indeed, some commentators have argued that ED is simply not in the best interests of children. The Nathaniel Centre, for example, argues that whilst there may be some circumstances where children may need to be separated from their genetic families, "to set out to deliberately deprive children of this link for the sake of adults involved is quite another. It is inconsistent with respect for the family and for the child" (cited in Helm, 2008, p. 10).

Drawing on discourses of the embryo as child, and the welfare of the child discourse, seems also to have led in some cases to donors' desiring varying degrees of information-exchange and contact. In Frith et al.'s (2011) study, for example, most ED donors wanted an 'open relinquishment', with the ability to have access to information. In Fuscaldo et al.'s (2007) study on hypothetical scenarios, while anonymity was regarded as easier, it was seen as unfair to children who were held to have a right to this

information. In Frith et al.'s (2011) study, donors wanted some degree of contact, and while this was constructed as negotiable and evolving, it was seen as important for the donor-conceived child and for the donors' children to have the ability to build a relationship. Collard and Kashmeri (2011) report two models of relationship: one where families keep in contact, although redefine kinship relations, and the other, similar to classic adoption models, where they activate genetic siblingship later in life. In Paul et al.'s (2010) study, levels of desired contact varied from photos and card/email exchange, to meeting for special occasions, to closer relationships. Establishing a comfortable degree of contact and relationship-building was presented as a challenge, with donors expressing uncertainty and caution in terms of how to go about fostering the relationship in a way that respected recipients' privacy and wasn't too intrusive. However, as comfort levels with their decisions and the other couple increased, more contact tended to be established. While this was not necessarily always regular, many described it as close, with one participant describing the relationship in the following way: "It is not so much an intensive relationship... it is more intimate. The four of us have remained open and willing to share information. It is as friendship that crosses all boundaries. We share a wonderful love for a little boy" (p. 268). For donors, concerns remained about the ongoing health and wellbeing of the children they had helped create. Concerns centred on child-rearing, values and safety, with one donor commenting that "since I would not obviously be there in person to protect the child, I do feel that it is my obligation to do so as much as I can" (p. 268). Finally, in Fuscaldo et al.'s (2007) study, while some regarded involvement as a positive factor, others saw this as the continuation of an emotional tie that would be problematic, making it less possible to achieve closure. It was also regarded as potentially confusing for the child in having several adults in potentially competing roles, and as undermining for the recipients.

In the New Zealand context, genetic connectedness is given tremendous importance by the Māori indigenous population through the concept of whakapapa, "a conceptual framework for... considerations of relatedness, personhood and reproduction" (Glover & Rousseau, 2007, p. 119). Whakapapa establishes and determines an individual's status within the immediate and wider family and society (Lovelock, 2010). Individual status requires full knowledge of genetic heritage, as the individual is located as the child of two genetic parents and as the offspring of the whānau (extended family), hapū (sub-tribe) and iwi (tribe) (Daniels, 2004). The embryo may thus similarly be constructed as a child and as a symbol of such genetic connectedness, and may assume a role in decisions to proceed with ED. While no

studies have focused directly on Māori experiences of ED, and Māori uptake of ED in New Zealand has been low (ECART, 2012), Glover's (2008) study on Māori attitudes towards assisted human reproduction suggests that the sustaining of Māoridom is a priority, and that ARTs may be seen in the service of this greater kaupapa (principle). ED may thus be constructed as viable, and be seen to have parallels with whāngai (the placement of children with members of the whānau). However, Glover (2008) suggests that for Māori, 'within whānau' solutions to infertility are preferred, along with an emphasis on ensuring that Māori have access to knowledge about genetic origins to enable children "to be able to recount their whakapapa" (p. 56). The wellbeing of children is thus similarly emphasised, and conditional donation may be of particular relevance here as by directing donation to another Māori family, for example, there is some reassurance that the child will be raised socially and culturally to be Māori (de Lacey et al., 2010).

Māori notions of whakapapa and the importance of whānau also highlight another issue that has been identified not only for Māori, but for others also: that genetic connection may be important not just for the parent and child and siblings, but also for the wider family network. Daniels, Kramer and Perez-y-Perez (2012), for example, suggest donation affects the wider family network, and one participant in Collard and Kashmeri's (2011) study stated: "when a placing family relinquishes, they are relinquishing parenthood and the child... as well as sister, brother, aunt, uncle, mother, father" (p. 316). The genetic or kinship discourse then may position donors and recipients as needing to take into account the wellbeing not only of the donor-conceived child, and his or her siblings, but also the wider family network. A 'welfare of the family' discourse is enabled through constructing the embryo as a family member.

Research findings have also been contradictory, however, in that some discard rather than donate their embryos even where they regard them as their children (Kirkman, 2003b; Melamed et al., 2009). Melamed et al. (2009) suggest this is because donors will be unable to parent 'their' children and ensure their welfare. Likewise, Lyerly et al. (2010) suggest that those with a high concern about their embryo or future child's wellbeing, and those who held notions of 'parental responsibility', were more likely to thaw and discard their embryos, freeze indefinitely, or elect for compassionate transfer or a disposal ceremony than to donate to another couple. Participants in Fuscaldo et al.'s (2007) study saw storage and donation to others as a continuation of emotional ties to 'their' embryos; discarding, however, constituted terminating such attachments and thus closure. The possibilities enabled by constructions of the embryo

as ‘their’ genetic child may thus paradoxically include both discarding and donating, but both options may stem from a subject position of ‘responsible parent’ to their embryos.

Prospective recipients may also draw on this kinship discourse, constructing the embryos as genetic symbols and inherently tied to the donors’ family. Recipients that cannot conceive with their own gametes have been reported to face significant grief issues related to the loss of their genetic connectedness to the child, feeling that this may have implications for the parent–child bond (Daniels, 2005a; Goedeke & Payne, 2009; Provoost et al., 2009; Söderström-Anttila et al., 2001). In a pilot study in New Zealand, potential recipients spoke of the implications of this loss, and that, particularly in light of the possibility of ongoing contact between donor and recipient families, ED would constitute ‘shared parenting’ at best, and that this would be difficult to manage (Goedeke & Payne, 2009). Further, where donors have set restrictions, recipients may experience themselves as vulnerable since they must fit certain criteria and pass tests before they are deemed eligible for ED (Goedeke & Payne, 2009). They may thus experience themselves as disempowered, possibly even not the ‘real’ parents, and they may choose to conceal the donor conception, which, as Manning (2004) argues, is entirely possible as ED provides the ability to “conceal the whole genetic tree” (p. 679).

N. D. Johnson (2003) suggests that for couples where one person is fertile and the other is not, ED may be attractive in that the couple may be more comfortable with idea of having a child genetically unrelated to *both* of them as opposed to only one of them. Neither parent can thus assert a greater claim to the child on the basis of genetic connectedness. For other recipients, having an embryo genetically unrelated to them but to another couple who created the embryo may be constructed as a better option than creating embryos separately from donated sperm and eggs, where the embryos would have no full genetic links to another family. N. D. Johnson (2003) reflects that “they prefer knowing that the embryo they adopt was conceived by a couple who longed to be parents and went to great lengths to achieve that goal” (p. 865) – that it was constructed in the context of a family structure. Recipients’ value on genetic connection was also highlighted in a follow-up study of donors and recipients (Collard & Kashmeri, 2011), where recipients frequently tried to have children from the same set of donors. Collard and Kashmeri describe this tendency as ‘siblingship trumps descent’, in that the recipients often made reference to their children at least ‘having each other’ through having a shared genetic bond, that could potentially make ED easier for them and strengthen the cohesiveness of their family. But again, in this way, emphasis is placed on the genetic connection in terms of emotional attachments and relationships.

A kinship discourse is thus apparent in much of the literature. De Lacey (2005) suggests that there is a need to research further to explore the cultural meaning of donating an embryo for gestation “within a social context where genetic relatedness is a dominant discourse” (p. 1669). Note that some authors have also suggested that clinic practice, which tends to proceed from offering couples the opportunity to try IVF first with their own gametes, then donor gametes, and only as a last resort, donor embryos, ‘persuades’ patients that families created from genetic ties (or at least partial genetic ties) are stronger and more desirable than those created by adoption or in other ways (Collard & Kashmeri, 2011; N. D. Johnson, 2003, p. 873). Likewise, Collard and Kashmeri (2011) note how some agencies may reinforce the importance of genetics by recommending that they do not ‘mix embryos’ from different sets of donors.

In sum, this genetic and kinship discourse positions donors and recipients in particular ways: for donors, the genetic or kinship tie may reinforce a position of rightful or responsible parent, or of having ongoing rights and responsibilities towards the donor-conceived child, and it opens up a ‘welfare of the child/family’ discourse. For the recipients, this discourse may challenge their sense of being able to claim full parenting authority and relationships, and may threaten their role as parents.

4.3.5 Couple unit discourse: The embryo as symbol of a couple’s relationship

Studies have also suggested that the embryo may be regarded as the product of, and be symbolic of, the couple’s relationship and unity (Klipstein, Reindollar, Regan & Alper, 2001; Provoost et al., 2009; Provoost et al., 2010; Provoost, Pennings, De Sutter & Dhont, 2012b). Larijani and Zahedi (2007), writing from an Islamic perspective, suggest that the embryo is symbolic of genetic heritage as the exclusive product of a married couple. Such a discourse of embryo as symbol of the relationship may lead to a reluctance to donate (see e.g. Provoost et al., 2012b). In some cultures, donation, which introduces embryos from those outside the marital relationship, may constitute adultery, as well as confusing issues of kinship, descent and inheritance, potentially ‘destroying a child’s lineage’ and leading to a ‘mixture of relations’ (Gürtin & Vayena, 2012; Inhorn, 2006). While some fatwas (religious rulings) have shown greater flexibility, and may allow ED, preference for continuity of lineage by donation from relatives in Iran continues (Tremayne-Sheibani, 2006, cited in Larijani & Zahedi, 2007). Similarly, ED is prohibited in Turkey under 2010 legislation in order to preserve both the “unity of the

family” as well as the “racial purity of the nation” (Urman & Yakin, 2010, p. 730). In Western contexts, in Klipstein et al.’s (2001) study couples indicated that if they separated or divorced, they would rather discard their embryos. The authors comment that this constitutes an attempt to remove unborn children from the equation in the event that the couple’s status as a decision-making unit were to be destroyed. Similarly, a 2000 Massachusetts Supreme Judicial Court decision ruled that a woman could not use embryos created by her and her ex-husband, as this would ‘compel’ him to enter into familiar relationships (Annas, 2000). Klipstein et al. (2001) also report that the majority of couples elect to discard embryos in the event of the female’s death, but not if the male dies, in which case the embryo would most likely be transferred to the woman’s body. It is possible that this is based on logistics or on the assumption that women are more capable of raising children on their own (Klipstein et al., 2001). However, it may also be that the embryo is regarded as symbolic of and belonging within the couple context, and not to be used in the context of a ‘new’ unit, necessary if the male wishes to use the embryo.

4.3.6 Genetic blueprint and ‘genetically dubious’ discourse

The construction of the embryo as genetic blueprint can be identified in several studies. In de Lacey’s 2005 study participants emphasised the ‘full bloodedness’ of their embryos as having complete genetic relatedness, with associations of recognisable characteristics arising from their genetic makeup. This was constructed as embryos being ‘spitting images’ of their siblings, particularly as they were ‘from the same batch’ of embryos. The embryos were seen as carriers of particular characteristics that may be important to know about, or had implications for feelings of family connectedness.

The discourse is also evident in a related concern expressed by potential embryo recipients about the genetic composition of the embryo, and the possible inheritance of characteristics and problems that could have a genetic basis (Goedeke & Payne, 2009). One potential recipient in Goedeke and Payne’s (2009) study, for example, commented:

I want my baby, ‘my’ genes, ‘my’ personality traits and deficiencies; I want to know what’s inside it and where it came from. I don’t want somebody else’s stuff... pretty fixated on that... the genetic creating of them; any lurking disease – you can’t tell by looking at someone or even knowing them a wee bit... are they some sort of carrier or something that’s going to ‘pop out’ in my baby? How can I get a CV of an embryo? (p. 1942)

Similarly, others expressed concern about the potential for negative inherited characteristics. Participants feared the unknown nature of the characteristics donor-

conceived children may have based on a construction of the embryo as ‘genetic blueprint’. Likewise, two participants in McMahon et al.’s (2000) study were reluctant to donate or use embryos because the children had significant behaviour problems, raising concerns that embryos from the ‘same batch’ might have similar problems.

Such a discourse must be considered in the context of developments in genetic research, and media attention bringing these developments to public attention. These developments have underscored the genetic basis of health and disease, with a person’s genetic inheritance and genealogy thus becoming increasingly significant (Grace & Daniels, 2007; Michelle, 2006). Kirkman (2003c) refers to an “escalating discourse of the significance of genes and genetic inheritance” (p. 2230), and Kitcher to a “genes-talk” (as cited in Michelle, 2006, p. 115). This genetic blueprint discourse underscores a need to have access to genetic knowledge in order to have ‘full information’ about propensity to certain characteristics and conditions, with the argument that undesirable conditions may be avoided, controlled for or treated, and desirable characteristics may be enhanced by foreknowledge (N. D. Johnson, 2003; Michelle, 2006). This discourse, however, also reinforces the power of genetic inheritance and marginalises environmental determinants (Michelle, 2006). In the New Zealand context, this discourse may be reinforced by obligations to preserve and acknowledge the importance of genealogical links or blood ties in accordance with the Māori concept of whakapapa (Else, 1999; Legge, Fitzgerald & Frank, 2007).

The discourse may also result in what Finkler (2001, as cited in Grace & Daniels, 2007) has termed a ‘medicalisation of kinship’, introducing a newly constructed genetic kinship independent from the social bonds of families. While families are becoming more diverse and less reliant on blood ties in their creation, this diversity is challenged by an emphasis on the medical importance of genetic connectedness (Grace & Daniels, 2007). Finkler, Skrzynia and Evans (2003) argue that this medicalisation is “bringing hitherto unknown relatives not only into connection with one another but literally into being” and that it may be “uniting those who may not feel connected, and who may not choose to be united” (p. 406, as cited in Grace & Daniels, 2007, p. 696).

On the other hand, Strathern (1992) suggests the ‘reading’ of the human genome may displace the need for knowledge of family genetic history as the individual’s genome may be read for information in isolation, as “an entity judged by no measure outside of itself, to be related neither to nature or to society” (pp. 358–359, as cited in Grace & Daniels, 2007, p. 706). However, others (e.g. Oyama, 2000) have argued that

genes can only be interpreted in the context of the developmental system, implying a need for knowledge about the genetic history of other family members. It is therefore family genetic history, rather than individual genetic history, that needs to be known, and the medicine of the future will not be the medicine of the individual but of the family (Finkler et al., 2003, as cited in Grace & Daniels, 2007).

Such a genetic blueprint discourse raises the question of whether anonymous donation, without the ability for offspring to learn about their own and their family's genetic heritage, is ethically responsible (N. D. Johnson, 2003). This places potential donors in a position where they 'should' at the least provide full medical and psychosocial histories and update these regularly so that the resulting donor-conceived child has access to this information. For recipients, these constructions may constrain decisions to conceal the method of conception and information about donors from their children. It implies a moral obligation for recipients to ensure that children have access to their genetic background. This is discussed further later in the chapter.

A related discourse of the embryo as potentially 'genetically dubious' (a term I have adopted from de Lacey and Norman, 2004) may also be identified. Indeed, IVF may be constructed by potential recipients as an artificial process, allowing the 'forced creation' of embryos from couples whose health is already compromised (Goedeke & Payne, 2009) and which may carry known or unknown genetic alterations related to the fertility problems of the couple (Eydoux et al., 2004). Thus the embryos available for donation may be constructed as being of poorer quality than embryos created naturally, and these 'artificially created' embryos constructed as dubious, or 'not a great starting point' and second rate (Goedeke & Payne, 2009). Further, Helm (2008) writes that the embryos are usually the donors' 'second best' embryos, with the healthiest embryos having been used in the donors' own treatment. Eydoux et al. (2004) suggest that an embryo's 'pedigree' should be established in order to identify the risk of genetic disease (allowing recipients some degree of certainty about embryo quality).

Such constructions may have implications for donors and recipients, and their ability as well as willingness to proceed with ED. De Lacey and Norman (2004), for example, reflect on two cases in which a child from the same batch of embryos available for donation appeared to have congenital symptoms suggestive of a genetic disorder; that is, it was possible that the embryos were genetically affected or 'dubious'. In these cases, however, while healthcare professionals recommended discarding, the patients (potential donors) were distressed and refused to do so, and in one case advertised for potential recipients who were willing to carry the risk of having a child

with a congenital condition. Note that where donors and recipients elect to proceed with ED in the context of ‘genetically dubious’ embryos, it appears they may be positioned as having compromised judgement by virtue of their infertility and its emotional consequences; they are framed as potentially irrational and incapable of making informed, sensible decisions (de Lacey & Norman, 2004).

The ‘genetically dubious’ discourse may also open up concerns about the possible future emotional implications for children: that the children may likewise come to construct themselves as ‘second rate’ and the ‘less desirable’, the ones discarded by their genetic parents in favour of their first choice, ‘better quality’ sibling selected by the donating family (Goedeke & Payne, 2009).

4.3.7 Property discourse: The embryo as individual versus public property

The issue of whether embryos can be considered ‘property’ has been the subject of much debate in the literature (Bennett, 2000; de Lacey, 2007b; de Lacey et al., 2012; O’Brien, 2010). As has been discussed in sub-section 4.3.3 above, some authors (e.g. Anderson, 2006; Helm, 2008) have discussed how health or contract law, not family law, has been used in disputes regarding embryos, and how guidelines (e.g. National Health and Medical Research Council guidelines in Australia) have stipulated that gametes or embryos must not be used in a manner contrary to donors’ wishes (de Lacey et al., 2010). While de Lacey et al. (2012) suggest that the accepted legal position in Australia is that you cannot ‘own’ an embryo, and thus the attendant bundle of rights relating to their use is lacking, practices following the wishes of couples may serve to construct embryos as property. Indeed, de Lacey et al. (2012) in their study of community perceptions of embryo status and use report that participants viewed the woman and man involved in the embryo creation as having the authority to make disposal decisions, thus suggesting ‘ownership’. By drawing on the embryo as property status or discourse, then, donors have the right to decide the fate of their genetic material, including the right to possess, discard, sell or transfer ownership to another as well as to set restrictions on its use (Gorny, 2004; Jain & Missmer, 2008; N. D. Johnson, 2003; Pennings, 2000).

Naffine and Richards (2012) suggest, however, that the embryo has only ‘quasi property’ status, as legal frameworks exclude some of the powerful forms of property law in recognition that the embryo has a potential personhood. The embryo cannot be

regarded as a mere body part since “no other body part gets up and walks away on its own eventually” (MacKinnon, 1991, as cited in Naffine & Richards, 2012, p. 51). In reality, the control donors can exercise over their embryos is weak, yet Naffine and Richards (2012) argue that the regulated consent process followed in jurisdictions such as Australia (and I suggest New Zealand) may give the impression that donors’ instructions and wishes will be followed, when in fact their legal directions can operate as little more than a legislatively endorsed, strongly worded wish, a situation that may be misleading to potential donors.

A property discourse would further imply that once property has been ‘transferred’ or donated, rights to and responsibility for the property (and its potential results, i.e. children) would thus fall entirely to the recipient, who assumes ownership and control (as is the case in Canada). But as has been described already, this is not quite the case in New Zealand, where donors have the right to withdraw their initial consent to donate until such point that the embryo is transferred to the recipient woman. Agreement to proceed with ED can thus not be framed as a transfer of ownership of embryos. Further, guidelines in New Zealand currently stipulate that responsibility for unused embryos, even subsequent to consent and approval for donation, remains that of the donors – there is no ‘property’ transfer from donors to recipients (Helm, 2008). Thus the donors retain some responsibility even after donating embryos, which may potentially create uncertainty for donors and recipients as to where donor responsibility begins and ends. This is discussed further in Chapter 5.

Where there is a commercial transaction as part of ED, a property discourse may be reinforced: the donor has ‘sold’ his or her property, and the recipient ‘paid for’ the transaction. While many jurisdictions prohibit the selling of human embryos, Jain and Missmer (2008) provide several examples of embryos being ‘sold’ or couples compensated for ED, and they report that 56% of 1,350 women they surveyed at a university fertility centre agreed that selling embryos should be allowed.

If embryos are constructed as property that can be ‘owned’, there is also some contention that embryos ‘should’ be regarded as not just belonging to those with embryos in storage, but that the clinics, with whose assistance the embryos were created, are also due at least partial ownership rights for ‘their product’. This may be particularly relevant in jurisdictions where fertility treatments are state-funded. De Lacey et al. (2010) have suggested that since the clinics can be regarded as acting on behalf of society, and since the embryos were created with the assistance of a medical health team, embryo disposal should take place in the service of the best interests of the

general public, rather than the individual progenitors. Thus, practices such as directed donation, whereby patients can set restrictions on the use of the embryos and specify the characteristics of potential recipients, may be constructed as discriminatory and in contravention with anti-discrimination legislation. De Lacey et al. (2010) describe how the Equal Opportunity Commission advised the South Australian Council on Reproductive Technology that ED potentially falls within the scope of the provision of 'goods and services' under the Sex Discrimination ACT 1984. If so, then an embryo as property discourse is drawn on; embryos/ED may be constructed as goods and services; and the responsibility for the provision of such goods or services may fall on the clinic rather than the donors. This raises the question as to the appropriate role of the clinic with respect to embryos, and whose interests they are obligated to serve in facilitating disposition: the individual progenitors, those of other patients seeking access to treatment, or those of wider society, for example research efforts. The construct of embryos as public property also raises difficult issues for donors who may find themselves obligated to donate in the service of others and/or society.

4.3.8 Personal investment discourse: The embryo as precious

The goal of IVF is usually to create as many embryos as possible, and those that cannot be transferred may be frozen for later use. Initially then, the embryo is much longed for and desired, and may be seen as a successful endpoint of conception or as symbol of potential parenthood (de Lacey, 2005, 2007a, 2007b; Gorny, 2004). While some have suggested that once treatment is complete these views change, so that the embryos might be regarded as 'surplus', even as burdens, problems or 'unnecessary' (Heng, 2006; N. D. Johnson, 2003), several studies suggest that patients continue to ascribe a high value to their stored, 'surplus' embryos. For example, participants describe their embryos as highly valued and their creation as having been 'hard work' involving sacrifice with a significant amount of time, energy, and financial resources expended (Cattoli et al., 2004; de Lacey, 2007a; Franklin, 2006; Fuscaldo et al., 2007; Kato & Sleeboom-Faulkner, 2011; Provoost et al., 2009). Further, Franklin (2006) writes that embryos are not just valuable in themselves, but because they are created by a couple within the context of their reproductive labour. They have a 'reproductive past' brought about by their production through the emotive and labour-intensive process of IVF. In this way, embryos are constructed as personal investments with a high value. The implication of such a discourse, as suggested by several authors, is that the embryos

should be used in some way that acknowledges their potential and value (Franklin, 2006; Kato & Sleebom-Faulkner, 2011; Melamed et al., 2009).

Thus discarding becomes constructed as ‘wasteful’, with the construct encompassing notions of a waste of personal effort, of sentimental value, of intrinsic value of the embryo, and of the potential for benefiting others (de Lacey, 2007a; Fuscaldo et al., 2007; Hammarberg & Tinney, 2006, Provoost et al., 2009). Franklin (2006) argues that embryos have a ‘dual reproductive identity’ in that they were created in the context of assisted reproduction, and they have future reproductive capacity either through donation or regenerative science. Those with stored embryos may thus want to make ‘good use’ of embryos through research or reproductive donation. Such constructions of the embryo can be understood with reference to a medical discourse, as well as wider community understandings about the value of biological material in the context of a current rhetoric of demand for donated organs, where demand frequently outstrips supply (McMahon et al., 2003; Melamed et al., 2009).

Discursive constructions of the embryo as investment may also lead to a personal attachment to the embryos, making it difficult to decide on their fate, and potentially translating into a preference for being able to direct their embryos’ destiny, for example through directed research (which projects they should go to) or directed donation (who the recipients of their donation were) (Burton & Saunders, 2004; Fuscaldo et al., 2007; Hug, 2008; Krones, Neuwohner et al., 2006; McMahon et al., 2000). Donors may thus position themselves as acting responsibly in relation to their investment by directing the embryos’ destination to worthwhile causes.

4.3.9 Sacred discourse: The embryo as profane or tapu

A discourse of the embryo as sacred can be identified in some research studies, for example that of Paul et al. (2010), where donors taking part in a Christian ED programme described the embryo as sacred and (again) as symbolic of the start of life, the sanctity of which is emphasised here. By drawing on a discourse of the embryo as sacred, destruction was constituted as morally wrong, and donation in contrast as respectful, even as a “mission” and a “God-thing” (p. 263). However, in some jurisdictions, constructing the embryo as sacred may lead to the prohibition of IVF and the creation of embryos outside of the body, to prohibiting storage of embryos, and to forbidding practices such as ED (which involve the transfer of embryos to a couple who were not involved in their creation) (Eisenberg & Schenker, 1998; Larijani & Zahedi,

2007; Richards et al., 2012). It positions potential donors and recipients as engaging in practices that are immoral, even violating their faith.

In Takahashi et al.'s (2012) study, the embryo is regarded as *mottainai*, which means 'sacred' in Japanese, more than one deserves, requiring appreciation, and not to be wasted. Participants felt that they needed to treat the embryos with respect and not waste them, but the concept of *mottainai* meant that many wished to store indefinitely; some were able to donate as a way of sublimating their guilt at not using their embryos, and others engaged in ceremonies to express thanks and apologise to their embryos if they were discarded.

Svendsen (2007) suggests that different cultures place different values on the embryo, with the United States regarding the embryos as inherently sacred, in contrast to Denmark, where he argues individuals do not invest the embryos with such moral value. Cultural differences may in part reflect religious affiliation as well as legislative practices and processes. In Lyerly et al.'s (2010) survey of disposal intentions, the emphasis was not so much on religious beliefs as they relate to the embryo, but on the moral status ascribed to the embryo. They report those that ascribed a high 'moral status' to their embryos were more likely to use the embryos themselves, to donate to others, and to choose methods such as compassionate transfer and ceremonies for discarding. On the other hand, those ascribing a lower status to their embryos were more likely to thaw and discard, as well as to donate to research. Morality in its broad, rather than religious, sense was also a factor affecting decisions in Provoost et al.'s (2011) study, where couples were more likely to opt for continued storage if they ascribed a higher moral status to the embryo.

In Glover's (2008) study of Māori viewpoints regarding infertility and ARTs, the embryo was also given a special status, seen as invested with a 'life force', and regarded as tapu (meaning sacred). For many Māori, maintaining the sanctity of tapu is critical and where this is violated divine protection may be forfeited; those that break tapu may be exposed to evil. Maintaining tapu means that certain actions and behaviours become prohibited. While there is debate about what exactly this means in terms of embryo use, and viewpoints aren't necessarily consistent across Māori, a common concern in Glover's study centred on breaches of tapu. Rather than the 'sacred' discourse here enabling options such as donation, in this case, the tapu discourse raises questions about the appropriateness of research donation (experimenting on the embryo), or reproductive donation (transferring the embryo to another person's body from which it did not originate). Such a discourse again

underscores that the embryos and their disposal will need to be treated with respect, by ensuring that appropriate tikanga, or culturally safe practices, are followed (Glover, 2008; R. Thompson, 2012).

In Goedeke and Payne's (2009) study in New Zealand, potential recipients similarly regarded the embryo as special and having a 'natural' home and use. Concern was expressed about having embryos transferred to their bodies, as if this was introducing something 'foreign' or alien, and was 'against nature'. Such constructions of the embryo may position ED as an unnatural practice and a violation of nature, thus situating donors and particularly recipients, who accept such embryos, in an uncomfortable position, as working against nature.

Thus, the discourse of embryo as sacred may enable and constrain options in a number of ways. In some cases, it may lead to a prohibition of creating embryos or storing them. In others, it may enable donation to others as the embryo is respected. In still other cases, for example for Māori, the sanctity of the embryo becomes undermined by transferring it away from its 'natural' place.

4.3.10 Gift discourse: The embryo as gift

A discourse of embryos/ED as gift can be identified in some research studies, as well as in books written for donors and recipients, and in clinic literature describing ED. For example, in a book written to help parents explain donor conception to their children, ED is described as a 'gift' (Celcer, 2007). In a clinic magazine outlining its services, the section on donor services includes a picture of a gift (Fertility Associates, 2014), and in research articles about ED, donors are frequently described as altruistic, and as 'giving the gift of life' (de Lacey, 2005; N. D. Johnson, 2003; Kirkman, 2003a; Lyerly et al., 2010; Svendsen, 2007). Such constructions bring with them implications for both donors and recipients however, and various authors have written extensively about the dynamics of gift-giving, including Tittmus (1997) in relation to blood donation, and Shaw (2008, 2010a, 2010b) in relation to organ donation. On the one hand, the gift-giver may be positioned as altruistic, as kind-hearted and as generous, promoting welfare and social cohesion, and the recipient as gratefully receiving a gift. On the other hand, as Shaw points to, gift-giving may also evoke expectations of reciprocity: the donor may thus potentially be positioned as powerful, and the recipient as indebted and obligated towards the donor. This may have implications for the positions ED donors and recipients can take up in relation to each other and expectations of rights and

responsibilities. Applegarth (2006) suggests that there may be a social-exchange relationship between donor and recipient who must “strike an internal balance between rewards and losses” (p. 360). In Svendsen’s (2007) study of patients who had donated their embryos to research, donors’ gratitude for their gift (of treatment, having children) facilitated their decision to donate, within what Svendsen terms a context of generalised exchange (a return of a gift for the fully funded IVF they received). In this context then, donors framed the embryos as a gift to themselves; that they were reciprocating by donating surplus embryos to research.

The ways in which the embryo is constructed thus have implications for the practices that are enabled or constrained, and the subject positions that can be taken up by donors and recipients. Note, however, that researchers have also identified that constructions of the embryo change, and that various factors may influence changing constructions over time. Furthermore, some researchers (e.g. Svendsen, 2007) suggest that patients may distinguish between their embryos, constructing those implanted, those frozen, and those donated differently. Their meaning may thus not be fixed or inherent but constituted in relation to their reproductive journeys, decision-making, and the embryos’ environment, subject to the influences of the various actors (such as embryologists and consultants), and policy and legislative frameworks that relate to the embryo. Patients may also draw on contradictory conceptualisations (constructions) of the embryo simultaneously (Provoost et al., 2009). Further, ED may be chosen not just because of the way the embryo is constructed and the possibilities that become available as a result, but also as a result of factors that enable or constrain the uptake of discourses. While each of the factors discussed below may be framed discursively, they fit into what Sims-Schouten (2004) and Sims-Schouten, Riley and Willig (2007) have termed ‘extra-discursive’ factors that may provide the conditions and context for discursive constructions of the embryo and ED.

4.4 Extra-discursive factors related to embryo/ED constructions

As discussed in Chapters 2 and 3, authors such as Sims-Schouten et al. (2007), Nightingale and Cromby (1999) and Willig (2010) suggest that aspects of individuals’ social and personal history and background are relevant for better understanding the uptake of particular discourses. In this section, I discuss factors that have been cited in the literature as relevant to the ways in which embryos are regarded (constructed) and

ED understood and experienced. This includes aspects related to personal background, embodiment and material conditions.

4.4.1 Personal background

4.4.1.1 Parenting experience and life events

Having a child conceived through IVF has been cited as one of the most important factors related to how the embryo is constructed and the willingness to donate (Bankowski et al., 2005; de Lacey, 2005, 2007a; Elford et al., 2004; Hug, 2008; Kato & Sleebom-Faulkner, 2011; Klipstein et al., 2001; McMahon et al., 2000, McMahon et al., 2003; McMahon & Saunders, 2007; Mohler-Kuo et al., 2009; Nachtigall et al., 2010; O'Brien, 2010). Having a child appears to serve as an example of what the embryos can become and may facilitate a less abstract and more personalised and maternal stance towards embryos (de Lacey, 2005; Elford et al., 2004; Fuscaldo et al., 2007). Likewise, O'Brien (2010) suggests that once an embryo has become a tangible child that they love, the embryos are no longer seen as tissue. Indeed, participants now evaluate options, including ED, from their standpoint as parents, and this may lead to concerns about relinquishing their child (rather than an embryo), with concurrent concerns about the welfare of their child (de Lacey, 2005). Newton et al. (2007) describe how, following successful IVF, those with stored embryos were more likely to update disposal directives, and more likely to discard rather than donate to research or to others.

Becoming a parent may thus alter the construction of the embryo and have implications for disposal options, although findings have been mixed, with some suggesting it will lead to less favourable viewpoints towards donation, and others suggesting that they may be more inclined to do so (de Lacey, 2005; Hammarberg & Tinney, 2006; Klipstein et al., 2001; Lornage et al., 1995; Mohler-Kuo et al., 2009). Kato and Sleebom-Faulkner (2011) suggest, however, that contradictory findings may stem from similar ontological perspectives. For some, once a child has been born, the ontological concept of a child may change from an embryo to that of a child; on the other hand, for some the true value of the embryo becomes apparent only after the realisation of the embryo as child. The embryo thus becomes constructed in different ways as a result of the same experience, leading to different disposal options being selected.

Further, personal and life circumstances such as marital separation or death of spouse also contribute to decisions (Hammarberg & Tinney, 2006; Hug, 2008; Klipstein et al., 2001; Klock et al., 2001; Provoost et al., 2012; VARTA, 2014), with Klipstein et al. (2001) suggesting that in the event of separation or the female's death, couples are more likely to discard, and in the event of the male death's, the female partner may choose to use the embryo herself. Stiel et al. (2010) also suggest that personality traits, such as having an external locus of control (relying on others for decision-making and regarding oneself as having little control) were related to a greater likelihood to store embryos.

4.4.2 Embodiment

4.4.2.1 Fertility journey

Factors related to reproductive history, such as complicated obstetric history, gynaecological events, preterm delivery, and morbidity of children have been cited as reasons for not having embryos transferred autologously (Bangsbøll et al., 2004; de Lacey, 2007b). Paul et al. (2010) report that the mother's or existing children's health, as well as emotional exhaustion, were factors affecting couples' decisions not to use embryos but to donate instead. Personal circumstances, such as perceived success rates of IVF, finding IVF too stressful, and a belief that it would not work also contributed to decisions (Hammarberg & Tinney, 2006; Hug, 2008; Provoost et al., 2011; Svanberg et al., 2001). Krones, Neuwohner et al. (2006), for example, have reported that those that subjectively rated success rates of IVF as being high were more willing to donate to research.

4.4.2.2 Technological advances: The visibility of the embryo

Being able to sight the embryo, for example through a microscope or having photographs of it, provides tangible, visual evidence of conception, and thus pregnancy (de Lacey, 2005; McMahon et al., 2000) and may facilitate a construction of the embryo as an actual, biological child. Further, de Lacey (2005) reports that a "sensing of their [the embryos'] presence inside their bodies allowed patients to witness the continuum of human development from embryonic cells, to real live children" (p. 1666), and it was this tangible, physical, embodied experience that was a powerful influence affecting the way in which participants regarded their embryos. Likewise, for participants in Nachtigall et al.'s (2010) study, having a photo of their embryos increased their attachment to them, and for many complicated or delayed their decision-making. Kato

and Sleebom-Faulkner (2011) argue that those that have undergone IVF show a stronger tendency to ascribe innate capacities to the embryo, to attribute a will to the embryo and to see them as children. They suggest that modern technologies such as ultrasound, which enables visualisation of the prospective child, facilitate this process and shift the boundaries of when women begin to construct the embryo/foetus as their child. Collard and Kashmeri (2011) suggest that ARTs have led to a greater awareness of life at the embryonic level, with the consequence that parents may construct embryos as children far sooner than would otherwise have occurred, and that they make decisions about, and ascribe siblingship, far earlier in the reproductive process than they would otherwise have.

4.4.2.3 Synchronous creation

Studies suggest that if couples have had children from the ‘same batch’ of embryos, embryos in storage are regarded not just as genetic siblings to children born, but akin to ‘twin siblings’, with the same genetic makeup (Collard & Kashmeri, 2011; de Lacey, 2005). Collard and Kashmeri (2011) suggest that by nature of their simultaneous creation, the genetic ties of the siblings and their close proximity to each other become emphasised, thereby complicating the decision-making process.

4.4.2.4 Number of embryos

The number of embryos in storage has also been reported to affect disposal decisions, although studies present contradictory results. Some suggest that those with fewer embryos in storage, for example, tend to lose contact with the clinics and are less likely to give final disposal directives (Brzyski, 1998), or may be more likely to discard (Nachtigall et al., 2010). Others suggest that where there are only one or two embryos, patients are more likely to use them (McMahon et al., 2010). Choudhary et al. (2004), on the other hand, suggest that if patients have a high number of embryos, they may be more likely to donate to research, possibly because they are more assured of having enough for their own treatment. They may however be reluctant to donate to others as donation may not result in all the embryos being used. The relationship between number and quality of embryos and disposal options remains unclear.

4.4.2.5 Time in storage

Hammarberg and Tinney (2006) suggest that storage time is not necessarily associated with disposition choice, but others suggest that less than two years provides insufficient time to adequately think through and select options (Bangsbøll et al., 2004; Svanberg et

al., 2001). On the other hand, Lyster et al. (2010) report that respondents who had stored embryos for longer than five years were more likely to discard, or opt for continued storage, suggesting that beyond a certain point patients are no longer willing to consider 'active use' (e.g. donation). Similarly Brzyski (1998) suggests a link between longer storage and losing contact with the clinic, and Provoost et al. (2012) between longer storage length and discarding. Nachtigall et al. (2010) and Provoost et al. (2012) suggest that some participants have concerns about the effect of long-term storage on their embryos, and whether this decreased their viability. De Lacey (2007b) in contrast, comments that it seems like the longer embryos are stored, the more concerned patients are about them, but it is difficult to ascertain if storage length is a consequence of concern or if concern is a cause of longer storage periods. While storage time limits may appear somewhat arbitrary, it is possible that length of storage may affect how the embryos are constructed and what decisions are made.

4.4.2.6 Embryo quality

Poorer embryo quality has been linked to greater willingness to donate to research (Bjresten & Hovatta, 2003; Choudhary et al., 2004). Svendsen (2007) suggests that if clinicians frame embryos as 'poor quality' it makes it more possible for patients to shift their embryos from the 'pregnancy trail', and to frame them as ethical sources for research donation. Nachtigall et al. (2010) similarly suggest that when participants regard their embryos as 'low grade', they may wonder whether they are worth the emotional and financial investment to use for reproductive purposes or reproductive donation, and choose other options instead. Where the embryos are rated as 'good quality', however, they may be regarded as having a stronger link to a successful outcome, and they are given considerable value by staff and patients (Parry, 2006).

4.4.2.7 Age

Some studies have suggested that patients who were older at the time of embryo storage may be less likely to use embryos themselves (Bangsbøll et al., 2004), less likely to give final disposal directives; and less likely to choose options such as donation (Brzyski, 1998; Krones, Neuwohner et al., 2006a). Krones, Neuwohner et al. (2006) suggest that older patients may have more difficulty with the concept of using embryos for research purposes, and indeed in Bangsbøll et al.'s (2004) study, it was women under the age of 35 years who were more likely to consider research donation. In contrast, Mohler-Kuo et al. (2009) report that those patients over 40 who had also not been successful with treatment were more likely to agree to research donation. While Hammarberg and

Tinney (2006) assert that age makes no difference, it is possible that age in combination with other factors, such as treatment success and storage length, may be influential in decision-making. Lysterly et al. (2006) suggest that age may be relevant as patients' perceive themselves to move beyond 'normal' reproductive years. Indeed, Stiel et al. (2010) report that those participants that still had embryos in storage after five years tended to be younger, and the authors theorise that as such women may have been hesitant to make decisions about embryos that could possibly still be used in family-building, even if they no longer wanted more children.

4.4.2.8 Gender

While some studies report that gender plays no role in disposition decisions (e.g. Lysterly et al., 2010), others (de Lacey et al., 2012; Paul et al., 2010) suggest that women may take a more active role, having a greater investment in the embryos and a greater sense of responsibility towards the embryos. De Lacey et al. (2012), in their study of community attitudes towards embryo status and use, suggest that women tend to assume a greater role in reproductive decision-making in general, and also tend to ascribe human status to embryos, in contrast to men who were more likely to describe the embryo in terms of biological terms. They suggest that women may thus be more likely to support reproductive uses over research ones, but note that this study was a study of attitudes of the general population. Indeed, Krones, Schluter et al. (2006) report that the gender differences in embryo status noted in their general population were not significant in their IVF sample, suggesting that experience of one's own reproductive journey changes the status ascribed to the embryo and the responsibility felt. However, Paul et al. (2010) also suggest that women tend to lead the decision-making process, and suggest since they are the ones who carry the embryos, they have a greater emotional investment in embryo disposition. Yet in this study decisions were also often made through balanced leadership or were husband-led. Paul et al. (2010) suggest that this aspect requires further exploration.

4.4.2.9 Donated gametes

Embryos formed from donated gametes have been suggested to be more readily offered up for donation (Brzyski et al., 2001; Hill & Freeman, 2011; Sehnert & Chetkowski, 1998). It may be that these embryos are considered to reflect a greater genetic distance (from the donors), making it easier to donate them. Such an interpretation would lend support to the hypothesis that constructions of the embryo as genetically linked to the couple negatively affect couples' likelihood to donate. It is further possible that having

been recipients of donated materials (either egg, sperm or both), there is a greater willingness to donate in a sense of altruistic reciprocity. In Hill and Freeman's (2011) study comparing the disposal choices made by patients using their own, versus donor oocytes, results indicated that 21% of those using autologous oocytes in the creation of embryos elected to donate to other couples, whereas those that used donor oocytes were far more likely to donate to other infertile couples (56%), as well as less likely to discard. Saunders et al. (1995) suggest that there is less anxiety about embryos when formed from donor gametes. On the other hand, Hammarberg and Tinney (2006) report that couples who had used donor gametes were *not* more likely to donate to another couple, and that embryos remaining were regarded as full siblings to existing children, as was the case in Nachtigall et al.'s (2005) study. Some jurisdictions, such as New Zealand, restrict donation of embryos from donor gametes (the implications of this are discussed in the next chapter).

4.4.3 Material factors

4.4.3.1 Financial factors

In Lacey's (2007b) review, she asserts that financial factors may affect couples' likelihood of making disposal decisions. Indeed, Brzyski et al. (2000) report that when their clinic introduced a storage fee for embryos, there was an increase in the numbers of patients making firm disposition decisions, with a three-fold increase in discarding. Other authors (Nachtigall et al., 2010; Paul et al., 2010) have more recently reported that fees for continued storage served as a 'triggering event' for decision-making (although these are regarded by some as coercive and not related to actual costs carried by the clinic). On the other hand, it may be that is not necessarily the fee that is related to patients making decisions, but rather that sending out invoices involves regular contact with the clinic and that "this in itself motivated patients to make a decision independent of economic considerations" (Brzyski et al., 2000, p. 815). Note that most studies reviewed here, while indicating that financial factors may encourage decision-making, do not appear to report or suggest that ED is more readily selected. As regards recipients, ED is referred to in the literature as a cost-effective solution, potentially circumventing the need for expensive IVF treatment (Blyth et al., 2011; Brzyski, 1998; Eisenberg & Schenker, 1998; Hill & Freeman, 2011; N. D. Johnson, 2003; Keenan et al., 2012; Manning, 2004).

4.4.3.2 Media and information

The level of familiarity with bioscience has been cited as a factor that may positively influence patients' decisions to donate to research (Bjuresten & Hovatta, 2003; Hammarberg & Tinney, 2006; Hug, 2008). Hammarberg and Tinney (2006), for example, propose that the higher rate of willingness to donate to research in their survey could be explained by an intensive media campaign in Victoria (Australia), and the subsequent public debate. The implication is that media campaigns may promote or normalise practices such as donation, thus increasing uptake. As has been discussed, the issue of whether clinics provide sufficient information for patients to make decisions has been raised, with some suggesting that this may facilitate decision-making (Fuscaldo et al., 2007; Lysterly et al., 2006; Nachtigall et al., 2010; Paul et al., 2010).

4.4.3.3 Policy, infrastructure and clinic practice and policy

Disposal decisions must of course also be evaluated in terms of clinical practice and social policy, and how these differ across states and countries (de Lacey, 2007b; Franklin, 2006; Hug, 2008; S. Parry, 2006). Where options such as research or reproductive donation are prohibited or restricted, donors may construct these options as illegal, risky or precarious. The options that are allowed or restricted, and how guidelines or legislative frameworks construct these options, may thus all shape discursive constructions and the decisions made. I analyse the role of policy and legislative frameworks in New Zealand in the next chapter.

Further, clinic practices may either directly or indirectly shape patients' constructions of the desirability of options. Nachtigall et al. (2010), for example, suggest that ED to others in their study was seldom selected because of a perceived lack of appropriate clinic infrastructure to facilitate donation. On the other hand, patients in their study had more information about research donation, which could be seen as implicit or explicit encouragement. Participants reported that they were thankful for their positive experiences with clinics; that trust had been established over the course of treatment; and that this had affected their decision to donate to clinic-affiliated projects. Heng (2006) expresses concern that clinics may exert undue influence on patients who may feel obligated to donate out of an expression of gratitude. The concept of donating in return for services received was likewise relevant in Svendsen's (2007) study, where research donation occurred within a context of generalised exchange (in return for fully state-funded IVF). How clinics manage and explain donation and the information they provide may be influential.

The factors outlined above may provide some insight into reasons for constructing the embryo and ED in particular ways or for appropriating such discourses, with consequences for engaging in ED. Such factors and events may of course themselves be discursively constructed, and employed in order to justify or motivate for particular decisions. In the next section, I move on to further contexts that may create ‘conditions of emergence’ for the development, transformation and maintenance of the various discourses of ED. These include changes in adoption and gamete donation policies and practices. My discussion of these areas will of necessity be brief and provide merely an overview of this large field of research and literature, focusing on the context for ED.

4.5 Donor conception and adoption practices and policy: Context and discourses

Borrero (2002) comments that in the early years of fertility treatment, the emphasis was on treating fertility as problem and achieving a successful outcome: a baby. Little consideration was given to the longer-term psychosocial implications for children and their families (Daniels, 2005a). A medical discourse with the focus on treatment of the individual patient’s presenting medical issues, and not on longer-term implications, can be seen to inhabit the practices and writings of this time. Gamete donations were practised anonymously, with no ability for the donor-conceived child to access information about genetic heritage. Patients were generally advised not to disclose the method of conception, to regard it as a ‘non issue’, and to effectively ‘erase’ the donor from relevance to the recipient family (Appleby, Blake & Freeman, 2012; Daniels, 2005a; Daniels & Douglass, 2008; MacCallum & Golombok, 2007; Turner & Coyle, 2000; Richards et al., 2012).

Blyth et al. (2011) however, point out that while conventional anonymous models still exist in many jurisdictions, they have been subject to challenge, based at least in part on the reports from and studies of adopted children, particularly as they reached adulthood. These have suggested that closed, anonymous adoption was problematic, that adopted children have a need for knowledge of their complete identity, and that their psychosocial wellbeing may be adversely affected by the inability to access such information (Anderson, 2006; Haimes, 2005; Manning, 2004). The development of a coherent sense of identity has been theorised to involve incorporating knowledge about past and family into the sense of self (Erikson, 1968), and Velleman

(as cited in Karnein, 2012, p. 58), suggests that it is biological kinship that allows children to feel rooted in the world, providing them with a unique and determinable place in the chain of reproduction. In the context of closed adoption, adoptees lack this genealogical continuity and arguably may find it difficult to establish a healthy and secure sense of self, possibly experiencing emotional upheaval and insecurity (Helm, 2008). Such recognitions have led to an increase in open adoption practices, where birth parent details are recorded, and adopted children have access to identifying information and their genetic backgrounds (Palacios & Brodinsky, 2010). A disclosure or truth discourse can be identified, with disclosure framed positively as in the best interests of the child. There is thus also a concurrent shift to the wellbeing of the child resulting from such family formations, and I have termed this the 'welfare of the child' discourse.

The disclosure discourse can also be identified in gamete donation research, where over the past two decades similar concerns to adoption have been expressed with reference to the possibly negative effects of secrecy and non-disclosure (Appleby et al., 2012; Blyth, 2012; Daniels, 2004; Daniels, Grace & Gillett, 2011; Daniels & Haines, 1998; Daniels & Taylor, 1993; Feast, 2003; Hammarberg et al., 2011; Richards et al., 2012; Turner & Coyle, 2000). Initial concerns centred on the need for openness about genetic inheritance for health reasons, particularly with increasing recognition that the onset of diseases and conditions may be rooted in genetic susceptibility, as discussed earlier in this chapter (Grace & Daniels, 2007; MacCallum & Golombok, 2007; Silva & Machado, 2011). Further concerns mentioned included fear about unknown consanguinity, possible future contact with unknown children, and that donor-conceived children would face similar identity issues to those of adopted children sharing the same psychological need for information about their genetic parents (Allan, 2010; Blyth, 2002; Daniels et al., 2011; MacCallum & Golombok, 2007; McWhinnie & Idreos Education Trust, 2006; Scheib & Ruby, 2008). Other related fears cited were that donor-conceived children experience a sense of genetic disconnection from their social families, and that particularly in the context of advances in DNA paternity testing and databases, they would work out that they were not fully genetically related to their families, or that others would tell the child of his or her origins (Blyth, 2012; Daniels et al., 2011; MacCallum & Golombok, 2007; Richards et al., 2012; Turner & Coyle, 2000). Indeed, several authors have suggested that as donor-conceived individuals have reached the age of maturity, many have increasingly come to challenge secrecy and assert their right to information (Allan, 2010; Beeson, Jennings & Kramer., 2011; Blyth, 2002; Blyth, 2012; Hammarberg et al., 2011; Helm, 2008; L. Johnson, Bourne, &

Hammarberg, 2012). Offspring are reported to want information such as the donor's name and health history, motivation for donation, information about what the donor family are like, and to express interest in contact (Blyth, 2002; Janssens, 2009; Rodino, Burton & Sanders, 2011). Janssens (2009) suggests that "real encounters are the ultimate desire" (p. 502). Studies report that children respond largely positively, or neutrally, to disclosure, but that the response is harder when told later in life or the longer disclosure is left (Appleby et al., 2012; Blyth, 2002; Daniels et al., 2011; Jadva, Freeman, Kramer, & Golombok, 2009; Turner & Coyle, 2000). In a similar way then, the disclosure discourse and a welfare of the child discourse can be identified in gamete donation research efforts.

The welfare of the child discourse may also be identified in the United Nations Convention of the Child, where article 8(1) outlines a state's responsibility to respect the child's right to "preserve his or her identity, including family relations as recognised by law". While the Convention does not specifically refer to reproductive donation, and cannot be relied upon to provide an unambiguous endorsement of donor identity (Blyth, 2002; Frith, 2001a), many interpret these provisions as implying that all children have the right to know the identity of their genetic parents (Allan, 2010; Daniels & Haimes, 1998; Else, 1999; Michelle, 2006). Many jurisdictions and organisations have introduced clauses and provisos into their ART policies that underscore the welfare of the child, suggesting that the interests of any children born as a result of fertility treatment should at the very least be given significant consideration (Blyth & Frith, 2009). The Canadian Medical Association, for example, states unequivocally that a child is entitled to the same respect and treatment as all other people, and thus developments in reproductive technology must sustain such a perspective and not reduce a child to the status of an object (Guichon et al., 2010).

Several authors have extended their focus and reflected on the possible adverse effect of secrecy, not just on the individual donor-conceived child, but also on family relationships (Appleby et al., 2012; Blyth, 2002; Daniels et al., 2011; Daniels & Meadows, 2006; Daniels & Taylor, 1993; Grace & Daniels, 2007; MacCallum & Golombok, 2007). In this way, the welfare of the child discourse has been extended to the 'welfare of the family' discourse. This can be identified in comments by the Warnock Committee in the United Kingdom, for example, which expressed concern that family secrets could undermine the network of family relationships (Blyth, Frith, Jones & Speirs, 2009). Similarly, others (Blyth, 2002; Daniels & Taylor, 1993) have argued that secrecy might 'damage' family relationships, and create a conflict between

the donors' and recipients' rights to privacy, and the donor-conceived child's right to information. Daniels et al.'s (2011) study of sperm donor recipients' decisions to disclose to adult offspring suggested that keeping the use of donor insemination a secret created significant pressure and stress for parents.

Again, not only a welfare of the child but a welfare of the family discourse can be identified, as researchers argue that since secrecy may create stress and negatively affect family relationships, disclosure is not just in the interests of the child, but also of the wider family (Berger & Paul, 2008; Daniels et al., 2011). Researchers have also suggested the need to consider the views of other family members involved (Blyth & Frith, 2009; Haines, 1998). Haines (1998) makes the point that recipients and donors do not exist in isolation, but that in choosing to donate, the donor is adding genetically, if not socially, to a kinship network; parents of donors may unknowingly become grandparents and their rights and interests in relation to the donor, the donation, the child and the recipient families may need consideration. Further, Blyth and Frith (2009) argue that donor siblings and other children of the donor have a right to information, and that such information may be important for descendants also. Thus, the welfare of *both* families needs to be considered.

Follow-up studies of donor-conceived individuals suggest that it is not just knowledge of and contact with the donor that may be sought, but that contact between siblings is also often desired. The US Donor Sibling Registry (DSR) in the United States, the UK DonorLink, and the Australian Donor Conception Support Group (DCSG) have also done much to contribute to increasing awareness of such issues (Blyth, 2012; Daniels et al., 2012, Hammarberg et al., 2011; Scheib & Ruby, 2008). Such contact is generally positively described in research efforts, with Freeman, Appleby and Jadvá (2012) suggesting that donor-conceived individuals who made contact with each other felt intuitively bonded, and Blyth (2012), in his study of sibling interactions of individuals who shared the same sperm donor, suggesting that participants were positive about meeting even though this was emotionally charged and led to a need to "synthesize their accumulated knowledge, understanding and experience into revised personal biographies and new social networks" (p. 5). The welfare of the family discourse can further be identified in researchers' suggestions that there is a need to consider ramifications for families who become linked in such a way (Daniel et al., 2012); that we need to start recognising these 'latent webs' as new family forms in the twenty-first century (Blyth, 2012); and that we need to explore this

uncharted territory, for which we have no cultural paradigms (Blyth, 2012; Daniels et al., 2012; Freeman et al., 2012).

Within this context of both a genetic discourse and a disclosure discourse, informing offspring about donor conception is increasingly considered by professionals and policy-makers to be desirable and to be encouraged, and as constituting a fundamental human right (Appleby et al., 2012; Blyth, 2002; Glennon, 2012; Grace & Daniels, 2007; Hammarberg et al., 2011; Michelle, 2006; Rodino et al., 2011). As far back as 1984, the UK Warnock Committee issued recommendations about the management of biological origins that includes information-keeping and disclosure (Blyth, 2002; Haimes, 2005) The state of Victoria in Australia was the first to introduce comprehensive legislation including the establishment of a donor register, and its ethical guidelines emphasise that donor-conceived individuals have a right to, and are entitled to, access information about their genetic parents even though access to such information still varies across Australia (Hammarberg et al., 2011). Ravitsky (2010, as cited in Glennon, 2012, p. 106) suggests that rights extend to knowledge of full medical history and genetic information; the right to know personal information relevant to identity development; relational rights (the right to know and be able to make contact with donors); and parental disclosure rights (the rights to be made aware of donor conception). Such a disclosure discourse means recipient parents need to tell their children of their origins if they are to assume positions of “responsible parenthood” (Montuschi & Merricks, 2000, as cited in Blyth, 2002, p. 189).

Yet while the disclosure discourse can readily be identified in much of the writing about donation, there is resistance to this discourse, with suggestions that caution should be exercised in making the assumption that openness and truth are unproblematically good, and secrecy unproblematically bad (Bok, as cited in Haimes, 1998; Walker & Broderick, 1999). Many studies still point to a continued reluctance by recipients to disclose, with reasons including stigma or the implications for the wider family (Haimes 1998); views about the moral right of a child to know about donor conception (Frith, 2001a, 2001b); parental relationship status; lack of agreement about disclosure between parents, donors and recipients; and concern about the intrusion of a third party into the relationship (Blyth, 2002; L. Johnson et al., 2012; Scheib & Ruby, 2008; Shehab et al., 2008). Uncertainty about how to tell donor-conceived children as well as a lack of information about the donor may also partly explain decisions not to disclose (Daniels et al., 2011). Even where donor registration exists, recipients may have limited access to information about the donors until the donor-conceived child

reaches the age of maturity, and may thus feel unable to tell their children much information or address any of their questions (Haines, 1998; MacCallum, 2009; Rodino et al., 2011).

Further, even in jurisdictions where openness is promoted, there is no statutory requirement enforcing disclosure to donor-conceived children (Appleby et al., 2012; Blyth & Frith, 2009; Frith, 2001a; Glennon, 2012; Helm, 2008). Openness may be strongly advocated and information recorded, but some recipients may still be unwilling or find it difficult to tell, and telling children of their origins often rests on a 'moral obligation' of recipient parents to tell (Blyth, 2002; Hammarberg et al., 2011; Helm, 2008). Guichon et al. (2010) thus question who will assume an advocacy right for children in view of the fact that recipient parents in Canada have no legal obligation to tell the child about donor conception, or the existence of siblings in another genetic family. Allan (2010) has argued that "it is a complete contradiction to recognise that donor-conceived individuals have a need and a right to information about their genetic heritage and then to leave the access to information to chance" (p. 17). In some countries, for example Australia and the United Kingdom, there has been debate about placing annotations on birth certificates, or issuing two certificates as a way of signalling to the child that he or she is donor-conceived (Allan, 2010; Blyth et al., 2009; Frith, 2001a; Hammarberg et al., 2011; Helm, 2008). In Australia, however, the federal government has delegated decision-making in this regard to individual states (Australian Government, 2012). The Victoria Assisted Reproductive Treatment Act of 2008 specifies that children born as a result of donor conception as of 2010 will have an addendum to their birth certificates informing them that additional information about their birth is available – it is argued that this will provide an additional incentive for parents to inform children of their origins (Hammarberg et al., 2011). The Warnock Committee likewise recommended that birth certificates should record the fact of donor conception (Blyth et al., 2009; Frith, 2001a), and in 2005 the New Zealand Law Commission concurred with such a recommendation. Such suggestions have won mixed reception, with many jurisdictions, for example New Zealand, preferring to adopt an educative stance rather than birth certificate annotation to promote disclosure (Blyth et al., 2009). While privacy concerns for parents and offspring may be raised (e.g. Blyth et al., 2009), Helm (2008) argues that since the state allows and facilitates assisted reproduction, it should also take responsibility to ensure that offspring are informed about their origins. Blyth et al. (2009) argue that the state should not be complicit in donor-conceived people's deception about their origins, or create a 'legal fiction'. In

this way then, lack of legislative frameworks to support disclosure may serve to undermine the disclosure discourse.

The discourse is also resisted in that there remain jurisdictions where openness is not practised, such as Spain, Denmark, Greece, Portugal, the Czech Republic and Bulgaria (Garcia-Ruiz & Guerra-Diaz, 2012). This results in what Grtin and Vayena (2012) have described as a “dazzling panoply” (p. 74). Further, others suggest that open identity donation is still in its early stages in most countries and that we are as yet uncertain as to the outcomes, and as such it may still be years before the social effects of these practices are realised (Freeman et al., 2012; Richards et al., 2012).

Nonetheless, the discourses of disclosure and welfare of the child/family provide a context for ED. These discourses can be seen to fall under the umbrella of a wider discourse: a psychosocial discourse. Such a discourse, in contrast to a medical discourse, constructs health and wellbeing not just from a medical and biological perspective, but also from a psychological and social perspective. This can be identified in the research efforts and texts where a shift has been made to include the wider implications of treatment, and not just for the individual but also the families concerned. As Daniels (2002, 2005a) comments, there has been a shift to a dual focus: treating infertility, and building families – fostering the medical, psychological and social wellbeing, not just of the individuals seeking treatment, but all of those potentially affected by treatment. As part of this shift, and in the context of a discourse of infertility and its treatment as challenging, various calls for counselling support for those experiencing infertility have been made. For example, counselling has been suggested to play an important role in educating, assessing and supporting people experiencing infertility in general (Australian and New Zealand Infertility Counsellors' Association [ANZICA], 2003; Daniels, 1993, 2007; Machin, 2011; Wischmann, 2008). Third party reproduction involving people and genetic material external to the couple creating a child has been described as raising even more emotional, psychological, ethical and legal issues than other forms of ART not involving donation (Boivin et al., 2001; Hammarberg, Carmichael, Tinney & Mulder, 2008). Thus the importance of counselling in order to understand the implications of donation has been highlighted, and indeed in some jurisdictions clinics are obliged to offer additional counselling in the case of donor-assisted conception (Boivin et al., 2001; Daniels, 2007; Hammarberg et al., 2011; Machin, 2011; Paul et al., 2010). In this way, a hierarchy exists around the provision of counselling services (Machin, 2011) In New Zealand, counselling is required for those considering gamete donation, and in the case of ED, as will be

discussed in the next chapter, both mandatory individual and joint counselling is required to explore the issues and implications with potential donors and recipients as well as their families (Daniels, 2007). In framing third party reproduction, in particular ED, as requiring counselling and being ‘at the top of the hierarchy’, these forms of reproduction are constructed as complex, and as Machin (2011) suggests, an association between counselling and ‘problematic’ treatments is formed.

Mandatory counselling may also serve to construct counselling as an obstacle, however, something that has to be done in order to proceed with treatment. Machin (2011), for example, expresses concern that compulsory policies may undermine the value of counselling. On the other hand, when counselling is simply something that is ‘available’ to those who desire it, it may become difficult to access and be associated with stigma and perceived vulnerability. Machin (2011) comments that counselling should be promoted for those pursuing treatment regardless of the type of treatment, and offered throughout the treatment process, as infertility is stressful and the treatment journey does not necessarily end with the birth of a child.

Further, L. Johnson, et al. (2012) comment that legal changes regarding identity disclosure and access by those involved in donor conception should be accompanied by services to facilitate those that seek contact, suggesting that “it becomes essential that adequate support to negotiate these new and complex relationships is available for those involved” (p. 816). Likewise, Allan (2010) has recommended that counselling be available on an ongoing basis for parents, donors and children. In Victoria, Australia, an independent statutory body was set up to administer the law and manage donor registers (the Independent Treatment Authority [ITA], which became VARTA in 2010). Through this body a ‘time to tell’ campaign was set up that provides information and education for parents about disclosure, as well as a service model for linking related parties (Hammarberg et al., 2011). These discursive practices further serve to underscore constructions of donor conception as complex and having long-term implications that require all parties involved to have access to sufficient support to negotiate new family formations.

In this way, ED needs to be considered against developments in gamete donation and adoption, medical and psychosocial discourses, and discourses of genetics, disclosure, and the welfare of the child/family. Depending on their country of origin, children and families created as a result of donation may be affected by varying discourses and may be positioned in different ways, with implications for their experiences. New Zealand policy will be discussed in the next chapter, but first I turn to

consider the various ways in which ED as a practice has been constructed in the literature.

4.6 Discursive constructions of ED

The ways in which the embryo is constructed, and the action possibilities and positions that may be enabled or disabled, may offer insight into individuals' choices and experience of ED. However, de Lacey (2005) suggests that we need to extend our understanding of ED by reflecting on the metaphors (akin to discursive constructions) that donors and recipients draw on in relation to discarding and ED *as a practice*.

From my reading of the literature, two overarching, competing discourses with regard to ED practice may be identified: an ED discourse and an embryo adoption (EA) discourse. These discourses, or metaphors, have been identified and discussed by de Lacey (2007a) and Blyth et al. (2011) with reference to decision-making in ED. De Lacey (2007a), however, identifies a third metaphor of pregnancy termination as an important discourse framing donation. These metaphors or discourses are explored further below, along with a number of 'sub-discourses' that I have identified from my reading of the literature.

4.6.1 The donation discourse

A donation discourse can be identified in some research studies (e.g. de Lacey, 2007a; Blyth et al., 2011; MacCallum, 2009) that have explored the 'metaphorical structures' that donors may draw on, and in commentary on ED policies and practices. In these texts, giving embryos to others for their reproductive use may be framed as an act of donation, similar to donating gametes for the reproductive use of other couples, or donating organs or tissues. For example, in de Lacey's (2007a) study, those who donated their embryos framed the process as akin to organ or tissue donation. Donors who draw on donation metaphors may construct the embryo as seeding material (biomedical discourse) with the potential for life, but not yet life.

The report on ED by the Ethics Committee of the ASRM (2009) similarly encourages a view of embryo relinquishment as the donation of biological material, describing it as "fundamentally a medical procedure intended to result in pregnancy" (p. 1819). The ASRM Ethics Committee further argues that "ED more closely approximates normal human reproduction than it does traditional legal adoption" (p. 1819). This donation discourse is informed by an overarching medical discourse, in

which a problem (infertility) is identified, for which medicine can offer a ‘solution’ (Daniels, 2005a); one that is also less expensive and less medically risky, with better chances for pregnancy than other options (Eisenberg & Schenker, 1998).

By drawing on a discourse of donation, a clinical, almost distant stance towards ED may be enabled (Brakman, 2007). As Anderson (2006) writes, “by embracing the term ‘donation’ rather than ‘adoption’, fewer emotional responses arise. Rather than calling to mind the adoption of a child, it implies a more scientific or technical process” (p. 620). Donation within this context can be constructed as a ‘once-off’ event limited to providing biological material to assist others, and without longer-term consequences or responsibilities. This may particularly be the case in jurisdictions where anonymous donation is possible. Donors may be offered positions that involve no ongoing responsibility, and indeed their act of donation to help others opens up commendable subject positions such as altruistic and philanthropic members of society. Further, recipients may be offered comfortable positions in that they can accept the donation without further responsibilities towards the donors and in the context of a clinical process.

MacCallum and Golombok’s (2007) study in the United Kingdom explored the experiences of adoptive families and 21 ED families with children aged between 2–5 years, and who had received donated embryos prior to the United Kingdom’s requirement for donor registration and recommendations of openness. In this study, it appears as if ED was indeed constructed by the recipients as a one-off event. Most reported rarely or only occasionally thinking or talking about the donors. Only 9% had told their children of the manner of their conception, 43% of recipients were not planning on telling, and 24% were undecided. This contrasts with adoptive parents, who were far more inclined to tell their children and others about their method of family creation and to discuss the birth parents. While these recipients may change their minds about disclosure at a later date, reasons given for not telling included a belief that disclosure is unnecessary and that the social relationship is more important than the genetic relationship. These findings were however replicated in a later follow-up study by MacCallum and Keeley (2012) when the children were aged 5–9 years, again suggesting that ED mothers were less likely to disclose, with only 43% inclined towards disclosing and then giving only partial explanations of the child’s conception. This supports the notion that recipients may draw on a donation discourse, framing ED as a one-off event that is later a non-issue. Donors assume a position of relative unimportance (MacCallum, 2009), and the two processes of non-genetic parenthood

(ED and adoption) were not viewed by participants in the same way, suggesting that comparisons are not helpful (MacCallum & Keeley, 2012). However, recipients' failure to disclose may also in part be affected by limited information about donors, as in spite of changes in legislation allowing access at age 18 years in the United Kingdom, this does not necessarily translate into the recipients having greater information about their donors (MacCallum, 2009; MacCallum & Golombok, 2007). MacCallum (2009) comments that in this way the policy and practice place less significance on the genetic relationship between donor-conceived children and genetic parents and on the longer-term implications, and that this may be reflected in the mind-sets of the recipient or rearing parents. On the other hand, recipients in MacCallum and Golombok's (2007) study also acknowledged concern that relationships between recipient parents and the donor-conceived child would be damaged as a result of non-disclosure.

This discourse or metaphor has however been challenged on a number of fronts. For example, several authors suggest that because ED involves donating genetic material of the donor couple, and full genetic children and siblings of the donors' children, and the recipient couple (unlike gamete donation) makes no contribution to the genetic background of the child, more complex issues and stronger welfare concerns are implied than in other forms of donation (Eydoux et al., 2004; Helm, 2008). ED is not just about treating infertility, but longer-term psychological and social consequences, not just for the individuals affected by infertility, but also the families created through donation need consideration (Daniels, 2005a; Daniels et al., 2011; Helm, 2008; Richards et al., 2012). Blyth (2002) for example, suggests that donor assisted conception "should be perceived as a means of creating another human being rather than as a technical procedure that bypasses fertility difficulties or resolves involuntary childlessness", and that "it is not just a one-off event... but a long-term and potentially intergenerational process" (p. 189).

The donation discourse has further been resisted by emphasising the differences between ED and gamete donation in terms of the intention to parent, which I have termed the 'parenting intent' discourse. Blyth et al. (2011) argue that the ASRM model, equating gamete donation to ED, is inherently flawed as it fails to take into account that in gamete donation the donors' participation from the outset is predicated on their intention to help others build their families, not to engage in a parental project, or to parent the children. In ED, by contrast, a couple has engaged in a joint parental project, attempting to produce embryos in their desire to have children. The embryos that become available for donation are a product of the couple's parenting project; they were

originally destined to be members of the couple's family (Apel, 2005) and are thus constructed differently than gametes. Brakman (2007) suggests that egg and sperm donors do not regard embryos resulting from donation as 'theirs' or as a genetic or biological embodiment of themselves, whereas embryo donors do. Thus Blyth et al. (2011) argue that the act of donation means something different in gamete donation and ED. In other words, where there is parental intent to build a family, donation becomes less feasible and it becomes difficult to construct ED as 'mere' donation. Indeed, Brakman (2007) suggests that the term donation "not merely obscures but rather exacerbates the discomfort of couples by not speaking to their reality and experience. To their mind they are not merely donating tissues but something rather much more monumental' (p. 202).

Further, several countries now have professional guidelines and practice mandatory registration of donor identity and access of the child to identifying information of the donor/s at the age of maturity. Such trends make it difficult to construct gamete donation, and indeed ED, as types of tissue donation, as more long-term implications and responsibilities may be evoked. As Blyth et al. (2011) comment, "the operation of both legislation and professional guidelines suggest that lawmakers and practitioners in a number of jurisdictions consider the practice to be qualitatively different from, and more problematic than gamete donation (p. 262).

4.6.2 The pregnancy termination or miscarriage discourse

De Lacey (2007) reports that both those who donated and those who discarded their embryos constructed discarding as akin to termination. However, for those that chose to donate, the termination was regarded as a deliberate, planned act to terminate a life, and some felt that these embryos had an inherent 'right to life' and that discarding was a decision they could not make. These findings resonate with the suggestions that potential donors may be reluctant to discard because they equate the process with the discarding of unborn children (Elford et al., 2004; Paul et al., 2010). De Lacey's (2007) 'discard' group, on the other hand, while describing feelings of regret, saw discarding as something akin to a *spontaneous* pregnancy termination, a miscarriage, and thus as something that could happen naturally in the course of a reproductive journey. Similarly, one participant in Provoost et al.'s (2009) study framed discarding as "an accident of fate" (p. 904). Provoost et al. however comment that using a miscarriage

metaphor may be a way to rationalise and cope with decisions after they have been made, rather than a way to choose between different options.

4.6.3 The adoption discourse

The issue of whether ED can be seen as adoption has been the subject of much debate in the literature (Applegarth, 2006; Brakman, 2007; Helm, 2008; Manning, 2004; Söderström-Anttila et al., 2001). In some texts, ED is directly referred to as ‘embryo adoption’, ‘very early adoption’, ‘prebirth adoption’, and arguments are made in favour of a terminology change from ED to EA in the belief that this term more accurately captures the essence of the practice and provides the proper lens through which to analyse the moral issues (Brakman, 2007). Such authors argue that the successful outcome of an ED – the raising of a child by parents who have no genetic relationship to the child, and who may have full genetic siblings being raised in another family by their shared genetic parents – has many parallels to traditional adoption, with Manning (2004) describing it as “the social equivalent” (p. 718). Indeed, Brakman (2007) suggests that because a child of a couple is created through ED, “no such prior interest in genetic material exists for any other ART and certainly does not exist for those who donate gametes under the intention to never parent the children that may come into existence as a result of their actions” (p. 202). Helm (2008) suggests that in this way ED evokes much stronger welfare concerns than is the case for gamete donation.

Some of the same social aspects have been cited as relevant for both adoptees and donor-conceived children, including (in the context of anonymous donation or closed adoption) unknowingly marrying a sibling, questions around identity, and curiosity about genetic parents and siblings. Similarly, birth parents and donors have been described as sharing similar concerns, such as for the welfare of the child and about future contact (de Lacey, 2005; Kirkman, 2003a; McMahon et al., 2000; Nachtigall et al., 2005; Paul et al., 2010). Finally, recipients and adoptive parents are presented as facing similar issues such as raising a child not genetically related to them, concerns around disclosure, information-sharing, and parenting status (Brakman, 2007).

Glover (2008) also points to the similarity between ED and the Māori practice of *whāngai*, an informal ‘adoption’ practice in which birth parents may place children with *whānau* for reasons including the recipients’ infertility, or because the birth parents are unable to raise the child. *Whāngai* children know about their birth parents and are able to have contact with them so that they are able to recount their *whakapapa* and to

answer “ko wai koe?” (Who are you?) (p. 56). Placements are arranged to secure and strengthen whānau and kin links (McRae & Nikora, 2006). Glover (2008) suggests that New Zealand’s model of ‘open’ ED could be seen as ‘early whāngai’, in that a genetic child is raised by another family but in the context of openness and acknowledgement of kinship ties, although in whāngai the placement is with extended family members.

By pointing to the similarities between ED and adoption and by direct references to ED as adoption, an adoption discourse can be identified. Blyth et al. (2011) suggest that the origins of presenting ED as adoption can be traced to a Californian infant adoption agency: Nightlight Christian Adoptions. As mentioned earlier in this chapter, in 1997 the agency established its Snowflakes Embryo Adoption Program, purportedly as a response to the numbers of cryopreserved embryos in the United States. As a Christian agency, the embryos were regarded as life and as children, and an ‘adoption program’ for embryos was created to ‘rescue’ embryos from ‘death and destruction’ (Collard & Kashmeri, 2011). In 2002 the US federal government lent its support through the allocation of significant funding to promote public awareness campaigns on EA. This move, and the express use of the term ‘embryo adoption’, raised considerable, albeit controversial, public exposure and debate. By 2010, almost \$18 million had been disbursed to agencies under this programme (Blyth et al., 2011). There are currently seven agencies operating in the United States and, since 2010, one EA programme run by Beginnings Family Services in Canada. These agencies have done much to promote a discursive construction of ED as adoption, and indeed, the terminology of ‘snowflake’ and ‘embryo adoption’ have been adopted by popular culture (Blyth et al., 2011). The key elements of the Snowflakes model bear a strong resemblance to adoption programmes, including:

- Provision of counselling for relinquishing couples;
- The ability of relinquishing couples to select (and possibly meet) potential recipients of embryos in advance of transfer;
- Completion of a home study (including both education and counselling) and screening of potential recipients; and
- (As may be the case in open adoption arrangements) the ability of relinquishing couples and recipients to agree on arrangements for future information exchange and contact. (Blyth et al., 2011)

The Snowflakes programme thus constructs ED as adoption, particularly with its emphasis on the screening of the potential recipients, and attempting to achieve a good

‘fit’ between the donating/relinquishing and adoptive/recipient parents. In 2010, Snowflakes reported that it had matched 441 genetic families (3,234 embryos) with 302 adopting families. In the same year there were 223 Snowflakes children and 14 families expecting 19 babies. While the agency is Christian, it assists people from any background and emphasises that it is not encouraging the creation and freezing of embryos, but is offering EA as a solution for an already-existing problem (Collard & Kashmeri, 2011; N. D. Johnson, 2003), just as adoption provides a solution for a pre-existing ‘problem’.

The Snowflakes model can thus be seen to actively promote a discourse of ED as adoption, but internationally there is a range of ways in which ED is practised that may offer constructions of ED either as donation or as adoption. Anonymous donation, for example, may make it easier to draw on a donation discourse, as in these cases, as for tissue or organ donation, the practice involves screening recipients for medical suitability, allocating on the basis of need, and no further involvement of the donors. Anonymous donation, as outlined in section 4.2.4, can however, also be practised as ‘conditional’ or ‘directed, anonymous donation’, where embryos are donated to unknown recipients with specified characteristics (de Lacey et al., 2010; Frith & Blyth, 2013). In Australia, where de Lacey et al. (2010) are based, directed, anonymous donation is possible in some states, and while this still differs from adoption practice where birth parents select adoptive parents from profiles, placing restrictions on recipients based on characteristics distinguishes ED from tissue donation practices, and may underscore an adoption discourse. For example, de Lacey (2007a) has written how “the best interests of the child” are facilitated in several states in Australia through counselling practices which are “at least encouraged to assume practices from adoption” (Widdows & MacCallum, 2002, as cited in de Lacey, 2007a, p. 1757). These practices may include attempts at some type of matching and selection of families, for example directed donation practices (de Lacey et al., 2010), registration of donor identity and access to information, and criminal record and child protection order checks (Hammarberg et al., 2011). The ASRM (2013) recommendations for ED include assessment of the donors’ stability, life stressors, coping skills, relationships, psychiatric history, and emotional attachment to embryos, and suggest exclusion criteria that include psychopathology, current use of psychoactive medications, excessive stress, and marital instability. In New Zealand, guidelines allow donors to review recipients’ profiles and on the basis of these select recipients that they wish to meet for joint counselling. Such practices may invite comparisons with adoption.

Some commentators have suggested that ED practice is not sufficiently similar to adoption practice and that current practices of police checks and setting restrictions on donation may give donors a false sense of security that recipients are fit to parent (Anderson, 2006). Adoption statutes generally require home evaluation studies of prospective parents in an attempt to ensure stable home environments (Anderson, 2006; Manning, 2004), but in most cases other than the Snowflakes programme (Collard & Kashmeri, 2011), ED programmes do not require this. For example, the ASRM (2013) guidelines for suitability are recommended, not mandated, and in New Zealand, while recipients must undergo police vetting checks (as introduced in the 2008 ACART guidelines), the guidelines stop short of recommending home studies. Larijani and Zahedi (2007) suggest that comprehensive assessment and screening of recipients may be critical to select ‘desirable’ parents, particularly to avoid what N. D. Johnson (2003) terms “consumer fraud”, as there is no guarantee that a recipient is “as advertised” (p. 866). Further, Bevc, Jerman, Ovsenik and Ovsenik (2003), writing in the context of adoption, have stressed that the process of coming to terms with infertility and its consequences is important for healthy family relationships and securing the child’s identity in the family – this would further serve to reinforce recipient assessment and support.

In jurisdictions where anonymous donation is prohibited, and donor-conceived children are given the right to access the identifying information of their genetic parents, it may be more difficult to construct ED as donation since, as has been discussed, donation cannot be framed as a one-off event with a particular endpoint. Counsellors involved in ED in New Zealand have reported that they see their roles as helping patients shift from a focus on their current situations to considering longer-term implications of donation, including for children and the wider families (Goedeke & Payne, 2010). Such practices have more in common with adoption than donation practices, and as Frith and Blyth (2013) point out; they are relational and herald the forming of new family relationships rather than one-off events conducted in the clinic.

Further, models for donor-linking, such as that described by VARTA discussed earlier in the chapter, explicitly draw on adoption reunion models, helping to negotiate and facilitate contact between the parties and providing counselling and mediation where necessary. The model takes into account that the desire for information and contact may intensify at various stages across the life cycle, including late adolescence, at the time of partnering and parenting, in mid-life, and at the time of death of a social

parent, and this is described as similar to what has been reported in adoption reunion practice. In this way, the adoption discourse is further supported.

These varying discursive practices thus serve to either enable or disable constructions of ED as adoption. However, the influence of the adoption discourse on the uptake of ED has been contradictory. Newton et al. (2003) and Collard and Kashmeri (2011) report that where participants held views congruent with a model of EA, they were more likely to donate. In Newton et al.'s (2003) study, those that were willing to contemplate donation did not see the act as an anonymous, disinterested gift, but wanted to be part of the child's life by providing information and being open to possible future contact. In contrast, de Lacey (2007a) reports that it was the 'discard group' in her study that related most strongly to the adoption metaphor. In other words, it appears that those that constructed ED as adoption rejected it as an option. For these participants, seeing the embryos as biologically bonded by genetics to their organic family unit, and as genetic replica of their existing children, meant that they were unable to donate them. Lack of control in not knowing where their children were or being able to ensure their wellbeing, and concerns about future contact affected their rejection of ED (de Lacey, 2005). In contrast, the 'donate group' drew on, but resisted the adoption metaphor, and described "how it did not fit" (de Lacey 2007a, p. 1754), emphasising the gestational experience as important. While this group did not deny the genetic link, they minimised it, reducing it to a 'mere biological fact' and seeing gestation, birth and the raising of the child as more important in the establishment of connections between the future child and the recipients, and the recipients' ownership of the child (de Lacey, 2007a). Note, however, that the donations took place prior to changes in South Australia requiring identity disclosure, which may be a relevant factor in acceptance or resistance to the adoption metaphor. Indeed, the perceived similarity of donation to closed adoption concerned participants in de Lacey's (2005) study, and they reported that they would always be worrying where the child was.

By constructing ED as adoption, donors may be positioned and position themselves as similar to birth parents in adoption contexts. Collard and Kashmeri (2011) suggest that taking on an adoption discourse allows individuals to make sense of new ways for forming families that can be perceived of as both 'normal' and 'moral'. They write, "In building their families and writing their own kinship scripts, these parents do not innovate totally but rather use models of current practices around them, borrowing often from other ART and adoption practices, especially open adoption and models of family recomposition after divorce" (p. 310). This may provide a measure of

reassurance. On the other hand, donors may also assume a position which, as for birth parents, entails responsibility in selecting suitable parents for ‘their’ embryos/children and a role in attempting to ensure their wellbeing (Goedeke & Payne, 2009). Even in the context of ‘open’ donation this may be difficult to achieve. Open donation practices, however, also underscore donors’ responsibility to record and disclose their identity, and their willingness to be contacted by the offspring, at the very least, at a later date. Further, framing the donation as adoption could reinforce constructs of the embryo as child, making transparent the donors’ choice to ‘give up’ their embryos and not to bear and raise their own genetic children, thus complicating the process and potentially making it more emotional (Goedeke & Payne, 2009) and raising concerns about transposability (Collard & Kashmeri, 2011). On the other hand, as some participants in Goedeke and Payne’s (2009) study suggested, donors may be seen as being in a more powerful position than birth parents in that they can choose whether or not to donate. In contrast, adopting was seen to take place from a position of vulnerability, where owing to circumstances birth parents were compelled to relinquish their child. Donors were thus portrayed as less emotionally vulnerable, and consequently less likely to experience regret and constitute a threat to the recipients’ role as parents.

The EA discourse also offers particular subject positions for recipients that may be similar to those occupied by adoptive parents. For example, the emphasis in programmes such as the Snowflakes programme on ‘rescuing’ the embryo and protecting life may position the recipients as saviours or as offering a service. This is a potentially powerful position. On the other hand, like adoptive parents, recipients may occupy a position in which the genetic bond between their children and the donors/birth parents is seen to constitute a threat, potentially undermining their position as parents and weakening the parent–child bond. In Goedeke and Payne’s (2009) study for example, recipients expressed particular concern about this and ED was constructed as a type of ‘shared’ parenting, where the child would be theirs, but not entirely theirs. Recipients felt that such shared parenting could both undermine their authority *and* offer benefits in terms of wider family networks and support. Further, where ED proceeds with donor registration, the recipient may be seen as occupying a subject position similar to that of adoptive parent: of needing to be found suitable for parenting and to act as a responsible parent by ensuring the child has access to genetic knowledge.

Thus the EA discourse enables subject positions for donors that may be both comfortable and familiar as well as anxiety-provoking, highlighting their lack of rights in relation to the child. For recipients, the discourse may likewise provide a model for

family creation, and yet it may offer both powerful positions (as embryo saviours offering a service) and vulnerable positions (uncertain about parenting role and status). Bernstein et al. (1996) further express concern that ED offspring may see themselves as ‘spare’ or ‘surplus’ goods, even though they have not been relinquished at birth.

Some researchers have suggested that it is how the role of genetic versus social parenting is seen (constructed) that may be relevant, with those who emphasise the psychosocial dimensions of family functioning and social bonding being more inclined to donate, in contrast to those who see genes as defining parenthood (Daniels, 2005a; Fuscaldo & Savulescu, 2005; Laruelle & Englert, 1995). If genetic connectedness is constructed as an essential and major component of parenting that is necessary for happy and healthy functioning, then donating an embryo, or accepting a child created through a non-genetic relationship, is going to present considerable challenges (Daniels, 2005a). On the other hand, if there is an acceptance that families can be built through love and nurturing, and a relational view of family is held (de Lacey, 2007a), then an adoption metaphor, which bestows the role of ‘real’ parent to the social parent, may be viewed more positively. In de Lacey’s (2007a) study the ‘discard’ group saw themselves as the ‘real’ parents in relation to their frozen embryos, whereas the ‘donate’ group constructed themselves as donors of reproductive or ‘seeding’ material, and the recipients as the eventual ‘real parents’.

Resistance to ED as adoption has included the fertility industry and some infant adoption stakeholders (Blyth et al., 2011). Crockin (2005b) expresses concern that the use of the emotive term ‘adoption’ constitutes ‘language creep’, elevating embryos to ‘constitutionally protected personhood’ with the same benefits and entitlement to protection. Frith et al. (2011) argue that prolife agendas underscore these representations, giving the embryo human status that enable choices such as donation, but undermine options such as research or discarding. They suggest that “It is patently evident that the language employed in the debate can be polarizing and inflammatory” (p. 3337), placing ‘burdens’ that are not appropriate for embryos on infertile recipients (Ethics Committee of the ASRM, 2009). Manning (2004) however suggests that drawing on adoption frameworks does not “make the embryo human” (p. 719). In fact, she argues that this approach rejects the notion that the embryo’s status must be defined, and instead expresses the parties’ intended use of embryos: to create a genetically unrelated family. It is at this point that ED becomes the functional equivalent of adoption, and thus should be subject to the same regulations. According to Manning, embryos do not become persons because the intending parents are subject to adoption

regulations, and the right to abortion is not infringed upon by requiring parties who intend to create genetically unrelated families to meet the standards of fitness of adoptive parents. Further, Manning suggests that unlike in adoption, children born from ED have not yet reached the age of majority, and that they too may “demand these (adoption law) protections” (p. 680), adding, “It is foolish to wait until a generation of children is grown to handle problems that will undoubtedly present themselves” (p. 719).

Criticism has also come from adoption practitioners such as Freundlich (2002) who have expressed concern that framing ED as adoption diverts attention from existing children who need families and instead encourages the use of ART to create children. Other authors have suggested that ED is ‘not quite’ adoption and carries some significant differences that set it apart from adoption. Anderson (2006), for example, points to the practical reality that in ED there is no child yet, and may well be no child. Others have made reference to the difference in intentions between birth parents and donors (the parenting intent discourse described in the previous subsection), as well as the role of gestation (what I have termed the ‘gestational discourse’). I discuss these next.

4.6.3.1 Gestational discourse – I gave birth to the child and am therefore its mother

ED allows recipients to experience pregnancy, birth and the parenting of a new-born, often cited as significant advantages over adoption that promote the parent–child bond (Collard & Kashmeri, 2011; Goedeke & Payne, 2009; MacCallum, 2009). Psychologically, MacCallum (2009) and Widdows and MacCallum (2012) assert that the experience of pregnancy and birth reinforces ED recipients’ constructions of themselves as the real parents from the start, and enables them to relegate the donors’ contribution to the parenting equation, that of genetics, to the back benches (MacCallum, 2009). Even here, the genetic contribution of the donors may be mitigated by recipients’ construction of the potential influence of gestation on the genetic makeup of the child, for example the idea that genes can be modified, switched ‘on or off’ depending on the prenatal environment (Goedeke & Payne, 2009). Thus recipients construct themselves as still having some influence over the genetic makeup of the child and are again able to assume a position of greater parenting authority than may be the case for adoptive parents.

In de Lacey's (2007a) study, donors likewise valued the biological difference of gestating and birthing a child. They drew on their own experiences of pregnancy and the attachments that they developed to their children through gestation, believing that the woman "who invested her body in the reproductive work of gestation was the child's mother, and that this motherhood determined ownership" (p. 1754). This perspective is of course reinforced through legal frameworks in Australia, where de Lacey's study was conducted, and in other countries where it is the gestational/birth mother who is regarded as the legal parent (MacCallum, 2009). Collard and Kashmeri (2011) point out that in some cultures such as Papua New Guinea it is even gestation, and not genetics, that defines filiation and siblingship. Helm (2008) however argues that while adoption overemphasises environment over hereditary, ED risks emphasising biology (gestation) over genetics, and in this way ED may repeat the mistakes of adoption and place the needs of parents above those of children.

4.6.3.2 Parenting intent discourse: Donors create the embryos because they planned to have children, but in adoption birth parents did not plan to have children

In adoption, pregnancy may be achieved in the absence of a parental project of the birth parents, whereas in ED donors set out to create embryos in order to parent them (N. D. Johnson, 2003). Glazer (as cited in N. D. Johnson, 2003, p. 872) asserts that

Unlike any other adoptee in history, their fate was not determined because a pregnancy was unplanned or unwanted or because social or financial circumstances prevented their biological parents from raising them. Rather, this new breed of adoptees will have been placed for adoption because of a simple twist of fate: an embryologist in a lab choose another embryo for transfer. This new breed of adoptees will grow up knowing that the random choice of an embryologist means that their biological siblings have the privilege of being raised by their intended parents and they do not.

Guichon et al. (2010) argue that in this way adoption and ED cannot be regarded as equivalent. They suggest that adoption occurs when pregnancy is unintended, and the aim of adoption is to minimise the harm of a sad situation: a genetic mother being unable to rear her child. In ED however, they assert that organisations "plan to initiate a pregnancy with the very purpose of separating the child from its genetic parents and full siblings who are its family" (p. 1). While these children may have access to their genetic knowledge, Guichon et al. raise concerns about the wellbeing of children, and ask: "If knowing your genetic origins is crucial then why deliberately rupture the genetic and

social aspects of parenting?” (p. 2). Their comments suggest that constructing ED as adoption may conceal some of these issues.

Manning (2004), however, continues to draw on an adoption metaphor/discourse, and suggests that in ED the intent on behalf of the recipients is clear: to create a child in the context of a genetically unrelated family. Thus, she argues that adoption laws should apply, as for the recipients at least, ED parallels adoption. Helm (2008) points out that the intent of ED for both donors and recipients could also be to ‘find families for existing embryos’. If this is the case, then the adoption discourse holds.

It is important to reflect, however, that while embryos may be created with the purpose of helping the donors fulfil their parenting intent, they may achieve this purpose and still have embryos remaining after they feel their families are complete. Their ‘parenting intent’ may never have been to have more than a certain number of children or as many children as their embryos potentially represent. Also, circumstances – such as health issues, reproductive issues, and financial issues – may, as in the case of adoption, prevent them from being able to use these embryos themselves.

4.6.4 Concluding comments: Donation or adoption?

Blyth et al. (2011) comment that these contrasting discourses or conceptualisations are more than a semantic exercise, and have implications for policy, practice and the experience of ED, affecting how ED is carried out and how the future relationships between parties is conceptualised and develops. Where ED is constructed as donation, and I would argue particularly in jurisdictions where anonymity and non-disclosure are common, it can be constructed as a one-off, reasonably clinical and altruistic, act. Where ED is constructed as adoption, longer-term psychosocial issues are evoked and concerns around the welfare of the child, the child’s placement, the suitability of recipients, are enabled (Helm, 2008).

These discursive constructions thus offer different action possibilities and subject positions and yet several authors (e.g. Nachtigall et al., 2010) have suggested that neither construction quite captures the practice. Blyth et al. (2011) suggest keeping both ‘models’ of ED and EA, which appears to imply the both constructions of ED can be useful and drawn upon by individuals in their decision-making. They propose a multimodel approach that they argue reflects individual choice and the diversity of contemporary cultures and communities, but with the proviso that access to information

about their genetic origins by donor-conceived individuals is facilitated. It appears that they are arguing for a system that:

- Paves the way for ED as donation (with policy and practice being more geared towards donation practices, but with the addition of registration of donor information, accessible to a recipient and child at age of majority); and
- Enables constructions of ED as adoption (with a greater emphasis on adoption policy and practice, especially open adoption practices, with screening of recipients, meetings between recipients and donors, access to information, and varying degrees of ongoing contact).

Similarly, Frith et al. (2011) suggest that those with stored embryos should have choices about how to relinquish their embryos so as to facilitate “the diversity of views on the amount, nature and organisation of contact between relinquishing and receiving families” (p. 3336). As far as Frith et al. are concerned, as long as these options do not harm others, “the principle of reproductive choice can be used to justify couples having options available to them that they find both morally and practically suitable” (p. 3337). Note that this viewpoint still appears based largely on a medical, individual rights discourse that fails to take into account the potential longer-term needs of donor-conceived individuals, their siblings, and their respective families.

As has already become apparent, the discursive constructions of ED must also be interpreted within the policy and legislative frameworks of different jurisdictions. It may be very different, for example, to frame ED as adoption in contexts where ED, or adoption, or both, are conducted anonymously and with secrecy, versus contexts of openness. To better understand individuals’ investment in and resistance to such metaphors, changes in policy and practice with regards to adoption, as well as gamete donation practice, need to be considered. In the next chapter, I discuss legislative frameworks and policy surrounding ED in New Zealand, the discourses and discursive practices that may be identified, and the implications of these for donors and recipients.

4.7 Conclusion

In this chapter I have identified a multitude of different, contradictory and complex discourses surrounding ED. These include: ED as novel and unknown, ED as last resort, ED as viable solution, ED as donation, and ED as adoption. Each of these discourses enables and opens up particular action possibilities and subject positions for donors and recipients, affecting their degree of comfort with ED and their experiences. I have also

explored how ED needs to be considered against the backdrop of discursive constructions of infertility and ARTs, including practices such as cryopreservation. I have discussed how the way in which the various disposal options: storage, discarding, research donation, and reproductive donation are constructed must be taken into account in understanding ED discourses and practices, particularly as ED may be chosen in resistance to other options, and not actively opted for. How the disposal decision itself is constructed likewise has been identified as having implications for the options chosen, and longer-term implications for experiences and relationships between donors and recipients. I have identified specific discourses of the embryo, and how these potentially both enable and disable the uptake of various options and position the donors and recipients. Two predominant discourses identified in the literature – the donation discourse and the adoption discourse – have been discussed with reference to their implications for understandings and experiences. Further, various factors that for the purposes of this study have been labelled as ‘extra-discursive’ have been presented, and these may help explain individuals’ investment in some discourses and not others. Finally, I have discussed how ED must also be considered against the backdrop of changes and developments in discursive practices in related fields such as adoption and gamete donation, and how these have informed ED policies and practice, including the role given to counselling. The discourses that may be identified in New Zealand legislative frameworks, policy documents and guidelines, and the action possibilities and subject positions that are made available through these form the focus of the next chapter.

Chapter 5: Results – Legislation, policy, guidelines and ED approval analysis

Jurisdictions across the world have adopted different approaches to address the social, ethical, legal, psychological and moral issues associated with reproductive regulation in ways that reflect their culture's needs and circumstances (Daniels, 2005b, 2007).

Whereas some jurisdictions have a hands-off approach with minimal state intervention, in others state involvement is rationalised with the arguments that ARTs raise questions over societal priorities; that a state has a duty to meet the interests and needs of children as well as consumers; and that public funding of services warrants governmental decision-making authority over access (Blank, 1988, as cited in Daniels, 2005b).

Donor conception is one of the more contentious areas in ART, and cultural responses range from its prohibition (as in many Muslim countries) to allowance and endorsement, to open-market trading and commercialisation of donor gametes, as in the United States of America (Glennon, 2012; Gürtin & Vayena, 2012). In Western cultures, individual rights, autonomy and self-determination are generally held as important values and given precedence in regulating reproductive decisions. In other cultures, relational autonomy may direct the decision-making process (Turolfo, 2010). The context within which third party reproductive arrangements occur includes what societies define as morally acceptable, as well as their individual political histories and constellations relevant to certain jurisdictions. For example, due to Germany's recent history of eugenics and state interference, manipulation and interference in genetic transmission are considered ethically unacceptable there; in Italy, Roman Catholic doctrine concerning the sanctity of life and marriage is related to that country's prohibition of ED (Gürtin & Vayena, 2012).

In this way, Inhorn and Birenbaum-Carmeli (2008) suggest that ARTs are culturally embedded "socio-technical products, which are shaped by human and non human factors, including the technical features of the ARTs themselves, as well as by the economic, political, cultural and moral environs in which they unfold" and that they are "intimately linked with power relations" (2008, p.178). Yet while regulations and guidelines may reflect broader political and social concerns, they also in turn shape attitudes and experiences. It is thus important to consider the context within which ART, and especially ED, occurs in New Zealand.

As Michelle (2006) points out, the narrative mechanisms, discursive assumptions, and representational strategies that operate through legislation and

guidelines carry with them certain implications: they may define and delimit the legitimate use of technologies; they may make visible circumstances considered desirable about who should parent and how they should parent; and they may legitimate some forms of family creation and not others. This is reflected in Kaye's assertion that "laws are important not only for what they prohibit or do not prohibit, but also for the attitudes they encourage or discourage within our society" (as cited in de Lacey et al., 2010, p. 7). ART regulations and monitoring processes may thus operate as "a set of disciplinary practices or techniques in a Foucauldian sense" (Michelle, 2006, p. 119). Discourses may enable or disable possibilities and positions, with implications for subjectivity and experience. As Daniels (2007) has commented, guidelines provide a framework through which personal dilemmas and considerations can be explored.

In this chapter I explore the New Zealand context of ED, in terms of legislation, policy, counselling practice guidelines and ED approval. In section 5.1 I provide an overview of these, including the Human Assisted Reproductive Technology Act 2004 (hereafter cited as the HART Act); the function of the Advisory Committee for Assisted Reproductive Technologies (ACART) and the Ethics Committee for Assisted Reproductive Technologies (ECART); the guidelines for ED practice in New Zealand as set out by the National Ethics Committee on Assisted Human Reproduction (NECAHR, 2005) and ACART (2008); ECART application forms for ED; minutes of ECART meetings detailing ED approvals between 2007 and the end of June 2012; and counselling documents, including the Australian and New Zealand (In)fertility Counsellors' Association (ANZICA) 2006 position paper in relation to ED; the ANZICA infertility counselling guidelines; and the Reproductive Technology Accreditation Committee (RTAC) Code of Practice.

In section 5.2 I discuss the discourses identified in the first, analysing how these enable action possibilities and subject positions for those undertaking or contemplating ED, and considering the possible implications for subjectivity and experience. In the third and final section I identify and discuss influences on the development of New Zealand's stance towards the regulation of ARTs in general, and ED in particular.

5.1 Overview of legislation, policy, guidelines and decisions relevant to ED

5.1.1 HART Act 2004

Prior to 2004, there was minimal formal regulation of ART in New Zealand.⁴ In 1984, the Warnock report was published in the United Kingdom with the brief to consider and make recommendations to government regarding appropriate responses to ART regulation issues. This report provided a platform for debate in New Zealand, which led to a group of various organisations including the Royal Society of New Zealand, the New Zealand Law Society, the Medical Council of New Zealand, the Medical Research Council of New Zealand, and the Medical Association of New Zealand approaching the government to appoint a committee to consider the legal, moral and social issues related to ART. A subsequent ‘issues paper’ was released in 1985 to promote public debate. However, this paper was mainly exploratory in nature (Daniels, 2007).

Several years later, in 1993, at the request of regional ethics committees confronted with issues related to reproductive decision-making, the Ministry of Health established the Interim National Ethics Committee on ART (INECART, which became NECAHR in 1995) under the Health and Disability Services Act 1993. This committee was charged with the task of ethical review, as well as the development of protocols and guidelines related to ARTs. At the same time, the Ministry of Justice appointed a two-person Ministerial Committee on ART (MCART), which in 1994 was of the opinion that no licensing system was necessary. Thus, for the next 10 years, NECAHR was the only government-appointed body overseeing ART, and it operated as an ethics committee, as well as a de facto policy committee (Daniels, 2005b). In 2004, parliament enacted the HART Act,⁵ which sets out primary purposes and principles that are to underpin decision-making in this area. The primary purposes of the Act relevant to this discussion are:

- to secure the benefits of assisted reproductive procedures, established procedures, and human reproductive research for individuals and society in general by taking appropriate measures for the protection and promotion of the health, safety, dignity, and rights of all individuals, but particularly those of women and children in the use of these procedures and research (section 3a)
- to prohibit certain commercial transactions (section 3c)

⁴ For the most comprehensive discussion of the development of legislation and policy in New Zealand, see Daniels (2007).

⁵ The Act can be accessed at: www.legislation.govt.nz/act/public/2004/0092/latest/whole.html

- to provide a robust and flexible framework for regulating and guiding the performance of assisted reproductive procedures and conduct of human reproductive research (section 3d) and,
- to establish a comprehensive information-keeping regime to ensure that people born from donated embryos or cells can find out about their genetic origins (section 3f).

The HART Act is based on specific guiding principles, including:

- The health and wellbeing of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure (section 4a)
- The human health, safety and dignity of present and future generations should be preserved and promoted (section 4b)
- No assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent (section 4d)
- Donor offspring should be made aware of their genetic origins and be able to access information about those origins (section 4e)
- The needs, values and beliefs of Māori should be considered and treated with respect (section 4f)
- The different ethical, spiritual and cultural perspectives in society should be considered and treated with respect (section 4g).

Part 2 of the Act sets out prohibited and regulated activities. Embryos may not be stored for a period of more than 10 years unless prior application has been made to ECART, for example, and there may be no valuable consideration given or received for the supply of a human embryo (with ‘valuable consideration’ including an inducement, discount or priority given in the provision of a service).

The HART Act makes provision for the establishment of two committees:

1. ACART was set up to issue guidelines and advice to ECART relating to reproductive procedures or research. ACART must include members with expertise in assisted reproductive procedures, law, research, ethics, Māori customary values and practice, the ability to articulate issues from a consumer perspective, and the ability to articulate the interests of children (Subpart 3, 34, 4g).
2. ECART was set up to consider, determine and monitor applications for approvals for ART procedures and reproductive research. Applications are assessed with

reference to ACART guidelines. ECART must be guided by the principles of the Act, and members are charged with “protecting the interests of human participants, including a potential child when this is appropriate, while promoting excellence in research and innovative practice” (ECART, Terms of Reference, 2013, p. 5).

Part 3 details the recording of information about donors and donor offspring, and the ability to obtain access to such information by donors, donor offspring, and/or their guardians, as well as donor siblings. The Act emphasises the importance of telling offspring about their conception. Access by offspring to identifying information about their donors is possible at age 18 years or younger at the request of their guardians, although an agency may refuse to give access if the disclosure “is likely to endanger any person” (Section 60, 3). The agency providing access must advise the person of the desirability of counselling, as well as advise the donor that access has been given. Provision is made for access to information about siblings if all offspring are aged 18 years or over, or with the consent of guardians. Donors may request information regarding children born, and *if* the offspring have formally consented, may have access to identifying information.

The above principles and requirements provided the legislative framework for the development of ED guidelines. The first set of draft guidelines was developed by NECAHR as one of its last activities before the establishment of ACART (Daniels, 2007). NECAHR began considering the ethical issues associated with ED in 2002, and developed guidelines in 2003 which were reviewed by the Ministry of Health and made available for public consultation in 2004. Following ministry sign-off, approval was granted and the guidelines were published in August 2005 (NECHAR, 2005).

5.1.2 NECAHR Guidelines for ED for Reproductive Purposes (2005)

ED is defined by NECAHR (2005) as “the donation by a couple, who have surplus embryos, of one or more of these embryos to an infertile couple or person” (p. 2).⁶ The guidelines make reference to key ethical issues related to ED, and those relating to the welfare of any child born including:

- The need to minimise harm to offspring
- The need for offspring to know about and be able to access information about their genetic background, including knowing about full genetic siblings, and,

⁶ This subsection summarises the key features of the guidelines. The full set of guidelines may be found in Appendix C.

- The need to ensure free and informed consent to ensure that donors are not pressured into donating, and that donors and recipients are fully informed of the psychological, social and ethical aspects involved in ED (NECAHR, 2005, pp .2–3).

The guidelines specify that applications made by the provider will be considered on a case-by-case basis by NECAHR. The original guidelines consist of six sections, including guidelines related to donors, recipients, and both, and guidelines concerning counselling, the approval process, and reporting required. As is outlined by Daniels (2007), the main areas addressed by these sections relate to requirements for ED, consent, counselling, and the engagement of donors and recipients. Requirements for ED can be summarised as follows:

- Only those embryos created from the donors' own gametes may be donated.
- These embryos must be 'surplus' to the donors' requirements - two years must have elapsed since the decision that their family is complete.
- Embryos may be donated to one family only.
- There must be 'medical conditions' precluding normal reproduction in respect of recipients, or unexplained infertility that has not responded to other treatments.
- Embryos must be screened for 'risk', and not donated if known to be affected by or carriers of significant genetic disease.
- Criminal records must be accessed for recipients.
- RTAC guidelines must be followed, including medical screening of the recipient woman.
- Both couples must be permanent residents of New Zealand, and.
- Both parties must be informed of the requirements regarding information-sharing under HART.
- Providers must notify NECAHR of outcomes (Daniels, 2007; NECAHR, 2005).

Consent issues can be summarised as follows:

- New patients must be informed about options available for surplus embryos, including storage, disposal and ED.
- No pressure may be exerted on couples to donate their embryos.
- Donors have the right to vary their agreed terms of donation, or to withdraw from the donation, up until the point of transfer to the recipient woman.
- Informed decision-making is required with both parties giving written consent.

- Implications counselling must be provided, and include the requirements of information-sharing under the HART Act (Daniels, 2007; NECAHR, 2005).

Counselling requirements include that:

- Both donors and recipients have implications counselling that is culturally appropriate, and makes provision for the inclusion of whanau/family and any children (on an age-appropriate basis).
- Implications counselling for donors is to address motivations for donation, current and future feelings related to donation, the effect of donating on existing children, the rights and needs of children born through ED, issues related to selecting recipients, understanding that the recipients will be the legal parents of the child, and the possibility of disability, genetic disorder and termination.
- Implications counselling for recipients is to address the implications of parenting a non-genetically related child, the rights and needs of offspring to access information and initiate contact with donors, and the possibility of disability, genetic disorder or termination.
- Donors and recipients have separate counsellors.
- Access to counselling is available throughout the process, and,
- There must be at least one joint counselling session with all adult parties, addressing the rights and needs of the child; and the needs, expectations and wishes of each party in relation to information-sharing and ongoing contact.

Counsellors are required to complete a report for ECART outlining issues addressed. Information about this report is detailed later in the chapter.

The joint counselling requirement relates to the engagement of donors and recipients as identified by Daniels (2007), who suggests that a central component of ED is that it occurs between two sets of adults who have met and selected each other. The guidelines set out that:

- Counsellors provide potential donors with non-identifying profiles of potential recipients, from which donors will select a person or couple.
- Donors provide non-identifying information to the provider, from which profiles are developed that donors must approve before they are shown to the recipients.
- If both parties agree, one or more joint counselling sessions are set up.
- Note that for recipients, profiles also include a criminal record check.

The NECAHR guidelines were revised by ACART and published in November 2008.

5.1.3 ACART Guidelines for ED for Reproductive Purposes (November 2008)

Most of the key components and requirements remain the same as NECAHR (2005), and the guidelines are prefaced by the advisement that ECART must be guided by the principles of the HART Act.⁷ The differences in the revised guidelines include:

- Both parties are required to have independent legal advice. Legal reports are required that signal that all legal issues are understood.
- There must be discussion, understanding and agreement related to the use, storage and disposal of any unused embryos.
- It is more clearly stated that parties must understand that donors may vary agreed terms and withdraw consent up until embryos are placed in the woman's uterus.
- The requirement that two years have elapsed since donors deem their family complete is substituted with ECART needing to take into account if the donors have 'completed' their family (i.e. there is no designated time period stated).
- Residency requirements are more specifically related to whether "residency safeguards the wellbeing of all parties, and especially any resulting child" (ACART, 2008, p. 3).
- The guidelines advise that ECART must take into account all relevant factors, including consent, counselling, needs of children, plans around disclosure/information-sharing/ongoing contact, and "any specific issues that may affect the health and wellbeing of any parties, and especially any resulting child" (2008, p. 3).

These provisions are reflected in the ECART application forms, which are outlined below.

5.1.4 ECART: ED for Reproductive Purposes Application Form (2008)

The 2008 application form⁸ is divided into five sections. Section 1 includes a declaration by the person responsible for the application, i.e. a nominated person from the providers, and requires a summary of the ethical, medical, legal, cultural and

⁷ The full set of guidelines may be found in Appendix B.

⁸ Application forms can be accessed online at: www.ecart.health.govt.nz/publications-and-resources/application-forms

psychological issues, as well as risks specific to the application. It includes a checklist for indicating that reports from medical specialists, legal advisors, counsellors, and letters from donors and recipients are included.

Section 2 includes medical reports for donors and recipients. The application form includes some provisos for various sections; of note here being the following:

- For donors, the reasons for residency questions are given as the need to safeguard the wellbeing of all parties, especially resulting children.
- For recipients, note is made that ED must be the preferred management option following a description of the “medical condition and/or treatments that have resulted in ED now being considered the preferred management option” (ECART, 2008, p. 9); Section 2B.8 requires the rationale for ED as a treatment with particular reference to why other treatments were not considered.

Section 3 includes the counselling reports for donors (section 3A) and recipients (section 3B). Reference is made to using face-to-face counselling as well as ensuring an interval between sessions to “allow for adequate time to consider all the issues”. For both donors and recipients there is a requirement to provide details of social history, including significant life experiences which may “predispose either to risk when moving into a new situation, or which may pose a risk to the donors, recipients or any resulting child” (ECART, 2008, pp. 12 and 18). Comment must be made on the relationship between donors and recipients, “with particular concern for the resulting child’s wellbeing, ongoing contact, future access to information” and for the possibility of change in relationships, the process for dispute resolution, and the needs of children under the HART Act (ECART, 2008, pp. 12–13 and 18–19).

Section 3C refers to the joint counselling report and must demonstrate that implications for the child, i.e. a. information-sharing; b. needs and rights to access; c. openness; d. others’ obtaining information; e. understanding each others’ wishes and needs; f. expectations and plans regarding ongoing contact and information-sharing, have been addressed. Counsellors’ observations of the relationship between the donors and recipients, including power relationships, evidence of coercion, and resolution processes discussed, must be outlined.

Section 4A concerns legal reports for both parties, and information about the rights given by the HART Act to offspring and guardians of donor offspring, as well as the rights given to donors and others to obtain information about offspring. A note is made that “a court might ultimately resolve disputes” (ECART, 2008, p. 26). Section 5

stipulates a statement from a key person, e.g. whānau member, kaumātua (tribal elder), or Māori counsellor.

The revised form (November 2011) addresses the same issues, but includes:

- A section on embryos, detailing information about the number of embryos to donate, reasons IVF was used to create embryos, restrictions set by the donors on use, and a description of what is to occur with non-viable embryos.
- Checklists for indicating if each of the principles of the HART Act has been upheld; indicating if key issues in the guidelines have been addressed, including for medical, counselling, and legal issues, and indicating the inclusion of ‘optional’ reports such as letters from other specialists, donors, recipients or significant others (e.g. whānau member, kaumātua (tribal elder), Māori counsellor or specified other).
- The reports are briefer and require yes/no answers, with detail provided for ‘no’ answers only. The counselling reports report on the number and dates of sessions and attendees, and are mainly in a yes/no format, covering the issues outlined in counselling requirements. Final questions ask for elaboration regarding any factors of which ECART needs to be aware.
- Legal reports require indication of the legal issues; provisions for information access; rights to withdraw consent; legal parentage status; and that disputes may have to be resolved by the Family Court (ECART, 2011).

5.1.5 ECART applications

ECART meets approximately five times per year to review applications and the minutes of their meetings are publicly available (www.ecart.health.govt.nz/meetings). Minutes detail application type (e.g. for ED, surrogacy, within-family donation), issues and comments in regards to applications, and indication of the decision made: approved, approved subject to conditions, deferred, or declined. No identifying information is provided or noted in the minutes. ECART also releases an annual report to parliament detailing applications received, decisions made, and outcomes of applications.

Between 2005 and June 2012, 53 applications for ED were reviewed by ECART (ECART, 2012). Of these applications, none were ultimately declined. By July 2012, ED had resulted in 14 births in New Zealand, with some cases ongoing and outcomes not yet reported. Only one application has been made for the withdrawal of consent for ED that had been approved (E08/06 approved in 2008, withdrawn 3 June 2010) and one application was withdrawn (E10/50 submitted 25 November 2010, deemed incomplete, and withdrawn following receipt of police-vetting information for the recipients. The

donors were the subject of a further application, E11/31, to another set of recipients, approved 21 June 2011).

Between 2006 and June 2012, seven applications were initially deferred, with subsequent approval at later meetings. Reasons for deferment included:

- Medical reasons e.g. further information required regarding recipient woman's weight, genetic disease or 'special needs' of a child, and incomplete medical reports. Note that in one case (E09/17) the application was deferred as a result of debate around the medical eligibility of the recipients, as they already had children through fertility treatment. The application was later declined as the committee decided that the recipient partner's condition did not meet the requirements for medical eligibility. The applicants appealed, providing additional information. The committee response was divided, and a decision delayed to allow time for consideration. Subsequent minutes indicate that the application was approved.
- Need for clarity around disposal of embryos remaining following donation.
- Need for clarity around recipients' understandings of the donor woman's Māori heritage and the implications for any resulting child, and a letter from the donor woman in connection with the exploration of her Māori heritage.
- Similarly, confirmation that donors and recipients share an understanding of how any resulting child will be raised in terms of cultural practices.
- Request for exploration of key issues in the recipient partner's social history.

Main issues noted by the committee between 2007–2012 include:

- Relationship or bond between donors and recipients, including agreement around contact expectations and arrangements.
- Psychosocial history of applicants, including the suitability of recipients, police-vetting of recipients, and the similarity of donors and recipients or 'matching'.
- Support networks and family involvement.
- Cultural significance of ED, particularly in relation to applications where one of the parties is Māori.
- Stability of environment the child may be born into; impact on the child.
- Disposal of surplus embryos, including ownership rights: who assumes responsibility and how this is to occur.
- Number and quality of embryos available for donation.

Note that the above represents an overview only, and is presented to provide a context for the discursive analysis to follow later in the chapter.

5.1.6 ANZICA Guidelines for Standards of Practice in Infertility Counselling (2003)

ANZICA was set up in 1989 by counsellors, social workers and psychologists attending the annual Australasian Fertility Society conference in Canberra (ANZICA, 2013). ANZICA falls under the umbrella of the Fertility Society of Australia (FSA), and provides a structure to promote the interests of fertility counsellors, foster the recognition of counselling in the context of infertility, promote professional development, undertake research to inform practice, and provide ethical guidance to its members. ANZICA's mission statement refers to the need to provide a high standard of counselling that will enable counsellors to support and benefit the individuals with whom they work, including 'the welfare and best interests of any potential child' (ANZICA, 2013).

ANZICA's Guidelines for Professional Standards of Practice Infertility Counselling (2003) set the parameters for counselling, and the focus and content of sessions. Note that section 1.1.6 states that while there is no mandate for assessment in the course of their work, counsellors may identify significant "risk factors" that in extreme cases may impact on clinical decision-making (ANZICA, 2003, p. 4). The 2007 Australian National Health and Medical Research Council (NHMRC) guidelines, which recommend that ARTs should be carried out with 'due regard' for the long-term health and psychosocial wellbeing of all participants, are referenced.

With reference to ED, section 2 reiterates the requirements of the RTAC, which provides a framework and criteria for auditing clinics across Australia and New Zealand, and issues an annual Code of Practice (COP) to accredited organisations for the delivery of fertility services (RTAC, 2010). All ART clinics are required to operate under the COP's minimum standards. In broad terms, the COP stipulates three principles: altruistic donation, right of access to genetic background and origins, and adequate information about the medical, social, psychological and legal implications of donor procedures (Hammarberg et al., 2011). Attachment 2 specifies support of the offspring's rights to know their genetic origins, thorough record-keeping, informed consent for patients, and the delivery of counselling services. It requires organisations to explain the provisions, responsibilities, and obligations associated with linking donors,

recipients and offspring. Further, it sets limits on the number of children and families created from one donor, and requires that donors and recipients are informed of the donation process, relevant legislation, the legal status of children, the process for disclosure of information, and the right to vary consent.

Within this framework, the standards of practice for counselling set out the following requirements related to the donation of gametes and embryos:

- Counselling, especially therapeutic counselling, implications counselling and decision-making counselling, must be offered.

Therapeutic counselling aims to address longer-term issues and pre-existing concerns such as depression, self-esteem issues, and grief and loss issues that may affect the experience of treatment; implications counselling aims to foster understanding of treatment implications for the patient, family and any child born; decision-making counselling aims to enhance capacity for informed decision-making, through reflecting on short and longer-term psychological implications of decisions made (ANZICA, 2003, pp. 4–5.)

Counselling should address: Grief and loss regarding genetic connection, impact on relationship/family and self-concept, motivations, risks and benefits, short- and long- term consequences for all parties, exploration of the importance of donor information, disclosure attitudes and guidelines, relevant legislation, cultural/religious/moral issues, realistic expectations, openness and contact.

- A ‘cooling-off period’ before consent is signed is recommended to allow thorough consideration of the issues raised in counselling.

Note the statement in section 2.2.5 that “the concept of ‘best interests of the child’ should be reflected in policies and procedures of clinics and counsellors. Donors and recipients need to be educated regarding this concept, particularly in relation to the right of an individual to knowledge about their genetic origins” (ANZICA 2003, p. 10). The guidelines for practice in infertility counselling provided a context for the position paper developed by ANZICA in relation to embryo donation, which was published in 2006.

5.1.7 ANZICA Position Paper: Donor Embryos (April 2006)

In the introduction of the paper ED is described as having potentially significant ethical and emotional implications. The paper outlines considerations for donors and their

children, recipients and people born through ED, as well as discussing ‘staff considerations’.⁹

Donor considerations include: issues associated with others parenting their genetic children (including guilt, telling others, choosing recipients, questions from children, informed consent, and contact and relationships with recipient children).

Recipient considerations include: issues associated with parenting children with whom they share no genetic history, including anxiety about rejection, information-sharing, and contact and relationship with donors and their children.

The considerations for donor offspring include: Grief for loss of life with genetic family; genealogical bewilderment, i.e. identity and attachment issues; feeling different from their social families; finding emotional accommodation about selection of embryos used by genetic parents; feelings of rejection; and the reliance on openness and honesty of parents to disclose information.

Key staff considerations include criteria for the selection and approval of recipients, social and ethical considerations, and access to support by offspring for developmental and emotional issues. Considerations further include the need for research about the implications of ED, the role counsellors play in facilitating ED, and their degree of accountability. It is emphasised that counsellors will need to “keep in mind the best interests of current children of the donors and prospective child for the recipients” (ANZICA, 2006, p. 5).

Concern is expressed as to whether it is the donors, recipients, or as yet unborn child that constitute the client, the potential conflicts of interest that may emerge, and who will serve as advocate for the offspring (ANZICA, 2006, p. 6). The summary suggests that ED has lifelong implications for all parties involved, and that there are few structures or research to support the process. It concludes with the statement that ‘The membership is of the opinion that the potential risks associated with the donation do not justify the potential benefits’ (ibid.).

5.2 Discourses, action possibilities and subject positions

In this section, I present discourses that I identified in the various legislative, policy, and counselling documents discussed in section 5.1, as well as in ECART decisions as recorded in minutes. I discuss implications of these discourses in terms of the action possibilities that emerge, and the positions enabled for donors and recipients.

⁹ The position paper can be accessed online at <http://www.fertilitysociety.com.au/anzica/policy-documents/>

5.2.1 Genetic discourse

A genetic discourse, constructing genetic knowledge as crucial for wellbeing and as bestowing social and cultural connections, can be identified in terms of the following requirements.

5.2.1.1 Requirements about information-keeping and access to genetic knowledge

The HART Act (2004) recommends that offspring be made aware of their genetic origins, and establishes an information-keeping regime, enabling donor-conceived offspring (where aware of their donor conception) to find out about their origins. Part 3 of the Act sets out the provisions for offspring to find out information about their donors and siblings, and for donors to find out about offspring born as a result of donation. Likewise, ACART's guidelines emphasise the need and right of children to know about their genetic background and the existence of siblings. ECART application forms must record all parties' awareness of the rights to information, and minutes regularly make reference to this. Through emphasising the rights to knowledge about genetic background, genetics is constructed as having important implications.

5.2.1.2 Requirements to consider implications

ED guidelines stipulate the need for counselling to consider the implications of donating genetically related embryos, or receiving embryos that may result in the parenting of children that have no genetic relationship to the parents. Motivations, current and future feelings that may arise, and the impact on offspring and any existing children are framed as needing discussion (ACART, 2008). The ANZICA (2006) position paper recommends that grief and loss issues, guilt, and anxiety about relationships and attachment are addressed for donors and recipients. With respect to donor offspring, the paper outlines the need to consider grief for the loss of life with the genetic family, 'genealogical bewilderment', and 'emotional accommodation' about the selection or non-selection of embryos used by the genetic parents. The paper raises the possibility that offspring may feel different from their social families and view the genetic family with jealousy and/or contempt; may have identity or abandonment issues; or may experience feelings of rejection (p. 4). The genetic discourse thus gives weight to the genetic relationship, and significant implications are held to arise from separating offspring from genetic parents.

The genetic relationship is also constructed as locating donors and offspring within an inevitable social and cultural network, linking donors and offspring in

ongoing ways. For example, ECART application E11/06 includes the comment that DW (donor woman) “accepts that she will have an emotional connection to any child born”. ECART minutes construct genetic heritage as bestowing a cultural heritage that cannot be undermined through being raised in a different environment. See, for example, the application in November 2010 which was initially deferred as the committee needed to be assured that the ‘Māori heritage’ of the potential child and the implications thereof had been fully worked through. In applications E09/32, E10/40, E11/09, E11/14, E11/49 the genetic heritage of the child as Māori is constructed as linked to access to iwi, whakapapa and land inheritance. The child is described as having the same rights and needs as any other ‘genealogical Māori child’ (E11/49). By requiring that these implications are considered, the significance attached to genetics is underscored.

5.2.1.3 Requirements to donate embryos from donors’ own gametes only, and to one family only

Only those embryos formed from the donors’ own gametes (not from egg or sperm donation) may be donated. Helm (2008) suggests that this requirement aims to protect the connection between donors and offspring, as on-donation would make it difficult to preserve family connections. Donating embryos formed from egg and/or sperm donation is held to link the offspring genetically to the embryo donors as well as the egg or sperm donors, and create too long and complex a chain between genetic parents and offspring (Konrad, 2005, as cited in Helm, 2008). Yet again, genetic heritage is constructed as bestowing social ties.

Further, ACART (2008) guidelines stipulate that embryos may be donated to one family only, with the result that there should not be full genetic siblings in more than two families. RTAC likewise recommend the setting of limits on the numbers of children and families that may be created through donation. Setting limits is framed as necessary to manage the complexity of relationships that may be developed where more parties are drawn into family-building. Daniels (2007), for example, suggests that limits recognise the “intensity of the engagement process between the two families, both in the lead up to donation and post-donation” (p. 102). Extending the network of connections too widely by including gamete donors or more recipients is held to create too many difficulties. Again, genetic connections are framed as inherently associated with social implications (relationships with others).

This opens up the possibility that there may be contact between the families in which genetically related siblings are raised. It positions recipients and donors as

needing to recognise these ties: ED is constructed as not just a medical procedure, but as the inevitable inheritance of a social network. Note that while ED is seen by some as offering a solution to those with embryos in storage, the implications of the requirements mean that this may not necessarily be the case. Embryos may remain following donation, and ED is not an option available to those using donor eggs or sperm.

5.2.1.4 Requirements for medical eligibility

ED recipients must be deemed ‘infertile’, i.e. have medical conditions precluding ‘normal reproduction’ or unexplained infertility that has not responded to other treatments (ACART, 2008). In this way, ED may be constructed as a ‘treatment’ that recipients may embark on only if they have exhausted options to have their ‘own’ genetic children, thereby (even if inadvertently) underscoring the significance of genetics. ECART application forms require explanation of why “ED is now being considered the preferred management option” and why other options, such as surrogacy or gamete donation (where ‘half’ of the genetic material of the offspring would stem from the parents) were not chosen (ECART, 2011). Minutes from ECART decisions make specific reference as to whether ‘medical eligibility’ requirements for ED have been met. In 2009, in application E09/17, definitions regarding the medical eligibility of the recipients, given that they already had children through IVF, caused significant debate. The application was initially denied, then deferred, and finally, following a split committee situation, approved in 2010. In another application, in 2010 (E10/02), ECART notes that the potential recipients had “opted for embryo donation relatively quickly”. ECART minutes from 2009 state that “there is no hierarchy of preferred treatment options”, and Daniels (2013, personal communication) has suggested that this criterion, rather than necessarily prioritising genetic parenting, relates to the risks and pressures associated with ED. The criterion nonetheless underscores genetic parenthood, giving it primacy, and positioning ED as a ‘last resort’ in building a family.

5.2.1.5 Requirements for risk screening of embryos and storage limits

Embryos are required to be screened for risk, and may be donated only if they are not affected by or carriers of ‘significant genetic disease’. This concept is however not clearly defined, and caused debate in an ECART application in 2007/8 as to the severity of genetic disease. The requirement gives weight to genetics, undermines decision-making with regard to embryos that may be considered genetically affected, and may carry implications regarding disability.

Of further interest is the HART Act's setting of a 10-year storage limit for embryos, which means that genetic siblings will not be separated by much more than a 10-year period. Note that scientists have commented that with advances in cryopreservation technology, storage length should not affect embryo quality or chances of successful thawing (Riggs et al., 2008). The rationale underlying the 10-year storage limit is not clearly delineated: Does it derive from constructions of genetic connections as bestowing social ties, with the belief that it may be better if genetic siblings are not separated by too large a time span (although what constitutes a large time span remains undefined)? Is the storage limit an attempt to encourage donors to make decisions about their embryos, or is the limit in place as a measure for clinics that carry the practical and administrative burden of storage?

In summary, legislation, policy, guidelines and decisions with regard to ED reflect a genetic discourse. Genetic knowledge is framed as central to wellbeing, and genetics as bestowing connections between donors and offspring. Such a discourse enables information-sharing and disclosure to become viable action possibilities and even to be constructed as in the 'best interests of the child'. A discourse of 'welfare of the child' runs alongside and draws on this genetic discourse, as is discussed below.

5.2.2 'Welfare of child' discourse, and the discourse of disclosure

Legislative and policy documents state that the child's welfare is an important consideration in decisions surrounding use of reproductive technology. Note that welfare needs are framed to include the rights to knowledge about, and access to, genetic heritage in order to be assured of a full identity, i.e. a 'disclosure' discourse may be identified alongside a 'welfare of the child' discourse, as presented below.

5.2.2.1 HART Act provisions

The HART Act (2004) aims to secure the benefits of reproductive technology by "taking appropriate measures for the protection and promotion of the health, safety, dignity and rights of all individuals, but particularly those of women and children" (section 3a). Thus the Act appears to confer special protection over children, which is also reflected in the guiding principles. The health and safety of children born as a result of AR are "an important consideration in all decisions about that procedure" (section 4a). Further, the second principle states that the health, safety and dignity of present and future generations should be preserved and promoted. A 'welfare of the child' discourse can thus readily be identified. This is further reflected in the membership specifications for ACART, which include the need to have a member who can articulate the interests

of children. Similarly, ECART's members are charged with "protecting the interests of human participants, including a potential child when this is appropriate" (ECART, 2013).

A further primary purpose of the Act is the establishment of an information-keeping regime to ensure access to genetic origins, and a related guiding principle is that donor offspring "should be made aware of their genetic origins and be able to access these origins" (section 4e). This links the 'welfare of the child' discourse with a need and right to access and know about genetic heritage. This is underscored by the principle of considering and respecting the values of Māori, for whom whakapapa is a key issue.

The 'welfare of the child' discourse inherent in policy brings to the fore the need to consider the welfare of offspring that result from donation. For donors, this may highlight the future implications of donation. Legislative frameworks may encourage constructions of the embryos as future children, and donors are thus positioned as needing to consider their responsibility in terms of ensuring the child's welfare. On the other hand, donors may draw reassurance from the Act, in the belief that the welfare of any child will be ensured and protected, and that the rights of the child to access information are enforced through legal frameworks (and yet, as is shown below, this is not the case).

Likewise, for recipients, the purposes and principles of the Act underscore the need for them to promote the child's wellbeing through facilitating knowledge about the child's genetic parents. It makes it difficult for recipients within this context to justify a desire to have anonymous donors or maintain silence about the donor conception, as it is framed in legislation as counter to the interests of the child.

Yet it is interesting to note the use of the phrase, 'important consideration' (section 4a), rather than, as is the case in policy designed specifically for child welfare purposes, and as evident in the United Nations Convention of the Child (Michelle, 2006), 'paramount consideration'. This is a significant difference as the implication may be that within the context of ART, children's rights do not 'trump' individual rights. Rather, there appears to be an attempt at a 'balancing' of the rights of adults to make autonomous decisions regarding reproductive choices and parenting, and the rights of as yet unborn children (Angus, 2012). The Act claims to attempt to secure the benefits of ARTs for both individuals and children, and to ensure the wellbeing of present and future generations.

While the legislation specifies the establishment of an information-keeping regime and underscores the principle of knowing, it stops short of putting measures in place to ensure that children will be informed about donor conception. Currently, the right to disclose or not remains with the recipients. The purpose of having a regime to ‘ensure access’ can be met only if recipients disclose this information, and/or if there are additional measures, such as birth certificate annotation, to enable offspring to find out about their origins. As such, perhaps the use of the word ‘ensure’ should be reconsidered, as this cannot be upheld without further measures.

5.2.2.2 Embryo donation guidelines

The ‘welfare of the child’ and related disclosure discourse can also be identified in ED guidelines, which stipulate the need to ‘minimize harm’ for offspring, and include requirements that appear related to wellbeing: criminal record checking for recipients, medical health screening of the recipient woman, and the need for both couples to be New Zealand residents. In the revised ECART (2011) form, the last of these points is explained with reference to the wellbeing of the child: “Residency safeguards the wellbeing of all parties, especially the child” (p. 2). Both individual and joint counselling requirements specify that the child’s rights and needs, including information-sharing and contact arrangements, must be considered. Again, the welfare of the child is linked to knowledge about genetic heritage, in that counselling requires that both parties must be informed of and understand the HART Act provisions. Angus (2012) has commented that New Zealand policies tend to be ‘educative’ rather than a ‘prohibitive’ in nature. This appears to be the case with regard to donation practices, in that counsellors are required to ‘educate’ donors and recipients about HART Act but there is no mandate for disclosure.

The fact that counsellors are required to write a report detailing their assessment of both parties’ understanding of these issues, that applications are approved on a case-by-case basis by an ethics committee, and that legal advice is required, creates a context in which the process may be understood as one that establishes that the recipients are suitable for parenting, that the welfare of the child is ensured, and that disclosure will occur.

Such practices potentially enable donors and recipients to construct donation as akin to adoption as practised in New Zealand. This may be reinforced by the practice of providing donors with profiles from which to select recipients. This bears similarity to adoption practice in which birth parents select adoptive parents, rather than some (international) gamete donation practices in which recipients may select donors based

on their characteristics. On the other hand, Daniels (2007) has also suggested that in ED, donors and recipients effectively select each other through the joint counselling process. In other words, it is more of a two-way process, less dependent on selection by professionals. Nonetheless, a ‘welfare of the child’ discourse may encourage the construction of ED as ‘adoption’, as a process of placing embryos in suitable homes.

5.2.2.3 ECART applications and decisions

ECART application forms similarly reflect ‘welfare of child’ and disclosure discourses. Both donors and recipients are required to provide details of their social histories that may “predispose either to moving to a new situation, or which may pose risk to the donors, recipients or any resulting child” (ECART, 2011, pp. 12, 18). In other words, factors that may affect the wellbeing of the future child are considered. The forms further require comment about the donor-recipient relationship with reference to “concern for the future child’s wellbeing, ongoing contact and access to information” and counselling reports require comment on all these matters.

The revised form’s checklists create a semblance of official sanction, and of a commitment by all parties to respect the principles of the Act. Weight is added to this process through the formal reports required from consultants, counsellors, lawyers and significant people such as Māori advisors, who need to indicate their degree of satisfaction with the application. In this way, donors and recipients may frame the process as officially controlled and sanctioned, thereby assuming positions of security. Practitioners writing the reports may be positioned as accountable, in that they have given sanction to the application, including indicating that the HART purposes and principles have been upheld.

Minutes noting ED decisions also reflect these discourses, for example:

- Deferral decisions related to the need for police vetting information for recipients (E10.50); information regarding ‘key issues’ in the recipient ‘partner’s social history’ (2010/11); and how the child will be raised in terms of cultural practices.
- Issues addressed including cultural factors relevant to offspring, suitability of recipients, donor/recipient similarity or ‘match’, levels of family support, psychosocial history, stability of the environment for the donor offspring, impact on the child, and contact arrangements. All of these factors reflect a ‘welfare of the child’ discourse. Note particularly minutes relating to application E09/34, which request information about the recipient’s foster care experience. Questions included are: ‘Was it respite care? Was it day-in, day-out care? What age were the children?’ These questions appear geared towards assessing the recipient’s suitability to parent.

There are regular references to donor-recipient fit, e.g. ‘both couples share similar values’ (E12/02); both ‘appear well matched and have similar values’ (E10/26).

Again, donors and recipients may assume that appropriate measures have been taken to protect the wellbeing of potential children. Further, the parallels with adoption may be underscored through this apparent assessment of the suitability of recipients and attempts to achieve a ‘match’ between the two families. By drawing on adoption discourse, both parties may assume similar processes and safety measures.

5.2.2.4 ANZICA, *counselling practices and guidelines*

ANZICA’s mission statement makes specific mention of the need to promote the welfare and interests of any potential child (ANZICA, 2013). Likewise, the ‘welfare of the child’ discourse and disclosure discourse are evident in the professional standards for counselling practice, which reference RTAC guidelines and include identifying ‘risk factors’, taking ‘due regard’ of the psychosocial wellbeing of all participants, supporting the ‘right to know’, and facilitating linking of donors, recipients and offspring.

Professional standards of practice for counselling specify a need for counselling to address short- and long-term consequences for all parties, the importance of information-sharing, attitudes towards openness and contact, and the provision of disclosure guidelines. Section 2.2.5 explicitly states that the ‘best interest of the child’ should be reflected in all policies and procedures, and that donors and recipients need to be educated regarding this concept, particularly in relation to information-sharing.

The same discourses are prominent in ANZICA’s (2006) position paper on ED, which outlines considerations not only for donors and recipients, but for offspring, including grief and loss, their reliance on the openness of their parents to provide information, and developmental and emotional needs (pp. 4–5). ANZICA constructs counsellors as having a role to play in terms of selecting appropriate recipients for ED (again, there may be parallels to adoption practice). The paper emphasises the need to keep in mind the “best interests of current children of the donors and the prospective child of the recipient” (p. 5). Specific mention is made of longer-term welfare concerns. For example, the paper asks, “In twenty years’ time or more, will clinics be blamed for providing a service that leads to psychological damage?” (p. 5) and “Who is the client? The donors, the recipients or the as yet unborn child?” Significant concern is expressed in that “Outcomes for all parties will only be known when children have reached adulthood” (p. 6). Amongst its conclusions is the statement that “At all times the best interests of persons conceived as a result of donation need to be the first consideration” (p. 7).

In this way, ANZICA (2006) constructs the welfare of the child as paramount, and positions counsellors as potentially accountable, expressing concomitant anxiety about their ability to ensure welfare. It is perhaps not surprising then that ANZICA's concluding statement is: "The potential risks associated with donation do not justify the potential benefits" (p. 6). While ED has continued since this paper, which was up for review by 2007, no revisions had been posted on ANZICA's website at the time of writing.

In sum, the 'welfare of the child' discourse may create a context in which one purpose of donation is seen to be to 'find an appropriate home for embryos'. The discourse places donors and recipients in a position of responsibility to ensure that the child's needs are met, and may invite constructions of ED as adoption. Donors may occupy a position similar to that of birth parents (in selecting suitable recipients and having some type of ongoing role). Recipients are potentially positioned as adoptive parents, with responsibilities to ensure information and contact with donors.

5.2.3 Enduring implications/connections discourse

In line with a 'welfare of the child' discourse, a discourse of ED as having enduring implications and connections can be identified. For example, the purpose of the HART Act to protect present and future generations extends the implications of ART from the immediate context (treatment of infertility of individuals) to the long-term future (wellbeing of all affected). The principle of access to genetic knowledge constructs a future relationship of some form between donors and donor-conceived children (and by implication, recipients as they will need to make the information available). Further, requirements that specify that donors have the right to vary consent until the embryo is transferred to the recipient woman's uterus, and retain a say in the storage, use and disposal of embryos that remain following donation, can be seen to construct the donors' involvement as extending beyond the act of donation. ECART minutes similarly reflect a concern with agreement around embryo disposal and 'ownership rights'. This creates a context in which donation is not simply a one-off event that is approved, finalised, and proceeds without further input from the donors. Instead, donors are positioned as having ongoing responsibility for the donated embryos, and recipients as having no rights over the embryos. This may cause ambiguity about donors' ongoing involvement, or make it more difficult for donors and recipients to establish where the role of the donors in relation to the embryo and/or child ends.

Counselling requirements that consider current and future feelings of donors and recipients and their children, and that make provision for the inclusion of all parties in counselling, similarly reinforce a discourse of ongoing implications and possible enduring connections. Joint counselling – bringing the two families together to consider wishes, needs and expectations in terms of information-sharing and future contact – and ECART application forms which detail these agreements and processes for dispute resolution underscore the possibility that donor and recipient families may have relationships and be connected in potentially enduring ways.

The enduring implications/connections discourse may thus draw donor and recipient families into a relationship with each other, and position donors as having some type of ongoing rights or involvement (be this information or contact). Of interest here is application E11/34, where the donors were to assume testamentary guardianship over donor offspring, and the recipients were guardians of the donors' existing child. While legal advice required in ED may clarify the absence of rights, the discourse of enduring connections may encourage donors and recipients to expect information and contact.

5.2.4 The embryo as being due 'respect'

While the embryo's status is not specifically defined in legislative and policy documents, the embryo appears to be constructed as 'worthy of respect'. Further, while conflicting discourses around the embryo as 'property' versus 'gift' can be identified, there is an overriding resistance to a discourse of commodification.

5.2.4.1 The embryo as having 'special' status

Part 2 of the HART Act prohibits the development of embryos past the fourteenth day after formation. Further, under Schedule 1 of prohibited actions, it is forbidden to artificially form or implant cloned or hybrid embryos. Part 2 stipulates that clinics have a 'duty' to stop the development of embryos or hybrid embryos. In this way, the integrity of the embryo as created from human gametes and designated for human reproductive use is underscored. The embryo is afforded a special status, although the nature of this is not defined. The HART Act's commitment to respect Māori values (Part 1, section 4f) may reinforce this status as for Māori the embryo is sacred and the embodiment of whakapapa. The storage, management and disposal of embryos need to follow appropriate tikanga or culturally safe practices in order to avoid breaches of tapu (that which is holy or sacred) (Thompson, 2010).

Interesting to consider also is the silence in legislation on the possibility of donating embryos for research purposes. While ACART had recommended research donation to the Minister of Health in New Zealand in 2010, the Ministry of Health and the New Zealand government have not responded to these recommendations. It is possible that this reflects a concern for public reaction to perceived experimentation on embryos that may be constructed as having special status.

The original ACART (2005) guidelines for ED specify that two years must have elapsed since the donors completed their family, and revised guidelines (2008) state that donors must consider their family complete before undertaking donation. The stipulation of a time period or a condition that a family be complete, meaning the embryos are ‘surplus’, may reflect the investment donors have in their embryos. ECART minutes reflect that donors have an attachment to their embryos, recording donors specifically requesting to dispose of embryos remaining after donation or to have embryos returned to them (E08/11, E08/12, E09/10, E11/32); donors wishing to donate only a certain number of their embryos (E08/06); donors opting to donate when they have only a single embryo available for donation (E09/17, E09/32, R11/38,); and donors withdrawing their consent for further use of their embryos (E08/06).

In summary, constructions of the embryo as ‘special’ or as having significance to their progenitors opens up action possibilities with reference to embryos being given careful consideration and respect. Embryos may be ‘more than’ collections of cells.

5.2.4.2 Resistance of commodification: The donated embryo as gift, property, or ‘ward’?

Part 2, section 13 of the HART Act (2004) prohibits the commercial supply of gametes and embryos, with the stipulation that ‘no person may give or receive or agree to give or receive, valuable consideration for the supply of a human embryo or human gamete’.

Failure to comply with these laws is punishable by imprisonment, fine or both.

Commodification of gametes and embryos is thus resisted, which may enable constructions of the embryo not just as valuable, but as a ‘gift’. Donors may consequently position themselves as altruists, donating embryos to recipients from a position of kindness (rather than financial gain).

In terms of the ACART requirements for ED, only those embryos that have been formed from the couple’s own gametes and that are ‘surplus’ to the couple’s requirements, i.e. remain after they have completed their treatment, may be considered for donation. Embryos cannot be created specifically for the purposes of donation. Again, this shows a resistance to the commodification of embryos, reflecting a respect

for already-created embryos. This respect for already-created embryos may stem in part from the construction of the embryos as having full siblings and genetic parents. Thus, the embryos may be seen to have significance because of their location within a kinship network. For Helm (2008), such constructions open up the possibility that ED in New Zealand is a means to find a home for an already existing embryo, rather than as a treatment for infertility (in which case she suggests, using embryos from separately donated gametes or creating embryos for the purposes of ED would not be an issue).

ACART guidelines, as reflected in ECART application forms, further require explicit discussion of the storage, disposal and use of embryos that may remain subsequent to donation, and the donors have the right to vary consent until the embryos are transferred. Minutes from ECART meetings between 2007 and 2012 make regular reference to agreements regarding disposal and use of embryos. Note that the use of the word 'ownership' or phrase 'ownership rights' with respect to the embryos appears repeatedly in ECART minutes (e.g. 2007, 'ownership rights'; 2009: 'ownership rights and consent'; 2010, E10/14: 'donors must be told of continuing ownership'). While this practice may reflect the value given to the embryo by donors, rights to vary consent and have ongoing say over disposal may position donors as 'owners' of the embryo and therefore the embryo as 'property'. However, full property rights are not available to donors: they cannot sell their embryos; they cannot choose to give their embryos to whomever they wish; and must be approved via ECART application. Donors may therefore experience themselves as 'disempowered owners'.

Thus while the status of the embryo is not delineated under current legislation, embryos are clearly given significance in some way: they cannot be created expressly for donation, they cannot be sold, and their progenitors have rights over their disposal until the point of transfer, and rights over disposal of subsequent unused embryos. Informed consent is emphasised in the legislation and guidelines. The value accorded the embryo, and the positioning of donors as having rights regarding disposal within the context of prohibition of commercial gain and embryo creation for donation, may enable positions for donors as being more akin to guardians, rather than owners, of their embryos. By extension, the embryos may assume the status of 'ward' of the donors. This position may invite comparison to the role of birth parents in relation to their genetic children – birth parents do not own the child, and yet (unlike organ donation where no stipulations can be set, and gamete donation where requirements can be set but recipients are usually not actively selected) they have a say in terms of the adoptive

parents selected, and have rights to vary their decision (until 12 days after birth) (CYF, 2013). Again, parallels to adoption may be invited.

5.2.5 Medical discourse

Alongside these discourses, a medical discourse can be identified. Only those who have medical conditions precluding ‘normal reproduction’ or unexplained infertility that has not responded to other treatments are eligible for ED (ACART, 2008). ECART minutes from 2007 to 2011 reflect an ongoing concern with ensuring that recipients have met this criterion. Minutes further reflect an interest in the number and quality of embryos available in relation to treatment and the possibility of successful outcomes.

Such a medical discourse constructs ED as a treatment for infertility, and *not* primarily as a solution for those with surplus embryos. Indeed, ECART minutes (application E09/17) specifically state that, “the guidelines for embryo donation developed as treatment for infertility and not as a solution to the fate of an embryo”. The implications of the medical discourse and the positions open to donors and recipients are quite different from the ‘welfare of the child’ and ‘enduring implications/connections’ discourses, however. The medical discourse positions donors as helping facilitate a treatment, which has a relatively clear endpoint. Child welfare and enduring implications discourses confer ongoing roles or rights to the donors. The medical discourse may therefore enable parallels to be drawn with donation of other bodily material. Donors with an investment in using their embryos may be in a difficult position when embryos remain following donation: they may construct requirements as favouring the needs of recipients (to have a child), rather than their own needs (to see the embryos used). Helm (2008) has argued that, at present, the framework for ED is ambiguous, and presents a mixture of child welfare and medical discourses.

Further, the medical discourse inherent in eligibility requirements may reinforce the hetero-normative family as the ‘ideal’. Requirements imply that lesbian couples may access ED only where both women in the relationship are considered infertile, and single women only if they are infertile. ED cannot be undertaken for ‘social reasons’. Gay men are automatically precluded from ED as it would require a further party (surrogate) to be brought into the relationship, and current surrogacy regulations state that “at least one of the intending parents will be a genetic parent of any resulting child” (ACART, 2007, p. 3). Note the comment in ECART minutes (June 2009) that “the guidelines were based on the premise that all couples would be heterosexual”. This may

position single and homosexual individuals or couples in a discriminatory way, regardless of whether or not this was the intent of the guidelines.

5.2.6 ED as complex and unknown: A ‘risk’ discourse

A discourse of ED as complex can be identified in legislation, guidelines, application forms and counselling documents. Firstly, under the HART Act, ED is designated as a regulated procedure requiring case-by-case ethics approval, and in this way it is constructed as a complex activity associated with significant implications. ED guidelines make specific reference to issues related to ED, and stipulate that donors and recipients will need to be informed of the “psychological, social and ethical aspects involved” (NECHAR, 2005, p. 3). Similarly, ECART application forms require a summary of the ethical, medical, legal cultural and psychological issues as well as risks relevant to the application. Further, the specification of in-depth implications counselling, the need for separate counsellors for recipient and donor parties, and the legal requirements added to the revised 2008 guidelines underscore constructions of complexity. The stipulation in the original guidelines that two years need to have elapsed from the time donors consider their family to be complete before they may consider donation; counselling reports (section 3) that ask for indication that adequate time has been allowed ‘to consider all the issues’; and counselling guidelines that suggest a ‘cooling off period’ all reflect a concern with the complexity of ED.

The discourse of ED as complex and unknown, even risky, may also be identified in the ANZICA (2006) position paper. Note for example, statements such as:

- “In twenty years’ time or more, will clinics be blamed for providing a service that leads to psychological damage?” (p. 5), and “Will counsellors be blamed for taking part in a process that leads to psychological damage?” (p. 6).
- “Outcomes for all parties will only be known when children have reached adulthood so no actual experience to guide us” (ibid.).
- “Experience and research from related fields tells us to be cautious” (ibid.).
- “There are few structures or research to support the participants, counsellors and other staff” (ibid.).
- “There is no evidence that ED will justify the potential benefits. The membership is of the opinion that the potential risks associated with the donation do not justify the potential benefits” (ibid.).
- “ANZICA recognises that ED is a relatively simple medical process and has advantages over more complex treatments such as surrogacy. This needs to be

balanced by the recognition of the complex and emotive ethical and social considerations” (p. 7)

Further, ECART minutes from 13 October 2009 note that ECART member Hutton emphasised the importance of measuring the social implications of ARTs to ensure that risks and harm are identified and controlled. Minutes from 20 November 2007 referred to the need to receive feedback on ED practice, including people’s thoughts and feelings on their involvement in ED. And in June 2010, ECART noted that it had an ongoing role to monitor ED arrangements.

Constructions of ED as complex, unknown, and potentially risky may create anxiety about implications and longer-term outcomes. Donors and recipients may be positioned as vulnerable through engaging with a procedure that has consequences constructed as unknown and as carrying significant risk. Counsellors and consultants may be positioned as vulnerable where they are expected to advise on and facilitate a procedure that they construct as complex, and having unknown, possible risky, implications.

5.3 Extra-discursive factors

A number of influences shaping New Zealand policy and guidelines have been identified, particularly by Daniels and Douglass (2008). While the factors discussed below may themselves be discursively constructed, for the purposes of this discussion they are regarded as factors that may create the *context* for some of the discourses identified, as well as facilitate investment in them.

5.3.1 New Zealand’s small population size

Daniels (2004) has pointed to New Zealand’s small population size (little more than 4 million) as influential in policies encouraging openness and disclosure. With a small population, the possibility of unknown consanguinity is higher, a concern that has been expressed in relation to third party ARTs (Blyth et al., 2011). Thus, having knowledge of the identity of donor children and siblings may be regarded as a sensible, practical measure. Daniels and Douglass (2008) also point out that having a small population not only means that donors and offspring are more likely to meet, but that professionals and consumers are more likely to know each other. This has meant that consumers and professionals have been able share perspectives more regularly through meetings and conferences, and may be a factor related to the culture of openness.

5.3.2 Māori as tāngata whenua (indigenous people, or ‘people of the land’)

Under the Treaty of Waitangi, New Zealand has an obligation to respect and value the needs and beliefs of indigenous Māori. Daniels and Douglass (2008) note that this has been reflected particularly over the last 20 years in New Zealand’s social and political developments. For example, for Māori, identity is inextricably linked to relationships with others, and may encompass knowledge of whakapapa (genealogy), te reo Māori (language), tikanga Māori (Māori custom), as well as lived experiences with iwi (tribes), hapū (subtribes) and whānau (Houkamau & Sibley, 2010). The formation of a strong identity is thus based partly on whakapapa rights, with a key element being the ability to access information regarding biological connections (Daniels, 2004; Daniels & Douglass, 2008). Protection of whakapapa requires that donor offspring have ‘unconstrained access’ to information identifying genetic parents (Daniels & Douglass, 2008). Daniels and Douglass (2008) point out that reviews of submissions to the ministerial committee demonstrate that such views have had an influence on shaping non-Māori views also. Protection of whakapapa is not an issue for Māori alone, but has contributed to an attitude of openness and access to knowledge in New Zealand society that may be less prevalent in other jurisdictions.

Further, the practice of whāngai, in which children may be raised by other members of the whānau, relies on such openness/access and may constitute a ‘within whānau’ solution to infertility (McRae & Nikora, 2006). While there are differences between ED and whāngai, parallels may be drawn that could shape ED discourses.

5.3.3 New Zealand’s adoption history

With the passing of the 1955 Adoption Act, closed-stranger adoption, where there was no exchange of information between birth mother and adoptive parents, became law in New Zealand. This differed from previous, more open practice, in that children were raised without knowledge of the identities of their birth parents, and indeed sometimes without knowledge that they were adopted. Trans-racial adoption practices (especially the placement of Māori children with Pākehā [European] parents) were common (West, 2012). It was assumed that closed practices protected the rights of the birth mother, and were beneficial to the child in terms of bonding with adoptive parents (Browning & Duncan, 2005). The practice was based on the ‘complete break theory’ (West, 2012). However, Browning and Duncan (2005) write that many of the children adopted under this system wanted to know who their ‘blood kin’ were. Further, closed practices

breached Treaty of Waitangi commitments by denying Māori control of their taonga (cultural treasure), as it broke the connection of children with their whānau, hapū and iwi (West, 2012).

Policy and practice in New Zealand have thus moved in favour of adopted persons' rights to know their birth origins (CYF, 2013). While the 1955 Act remains in place, the Adult Information Act of 1985 permits information to be disclosed to adopted people about their birth parents and vice versa (West, 2012). It recognises adopted persons' need and right to their kinship knowledge (Rockel & Ryburn, 1988) and indeed, a substantial number of adoptees have applied for the release of such information (Browning & Duncan, 2005). Current practice in New Zealand has developed to the point that open adoption practices are the norm, with degrees of information-sharing and some contact possible between adopted child and birth parents. Grotevant and McRoy (1988, as cited in Daniels, 2004, p. 150) have asserted that New Zealand has led Western adoption practice with respect to openness. Such experiences and practices may contribute to the way in which an open philosophy is embraced within the New Zealand context (Daniels & Douglass, 2008). Angus (2012) likewise suggests that the combination of valuing the significance of whakapapa and adoption precedents in New Zealand has set the scene for an attitude of disclosure.

5.3.4 Sperm donation practice and research

As with adoption, disclosure and anonymity have been hotly debated issues in sperm donation over the past twenty-five years (Daniels et al., 2011; Owen & Golombok, 2009). Daniels and his colleagues have been particularly influential in New Zealand in terms of bringing to the fore the needs of donor offspring, and the negative effects of secrecy and non-disclosure on psychological health, family functioning and relationships (see, e.g. Daniels et al., 2011). Gillett (2012) suggests that arguably New Zealand's greatest contribution in ART has been its stance towards openness, for which he gives credit to Daniels as a 'giant in the field', with his work in over 130 articles having impact not only in New Zealand, but also in many other countries.

5.3.5 Practitioners in the field

Daniels (2005b, 2007) and Daniels and Douglass (2008) suggest that policy development has been influenced by practitioners, and that counsellors (including social workers) have worked actively alongside and contributed to the approach adopted by

medical professionals in New Zealand. These mental health professionals have drawn on social welfare discourses that emphasise the rights and wellbeing of the individuals with whom they work, including children/donor offspring (Daniels & Douglass, 2008). They may also draw on systemic frameworks that frame reproductive treatment as part of a wider system, having an influence on other areas of wellbeing and other individuals within the system. Further, mental health professionals educated in New Zealand will be aware of the history of adoption practice and the negative consequences that arose out of closed and enforced adoption practices. Of the mental health practitioners described above, two of the three are parents of adopted children and had been open with their children regarding their adoptive history (Daniels & Douglass, 2008). As is stated in the ANZICA's (2006) position paper, there are few models for ED practice, but counsellors may draw on learning and experiences from what are constructed to be related fields, such as adoption.

5.3.6 Consumer input, and New Zealand culture

In 1988, the New Zealand Infertility Society was established. Later renamed Fertility New Zealand (FNZ), the society has long been active in promoting openness, facilitating a workshop on information-sharing as early as 1990, making ongoing submissions to the government regarding openness and the setting up of formal registers, and educating the public through media (Daniels & Douglass, 2008).

Daniels (2005b) has commented that whereas in other jurisdictions legislation may have been needed to enforce change with respect to openness and disclosure, legislation in New Zealand has endorsed and extended existing culture, systems and practice. It has followed changes in professional practice, consumer decision-making and community attitudes (Daniels & Douglass, 2008). New Zealand thus already had a culture of openness and support for the accessing of genetic information by offspring, and a canvassing of public opinion at the time of the Ministry of Justice-appointed committee found a "great weight of submissions and expressions of opinion favoured a policy of openness rather than secrecy" (Daniels & Douglass, 2008, p. 139).

Michelle (2006) notes that when the HART Act was introduced in 2004, politicians on all sides of the political spectrum echoed these sentiments. For example, Jill White spoke of the need to have access to genealogical history; Lianne Dalziel that the child has a "right to know"; and Judith Collins that "all children deserve to know their whakapapa" (p. 116). Legislation in New Zealand may thus have been more of a

‘coding practice’ rather than an attempt to set in motion a change in practice (Daniels, 2005b). Michelle (2006) comments, “These powerful discourses have informed much of the public, political and media discussion of legislation governing the provision and use of ART” (p. 116).

5.3.7 Altruism in New Zealand

Angus (2012) suggests that altruism is a strongly held principle in the New Zealand health sector, and is reflected in the prohibition of commercialisation or commodification of bodily parts or tissue. Likewise, Shaw (2008, 2010b) suggests that a ‘gift of life’ discourse is ‘robust’ in New Zealand, and goes on to describe policies and practices surrounding organ donation (New Zealanders can ‘opt in’ to indicate organ donation on their driver’s licence), and blood donation. These donations may be held to promote a general atmosphere of civic generosity (Shaw, 2010b, p. 614), and indeed the Office for the Community and Voluntary Sections of New Zealand suggests that New Zealand has a culture that values altruism and volunteerism. They cite that more than 1 million New Zealanders are involved in volunteering work, engaging in activities that bring no financial gain, offer benefit to third parties, and are undertaken in the spirit of free will. New Zealand is described by the department as a “leading nation in contributions made by volunteers” (Office for the Community and Voluntary Sector, Internal Affairs, 2013). All of the factors discussed above contribute to the context that shapes discourses of gifting and altruism in reproductive donation.

5.4 Summary

In the foregoing review of the relevant legislation, policy, guidelines and records of decision-making, a number of different and at times competing discourses can be identified that shape experiences and understandings of ED in New Zealand, and position donors and recipients in ambivalent positions. A discourse of genetics constructs genes as central in determining who an individual is, and in locating an individual within a wider social network. Genetic knowledge is thus constructed as central to identity development or ontological security (Ravelingen & Pennings, 2013). This is reflected in another discourse that may be identified, that of the welfare of the child. This discourse constructs the health and wellbeing of donor-conceived children as important, and opens up possibilities for considering how this may be ensured, e.g. by ensuring offspring’s access to their genealogical knowledge, and ensuring suitable parents. Related to this is a discourse of ED as involving enduring implications and

connections, which situates donors and recipients as connected to each other by virtue of the donation and receiving of embryos: the full genetic material of donors. Embryos are constructed as having special status, and while donors have rights in relation to their embryos, these are not full property rights. Instead, donors appear to be positioned in a guardian-type role in relation to their embryos, which extends to efforts to ensure the longer-term welfare of the child.

These discourses together invite the drawing of parallels with adoption, and may construct ED as a solution for those with surplus embryos. Donors are positioned as attached to their embryos and as having an ongoing interest in the welfare of the child, and recipients are positioned as akin to adoptive parents, with a responsibility to ensure that the offspring have access to information about the donor family.

In addition, a medical discourse can be identified alongside the above discourses. This discourse constructs ED primarily as a treatment for infertility, for which recipients need to be eligible, which donors help to facilitate, and which is undertaken by mutual consent. This discourse offers donors and recipients positions in which fewer ongoing responsibilities may be assumed. It enables comparisons to other forms of donation, such as tissue and organ donation. A discourse of ED as complex, unknown, and even risky in terms of longer-term outcomes may also be identified, which can be seen as generating uncertainty and anxiety about ED as a practice.

The discourses and discursive practices that may be seen to inhabit legislative and policy frameworks thus have the potential to shape the experience and understanding of those undertaking ED in the New Zealand context. In turn, these discourses may also be influenced by extra-discursive factors which include New Zealand's small population size, Māori as *tāngata whenua*, New Zealand's adoption history, consumer input, and cultural attitudes regarding altruism. Understandings and experiences of ED in New Zealand need to be understood by adopting a systemic approach that recognises the complex interplay of discourses available within society, discursive practices, and the influence of contextual and individual personal-social factors. In the next chapter, discourses identifiable in the talk of donors and recipients are presented, along with analysis of the implications of these discourses.

Chapter 6: Results – Donors and recipients

In the previous chapter, I presented a discursive analysis of the relevant legislation, policy and guideline documents, ECART minutes, and ECART decision-making in relation to ED applications. In this chapter, the transcribed interview data from donors and recipients are analysed. While I initially analysed the data for each group separately, I soon realised I was identifying similar discourses across the two sets of data. The combined analysis is thus presented in this chapter.

In the first section of the chapter, discourses related to the embryo and the donor-conceived child are identified. Next, a related discourse, that of the welfare of the child, is presented. Discourses are discussed with reference to actions and positions made possible through drawing on these discourses. In the second section, discourses related to ED practice are presented. How these discourses position donors and recipients in relation to each other, and how these potentially affect experience, is analysed. In the third section a brief analysis of donors' and recipients' constructions of the role of ECART and of counsellors is provided, as I propose that these too may have implications for understandings of ED and for donor: recipient relationships. Finally, 'extra-discursive' factors that may contribute to donors' and recipients' investment in discourses are identified.

6.1 The embryo, the donor-conceived child, and the 'welfare of the child'

6.1.1 Discursive constructions of the embryo

The data analysis process identified a range of discourses that enabled donors' decisions to donate, and precluded other options. While previous research has focused on donors' constructions, I identified that recipients also drew on discourses of the embryo in their decision-making. However, their decisions were affected by both their own constructions, as well as those they ascribed to donors. I discuss these below.

6.1.1.1 Embryo as a child/life already

Many donors constructed the embryo as a child/life. Theresa referred to her embryo as, "*this great beautiful human sitting there*" and "*a good-looking man walking around.*"

Brian drew on this discourse and simultaneously resisted a property discourse, commenting that, *“This is not a caravan; this is not a boat that someone might have sold that had finance owing on it. This is a **child!**”*

These constructions inhibited options such as discarding. Jonathon spoke of not being able to *“flush the child down the loo”* and Jack that *“One thing we did know, is that we didn’t want to destroy them.”* For Nathan, destruction of the embryo was akin to abortion, and he explained that *“I believe that life starts at that point way back there. Thawing those embryos was a little bit like an abortion.”*

The embryo-as-child discourse instead conferred a responsibility towards the embryo (Kimberley: *“I felt a responsibility to it”*). This responsibility included providing the opportunity for the embryo to become a child:

Jack: In our minds we had an obligation, if we could, to help them come to become living things.

Catherine: It's really good to bring it to real life, that's my feeling.

Brenda: We knew by giving them, we had done our utmost to give them the best chance of life; they had a chance of life.

It also involved passing responsibility for the life to someone who would take appropriate care of it. Pamela expressed this when she said:

It's a life, whether it's come to you already born, or whether it's going to be born. You are entrusting that life, or that embryo, to somebody.

In this way, donors aligned themselves with a ‘responsible adult’ or ‘good citizen’ position, taking responsibility for children, creating the opportunity for the ‘life force’ to be realised, and ensuring wellbeing.

Several recipients also drew on discourses of the embryo as a child. This was apparent in Neil’s assertion that *“We’ve adopted a little life”*; Sandra’s comment that *“I guess that was important to us – to not give up on what we saw as a baby”*; and Jenna’s comment that *“It’s a life; an actual life.”* This discourse enabled constructions of ED as akin to adoption, evident in Neil’s use of the word ‘adopt’, and in Wendy’s comment that, *“You have the consideration that there are embryos that would like a family.”* Some recipients also made reference to their donors’ constructions, with Zelda commenting that her donors *“didn’t want these embryos to die.”* Sandra appeared to take on her donors’ constructions of their embryos as children, when she referred to

their online posting: “*They (the donors) were saying they had an embryo looking for a home.*”

This discourse positioned recipients as ‘good citizens’, even ‘rescuers’, offering ‘children a home’, which is evident in Sandra’s quote when she commented that “*We could help out this embryo that was stuck in storage.*” From these positions, recipients potentially felt empowered, experienced a sense of doing something that was moral, and felt like they were helping both the embryos and the donors.

However, such positions also carried responsibility. Guilt was experienced if they ‘failed’ to achieve their ‘duty’ to bring the life to realisation:

Deborah: I felt bad for (the donors). They wanted to give them the best possible chance. I felt I was letting them down by not making the best of what I had.

Olivia: I’m hoping now that they don’t regret giving them to us, when they may have thought, ‘Well our donor’s (relative) could have had them.’

The difficulty of defining the nature of the embryo as child or life was however expressed. Theresa, for example, commented that “*I’ve got this potential human in the bank. It’s life. It’s potential. It’s, ‘Who knows?’*” This can also be identified in Mandy’s comment below:

I tend to use the word life force, a little spark of life that will either... I knew that from losing (X number of) wee babies, that it doesn’t mean that spark is going to develop into life, but for some reason, I really thought it would work.

6.1.1.2 Embryo as the donors’ child, connected to the donors: a genetic discourse

The above discourse extended beyond that of ‘a child’ (as a general construct) to the ‘donors’ child’ (a more personal construct). Frances (donor) for instance, referred to her embryos as “*my babies*”, and Rachel (donor) as “*my children (that) I couldn’t have. But they were still my children.*” The embryos were constructed as the donors’ creation, as symbolic of the couple unit, and as part of their family, as expressed by Isla and Brian:

Isla: They are actually little people; they’re ‘us’. To me, they were still part of us.

Brian: They were a part of us. We created their life. It means a lot to us and our family. This little (child) is part of them. If Z is part of us, Z is part of them.

This discourse gave the embryos personal significance, making discarding problematic (even akin to destroying one's own child). It positioned donors in a parenting or protector role, as is encapsulated in this comment by Brenda: "*You are defending your own embryos. I mean, you are your embryo's voice aren't you?*", and Roy's statement that "*It's the male protective role of looking after my family.*"

While the parenting position problematised discarding, the inability to assume a parenting role in the child's life also complicated the alternative: donation. Brenda spoke of her "*own child*" "*being brought up by someone else*" and explained her difficulty as, "*It's a maternal thing I think; a real 'mum' thing.*" For Otto, who elected not to proceed with ED following joint counselling, this was an insurmountable dilemma, saying, "*It's too special, too specific to us to just let it go out there and grow up without any input from us. I want to be a good Dad, and I can't be a Dad at all to the child that's out there.*"

This discourse also affected decisions around embryos remaining after donation. Rachel wanted the embryos to be buried with her; Mandy had her embryos returned so that "*They are home with us now in a safe place, waiting...(tearful)*"

This construction further made the possibility of the child being a different sex from existing children problematic. Stephen framed this as "*the hardest part to work through*", explaining that since he had two children of the same sex, it would be difficult if the recipients gave birth to "*his*" child of the opposite sex. For Rachel, there was relief that the child born to the recipients was of a certain sex, and she commented, "*I didn't say it to them of course, but they were **mine**. I just didn't want them to have more, because if they had a (sex), I think I would have been jealous.*"

Donors' attachment to the embryos was thus reinforced; they were not merely life or 'a child', but their children, to whom they felt connected and for whom they felt responsible, as parents. Note that in two instances, donors also engaged in resistance to this discourse, drawing on constructs of the embryo as a collection of cells. For example, Frances, who referred to the embryos as "*her babies*", simultaneously distanced herself by framing the embryos as cells: "*I said, 'that's exactly the point. It's not my baby that I'm giving away. I'm just giving away some cells. It may have the same DNA as (our child), but nothing to do with us as such.'*" This may have made donation easier.

While recipients did not directly refer to embryos as donors' children, they constructed the embryos as "*their*" (donors') embryos, even after donation. For example, Kieran commented that "*(You) look at it and say, 'OK well you've got to be sympathetic to the person whose embryo it is'*"; Maggie said, "*They were her embryos, you know...*" and Wendy, "*The embryos will always belong to them.*" Nonetheless, a property discourse was rejected, as recipients grappled to define the relationship between donors and embryos. Nadia commented that "*It's like: you are giving away a possession. Oh – It's probably not quite right*". Sandra expressed her astonishment at the legal process: "*(The lawyer) was like, 'The only comparison we have is a property transfer'. So, property; transferring a child? Because as far as I'm concerned, an embryo is a child.*"

Instead, constructs that denoted a type of custodianship or family ties were drawn on, with recipients positioning the donors as having ongoing interests in the embryos' fate. Several recipients spoke of their belief that the embryos were the donors' 'creation', and donors were positioned as having decision-making rights. As Maggie said, she wanted to return the embryos so that "*They could make that decision to dispose of them, rather than us dispose of what they had made.*" Olivia likewise felt that she could not make this decision, saying that "*I don't want it to be my decision. I think our donors should decide. I wanted to hear from the horse's mouth.*" She described her donors' reaction as reflecting that "*they care*", drawing on not only her own discourses but those she ascribed to her donors. While her comments reflected a need to diffuse responsibility, they also indicated a construction of the embryos as connected to the donors. As a consequence, most recipients spoke of the need to respect donors' views. As Kieran commented, "*There's a whole myriad of other issues that come from (that the embryos are those of the donors). You tread carefully.*" By taking up this discourse, recipients positioned themselves as subject to the donors' decision-making.

6.1.1.3 Embryo as resource/insurance

Donors initially constructed their embryos as resources to have another child if they so desired, and later, after they had had children, as 'insurance policies' in the event that something adverse happened to their children. This is encapsulated below:

Lance: We always wanted to keep that one just in case something went wrong with the first go/pregnancy. Then we decided to keep it for a while for ourselves. If something had happened to (our child), or something.

Dawn: Initially after you've got pregnant, you are never quite sure how things are going to go. So you just keep hanging on to them, and the babies were eventually born and you get through that little baby stage, and then you think, 'Well, what are we going to do with them in the future?' They are still sitting there, more now as my insurance policy I call them.

This discourse underlay decisions to extend storage, and initially positioned donors as sensible to do so. However, once donors constructed their children as being 'safe' or decided that they would not have more children, then storage became futile, even wasteful, and donors occupied a more uncomfortable position of engaging in something illogical. Mandy commented that *"Just leaving them there forever – we didn't want to do that. It was a wasted resource."* Jessica reiterated: *"It is such a waste you know. It's a potential for children to be created."* Drawing on this discourse enabled donation, and positioned donors as 'rational' and as 'good citizens'.

For many recipients, the embryo was constructed as a physical resource in their quest to have children. This was similar to how donors constructed their embryos at the outset of treatment, where the focus was on achieving a pregnancy, and embryos were given meaning in terms of their potential to fulfil this goal; in other words a medical discourse was drawn on. Wendy, for example, spoke about *"the consideration that there are these embryos that could be used"*; and Tanya emphasised their need for the embryos as resource: *"If we get a pregnancy from the 1st one, we won't be needing the second (embryo)."* Frequently the embryo was constructed as the 'missing' resource, needed when recipients had other factors in their favour:

Sandra: We had proven I could carry a pregnancy; it was getting the embryo in the first place. They gave us the embryo, which was the part we weren't achieving.

Maggie: It's our embryos that don't work. If we've got somebody else's embryos that do work, well, this is going to work.

Not making use of this resource was constructed as wasteful by both donors and recipients. Maggie commented that their donors *"had to recycle (the embryos), reuse them. They couldn't discard them. Everything has got a purpose in life; everything has got to be used to be sustainable."*

The construction of embryos as a resource positioned recipients as making sensible and rational decisions in making sound use of available embryos that were 'surplus'. This could justify their decision to undertake ED.

6.1.1.4 Embryos as intentional investment

Regardless of which discourse was drawn on, donors constructed the embryos as ‘hard won’ with significant ‘work’ (time, effort, emotional energy, financial commitment) having gone into their creation. Embryos were constructed as valuable and precious. Again, this made discarding problematic:

Roy: I’m certainly not going to destroy something I tried so hard to have, and even now I’m still... (tearful) so you can see from my reaction, to me it’s still very raw.

Brian: It took X years to create them, and a lot of heartache, and there were years and years of treatment that my wife went through. Then finally, finally, we got some embryos – so they meant a lot to us, and they still do...

Related to this investment discourse was a discourse of intent. It was significant that donors had actively chosen to create embryos. This gave the embryos particular meaning, and positioned donors as responsible. This was evident in the distinction that some donors, who had had previous experiences of termination or who voiced no objections to termination in principle, drew regarding discarding embryos. James says, “*I’ve got no problems with abortions or whatever depending on circumstance – but it seems like you go to all this effort to get them – you can’t just throw them away.*”

In summary, multiple and at times seemingly contradictory constructions of the embryo could be drawn on simultaneously, highlighting the complexity of the situation in which donors in particular found themselves. Indeed, some donors commented on the difficulty of working out what the embryos meant to them.

Dawn: I’ve tried to work out what meaning exactly they have and I can’t really. It’s so difficult to decide, but I felt they had enough meaning that I wasn’t just going to say, ‘Well we’ve finished our family; let’s dispose of them.’

Such multiple discourses helped explain how donors worked through the process of deciding to donate. Donors drew on discourses of the embryos as life potential and as resources, enabling action possibilities that involved using the embryos. Donation thus became constructed as a logical, rational choice, and donors were positioned as responsible adults in the process. However, constructions of the embryos as children and part of their family unit bestowed obligation, making donation difficult, as well as invested with possible ongoing responsibility. Additionally, as discussed in the next section, donors drew on not just constructions of the embryo but on what the embryo would become if donation was successful, i.e. a genetically related child, raised in

another family. It is thus possible that some potential donors discard embryos (even when seen as life) because they cannot assume a parenting role in relation to what they construct as their child. For the donors in this study, decision-making was grounded in constructions of outcomes (having a genetically related child raised elsewhere) that they constructed as difficult, but doable.

Recipients drew on similar constructions of the embryo as child or life. For them, the discourse supported ED as a logical choice. They constructed the embryos as having ties to the donor however, which potentially created ambivalence around authority over the embryo, with possible implications for donors' connections to offspring.

6.1.2 Constructions of the donor-conceived child

While discourses related to the embryo were drawn on, it was how donors and recipients constructed what the embryo would become i.e. a donor-conceived child, and the relationship of this child to the donors, that was significant in decision-making. In donors' talk, I identified a genetic discourse of the child as 'still theirs' in some way; and in that of recipients, that the donor-conceived child was theirs, and yet also had enduring ties to the donors. Such discourses carried implications for ED as a family-building practice.

6.1.2.1 Donors' constructions of the child: Our child, but...

Donors emphasised that the child was the recipients', and that recipients assumed full parenting authority. Mandy commented that "*They are definitely Mum and Dad to X*", and Lance that, "*Once you cross that line, it's their child.*" Jonathan emphasised that "*We were clear that this is **their** baby, and they'll make all of the decisions.*"

However, it was apparent that there was difficulty in distancing themselves in this way. While asserting that she had no connection to the child, Rachel mentioned that she could not donate more of her embryos as they were "*her babies*". Dawn commented, "*I thought I probably could manage the idea of being detached*", but went on to explain her inability to do so. The exchange below further reflects this ambivalence:

*Jonathon: You've got to think, 'Well this is silly! We can't be thinking like this. We've made the decision. It's **their** baby, and they are going to do a great job.' So you move on, because you can't dwell on, 'this is your baby' really. You can't think like that.*

Frances: No, because B never has been our baby.

Jonathon: Well...

Frances: No, B's never been our baby.

Jonathon: No, but when you are holding the baby it can be a bit different.

Donors also continued to construct the child as still 'partly' theirs or as connected to them in some way. Lance phrased this as *"It's not our child. Sort of. Still feel a connection."* Grace stated that *"People say, 'How many kids have you got?' Well (my husband) will always say X, and then you have to explain."* Her husband clarified: *"and I say, 'We've got Y here and one in (area) that's ours, or, sort of ours.'"*

The ambivalence of this construct was reflected in Brian's comments, where he emphasised that a child could not be owned, but nonetheless used a possessive pronoun in relation to the child, *"We were going to give them our child to raise. And the fact is, Z is **our** child. You can't take that away from us. Nobody owns a child. A child is created from somebody, and that's it."*

Through constructing the child as still 'sort of' theirs, a continued emotional attachment to the child was enabled. Nathan said, *"There's a little bit of a twinge there"* whenever he sees the child. Donors constructed this attachment as needing to be managed, to *"get your head around that"* (Jonathan), or as *"one thing you've got to try to keep under control, because it's not fair on them (recipients)"* (Cameron).

Donors drew on extended family constructs to make sense of this connection, and their relationship to the child. Pamela framed herself and her husband as *"Uncle and Aunty that can watch Z grow, make sure Z is safe."* Lance constructed their position as *"like godparents, in the background."* Nicholas emphasised that he would tell the child, *"(The recipients) are your parents; but we can be your other family."*

Donors clearly constructed themselves as positioned in a special way towards the child: as less than parents, but more than neutral bystanders. Jonathon commented that *"We didn't think ourselves as visitors in the normal sense, with that special association."*

On the other hand, donors constructed their children and the donor-conceived child as “*pure siblings*” (Janet) or “*full siblings; you can’t get much closer than that*” (Jack), by virtue of their genetic ties, as well as (as was often the case) simultaneous creation. Brian stressed, “*Don’t forget this little (child) out there is Y’s twin. Both conceived at the same time, and they look identical.*”

Furthermore, in the case of several donors, their parents continued to construct the child as their grandchild. Lance explained how his mother regarded the child as “*another family member*”. Frances described how her mother had arranged a present for the baby, and how she had discussed with the recipients:

...if it would be OK if my mum sent little things to B, because as I said, it's her grand(child), and I don't think she will ever think of B as any different. I would be surprised if B wasn't going to get into the will from mum and dad. I'd be very surprised if B didn't make it there. Because to my mum and dad, it's very much their grandchild. It's not any different from (our children).

This complicated the donors’ position. They constructed the child as still ‘partly theirs’, still their parents’ grandchild and their children’s sibling. This potentially placed donors in an ambivalent position, assuming a position of being ‘partly a parent’, but without parenting rights. Even as only ‘partly parents’ however, if they were to align themselves with ‘good parent’ positions, then they incurred responsibility to ensure the ongoing welfare of the child, as discussed in the next section.

6.1.2.2 Recipients’ constructions of the child: Our child, and yet...

Recipients constructed the child as theirs, although they framed the genetic ties the child shared with the donors as significant. Most recipients had originally hoped for and tried having children of their own. The inability to have their own genetic child was constructed as loss, involving grief (e.g. Wendy, Jenna) and emotional processing. Kieran commented that “*It’s challenging, absolutely, and a lot of people just want a child, they want it to be theirs*”, but that there was a need to decide that “*well this is the way it is.*” Deborah said that “*Clearly, if you can have a child genetically, or that’s half of you, that’s what we will do. But we didn’t have that choice. So you kind of just get past it, and deal with it, because you can.*”

For several recipients there was concern about the loss of this genetic connection in terms of the parent–child bond. Zelda commented that a child born from donor gametes (and one partner’s gametes) would have been “*more our child*”. Olivia worried that her grief at not having a genetic child implied that she loved her donor-conceived

child less, something that she had worked through in counselling: *“It’s OK to grieve for not having a biological (link). It doesn’t mean I love them any less.”*

Beth similarly pondered about the implication of a loss of genetic connection to her child in terms of both attachment and family membership:

When I did get pregnant, I suddenly had a whole lot of different thoughts. I thought, ‘Oh my God, I’ve got this life growing inside me that has absolutely no genetic connection at all.’ That took me a wee bit to get my head around... the other stuff (donor sperm), it was still going to be partly me. This child would be genetically nothing to do with me at all. I felt a bit like an incubator, and I didn’t really know how I felt about that. So that was part of the thing where I said, ‘What have I done, what have I done?’

Beth worried not only about losing her genetic input, but as was the case for several donors, accepting ‘unknown genes’. This translated into a need to have information about the donors and their children. Michael spoke of how he had wanted to meet the children to see *“what we were going to get”*. Zelda spoke of how:

You give up something when you have a donor. You lose your genes, and you have someone else’s genetic material, so in order to wrest back some of that control, you kind of want to know everything. You don’t want unknown things! You want to know. So it was like, ‘What are they going to look like? What are they going to be like?’ all that sort of thing.

By finding out as much as possible, recipients attempted to claim back control. Resemblance talk featured regularly, with recipients constructing resemblance as reinforcing connections between children and their donors. Wendy commented that *“Definitely X resembles X’s genetic mother as well. So with all of that I think it will be important to X to (have that contact) with that similarity there, and for a lot of other reasons too I guess. But yes, we can take it, and they have a bond.”* Likewise Tanya commented that *“There is a chance that they (donors) would (feel some connection) because there’s a chance that it will look like one of their children.”*

Similarly, the lack of resemblance was something several recipients had to process. Olivia commented, *“It’s a bit weird. Sometimes they’ll pull the same faces as the (donor) kids, and so it’s like, ‘That’s their (donors’) child.’ Sometimes it’s a reminder to me that they are not my genes. Give them a hug and get over it!”*

Recipients used strategies to minimise the importance of resemblance, simultaneously emphasising and distancing the role of genetics. Tanya commented:

I've never wanted a mini me. It's never been about me reproducing myself, or having that descendent. It's having this baby that you love and nurture and grow. It's raising a child, that's where I feel I do have something to contribute. It was never a question of having a donated embryo means it's not yours.

Neil, her partner, went on to say, “*So hopefully they won't have the bung eyes and crooked teeth that I've got.*” Tanya and Neil emphasised the social role of parenting to underscore their position and relationship to the child. In addition to the social role, recipients emphasised the gestational link in “*making (the ED child) part of our family*” (Wendy). The child became more ‘our child’ through the gestational and birthing process, and the legal structure that invested parenting rights with birth parents, as reflected below:

Kieran: Well (my wife) is going to be the birth mother, so in that sense and in every other sense that matters, she's mum, that's it. Jenna: And you're dad.

*Kieran: It's our child, and if we decided, 'hey guess what, we are going to the UK or off to Canada', the fact is that it's **our** life.*

By drawing on constructs of parenting as encompassing nurture and gestational ties, recipients constructed the child as part of their family, and themselves as parents. By drawing on a genetic discourse however, recipients constructed the child as linked to the donor family. The child was theirs, but also had a place in another family. Wendy said:

X will always know that X has these genetic relations, and that X has kind of got two families I guess. But we are X's family, and these people are people that are there if X wants to get to know them, and we are friends. So it's a non-threatening way.

Zelda drew on knowledge gained from an adoption seminar to make sense of her child's ties to another family:

*One of the exercises that stuck was that they had little bits of paper connected with string and it had birth mother, birth father, adoptive mother, adoptive father, child, adoptive uncles, all these people. Everyone in the group got given one bit of paper and then we were all tangled up. It was a really visual picture of the tangled web of connections. That really opened my eyes because I had thought, 'I'm going to get a child. It's going to be **my** child, end of story.' And then all of a sudden it was like, 'That's not the way it is! Of course it's not.'*

As for the donors, recipients attempted to make sense of the relationship by drawing on extended family constructs. Maggie explained how she grappled with working out who the donors were in relation to her child, “*Who are the couple? Are they a mum and dad? Are they an aunty and uncle? Who are they?*”

As for donors, recipients drew boundaries around the donors' position in relation to the child, and yet readily constructed the children's relationship as 'full sibling-ship' because of shared genetics. Wendy referred to the children as "*full brothers and sisters but they would have different parents.*" Beth commented that "*I thought that this child was going to have full blood siblings, which was wonderful.*" For most the relationship was constructed as close and potentially supportive, providing 'family' for each other. Beth, for example, commented:

At least when that child grows up, (he/she) will have full blood siblings to be with. I felt that I was letting them down a wee bit by just being me. I think it's nice for people to have big families and brothers and sisters if they can.

The construction of the child as genetically tied to another family, as having full siblings, and of the importance of knowing about such links, created ongoing ties between recipient and donor families. This placed recipients in a somewhat ambivalent position: While they were the child's legal parents, they were 'parents, but' or, 'parents, and'. There could be a sense of 'sharing' their child, as is evident in Kieran's comment below. This was, however, not necessarily constructed as a negative.

Kieran: We've realised that it doesn't in anyway dilute our experience by sharing it with somebody. In actual fact it enhances it.

Rather, the issue for recipients became how to align themselves with 'good parent' positions, given that they constructed the child as having ties to another family. As for donors, 'good parents' try to ensure the child's welfare. This is discussed further in the next section.

6.1.3 Welfare of the child and family

By constructing the child as partly theirs, donors positioned themselves as assuming some responsibility for the child's welfare. Likewise, in framing the child as tied to another family, recipients positioned themselves as responsible for taking the particular context into account in ensuring the child's wellbeing. Meeting the child's needs was constructed as paramount, as outweighing adult needs and wishes, and as ultimately ensuring the welfare of the wider family. This discourse of 'welfare of the child' can be identified in three areas: the selection of recipients; the disclosure of donor conception and access to genetic information; and the degrees of contact between donor and recipient families. I discuss these in turn.

6.1.3.1 Selection

Donors: ‘People like us’, or ‘people that fit with us’

Donors wanted to select suitable recipients, people “*you would like to have bring up your children*” (Jonathan). This was framed as important for the child’s wellbeing:

Grace: As much as we have no say in what happens with that child’s life, we still have an interest, and we want to make sure that they are doing, that X is being well looked after. It’s not that we give input, but you still want to make sure that you are giving that child the best you can, because you don’t want to put that child into a position of having a horrible life, because you made a bad choice.

Lance: We had an opportunity... a little bit of one to at least try and assist in where the child went, possibly in having a little bit of a better life.

For many donors, this involved selecting recipients who were “*the most like us*” (Roy); “*mimicked what we are like*” (Stephen); and were “*as close to yourselves as you can: socially, economically, morally, everything really*” (Grace). Grace explained this as “*wanting somebody who’s going to raise your children in a way you would want them raised.*” Jack similarly said, “*We wanted to choose us, because we would be the best people to bring up **our** children. They (recipients) were the nearest we could find to us.*”

Donors, as in the case of Jack above and Brian below, constructed themselves as the best parents for a genetically related child, and had concerns about others knowing how to manage genetically-determined, unfamiliar characteristics:

Brian: Z’s not going to have the same personality as them. We know what Y (our child) was like as a kid, and they (recipients) are in for some serious differing of opinions! But Y is our flesh and blood and so we can understand all that. They (recipients) won’t. What are they going to do? Say ‘go to your room?’

They also wished to avoid negative comparisons:

Janet: We didn’t want a big disparity and that my children look and say, ‘Oh I wish I had gone to that family and why can’t I go off there and have what they’ve got?’ or vice versa.

Grace: It could work both ways: If you chose a couple that were really really wealthy, and you’re not, you could be constantly jealous that that kid has got what your kids couldn’t have, and that could work in reverse too. If you were rich and you chose a couple the other way, it’s like that kid is not getting what you think it should have. So that’s why for us, we made that decision. We don’t know what their financial state is like, but we just tried to keep it similar. We could tell they weren’t outlandishly different from us.

Some donors felt that similarity wasn't as important as relating well, having a "connection" that felt "right" (Jack), or being "people that we could easily talk to about anything" (Jonathon). This was framed as providing the basis for future sound relationships, which was constructed as in the best interests of the child. Jonathon said, "You've really got to be on the same page, otherwise it could be a disaster."

However, most important for donors was being assured that the child would be well cared for. As Lance said, "It's more about knowing the child will be well looked after", and Jessica, "At the end of the day, I wanted the children to be given to a good family that will love them." Most donors had ideas around characteristics they wanted the recipient couples to have, and these were framed in terms of the welfare of the child.

For example, while donors did not construct wealth as important, financial security, in terms of the ability to care for a child, was. Lance explained:

It was never really about the money side of things for us; it was really more about the fact that so long as it wasn't going to be a poverty situation... just knowing that the child would be well looked after... we didn't want someone that was going to live on the bones of their arse.

Having family support that recipients could rely on was also constructed as important. Isla spoke of her recipient as having a "very good family network, a very supportive family" and expressed that "to us that was important." Further, the recipient couple's relationship was framed as significant and as contributing to a stable home environment. Mandy explained this as follows:

*The only thing we really wanted, was that they were in a committed relationship. We didn't want the baby to be in the middle of a custody battle. It was a funny thing, you don't normally say to another couple, 'You have to stay together!' We didn't say it like that, but the message was, and it was obviously framed nicely, 'It's really, really important to us that these embryos go to a couple that are really committed and really stable.' The bottom line was, 'You **need** to stay together.'*

For some donors, donating to a single parent was not problematic. Where there were two parents, however, the relationship needed to be stable. For some, sexual orientation was not an issue, and in one instance, donors donated to a lesbian couple. Others framed sexual orientation as important, but constructed this as achieving a family situation that was similar to their own, rather than as discrimination. Again, a genetic discourse was drawn on with concern for donor: recipient match. Stephen commented:

I was more upset about the same sex side of things, because I thought for someone who was of my genetic makeup, that's not us. We come from a heterosexual background, so I preferred a heterosexual background.

Donors spoke of being reassured if recipients had had previous experience of children, e.g. teaching or nursing, particularly with children that were different from 'normal', e.g. foster children. Kimberley framed this as the recipients thus being "*used to that side of things*", and Jack that "*they had dealt with those sorts of issues.*"

Health and age were also important, but only insofar as recipients were constructed as able to raise a child, because "*it's going to take energy to raise young children*" (Jessica).

While most couples expressed no religious preference, for those with a strong religious affiliation, donating to couples with similar beliefs was constructed as important. Jack mentioned, "*That was part of that process, with one of (the criteria) being that we would like to see the embryos go to a Christian home.*"

Recipients: 'Passing the test'

Meeting the donors and being selected for ED created significant anxiety for recipients, and was constructed as akin to an exam (Nadia) or a job interview in which they had to make a good impression, as evident in the following comments:

Tim: It's like a job interview on steroids! It's something that could be life-changing or could turn out to be quite devastating if it doesn't work out.

Deborah: It's like, 'Will they like the look of me? Will they like my personality? What if they don't like us? What if we don't get on or they've got different ideas?' You are being judged on how you look and everything, so it's all very personal, and so it's nerve-wracking. So you put your best foot forward.

The decision to proceed with ED was constructed by recipients as mainly that of the donors. As Sandra said, "*Are we going to meet whatever their criteria (are)?*" Jenna described it as "*'yes, they are happy with us'. They could say, 'no, they don't like you.'*"

This positioned donors as 'examiners' and recipients as 'examinees', creating significant vulnerability and a lack of control for the recipients. Deborah explained:

The whole time you are not in control of anything. You feel very vulnerable with all the questions you are being asked. You don't want to say the wrong thing, because they could then say, 'Well we don't want them to have it.'

On the other hand, recipients appeared to accept this situation, positioning the donors as 'good parents' by selecting recipients carefully. Wendy commented that

donors have to ask themselves, “*Are these people going to protect this child?*” And Tim explained donors’ concerns by pointing out that it is the recipients ultimately that control the upbringing of the child: “*The donor family has a lot less control over that. Well, almost no control! Basically it's their choice at the start, and then that's it.*”

Some recipients attempted to reassert their control in the selection process. Kieran, for example, positioned himself and his partner as ‘good enough’, saying, “*We would have to do something fundamentally wrong or give offence for them to suddenly go ‘no’.*” Further, while recipients wanted to make a good impression, honesty was emphasised in the interests of longer-term outcomes, as explained below:

Tanya: I think I did say, ‘Look we desperately want to be saying the right thing, but the reality is, we have to be honest with you and say how we really feel, because how can you move forward otherwise?’

Neil: We would rather fail truthfully than succeed with a lie, because it's going to come out later.

While for most recipients the focus of joint counselling was constructed as a test of their suitability, some recipients, as discussed previously, also emphasised that the meeting allowed them to collect information about, and assess their level of comfort with, the donors. Wendy said:

You want to be chosen by them and want it to work out, but you also have to be objective and think if there are any feelings of doubt about that relationship. It's to try and remain objective, when it's something you so passionately want.

Most recipients, however, acknowledged that negative information, or a perceived lack of fit, would not have dissuaded them. Nadia contemplated:

What if the couple had been awful? Would I have said no, I'm not having their child either? I don't know. No, that's completely ridiculous! Actually in hindsight, I wouldn't have done anything. I was so certain that was what I wanted to do, that it would have had to be something pretty horrendous to put me off.

Rather, recipients constructed meeting and getting to know the donors as preparing them for what to expect in the future. As Deborah commented, “*At the end of the day, if a child comes out of this, it's like, you'd need to know what to expect.*”

For recipients, achieving a ‘match’ between themselves and the donors was an advantage. Recipients emphasised that it would be important for the child to know that the donors were happy with their decision to donate. Maggie commented:

If you are thinking about just yourself, well, just give me the embryo. But ultimately there is going to be a human. That meeting is the first time we met your biological mum and dad. It gives you a base to start from for the child.

Since the recipients envisaged that the donors would have a relationship with them in the future, the advantages were highlighted. Maggie commented, “*We were almost fast-forwarding building a relationship because they were going to be in our life forever*”. Compatibility was constructed as facilitating relationships and lessening chances of donor ‘interference’:

Tim: If there is any breakdown, we’ll go to counselling, but I really can’t see it getting to that point because we’ve got very similar beliefs in terms of our religious beliefs. We’ve got really similar goals for our children, and similar ideas for how we want to bring them up. I think it helps an awful lot.

Wendy: I guess if they didn’t have similar values, they might feel that they wanted to step in and steer the way you were going.

Thus, recipients were more easily able to ensure the welfare of the child when donors and recipients could relate to each other; when recipients knew what to expect; and when donors were comfortable with donating.

6.1.3.2 Disclosure, truth and access to genetic information

Donors: The truth is good, the truth will out, but the truth is private

Donors constructed disclosure as fundamental, and as enabling the child to develop a sense of identity and have questions answered, as evident in the following comments:

Mandy: I started doing a scrapbook telling the story, because obviously that baby might eventually come back and say, ‘Why did you give me away? What was that about?’ We had to be able to tell the whole story.

Grace: It’s a proven fact that open adoption, where the kids know where they’ve come from, are much better accepting. They don’t have that searching, ‘Who am I?’ identity, and so that’s why we are prepared to be in B’s life, so B will know. It will never be, ‘Let’s meet these parents who we were created from.’ We have always been there. B’s seen us, and will continue to see us.

Disclosure and openness were framed as in the best interests not just of the donor-conceived child, but also the donors’ children. It was constructed as the “*respectful or decent thing to do*” (Janet). Jonathon commented that:

We didn’t want to say this is (baby’s name) and not ever say anything else, and then magically one day, ‘Oh by the way, we think you are old enough now. (Baby’s name) is your (sibling).’ We will just start now.

Mandy emphasised the potential difficulties of non-disclosure when she said, *“Who wants to find out at thirty that ‘You are not my biological parents?’ That would be devastating.”* All donors either had told their children or were planning to tell them when they got older. Rachel commented that *“We haven’t told our children yet that A’s here. We’ve told other people, friends. We’ve blurted it out sometimes, then thought, ‘Gosh we haven’t even told the children yet!’”* Donors were generally open with others, and this supported their telling of their children, as donors constructed the truth as ‘coming out’ regardless. As James said, *“if not by you, by someone you have told.”*

For some donors, the donation was not necessarily secret, but nevertheless more personal and private and spoken about when the context was appropriate. Isla commented that *“We’ve never hidden it; it’s never been a taboo subject. It’s just something you don’t bring up socially really, ‘Oh, by the way’.”* Frances explained how talking about ED involved sharing a significant part of her history that was generally private:

To me it's personal, because if I have to tell someone we've done the embryo donation, I have to tell them we've done the IVF thing – OK, that's how (our child) was conceived. I find that it's very personal.

One donor expressed concern how others would regard her children and the donor-conceived child, and felt uncomfortable with this:

Janet: It still wouldn't be something I would just tell to anybody. Is it putting a stigma on a child (donor-conceived) before he even comes, and everyone's going to know that 'oh that's the one that'.

Donors who chose to be open were mindful of how and to whom they disclosed, as they constructed donation as not just ‘their story’ but also that of the recipients and child. They wanted to respect the recipients’ privacy, and in particular did not want to do anything that could jeopardise a relationship with them. As Janet said:

I strongly feel it's not just myself or our family, there's also the couple in Place Z. There's absolutely no way I want to jeopardise any relationship. So there's a fine line, because you are also sharing information about people that we don't even know much, and they might not want the information shared.

Most donors had told their families, and had their support. Family members, *“realised what we’d gone through”* (Isla); *“understood our reasoning”* (Mandy); and *“knew that we weren’t going into it lightly”* (Karen). Others had experienced a mixture of concern and disapproval, which at times was based in religious or cultural beliefs. Kimberley commented, *“I don’t think my mother was very pleased to start with...”*

Giving babies away.” Frances’ mother had similar concerns, and for Frances telling her mother was complicated by not having previously shared her fertility difficulties, and by it being “*a bit difficult because in (my home country) it’s against the law.*”

Several donors spoke of how their parents or family members constructed ED as foreign and unknown, as is reflected in Nathan and Brenda’s comments below:

Nathan: My mother would just not have understood what the hell the whole process was about, and we just didn’t want that sort of pressure on us.

Brenda: So when you talk to family about donating, they hear it, but it’s so foreign. But they would always support really...

Ultimately, these donors framed the decision to donate as their own. Nathan commented that “*They are not part of the decision-making day-to-day for our family unit here.*” And Rachel stated that “*It had to be **our** decision.*”

In summary, donors constructed disclosure as essential. In this way they aligned themselves with ‘good parent’ positions in relation to the donor-conceived child and their own children. They were willing to be open with others, although in circumscribed ways, partly to protect the child and relationships between donors and recipients.

Recipients: The truth is good, the truth will out, but the truth is private

Openness about the conception was constructed as important, as “*healthy*” (Tanya) by recipients. Keeping secrets on the other hand was constructed as deceitful, as undermining trust, and as having negative consequences for the child:

Jenna: Our main focus will be the welfare of our child, and both of us feel that keeping secrets and not knowing where they have come from is detrimental... (That’s) not what we want for our child. They need to know to have a good quality of life, and have an understanding of who they are... And at some point it will come out; be it in ten years down the line, be it 50 years.

Kieran: Just from a point of who you are, your own personal identity, that can be absolutely devastating to some people. It unravels the true fabric of who you are. You couldn’t do that to a child. By denying someone a part of their life; an opportunity to explore their life, and for me that’s lying by omission. I think morally it’s wrong. There’s an overwhelming sense of betrayal.

Openness was also framed as important in preventing unknown consanguinity and facilitating medical procedures. Deborah explained, “*What if Z went to college (in Place A) and ran into siblings, or started dating (sibling)... You’ve got to be aware of that kind of thing.*” Olivia commented that:

The great thing about this whole openness. When the kids (have) got allergies and asthma, we know where it's come from. The doctors say, 'Do you or your husband have blah blah?' And I say, 'Yes their biological parents do.' It's good to have that type of background information.

Disclosure was constructed as in the best interests of the child, the siblings in the donor family, and even the adults. Wendy expressed her support for openness:

If anyone had doubts about the openness of a relationship, I would definitely tell them the benefits that we've seen so far in having an open relationship, for ourselves, but also for the children.

Disclosure was constructed as best occurring early in the child's life, with "knowing being the norm" (Maggie), and as reflected below:

Jenna: You let them understand from the beginning. I've kept documentation and written a little journal right from day 1 of IVF treatment, so I'm monitoring with photos all the way along and I will put together a book at some point.

Wendy: To grow up always pretty much having known, never having a point of being told the background. This story is just part of their lives.

As was the case with the donors, disclosure was constructed as paramount, and recipients were generally comfortable sharing with others. This was framed as in the child's best interests.

Wendy: That's one of the reasons we are quite open with people about what we've been through... We want X to sense that openness, and also we want X to have picked up from casual conversation that this is X's story.

It was interesting that recipients also constructed ED as involving contact with another family, and thus a practical issue underscoring the need to tell others. This was not framed to be the case in gamete donation. Zelda, for example, said:

We felt we had to be more open with more people, just based on the fact that we had a much stronger connection to another family. When it's egg donor, you haven't got a link. Well you have, but it's nowhere near as close.

ED was nonetheless constructed as a private matter not necessarily discussed with others unless there was occasion to do so. Sandra and Olivia commented:

Sandra: We are very open about the fact that (our child) is adopted but every Joe Blogs doesn't need to know.

Olivia: I don't want it to be a secret, but I don't necessarily want to scream it from the mountain top. It's nobody else's business.

Again, this was partly because ED was constructed as not just ‘their’ story, but their child’s story, and recipients wanted to involve their child in terms of how to manage disclosure. Zelda and Jenna reflected on this:

Zelda: (It’s) not because I don’t feel comfortable, but more for our child’s privacy... that’s actually revealing something very private for (my child) and if it was completely up to me, and didn’t impact on my (child), I would be telling every man and his dog because I’m completely comfortable...

Jenna: We are not going into any details, mainly because we are protecting the child, and it’s the child that needs to know first before everyone else.

For some recipients, anxiety about others’ reactions to their child were constructed as reasons for maintaining privacy. Tanya commented that “*I worry about whether anyone will say anything to our child. I’m already feeling the defensive mother lion thing.*” Maggie explained that her family’s reactions had been negative at first:

Everyone had an opinion, and we weren’t ready to tell people until we had all of the answers. It took us a long time to find the answers and I remember the first time we told mum and my brother. They both came at me with all these questions and huge opinions about what we were doing. They were very negative.

Likewise, Olivia did not initially tell her family about the donation:

I didn’t tell them it was embryo donation, because they are not very open-minded people. I thought they would think that they (the children) wouldn’t be part of the family. I thought they would have prejudices against it anyway.

Some had told their family members from early on, but nonetheless constructed the decision as their own. Others had elected to tell family only after knowing if ED had been successful, sometimes in an attempt to avoid their family’s disappointment in the event of unsuccessful pregnancy, or as self-protection:

Nadia: I just felt it had the potential to be too painful for them if it didn’t eventuate. I didn’t want to get their hopes up and put them through a lot of emotional heartache.

Tim: We didn’t tell people in our family that we were trying at that stage, just because we had already gone through grief, and we didn’t want to keep being asked when there was a possibility there would be no result. It would open up wounds that we were trying to heal.

The decision to proceed with ED however, was constructed as personal, as Kieran’s comment illustrates:

My argument was it was our decision. We are not looking for any form of vindication from anybody else. It’s a decision that we have made. In including

other people, it was a case of including them, not seeking their consent. I found it inappropriate when people started making a judgement and I thought, 'Seriously, why are we telling them?' The fact is, they have not gone through what we've gone through. They haven't walked that path.

Such constructions of ED as private and personal, but not a secret, served to position recipients as 'good parents' – good parents disclose donor conception to their children in the interests of their long-term welfare – but also to protect their children from potentially negative reactions. Through maintaining privacy, recipients were possibly attempting to reclaim control and privacy around family-building and reproductive choices. For some, this protected them from the judgement of others which may have undermined the security of their position.

6.1.3.3. Contact: Ongoing donor involvement

Donors: Watching over, from a distance – Good parents stay in touch

By drawing on the discourse of the child as still partly theirs, donors constructed themselves as willing not just to be identified, and open to contact, but also to have a degree of ongoing involvement in the child's life. While donors were clear about their lack of parenting rights, contact was framed as enabling a degree of oversight over the welfare of the child. As Roy stated, "*They are still part of me, and you are bringing up part of me, so I wanted to be part of their lives from a distance.*" Likewise Grace commented that "*We still have an interest, and we want to make sure that they are doing... that B is being well looked after and stuff like that.*"

Donors constructed contact as important to them and also in the interests of the child, as can be identified in Grace's comments below:

*It's what's the best interest for (the child). We've said to them, "It's not about what **we** want, or really what **you** want, it's about what's best for B. Because I said there may be times when we are wanting to see B more for us, but you may say, 'Look it's not a good time; just back off.' And that's OK. Or there may be times when you say to us, 'We need you to come and spend some time with B,' and it may be a bad time for us, but we will come and do it for B, because it's not about us, it's about B.*

The ability to have contact was emphasised to be in the interests of the siblings also. Brian, for example, felt that siblings 'should' grow up together:

We wanted our children, whether they live with us, or whether they grow up in another family with another Mum and Dad, to know each other, and to be part

of each other's lives. What is being a child growing up without being able to know your (siblings)? Isn't that part of your childhood?

Others suggested that siblings could provide support for each other in a range of ways in the future: “*one day*” in the form of “*companionship*” (Stephen); or “*on the sports field, or even for health reasons, bone marrow or anything*” (Isla). For Mandy and Grace, sibling relationships outlasted those of parents and could be enduring forms of support:

Mandy: The fact about it was that we are older parents; they are older parents. These kids could support each other later in life as well, and that having older parents would understand that.

Grace: We've all agreed that when we are dead and gone, these guys will still be siblings at the end of the day, so we have to do it for them.

Maintaining contact was thus considered important for the donor-conceived child, as well as siblings. By enabling contact, donors aligned themselves with doing what is right as a parent – acting in the interests of the children. However, most donors framed contact as being relatively infrequent. Stephen phrased this as “*I don't want to be your best friend, but it would be nice maybe to have contact every now and then... maybe 2 or 3 times a year, so we can keep in touch.*” Brian commented that “*We wanted to have contact with that child as it grew up, and we wanted that child to have contact with us as it grew up. We sort of envisaged that maybe once a month, we'd go over and see (the child) or (the child would) come and see us.*”

Contact to celebrate particular occasions was also constructed as appropriate, e.g. “*along those lines of birthdays, Christmas, those festival things*” (Nathan); and “*maybe the kids' birthdays, maybe Christmas, special get-togethers*” (Mandy).

The contact was constructed as social and as non-intrusive, with appropriate respect for boundaries. For example, Lance said that “*We never wanted to live in anyone's pockets*”, and Jonathon that “*We wanted to play a part in the baby's life, but not be overbearing or a nuisance.*” Donors were clear that recipients needed to occupy the position of the ‘real parents’. Rachel said that “*We are not going to tell them how to bring X up*”; Karen that “*We didn't want her to have to second guess everything with us*”; and Nathan that “*It's their world and their family and we don't dictate in any form.*”

Grace and Jack had given a great deal of thought as to the effect of their involvement as donors:

Grace: We definitely try not to be too intrusive, but we let them know that we are really happy and proud of what they are doing to alleviate any fears they may have that we are wanting B. I try not to send birthday presents on B's actual birthday, because that's their time with B. We always give B a present, but I try not to do it on B's birthday. That's B's family time, and we always take a present every time we see B.

Jack: We don't want to steal their thunder.

Donors were aware of the need for the donor-conceived child to form an attachment with the recipient family. As Janet commented, *"You don't want to confuse the child either. I mean the child needs to have a secure happy upbringing."* Thus, in the interests of the child, and the recipients' position as parents, they constructed their role as involved, but from a distance. Finally, for some, keeping a distance was framed as easier:

Jonathon: I'm pleased that they live that far away, because if they were just 5 minutes down the road and you had an awful lot more contact, it could be a lot more difficult for me. So it's good to have a bit of space.

Nathan: That was a factor in our decision: that the child was in another part of the country. If they were just down the road, that would have been harder.

Using information technology (email, Facebook, websites) was referenced as one way of maintaining involvement without overstepping boundaries. Jack explained:

They've got a website that they upload photos to, so whenever we feel like it, we can go and look. It's a really good tool to have, because you are not in their pockets, and you can look at it when you feel like looking at it. They can put up what they feel comfortable putting up, so we are not looking into areas of their life they don't want us to see. I think for me, that's really made a difference.

However, donors also constructed themselves as willing to play a more direct or supportive role where required, as expressed by both Lance and Grace:

Lance: If something ever happened to them, we would gladly take A as our own. They probably have other people they would rather leave A to if something happened, but the offer would always be there. Financially, if A was in trouble, we would also certainly consider helping out because we do feel quite a strong connection with A, although A's not our child.

Grace: When she had the pregnancy (difficulties) nobody knew. It was like, 'you need support.' So, a friend and I came up here, and I think that blew them away.

Donors were often uncertain as to how contact would unfold over time, leaving them in a position of vulnerability and careful not to be too demanding.

Nathan: We don't approach them at the moment. We are leaving the door open for them to keep updating us, because we don't want to encroach and make them

uncomfortable or uneasy. It's their universe, and when they are ready, they will develop that openness a bit more, hopefully, in the future.

Janet: I've sat back and let them (recipients) do the approaching, because I really, really want to have a relationship with them, but I don't want to force myself on them, to push them. So I just let them take the first steps.

Donors recognised – but grappled with – their limited rights. Karen said, “We knew that she could change her mind, and not let us in at all.” Grace commented, “If they change their minds, there's nothing we can do about it. We knew that from day 1: This is a risk; that they could get the babies they want, and then they can say, ‘See you later.’”

While donors were aware of their lack of rights in relation to contact, this challenged their ability to act in what they constructed as in the interests of all the children involved. Their position as ‘good parents’ was thus partly compromised.

Recipients: Good parents promote and manage contact

Many recipients likewise constructed their relationship with the donor family as one that would involve ongoing, although not frequent, contact. Contact was both face-to-face and indirect, through “*email, and we have a password protected blog*” (Wendy), and “*photos and updates*” (Deborah). Where recipients met up with donors relatively regularly, the contact was described positively. Wendy said:

Last time we met was not that long ago in (area B). We went out to (attraction) for the day, and it's cool just watching the kids run around and we sit and chat in the background. It's pretty much what we wanted it to be like.

The nature of the contact was constructed as information-sharing and social, with the donors' role a more peripheral one. Nadia said about her donors, “*I knew that they wouldn't be interfering. They wouldn't be on my doorstep every 5 minutes.*”

The degree and nature of contact were constructed as difficult to predict however, and as evolving. As Neil said, “*We made the point to them that it's very fluid*”, or as Maggie put it, “*We didn't really lay down any hard and fast guidelines.*” Generally relationships were framed as needing honesty and trust. Maggie commented:

We said we both trusted the other couple enough to make it work. We talked about trust a lot in there, and saying, ‘You're the kind of couple that we will work with, because we'll make it work, we'll make it easy.’

The relationship was however, constructed as under the control of the recipients. As Kieran and Deborah commented:

Kieran: They turn around and say that actually we would like to visit once a week, in fairness, it isn't going to happen!

Deborah: They are just happy to go with whatever we want to do; as little or as much communication. We lead the communication with them.

This enabled recipients to frame themselves as having full parenting authority, and positioned the donors as less threatening. For some recipients however, there was a sense of obligation towards the donors and recognition of their entitlement to contact.

Nadia: If they had wanted to spend every weekend with me, I would have said yes. It was just such a generous gift that I felt I couldn't refuse that.

Olivia: It was good to hear them say, 'Oh look, you bring them up the way you want to. It's all yours, you do what you want.' That was really good to hear. I do feel a little bit threatened by... they've got other parents out there... but I just sometimes I don't like being reminded I think.

However, the perceived rights of the child to have information about and some form of connection with the donors tended to outweigh recipients' anxieties. Recipients framed (controlled) contact with the donors as potentially important to their child, and emphasised that they would act in the child's best interests. As Neil pointed out, "It depends on the child... the interests of our child are going to be paramount." Likewise Kieran commented that "That would be controlled, and it would be measured and determined by or at our requirements and the child's requirements."

To align themselves with a 'good parent' position, recipients assumed their rights as parents to make decisions. In the interests of the child's welfare however, some form of contact, even where it might be threatening, was constructed as important.

6.2 Discursive constructions of ED practice

6.2.1 ED as adoption

In light of their constructions of the child as still connected to the donors in some way, both donors and recipients drew on adoption metaphors to make sense of ED. I discuss this below for donors and recipients in turn.

6.2.1.1 Donors: ED as 'adoption light' - less emotional than adoption

Most donors resisted the relevance of a donation discourse for ED. Gamete donation was framed as distinct from ED by virtue of the embryo being a full genetic entity

giving rise to a full sibling. As Janet explained, “*Someone can put their own input into that (gamete donation), and turn it into something different, not a pure sibling*”. Brenda commented that “*When you have egg or sperm donation, it's half of them, belonging to them. But with embryo, it's **completely** not theirs*”, while Brian emphasised, “*It's not a sperm or an egg. You just simply can't be entrusted with another person's child.*”

Instead, donors drew on adoption metaphors, as is evident below:

Brenda: It's no different from a normal adoption of having somebody else's baby. It's just that instead of having the baby at the end, you are going to carry the baby yourselves. It is different, but has so many parallels.

Isla: At the end of the day, its 2 or 3 steps off adoption for goodness sake.

Dawn: I thought it's a bit like if you adopt out a child, because it's pretty similar, except that you don't actually get to carry the child in your tummy.

However, donors also constructed ED as ‘not quite’ adoption, giving significance to the gestational relationship and birthing as creating bonds. Isla and Mandy drew the distinction between ED and adoption as follows:

Isla: Somebody said, 'Well how would you feel giving away a part of yourself?' It's different, because you are not carrying that embryo. I didn't carry it for 9 months; I don't have that attachment.

Mandy: And the other thing I find is, how those ones that adopt theirs out can do it? I had the easy way.

In this way, donors framed ED as ‘easier than’ adoption, what I have termed ‘adoption light’. ED was constructed as ‘adoption light’ in another way however: donors were constructed as having more circumscribed rights than birth parents.

6.2.1.2 Donors: ED as ‘adoption light’ - Fewer rights than adoption

Donors constructed themselves as having a lack of rights in two areas. Firstly, donors grappled with their inability to ensure measures to assess that the recipients were suitable parents. Brian, for example, expressed disbelief that:

*a home study is not done for ED. It's not a sperm or an egg. This is a **human life** that we have created. You simply can't be entrusted with another person's child, albeit at embryo stage, unless you pass criteria.*

Secondly, several donors struggled with the lack of measures to ensure disclosure and the honouring of information-exchange agreements:

Jack: Yeah, but at the end of the day it doesn't mean squat does it? Because if (our recipients) move to Timbuktu, we can't do a damn thing about it.

Brian: They made a lot of promises that we took as heartfelt promises. 'Yes, we'll make sure; if you give us this embryo and it turns into a child, or however many embryos turn into children, we'll make sure you've got contact.' They were just insistent about that. It was a case of they would tell us anything we wanted to hear just to get the child actually.

Janet: It scares me, and what I didn't know, but most of it, is all on trust.

Such constructions positioned donors as disempowered and vulnerable. As Roy commented, he felt that *"All the rights seem to go to the birth parent, but we were in effect, the birth, the biological parents"*. It was difficult for donors to be 'good parents' where they were unable to ensure measures to protect the child's welfare. Some of the donors framed this situation as inevitable. Lance explained:

The long and the short of it is, once we made that decision for it to happen, the majority of those things are out of your hands anyway. In good faith you say, 'You bring that child up in your best possible way' and we will be there to help support if you require anything, but it's your child. If they choose to have 50 more children, so be it. It's out of our hands. We are never going to have any say about that, and we always knew that. But you make that decision; you pick the people you are happy with, their basic personality, how they are and their beliefs and whether they are caring, giving people, because that's it.

Several donors explained how the knowledge that their recipients had undertaken CYF adoption courses, and/or had been approved either for foster care or for adoption, alleviated their anxiety. Some expressed interest in having formal measures, such as home studies to assess suitability. Birth certificate annotation to ensure that the child would have knowledge of the donor conception was also framed as *"not a silly idea"* (Grace), or *"very wise. That's all that needs to be said"* (Roy). Janet explained:

I think that's a very good idea because that at the moment, say, if someone got on the plane and disappeared, that child would have absolutely no idea or contact and would never know. Even in New Zealand they would never know.

Cameron however commented that *"Even if they do make a law that they have to stay and have contact, they could jump on a plane anyway."*

Constructing ED as a 'lighter' form of adoption enabled positions in which donors potentially felt more comfortable with the process (they were able to distance themselves through the lack of gestation), but also more disempowered and vulnerable than birth parents. Donors have no rights: they cannot ensure that the child is aware of its genetic heritage; they cannot enforce home study assessment of recipients; and they cannot ensure that the child will meet his or her siblings. This made it difficult for

donors to align themselves with ‘good parent’ positions, ensuring that the welfare of the donor-conceived child, and that of their own children, was met as far as possible.

6.2.1.3 Recipients: ED as ‘adoption with benefits’

Like donors, several recipients resisted constructing ED as akin to gamete donation. Instead, they constructed gamete donation as more clinical and distant than ED. Beth, for example, spoke of her experience of sperm donation as *“I think it was like, I was extracting part of somebody, but really not knowing anything about them, and I found that quite difficult.”* It was constructed as *“a little bit more selfish, like you are just doing this to satisfy your desire to have a child”* (Nadia). In contrast, ED was framed as a solution both for donors with embryos *“looking for a home”* (Sandra) as well as a means to have a child. This positioned ED recipients more comfortably as offering a service to donors and being good citizens, rather than acting merely out of self-interest.

Donation (of gametes) was also constructed as having more circumscribed implications, without ongoing connections and responsibilities. As Wendy commented, *“Everyone always confuses it with egg donation; they don’t realise that ED is... That this child will have fully-fledged, full genetic siblings, and that we might have an ongoing relationship with that family, which isn’t always the case with egg donation.”*

Rather, recipients drew on discourses of adoption to frame their understandings. Recipients referred to ED either as *“a lot like adoption: being brought up in a family where you are not genetically related”* (Wendy) or directly as adoption. For example:

Neil: While everyone calls it embryo donation, we call it embryo adoption. We’ve adopted a little life, or about to.

Tanya: We’ll be growing it. Just a very small baby, an early adoption.

Michael: This embryo adoption came up and I thought, ‘it’s the same’. Yeah, it was still adoption.

The adoption metaphor offered recipients a model of ED, and also helped them to explain what they were embarking on to other people, as is evident below:

Neil: That’s the way we have found that other people have accepted it more.

Tanya: Our idea (is) putting the notion of adopting the embryo into people’s minds. You would hope they understand and say adopting a child is no different.

Several recipients had attended CYF adoption workshops, either because they had pursued adoption as family-building, or because their counsellors had

recommended (some even insisted) that they take these courses to prepare for ED. The workshops reinforced constructions of ED as adoption.

Jenna: We actually had to go and do a 3-day course with Child Youth and Family...

Kieran: It (CYF course) was a requirement for us to accept what we were undertaking, and it was an adoption.

Zelda: The CYF courses were excellent in terms of coming to terms with ED because we really felt like it was moving on the continuum towards adoption.

Recipients thus readily drew parallels between ED and adoption, but constructed ED as better than adoption. Tim termed ED as “*adoption with benefits*”; Deborah framed it as “*Grow your own adoption*”; and Zelda commented, “*We heard about ED, and we were thinking that that’s a much better option than adoption!*”

Recipients also constructed ED as offering better chances of success; it allowed them to experience pregnancy, birth, and the parenting of a young child, and it was constructed as a potentially less complex process. I discuss these aspects next.

6.2.1.4 Recipients: ED as ‘adoption with benefits’ - Success and cost: The economic discourse

Recipients constructed the likelihood of having a child through adoption as poor, given the small number of children placed for adoption and the large number of prospective parents. In contrast, ED was framed as a better option as there was a smaller pool of people interested in ED. Tim explained:

Tim: We were quite overwhelmed with how many people were keen to adopt, and given the number of successful adoptions, we just felt that our chances going through that route were not high. This way was actually easier in terms of there being a smaller pool of recipients than that went through adoption. So there was a higher chance that we would get chosen which was wonderful.

While recipients drew parallels between adoption and ED practice in that they needed to be selected in both, they constructed the selection for ED as less stringent. This was held to increase their chances of success. Deborah for example, commented that “*In adoption, (you) have to go through so much vetting. So this is better.*” Beth stated, “*I think it would be very unlikely to have somebody who would adopt out to a single person in New Zealand. They don’t need to do that -there are really good couples out there.*” On the other hand, Michael (for whom ED was not successful) stated his

reservation that the outcome of ED was uncertain: *“At least with the adoption, if it happens, you get something, whereas IVF is just false hopes all the time.”*

Extending the economic discourse, ED was constructed by recipients as less expensive than IVF treatment: *“Certainly cost-wise you haven’t had to pay for the treatment to collect those eggs and everything else, so it’s not as horrendously priced”* (Deborah); and (international) adoption, *“A very close friend of mine has a daughter she adopted from Russia but the costs are exorbitant”* (Tanya).

By framing ED as offering better chances of success and being less costly than other options, recipients positioned themselves as making rational decisions in pursuing ED.

6.2.1.5 Recipients: ED as ‘adoption with benefits’ - Gestational and birthing discourse: ‘Normality’, attachment, and control

Recipients constructed pregnancy and birth as desirable. For example, Nadia commented that *“I wanted to be pregnant. I wanted to experience that, and that was quite a big part of it as well.”* They allowed recipients to position themselves as being *“like any other normal couple”* (Tim), and keep their method of family-building private if they so desired. Zelda explained that *“For my husband (adoption) was more public that we were infertile, whereas egg donor can be pretty private, and embryo donor too really. It’s not the same level of everyone knowing you are infertile.”*

The gestational and birthing experience was constructed as facilitating a bond between parents and child. Deborah referred to the pregnancy as *“that chance to bond and grow with the child.”* Michael contrasted this with adoption:

If you had that choice, you’d go for the embryos, carry them and have it all. I think most women would want to carry a baby, rather than just meet, and go, ‘oh you have a baby, and you weren’t even pregnant.’

Recipients further drew on the gestation period as giving them control over the pregnancy and the development of the child, as evident in the comments below:

Sandra: The idea that we could get to still do the pregnancy and avoid some of the domestic adoption issues, as far as the way the Mum has carried the pregnancy, smoking, all of those health issues. It just all ticked lots of boxes...

Tanya: As my friend said, ‘I wish they could find a new term for ‘biological’ because she said you’re growing it, it’s your love and nurturing, and what you are eating and everything that is going into it, so that original biology’.

Recipients were thus able to assert their role as ‘good parents’ to the developing child. For Maggie and Beth in particular, their construction of ‘growing the child’ underscored their contribution, and thus the child as being theirs.

Maggie: Physically everything that went into that child to grow its brain, its fingernails, its skin, was going to come from me. So that was my child.

Beth: Even though genetically there’s nothing in the embryo of me, the fact that I would be carrying the baby, meant that I would put some genetic differences in the child than what they would have been if they had have been in the birth mother. That made me feel a lot better, because there would be part of me. A very tiny part, and nothing genetic, but there would be something that my body had done. Because otherwise I would feel like there’s no part of me in this child, and that takes quite a bit to get your head around.

Recipients positioned themselves more clearly as parents with full parenting rights by virtue of the biological link. As Kieran asserted, “(My wife) is going to be the birth mother, so in that sense and in every other sense that matters, she’s mum.” The importance of gestation for parenting status was emphasised by Jenna below:

I said that I would like to have a pregnancy portrait done of me with my bump because it is so special. It will mean so much to me, and to explain to the child as well later on: ‘You know, you were an ED, but you still were inside me, and you are going to be our child.’

Finally, ED meant that recipients could parent a child from birth, which was framed as less complex than parenting an older, adopted child that might have emotional or behavioural difficulties. Nadia commented that “*I just think with an older child, they are pretty damaged.*” ED allowed the ability to “grow with” (Beth) and bond with the child during what was constructed as a critical developmental time: “*I had done lots of research on bonding. That’s really important to me*” (Sandra).

By undertaking ED which allows for pregnancy, birth, and parenting a younger child, recipients positioned themselves more fully as the parents: the child was constructed as ‘more’ their child than in adoption. From this position, recipients framed themselves as having greater rights, and feeling less threatened than they would have had they adopted a child, as is discussed below.

6.2.1.6 Recipients: ED as ‘adoption with benefits’- Greater rights: It’s more our child

Recipients drew attention to adoption practices following birth and how these potentially undermined and threatened parental roles and parent–child attachment. Tim

commented, “*Even once you were chosen, it doesn’t necessarily mean that the mother will agree after the birth that she still wants to give the baby away.*” And Sandra said:

This 12 day stand down with domestic adoption would kill me, knowing that there’s a baby out there that’s going to be ours forever, but we are not able to nurture it for that first 2 weeks... whereas because of the way New Zealand law works, we had (our child conceived through embryo donation) the whole time.

For Deborah, the concern about birth parents’ rights was ongoing:

I always felt quite threatened myself about open adoption, because you’ve adopted this child, and you’re the parents, and then you’ve got the birth mother interfering. From what I can understand they can. I know there’s meant to be boundaries, but you can’t control people’s emotions or how they behave, and they’ve been quite invasive in the child’s life.

Beth’s experience of fostering likewise created anxiety about the rights of birth parents: “*You always had that parent in the background. They had all these rights. They’d say, ‘jump!’ and I’m the one who is jumping.*”

In contrast, recipients framed the rights of donors as more circumscribed. Several constructed adoption as proceeding from a position of the birth parents’ vulnerability: their inability to care for a child and their subsequent reluctant decision to put their child up for adoption. On the other hand, recipients constructed ED as proceeding from a position of power; as a proactive decision. This offered positions of greater security, as in Michael’s case:

With embryo, they are giving it up willingly; they’ve got what they want. It’s totally different, (the donors) are content and like well, ‘this is extra’. I think it’s, ‘well we’ve got our family we don’t need this, let’s help someone else,’ whereas adoption is, ‘I’m not ready’, or ‘I can’t offer it enough, you will do better’. So they might be a bit more clingy than (donors). I don’t think (donors) want much interest after. If you come round a bit, (donors) are, ‘oh, great, good to see you are doing alright’, whereas with the adoption the mother might always be questioning your decisions. So she would want to keep contact, and you would always be thinking maybe she will want him back.

Kieran, while earlier pointing to the similarity between ED and adoption, emphasised the difference, saying that “*I know some people, if you look at it objectively and you are looking in, you say ‘oh well you’ve adopted an embryo so it’s similar to a child’. No, it isn’t, it’s ours.*” For him, the child born through ED is more ‘their’ child than an adopted child is to adoptive parents.

The adoption discourse thus offered a framework through which to make sense of ED but recipients framed ED as preferable; it was ‘adoption with benefits’.

6.2.2 ED as building new family – extending the whānau

By constructing the child as still connected to the donors, and by framing disclosure and information exchange as important to the child's wellbeing, donors and recipients constructed ED as the creation of a new kind of extended family.

6.2.2.1 Donors: *We are family*

As has been discussed, donors drew on discourses of extended family to describe their relationship to the child. Donors framed themselves as “*Uncle and Aunty*” (Pamela); “*godparents*” (Lance); and “*your other family*” (Nicholas). Simultaneously, the children in the two families were constructed as full siblings, and in some cases, the donors' parents positioned themselves as the child's grandparents. By drawing on discourses of extended family and family constructs, donors were able to locate themselves as having some type of continued role in the child's life, almost a ‘right’ and ‘responsibility’ to involvement – just like extended family may have in ‘typical family’ circumstances. Mandy, for example, commented, “*If there had been silly stuff going on, we would probably be right in there. We were hoping we could help support (our recipients).*” Similarly other donors expressed a willingness to be supportive, just as would be the case in families generally. Pamela commented, “*If perhaps there's a short fall, and Z does need braces or something, as a family member, everybody sort of helps.*”

Donors' rights however were restricted to those accorded to adults in extended family circles, and so their involvement could be supportive but distanced. Yet by framing ED as creating extended family, the children from the two families were able to be brought into connection with each other. Mandy, for example, commented that “*We thought, 'Wow what a blessing for (our child). If A did have a brother or sister.' We thought, 'how unique'*” and she constructed the relationship between siblings as “*the kids were going to grow up together.*” Karen spoke of how their recipient “*wanted contact because she wasn't going to have any more children, so she wanted to have that extended family type thing, which was fantastic.*”

Donors not only drew on this discourse to construct their relationship to the child but also to refer to the relationship between the adult parties, as identified below:

Kimberley: We talked about it would be like a sister thing, but I don't have sisters... so it sounds a bit odd.

Roy: Instead of this 'donor couple and recipient couple', the (situation is) like a marriage of a family. It's more like your in-laws. You certainly are unwise to get married to someone if you absolutely can't stand the in-laws, regardless of which side it's on! If you don't like them, then you need to be very aware that that's going to be a problem, and it isn't going to go away.

Thus, it was not just the donor and child or the siblings that were brought into extended family relationship with each other, but the adults as well. The relationship between the families was framed as enduring. Janet commented, *"It's for the rest of our lives"*.

Building and developing this 'extended family' relationship, however, was constructed as taking time. For donors and recipients who 'found each other' through using online forums or mutual contacts, the relationship appeared to develop more naturally. For those who relied on clinics to facilitate linking, the initial joint counselling was constructed as significant. For example, for Otto and Dawn, it was this meeting that underscored their decision not to proceed: *"I don't think it would have been a happy marriage. She wouldn't have been easy to work around. She's quite strong-willed and forthright, so if anything didn't suit her she'd just sway her power. She was a little bit abrupt and difficult to work with in the interview, let alone further down the track. So that meeting is probably quite crucial. Unless you want to totally detach yourself from the child, you are going to have to work with that person at some level in the future."*

Donors regarded having just one counselling session within which to meet the recipients, discuss issues, and make decisions as to whether they could relate to them sufficiently to donate to them – to become extended family to them – as extremely difficult. Grace reflected:

What we found hard was that we met them for an hour or so in the joint counselling. We kind of knew that they ticked all the boxes, and we could tell that there was a connection there. So we decided pretty much then and there, but you are not allowed any contact with them. It's very, very artificial. We found that kind of hard, because we weren't allowed any further details until the ethics committee approved it. We were allowed no contact with them whatsoever. We weren't even allowed to go and have a coffee with them because you might exchange details. I can understand why they do that, because the recipients may put pressure on the donors and harass them. I understand all of that, but you still need to know if you can work with this couple, because it's a lifelong commitment, and if they are going to put pressure on you at that stage, they are going to give you grief later. You know then that that's not the couple for you. You need to know that before you've made that commitment, before it's too late, and you find that we have a child now and this is not the right couple; this

relationship is not working and it's too late. It's like a marriage that breaks in divorce, so you need to know... How can you make a lifelong decision like that? You don't go and meet a lady or a man and then say, 'I'm going to marry you and spend the rest of my life with you,' after an hour's meeting.

Other donors likewise commented on their difficulties in the same situation:

Jack: You are not allowed to form a relationship with these people that you are going to have a relationship with for the rest of your life!

Janet: It's very hard when you have only met these people two times. You are trying to build a relationship, as well as go through all this with them as well.

While most donors had had the experience of being 'allowed' to meet the one time only, some had met in other contexts. This was framed as helpful. Nathan, for example, commented, *"We went out and had a coffee in a café... that was the best thing we did; get rid of the formal context."* Several donors expressed a preference for greater contact to get to know the recipients more fully, and in order to make what they constructed as more informed decisions. Jack said, *"I think if maybe (clinics) could conference about that, the way you meet, the way you feel about the ongoing relationship, or how that relationship starts early on."*

Donors clearly constructed this meeting as the start of building enduring connections, which was again reflected in the use of 'family construct' words such as 'marriage'. However, some donors expressed caution as to using ED as a way of having another child within the framework of extended family creation. Grace commented, *"We weren't doing it to have another child in our lives. The main thing for me, is not to do it because you want a child in your life. If you've got a yearning to have another child, that's just not the reason to do it."*

For one donor couple, creating extended family in this way and having siblings growing up in different families worked well, and they expressed the belief that they could manage donation to a second family also.

Jack: The law at the time said we couldn't donate to two different people, and we were hoping that if (our recipients) were successful early on, and had had 3 or 4 kids and then used up their (number of) embryos, and then we'd have (number) left over, that we could maybe press the cause for changing the law to be able to donate them to someone else.

For others however, while the network of relationships created appeared manageable, the thought of extending this further was too complex. Janet commented that *"I am very pleased that you can only donate to one family. To start with I thought it*

was funny, but I think it would cause too many complications. I believe it is the right thing because you could end up having a relationship with this one and that one, and be comparing... and there would be siblings all around."

6.2.2.2 Recipients: We are family

Family construct words could similarly be identified in the talk of recipients. They framed the donor family as akin to step family, blended family, in-laws, the 'other' family, or aunts/uncles in order to define their relationship with them. Such constructs positioned the donors as relatively close to the recipients; the donors were "*our donor family*" and the child had "*two families*" (Wendy). Negotiating and defining the form of this extended family required some initial adjustment, as pointed out by Tim:

Actually, we call them family. The situation that I compared it to was like when you've got a daughter and she's brought home a man and said, 'oh this is the guy I'm going to marry.' Then you are meeting the in-laws and thinking, 'Oh golly all these people we've got to have a relationship with from now on.'

Positioning the donors as extended family allowed the donors to be sufficiently distanced so as not to present a threat. In fact, several recipients constructed the donors as occupying a supportive role. For Olivia, for example, the donor woman was a support when she was struggling with health questions related to her child. For Wendy, the donors provided support during her difficult pregnancy. She commented:

The whole way through, our donor family were very supportive of us. We felt like we shared the journey with them. There are not very many other people who have done this, so we don't know any recipient families. We haven't met anybody who has been through this, but our own experience is that our donors have been with us through it.

For Maggie, the donor woman became a source of support during her treatment:

Maggie: We kept in contact by email all the time, and she was really lovely, very supportive, really lovely emails. I remember saying, 'Oh I've got my trigger injection tonight' and emailing her. We became friends, and it was always really exciting emailing her and I would be waiting for her to email back to see what she thought and stuff like that. We definitely had quite a strong bond because of what we were about to go through.

For Olivia, the strength of the connection was reflected in guardianship decisions:

We finally did our wills, and we put down that in the event that we both die at the same time, the kids should go to my sister. I do have another brother and sister, but should they not be around, we would like them to go to (the donors).

ED was thus constructed as creating extended connections, even extending the family, in enduring and positive ways, as can be seen in the comments below:

Wendy: You could put aside your fears for the future, and think about that family love can be created like this... and then it just yeah, it was quite cool...

Kieran: They weren't going to buy into our lives. We didn't suddenly have this appendage... In actual fact, it enhances it.

Tim: I was very pleased that that could happen, and I really like the relationship we have today. It's wonderful.

It was interesting that several recipients spoke of maintaining relationships with donors when ED had not been successful. Indeed, where recipients went on to other options to have children, donors often remained a source of support. In some cases, when the relationship ended, recipients expressed sadness. Maggie commented:

I was really, really amazed because I really felt like we had a connection. I never heard from her again, and it still surprises me to this day. It's the strangest, strangest thing.

The construction of ED as creating an extended family enabled positions for recipients from which they could draw on the support of donors as extended family members, while not being obligated to have input from them. Positioning the donors as (some type of) family members however enabled social ties that drew the donors close to the recipient family in a potentially enduring way.

6.2.3 ED as gift-giving: Gratitude, indebtedness and reciprocation

Both donors and recipients drew on constructions of ED as gift-giving, which enabled particular positions in relation to each other, as is discussed below.

6.2.3.1 Donors: We have received a gift and we are giving a gift

Donors constructed ED as a form of gift-giving: as giving “*the greatest gift of all, life*” (Pamela); as giving “*them a child*” (Brian); as giving “*her the joy that I've got*” (Karen); and as making “*someone's dream come true*” (Grace). Their gift-giving was framed in the context of empathy, as they themselves had experienced the “*terrible journey*” (Mandy) of infertility. For some, their gift-giving was constructed as reciprocity; repaying the gift (of having children) that they had received:

Nathan: I was of the mind that these were a gift to us from God. So my way of thinking was to give them up for donation, and in my way of thinking, that's tantamount to giving them back to God, and he arranges what will happen.

Brian: We know what it's like to receive, and we know what it's like to go without (children). So what we wanted to do, was to give back.

Such constructions of ED as gift-giving enabled donors to align themselves with altruistic subject positions: they could construct themselves as generous and empathic, and expressed pride in what they had done. This can be identified in the following comments:

Jack: We are quite proud of it really; proud of being able to help someone.

Nathan: How many people can say that just in a little wee way, they have helped another family? That's pretty cool.

Lance: I feel like we did something really awesome for someone else, that helps someone else, and when we had an opportunity to do so.

However, constructing ED as gift-giving also evoked expectations. There was some anticipation of acknowledgement on the part some donors. This was reflected in several ways. The gift given, for example, was constructed as substantial. Frances commented:

It was quite funny when we went to visit (the baby). I said to my husband, 'What do we bring? What shall we bring— something exciting for the baby?' My husband just said, 'We gave them the baby, we don't need to take them anything else! There's our DNA!'

Some donors expressed surprise when they had to pay for services related to donation, and several anticipated that recipients would cover these costs in acknowledgement of the gift they were receiving. Jonathon, for example, stated:

I'll be honest. I was thinking that they would probably front up with that, because I thought it was pretty good of us. It was a good enough thing to give those away, and we obviously attended a counselling session, no big deal, but then being faced with the legal bill, I thought it would probably be absorbed by them (recipients). I wouldn't have said no if they offered, but they never did... It's no big deal, but...

Donors further anticipated that their gift would be acknowledged by respecting their ongoing interest in the child's life and by honouring commitments to openness, disclosure and contact. As Brenda said when reflecting on their lack of rights, "*We are giving a huge gift; (we should) not be taken advantage of.*" In one case where relationships soured between donors and recipients, donors expressed disbelief at the outcome and felt taken advantage of, particularly in lieu of what they had given.

*Pamela: How can you give somebody the greatest gift of all, life, and then treat them like this? **How can you actually do that?***

*Brian: We are the givers here. We gave, and **this** is how we get treated. It's not what this is about. It wasn't about us saying, 'Look, we'll give you money and you can bribe us and play contact with Z off against money.' You can't buy a child.*

Interestingly, one donor, Mandy, spoke of her recipient's guilt about the ED not working – as if the recipient had to 'repay' the gift by ensuring that the embryo became a child. In this particular case, however, Mandy also seemed to assume responsibility for the gift 'not working':

She was gutted when it didn't work; mainly she felt really guilty that she had let us down. It was terrible that she felt she had failed us by it not working; just the grief thing of guilt. But it was more like, 'Well, our embryo didn't work for you', rather than the other way around.

The construction of ED as gift therefore sets up expectations of each other within the gift exchange system of gifting-receiving-reciprocating.

6.2.3.2 Recipients: Gifting and gratitude, or service?

Several recipients made reference to the ED as a form of gift-giving: "It was this huge gift" (Tim); "It was just such a generous gift" (Nadia). The gift-givers, the donors, were constructed as generous and their motivations as stemming from kindness and empathy, as can be identified in the comments below:

Neil: Their reasons are very honourable, very generous. There's no selfishness there: It's just – let's help somebody if we can.

Nadia: They had been through treatment themselves, and they've had their (child) through IVF. They felt they wanted to give back. That's quite extraordinary, but some people are very altruistic. Very generous, kind, good.

Zelda: They are doing this really nice thing, and their motivation is really clear. It's not about money; it's purely altruistic. There's no other reason why. So it just felt comfortable, whereas I think contrasting that with the US experience, because I think money is involved, you've always got this question mark as to what the motivation is.

The construction of ED as altruistic and as gifting, rather than as 'selling' and 'buying', offered more comfortable positions for the donors, as well as the recipients, enabling them to see themselves as being moral and good citizens. On the other hand, a donation or an altruistic act by definition involves no expectation of personal gain or reciprocity. Constructing ED as gifting evoked a set of social ties between gift-giver and gift-recipient. Recipients in this study positioned themselves as grateful and indebted to

the donors. Nadia, for example, wanted to ensure that her donors knew how much she had appreciated their donation: *“It’s such a huge deal, and I just really made sure they knew how much I appreciated what they were doing.”* Deborah, when talking about a case of ED in the media, expressed the belief that the recipients should be grateful for the donation: *“You should be grateful you’ve got the gift of a child, let alone try and demand money.”*

In addition to gratitude, some recipients constructed their role as bringing the embryo to life. There was guilt when they could not fulfil what they framed as their obligation to the donors. Deborah commented:

I felt bad because I know when they donated they felt that each one of those was a potential child, which it is, and they wanted to give them the best possible chance. I felt like I was letting them down by not making the best of what I had.

Similarly Beth worried that her donors might have regrets because she hadn’t achieved a pregnancy:

Then I felt really bad for the donors, because I thought they had done such an amazing thing, and I’ve just wasted their chance of maybe... If they had put those embryos into somebody else, maybe they would have ‘caught’.

For others, gratitude at the gift they had received translated into a need to honour and respect the donors’ wishes around openness, disclosure and contact.

Tanya: I mean it’s such a huge thing they are doing – you owe it to them to be honest. I can’t imagine that we would cease contact anyway, because I acknowledge and appreciate what they have done.

Nadia: I would have been so immensely grateful if that had happened, that I would have had contact, or none, or whatever they wanted.

Through framing ED as gift, and themselves as gift recipients, recipients drew on gift dynamics, with some sense of obligation to reciprocate. On the other hand, some recipients resisted this position, framing ED as a service or reciprocal exchange, where both donors and recipients had their needs met: donors were able to use their embryos in an acceptable way, and recipients were able to attempt to have a child. Sandra, for example, commented that *“the idea that we could add to our family, and that we could help out this embryo that was stuck in storage.”* Beth mentioned that her counsellor had made her aware that *“The donors haven’t destroyed them for a reason. They want to try and give them a go, so they are having a need met as well.”* Further, some recipients constructed the donation as their donors ‘giving back’ the gift they had received, i.e. the donors had received the ‘gift’ of a child through their IVF, and they were reciprocating

through their act of donation. Nadia commented, “*They had been through fertility treatment themselves, and they’ve had their (child) through IVF- they felt they wanted to give something back.*” Such constructions placed donors and recipients in a more equitable position, with more evenly aligned positions of power and vulnerability.

6.2.4 ED as the ‘last/only option’/‘last chance, last choice’

How donors and recipients constructed donors’ decision to donate and recipients’ decision to try ED as a family-building option carried implications for their experience and the relationships between donors and recipients, as discussed below.

6.2.4.1 Donors: ED as last option, or as resolution?

Donors constructed their decision as occurring within the context of consequences that they had not foreseen or had initially avoided. Kimberley explained this as related to uncertainty around treatment outcome, and the difficult nature of the treatment. She said:

Didn’t think about it... because you don’t know how many eggs, and it all happens in a 3 day period and you have no idea how many they are going to take out, or how many are going to be fertilised or how many are going to be worth putting in, and you are full of hormones...

For others, such as Jonathon and Nathan, IVF and cryopreservation were logical steps in the treatment process as recommended by their clinics, and they felt swept along by the process. Nathan commented:

One step led to another, and we found ourselves in this process. So when we made decisions they were just responses to what was going on in front of us. There was no planned attack, no rocket science or anything! We did it, and didn’t know, and that was good because if we did know, we might not have gone down that track, the IVF, or whatever.

Constructing the consequences as ‘unforeseen’ positioned donors as disempowered, and for some donors this created frustration. Janet commented that “*What frustrates me the most when I look back, is maybe, I don’t know how feasible it is or not, but I really feel that did they need to fertilise all (number) of them in the first place? We wouldn’t be in this situation. It’s putting people into situations.*”(tearful)

Yet while Janet's comments appear to give responsibility for consequences to medical staff, several donors constructed the consequences as ones they had ignored, either to deny dilemmas or because of a determined pursuit of parenthood. For example:

Frances: The important part was to pick the one that's best and growing the fastest and best, and getting it back in. So embryos left over... No, no concern to us!

Dawn: I think I knew at the back of my mind, 'What would you do if you had too many embryos?' But you didn't even know how you would go, and whether you would have any success. You were really just geared to, 'Got to have these kids.' I'd do anything to have a child. You don't really think about it. You are delighted when you have got a good number of embryos, because that's what you are trying to get so that you give yourself a good chance.

Constructing the consequences as ignored positioned donors as vulnerable, even irrational in their pursuit of a parenthood goal.

Several donors constructed donation as their only viable option, particularly given constructions of the embryos as life, potential life, and investments. It was a restricted decision. Jonathan expressed the dilemma as "You've got two choices really: either flush them, or give them away." For donors this implied that "There aren't any others really" (Kimberley); "We didn't have a choice" (Brenda); or that "Nothing sits well" (Theresa).

At the same time, donors constructed the decision as enforced, because it eventually had to be made given the 10-year storage limit. Jonathan said, "You can't go on freezing the things forever. So we had to make a decision at some point"; while Cameron commented, "We are not sure if we would have done this if we were allowed to keep the embryos indefinitely, but that wasn't a choice. That choice is taken away from you with your 10-year limit."

Given such constructions, donors experienced difficulty with this decision. Janet said, "I just wish we didn't have to do this." Some donors constructed themselves as being 'forced into' a decision to donate, and this potentially had implications for their ongoing experience of ED, which included feelings of regret and ambivalence. Indeed, the decision was regularly constructed by donors as a fraught: one that was time-consuming (because there were so many issues to consider) and both difficult and painful:

Frances: To me it was heart-wrenching to give those embryos away, because I really wanted them myself!

Janet: It's a hard thing to do.

Donors also spoke about the difficulty achieving consensus amongst themselves as a couple. Nathan commented, *"It was quite tense and heated on occasions. We were both pretty set where we were. So that's why it took a bit longer."*

On the other hand, many donors were also simultaneously able to construct the decision as a rational or responsible decision. For many, the decision had entailed a considerable amount of deliberation, as well as uncertainty. As Isla said, *"It just kept going and going, and what are we going to do? Are we going to give them to science, or are we just going to get them to give them to us, and we flush them down the toilet?"*

Donors had reflected on the possibilities available, and had ultimately made a rational decision. As Isla said, *"We discussed the pros and cons, and the pros outweighed any cons that we might have ever had, and it wasn't a hard decision in the end."* This positioned donors as responsible adults, capable of making mature decisions. As Mandy said, *"I think at some point, you just take the adult decision in the end. You finish the process."* This cast donors in a more comfortable position, where they were able to frame issues related to ED as part of the responsibility of making difficult, but rational, decisions. Mandy framed this as *"a big decision. We didn't take it lightly, but we thought, 'Wow, what a blessing.' Sure there would be challenges, but they weren't going to be insurmountable; something we couldn't deal with."*

Several donors also constructed the decision as moral, as 'doing the right thing', which enabled them to be at peace with their decision. Karen commented, *"Life's too short to not do things if you think they are right really"*; and Brian said, *"Why don't we do the right thing? Why don't we give someone who has no chance, a chance?"*

Some donors constructed ED as meeting their needs. Frances commented:

I had to help myself, by helping someone else. Because the whole IVF was really painful, I hated it. So having those embryos just sitting there, doing nothing. I always told the mother that I wasn't just doing that from the goodness of my heart. I'm doing it for myself, as much as I'm doing it for her.

For Mandy and Isla the donation brought a sense of closure to their IVF journey:

Mandy: I remember the last day. We walked out of the clinic, and we knew that was going to be our last day ever at the clinic. It was such a good feeling, like we had done all we could do.

Isla: So it closes a chapter in our lives as well. That's it now; there's no more; there's nothing. Just another chapter in your life's story that's finished.

For some, there was ambivalence when donation was unsuccessful: they felt sad for the recipients, and sadness that 'their embryos' had not become children. Karen commented, "*When I found out, I was really sad for myself, and I don't know why. Then I thought, poor (recipient); it's over.*" However, there was also relief at not having to confront issues associated with having a genetic child raised elsewhere. Brenda said:

*It was the saddest, saddest thing, but in my own heart, I was also so relieved. I kind of felt it was really selfish, but we would have a biological child out there... that is **our own** being brought up by someone else.*

Mandy similarly described her relief when she later discovered a condition in her family with a strong hereditary component: "*We were upset at the time. (Later) we were grateful that the transfer hadn't been positive, that we, and (the recipients), weren't having to deal with the whole (hereditary) issue on top of things...*"

'Unsuccessful' donors constructed ED as bringing closure to their journey. However, for donors that donated successfully, while there was some degree of closure, there was also a sense of their fertility journey having ongoing issues and responsibilities. As Lance said, "*It's all part of the same process as far as I'm concerned; it's just the final chapter. Well, it's not be the final chapter. Who knows what happens in life?*"

Similarly Janet commented:

I do believe that what's to come will be possibly more challenging. Normally in life you make a decision and move on, but this is now of the rest of your life.

In this way, ED extended the issues associated with infertility indefinitely.

In sum, framing the donation as a positive, rational and moral decision, and donation as achieving a degree of resolution of the IVF journey, bestowed a more comfortable position on donors, potentially evoking less regret. Arguably, relationships between donors and recipients may be less fraught when the donation occurs against such a background. It was interesting that in interviews with recipients several reflected on what the donation decision meant to donors. Several had thought about how they themselves would construct donation if they were in a similar position. These constructions contributed to how recipients understood ED and their position in relation

to the donors. Donors' decision to donate was framed both as rational and difficult.

Michael and Kieran, for example, highlighted ED as a rational choice:

Michael: Most people that give them up or donate the embryos are content, so what's the point in storing them? What for? It's costing money and they are not being used, so you might as well use them for something good I think.

Kieran: Sometimes you have to draw a line under some things. Someone has to make the hard decision and say, 'OK this is what is going to happen, you might not like it, you might have invested a lot in it, but you just draw a line under it and say decision is made, live with it, move on, come up with another plan because that's the way it is'. You can't carry things on indefinitely on the 'what if?' You can do 'what ifs' for ever.

Most however constructed donation as emotionally difficult. Indeed, Maggie reflected that had she found herself in a similar situation, she would have struggled to donate, but would have done so out of a sense of obligation.

If someone asks me could I do it, I've said 'yes, but it would be really hard', and even for someone whose been there and had a donor embryo, it would be one of the hardest decisions you ever made. I think I would do it because I should, more than something I would really want to do.

For Maggie, there was a moral imperative to donate. Constructing the donors' decision as rational and moral enabled a subject position for recipients of security: donors were constructed as having made a decision with which they are comfortable, and hence about which they were unlikely to have ongoing concerns. Donors were thus positioned as unlikely to challenge recipients' position as parents. In contrast, constructing the decision as difficult and emotional potentially created anxiety for recipients about whether donors would regret their decisions. Donors were more likely to be perceived as threats from within this position. Maggie seemed to be attempting to manage this threat when she explained her donors' decision to donate as reflecting a lack of emotional connection to the embryo.

So this couple must be quite cold? Not cold, quite detached. Yeah, but I don't think they had made a huge attachment to the embryo to be able to give it away.

This may have offered her a position of greater security in her parenting status.

6.2.4.2 Recipients: ED as last chance or as last choice

Many recipients framed ED as their last opportunity to have a child, as "last stop stuff" (Deborah). It was also constructed as initially being "something that we couldn't even contemplate" (Jenna). Deborah commented that "For a lot of people, it is probably

their last chance with that ED, and probably their last choice as well.” ED was framed as something that had to be built up to gradually. Kieran explained:

There are different ways of breaking news. If you allow the person to become accustomed or acclimatised to a condition, it's not a big leap to introduce something else, and then another step, so you are just taking small steps. If we went into the clinic and the specialist turned around and said, 'Actually you are not going to have kids, you might just as well adopt an embryo', I think that whole idea would have been a lot harder for us to take on board. It would have taken a long time, and probably we'd never have got to where we are.

For some, the availability of this option presented a dilemma as they grappled with drawing boundaries around their continuing attempts to have a child. The option of ED, while offering hope, also extended their journey towards having a child, possibly making it more difficult to resolve. This is expressed in the comments below:

Deborah: We had actually said with (our child's) replacement, if it doesn't work, that's it. We are not going down that track anymore. It's too hard for everybody involved. This is it, no more. You have to draw a line, otherwise you just keep going on forever and become obsessed. Not only the cost, but the emotional toll.

Beth: I had got to that point where I thought, 'This is it, I've done it, I've tried it, it hasn't worked, I need to move on.' So I actually got a hell of a shock when I got a call from the clinic, and the first thing I thought was, 'Oh, do I want to go through all that again?' when I had put it behind me. There's always one more thing, and I didn't know if it was a good thing or a bad thing that there was one more thing because I had decided that that was it, over.

Some recipients, such as Maggie and Kieran, reflected that even though ED was a last resort, they had been willing to try anything.

Kieran: Emotions run high and if you turn around and say what would you give? Is there a price, is there any cheque that you wouldn't write out? Is there anything you wouldn't do? I'm not being flippant, but people steal babies because they want a baby, such is the drive, so when you put that up against what's best...

Maggie: But do you know what? If someone came to me tomorrow and said 'Do you want to do a donor embryo transfer?' After everything I've been through, if (my partner) said I could, I still would. After everything. I don't know why.

The availability of ED offered hope that recipients could have a child. However, its availability potentially contributed to recipients positioning themselves as *obligated* to pursue ED. Failure to try ED could cast doubt on their desire to have a child, and ED's availability created a difficulty in setting a limit on pursuit of treatments. This underscored the position with which those who undergo fertility treatments potentially

find themselves aligned: with the ‘mad, bad or sad’, willing to go to any length to have a child. Recipients were thus in a potentially ambivalent position.

6.2.5 ED as novel

Both donors and recipients drew on a discourse of ED as novel. This positioned them as pioneers, with implications for their experiences of it, as discussed below.

6.2.5.1 Donors: *New and unknown*

Donors constructed ED as novel and that were no guidelines to follow. Mandy said, “*There’s not a rule book for how embryo donation works*”. Grace commented:

You’ve got all the stuff in America and England where it’s completely different from here, and the clinics won’t put you in touch with anyone else who is going through the same thing as you, so you are bouncing your thoughts and ideas off family and friends, who really have no idea.

Such constructions evoked uncertainty, with donors facing unknown implications that they could not plan for. Rather, donors constructed and positioned themselves as needing to deal with issues as they unfolded. Janet commented:

It’s just going to have to happen as it happens, and just whether it’s right, wrong or indifferent, it’s just something you have to deal with at the time. I don’t think there is any set process. You could write something and say ‘do it like this’ but all people are different, situations are different, and you just have to go with that.

Constructing ED as novel and unknown aligned donors with pioneering positions. As Mandy commented, “*You just have to have faith that it’s going to be ok. And just be pioneers, and explore a path and make it work.*” Pioneers go where others have not gone, and may face “*all sorts of scenarios and possibilities and unexpected things*” (Janet).

Most donors positioned themselves as equipped to deal with this position. Kimberley and Nathan, for example, positioned themselves as follows:

Kimberley: Most people can’t think for themselves. They don’t like to be trailblazers. That’s a weird thing, I can’t understand that.

Nathan: I’m always wanting to try different things, and I get myself into trouble for it every time! We can put a lot of different experience notches on the belt, different things that we’ve done in our lives which are different from normal.

Kimberley's partner framed this as having the necessary qualities to be a pioneer:

Some people aren't wired that way at all. There are only a certain amount of people that think like you in this world, but not everyone will be in that scenario. They won't have that drive because that's not their personality.

For most, being pioneers was a difficult and lonely – but also positive – position. Nathan described ED in terms of “*What a privilege.*” For Brian and Pamela, the experience had not been positive, as reflected in the exchange below. For them, until safeguards more closely approximating adoption are put in place in New Zealand, ED should not proceed.

*Brian: ED in New Zealand is **wrong** – full stop – and until they get their act together, there should not be one more single ED in New Zealand. **No one** is protecting the rights of the child that result from it...*

Pamela: When it's done right I think it can be successful. There are successful adoptions. In theory, this is basically the same: you have a child evolve, you look after it – but there have to be things in place.

6.2.5.2. Recipients: Scary and unknown; exciting

Most recipients constructed ED as unknown; something that they had known little about. Wendy said, “*We'd never actually heard of it*”; and Nadia, “*I didn't even know it existed.*” Beth described her experience of trying to find information about ED:

There's not a lot of (research) about. Obviously when you are in this situation, you do look around, but I haven't found a lot that I have felt has pertained to me, but that's just one of those things. You put in 'embryo donation' and it comes back with things like cattle!

ED was also constructed as something that could unfold in unknown ways. Beth commented that “*You don't really quite know how it's going to be*”; and Kieran that “*For all of this discussion, all we are doing is absolutely speculating on the future, because truth be told, you don't know how people are going to react.*”

While most recipients positioned themselves as willing to tolerate this uncertainty, discursive constructions of ED as engaging in the unknown created anxiety about the future. Zelda commented:

We could have this lovely meeting now, and then everything could be completely different. The motivations are all good, but then it could all go pear shaped. You

don't know how people are going to respond. You just don't know! It's so new, and can you really think through all the implications in advance?

Some recipients constructed the novelty of ED and lack of information about it as contributing to a lack of understanding or a negative judgement from others.

Jenna: But the few people that we have mentioned the process to, can't really get their heads round it and don't understand it at all.

Zelda: They said 'No, no, we would never consider that option'... I don't know, but they were very anti it, very uncomfortable with it.

Others emphasised people's increasing willingness to accept alternative forms of family-building. Beth said, *"I think that maybe these days it's more accepted, which is great that families are made up in a whole variety of different ways."*

For some recipients, however, ED was constructed as potentially violating the natural order of things, as being *"science fiction"* (Tanya); *"like space age, scientific playing with nature"* (Maggie). Maggie further expressed this as follows:

I think we almost felt – that what we were doing wasn't right; it was wrong. It was almost a bit against the way of nature.

For Zelda, IVF itself had been difficult, as it involved *"going off the natural way"*. Pursuing donation subsequently was *"a leap because that was, OK, this is like suddenly we're involving someone else."* Such constructions were anxiety-provoking. Other recipients constructed the unknown, novel nature of ED positively, as reflecting scientific advances. Jenna said, *"It's just pretty amazing really. We've got to a point where medical expertise allows us to do this."*

In their decisions to proceed with something 'unknown', recipients drew on their constructions of the ED process in New Zealand as something they felt was morally acceptable and well regulated. Kieran said, *"I think they are leading the way. I think it's the right way to go. It's morally correct, and it's ethically correct."* Constructing the ED process in New Zealand as regulated mitigated some of the anxiety involved, although some recipients continued to hold concerns about the novelty of the procedure in terms of their children, and what it would be like to be born from ED.

Olivia: I wanted our (child) to know someone else (who has been born this way). Because there's egg donor children groups that get together. I didn't want him/her to think he/she was on his own.

Others were able to hold on to constructions of ED as new, but special, in reflecting on their child/children's experience. Sandra reflected:

It's not something we are ashamed of. We are proud A's got such a special history. And we want A to grow up also being proud of that, knowing that A was so much wanted and we went through all of this to get A, and that A's so lucky to have the genetic family that (our child's) got contact with.

Such constructions enabled conflicting subject positions: constructing ED as a novel advance in reproductive treatment offered the position of a pioneer embarking on a new journey in pursuit of a dream, and being fortunate to have access to such novel options. Constructing ED as unknown and as potentially violating the natural order, conveyed a subject position of being foolish – 'going where angels fear to tread'. Both positions created feelings of loneliness and anxiety.

6.3 Discursive constructions of ECART and counselling

In my interviews with donors and recipients I was interested in how they constructed the mandatory counselling and ethics application as these may have influenced their understandings and experiences of ED. As I identified similar discourses for donors and recipients with regard to the role of counselling and ECART, I present them in an integrated form below: first with reference to ECART, and then to counselling.

6.3.1 ECART: 'Safety net' versus 'Big Brother'

Many donors and recipients constructed ECART as a 'safety net', as an objective committee that would provide a measure of control and sanction over ED applications. Nathan (donor) commented:

We had to really prove that we had our thinking straight, and what we were doing, and what we were going to expect legally, from the ethics.

Wendy (recipient) said:

You have some objective outsiders looking at your application and making sure it all fits together. It does seem fair to any resulting children that lots of professionals are looking at the situation, because we only ever see our side of the application. Even having a full and open relationship with our donor family, we never see their part or any of their counselling, so I imagine outsiders could

look at both our notes, and say well at this point the donors said this but the recipients said this.

Likewise Dawn (donor) pointed to the necessity of an independent body reviewing applications:

I think it is such a big decision that having an independent view is important. They obviously don't just rubber stamp; they take it very seriously. So I think having that third party is probably a good idea.

The 'safety net' discourse provided reassurance that the 'right' decisions were being made; that ECART would ensure the "minimising (of) any problems that might occur" (Jonathon [donor]). This can be further identified in the following comments:

Wendy (recipient): They are double-checking it and making sure that it's all ok... that they would pick up anything that might cause a problem in the future.

Deborah (recipient): It stops silly things happening.

Nadia (recipient): That's where the ethics committee comes in, otherwise there could be all sorts of stuff going on around the country.

In this way the discourse of ED as complex, as novel, and as having unknown implications was underscored. Donors and recipients were positioned as sensible in seeking sanction from ECART. If ECART approved, then donors and recipients constructed the ED as appropriate, assumed that both parties were suitable for ED, and that the possibility of future difficulties was minimised. ECART was thus invested with authority in providing an oversight role.

Several donors and recipients struggled with the role of ECART, however, constructing the committee as 'Big Brother', controlling major aspects of their lives in an authoritarian manner, as is evident in the comments below:

*Kimberley (donor): Well for me if I see something that obviously is so right, then **why** should I have to convince anyone? Is it necessary? I don't know? What are they doing? Sitting around drinking cups of tea saying yes or no? It's like they're playing God, so what is the point of that?*

*Maggie (recipient): This was these group of people saying I was worthy of this embryo and I just couldn't fathom how someone who had never met me could think that I was worthy enough or my infertility was worthy enough of this embryo. It kind of frustrated me **so much**, because I thought, 'How can you, as a group who don't even know me,' (and that's what it felt like), 'Is she worthy? Is she a good enough case for it?'*

For Grace (donor) and Sandra (recipient) there was frustration in that they constructed themselves as disempowered in contrast to birth parents:

Grace (donor): Why can the ethics committee tell us what we can do with our embryos, when had I given birth to them, no one else would have batted an eyelid if I went and adopted them out to (number) different families? I don't see why a boardroom full of people should be able to dictate what we should do with our embryos, when in an adoption it's just a mother that has all the say. Yes, she gets counselled and stuff, but at the end of the day, she has all the say, and there's no ethics committee involved.

Sandra: When did these people (referring to donors), as genetic parents, get their parental rights to choose who raises their child? Because with domestic adopting they have the rights to choose, within reason, someone who raises that child. So because they were holding an embryo at the very first stage of being a child, that parental right to choose who raises it, was essentially being taken away from them by the Ethics committee.

Donors and recipients questioned the rights of committee members to make decisions about their lives, given their experience, qualifications and possible motivations. Frances (donor) referred to the committee as “*just some random bunch of very clever people who were playing God.*” Grace (donor) expressed concern as to their relevant experience, and Kimberley (donor) and Tanya (recipient) as to their financial investment in IVF. And Jonathon (donor) wondered, “*How long do they spend actually looking at the stuff? Is it half an hour to review some reports, and they all have a show of hands?*”

ECART members were thus not necessarily constructed as objective and neutral. Further, the cost, bureaucracy and timeframe associated with the ECART application were framed by recipients as adding to the burden of their journey rather than as serving the function of ‘protecting’ the various parties’ interests. Maggie commented:

*I can see why we are doing it: We are trying to protect people, but when it came down to it, whatever they did, of all of those things they put in place, nothing protected me from the pain. If that wasn't there, would the pain have been worse? **No.** Would the pain have been less? No, it would have been exactly the same. In fact it might have been less even, because the whole process had built it up.*

Through constructing ECART as ‘Big Brother’, donors and recipients were positioned as disempowered and many expressed frustration. Tanya (recipient) commented that “*You feel very vulnerable; you don't have any say*”; and Maggie (recipient) said, “*I like to be in control and I think that's the whole thing of infertility; you have no control. But this was even further removed from my control.*”

Some donors actively resisted this position, and attempted to regain some of their perceived loss of control by asserting their right to make decisions.

Grace (donor): I'm pretty sure I remember we got an email saying that ECART had approved it. It was like 'Ppfff – you'll be hearing from me if you didn't. I'll fight a fight if need be.' That's unnecessary stress!

The opposing discursive constructions of ECART as 'Big Brother' and as 'safety net' both however positioned the committee as having a degree of responsibility for the outcome of ED. Donors and recipients were potentially aligned with 'good parent' or 'good citizen' positions by having obtained ECART approval for donation. But both donors' and recipients' confidence in ECART's role appeared somewhat undermined as they reflected on a case that had appeared in the media. Zelda (recipient) commented that '*Obviously in the case of that Sunday programme that got approval, it's all gone difficult, and well, ECART approved it! So how valuable is it?*' Brian (donor) commented, "*It's like Toyota making a car that they knew was dangerous, but still selling them on the lot anyway.*" Such constructions created anxiety about the longer-term implications of ED.

6.3.2 Counselling: 'Sounding board' versus 'rubber stamping'

For most, counselling was constructed as beneficial for working through issues and for providing a 'sounding board'.

Zelda (recipient): I really can't stress how important that was. This stuff is so complicated. You so need fertility counsellors, and not just a regular counsellor who doesn't understand all the issues.

Jack (donor): I'm a (X), and sometimes when you are (working), it might be that you know what you are doing, but you still bounce that idea off someone else. You can still say, 'Should I do this, this and this?' You know you are doing the right thing, but it's having that sounding board there to just reassure you. (The counselling) brought things out into an area where you could discuss it. So they made us look at things in depth a bit more; expanding things.

Counselling was constructed as helpful in nurturing an objective or neutral stance, as identified in Kieran's (recipient) comments:

Your emotions run and you go, 'OK I'm looking at this subjectively; you are looking at it objectively. Am I going to trust your judgement? Because at the end of the day, do you want a child unconditionally regardless of what the risk is like; are you that desperate?

Counselling was framed as important for donors and recipients individually, as well as to address the issues that could occur between donors and recipients. Zelda (recipient) described it as *“the glue between you and the donor or vice versa; it's too close otherwise.”* Jack (donor) commented on the role of counsellors in mediating:

If there's an opportunity that things aren't going to happen, and you want to pull back from it, then they are there to support you with that decision so it makes it a bit easier. It's a bit of a safeguard.

In this way, counselling was constructed as providing sanction for ED, from which donors and recipients drew reassurance that they were ‘doing the right thing’. Counsellors were positioned as assessors, controlling access to ED and managing the relationship between donors and recipients. This can be identified in the comments below:

Deborah (recipient): You would expect the counsellors to have vetted the people. I think, in those situations, or look at similar backgrounds.

Kieran (recipient): We have to be respectful of the fact that they are the experts. They know what they are doing, and it's easy to sit on the outside, ignore the details or complexities and go ‘Right, this is what you ought to do’. The fact that it's not viable or feasible, or it's just bloody insane. We were faced with a situation where someone wanted to donate, and we were desperate. We were told that there were going to be ramifications if we did. We actually contemplated the fact that we will deal with it, and we had a counsellor who said, ‘You do not want to do this’. ‘Oh yeah we do’. What price wouldn't you pay?

For one donor, Janet, the counselling was constructed not just as implications counselling, but as ‘pushing’ her to proceed with ED, as is evident in her following comment: *“I just feel they push you along... and I felt they kept pushing whether you felt emotionally ready for it or not.”* This positioned counsellors in a role of responsibility, and as potentially accountable for longer-term implications of ED. Some also constructed counselling as having a longer-term role, managing issues either where ED had not been successful, or in terms of managing challenges related to ED. Nadia (recipient) commented that there was a need for *“a bit of support afterwards. Potentially, there are people that might not be offered that. That would be quite a failing if you let people just coast off and come to terms with it -because it quite a big build-up beforehand, so post-counselling might be a good idea.”*

Discursive constructions of counsellors as experts and assessors bringing the implications of ED to the fore, and assessing suitability for ED, served to underscore the complexity of the ED process. This potentially positioned donors and recipients as

‘responsible adults’ by consulting with counsellors who have knowledge in the area. However, it also positioned them as vulnerable and disempowered: as needing support to facilitate their decisions. Some donors and recipients resisted this position, and constructed the counselling process as an obstacle, as unnecessarily bureaucratic, and as undermining their own decision-making power. Maggie (recipient) commented:

I think it was over the top. I think that by the time you make the decision to have a donor embryo there’s nothing more anyone can tell you. It’s a huge decision, and generally by the time you’ve made that decision you’ve been through such a lot already, that I don’t see what you are going to get out of that counselling.

The ability to engage honestly with the counselling process and use it for implications counselling was also framed as uncertain. As Tanya (recipient) commented, “*You are a bit limited in terms of what you can say in front of the counsellors.*” Since counsellors were cast as assessors, this undermined counsellors’ ability to provide objective, independent counselling.

For donors who had met independently prior to applying for ED, counselling was constructed as a formality, a ‘rubber stamping’ process:

Kimberley (donor): It was just a formality really, sitting there and repeating so they could write it in a report.

Jonathon (donor): We had thought it through really carefully, so for us the counselling sessions were easy, because we had covered it all in our heads.

The process of ED application (including counselling, legal consultation, and ECART application) was constructed as time-consuming and intensive. This was varyingly constructed as necessary to facilitate a thorough process, with Mandy (donor), saying, “*We felt each step made it – you are going into it really consciously*”, as well as onerous and off-putting, with Frances (donor) commenting, “*If you know from the beginning what you had to go through until the end, you probably wouldn’t want to go there!*”

6.4 Extra-discursive factors: Embodiment, personal-social factors, and material conditions

In analysing donors’ and recipients’ talk, particular personal, social and material conditions that created ‘potentialities’ for individuals to invest in particular discourses of ED and not others could be identified. These included experiences of embodiment,

reference to personal history and background, and material conditions. While these ‘factors’ may and were themselves discursively constructed, and I discuss them using discursive language, my particular interest was in how they provided a context through which investment in particular discourses related to ED could more readily be understood. It was in this sense that they were ‘extra-discursive’.

6.4.1 Embodiment

6.4.1.1 Fertility journey

On being asked to talk about their ED journey, donors and recipients began with descriptions of their journey towards having children, and accounts of their reproductive history. Most had had significant difficulties in conceiving a child, and many had undergone years of treatment and a vast range of treatments. Many had experienced significant losses along the way, including miscarriage, ectopic pregnancy, and stillbirth. These experiences of embodiment were given a critical role by both donors and recipients in facilitating their pursuit of ED, i.e. they provided a context in which certain discursive constructions of ED were more readily enabled. For donors, it was their experiences of infertility that enabled ED as a possible option – a way for them to assist others undergoing similar difficulties. Grace, for example, commented:

We were doing it because we'd been in that bad space of not being able to have children. It took us X years to have ours, and we knew how heart-breaking and soul-destroying it is.

For recipients, it was their experience of having pursued many other options that created the conditions for ED to be constructed as a possibility. Maggie commented how IVF had changed her, and made it possible to consider building a family using ED:

If that had been there at the beginning of my journey, I don't know what I would have said, because I was such a different person at the beginning of the journey. It changed me. X years has changed me so much from the person that I was. I've grown through things, but I've definitely become a different person.

6.4.1.2 Health

Donors and recipients made reference to health factors and complications with pregnancy and birth as factors in their decision-making. Donors discussed circumstances in which they were advised by doctors not to use embryos, or where they felt unable to use them because of a threat to their health and/or a baby's. Rachel

commented, “*I’m not allowed any more*”; while Jessica stated, “*The doctor said when you have premature births, the risk is quite high, and it gets earlier.*” Catherine framed her difficult pregnancy and birth experiences as “*I can’t go through with it again.*” Health complications thus created a context in which donors were more readily able to make a decision in favour of ED.

Recipients likewise cited health factors and fertility issues as enabling ED, as well as making it difficult for them to pursue further ED. Wendy reflected:

There might be a physical stopping point, even though it's not to do with my own (eggs), and the maternal age (for the embryos) is frozen in time, but what my body is capable of. If all the pregnancies were going to be as difficult, could we cope physically?

Such factors affected recipients’ investment in discourses, e.g. while for Tim and his partner the embryos were framed as life, the threat to his wife’s health and the wellbeing of his children relegated this discourse into the background. He said:

I don’t want to be conceding more just for the sake of the embryos, if it is going to have a large effect on our current family. That’s important to me: that our children are safe and happy, and not being deprived because of this feeling that we have to give these embryos a go, that we can give the best of ourselves to the children that we already have.

6.4.1.3 Age

Donors and recipients constructed age as setting limits on their ability to pursue reproductive options and to parent young children. For donors, age was a factor limiting their ability to use the embryos and become parents again. Nathan said:

But by that time, I’m (age) this year, so I don’t want to be going in to high school when I’m retired. Not a good look! I think age was the biggest (factor), and the fairness of the child at the other end of life as well. Would you be around to support them, if you were a lot older? To leave a child at 20? I wanted the quality with my children, and not being a really, really old dad.

Recipients were likewise very aware of medical discourses surrounding the influence of a woman’s age, and constructed this as setting limits on their ability to pursue reproductive options. For some, increasing age, and clinics’ restrictions around access to fertility treatments based on age, were factors specifically linked to their willingness to pursue ED. As Beth explained, ED became an option because “*They basically said to me at the end of that point, ‘your eggs are getting too old.’*”

6.4.1.4 Having children through IVF

Having children through IVF and having seen the realisation of their embryos' potential was a factor that donors drew on in their decision to donate. For example:

Theresa: Maybe if X was the third attempt that might be different. Maybe I'd think, 'OK some work, and some don't' – but my child was first pop.

Kimberley: So we had this embryo... It's a child, so I suppose the same as (recipients); some people don't see them as children but because we always have big, big healthy children, we knew it would be healthy.

Having had children from IVF led to the embryos being seen as viable, as having value and potential that needed to be used.

6.4.2 Personal-social factors

6.4.2.1 Adoption familiarity

Familiarity with adoption or alternative family-building methods (such as gamete donation) provided a context for willingness to pursue ED. For some donors it was experience with adoption, either in their own family-building or that of family or friends, that made the prospect of ED more likely. Brian commented, "*We were recipients of X, (an adopted child). We know what it's like to receive, and we know what it's like to go without (children).*" Likewise Frances explained:

So because I had so much to do with people having surrogate babies, just about all my friends were surrogates or with IVF related children, or adopted children. So there was always that sort of talk; that didn't feel odd.

All of the recipients in this study had had some experience with adoption, either through their own family history, having friends who were adopted or who had adopted children, or through pursuing this as an option themselves prior to considering ED. For example:

Nadia: There are quite a few adopted children in my wider family. My mother was a foster child, so I wasn't worried about that.

Sandra: My Mum's best friend adopted both of her kids and I was brought up in Christian church circles, and so adoption was always something that was talked about. I always knew of people who had gone overseas and done this and that, and I possibly had a couple of friends at school that were adopted. It's something I guess that has always interested me, and I have been open to. So, when we were stuck ourselves, that was something we looked into.

Experiences such as these provided a framework with which to understand ED, making a novel practice less unfamiliar. Such a framework also provided a blueprint for the way in which donors and recipients expected ED would proceed: with disclosure, openness, and possible contact. Two recipients explained:

Wendy: We got that perspective on what a child might need or want: that connection with their genetic family. We came into it from that point of view.

Maggie: I think that came from one of my boyfriends at school; long-term boyfriend. He had been adopted, and the search for his parents was so painful and destroying of a 17 year old boy, that back then, if only I knew what direction I was heading then... I think that really affected me.

Many recipients also made reference to the CYF adoption courses on offer in New Zealand and how this shaped their thinking. Refer back to Zelda's comment in section 6.2.1.3 where she comments how the courses helped her 'come to terms' with ED. Similarly, Jenna said "We were open to that thought process a lot more when we did the course."

Some recipients had done these courses in the process of seeking to adopt; others mentioned that their counsellors had encouraged them to take them. Likewise, knowing that recipients had had some experience with adoption or alternative family-building, or had attended CYF courses, increased donors' willingness to consider donating as it was seen as a factor that would allow the ED to proceed under the conditions they desired. Cameron commented:

One of the driving factors that I really liked about this couple, and I think my decision would have been different if these circumstances didn't relate to this couple, was X has a sister adopted, so he was brought up in a family with an adopted child all his life. He knows what it's like to have a non-genetic sibling.

Familiarity with adoption brought to the fore possible similarities in the two forms of family-building, underscoring discourses related to the welfare of the child and adoption, and providing a model for two families coming together.

6.4.2.2 Family completeness, having other children, and life stage

Having completed their families, or having reached the stage of life where further children was not an option, were factors that affected donors' ability to invest in a donation decision. Lance commented, "You go through your life and you get to a point that you've got to have some time for yourself and the kids are older." Likewise Stephen stated:

We got to the stage that we felt if anything happened that we wouldn't go back down the track and have more kids, so what are we going to do?

Note however the dilemma faced by one set of donors who conceived naturally after they had proceeded with ED: “*So here I'm pregnant, and I'm trying to give my embryos away*” (Frances). In her case however, since she had wanted more children when her husband did not, and this made the donating easier:

It made the process of giving those embryos away so much easier. I could imagine I would have been a bit more heart-wrenched to give them away otherwise, but I was committed to it because I knew I wasn't going to be able to use them.

6.4.2.3 Religion

Religious affiliation placed some donors in a position in which they were more readily able to make donation decisions, in that it enabled an investment in the discourse of the embryo as life that needed to be realised. Jack and Nathan explained this as follows:

Jack: To us, God created life, and in our minds we had an obligation, if we could, to help them come to become living things.

Nathan: I know that I am under a higher power, and at some point I'm going to be accountable and have to explain, particularly in a family situation.

For Nathan, thawing was constructed as not “*giving them a chance to be what God intends them to be.*” For some recipients, religious beliefs underlay their constructions of the embryos as life, and thus they were invested in pursuing a family-building option that would offer these ‘life forms’ an opportunity to become children.

6.4.2.4 Media case: ‘Donors warn over lack of rights’

In 2011, the New Zealand current affairs programme *Sunday* had an item entitled ‘Donors warn over lack of rights’ in which donors reported that they had been denied contact with the donor-conceived child under difficult circumstances. Several donors and recipients made specific reference to this programme, and how it had affected them and their constructions of ED:

Cameron (donor): I don't know if you saw the programme Sunday, about that couple that donated and the other people wanted the money, and they just cut them off. Ooohhh. But we are sure that's not going to happen in our case, but it still gives you a fright.

Janet (donor): The TV programmes frighten you...

Zelda (recipient): I've seen that Sunday programme now, and I think well OK, we could have this lovely meeting now, and then everything could be completely different... so that was a real eye opener.

Olivia (recipient): People have always got it in the back of their minds, 'that could happen to us!'

The programme highlighted the possible complications of ED and created anxiety and uncertainty about outcomes. However, what was interesting in the reactions of donors and recipients was how they distanced themselves from the scenario in the programme by highlighting the differences between themselves and the couples involved. Both donors and recipients drew on constructions of similarity with each other, and the existence of good relationships and clear expectations. Janet (donor) commented:

There was quite a disparity between the two families. That's what struck me straight away. I thought 'Oh my God', but then came away thinking about the disparities. Whereas I don't feel like that with our situation at all.

In other words, donors and recipients' investment in achieving a fit between donor and recipient families was underscored. So too were constructions of ED as adoption, and thus in need of the same checks (such as home assessment).

6.4.3 Material conditions

6.4.3.1 Financial factors

Financial factors were frequently referenced by donors as providing a context for ED. Frances and Nicholas cited the fees for extended storage as a factor:

Frances: So when that bill kept on coming, I had already said to my husband, 'Should we look into embryo donation?' You may not think about them for a year, and then the bill comes in and it's quite expensive just to store them again. That's when it all started to kick off again of course.

Nicholas: We just couldn't afford to pay to keep them in storage.

Jessica referred to the cost of having children, saying, "We have a 2 bedroom house, so it would be too small for one more, and I think (number) is expensive enough already." For some donors, being asked to pay counselling or legal fees challenged their constructions of ED as a gift and service to the recipients. For some recipients, it opened up the possibility that donation was also a service for the donors.

Likewise the amount of money recipients had spent was frequently mentioned. ED costs significantly less than other options such as further IVF cycles or international adoption, and recipients made reference to such factors enabling their decisions to proceed with ED and allowing them to frame ED as ‘adoption with benefits’.

Beth: It was just too expensive to go down that route (international adoption), after I've spent so much money.

Financial issues were also factors that influenced recipients' experience of ED, and their constructions of the rights and responsibilities of each party. For example, in some cases, recipients had been asked to cover some of the costs associated with the donors' donation, e.g. counselling fees. Maggie commented:

We would be paying the couple's lawyer's fees as well as our own lawyer's fees, and we pay for the couple's counselling as well as our counselling. We had to pay for storage of the embryos.

For some, covering the costs associated with the donors' donation reinforced their constructions of needing to reciprocate the gift donors were giving, and their sense of obligation to the donors. For others, covering costs may have been constructed as a way of expressing thanks, and thus reducing further responsibility towards the donors.

6.4.3.2 Number and quality of embryos

Where donors had several surplus embryos, this was cited as a factor explaining their decision not to proceed with using the embryos themselves. It provided a context for their investment in a donation decision, as is evident in the comments below:

Jessica: I can't picture me having (number) children. There's (number) left over and I could have one child from every one, that's (number) kids! I don't think I can fit them all.

Janet: If I could use them I would, but it's not possible, is it? It's not physically possible, so if I could have had all of the children, I would have, but it's not realistic.

Dawn: As you imagine, one is worn out and tired with (number of children), and you think, 'Oh hang, (number) embryos!' I don't think we could cope with trying for any more. There was the conflict in my mind saying, 'If there had only been a few embryos we might have given it a go.' But I thought, 'Well if you got another child, and there were still (number) there, then what do you do?' You might still have (number); you might get pregnant on the first one. Having a child for the sake of using up embryos, I realised that would be a foolish thing. We were quite stretched with our little family, so I couldn't really have a rugby team.

The viability donors ascribed to remaining embryos also came into play. As discussed earlier, Theresa and Kimberley assumed their donations would be successful because they had had children from their embryos. The number of embryos (and the possibility that they were ‘viable’ and could become children) was thus a factor cited as providing a material constraint that prevented donors using the embryos, in spite of drawing on discourses of the embryos as life or children. Instead, the embryos as a resource discourse was brought to the fore.

Recipients drew reassurance from the numbers of embryos and the donors’ success. Beth said, *“They had about X embryos, so I thought there was obviously a good chance. They had (used) Z, and it had worked for them each time.”* Zelda commented:

These are embryos that are from a couple that have managed to have actual children, so, instead of an egg donor where maybe there’s still something wrong with my husband’s sperm that’s making the embryos not right, here we go, ‘There’s a male and a female which have actually worked!’

For several recipients, the fact that donors had children from the same ‘batch’ of embryos was constructed as an indication of potential success. Michael said, *“I didn’t think for one minute that it wouldn’t work. No way. I was, ‘Well, it’s the same batch, it’s not us. It’s bound to work’.”* Olivia made reference to the quality of the embryos her children had developed from, and thought the remaining embryos would likewise be viable.

Olivia: (Our one child) was an 8 cell – all perfect sizes! Our (other child) was 9 cell. At the time, they said there was an 8 cell with perfect cells left. There was an 8 cell with fragmented ones, there was a 6 cell, and there was another one that wasn’t very good at all. So there’s two viable ones sitting there. If they were just one cell embryos, that’s different, because you don’t know if they are viable.

For others, however, there were doubts as to quality and likely outcomes. As Zelda put it, *“These are often couples who have had fertility problems; they’ve got left-over ones, and are they the ones that won’t work anyway?”*

The construction of embryos as resource positioned recipients as making rational decisions based on the number and viability of resources available, and as making sound use of embryos that were ‘surplus’. This enabled them to justify their decision to undertake ED.

In sum, a range of factors contributing to donors' and recipients' investment in particular discourses were identified during the analysis of the interview data. These potentially provide some account for why individuals may invest in some discourses and not others, given the complexity of, and contradictions inherent in, the available discourses.

6.5 Summary

Discourses related to ED in the interview data were imbued with complexity. When donors and recipients spoke about ED, they drew on their constructions of the embryo and the donor-conceived child in ways that enabled them to pursue ED. Embryos were constructed as valuable, as investments, and as life potential, positioning both donors and recipients as rational and sensible in their choice of ED: they were 'good citizens' to use and not waste available and intentionally-created resources and to find solutions to the dilemma of surplus embryos.

However, embryos were also constructed not just as children in a general sense, but as, in some way, the children of the donors. Similarly, even where donors invested in a discourse of the embryos as resource, both donors and recipients reflected on what the embryo would become if the ED was successful. They constructed the donor-conceived child as having ongoing ties to the donors: it was the donors' child but at the same time it wasn't; it was the recipients' child but at the same time it had inherent connections to the donors. A genetic discourse could be identified in the talk of both donors and recipients.

For donors, this translated into an ongoing concern for the welfare of the child. Likewise, recipients drew on a 'welfare of the child' discourse in considering how best to parent a child that remained connected to the donors. Donors and recipients thus aligned themselves with 'good parent' positions, with implications for recipient selection and/or donor: recipient match, disclosure of donor conception, and contact between donor and recipient families.

It was against the backdrop of these discourses that donors and recipients drew on adoption discourse to make sense of ED. Donors framed ED as easier than adoption, in that the giving of an embryo was constructed as less emotionally challenging than relinquishing a child. However, ED was also constructed as entailing fewer rights for

donors than those ascribed to birth parents. Recipients constructed ED as ‘adoption with benefits’, offering advantages over adoption. They drew on a gestational discourse that enabled them to position themselves as ‘more the parents’ than in the case of adoption. The discourse of adoption appeared to offer a useful framework for donors and recipients, but also served to make transparent the complexity of the issues associated with the donation.

A discourse of creating extended family, or building the whānau, allowed donors and recipients to make sense of their relationships with each other and the child. By positioning each other as extended family, they were able to distance each other as adult parties – allowing the donors to ‘relinquish’ their genetic children and recipients to assume parenting authority. As the same time, this construct allowed the drawing near of siblings, and facilitated ongoing investment and contact, albeit within boundaries.

Relationships between donors and recipients and their families were also affected by the interplay of the above discourses with the discourse of ED as gift-giving. Donors were constructed as givers; recipients as receivers of a gift – embryos – which because they remained connected to donors, were inalienable from them. This located donors as benevolent and powerful, and recipients as indebted and vulnerable. It located their interactions in gift-exchange dynamics. For some, this translated into obligations for recipients to acknowledge the donors and honour commitments in terms of disclosure and contact. Such positions were mediated by reframing the donation as a form of reciprocal exchange, where both parties benefited.

Further, the construction of ED as a last choice for donors had implications for the way in which ED was experienced and how donors and recipients related to each other. Where donors constructed donation as enforced, restricted or unfavourable, ambivalence and regret could colour relationships. Where donors were able to construct donation as rational, mature and moral, more comfortable positions were enabled: donors were positioned as less likely to have ongoing concerns and to constitute a threat to the recipients’ parenting. Donors could assume positions of ‘good citizens’ and ‘responsible adults’.

Recipients also constructed ED as a last choice or last resort. For many, ED followed attempts to have ‘their own’ children. In some cases there was a degree of obligation to try ED. By drawing on such a discourse, recipients (at least initially) framed genetic parenting as having precedence, with possible implications for the way

they constructed their relationship with the child and their role as parents. However, most recipients worked at reframing the construct of what it meant to be a parent, drawing on the 'adoption with benefits' discourse and the gestational relationship to reposition themselves. They were able to construct ED as a unique and positive way to build their families.

Further, participants' experiences of ED were influenced by the construction of ED as novel and uncertain. Both donors and recipients positioned themselves as pioneers by undertaking ED, particularly in the New Zealand context with its unique requirements. Being aligned with this position involved courage and the ability to adapt to circumstances as they arose, as it was difficult to plan for the unknown. For some, this position created anxiety and uncertainty as the longer-term outcomes remained unclear.

Finally, discursive constructs of the roles of ECART and counselling served to inform ED discourses. For example, ECART and counsellors were constructed as holding an oversight role, ensuring that the implications of ED were appropriately considered, and that the 'candidates' were suitable for ED. This could reinforce constructs of ED as adoption, as it involved a similar process and an agency responsible for oversight. Donors and recipients constructed ECART both as a 'safety net' and as 'Big Brother', enforcing unnecessary bureaucracy and oversight. Where the former discourse was adopted, ED as a complex form of family-building with significant implications was underscored. Donors and recipients, while vulnerable and needing support, were positioned as rational and sensible in ensuring that they accessed adequate support and oversight. Where the latter discourse was adopted, donors and recipients were positioned as more able to make their own choices without the need for sanction.

It is clear from the above that both donors and recipients had access to a number of available discourses in relation to ED, and that this positioned them in potentially contradictory ways. By identifying extra-discursive factors, I sought to understand how, given the available discourses, donors and recipients invested in certain discourses. Of note here were factors related to embodiment, such as the nature of fertility experiences and treatment, which placed donors and recipients in positions where they were able to appropriate these discourses. Likewise, aspects of their personal-social lives, such as familiarity with alternative forms of family-building, made it more likely that constructions such as ED as adoption would be drawn on. Lastly, material conditions

such as financial constraints helped explain decisions to undertake ED, and the positions with which donors and recipients aligned themselves.

In conclusion, the discourses of the embryo, the child and ED utilised by the participants contained a number of complexities and offered conflicting positions. Donors and recipients had to manage these as they made their decisions and navigated their way through the network of relationships and their associated issues of power and vulnerability, and the rights and responsibilities that developed as a consequence. In the next chapter, I present a discursive analysis of the transcribed interview data from counsellors, and suggest that the way in which counsellors constructed ED further aligned donors and recipients with particular subject positions, with implications for their experiences of ED.

Chapter 7: Results – Counsellors

In pursuing ED, donors and recipients are required to undertake counselling. Counsellors consequently assume an integral role in the ED process, and the way in which they construct ED and their counselling roles may contribute to donor and recipient understandings and experiences. In the first part of this chapter, I identify the discourses of ED evident in the counsellors' interviews. In the second section, I analyse counsellors' constructions of their roles, and reflect on the implications for donors and recipients. Next, I identify the ways in which counsellors framed the role of ECART and consider how this positioned them and those undertaking ED. Finally, I identify factors that provided a context for counsellors' discourses.

7.1 Discourses related to embryo donation

In my analysis of counsellors' talk, I identified a number of discourses related to ED, which informed and intersected with each other, and provided a context for the way in which counsellors constructed their roles. These are described in the subsections below.

7.1.1 Genetic discourse

A central discourse identified, and one that underpinned other discourses related to ED, was that of genetics. Genetics was constructed as significant for all parties involved. Firstly, genetic makeup was framed as important for children in that it was held to bestow personality characteristics. Emma, for example, said, *"I think genes are quite strong, and I've found that as children have got older, more characteristics come out."*

Such genetically determined characteristics were constructed as important to know about, as fitting with the genetic family, and potentially leading to a 'mismatch' between the child and social family. Emma explained that *"I can see how as a child growing up, you might feel like a square peg in a hole. It's more I think, around later on, sort of feeling like you belong and feeling that you fit in."* For Emma, the question that consequently arose was whether *"we are really acting in the best interests of the child"* through facilitating ED.

Further, having genetic ties between parent and child was constructed as something that most recipients desired. As Ingrid commented, *"Most people want to*

have their own baby, and treatment has got better.” Counsellors constructed ART as logically progressing from building a family using autologous gametes, to donor gametes, and finally, to donor embryos. Counsellors framed the existence of a genetic tie to at least one partner in the couple as desirable, and as desired by those seeking to become parents. Ingrid went on to say:

I think most people would prefer to go down that track (gamete donation) than they would ED. Partly because at least one of the parents is a genetic parent.

In this way, ED was constructed as an option selected when other possibilities had failed, and genetic parenthood was given primacy. As Gail commented, *“It’s still considered a last option for many recipients.”*

Further, genetic ties were framed as bestowing immutable ties between donors and child. Lisa, for example, said that *“We are aware of the ongoing connection that they have with the child.”* Likewise, Ingrid commented that donors regarded themselves as having ongoing links to the child, along with ongoing associated issues:

They realise that this is not going to absolve them of responsibilities whatsoever. In many ways, they are going to be confronted by potential problems and ongoing responsibility, and can never be absolved of that.

The difficulty of the situation for donors was summarised by Ingrid:

They’re being asked to let go, but they’re also being asked to maintain responsibility, and you know, they are being asked to be ambivalent.

Genetic connections were also given significance in terms of the donors’ extended family. Vera, for example, reflected on:

...the implications for (the donors’) family in donating, particularly for grandparents, and that loss of connection potentially with those children. How do grandparents feel?

Renee similarly expressed concern about the recipients’ family, and the position of the donor-conceived child within the family. She commented, *“We need to be sure this child will be accepted in the family network.”*

Counsellors thus constructed ED as involving a degree of loss for recipients and their families; a loss that needed to be managed. They constructed ED as entailing ongoing ties and ambivalence for donors, and for children, and as potentially involving a lack of genetic fit with the family. Investment in this central genetic discourse underscored and enabled related discourses of ED as last resort or option, and ED as having enduring, unknown and complex implications.

7.1.2 ED as having complex implications: more than adoption

Counsellors constructed ED as having significant, enduring implications. Renee commented that ED was “*fraught with potential issues*”, and Ingrid that it involved “*a lifetime of implications, not necessarily problems, but potential problems.*” Counsellors framed such implications as uncertain. Lisa, for example, said that, “*We don’t have a lot of examples of how things go long-term.*”

Counsellors drew parallels between the implications of ED and adoption: the raising of a non-genetic child and having a genetic child growing up in another family. Lisa commented that where donors or recipients were familiar with adoption, and had attended CYF adoption courses, they had “*greater understanding of what it will be like for them as parents, and their child’s needs as well.*” The adoption discourse potentially brought to the fore implications of ED, with Ingrid commenting, “*(We’re) not wanting to repeat the mistakes of the adoption process.*”

Yet counsellors also drew distinctions between adoption practice and ED, framing adoption discourse as not quite appropriate. Vera said that “*There are no models here – the adoption experience has some similarities; but it is still quite different; the pregnancy is in a different place so it has changed the dynamics.*” Thus, while the adoption discourse made visible potential implications, the implications of ED remained unknown. This unpredictability was framed by some counsellors in terms of a ‘risk’ discourse. Ingrid explained:

Embryo donation involves risks for every party. For recipients: what happens if at the last minute the donors change their mind and withdraw consent – no embryos, and you’ve been through all that process. That’s a risk that people have to face and live with, and be anxious and nervous about things. For donors, the risk is that (the recipients) get the baby and off they go and disappear. All real possibilities. I don’t think probabilities, but possibilities, and that’s what people have to live with...

Vera expressed concern about the welfare of children, commenting that:

The rights of the children down the track, how they will react? We don’t know that about ED yet. What’s going on here and how is it going to unfold?

She extended the implications to the donors’ children also: “*(Donors) are taking a risk on behalf of their children as well; a risk that they may never know or never have contact with those siblings.*”

Several counsellors expressed concern about the management of such risks. Renee, for example, commented, *“I still think that there aren’t enough safeguards around both donors and recipients following the treatment and successful pregnancy.”*

The implications were framed as complex for all the parties involved. Ingrid said, it is *“not straightforward ... it’s a **huge, huge** thing.”* With regard to donors, Gail commented that the complexity had become more apparent for her with experience:

One of the issues that I have now that I didn’t have before we started doing all this is the enormity of what people are actually doing. That’s because we’ve now walked alongside people who’ve made that choice. At times I’ve thought, ‘Gosh this is such a big thing to be doing; are people able to make a decision about giving up this embryo before it’s turned into a baby?’ That’s enormous!

Indeed, some counsellors framed ED not just as complex, but as *“the most extreme treatment that we do”* (Renee). Gail reflected:

I think that in terms of fertility treatments and options for people, not all things are equal. When I first started, I thought, ‘Why not? Of course, why not? Yes, there are all these options: surrogacy, IVF, donation: all of these things in a row.’ But now, I actually think not all things are equal in terms of possible outcomes, complications and lifelong implications.

The unknown and difficult implications as well as the risks ascribed to ED, cast it as potentially a less-than-ideal form of family-building. Emma commented:

This option exists. I can understand people are desperate for a child and people do their best, and I guess lots of children grow up in less than perfect situations.

Ingrid worked at reframing her constructs of family and the ‘ideal’ in order to achieve a more comfortable position in relation to ED:

I’ve begun to think that this is the 21st century, and every age has to adjust to new societal ways of doing things in terms of family life and family structure, the way children are brought up, the constructs of families. There have always been changes, always. Children have always had to adapt to different ways of being raised and finding their identities and managing it. I’ve come to a realisation that this is part of that whole evolutionary process, and it’s happening: It is what is. Yes, and as a society we have ways of dealing with things that aren’t ideal. That’s the other thing, what is ideal? I mean the nuclear family only got invented about a hundred years ago, but we’ve forgotten that conveniently, and think that that’s the ideal. Who said it was?

Such constructions of ED as complex and with unknown, enduring implications created anxiety and concern. Vera commented that *“There are bits of it that niggle”*; and Gail that *“There’s sort of a big question mark for me around that now. I’m not saying it’s the wrong thing; it’s just a question mark.”*

The distinctions that counsellors drew from adoption contributed to their concern. Ingrid pointed to how in ED *“there has to be a medical intervention for (ED) to occur, it’s not an action of the donors.”* Emma similarly commented:

The difference with adoption is this child already exists, this child (resulting from adoption) has been brought into this world, we are not creating it (as in ED); this child needs a family.

Adoption was framed as placing already-existing children, and thus representing a solution to a pre-existing situation. ED on the other hand was constructed as creating children for the purposes of having a family: an intervention was required and there was a deliberate separating of genetic and social parenting. This created discomfort and, as will be discussed later in this chapter, a sense of responsibility in counsellors.

7.1.3 Viability discourse

Counsellors drew on discourses of viability in relation to ED. Amanda, for example, commented that *“That’s part of our difficulty I think, in that you’ve got to be quite positive about it but on the other hand you’ve got to say, ‘This is new technology – it may not work. You don’t really know.’”* Likewise, Emma spoke of her initial belief that *“Part of it for me was believing it would ever work. Part of me was thinking, ‘This is just a waste of time’ and ... it felt very like giving people almost false hope, so I felt a bit uncomfortable with it for that reason.”*

Concern with outcome was particularly strong where donors had only a few embryos or ‘poor quality’ embryos to donate. While counsellors partly drew on a medical discourse, they also drew on a bio-psychosocial discourse, constructing ED as emotionally intense and time-consuming, and involving significant distress in the event of ED not being successful. Renee explained:

That’s part of the morality for me. Some of the donors I’ve got, have not got great embryos. Probably the biggest dilemma for all of us is people with one embryo. Those people have a right to be on the list as donors, but they also need to understand that they may never be chosen because of that. I put everyone on the list, but I’m really careful when I offer people with one embryo - the recipients (need to) understand that it’s one embryo, of this quality, that it has a 70% chance of defrosting, and then about 35% chance of (success).

As is evident above, however, counsellors acknowledged the difficulty for donors wishing to donate a small number of embryos. On the other hand, just as too few embryos are constructed as problematic, so were too many. Lisa said:

Where there have been a larger number of embryos remaining to donate, donors have looked at only wanting to donate to younger couples, where there is perhaps more likelihood that more embryos will be used. But then, there's that sense sometimes for recipients of feeling a bit pressured to think ahead, to 'Maybe we do need to think about having more children than we initially thought about.' So there are some issues that are coming up. It's a dilemma.

Counsellors thus expressed ambivalence about the viability of ED in terms of success rates, and the emotional implications for recipients and donors when there were either 'too few' or 'too many' embryos.

7.1.4 Mutual benefit discourse

Counsellors spoke of how ED was constructed by donors and recipients as a form of gift-giving. Emily however commented, *"I don't think from what we see in our experience of ED that gift is the most accurate word. I am not saying that that's not how donors see it, but I think it's not (accurate)."* Further, counsellors spoke of how their own constructions of ED had shifted over time, from a discourse of gift-giving to one of mutual benefit. Donors were constructed as also benefiting in that they were able use their embryos in a way that was acceptable to them. Emily commented:

It is a gift in some ways, but it's not as simple as that at any level. It's a service. Yes, that was the word – it's a service for the donors, in a sense, isn't it?

Thus the donation became both *"a service for the recipients"* and a *"service for the donors"* (Linda). How financial costs were managed in the ED process thus took on particular significance. In most clinics, recipients assumed costs such as the ECART application fees. In some cases, recipients also carried the costs for both parties' counselling fees (whereas legal fees tended to be carried by each party independently, unless negotiated otherwise). However, counsellors framed this as problematic, and questioned how such practices potentially constructed relationships.

Where recipients assumed most of the costs involved in the donation, for example, counsellors spoke of how donation was constructed as gift-giving, with recipients assuming the costs in acknowledgement of the gift given. Donors' constructions of their acts as gift-giving, and their expectations of acknowledgement,

were potentially underscored. Gail said, “*I think it does actually place a burden on the recipient, and also it adds to the inequality of the power factors (between donor and recipient).*” Gail however also reflected on the possibility that when costs were assumed by the recipients, donors would “*feel that they should do that (proceed with embryo donation), because the recipient is paying.*” Either way, counsellors constructed payment as a significant factor affecting donor and recipient understandings of ED and issues of power and vulnerability in their relationships. They therefore supported the splitting of costs, although they acknowledged that this could be difficult. Gail commented:

I agree with all that, but I would almost feel embarrassed about requesting that the donors pay. There’s a real sense for me of embarrassment if we were to ask them to do that.

7.2 Discourses of the counselling role

7.2.1 Navigating uncharted territory

By framing ED as complex, with unknown implications and risks, counsellors constructed their roles as uncharted, and themselves as having no relevant models to follow. Lisa and Ingrid commented:

Lisa: We are very much learning as we go, and are very aware of that. With people, when they ask about the research to back up how things might be, we are very aware that it’s still new. Even though we are a few more years into it, partly because the numbers have been very low, there is still limited experience to go on. So we are learning with each individual case.

Ingrid: I think it is a difficult area for counselling because we don’t have any maps, and we haven’t got the research. It’s so hard to draw on experiences from elsewhere because they don’t apply here. They don’t fit, and so when people say, ‘What are the answers?’ we just don’t have any answers.

While experience was framed as helpful in terms of developing an understanding of what their roles encompassed, it did not necessarily translate into increased comfort with ED and their associated roles. Rather, several counsellors constructed experience as contributing to a greater awareness of the complexity of ED. Gail commented that she was “*more circumspect*” about ED now. Linda reflected that:

Now, when I see people, I take other people’s experiences into account when I’m asking the questions. Whereas before, it was a blank wall. We didn’t really (know). Now, we have people’s different experiences, so I might be more considerate and careful about asking about relationships, and how that might be

important for a child in the future, and how might they resolve any issues if they were to come up. It's having a bit more experience about the reality of it.

Linda went on to comment about her experience of an ED case that had not resulted in positive relationships. She said:

I guess if you look at the low numbers in New Zealand of families that have been formed this way, and we already have one situation that's gone wrong, proportionally that's probably quite a high percentage. It's only one, but it's one out of a small group.

For her, this created “*a lot of anxiety about the programme.*”

In the face of such uncertainty, counsellors constructed their role as carrying a high degree of responsibility and needing to ensure that they did the best possible job they could. This also related to counsellors' constructions of ED as entailing clinic intervention, and thus a degree of responsibility. Renee spoke about her role:

I think I've been over careful, but I will not stop being over careful. One of the things is that when you consider an activity like this that has so many huge implications, and the responsibility for creating a child like this is so big, you challenge a huge amount of yourself as a counsellor.

Counsellors' anxiety around ED may potentially be relayed to donors and recipients, and could underscore the complexity ascribed to ED.

7.2.2 Educating and exploring the ‘what ifs’

Counsellors constructed their role as making donors and recipients aware of the potentially long-term implications, the ‘what ifs’ of ED. Emma framed this as “*alerting them to some of the pitfalls*” and Ingrid described her role as “*much more a role of education and exploration of possibilities.*” Linda spoke about the terms she used to translate abstract and hypothetical issues into concrete constructs. She said:

I'm quite direct. I say, ‘I want you to think about what it will be like for you to donate the baby.’ I actually use all of those words now – not just ‘baby’, but ‘baby’, ‘toddler’, ‘child’, ‘teenager’. Or a teenager asking why you made that decision to have only two children, but to give me away – all of those things.

By using such terms, discourses of the embryo as a child and as connected to the donors were reinforced, as were discourses of ED as having significant long-term implications. Counsellors also framed it as their role to assist donors and recipients to consider the effects of ED on the wider family network, e.g. grandparents.

Linda: Talking to the donors about their own parents, that's something that I've learnt is much more important than I thought it was, earlier on. People look at me strangely, 'Why are you asking about that?' but it is important, and I'm a lot more direct when asking about that now.

While counsellors encouraged this process, many reported that donors and recipients constructed donation as a private, personal decision that did not necessarily involve family. Emily said, *"There seems to be quite a strong sense that this is our decision, and no one else's"*, and Gail that *"they are very much a self-contained unit."*

Counsellors constructed the adoption courses run by CYF as helpful in developing awareness of the implications of ED. Amanda commented that course attendance implied that *"they are really on the ball and you don't have to do as much work in terms of thinking through implications."* Ingrid reflected that *"If people have done that, then our job is much, much easier and their process is going to be shorter, because they've done a lot of what they needed to do."*

In some cases, counsellors actively promoted the courses. Lisa said:

We strongly recommend that if people haven't already been a part of the adoption process, that if they can, they link into that somehow. They will gain a lot from that – to have some greater understanding of what it will be like for them as parents, and their child's needs as well. Certainly, where people have had that link with adoption already, they get it straight away.

Note, however, that in this way counsellor practice (even if unintentionally) potentially reinforced constructs of ED as adoption. Ingrid reflected on patients' discourses of adoption, and how this, in part, was supported by policy and practice:

People call it embryo adoption. Whether that's because the process treats it like that, like adoption, or whether it's because that's more comfortable than the word donation, or a mixture of both. It's probably a bit of all of those things, but the process treats it like that, so why wouldn't they call it that?

The difficulty of asking people to think through hypothetical long-term implications was acknowledged. Emily discussed this in relation to the donors:

In the back of their minds, that embryo might not even make it, so they may still be thinking, 'Well, this may not even happen.' It must be so hard to imagine. I wonder whether people ever really totally get it, or whether they can totally appreciate what that might be like both for their own children, and then to see a child that's so remarkably like their own children being brought up in another family. It's all hypothetical, and even the form that we fill in that says 'your future feelings'. How can you know what your future feelings are?

Lisa reflected on the difficulty for recipients:

They haven't necessarily allowed themselves to think through how it might be for them as parents, because they are still protecting their hopes, and being a bit more cautious. So there's still a bit more risky thinking to say, 'Ok, if you do have a child and it goes to plan, how will that be? What will be the different issues be then?'

ED as having implications for which one cannot fully prepare was underscored. Further, counsellors reflected on the limits of their ability to ensure that donors and recipients had appreciated the implications of ED. Ingrid said:

You can't have mandatory counselling –if people aren't meeting you at least a quarter of the way, yes, we can be miracle workers, but they have to, to some extent, be on the same page. We do have our persuasive ways and can sometimes work miracles, but you can't force the issue.

She went on to explain that people could claim to have processed the implications, without actually having done so. However, she reflected that they could come to appreciate and manage the implications given time:

However many times we might challenge people about their beliefs, and what they are saying and their contradictions, if they are saying, 'Oh no, that's what I believe, or that's what I think is a good idea,' even if we think they are not genuine in that response, what do you do with that? Does that mean they are always going to be like that? Does that mean they might not come to genuinely believe it later on? Well, they might. They might have to wait for their child to be the person who is the catalyst for changing their thinking, and they haven't got the child yet at the point where we see them.

7.2.3 Gate-keeping and match-making

Several counsellors framed their role as gate-keeping to ensure that the people proceeding with ED could manage the process. Renee explained that she would sometimes channel people in other directions, or in her words, “*define another pathway because that's what (they) need.*” This was because of her sense that “*not all the people who are in there (waiting list for donor embryos) are going to cope with the need for boundaries and respect and things.*”

Further, drawing on the genetics discourse, achieving a ‘match’ between donor and recipient families was constructed as important, particularly for donors. Emily said:

Most people do have deal-breaker points based on their core values or general life values, for example about parenting. Maybe at the end of the day, most donors really do want a recipient who is similar to them, at least in some of those core ways.

Some counsellors constructed it as their role to achieve this match. Ingrid for example, said that her hope was, *“that we’ve done quite a good job as well, and (that we are) not bringing people together where you know it is not going to work.”*

For Gail, this involved clarifying with the donors their specific requirements early on in this process, to act as a *“filtering process”*. Lisa spoke about reviewing the profiles of potential donors and recipients, and *“trying to meet each of their needs around the donation. It’s going through almost one at a time, just to see. This potential offer has come up, is that going to be a possible match for anyone who is hoping to receive embryos?”*

The difficulty of achieving matches, given the small numbers of potential donors and recipients complicated counsellors’ match-making, however. Vera commented that *“They don’t have a huge number of choices anyway.”* Renee described how she would:

offer them (donors) a profile which won’t meet their needs, because I think these people (recipients) are really nice people and it might work if they can get beyond (some things), like the education stuff.

There was however a degree of ambivalence about matching. Gail reflected on whether matching leads to better results, and whether she knew the people well enough to make such judgements:

Might that (matching) be better, in terms of making a match better ... or is not matching better, and what are the uncertainties in either of those? But (I also have to ask myself) how well do I really know the donors? There are those kinds of thoughts.

Others expressed discomfort at assuming such a role of assessment, authority and responsibility. Linda and Emma reflected:

Linda: I’d be really uncomfortable with doing it. We can ask the right questions, and we can say to them, ‘What’s a deal breaker?’ We can talk about those things – but I wouldn’t want to be in the position myself of doing matching. I’d prefer for people to make that decision themselves.

Emma: It almost feels like playing God when you are choosing a family for this baby.

Nonetheless, counsellors constructed themselves as having a responsibility to ensure that relationships would develop smoothly, and part of this was ensuring that donor and recipient families could work with each other.

Two things were particularly interesting to note in terms of counsellors' practice here. First, the counsellors presented recipient profiles to the donors first. This came across in the way in which counsellors described their matching process. For example, Gail commented:

If I'm presenting recipient profiles to donors, what are the key considerations that the donor would like to have in the recipient, and can I see those in recipient profiles, and then how do I present that?

In this way, counsellors appeared to resist the donation discourse/practice, in which recipients traditionally are the ones who select from a range of donor profiles. Second, counsellors operated on the premise that matching could be useful as well as desired, particularly by donors. In this way, their practice bore similarity to adoption, where birth parents are involved in the selection of adoptive parents and where matching of families is constructed as important in terms of the wellbeing of the child.

7.2.4 Relationship mediation

Counsellors framed the connection between donor and recipient families as potentially ongoing, and constructed their role as facilitators and mediators helping develop relationships with appropriate boundaries. Gail commented:

That's something we have to manage in terms of that being something that you balance out, even when you are talking about the possibilities for setting that up. These people, if there's a pregnancy, are going to be part of your lives onwards ... trying to get your head around that.

Emma commented that they were “*asking people to think about having a long-term relationship if it's all successful, and thinking about all of that.*” The boundaries of this ongoing relationship were varyingly constructed by counsellors, as reflected in Renee's comments where she spoke about the relationship in terms of friendship (“*a lifetime to develop this friendship*”) while at the same time setting limits to the closeness of the relationship (“*I talk really clearly to people about how we don't want them to be best friends, and that we don't want the families meshed.*”)

Initially, counsellors controlled the contact, usually until such time that donors and recipients had independently made their decisions whether or not to proceed with ED and the ECART application had been approved. This was framed as important to ensure there was no coercion and that implications were considered. Linda commented:

Emotions run high, and people might feel compelled to share information more than they usually would. It's really hard, and we might come across as trying to be gatekeepers, so it is quite fraught at times. We do make that clear to people in the joint counselling, that we are happy to facilitate mutually agreed sharing of information or contact, but we just suggest that they hold off at first, that they go away from the joint counselling, and have a think about things.

Similarly Renee commented that “*You know how some people fall in love with each other and instantly want to (run off into the sunset)? I don't encourage that.*” Counsellors spoke of the need for “*a cooling off period*” (Vera) or “*cool down*” (Renee) following the initial meeting, and before they ‘allowed’ donors and recipients to liaise with each other independent of counsellors’ presence. Renee said:

Then I email them and say, ‘Do you still want to?’ So I’ve got email consent, and then I let them go for it. All the time I’m saying to them, when I send out an email with the two addresses on the same email, I say, ‘Remember please the talk about boundaries. Take this slowly. You probably will have a lifetime to develop this friendship. You don’t need to race into it.’

In this way, counsellors constructed donors and recipients as somewhat vulnerable, and not necessarily in a position to fully comprehend and work through the issues associated with ED without guidance. As Ingrid and Vera reflected:

Ingrid: I think, to some extent, recipients will do anything. You know that famous story of the patient who would say, ‘You can hang me from the ceiling by my ankles for a week. If that’s what it takes to get a baby, I’ll do it.’

Vera: I think the recipients come in open to accepting whatever they can get, and so it tends to come down to, if the donor says they want this or that, then the recipients will often agree to it. It’s trying to work out what people really want in that joint meeting, and can they put that out there?

Counsellors constructed the potential relationship that could develop between couples as an intense one. This was reflected in Renee’s comments about how when ED had been unsuccessful for one couple (no pregnancy), it took time before the donor couple could consider another recipient couple for ED.

I have had some of my donors, where they have donated first to one family then another family, being comfortable with that transition, but needed space between letting one go, and being matched with the other. You need to let go before moving on to another.

For some counsellors, giving couples space to develop and negotiate their own relationships as the donation unfolded was important. Lisa commented that “*I guess we wanted to be a little more hands off with this, and let people establish things.*” For many counsellors however, longer-term follow up to assist donor and recipient families

with managing their ongoing relationships, both where the donation had been successful and where it had not, was called for. Gail reflected on how couples potentially needed “*some time discussing the finishing process if it’s not successful.*” Renee spoke about maintaining contact because “*I think morally I should.*” Emma expressed her view that “*maybe more ongoing support afterwards is probably more something that we should be offering, or people followed up more.*”

However, counsellors also pointed to the difficulty patients had in accessing longer-term follow up. Vera and Ingrid commented:

Vera: You can say to people that you know that counselling is available afterwards and you can come back, but it’s a big step to come and do that.

Ingrid: This process, to some extent, prevents people coming back to see us. They’ve convinced us that everything will be fine if they get this baby. If it’s not, they are not going to be coming back and saying, ‘What I told you before ... hasn’t come to be.’ The doors are open, but I think there are impediments to people accessing that.

Constructing their role as mediating and facilitating relationships, underscored constructs of ED as involving lifelong connections.

7.2.5 Ambiguity: Counselling versus assessment

As Ingrid’s comments above point towards, counsellors framed their role as potentially ambiguous. They were required to provide counselling as well as to assess donors’ and recipients’ understandings of issues as indicated in the ECART application. This created potential role conflict: counsellors assumed positions as counsellors as well as assessors, which Ingrid constructed as undermining their ability to be neutral and “*chang(ing) our role enormously.*” Renee commented:

We can say very little in (the forms) if we want to, but it’s still an assessment process, and counselling should never be about assessment ... the process gets in the way of good counselling.

This practice potentially circumscribed donors’ and recipients’ ability to reflect in depth and with honesty on ED and its implications. They were placed in the position of ‘examinees’, needing to convince the counsellors that they were able to manage the process of ED. As Gail commented:

Sometimes people come in and they are presenting the best of themselves; that that they want to present. Part of that is they want to put themselves in the best light that they can in front of us. So they may be reluctant to say what is actually

a deal breaker, however much reassurance we give, or environmental space that we've tried to create so that they are not concerned about what we think.

7.3 ECART discourses

While the process of ECART application required work and was framed by some counsellors as “*cumbersome*” (Renee), it was also constructed as useful in that it underscored the significant implications counsellors ascribed to ED. Amanda commented that “*it gives you a bit of grunt or gravitas in that this is important. Having children is not easy and it deserves the attention that it's having.*” Vera likewise constructed the ECART process as providing “*a structure that you have to work with, and they (donors and recipients) know that they don't have any option then; they can't get around it.*” ECART was thus framed as helpful in ensuring that the complexity of this form of family-building was brought to the fore.

ECART was further constructed as providing a safety net for counsellors. Gail described ECART as “*a great backstop.*” Emma framed the committee as “*a watchdog almost*” and as a means for counsellors “*to say no*”, and Gail spoke of ECART's role as that of “*gate-keeping*”. In this way, counsellors were potentially absolved from some of the responsibility for approving ED, and for its consequences. This provided reassurance within a context counsellors framed as being characterised by uncertain implications. Gail however expressed concern about the ongoing role of ECART, commenting that:

My concern is that ECART's decisions will be minimised over time, as other things are happening in the community more and more without clinic involvement, and without ECART involvement. So therefore their decisions have kind of washed away, and diminished. I am a bit concerned about that.

Again, constructing ECART in this way underscored ED as complex; as a process that required oversight. On the other hand, the role of ECART was sometimes constructed as not quite clear. Ingrid, while acknowledging the potential utility of ECART wondered, “*I'm not sure that gate keeping and ethics is the same thing ... And is there a need for gate keeping?*” She pointed to a potential ambiguity in the function of ECART. Vera questioned the utility of ECART given that ED applications tended to be approved. She commented that “*I would struggle to find a situation that wouldn't be approved, unless it was within family.*” Again, she saw the value as more giving “*a vehicle for saying, 'Actually, this wouldn't go ahead. It wouldn't be approved.'*”

7.4 Extra-discursive factors

As was done for the donors and recipients in the previous chapter, I also identified factors that provided a context for counsellors' discourses. While these can be discursively constructed, I was interested in how they created conditions that enabled counsellors to invest in discourses. These factors included personal and occupational experiences, as well as macro issues related to the New Zealand context. I discuss these below.

7.4.1 Experience of and contact with adoption

Several of the counsellors specifically referenced experiences of and familiarity with adoption as shaping their constructions, and affecting their practice. For Renee, it was personal experience of adoption that drew her attention to issues that could arise. She commented, *"I know I'm slightly over the top about my concern for these families, but I parent a non-genetic child, and I know things occur."*

For Ingrid, her occupational experiences, and her awareness of historical issues related to adoption practice, contributed to her construct of the relevance of genetics and genetic heritage. This can be identified in her comments below:

(We're) not wanting to repeat the mistakes of adoption. Because of our population, practically every single person in this country, certainly in the 50's, 60's, 70's and probably 80's, was affected by adoption. That's part of people's life experience. To some extent, social workers and counsellors have themselves to 'blame' if you like, for this as well. We spoke loudly and lobbied vehemently that children needed to have access to the truth of their birth stories.

7.4.2 New Zealand context: Māori culture; small population

Counsellors also referred to the New Zealand context as significant in providing a framework for their understandings and practice. For example, New Zealand's relatively small population size was cited as a material condition influencing policy and practice, with the risks of consanguinity framed as greater. Further, the influence of the indigenous Māori culture, which places great significance on genetic heritage and the sanctity of bodily tissues, was framed as significant. These points can be identified in Ingrid's comments below:

I think it's partly to do with our indigenous people's beliefs and culture, and attitude to tissue and whakapapa, heritage, ancestry. This has certainly made an influence in our legislations and bureaucracies. I think also, partly the size of our population has an influence ... and that whole emphasis on not treating children as commodities. Where you were born and where you are then placed, has such an influence on how you are and how you identify yourself ... So therefore in a sense, the culture around stored embryos influences the way people think, and the burden of responsibility they might hold. So if the attitude of the whole country is that embryos are just cells, and you can share them and you can donate them, and not know where they go and those sorts of things, then probably people are less likely to feel responsibility.

Ingrid's comments reflect factors she framed as shaping both her own constructs and those of the wider community.

7.4.3 TV current affairs item: "Donors warn over lack of rights"

Counsellors had seen the TV programme which aired in 2011 in which donors reflected on their negative experiences of ED and spoke of their lack of rights. This programme created anxiety about the implications of the practice, as well as about counselling roles. Lisa spoke of how it contributed to her uncertainty: while it was only one case that had "gone wrong", the total number of cases was very small ("*proportionally that's quite a high percentage*"). The issues addressed in the programme underscored the complexity of ED, the need for donor and recipients to be well matched, and emphasised the building of sound relationships. It reinforced counsellors' sense of responsibility for ED outcomes, and their commitment to thorough implications counselling.

In sum, factors such as adoption familiarity and Māori constructions of whakapapa contributed to counsellors framing genetics as important, and underscored the potential implications that could arise from ED. Adoption familiarity enabled similarities to be constructed, but also brought to the fore some of the differences. Negative publicity around ED contributed to counsellors' discourses of ED as being complex and as carrying significant risks and implications, and highlighted the need for caution and some form of control over the process.

7.5 Summary

In conclusion, counsellors drew on their own discourses of ED and what their roles entailed in advising donors and recipients. They ascribed a central role to genetics (bestowing characteristics and kinship ties), and constructed ED as having both similarities to and differences from adoption. They constructed ED as having significant long-term implications, which were potentially complex, fraught, unknown, and even 'risky'. Counsellors also drew on a viability discourse, questioning the success rates of ED. ED was thus framed as a last resort, or less-than-ideal option. A gifting discourse was resisted, with counsellors constructing ED as a practice of mutual benefit for donors and recipients. Counsellors drew on these discourses to frame their counselling role, which they constructed as navigating uncharted territory, educating and helping clients explore the 'what ifs', gate-keeping and match-making, and mediating relationships between donor and recipient parties.

Such discourses of ED and counselling carry implications for the donors and recipients with whom counsellors work. Through ED being framed as a form of mutual exchange, for example, donors and recipients were more equally positioned in relation to each other than when constructs of gifting were drawn on, and this has implications for relationships between donors and recipients. Further, discourses positioned donors and recipients as undertaking a form of family-building that was complex, bearing some similarity with adoption practice. Recipients could experience themselves as examinees, needing to be approved for ED; they could feel disempowered in decision-making and in negotiating relationships. However, donors and recipients could also draw reassurance from counselling, framing themselves as responsible by accessing counselling support and ensuring approval for ED.

In the next and final chapter, I bring together the analyses from the previous chapters. I discuss and summarise the intersections of the discourses and subject positions identified in the talk of donors, recipients and counsellors with those that I have identified in legislation and guideline documents. I also outline the implications of discourses and subject positions for those undertaking ED and their families, and reflect on issues that may arise from a policy and practice perspective.

Chapter 8: Discussion and conclusion

My aim in this research was to explore how embryo donation (ED), both as a form of family-building and an option for embryos remaining after IVF, is understood and experienced in the New Zealand context. ED in New Zealand is relatively novel, and has unique guidelines with respect to donor identity registration, mandatory individual and joint donor recipient counselling, and approval by an ethics committee. ED has been represented as complex, potentially fraught, and as having unknown implications for all parties, including offspring, even in jurisdictions with longer-standing histories of ED, since it involves the donating of full genetic material of a couple and the introduction of third parties into family-building.

In this study I explored how ED was portrayed across a number of sites: New Zealand's legislative frameworks and policy guidelines; by counsellors, who assume an integral role in the ED process; the academic literature; and finally, by the donors and recipients themselves. Given that ED has been variously described and referenced as ED, embryo adoption and embryo relinquishment, I used discourse analysis as my method. I was then able to identify and examine discourses of ED, the action possibilities and positions made available and assumed through such discursive constructions; and their implications for donors, recipients and their families.

In the first section of this chapter, I discuss the significance ascribed to genetics in spite of ED resulting in gestational and social, but not genetic, parenthood. I reflect on action possibilities and related discourses enabled through a genetic discourse, including concern for the welfare of the child, and ED as a last resort/option. I also reflect on the potentially ambivalent subject positions made available for both donors and recipients. I then discuss how donors and recipients draw on a range of discourses: adoption, gestational, gifting/reciprocal exchange, and extended family-building to handle the complexity of the interrelationship of genetic, gestational and social elements of reproduction and parenting. I discuss the implications for donors' and recipients' experiences, their relationships, and the forms of kinship built. In the second section, I consider the study's implications and make recommendations for policy and practice. In the third and last section, I identify challenges encountered in the study, and suggest directions for future research.

8.1 Discourses of ED, donor–recipient relationships and extended family-building

8.1.1 The genetic discourse: The child as still partly that of the donors

As Taylor (2005) comments, ED involves a unique way of forming families in that the three previously unified elements of reproduction: genetic, gestational and social, are separated out into distinguishable elements. ED thus offers the potential to “challenge previously held cultural constructions of kinship” in which kinship ties are based on genetic ties (p. 189). ED recipients are gestational, birth and social parents, making it possible to conceal the genetic element of reproduction and relegate the donors’ role to the background. In this study however, I identified genetics as a significant discourse across the various sites of analysis.

Both donors and recipients constructed genetic makeup, genealogy and genetic knowledge as critical for psychological and physical wellbeing and identity, and as bestowing immutable kinship ties between donors and offspring. For many donors, their embryos were constructed not just as life forces or as children, but as ‘their’ children. as in several other studies (Blyth et al., 2011; de Lacey, 2005, 2007a; Kato & Sleeboom-Faulkner, 2011; Kirkman, 2003a; McMahon et al., 2000, 2003; Melamed et al., 2009; Nachtigall et al., 2005; Paul et al., 2010; Provoost et al., 2009; Stiel et al., 2010). The embryos were constructed as carrying ‘their’ genetic blueprint that could determine physical and psychological qualities. While a few donors simultaneously held discourses of the embryos as cells or seeding material, and thus did not necessarily struggle with embryos needing to be destroyed subsequent to ED, their decision-making was based not only on the current status they ascribed to the embryos, but on what the embryos would become if ED was successful: ‘their’ genetic children, imbued with genetically- predetermined qualities that ‘fitted with’ and could best be accommodated by the donor family. As for Kirkman (2003a, 2008), a master narrative (discourse) could be identified, constructing parenthood as strongest when parent and child are genetically related, potentially locating the genetic parent as the real parent. Since donors constructed offspring as still partly ‘theirs’, they were positioned as still parents in some way, even though this position involved no legal parenting rights. They were located in ‘parents, but not...’ position.

Recipients had attempted to have genetic children prior to ED; several had tried donor gametes to maintain a genetic connection to one parent. They too drew on a

genetic discourse: constructing genetic ties as important for social bonds. They had thus mourned the loss of such ties, and at least initially, had concerns about the implications for the parent–child bond and the offspring’s attachments to the donors. While recipients asserted their parenting rights, the genetic discourse positioned them as ‘not quite the real’ or ‘full’ parents. They constructed the offspring as enduringly connected to the donors by genetics, positioning them as parents that had to include the existence of another family in their parenting. Thus they were located in a ‘parent, and yet...’ position. The genetic discourse also located the donors’ children and the recipients’ donor-conceived child as full siblings, with both donors and recipients constructing the relationship as not just sibling-ship, but as twin-ship or batch siblings, sharing genes and the time of creation (as also described in Collard & Kashmeri, 2011; de Lacey, 2005).

Such constructions must, of course, be considered against a backdrop of legislative frameworks (HART Act), ED guidelines (ACART, 2008) and clinic policies – in particular counselling practice. In their emphasis on the rights to access genetic knowledge, prohibition of anonymous donation, and constructions of donation of genetic material as carrying long-term implications, the psychological and social importance of genetics is underscored (van den Akker, 2001, 2006) and a genetic discourse is privileged. Open adoption practices in Zealand, and the recognition in legislation of Māori beliefs around whakapapa, further underscore constructions of genetic knowledge as critical and have set precedents for ED (Angus, 2012). Counsellors frequently recommend CYF adoption courses, and construct their role as bringing to the fore the long-term implications of donation: having a genetically related child raised in another family or incorporating a non-genetic child into the family. In the New Zealand context then, genetic connections between family members are constructed as important and leading to social ties (Hargreaves, 2006; Hargreaves & Daniels, 2007; Lovelock, 2010), ties that cannot be abrogated (Fuscaldo, 2006).

The genetic discourse thus evoked particular action possibilities and positions for both donors and recipients. For donors, constructing the child as still partly theirs by virtue of genetic ties positioned them as still, in some way, parents to the child. By being located as parents, interest in the child’s wellbeing and even responsibility for the child’s welfare were enabled. This made ED problematic for donors given their lack of legal parenting rights. For recipients, the genetic discourse implied that the child had enduring and socially significant ties to another family that they, as parents to a donor-conceived child, needed to acknowledge and accommodate in the interests of the child’s

wellbeing. This potentially undermined their position as ‘full’ parents who could parent independently of others, and likewise, made ED a difficult option. I discuss these action possibilities or related discourses next.

8.1.1.1 Welfare of the child

By drawing on a genetic discourse, concerns for the welfare of the child were enabled. For donors, since they constructed the child as theirs and themselves as parents in some way, an enduring interest in and even moral responsibility towards ensuring the child’s wellbeing was enabled. Concern for wellbeing has been cited in other studies (de Lacey 2005, 2007a; Kirkman, 2003b; Lyerly et al., 2010, Mohler-Kuo et al., 2009; Paul et al., 2010; Söderström-Anttila et al., 2001) and links with Māori beliefs that those who donate genetic material must be responsible for its use (Nicholas, 1996).

Donors located themselves as responsible for the child’s wellbeing in two ways: Firstly, through attempting to ensure that recipients were ‘suitable’ parents (as for Collard & Kashmeri, 2011; Frith et al., 2011; MacMahon & Saunders, 2007; Paul et al., 2010), not just for any child, but for their genetic child with its unique qualities. Thus, they tried to choose recipients constructed to be ‘just like’ or to ‘fit with’ them, so that the child would be raised in a way with which they were comfortable. Secondly, donors constructed disclosure and access to genetic heritage as crucial to wellbeing. As in Frith et al.’s (2011) and Paul et al.’s (2010) studies, donors wanted the offspring to have information about them and their family, and constructed this as central to the identity and wellbeing of not just the donor-conceived child but also their children.

Recipients constructed the child as having genetically predetermined characteristics and immutable kinship ties that, in the interests of the child’s wellbeing, they needed to be aware of and acknowledge. They were located as needing to take the child’s unique background into account in order to parent the child appropriately. This included gathering as much information as possible about the donors and their family, to equip them with knowledge about what the donor-conceived child might be like and to control for their lack of genetic contribution. Further, it implied a need for their assessment to be selected for ED. While this led to some anxiety, vulnerability and resentment, most recipients were able to draw on and understand the donors’ constructions of the child as still theirs in some way, and thus their wanting to choose appropriate parents. Most recipients also constructed a ‘fit’ between families as desirable so that their child would not compare his or her environment unfavourably to

that of the donor family, and also so that there would be less likelihood of the donors interfering because of different values and parenting practices. Finally, recipients constructed keeping secrets as detrimental to their child and their relationship with them. They had been or planned on being open with the child, constructing disclosure as important for medical and health reasons, to promote a healthy sense of identity, and to have the ability to get to know their genetic siblings and family. Both donors and recipients aligned themselves with 'good parent' positions by being open about the conception, acknowledging genetic ties, and achieving a fit between the families.

The genetic discourse enabled a concern for the welfare of the child for both donors and recipients. It is interesting that this concern can also be identified as a discourse in the legislative frameworks, policies and counselling practice. For example, the HART Act (2004) stipulates that the health and wellbeing of children should be important considerations in ARTs; and ED guidelines and counselling sessions emphasise the wellbeing of the child. Legislation, policy and counselling practice further construct child welfare as linked to the needs of children to have access to their genetic knowledge, as evident in ED guidelines stipulating information-sharing and disclosure. In addition, child welfare needs are constructed as best met when donors and recipients are suitable for ED, and have sound relationships. This is reflected in counsellors' attempts to enable and facilitate positive relationships, to achieve a good fit between the families, and in minutes of ECART applications detailing donor–recipient relationships with reference to the child's wellbeing, and social histories of donors and recipients that may pose a risk to the wellbeing of the child.

A child welfare discourse constructs donation as having long-term implications for the child, and thus not as a one-off, medical event. Donors are positioned as needing to be prepared to be contacted by offspring in the future; recipients are located as needing to ensure offspring have access to information constructed as central for wellbeing. As Grace (2008) and Grace, Daniels and Gillett (2008) discuss, policy that encourages openness reverses the negation of the donor made possible by anonymous donation. If disclosure is framed as in the child's interests, the donor appears as a person entering into the discourse of the family. This makes it more difficult to position donors as relatively unimportant, as in MacCallum and Golombok (2007) and MacCallum and Keeley's (2012) studies, where ED was anonymous. Indeed, Nelson (in Fuscaldo, 2006) argues that genetic parents (donors) have a *prima facie* obligation to remain in a child's life in an ongoing way.

Indeed, in this study, for several donors the genetic discourse and ensuing concern enabled for child welfare led to a willingness not only to be contacted and to share information, but to be a part of the child's life. Donors wanted varying degrees of involvement and contact, some even expressing a willingness to assist the child (and family) in the event of financial or emotional need. Several studies (e.g. Crawshaw Gunter, Tidy & Atherton, 2013 ; Daniels, 1989; Daniels et al., 2012; Jadva, Freeman, Kramer & Golombok, 2011; Kirkman, 2004; Riggs & Scholz, 2011; Speirs, 2012) have reported similar ongoing interest and/or moral commitment from donors (even in gamete donation, rather than ED). Donors and recipients were thus brought into a relationship with each other through a genetic discourse: through the shared genetic connections between donors and offspring, and the need for knowledge and disclosure of these connections. As one counsellor commented, "*(Donors) are being asked to hold on, and to let go*". This captured her understanding that donors occupied an ambivalent position: they were expected to remain available to the child (even if only in the future) as their genetic 'parents', and also to relinquish their social parenting rights. Her comment could also apply to recipients, in that the genetic discourse also positioned them as needing to 'hold on' (to genetic ties), facilitating information access and disclosure, but also to 'let go' (of these ties) in bonding with the child and assuming their parenting authority. Donors and recipients can have difficulty with this process of 'holding on' and 'letting go': by drawing on a discourse of the child as still partly that of the donors, ED as an action possibility was made difficult for both donors and recipients, which is discussed next.

8.1.1.2 ED as difficult: A last choice, last resort

The genetic discourse positioned donors as parents of a sort, with a responsibility towards the donor-conceived child and his or her welfare. This made ED a difficult decision, given donors' inability to ensure the welfare of what was still in some way 'their' child. As has been reported in other studies (de Lacey, 2005, 2007a; Frith et al., 2011; Fuscaldo et al., 2007; Hammarberg & Tinney, 2006; Klock et al., 2001; Lysterly et al., 2006; McMahon et al., 2000; Nachtigall et al., 2005; Newton et al., 2007; Paul et al., 2010; Provoost et al., 2011; Svanberg et al., 2001), ED was constructed as fraught, and often not a positive choice, but a negative one, representing the rejection of other options. Analysis here suggests that as in other studies (Cattoli et al., 2004; de Lacey, 2007a; Franklin, 2006; Fuscaldo et al., 2007; Kato & Sleeboom-Faulkner, 2011; Lysterly et al., 2010; Provoost et al., 2011), donors positioned themselves as unable to discard

embryos because they drew on discourses of the embryo as life, child, valuable resource, and intentional creation. Donation however, was difficult in the context of constructions of the child as still partly theirs. For many donors, having surplus embryos was not something they had actively contemplated prior to IVF. Where their decision was constructed as reluctant or enforced, donors were positioned as disempowered, and resentment, regret and uncertainty was possible. This may have implications for donor–recipient relationships, and recipients’ anxiety about donors’ future claims or roles.

Several donors drew on extra-discursive factors, also cited in other studies (e.g. de Lacey, 2007b; Lysterly et al., 2006; Nachtigall et al., 2009; Paul et al., 2010; Provoost et al., 2012), such as large numbers of surplus embryos, complicated obstetric histories, and health and age factors, to justify their decisions to donate and not use their embryos themselves. They constructed ED as rational and responsible given the context: the existence of embryos that others wished to use, storage limits, the circumstances restricting their ability to use the embryos, and the disposal options available. ED was framed as meeting their obligation to use ‘resources’ they had intentionally created and deal appropriately with the consequences of their actions (of undergoing IVF and cryopreservation). In this way, donors located themselves as responsible adults, making logical and mature decisions even where these were difficult. Further, they framed donation as morally sound, according respect to the embryos, and giving opportunity for life. For some, donation offered a resolution of their fertility journey. The conditions of openness under which donation occurred, and which donors supported (as in the interests of the child) however, extended that journey. Some donors, while expressing empathy for recipients where donation did not work, acknowledged relief that they would not have to confront the ongoing implications.

The genetic discourse complicated ED as an action possibility for recipients. As reported by Kirkman (2004), it was initially difficult for some to accept the concept of parenting non-genetic children in the context of genetic significance. It required ‘extra work’, with some feeling obligated to try ED owing to its availability, an issue identified in other studies of ART also (McMahon et al., 2000; MacCallum & Widdows, 2012). ED was thus constructed as a ‘last resort’ in their pursuit of parenthood (as also reported in Goedeke & Payne, 2009). This highlights the significance given to conforming to normative procreative roles (Hargreaves, 2006). While recipients constructed the embryos as connected to the donors, they also constructed them as life potential and as resources. They drew on factors such as the

practical reality of having few options, and had to actively construct ED as a symbol of their parenthood dream and a unique way of family-building (Goedeke & Payne, 2009).

Legislation and policy contribute to a discourse of ED as ‘last resort’. Guidelines stipulate that ED is available only for those that are infertile; ECART minutes reflect a need for recipients to have considered other options first; counsellors construct ED as selected only when other options have been exhausted, and in their practice explore the loss and grief issues associated with separating genetic and social parenting. While this may relate to constructions of ED as complex, genetic parenthood may also be prioritised.

However, whereas some research has suggested that where embryos are constructed as donors’ children, ED as an action possibility is inhibited, and is less likely to be chosen (see e.g. Blyth et al., 2011; Lyerly et al., 2010; Melamed et al., 2009), in this study, donors and recipients proceeded with ED against the backdrop of a genetic discourse. As discussed above, donors and recipients drew on discourses of the embryo, for example as life potential or a resource, as well as various extra-discursive factors, such as the number of embryos, fertility history, health and age, to make ED possible within this context. However, donors and recipients also drew on a range of discourses such as adoption, gestational, reciprocal exchange, and extended family discourses in order to negotiate a genetic discourse and constructions of the child as still that of the donors, and to be able to proceed with ED. I discuss this next.

8.1.2 Negotiating genetics

Kirkman (2008) suggests that donors and recipients have to strategise to reconstruct the significance of genetic and social connectedness and negotiate a new script for what constitutes family. In this study, donors and recipients drew on a range of discourses – adoption, gestational, gifting/reciprocal exchange and extended family – which enabled them to handle the complexity of the interrelationship of genetic, gestational and social aspects of reproduction and parenting, and to make ED possible.

8.1.2.1 Adoption discourse

Donors and recipients alike constructed ED as adoption, framing adoption as a family-building mechanism similar to ED in which genetic and social parenting were likewise

separated. Many referred to ED directly as embryo adoption, or as ‘one step removed from adoption’. They constructed parallels with adoption practice in New Zealand, where the birth parent chooses the profile of adoptive parents, openness is encouraged, and there is oversight by a government agency. The practice in ED of allowing donors to select recipients’ profiles, the openness and disclosure encouraged, and the perceived oversight by a government-appointed body (ECART) underscored constructions of ED as adoption. Similarly, where counsellors encouraged recipients to undertake CYF adoption courses to facilitate an awareness of issues, the discourse was reinforced. Counselling also required consideration of similar issues confronted by birth and adoptive parents. Helm (2008) argues that such practices frame ED as more akin to adoption (placement of embryos) than donation (treatment of infertility); they are more relational practices (Frith & Blyth, 2013). Donors and recipients were thus able to draw on adoption discourse as a naturalising strategy (Lovelock, 2010), constructing ED as a viable option and making sense of and structuring their experiences. The discourse was both taken up and underplayed however, and used strategically to assert as well as minimise rights and responsibilities among donors, recipients and offspring.

Rather than the adoption discourse inhibiting donation, as suggested in some studies (e.g. de Lacey, 2007a), for donors in this study the adoption discourse provided a familiar and acceptable model for ED. This may be because in the New Zealand legislative context of disclosure and donor registration, ED is constructed more as open adoption, which allows the possibility of information about and contact with the donor-conceived child. Indeed, Lovelock (2010) suggests that open adoption practices have served as important antecedents for ED in New Zealand. Donors in this study would not have donated under anonymous conditions, and the requirements of ED in New Zealand made it more possible to donate embryos that would still be in some way ‘their’ children. Donors could locate themselves as ‘good parents’ within this context.

For some donors, however, the adoption discourse brought to the fore a lack of ‘safeguards’ in place for ED; ED practice was constructed as not sufficiently like adoption practice. While donors were able to choose recipients, they positioned themselves as having less rights than birth parents as no home study assessment is required in ED as it is in adoption. Several donors constructed selection by profile and a single joint meeting as inadequate. Further, donors assumed that adopted children had greater access to information about their genetic parents than do donor offspring. The lack of mechanisms, such as birth certificate annotation, to ensure that offspring would

be aware of their background, was constructed as potentially problematic. As has been pointed out (e.g. Blyth, 2002; Hammarberg et al., 2011; Helm, 2008), disclosure rests on a moral obligation of the recipients. Donors are positioned as disempowered in relation to recipients who, once the embryos had been transferred, have full authority. Some donors spoke of needing to accept this; several supported legislative changes that made provision for screening and disclosure, making ED more like adoption.

Finally, for some donors, the adoption discourse made transparent their decisions to 'relinquish' in that it underscored constructions of the embryo as genetic child of the donors. Similar to birth parents 'having' to relinquish their children, some framed themselves as confronted with limited, emotionally laden, enforced decisions. Thus, the adoption discourse was useful to donors but also complicated their experiences. Donors managed this in different ways. Some extended their construct of 'good parents' to include donation (allowing the embryo a chance at life, and within the context of openness) or positioned themselves as 'good citizens' through 'gifting' embryos. Some drew on extra-discursive factors, as discussed above, to rationalise their decisions. And others constructed the adoption metaphor as not quite fitting, emphasising the distinction between an embryo and child, and framing the donation of an embryo as easier emotionally than relinquishing a child that they had carried and given birth to.

Recipients likewise drew on an adoption discourse to develop a framework for ED and enable it as a family-building option, a finding also reported in Collard and Kashmeri's (2011) study. Several made reference to their familiarity with adoption in the New Zealand context, or discussed their experiences of adoption courses and their counsellors' support of these courses. The adoption discourse provided a way for recipients to accept the parenting of a non-genetic child, for asserting the social role in parenting, and, in the context of open adoption, being 'good parents' by facilitating openness and information exchange. Some recipients also located themselves as occupying similar positions to adoptive parents, grateful for the opportunity to have a child and in a position of power, offering a 'home' to embryos, similar to those 'rescuing' children relinquished by their birth parents.

For recipients, however, the discourse was also one of 'adoption with benefits', including advantages referenced in other research such as fewer bureaucratic processes, a greater likelihood of being selected, the opportunity to experience pregnancy,

childbirth, and parenting from birth, as well as the ability to appear more like ‘other’ families (Blyth et al., 2011; Check et al., 2004; Eisenberg & Schenker, 1998; Hill & Freeman, 2011; N. D. Johnson, 2003; Keenan et al., 2012). While the adoption discourse allowed recipients to draw parallels between their position and that of adoptive parents, they also drew on a gestational discourse to set ED apart from adoption. Both donors and recipients drew on this discourse to distance the genetic parents, and construct intimate ties between recipients and donor offspring, which is discussed next.

8.1.2.2 The gestational discourse

Donors and recipients, as well as counsellors, constructed the biological connection the recipient mother has with the child through gestation as significant for attachment (as was the case in MacCallum, 2009 and as reported by MacCallum and Widdows, 2012). The lack of a gestational relationship between donors and the children on the other hand was constructed as distancing the donors from the child, and making donation less challenging than relinquishing a child that a woman had gestated and given birth to. Donors were thus positioned as less likely to have regrets and to make future claims on the child.

For recipients, gestation was also constructed as offering control over the child’s prenatal development, and even affecting genetic makeup. Hargreaves (2006) observes that physical resemblance between child and parents locates a child as part of a kin group. By constructing gestation as influencing genetic makeup and thus the manifest characteristics of the child, offspring were drawn into the recipient family. Further, while recipients referred to characteristics that the child shared with donors, as in Kirkman’s (2008) study, many gamete recipients relegated these to the background, or reinterpreted the break in genetic continuity, constructing it as to the child’s advantage by avoiding the inheritance of their undesirable characteristics (e.g. ‘they won’t inherit my bad teeth!’). In this way, they drew on adoption discourse as a naturalising strategy providing a framework for family-building, and simultaneously diluted the strength of the genetic tie, drawing on a gestational discourse to make the child ‘more their own’, and positioning themselves as ‘more the parents’ than is the case in adoption. Counsellors also constructed the gestational relationship as changing the dynamics from the adoption experience. This mirrors the findings of Kirkman (2008), who suggests that egg recipients downplay genetics and claim maternity through gestation; while they

may not entirely locate themselves as the ‘real mothers’, they adopt a consoling plot, using biology to mediate genes and relationships. The position of recipients is strengthened in New Zealand in that it is the birth mother and partner that are legally recognised as the child’s parents. As in Indekeu, Hooghe, Daniels, Dierickx and Rober’s (2014) study, this also enabled recipients to be acknowledged by others to be the parent, normalising parenting through donation.

An adoption discourse then, may serve as an antecedent and provide a model for ED, as well as making transparent issues associated with separating genetic and social parenting. By drawing on a gestational discourse, donors and recipients may transform the adoption discourse, distancing the donors from the donor-conceived child and drawing the recipients closer to the child. A third discourse, however, that of ED as gifting and reciprocal exchange, emphasises the ties inherent in donating genetic material, and this is discussed next.

8.1.2.3 Gifting and reciprocal exchange discourse

In this study, donors and recipients rejected a discourse of the embryo as commodity that could be transferred from donor to recipient, a position which may be reinforced by policy in New Zealand that prohibits the commercialisation of ED. Where donation occurs in a context of commercialisation however, and embryos are constructed as commodities, donation may be constructed as a transaction that can be completed, where nothing is owed, and the future role of the donor can be minimised (Daniels & Lewis, 1996). In contrast, in this study, while donors and recipients framed embryos as resources, they constructed them as meaningful also because they constituted children and the full genetic material of the donors. Instead of constructing ED as a property transaction then, they drew on discourses of ED as gifting.

The gifting discourse positioned donors as benevolent benefactors which, as Riggs and Scholz (2011) have suggested in the context of sperm donation, constructs a positive identity for donors as persons, not just as providers of a commodity. The gifting discourse may also have offered recipients a more comfortable position of accepting a gift, rather than ‘buying’ a child. As in other studies (e.g. de Lacey, 2005, 2007b; N. D. Johnson, 2003; Kirkman, 2003a; Lysterly et al., 2010; Svendsen, 2007), the donation was framed as altruistic, which potentially positioned the donors as more empowered than birth parents in adoption, able to make less enforced and more proactive decisions, with less possibility for regret. However, by constructing ED as gifting, the idea of donors as

'faceless' people that could be kept at a distance was negated. Instead, gifting discourse (as for adoption and disclosure discourse) rendered the donors visible, and located donors and recipients within a giving-reciprocating-giving dynamic that Shaw (2008, 2010a, 2010b) sees as characteristic of gifting relationships within consumer economies. Recipients were positioned as grateful, almost indebted, and vulnerable to manipulation by their 'creditors' (as Daniels & Lewis, 1996, suggest in sperm donation contexts). While donors expected no financial compensation, they did expect that the gift would be acknowledged (Daniels & Lewis, 1996; Riggs & Scholz, 2011), through the honouring of disclosure or contact agreements. Counsellors in this study partly reinforced this discourse through the expectation that recipients would express thanks to donors. A relationship between donor and recipients was thus engendered through this discourse, potentially creating a network of ongoing obligations and counter-obligations, as well as power imbalances.

The gifting discourse was not always constructed as adequately capturing the practice of donation however. As Shaw (2008, 2010a, 2010b) argues, the gifting of bodily donor material is complex because it is inalienable. She suggests that in the context of organ donation, bodily material is not property, and even if 'given away' it remains connected to the donor or lives on through the donated material in some way. It is 'more than' a gift. Shaw argues that as a result organ donors may have some expectation of knowing where (to whom) the organ went, and frequently express interest in information about or even having contact with recipients. Likewise, I suggest, embryos in this study were constructed as 'bodily gifts': inalienable from and enduringly connected to the donors as 'their' bodily material, made particularly significant by being genetic material. The construct of inalienability may be reinforced through policy which allows donors to withdraw consent up until transfer, and confers on donors ongoing rights over unused embryos that may remain subsequent to donation. This may make it difficult for donors to draw boundaries in terms of where their responsibilities end, not just in relation to the embryo, but also to donor offspring.

However, several donors, recipients and counsellors resisted a gifting discourse and its implications. Instead, they constructed ED as a solution for both donors and recipients, one that was morally acceptable and rewarding for donors wishing to use their embryos and express thanks for having children, and a way for recipients to have children. Indeed, Applegarth (2006), drawing on social exchange theory, suggests that ED could be constructed as a relationship of reciprocal social exchange where both

parties benefit. Such a reciprocal exchange discourse potentially offers a greater balance of power between donors and recipients, with fewer obligations and counter-obligations evoked. Since ED involves the gifting of genetic, inalienable bodily material however, ongoing social ties may still be evoked as the donor and offspring remain connected. The reciprocal exchange discourse can potentially accommodate this, allowing donors and recipients to approach ED with shared goals of giving, receiving and family-building: they may work together to develop solutions for embryos and to ensure donor offspring are raised appropriately, within the context of a genetic discourse, and embryos as inalienable bodily material. Constructions of ED as reciprocal exchange or mutual benefit thus provide a social framework which allows the holding of genetic ties in a way that positions donors and recipients in more equitable ways than made possible through a gifting discourse.

Finally, a discourse of ED as building extended family was identified that can accommodate a relationship of social exchange and shared goals, and offer a model for holding the interrelationship of genetic, gestational and social elements of reproduction and parenting. I discuss this next.

8.1.2.4 The extended family discourse

In attempts to understand and manage ED, the relationship between the donor and recipient families in this study was constructed in terms of extended family. This discourse is supported by legislative and policy frameworks that suggest enduring implications and connections between families created through ED. Similarly, counsellors construct their role as helping to build and facilitate relationships they framed as potentially intense and long-term, and as involving offspring having access to information and genetic kin. Both donors and recipients referred to each other using family terms, such as aunts or uncles, and some constructed ED as akin to marriage into a family. These are interesting constructs, as they have implications for the types of relationships that can ensue and the various parties' rights and responsibilities. They also constituted an attempt to manage genetic and social connections. As Hargreaves (2006) observes, relatives may be seen to have a claim on one another by virtue of genetic makeup. Constructing the other party as relatives, as extended family, allowed investment in the others' wellbeing and an interest in maintaining connections, but bestowed no legal rights or authority in relation to each other. It allowed for a degree of contact between donor and recipient families to be normalised, as is the case for

extended families, but this could be flexible, and activated by choice (although mainly by the recipients). Indeed, several donors and recipients had a range of information-exchange and contact arrangements, from indirect contact (e.g. Facebook, email) to direct contact for significant family occasions such as birthdays. Contact was framed as healthy for all the children involved as well as reassuring for adults. It was constructed as non-intrusive (e.g. through social networking), and not necessarily frequent. As in Paul et al.'s (2010) study, both parties acknowledged the possibility of challenges in the relationship: donors did not want to interfere by making comments about the child or parenting; recipients were anxious about judgement of their parenting. But by locating each other as extended family, donors were afforded some involvement and degree of 'family rights', allowing them to express interest while staying on the periphery in relation to the child. Donors may become more comfortable with their lack of legal rights by drawing on a discourse that reinforces family ties as immutable even where these are not actioned through regular social contact.

As is the case in sperm donation recipients (see Indekeu et al., 2014), recipients in this study were confronted with the challenge of asserting authority as a parent in the absence of a genetic tie while living in a culture where biogenetic connections between family members are valued. Like donors, recipients drew on extended family discourses which enabled them to bring the donor family into a form of relation with their family while simultaneously placing a distance between the donors and the child. This may have enabled them to inhabit a position of authority over their children, take on board or ignore any suggestions, and position the donor family in significant, but less threatening, even supportive, ways. Indeed, as was pointed out by some participants, donors and recipients provided support to each other in a range of ways (parenting advice, support through pregnancy).

Of further interest were donor and recipient reactions when ED did not lead to a pregnancy and birth. Several spoke of still feeling or remaining connected, even becoming each other's support for future ED experiences or in their continued journeys towards parenthood. Counsellors spoke of there being a need for time to elapse before donors could donate to another family when the first donation had not led to a pregnancy or birth, framing the engagement between the two families as intense. The relationship, the construct of 'extended family', endured. Where this did not happen, some participants expressed disappointment, as they had assumed they would be connected 'forever'.

The discourse of extended family allowed some of its members to be distanced, and yet others (e.g. siblings) could be drawn near and could occupy ‘full family’ roles in relation to each other. Most participants constructed the opportunity to get to know each other as the children’s right. For some, it was important that siblings developed supportive relationships from an early age, while others, as suggested in Collard and Kashmeri’s (2011) study, were comfortable with activating contact later. As in Blyth’s (2012) study, siblings were constructed as a protective band. The discourse also acknowledged the effects of donation on the wider families, something pointed to in other research (e.g. Berger & Paul, 2008; Blyth & Frith, 2009; Daniels et al., 2011; Daniels et al., 2012; Haimes, 1998). In this study, several donors reported that their parents constructed themselves as related to donor offspring in a grand-parenting capacity. Similarly, counsellors constructed the role of donors’ and recipients’ families as significant, and described the relationship between donors’ and donor offspring in family terms.

The extended family discourse was thus useful for donors and recipients in a context where genetic connection is a powerful cultural theme, and where blood ties symbolise permanence in human relationships (Taylor, 2005). It provided a model for ‘holding on and letting go’, and for managing endings and beginnings. Lovelock (2010) suggests that Māori adoption, or whāngai, can serve as a model from which to understand family formation. In whāngai, Māori children are placed with biologically connected kin, with access to whānau and whakapapa. The relationship between adoptive and birth parents in this context is also one of extended family.

8.1.2.5 Blending the three elements of reproduction/parenting; creating new kinship forms

As in Grace and Daniels’ (2007) study which looked at other donor situations, donors and recipients (and counsellors) in this study made use of a fluidity of concepts, encompassing both social and natural constructs in a choreography; at times combining and at other times separating them in order to manage the network of relationships. They managed the implications and inherent tensions of a genetic/kinship discourse by drawing on an adoption discourse, which provided a framework for managing issues related to welfare issues and disclosure, and by simultaneously giving weight to a gestational discourse which underplayed the significance of genetic inheritance and strengthened the ties between recipients and donor offspring. They negotiated the

implications of gifting and receiving genetic material by constructing ED as a form of reciprocal exchange, with shared goals. They invested in a discourse of ED as building extended families, which allowed them to activate genetic kinship in a way that acknowledged and placed boundaries around the rights and responsibilities of each party. Rather than parenting and families being constructed as either biological (genetic), gestational or social in nature, donors and recipients drew on ways to hold the various elements together and recognise them all, and appropriated them strategically. They thus recrafted what it means to be donor/recipient families by integrating dichotomies and blurring the boundaries between the aspects involved. While genealogy remained of importance in family constructs, they were able to hold on to this in ways that did not destabilise family relationships and boundaries. Rather, they combined 'parts of distinct and separate wholes into new hybrid forms reflecting the obscured and contradictory simultaneity at the heart of knowledge practices of modernity' (Grace & Daniels, 2007, p. 694). As Wade (2002, as cited in Lovelock, 2010) comments in relation to donor contexts, in these family forms the relationship between the biological and social might better be conceptualised as a horizontal relationship, where both can be equal and where the boundaries are not always clear.

By placing the various elements of reproduction and family-building in equal relationship with each other, Wallbank (2002, as cited in Grace & Daniels, 2007) argues that a family need not constitute one and only one set of parents. Building family through ED has the potential to lengthen the chains of connectedness between people, and those who make up this chain may operate at different levels and have different priorities (Lovelock, 2010). This challenges the notions of what is natural, and may provide a foundation for society and families in terms of responsibilities and obligations in child-rearing. Indeed, Wallbank (2002, as cited in Grace & Daniels, 2007) suggests that technologies such as donor insemination and surrogacy do not necessarily have to lead to parental exclusivity. Grace (2008), in relation to sperm donation, has written that where both genes and environment are important, donor offspring potentially have two men in their lives that each represent facets of the paternal figure. Likewise, I suggest, in ED offspring may be constructed to have two families. ED was characterised as shared parenting in Goedeke and Payne's (2009) study, and while this has the potential to be threatening, it was also framed as offering a unique way of building families.

Such a redefinition of families through ED is however new, and donors, recipients and counsellors alike constructed ED as a novel, and uncertain practice. This

is reinforced by ED's classification in the HART Act as a restricted practice, requiring case-by-case approval from ECART. Donors and recipients were thus positioned as pioneers in undertaking ED, which generated some anxiety, ambivalence and uncertainty about longer-term implications, not just for donors and recipients, but also for the counsellors facilitating ED. Some donors and recipients were anxious about being in a 'guinea pig' position, and located themselves as vulnerable. Further, many participants had seen the current affairs programme about an ED case that had not worked well, which heightened their anxiety. Indekeu et al. (2014), in the context of sperm donation, have suggested that recipients are more likely to disclose where they feel confident with donor family-building. In this study, while most were open about the donation and had either told or were planning to tell their children, many constructed ED as private, and as disclosed on a need-to-know basis. Further, while most had told their families, very few family members were invited by participants to be a part of this study, and, when invited, very few elected to participate. This may, in part, reflect the degree to which ED was accepted (by couples and families) or may reflect the complex and contested nature of this new practice.

Most donors and recipients appeared able to alleviate this anxiety by constructing themselves as having the necessary qualities (such as courage, initiative, and strength of character) or experiences (familiarity with adoption) to assume a 'pioneering' position. Counsellors managed their anxiety by attempting to be thorough in their practice. Donors, recipients and counsellors drew on the ECART approval process, including the legal requirements, as safety measures giving sanction to this new form of family. They could construct ED as representing positive new advances and solutions both for those with stored embryos and those seeking to become parents, but located these understandings within a biopsychosocial model rather than a medical model, acknowledging not only the medical but also psychological and social implications associated with balancing genetic, gestational and social parenting.

8.2 Implications for policy and practice

Several implications for policy and practice arise from the discursive constructions of ED identified in this study, and these are discussed below.

8.2.1 Assessment/selection of recipients and donors

The genetic discourse underscored an ongoing concern for the welfare of the child resulting from ED. Parallels were drawn with adoption, and donors framed the assessment of recipients' parenting suitability as important for the child's wellbeing. Yet while ECART minutes reflected a concern with donor–recipient match, ED policy does not require formal assessment or home studies, and recipients are required to have police checks only. Current emphasis is on a balancing of individual (adult) rights and the rights of the (future) child, where both are given important consideration (Angus, 2012). Since in ED there is not yet a child to protect, assessment may be seen as unnecessary, as well as an infringement of reproductive rights and individual choice (Anderson, 2006; de Lacey et al., 2010). For some recipients in this study the differences in assessment requirements from adoption were also constructed positively. Nonetheless, given the genetic discourse and the enduring connections potentially formed between families, drawing on some of the elements of adoption such as screening and home assessment may be helpful. It may circumvent some future issues, such as donors' concern about parenting suitability, or alternatively, that the recipients are 'as advertised' (N. D. Johnson, 2003, p. 866). In 2006, the New Zealand government declined a recommendation by the Law Commission (2005) to impose mandatory screening for parents having a child through ED, commenting that it was premature to do so (New Zealand Ministry of Justice, 2006). As suggested by several donors in this study, these recommendations may need to be revisited.

The focus in ED to date has been on mutual selection, with donors and recipients meeting and making decisions to proceed with ED on the basis of a joint meeting and ECART approval. While recipients in this study expressed concerns about the donor–recipient match, and had the option to reject the donors, several acknowledged that they would have proceeded with ED even had they not felt comfortable with the donors. Since donors may have contact with and potentially have an influence on the recipient family and the child, however, I suggest that the need for assessing donor suitability also arises. In this regard, it is interesting to reflect on the comment of one counsellor that she does not 'allow' all potential donors to proceed with ED, as they may not be able to

deal with the need for appropriate boundaries. (This may also explain the low number of donors and recipients withdrawing after joint counselling, as counsellors do not ‘allow’ them to get to the point of joint counselling.) ECART application and counselling processes may be providing some assessment of donor suitability, in that counsellors must report on issues that may affect both the recipients’ and the donors’ ability to manage ED. In the interests of the welfare of the child however, this process may need to be formalised. As Wilde, McTavish and Crawshaw (2014) argue, the use of embryos needs to be recognised not just as a treatment pathway, but as a family-building process, with mechanisms in place to support this.

Further, current policy allows donation to be made only to medically eligible, i.e. infertile recipients, which emphasises a construction of ED as a treatment for infertility, and effectively undermines donors’ ability to give their embryos to individuals (infertile or not) of their choice. Given the significance accorded genetic ties, and that ED was constructed as building extended family, I suggest that donors should be able to make donations to family members or to individuals of their choice where these are assessed as suitable. This would align ED more closely with the Māori practice of whāngai. It has the potential to address concerns about discrimination, as ED may currently be seen to reinforce heteronormative families, giving access to only those single women who are infertile, and to lesbian couples only where both women are deemed infertile.

8.2.2 Donation limits

ED currently offers only a limited solution for those with surplus embryos as embryos may remain following donation. Donation to an additional family could however, prove problematic, particularly given the construct of ED as extended family, and since, as Daniels (2007) points out, it raises questions about the numbers of individuals that become connected to each other in such forms of kinship; the complexities and intensity of engagement involved; and rights and responsibilities in terms of consent, disclosure and access. Further, as Speirs (2012) notes, making and maintaining kinship involves work in terms of time and energy. While donors may be invested in having all of their embryos used, donation to a second family may privilege the interests of adult parties. Donation limits need to take into account the rights and wellbeing of children born from

donation and of their siblings, and thus how they would manage the complexities of having genetically related siblings being raised in a number of different families.

Restricting the numbers of embryos created and stored may be another solution to the issue of surplus embryos (e.g. Mohler-Kuo et al., 2009). However this is problematic given that IVF is a physically and emotionally demanding procedure, and that in New Zealand there is limited government funding for fertility treatment.

8.2.3 Disclosure mechanisms

Disclosure and access to genetic information were constructed as critical in this study. Currently only the latter is protected by law in New Zealand, but clearly this becomes irrelevant if the child is not informed of the conception. The approach adopted in New Zealand has been educative, rather than legislated and punitive (Angus, 2012). In 2005, the Law Commission recommended that birth certificate annotation be considered. However the government response, while acknowledging the need to give consideration to such issues, was negative (New Zealand Ministry of Justice, 2006). While some have suggested that legislation would constitute an intrusion into individual choices and privacy, and would not necessarily translate into greater numbers of recipients telling their children, asserting the psychosocial importance of genealogy and offspring's rights to access their genetic knowledge in the absence of mechanisms to ensure that this occurs is inherently contradictory (Allan, 2010). It has the potential to make the state complicit in acts of deception (Blyth et al., 2009), and arguably undermines the ability to respect the best interests of children born from ARTs. Further, donors and recipients in this study drew on a discourse of ED as extended family. The rights to action the construct of extended family however, currently rests with the recipients as there are no legal mechanisms requiring disclosure of donor conception. Both donors and recipients constructed disclosure as important, and donors in particular would support more formal mechanisms to facilitate this process. I suggest that disclosure mechanisms, such as birth certificate annotation, be implemented in the interests of the child's right to knowledge of, and access to, their genetic background.

8.2.4 Counselling

8.2.4.1 Counselling/preparation and assessment roles

Several authors (e.g. Applegarth, 2006; Daniels, 2005a) highlight the importance of mental health professionals in assisting new families built through ED, and that counselling may impact not only the parents, but other family members, as well as the willingness to disclose and have contact. In this study, counsellors constructed their role as implications counselling and psycho-education: exploring current and longer-term consequences of donation, clarifying expectations and needs of all parties, facilitating relationships between donors and recipients, and encouraging disclosure. For many counsellors, however, their role was constructed as ambiguous, in that it entailed both counselling (exploring issues and concerns) and assessment of donors' and recipients' suitability for ED, as reflected in the reports counsellors are required to provide to ECART. Many counsellors constructed this dual role as restricting their counselling role, limiting their ability to provide a context for in-depth and honest exploration of issues and concerns. Indeed, several participants framed the counsellor's role as an assessment role, potentially making them reluctant to explore their concerns in counselling.

Further, for counsellors their location as assessors positioned them as responsible for ensuring that ED proceeded successfully. This created anxiety for counsellors. While they drew reassurance from having ECART assuming the final decision-making authority over ED, they expressed concern that, along with the clinic, they would be held accountable for negative outcomes.

Counselling and assessment roles would thus best be differentiated, and held by different practitioners. This would remove the role ambiguity for counsellors, and allow donors and recipients to take full advantage of counselling without concern that this may impact on the assessment process and their deemed suitability for ED.

8.2.4.2 Preparation and psycho-education around cryopreservation

Similar to what has been reported elsewhere (Brzyski et al., 2000; N. D. Johnson, 2003; Lyerly et al., 2010; Melamed et al., 2009; O'Brien, 2010), for many donors in this study the issue of 'surplus' embryos and their disposal was constructed as burdensome, and as a decision they had not envisaged making. Donors spoke of their IVF as either having unforeseen consequences or consequences which they avoided. Several constructed

their decision to donate as a restricted and enforced decision, evoking possibilities of regret and ambivalence. While cryopreservation may be regarded as standard, routine practice (Provoost et al., 2010), and there may be a challenge in getting donors to consider future implications (Lyerly et al., 2006; Paul et al., 2010), I suggest that the potential consequences of storing embryos need to be explored more fully with donors before they store embryos, and disposal options need to be revisited regularly. While this may not inhibit decisions to store (Lyerly et al., 2006), it may facilitate more in-depth awareness of possible issues that may arise.

8.2.4.3 Gate-keeping and enabling

Counsellors discourage, even prohibit, contact between donors and recipients before ECART approval out of a concern for coercion and informed consent. Several participants expressed frustration with this, arguing that it was difficult to make decisions in the context of having little information about another couple/individual. Drawing on constructs of extended family, some likened this to agreeing to a marriage without having developed a prior relationship. They argued that coercion at this early stage indicated a poor precedent for the future, and would affect decision-making. It was interesting that those participants who had found their own donors or recipients reported this as positive and empowering. They appeared to have managed the power issues that could arise independently of external assistance. I suggest that donors and recipients should be able to have greater contact prior to making decisions, but with counsellors available to enable relationship-building and provide support where required, and with external assessment mechanisms in place to control for issues related to coercion.

8.2.4.4 Ongoing support

While counsellors expressed a willingness to be involved following ED, the current emphasis is on preparation for ED. The extended family discourse that donors and recipients drew on has implications for longer-term relationships, however, as these may be complex, dynamic and require mediation as needs and expectations evolve. Relationships may also be affected by drawing on a discourse of ED as gifting, with implications for the power and vulnerability donors and recipients assume in relation to each other. Donors and recipients must thus negotiate the implications of their various positions: those of ‘good parent’, ‘good citizen’, ‘extended family member’, ‘gift-giver’ and ‘gift-recipient’. Where one party’s rights and responsibilities begin and end may

need re-evaluation as relationships develop; boundaries, information exchange, and contact arrangements may need to be renegotiated. Particularly given the constructions of ED's novelty and the lack of blueprints to guide experience, longer-term support should be available to both donor and recipient families. Such support could take various forms, including access to counselling, or the establishment of support groups.

8.2.4.5 Professional development for counsellors

Counsellors constructed ED as an unknown and as a complex family-building approach with enduring implications. This created considerable anxiety and concern. While counsellors have access to supervision in which they can access support and reflect on these concerns, perhaps more formal peer-support structures and professional development opportunities in which strategies and concerns that may arise are addressed could be useful.

8.2.5 The role of ECART

ECART was constructed by donors and recipients as an external control mechanism, framed either as a safety net providing reassurance and sanctioning suitability for ED, or as 'Big Brother', an intrusive and disempowering entity. Nonetheless, both discourses positioned ECART as responsible for the outcomes of ED, similar to the position that CYF may occupy in overseeing adoption placements. ECART was set up with the brief to approve and monitor treatments for infertility, while also taking into account the health and welfare of all parties involved, including children. As identified in this study, however, there may be some ambivalence in the role ascribed to ECART, in that it is unclear to what extent ECART has responsibility for monitoring child welfare on an ongoing basis. I suggest that the role of ECART in assessing applications for ART use and the basis for decision-making be reviewed and clarified. Further, the role of ECART in monitoring outcomes of ARTs, and the longer-term welfare of children born as a result, also needs to be made explicit to donors, recipients and clinics.

This study endorses Daniels' (2005a) position that healthy and well-functioning families created through third party ARTs emerge from confident and secure parents, supported and empowered by professionals, and through appropriate policies and laws that can provide a context in which different types of families are built and accepted. In sum, the recommendations suggested above may assist in ensuring that these conditions

are in place, and help ensure ED is carried out appropriately as a means both to have children and to manage having ‘surplus’ embryos following treatment.

8.3 Study challenges and recommendations for future research

A number of challenges were encountered in this research. Given the multitude of ways in which embryos and ED have been portrayed, I elected to use discourse analysis as my method of enquiry. One of the potential pitfalls of such an approach is that the identified discourses can become reified, rather than recognised as social constructions. Thus, in my presentation of results I have emphasised that these are discourses that I have identified, and have provided examples so that the reader may understand the way in which I constructed these discourses.

Further, I wanted to use a method that could accommodate the holistic nature of my enquiry and my systemic orientation, accounting for a multitude of factors shaping and affecting understandings and experiences of ED in New Zealand. I wanted an approach that could hold together how individuals construct ED, how counsellors (given their central role) may influence these constructions, how family members and significant others respond and shape constructions, and how discourses made available in legislation and policy affect ED understandings and thus experiences. However, blending a macro approach with some of the features of a micro approach, as well as incorporating extra-discursive aspects within a systemic framework, proved to be a challenging enterprise. I attempted to manage this by balancing active and passive positions: considering how discourses make available particular possibilities and positions; how donors and recipients may actively draw on such discourses to enable options and assume positions; and how a range of factors may more readily enable them to invest in some discourses and not others. The emphasis in the different chapters varied, with, for example, the policy and counselling chapters drawing more on a macro approach and bringing to the foreground the ‘discursive economy’ available.

In my attempts to identify extra-discursive factors, my focus remained on those that emerged within my interviews and to which participants oriented. I did not ask directly, for example, about many of the variables identified in other studies. Rather, my questions were more general (Appendix K). Perhaps, had I asked directly, other factors may have been identified. As I proceeded with my study, the challenges of integrating

such extra-discursive factors with discursive ones became apparent, as of course these factors can themselves be constructed. However, identifying such factors helped explain the uptake of particular discourses, and fitted well with my systemic model, which recognised that understandings may be affected by a multiplicity of factors: legislation and policy, clinic and counselling practice, material conditions, embodiment, and personal social biographies.

Another challenge was that I recruited participants at various stages of the ED process: some had only recently been approved for ED; for some the donation had occurred a few years previously; some had had unsuccessful outcomes; others had had one or more children through ED; and for those with children, the children were still young. Part of the challenge in embarking on this study was the small number of ED cases that had proceeded by the time of recruitment, and thus my recruitment was based on participants having achieved ECART approval. In my initial analysis, I separated out those donors and recipients that had ‘successfully’ donated, and those that had not. However I found no differences in the discourses that I identified, and Willig (2010) suggests that where a discourse can be identified, its availability within that particular culture can be assumed. I thus elected to combine the donors’ and recipients’ responses. ED is however, not experienced as a static, one-off event. As Kirkman (2004) observes, meanings may change over time and circumstance, particularly as children mature, as disclosure becomes an issue, and as relationships develop. Further studies will be useful to research these developments, as well as to explore the outcomes for donor-conceived children, particularly given the lack of follow-up studies of families formed through donation (Blyth et al., 2011; Frith et al., 2011; Kirkman, Bourne, Fisher, Johnson & Hammarberg, 2014; MacCallum et al., 2007; Paul et al., 2010).

Also in relation to recruitment, at the suggestion of the Kawa Whakaruruhau Committee I gave my participants a choice in terms of being interviewed separately or as a couple, with or without family members present. Most of those participants in partnerships elected to be interviewed together, in one case a husband and wife elected to be interviewed separately, and in two cases only the wife was interviewed (although in one of these two cases, the husband had unexpected commitments at the time of the interview). It is possible that relationship dynamics may have affected the context and nature of the interview process. In addition, especially given the relevance of Māori beliefs in shaping practice and policy, I had hoped to interview Māori who had undertaken ED. However, only a very small number of individuals who identify as

Māori have proceeded with ED, and none volunteered to participate. Researchers (e.g. Glover, 2008) have suggested that Māori may prefer within-whānau solutions for infertility, which may account for the low numbers. These issues warrant exploration in research efforts aimed specifically at Māori. Further, it may be interesting to explore and compare the understandings and experiences of individuals that have been birth parents, matua whāngai (person who raises or cares for a child through whāngai), or tamaiti whāngai (child placed through whāngai) in whāngai arrangements, given some of the parallels that may be identified in these types of family formation and kinship practices.

Finally, it was interesting that in spite of the opportunity provided, family were not invited by the participants to take part in the interview process. This may have been as a result of discourses of ED as novel and unknown for donors, recipients and their families, or donor and recipient concerns about family members' reactions, even though most spoke of having consulted with their families. Nonetheless, given the discourse of ED as building extended families, and that donation has been described as affecting the whole family (Collard & Kashmeri, 2011; Daniels et al., 2012), it would be interesting to explore how such relationships unfold over time in relation to wider family networks.

8.4 Conclusion

ED has the potential to offer hope to individuals and couples struggling to have children, as well as to provide a viable solution for those with embryos that remain after IVF treatment. At the same time, however, ED brings new challenges as families are built in novel ways that involve the interweaving and transformation of biogenetic and social aspects of parenting and family formation, and that attempt to ensure the wellbeing of children and future generations. Some have suggested that ED is risky, even experimental (Guichon et al., 2010). Some jurisdictions have opted to prohibit cryopreservation or ED, or allow only those embryos that the couple will be able to use to be frozen. ED in New Zealand may indeed “bring about new kinds of social relations in which kinship boundaries are redefined” (Taylor, 2005, p. 189). Such expanded constructs of family and kinship may involve ambivalence and complexity, and the implications for future generations may be uncertain. The social, ethical, legal, and psychological implications, both in the short and long term, need to be considered by all that undertake ED and help facilitate it. While we should not be afraid to seek new

answers to the dilemmas associated with reproductive technologies, we should proceed carefully and cautiously. We should take into account the rights and needs of individuals, children and their families, and the cultural and social context within which reproductive technology occurs. We also need to draw on research and the experiences of those that proceed with ED to guide us. Based on the research reported in this thesis, I would suggest that in the context of New Zealand this means continuing to develop appropriate strategies, policies, and legislative frameworks through which to support donors and recipients in working towards novel, shared solutions both for unused embryos and for building families through valuing, combining and separating genetic, biological and social parenting roles. As in 2014 the first embryos will reach their storage limits under the 2004 regulations, and ED constitutes one of limited options available for frozen embryos, there is a need to ensure such support structures are in place.

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Appendix A

Glossary

ACART	Advisory Committee on Assisted Reproductive Technology, set up under the HART Act (2004) by the Ministry of Health to issue guidelines and advice to ECART relating to reproductive procedures or research.
donor conception	conception via the donation of sperm, ova (eggs) or embryos
donor offspring	or donor-conceived persons are conceived via the donation of sperm, eggs, or both; or may be conceived via the donation of embryos
ECART	Ethics Committee for Assisted Reproductive Technologies, set up to consider, determine and monitor applications for approvals for ART procedures and reproductive research. Applications are assessed with reference to ACART guidelines. ECART must be guided by the principles of the HART Act (2004)
egg (oocyte) donation	a process whereby a woman provides several eggs (ova or oocytes) for the purposes of reproduction by another woman
gamete donation	donation of gametes (egg or sperm) for reproduction
hapū	Māori word for clan or subtribe
HART Act (2004)	Human Assisted Reproductive Technology Act 2004
iwi	Māori word for tribe (within each iwi are hapū, made up of whānau)
kaumātua	Māori word for tribal elder
kaupapa	Māori word for principles, ideals or values
Kawa Whakaruruhau Committee	a committee within the School of Health Care Practice at AUT University which provides assessment and consultation on research in terms of cultural safety, and adherence to the principles of the Treaty of Waitangi
Māori	the indigenous people of New Zealand
matua whāngai	person who raises a tamaiti whāngai

Pākehā	Māori term for Europeans
tamaiti whāngai	the term for a child that was placed for whāngai; a child nurtured or raised by someone other than his or her birth parents (but typically by members of the whānau)
tāngata whenua	Māori term for indigenous people, or ‘people of the land’
taonga	Māori term for cultural treasures
tapu	Māori word meaning holy, sacred
Te Ara Tika	guidelines for Māori research ethics as published by the Health Research Council of New Zealand
te reo Māori	Māori language
tikanga	refers to protocol, customs or ethical behaviour guidelines associated with Māori values, beliefs and worldview.
whakapapa	genealogy or ancestry, a fundamental principle of Māori culture. Access to knowledge regarding whakapapa is considered central to identity.
whānau	Māori term for family or extended family
whāngai	a customary practice in which a Māori child is placed to be raised with a member of the whānau. This can occur for a range of reasons including the inability of the child’s parents to care for the child or a whānau member’s infertility. Whāngai occurs within the child’s whānau which means that whakapapa (or genealogy) is acknowledged and whānau links are maintained and strengthened

Appendix B

**Advisory Committee on Assisted Reproductive Technology (ACART) (2008):
Guidelines on Embryo Donation for Reproductive Purposes** - Issued to the Ethics
Committee on Assisted Reproductive Technology on 17 November 2008

These guidelines may be retrieved from:

www.acart.health.govt.nz/publications-and-resources/guidelines-and-advice-issued-ecart/guidelines-embryo-donation

Appendix C

Guidelines on Embryo Donation for Reproductive Purposes

Prepared by the National Ethics Committee on Assisted Human Reproduction, August 2005

Retrieved August 24, 2006 from www.newhealth.govt.nz/acart/guidelines/

Section One – Guidelines relating to donor couples

1. All new clients seeking treatment that involves the creation of embryo must be informed about the options available for the storage and disposal of surplus embryos, including the option of embryo donation for reproductive purposes. Existing clients with surplus frozen embryo must be informed that embryo donation to other infertile people is an option for them.
2. Couples wishing to donate surplus embryos must undertake implications counselling before entering into the donation process.
3. Only couple who have embryos created from their own gametes, intended for their own use, may donate surplus embryos to other people.
4. Pressure must not be exerted on potential donor couples.
5. Donor couples have the right to vary the agreed terms of donation at any time, until the embryos have been transferred to the recipient woman. (Note: Any alteration to an embryo donation arrangement previously approved by NECAHR must be resubmitted to NECAHR for ethics approval.)
6. Donor couples have the right to withdraw from the donation at any time, until the embryos have been transferred to the recipient woman.
7. Donor couples must be advised that embryos may not be able to be refrozen if they decide to withdraw from the arrangement after the embryos have been thawed.
8. Embryo donation may occur only when both partners of a potential donor couple have given their written consent to the donation. If one partner of a potential couple is deceased, embryo donation may proceed only if prior written consent to embryo donation has been obtained from the person.

9. Counsellors must provide potential donor couples with non-identifying profiles of potential recipients from which they will select a person/couple to receive their surplus embryos.
10. Potential donor couples must provide non-identifying information to the provider from which profiles will be developed. All profiles must be approved by donor couples. Written consent must be provided by potential donor couples for their profiles to be given to potential recipients.
11. Donor couples may not embark on the donation process until at least two years have elapsed since the decision that their families are complete.
12. Donor couples can only donate to one family.
13. Providers must keep the following information on donor couples:
 - 13.1 Names
 - 13.2 Address (should be kept up to date where possible)
 - 13.3 Date, place and country of births
 - 13.4 Heights
 - 13.5 Eye and hair colours
 - 13.6 Ethnicity and any relevant cultural affiliations
 - 13.7 In the case of Māori donors, the whānau , hapu, and iwi, to the extent that the donors are aware of these affiliations
 - 13.8 Any aspects, considered significant by the provider, of the medical history of:
 - 13.8.1 The donors
 - 13.8.2 The donors' parents and grandparents
 - 13.8.3 The donors' children (if any)
 - 13.8.4 The donors' siblings (if any)
 - 13.9 Reasons for donating

Section Two – Guidelines relating to recipients

14. Embryo donation for reproductive purpose should be proved only when there are medical conditions precluding normal reproduction in respect of the recipient/s or unexplained infertility that has not responded to other treatments, (when conception may be possible, appropriate contraception during the embryo transfer is required.)
15. Potential recipients of donated embryos must be provided with implications counselling before entering into the donation process.
16. Potential recipients must provide non-identifying information to the provider on which profiles will be developed.
17. Providers must apply to the Ministry of Justice under the Privacy Act of 1993 for a copy of potential recipients' criminal records held on the Ministry's computer systems. The appropriate application form is located on the Ministry of Justice website: www.justice.govt.nz/privacy/request-by-third-party.pdf. The provider must remove all personal identifying information on potential recipients' records (e.g. names and addresses) and attach the edited records to the potential recipients' profiles.
18. Written consent must be provided by potential recipients for their profiles to be given to potential donor couples.
19. Counsellors must provide potential recipients with a non-identifying profile of a donor couple that is considering donating surplus embryos to them.
20. Providers must assess the potential recipient woman and be satisfied that implanting donated embryo/s would pose no adverse physical risk to her, other than that what is normally encountered during embryo implantation and pregnancy.
21. Providers must keep the following information on recipient/s:
 - 21.1 Names
 - 21.2 Address (should be keep up to date where possible)
 - 21.3 Date, place and country of births
 - 21.4 Ethnicity and any relevant cultural affiliations
 - 21.5 In the case of Māori recipient/s, whānau , hapu, and iwi, to the extent that the recipient/s are aware of these affiliations

Section Three – Guidelines relating to both donor couples and recipients

22. The treatment must be in accordance with the Reproductive Technology Accreditation Committee (RTAC) guidelines on embryo transfer (donation). Screening of the donor couples and recipients must be carried out in accordance with RTAC guidelines. In addition to the screening carried out prior to a potential donor couple's treatment, all donor couples are required to be screened (in accordance with RTAC guidelines) at least six months after the embryos were created.
23. Embryos must not be donated if they have been subjected to procedures that carry any known risk to the embryo other than those that are normally encountered in IVF procedures.
24. Embryos must not be donated if they are known to be affected by, or carriers of, a significant genetic disease.
25. Informed decision-making is required for all participants in embryo donation. Participants must be given all information that may be of significance, including the provisions of the Human Assisted Reproductive Technologies Act 2004 and the Status of Child Act 1968, in a way that is appropriate to, and sufficient for informed decision-making. All those who are to give their consent must be given a culturally appropriate oral explanation, supported by written information in plain language that is provided to them in sufficient time for it to be taken away, read and considered, prior to the giving of consent.
26. A formal record of consent must be kept by the provider.
27. Providers must inform donor couples and recipients of requirements regarding information sharing under the Human Assisted Reproductive Technologies Act.
28. Both donor and recipient couples must be permanent residents in New Zealand.

Section Four – Guidelines relating to counselling

29. All parties undergoing embryo donation must be provided with formal counselling. Two counsellors must be involved, one for the donating couple and one for the recipient/s.
30. Donor couples and recipients must have access to counselling throughout the embryo donation process.

31. Counselling must be undertaken by qualified counsellors and be culturally appropriate. Whānau /extended family involvement should be provided for at least the initial interview, but recognising that the parties gave the right to accept or refuse this support.
32. Where there are children involved with either the donor couples or recipients, they should be included in counselling sessions on an age-appropriate basis.
33. In addition to separate counselling sessions with the donor couple and recipient/s, counselling must include at least one counselling session where all adult parties are involved. Both counsellors must be present at this joint session.

Counselling for the donor couple

34. The counselling report for the donor couple must confirm to NECAHR that the following issues have been discussed and, in the professional assessment of the counsellors, have been adequately understood:
 - 34.1 The couple's reasons for donating embryos
 - 34.2 The couple's feelings now, and feelings they may experience in the future, concerning the donation of embryos
 - 34.3 The impact of donating embryos on their existing child/ren
 - 34.4 The rights and needs of any child resulting from embryo donation and in particular, the child's rights to access information about the donor couple and to contact them in the future
 - 34.5 The issues associated with the process of selecting a recipient profile
 - 34.6 The understanding that the recipient/s will be the legal parent/s of any resulting child
 - 34.7 The possibility that the resulting child may be born with disabilities or genetic disorders
 - 34.8 The possibility of legal termination of the pregnancy by the recipient/s.

35. Counsellors are also expected to follow the usual counselling practice of recording the family history of the donor couple. If there are issues that may affect the health and wellbeing of the donor couple and/or potential child, these must be referred to and discussed in the counselling report.

Counselling for recipient/s

36. The counselling report for the recipients must confirm to NECAHR that the following issues have been discussed and, in the professional assessment of the counsellors have been adequately understood:

36.1 The implications of accepting a donated embryos and therefore having a child that is not genetically related to them

36.2 The rights and needs of any child resulting from embryo donation and in particular, the child's rights to access information about the donor couple and to initiate contact in the future

36.3 The possibility that the resulting child will be born with disabilities or genetic disorders

36.4 The possibility of legal termination of the pregnancy

36.5 The attitude of both parties (donor couples and recipients) to openness about the donation, especially with any resulting child

37. Counsellors are also expected to follow the usual counselling practice of recording the family history of the recipient/s. If there are issues that may affect the health and wellbeing of the recipient/s and/or potential child, these must be referred to and discussed in the counselling report.

Joint counselling

38. The counselling report for the joint counselling session must conform to NECAHR that the following issues have been discussed and, in the professional assessment of the counsellors, have been adequately understood:

38.1 The rights and needs of any child resulting from embryo donation and in particular, the child's rights to access information about their genetic origins and the implications of this for all parties

38.2 The donor couple and recipient/s' understanding of each other's needs and wishes

38.3 The expectations and plans of all parties regarding ongoing contact and information sharing

Section Five – Approval process

39 NECAHR requires all applications for embryo donation for reproductive purposes to be submitted for ethical approval on a case-by-case basis. The guidelines and application process will be reviewed no later than 2007.

Section Six – Reporting requirements for providers

40 Providers must notify NECAHR at the time of each annual report in the case of approved embryo donation for reproductive purposes:

40.1 What, if any, counselling in addition to implications counselling has been provided to both parties

40.2 When pregnancy is confirmed

40.3 Of any adverse events

40.4 Of the outcome of the pregnancy

Appendix D

Participant Information Sheet: Donors and Recipients

Participant Information Sheet



Date Information Sheet Produced:

December 2011

Project Title

Understandings and experiences of embryo donation

An Invitation

My name is Sonja Goedeke and I am a senior lecturer in the Department of Psychology at AUT, and enrolled as a PhD student at AUT.

You are invited to participate in this PhD study which explores how actual and potential donors and recipients of embryos, and their families/friends ('significant others'), have understood and experienced embryo donation, and how counsellors and consultants view embryo donation. Your participation in the study is voluntary.

My PhD supervisor is Dr Mark Thorpe (AUT).

What is the purpose of this research?

Embryo donation is a relatively new practice in New Zealand, approved in late 2005 only, and under specific conditions including the disclosure of donor identity, and mandatory joint counselling for donors and recipients. I would like to do this research to explore how donors and recipients have experienced the process and practice of embryo donation with its particular guidelines.

I would like to do this research to explore how actual and prospective donors and recipients have experienced the process and practice of embryo donation with its particular guidelines, and how counsellors and consultants have experienced the practice.

I hope that this research will help people in understanding the issues involved and any factors that might influence their decision-making around embryo donation. The research forms the basis of my PhD study, and I would like to present the findings from the research to fertility professionals, academics working in the area, and policy-makers, and publish in magazines and academic journals.

What will happen in this research?

You have been sent this information sheet by your clinic counsellor. Please read this information sheet and if you would like to take part in the study, please contact me either by emailing me or contacting me at the numbers below. You can also contact me to discuss the study in more depth, ask any questions you may have, or discuss your possible involvement –

this can occur via phone, email or in person. If you agree to participate, this will involve an interview at a time and place convenient to you. With your permission, I would like to tape record and transcribe the interview, with any identifying information removed. The interview can take as long as you like, but you can expect it to last about 1 ½ hours.

Who can participate in the research?

1. Men or women who have had applications submitted to ECART to donate or receive embryos.
2. Men or women who have seriously considered embryo donation, undertaken joint counselling, but elected not to proceed.
3. Family members or friends ('significant others') of donors and recipients, by invitation from donors and recipients.
4. Counsellors and consultants counselling and advising in relation to embryo donation.

You need to be able to converse fluently in English to participate. I would like to interview at least 5 donors and 5 recipients, 3 prospective donors and 3 recipients who elected not to proceed, 3 consultants, and all counsellors who have had experience in embryo donation counselling who are willing to participate.

With respect to donors and recipients, with your permission, and where appropriate, I would like to interview any of your family members and whanau or friends significant in your decision-making who may be willing to talk about their perceptions of embryo donation. This can be discussed with me either at the interview or when you make contact to discuss your participation.

What are the discomforts and risks?

Infertility can be a stressful and difficult experience, and talking about what you have gone through may be uncomfortable for you.

How will these discomforts and risks be alleviated?

I am an experienced health professional and I aim to ensure a comfortable and safe environment for you to talk. You can choose to stop the interview at any time or choose to stop talking about an issue about which you feel uncomfortable. You may also have a friend, family or whanau support to help you understand the risks and/or benefits of this study or any other explanation you may require. Should the study cause you any distress, three free research-related counselling sessions can be obtained through AUT's Health and Counselling Centre (ph: 09 921 9992 City Campus or 09 921 9998 North Shore campus).

What are the benefits?

You may find it beneficial to talk about your experiences and views and explore the issue of embryo donation in the interview. The research based on this study may contribute to policy development and guide practice in this area.

How will my privacy be protected?

You will be asked to provide a pseudonym by which you will be known in the study. All references made during the interviews to names of other people (e.g. practitioners), place names and organisations, or any other details that could compromise confidentiality will either be deleted or altered to protect confidentiality as much as possible. Owing to the small numbers of people who have experienced embryo donation to date, it is possible that those familiar with your story may recognise descriptions of your experience. You will however receive a transcript of the interview and you will be free to make any changes to the transcript. Audiotapes of interviews will be destroyed following transcription. Transcripts will be kept in a locked filing cabinet at AUT for a period of 10 years and then destroyed.

What are the costs of participating in this research?

There are no costs to you other than your time.

What opportunity do I have to consider this invitation?

Please contact me within two weeks of receiving this information sheet if you would like to participate. Please feel free to contact me with any questions and to discuss your participation in this study with me.

How do I agree to participate in this research?

Please contact me using the details given below. To participate in the interview you will need to sign a consent form. If you do agree to take part, you are free to withdraw from the study at any time without having to give a reason and this will in no way affect your future health care.

Will I receive feedback on the results of this research?

I will send you a report of my research findings as well as details of any resulting publications. I expect to complete my PhD in May 2014, but will be sending you updates throughout the course of the project, and you are welcome to contact me at any time to discuss study progress and findings.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project can be notified to the Researcher, Sonja Goedeke, sonja.goedeke@aut.ac.nz, ph: 09 9219999 ext 7186, or primary supervisor: Dr Mark Thorpe, mark.thorpe@aut.ac.nz, ph: 09 9219999 ext. 7786.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate. Free phone: 0800 555 050; Free fax: 0800 2 SUPPORT (0800 2787 7678). Email: advocacy@hdc.org.nz

Please feel free to contact the researcher if you have any questions about this study:

Researcher Contact Details:

Sonja Goedeke

Senior Lecturer and PhD student

Department of Psychology

Faculty of Health and Environmental Sciences

AUT University

Private Bag 92006

Auckland 1142

Phone: 09 9219999 ext 7186

Email: sonja.goedeke@aut.ac.nz

PhD Supervisor Contact Details:

Dr Mark Thorpe

Head of Department

Department of Psychology

Faculty of Health and Environmental Sciences

AUT University

Private Bag 92006

Auckland 1142

Phone: 09 9219999 ext 7786

This study has received ethical approval from the Central Regional Ethics Committee, which reviews national and multi regional studies, ethics reference number CEN/11/12/071

Appendix E

Participant Information Sheet: (Declined) Donors and Recipients

Participant Information Sheet



Date Information Sheet Produced:

December 2011

Project Title

Understandings and experiences of embryo donation

An Invitation

My name is Sonja Goedeke and I am a senior lecturer in the Department of Psychology at AUT, and enrolled as a PhD student at AUT.

You are invited to participate in this PhD study which explores how actual and potential donors and recipients of embryos have understood and experienced embryo donation. Your participation in the study is voluntary.

My PhD supervisor is Dr Mark Thorpe (AUT).

What is the purpose of this research?

Embryo donation is a relatively new practice in New Zealand, approved in late 2005 only, and under specific conditions including the disclosure of donor identity, and mandatory joint counselling for donors and recipients. I would like to do this research to explore how actual and potential donors and recipients have experienced the process and practice of embryo donation with its particular guidelines.

I hope that this research will help people in understanding the issues involved and any factors that might influence their decision-making around embryo donation. The research forms the basis of my PhD study, and I would like to present the findings from the research to fertility professionals, academics working in the area, and policy-makers, and publish in magazines and academic journals.

What will happen in this research?

You have been sent this information sheet by your clinic counsellor. Please read this information sheet and if you would like to take part in the study, please contact me either by emailing me or contacting me at the numbers below. You can also contact me to discuss the study in more depth, ask any questions you may have, or discuss your possible involvement – this can occur via phone, email or in person. If you agree to participate, this will involve an interview at a time and place convenient to you. With your permission, I would like to tape record and transcribe the interview, with any identifying information removed. The interview can take as long as you like, but you can expect it to last about 1 ½ hours.

Who can participate in the research?

1. Men or women who have had applications submitted to ECART to donate or receive embryos.
2. Men or women who have seriously considered embryo donation, undertaken joint counselling, but elected not to proceed.
3. Family members or friends ('significant others') of donors and recipients, by invitation from donors and recipients.
4. Counsellors and consultants counselling and advising in relation to embryo donation.

You need to be able to converse fluently in English to participate. I would like to interview at least 5 donors, 5 recipients and their invited family members, 3 prospective donors and 3 recipients who elected not to proceed, 3 consultants, and all counsellors who have had experience in embryo donation counselling who are willing to participate.

What are the discomforts and risks?

Infertility can be a stressful and difficult experience, and talking about what you have gone through may be uncomfortable for you.

How will these discomforts and risks be alleviated?

I am an experienced health professional and I aim to ensure a comfortable and safe environment for you to talk. You can choose to stop the interview at any time or choose to stop talking about an issue about which you feel uncomfortable. You may also have a friend, family or whanau support to help you understand the risks and/or benefits of this study or any other explanation you may require. Should the study cause you any distress, three free research-related counselling sessions can be obtained through AUT's Health and Counselling Centre.

What are the benefits?

You may find it beneficial to talk about your experiences and views and explore the issue of embryo donation in the interview. The research based on this study may contribute to policy development and guide practice in this area. You will be offered a \$20 voucher as koha.

How will my privacy be protected?

You will be asked to provide a pseudonym by which you will be known in the study. All references made during the interviews to names of other people (e.g. practitioners), place names and organisations, or any other details that could compromise confidentiality will either be deleted or altered to protect confidentiality as much as possible. You will also receive a transcript of the interview and you will be free to make any changes to the transcript. Audiotapes of interviews will be destroyed following transcription. Transcripts will be kept in a locked filing cabinet at AUT for a period of 10 years and then destroyed.

What are the costs of participating in this research?

There are no costs to you other than your time.

What opportunity do I have to consider this invitation?

Please contact me within two weeks of receiving this information sheet if you would like to participate. Please feel free to contact me with any questions and to discuss your participation in this study with me.

How do I agree to participate in this research?

Please contact me using the details given below. To participate in the interview you will need to sign a consent form. If you do agree to take part, you are free to withdraw from the study at any time without having to give a reason and this will in no way affect your future health care.

Will I receive feedback on the results of this research?

I will send you a report of my research findings as well as details of any resulting publications. I expect to complete my PhD in May 2014, but will be sending you updates throughout the course of the project, and you are welcome to contact me at any time to discuss study progress and findings.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project can be notified to the Researcher, Sonja Goedeke, sonja.goedeke@aut.ac.nz, ph: 09 9219999 ext 7186, or primary supervisor: Dr Mark Thorpe, mark.thorpe@aut.ac.nz, ph: 09 9219999 ext. 7786.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate. Free phone: 0800 555 050; Free fax: 0800 2 SUPPORT (0800 2787 7678). Email: advocacy@hdc.org.nz

Please feel free to contact the researcher if you have any questions about this study:

Researcher Contact Details:

Sonja Goedeke

Senior Lecturer and PhD student

Department of Psychology

Faculty of Health and Environmental Sciences

AUT University

Private Bag 92006, Auckland 1142

Phone: 09 9219999 ext 7186

Email: sonja.goedeke@aut.ac.nz

PhD Supervisor Contact Details:

Dr Mark Thorpe

Head of Department

Department of Psychology

Faculty of Health and Environmental Sciences

AUT University

Private Bag 92006, Auckland 1142

Phone: 09 9219999 ext 7786

This study has received ethical approval from the Central Regional Ethics Committee, which reviews national and multi regional studies, ethics reference number CEN/11/12/071

Appendix F

Participant Information Sheet: Family and Friends

Participant Information Sheet



Date Information Sheet Produced:

December 2011

Project Title

Understandings and experiences of embryo donation

An Invitation

My name is Sonja Goedeke and I am a senior lecturer in the Department of Psychology at AUT, and enrolled as a PhD student at AUT.

You are invited to participate in this PhD study which explores how actual and potential embryo donors and recipients, and their families or friends, have made sense of and experienced embryo donation. Your participation in the study is voluntary.

My PhD supervisor is Dr Mark Thorpe (AUT).

What is the purpose of this research?

Embryo donation is a relatively new practice in New Zealand, approved in late 2005 only, and under specific conditions including the disclosure of donor identity, and counselling for donors and recipients, which can include family members. For some donors and recipients, friends may also be influential in their decision to undertake embryo donation. I would like to do this research to explore how donors and recipients, and their families/ friends, have understood embryo donation and experienced the process and practice of embryo donation with its particular guidelines.

I hope that this research will help people in understanding the issues involved and any factors that might influence decision-making around embryo donation. The research forms the basis of my PhD study, and I would like to present the findings from the research to fertility professionals, academics working in the area, and policy-makers, and publish in magazines and academic journals.

What will happen in this research?

You have been provided with this information sheet by a member of your family or a friend that has been involved in embryo donation. Please read this information sheet and if you would like to take part in the study, please contact me either by emailing me or contacting me at the numbers below. You can also contact me to discuss the study in more depth, ask any questions you may have, or discuss your possible involvement – this can occur via phone, email or in person. If you agree to participate, this will involve an interview at a time and place convenient

to you. With your permission, I would like to tape record and transcribe the interview, with any identifying information removed. The interview can take as long as you like, but you can expect it to last a maximum of 1 ½ hours.

Who can participate in the research?

1. Men or women who have had applications submitted to ECART to donate or receive embryos.
2. Men or women who have seriously considered embryo donation, undertaken joint counselling, but elected not to proceed.
3. Family members or friends ('significant others') of donors and recipients, by invitation from donors and recipients.
4. Counsellors and consultants counselling and advising in relation to embryo donation.

You need to be able to converse fluently in English to participate. I would like to interview at least 5 donors, 5 recipients and their invited family members, 3 prospective donors and 3 recipients who elected not to proceed, 3 consultants, and all counsellors who have had experience in embryo donation counselling who are willing to participate.

What are the discomforts and risks?

The experience of infertility and its associated treatments can be difficult not only for the individuals affected, but also their family members or friends. Whilst it is not anticipated that the interview will present any distress for you, talking about some aspects of what you and your family/friend have experienced may be uncomfortable.

How will these discomforts and risks be alleviated?

I am an experienced health professional and I aim to ensure a comfortable and safe environment for you to talk. You can choose to stop the interview at any time or choose to stop talking about an issue about which you feel uncomfortable. You may also have a friend, family or whanau support to help you understand the risks and/or benefits of this study or any other explanation you may require. Should the study cause you any distress, three free research-related counselling sessions can be obtained through AUT's Health and Counselling Centre (ph: 09 921 9992 City Campus or 09 921 9998 North Shore campus).

What are the benefits?

You may find it beneficial to talk about your experiences and views and explore the issue of embryo donation in the interview. The research based on this study may contribute to policy development and guide practice in this area.

How will my privacy be protected?

No material that could personally identify you will be used in any reports on this study. You will be asked to provide a pseudonym by which you will be known in the study. All references made during the interviews to names of other people (e.g. practitioners), place names and organisations, or any other details that could compromise confidentiality will either be deleted or altered to protect confidentiality. You will receive a transcript of the interview and you will be free to make any changes to the transcript.

Audiotapes of interviews will be destroyed following transcription. Transcripts will be kept in a locked filing cabinet at AUT for a period of 10 years and then destroyed.

What are the costs of participating in this research?

There are no costs to you other than your time.

What opportunity do I have to consider this invitation?

Please contact me within two weeks of receiving this information sheet if you would like to participate. Please feel free to contact me with any questions and to discuss your participation in this study with me.

How do I agree to participate in this research?

Please contact me using the details given below. To participate in the interview you will need to sign a consent form. If you do agree to take part, you are free to withdraw from the study at any time without having to give a reason and this will in no way affect future health care.

Will I receive feedback on the results of this research?

I will send you a report of my research findings as well as details of any resulting publications. I expect to complete my PhD in May 2014, but will be sending you updates throughout the course of the project, and you are welcome to contact me at any time to discuss progress and findings.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project can be notified to the Researcher, Sonja Goedeke, sonja.goedeke@aut.ac.nz, ph: 09 9219999 ext 7186, or primary supervisor: Dr Mark Thorpe, mark.thorpe@aut.ac.nz, ph: 09 9219999 ext. 7786.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate. Free phone: 0800 555 050; Free fax: 0800 2 SUPPORT (0800 2787 7678). Email: advocacy@hdc.org.nz

Please feel free to contact the researcher if you have any questions about this study:

Researcher Contact Details:

Sonja Goedeke

Senior Lecturer and PhD student

Department of Psychology

Faculty of Health and Environmental Sciences

AUT University, Private Bag 92006, Auckland 1142

Phone: 09 9219999 ext 7186

Email: sonja.goedeke@aut.ac.nz

PhD Supervisor Contact Details:

Dr Mark Thorpe

Head of Department, Department of Psychology

Faculty of Health and Environmental Sciences

AUT University, Private Bag 92006, Auckland 1142

Phone: 09 9219999 ext 7786

This study has received ethical approval from the Central Regional Ethics Committee, which reviews national and multi regional studies, ethics reference number CEN/11/12/071

Appendix G

Participant Information Sheet: Counsellors

Participant Information Sheet



Date Information Sheet Produced:

December 2011

Project Title

Understandings and experiences of embryo donation

An Invitation

My name is Sonja Goedeke and I am a senior lecturer in the Department of Psychology at AUT, and enrolled as a PhD student at AUT.

You are invited to participate in this PhD study which explores how actual and potential donors and recipients of embryos, and their families/friends ('significant others'), have understood and experienced embryo donation, and how counsellors and consultants view embryo donation. Your participation in the study is voluntary.

My PhD supervisor is Dr Mark Thorpe (AUT).

What is the purpose of this research?

Embryo donation is a relatively new practice in New Zealand, approved in late 2005 only, and under specific conditions including the disclosure of donor identity, and mandatory joint counselling for donors and recipients. I would like to do this research to explore how actual and prospective donors and recipients have experienced embryo donation and how counsellors and consultants have experienced the practice.

I hope that this research will help people in understanding the issues involved and any factors that might influence decision-making around embryo donation. The research forms the basis of my PhD study, and I would like to present the findings from the research to fertility professionals, academics working in the area, and policy-makers, and publish in magazines and academic journals.

What will happen in this research?

Please read this information sheet and if you wish to proceed with the study, you can either contact me via email or at the numbers below. You can also contact me to discuss the study in more depth, ask any questions you may have, or discuss your possible involvement – this can occur via phone, email or in person. If you agree to participate, this will involve an interview at a time and place convenient to you. With your permission, I would like to tape record and transcribe the interview, with all identifying information removed. The interview can take as long as you like, but you can expect it to last about 1 ½ hours.

Who can participate in the research?

1. Men or women who have had applications submitted to ECART to donate or receive embryos.
2. Men or women who have seriously considered embryo donation, undertaken joint counselling, but elected not to proceed.
3. Family members or friends ('significant others') of donors and recipients, by invitation from donors and recipients.
4. Counsellors and consultants counselling and advising in relation to embryo donation.

I would like to interview at least 5 donors, 5 recipients and their invited family members, 3 prospective donors and 3 recipients who elected not to proceed, 3 consultants, and all counsellors who have had experience in embryo donation counselling who are willing to participate.

What are the discomforts and risks?

I do not envisage risks from participating in this study. However, talking about your viewpoints and experiences with regards to embryo donation may heighten awareness of professional issues that you are confronting.

How will these discomforts and risks be alleviated?

I aim to ensure a comfortable and safe environment for you to talk. You can choose to stop the interview at any time or choose to stop talking about an issue about which you feel uncomfortable. If there are professional issues that you feel you need to address we might discuss the strategy of seeking further supervision from existing supervision arrangements or professional bodies.

What are the benefits?

You may find it beneficial to talk about your experiences and views and explore the issue of embryo donation. I hope that findings may help to inform your practice in this area. You may be offered a \$20 voucher as koha.

How will my privacy be protected?

No material that could personally identify you will be used in any reports on this study. You will be asked to provide a pseudonym by which you will be known in the study. All references made during the interviews to names of other people (e.g. practitioners), place names and organisations, or any other details that could compromise confidentiality will either be deleted or altered to ensure confidentiality. Audiotapes of interviews will be destroyed following transcription. You will be given the opportunity to review and amend your transcript. Transcripts will be kept in a locked filing cabinet at AUT for a period of 10 years and then destroyed.

What are the costs of participating in this research?

There are no costs to you other than your time.

What opportunity do I have to consider this invitation?

I will contact you within two weeks of receiving this information sheet. Please feel free to discuss your participation in this study with me.

How do I agree to participate in this research?

Please contact me using the details given below. To participate you will need to sign a consent form. If you do agree to take part, you are free to withdraw from the study at any time without having to give a reason.

Will I receive feedback on the results of this research?

I will send you a report of research findings and details of any resulting publications. I expect to complete my PhD in May 2014, but will be sending you updates throughout the course of the project, and you are welcome to contact me at any time to discuss study progress and findings.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project can be notified to the Researcher, Sonja Goedeke, sonja.goedeke@aut.ac.nz, ph: 09 9219999 ext 7186, or primary supervisor: Dr Mark Thorpe, mark.thorpe@aut.ac.nz, ph: 09 9219999 ext. 7786.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organisation.

Research approval:

The Director/ Group Operations Manager (Margaret Merrilees/John Peek) of your clinic has given permission for this study to be carried out.

Please feel free to contact the researcher if you have any questions about this study:

Researcher Contact Details:

Sonja Goedeke

Senior Lecturer and PhD student

Department of Psychology

Faculty of Health and Environmental Sciences

AUT University, Private Bag 92006, Auckland 1142

Phone: 09 9219999 ext 7186

Email: sonja.goedeke@aut.ac.nz

PhD Supervisor Contact Details:

Dr Mark Thorpe

Head of Department

Department of Psychology

Faculty of Health and Environmental Sciences

AUT University, Private Bag 92006, Auckland 1142

Phone: 09 9219999 ext 7786

This study has received ethical approval from the Central Regional Ethics Committee, which reviews national and multi regional studies, ethics reference number CEN/11/12/071

Appendix H

Consent Form: Donors and Recipients

Consent Form



Project title: Understandings and experiences of embryo donation

Researcher: Sonja Goedeke

- I have read and I understand the information sheet dated December 2011 for volunteers taking part in this study exploring experience of embryo donation practice. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I understand that taking part in this study is voluntary (my choice), and that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without giving a reason, and without being disadvantaged in any way. If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I understand that my participation in this study is confidential and that identifying material will be disguised in any reports on this study.
- I understand that notes will be taken during the interviews and that they will be audio-taped and transcribed.
- I have had time to consider whether to take part in the study.
- I know who to contact if I have any questions about the study.

I consent to my interview being audiotaped.

Yes No

I wish to receive a copy of the results.

Yes No

I (*full name*) hereby consent to take part in this study.

Date:

Signature:

Full names of researcher:

Sonja Goedeke

Contact phone number for researcher:

09 9219999 ext. 7186

Project explained by:

Project role:

Signature:

Date:

Approved by the Central Regional Ethics Committee, CEN/11/12/071

Appendix I

Consent Form: Family



Project title: Understandings and experiences of embryo donation
 Researcher: Sonja Goedeke

- I have read and I understand the information sheet dated December 2011 for volunteers taking part in this study exploring experience of embryo donation. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- I understand that taking part in this study is voluntary (my choice), and that I may withdraw myself or any information that I have provided at any time prior to completion of data collection, without giving a reason, without being disadvantaged in any way and that this will in no way affect future health care. If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I understand that my participation in this study is confidential and that identifying material will be disguised in any reports on this study.
- I understand that notes will be taken during the interviews and that they will be audio-taped and transcribed.
- I have had time to consider whether to take part in the study.
- I know who to contact if I have any questions about the study.

I consent to my interview being audiotaped/videotaped. Yes No

I wish to receive a copy of the results. Yes No

I (*full name*) hereby consent to take part in this study.

Date:

Signature:

Full names of researcher:

Contact phone number for researcher:

Project explained by:

Project role:

Signature:

Date:

Approved by the Central Regional Ethics Committee, CEN/11/12/071

Appendix J

Consent Form: Counsellors



Project title: Understandings and experiences of embryo donation

Researcher: Sonja Goedeke

- I have read and I understand the information sheet dated December 2011 for volunteers taking part in this study exploring experience of embryo donation practice. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I understand that taking part in this study is voluntary (my choice), and that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without giving a reason, and without being disadvantaged in any way. If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I understand that my participation in this study is confidential and that identifying material will be disguised in any reports on this study.
- I understand that notes will be taken during the interviews and that they will be audio-taped and transcribed.
- I have had time to consider whether to take part in the study.
- I know who to contact if I have any questions about the study.

I consent to my interview being audiotaped.

Yes No

I wish to receive a copy of the results.

Yes No

I (*full name*) hereby consent to take part in this study.

Date:

Signature:

Full names of researcher:

Sonja Goedeke

Contact phone number for researcher:

09 9219999 ext. 7186

Project explained by:

Project role:

Signature:

Date:

Approved by the Central Regional Ethics Committee, CEN/11/12/071

Appendix K

Interview Guides

1. Interview guide for donors and recipients

Using semi-structured, in-depth interviews participants will be interviewed face-to-face in a location, and at a time, that is convenient for them. Each participant will be asked which ethnic group(s) they identify with. Participants will be asked to discuss the following topics:

- Background of infertility – experience of infertility and treatment
- Views of the embryo
- Views and experiences of embryo donation
 - personal, couple, family
 - embryo donation practice and policy (including openness, information-sharing, counselling)
 - current and future issues and concerns (e.g. disclosure, family relationships)
- Factors affecting choices (including personal and social factors, factors related to infertility experience, material conditions)
- Demographic details (age, education level, religious affiliation and commitment, number of children)

2. Interview guide for potential donors and recipients who declined to proceed

Using semi-structured, in-depth interviews participants will be interviewed face-to-face in a location, and at a time, that is convenient for them. Each participant will be asked which ethnic group(s) they identify with. Participants will be asked to discuss the following topics:

- Background of infertility – experience of infertility and treatment
- Views of the embryo
- Views and experiences of embryo donation
 - personal, couple, family

- embryo donation practice and policy (including openness, information-sharing, counselling)
- issues and concerns (e.g. disclosure, family relationships)
- Factors affecting choices (including personal and social factors, factors related to infertility experience, material conditions)
- Demographic details (age, education level, religious affiliation and commitment, number of children)

3. Interview guide for family members/friends of donors and recipients

Using semi-structured, in-depth interviews participants will be interviewed face-to-face in a location, and at a time, that is convenient for them. Each participant will be asked which ethnic group(s) they identify with.

Participants will be asked to discuss the following topics:

- How did you come to hear about X's (donor or recipient) choice to pursue embryo donation?
- What was your reaction?
- Views of embryo
- Views and experiences of embryo donation practice and policy

4. Interview guide for counsellors

Using semi-structured, in-depth interviews participants will be interviewed face-to-face in a location, and at a time, that is convenient for them.

Participants will be asked to discuss the following topics:

- What has been your experience counselling couples considering and undergoing embryo donation?
- What are your views of embryo donation/ views of embryo?
- What factors do you think influence the decision to use embryo donation?
- What concerns, if any, do you have about embryo donation policy, and practice?