WOMEN’S AUTONOMY AND REPRODUCTIVE RESPONSIBILITIES DURING THE COURSE OF ASSISTED REPRODUCTIVE TECHNOLOGY

AN ANALYSIS USING THREE HYPOTHETICAL SCENARIOS THAT HAVE RESULTED IN THE BIRTH OF A DISABLED CHILD

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CERTIFICATE OF ORIGINAL AUTHORSHIP

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

29th of February 2016

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Zu gudder laescht well ech ménger Mamm a méngem Papp villmols Merci soen, well si mëch ëmmerzou ennerstëtzt hun an dem André ee grousse Merci, deen ni opgehalen huet u mech ze gleewen an deem séng Präsenz onendlech vill wärt ass.

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LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
AHEC	Australian Health Ethics Committee
AHRA	Assisted Human Reproduction Act (in Canada)
AI	Artificial Insemination
ALRC	Australian Law Reform Commission
AMA	Australian Medical Association
APPs	Australian Privacy Principles
ART	Assisted Reproductive Technology
AT 3	Anti-thrombin 3
DNA	Deoxyribonucleic Acid
FSA	Fertility Society of Australia
ICMART	International Committee for Monitoring Assisted Reproductive Technologies
HTLV	Human T-cell Lymphotrophic Virus
ICF	International Classification of Functioning, Disability and Health
IVF	In Vitro Fertilisation
mtDNA	mitochondrial genome DNA
MM	Mitochondrial myopathy
MPNST	Malignant peripheral nerve sheath tumour
nDNA	Nuclear DNA
NF1	Neurofibromatosis type 1
NF2	Neurofibromatosis type 2
NHMRC	National Health and Medical Research Council
NHMRC ART Guidelines	Ethical guidelines on the use of assisted reproductive technology in clinical practice and research
NSW	New South Wales
NSW ART Act	NSW Assisted Reproductive Technology Act 2007
PGD	Preimplantation Genetic Diagnosis

PGS	Preimplantation Genetic Screening
PND	Prenatal Diagnosis
PNS	Prenatal Screening
RTAC	Reproductive Technology Accreditation Committee
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
SA	South Australia
SOGC	Society of Obstetricians and Gynaecologists of Canada
SMA	Spinal Muscular Atrophy
UN	United Nations
VARTA	Victorian Assisted Reproductive Treatment Authority
VIC	Victoria
VIC ART Act	VIC Assisted Reproductive Treatment Act 2008
VIC ART Regulations	VIC Assisted Reproductive Treatment Regulations 2009
WB	Wrongful Birth
WL	Wrongful Life
WHO	World Health Organisation

ABSTRACT

This thesis examines, whether it is appropriate to hold a woman ethically or legally responsible for decisions made by her during assisted reproductive technology (ART) treatment that result in disability in the child born subsequently.

This question is explored through three hypothetical scenarios that are fictional narrations of potentially real-life clinical situations that could occur within an ART procedure. They are used to illustrate the ethical and legal issues that may arise and involve the following different circumstances:

The first scenario involves a single woman using donor sperm in New South Wales (NSW). The second scenario concerns a couple using their own gametes in Victoria (VIC), where the woman has an undisclosed genetic condition. In the third scenario, a NSW couple uses their own gametes and, after the birth, they discover that the woman and the child have a genetic condition.

As a non-lawyer, my aim is to apply a feminist bioethical lens to selected laws that regulate this area, rather than to provide a comprehensive account and critique of those laws. Prior to undertaking this thesis I completed a Master of Science at the University of Geneva, focusing on how medical responsibility was assigned to the health professionals involved in six Swiss court cases where there was an unwanted birth (including both an able bodied and a disabled child).[1] In this project I build on my previous Master’s research along with my professional expertise as a midwife, to develop a thesis which focuses on the legal and ethical rights and responsibilities of women. I draw on feminist, disability and bioethics scholarship and examine selected points of ART legislation and regulation in Australia.

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[1] Title of the Master of Science thesis: La responsabilité médicale lors d’une naissance non voulue d’un enfant non-handicapé ou handicapé. (The medical responsibility on the occasion of an unwanted birth of an able bodied or a disabled child). The thesis is a comparative analysis of six Swiss court cases conducted under the supervision of Professor Pierre-Alain Recordon, Emeritus Professor, Faculty of Economics and Social Sciences, University of Geneva.

This thesis establishes that the new challenges posed by ART, the increased opportunities for decision-making throughout ART processes, and the involvement of multiple decision-makers, have raised novel considerations about health risks and ethical responsibilities that have a major impact on a woman's reproductive autonomy.

The majority of the legislation, regulations and guidelines I analyse are silent about the woman and her legal rights and responsibilities, instead focussing on the responsibilities of the clinics. I argue that, though it is sometimes beneficial for women to be absent from the law, ultimately the law should directly address a woman's rights and responsibilities in order to grant her the rightful place she deserves as central to reproduction and also to protect and guarantee her rights and interests. In the documents consulted here, the woman, who is a key player and decision-maker in the reproduction process, is conspicuously absent.

The thesis demonstrates that holding a woman ethically responsible at every decision-making point in ART will result in an unfair, onerous increase in her responsibility and transgress her reproductive autonomy. The thesis argues that a complex balance is needed between the interests and rights of the woman, the interests of the future child, concerns based on the rights and interests of people living with a disability and the more general values of non-discrimination and diversity of life. All these factors are essential considerations as they have an impact on a woman's decision-making processes within ART.

1 CHAPTER ONE

1.1 INTRODUCTION

Assisted reproductive technology (ART) has come a long way since the birth of Louise Brown,[2] the first ever in vitro fertilisation (IVF) birth, which occurred in England on July 25, 1978. Since then, according to the International Committee for Monitoring Assisted Reproductive Technologies (ICMART) an estimated five million children have been conceived by way of ART.[3]

ART is still a relatively young medical area, one which deals with cutting edge medical technology, and it has changed societal views of human reproduction. However, the advent of ART has not changed the fact that the woman remains the main actor in human reproduction, as she is still the one who gestates and gives birth to the child. But the arrival of these new technologies, particularly in vitro fertilisation (IVF), has, I will argue, shifted the focus away from women's autonomous reproductive decision making. The key reasons for this are that: ART has introduced an array of additional participants into the reproductive process; a host of decision-making points now oblige women to make choices that they do not have to make when not using ART; and they need to make these choices in a regulatory and medical environment where the future child's interests are paramount, sometimes obscuring the interests of the woman.

As will be argued in Chapter Two upholding and protecting women's autonomy during an ART process is a fundamental commitment of the jurisdictions discussed in this thesis. It is necessary therefore, to ensure that an individual woman's decisions and those taken on her behalf are in accordance with her autonomous choices and values.

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[2] Dieter Giesen, *International Medical Malpractice Law : A Comparative Law Study of Civil Liability Arising from Medical Care* (J. C. B. Mohr, 1988) 631.

[3] *Fertility Society of Australia Reproductive Technology Accreditation Committee, Code of Practice for Assisted Reproductive Technology Units, 2007* 27.The Code of Practice defines ART as 'clinical treatments; counselling services; and laboratory procedures for the assessment and preparation of human oocytes, sperm or embryos. ART includes IVF; gamete intrafallopian transfer; zygote intrafallopian transfer; intracytoplasmic sperm injection; embryo or gamete cryopreservation; surgical sperm recovery; oocyte, semen or embryo donation; blastomere biopsy for preimplantation genetic diagnosis; gestational surrogacy and intrauterine insemination (IUI).'

In light of an overarching commitment to women's reproductive autonomy, this thesis thus explores whether it is ever appropriate to hold a woman responsible for decisions made by her during ART that result in disability in the child born subsequently. This question is examined from both legal and ethical perspectives. As assisted reproduction technologies develop and proliferate, they present new ethical challenges and require a continuous adaption of policy and legislation, making the research question posed in this project increasingly urgent.

The issues and questions raised by ART are the result of events which began in the 1960s when women obtained greater reproductive autonomy with the emergence of oral contraceptives and the liberalisation and decriminalisation of termination of pregnancy in many jurisdictions.[4]

Over the years society has increasingly accepted ART, to such a degree that nowadays assisted reproductive treatments and technologies are requested not only for medical reasons but as a means of managing reproduction in ways that help women satisfy their personal life goals. However, while this increase in choice has had many positive effects, women also have to make decisions that they did not previously have to make. ART involves an increased number of individuals at all stages of decision making during the reproduction process. For each stage, a multidisciplinary team is available to patients in ART clinics. This team usually consists of fertility specialists, gynaecologists, obstetricians, nurses, clinical geneticists, genetic counsellors, scientists specialising in embryology, andrology and pathology, religious and external specialists. In terms of the reproductive act of conception, the ART treatment is divided into different stages and the first stage often starts well before the conception of the child. Contrary to natural conception, the future parent who wants or needs to conceive via ART has no choice but to consult or deal with a third person outside the sexual dyad during the process of becoming a parent.

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[4] Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), 'Medically Assisted Reproduction Ethical Considerations and Recommendations for the Future' (Opinion 22, Swiss National Advisory Commission on Biomedical Ethics, NEK-CNE, 2013) 56, 9.

My research project focuses on some of the unique issues raised for women undertaking ART. Certain questions a future parent might have, in regard to reproduction are common to both natural and assisted conception. For example a woman who wishes to conceive might find herself in a situation where, even before conception, she needs to consider whether she is prepared to risk conceiving a disabled child. Whatever the woman's method of conception, assisted or unassisted, she may feel pressured to consider proceeding only with screening via preconception or prenatal testing. All future mothers are confronted with questions and assumptions resulting from technological advances and, specifically, whether one should take advantage of these technological interventions. In circumstances where a woman is using ART however, there is both increased psychological pressure due to the significant level of medical intervention and surveillance and increased medical and regulatory control of the process. As noted above, many more individuals are involved in the decision-making process. Therefore, the focus of this thesis is the woman's responsibilities for her decision making in the ART context. The ART context raises issues which are unique to that domain and have not been adequately considered elsewhere.

1.2 METHODOLOGY

This thesis is divided into six chapters. The research question and its significance, and the methodology employed to address it, are described in the first chapter. In the second chapter I explore four significant and overlapping concepts that frame the ethical issues raised by this research, namely: reproductive autonomy; responsibility; choice; and disability. In the chapters that follow, I provide three scenarios drawing on hypothetical case studies, in order to test and consider the research question. The last chapter draws conclusions and answers the research question.

My research is a bioethical inquiry which engages with scholarship on the ethics of ART more broadly, but examines the range of ethical responses and responsibilities that arise with respect to the potential for disability in the future child. It focuses on the role of woman as key actor, decision-maker and embodied subject during the ART process. Every decision or choice a woman makes concerning her reproductive opportunities within ART potentially gives rise to a corresponding ethical or legal responsibility. In the next chapters I provide a thorough discussion and critique of this literature.

The research question is analysed from a feminist perspective and is thus founded in the view that women's reproductive autonomy, which I define below, is absolutely essential to her personhood. An important aspect of reproductive autonomy to consider is the potential conflict between the feminist disability rights approach and the feminist choice approach. The former argues that new reproductive technologies, which are either implicitly or explicitly directed at avoiding disability in a future child, may not in fact give a woman greater choice. Rather, as Lippman suggests, the new testing technologies may give rise to increased pressure to make particular choices and may artificially inflate the sense of need for a woman to resort to such technologies.[5] The feminist choice scholars argue that ART technologies do in fact, provide women with a real set of choices, and that this is a positive contribution to women's reproductive autonomy. Women have a 'right to self-determination over their own bodies',[6] and as long as women make choices knowingly and without coercion, what happens with their bodies is a matter for the women to decide. For Purdy 'one major benefit of artificial reproductive technologies is to help women to have babies safely'.[7]

Nevertheless, there is strong alignment between these two feminist approaches as well. Feminist disability scholars also argue that a woman, who uses reproductive technologies, should be able to make autonomous reproductive decisions in regard to potential disability, by taking into consideration what life with a disability would be like

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[5] Abby Lippman, 'Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities' (1991) 17 *American Journal of Law and Medicine* 15, 29.

[6] Jyotsna Agnihotri Gupta, 'Towards Transnational Feminisms Some Reflections and Concerns in Relation to the Globalization of Reproductive Technologies' (2006) 13 *European Journal of Women's Studies* 23, 32. This right of self-determination was mentioned by Lori Andrews and some others when they argued for a liberalisation of almost all laws that stand in the way of full-fledged commercialisation of reproduction.

[7] Laura M Purdy, *Reproducing Persons : Issues in Feminist Bioethics* (Cornell University Press, 1996) 181.

in reality for her future child and herself. For Asch, everyone obtaining testing or seeking information about genetic or prenatally diagnosable disability should receive appropriate information about foreseeable difficulties, support services, and life events related to a disabling condition to allow them to reflect on how a child's disability would correspond with their own hopes for parenthood.[8] The tension between these approaches is reflected throughout the whole of this thesis. The two approaches are analysed more closely in the next chapter, in order to assess their impact on the research question.

1.2.1 IMPORTANCE OF THE SCENARIOS

There is extensive scholarship dealing with the broad topics of my research question, namely, the impact of ART on women and the corresponding responsibility of doctors and clinics. However, very little discussion relates to the question of when, if at all, a woman should be assigned ethical or legal responsibility for decisions made during ART that result in disability. In order to broach my question, I am relying on hypothetical scenarios, which in the absence of real-life cases, provide the necessary elements to test my question. These scenarios have been developed in reference to real-life situations encountered in both my own experience as a midwife, and from the research and limited case law that does exist.

During my work as a midwife I have faced, and continue to face, situations where a family is informed about a disability identified at birth or, following diagnosis, a few weeks after birth. After the initial reaction, questions start to be asked concerning, as one mother said, “what went wrong?” A detection process commences, antenatal reports are consulted and examined, all in the hope of giving the parent answers to the question of where the disability originated and why it had gone undetected prior to birth. At the same time, depending on the nature of the disability, the parents are asked to undergo tests, such as genetic testing or pathology tests, to trace the origin of the disability. What has struck me when these situations arise is how negatively

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[8] Adrienne Asch, ‘Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy’, (1999) 89 *American Journal of Public Health* 1649, 1655.

disability is dealt with in our society and especially in a maternity setting. It has also saddened me to see how the mothers often feel guilt, and question their actions and decisions before and during pregnancy. This experience has drawn me to the question of this thesis.

Real-life court cases occurring in Australia, involving ART and a disabled child are very rare. The only case to touch on this issue in Australia so far is *Waller v James,*[9] where the clinic failed to test the father for his blood disorder, known as anti-thrombin 3 deficiency (AT3), despite the fact that the father's condition was known to the physician. AT3 deficiency is an autosomal dominant disorder.[10] This case was first brought as a Wrongful Life (WL)[11] claim and then a Wrongful Birth (WB)[12] claim[13] a few years later. This case, however, is of limited use as it did not focus on the woman's reproductive decision-making, but rather on the allegedly negligent actions of the health practitioners. It is, nevertheless, a useful starting point in creating realistic hypothetical scenarios. Some of the relevant issues raised by the case include: whether there is, or should be, an ethical or legal requirement of disclosure of a known genetic condition by an intending parent; and whether a child that is born from an embryo

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[9] *Waller v James* [2002] NSWSC 462. The Case was brought before the Supreme Court in New South Wales (NSW) in 2002. The matter went on appeal up to the High Court: see Waller v James [2006] HCA 16; (2006) 226 CLR 136. A majority in the High Court (Kirby J dissenting) dismissed the appeal, affirming the decision of Studdert J at first instance. Deborah and Lawrence Waller underwent an IVF procedure in 1999. The father had AT3 deficiency. The child Keeden Waller was born with AT3 deficiency in 2000. The claims of the parents were pleaded in negligence and in breach of contract, whereas the claim of the child was pleaded in negligence only. The Court stated that the defendants did not breach the duty of care, which was defined as a duty not to injure the child. The child was not born disabled because of any failure of the duty of care. In 2013 the "wrongful life" claim was rejected by the Court, because it would not be possible to determine that the child suffered from "damage" by the fact of being born disabled or with AT3 deficiency and it would be impossible to calculate compensatory damages.

[10] James L Harper, *Antithrombin III Deficiency* (10 July 2015) Medscape <http://emedicine.medscape.com/article/954688-overview>. 'Congenital antithrombin III deficiency is an autosomal dominant disorder in which an individual inherits one copy of the *SERPINC1* (also called *AT3*) gene on chromosome 1q25.1, which encodes antithrombin III. This condition leads to increased risk of venous and arterial thrombosis, with an onset of clinical manifestations typically appearing in young adulthood. This form is most commonly diagnosed during childhood by screening after an affected family member has been identified or after a child has had a thrombotic event'.

[11] Pam Stewart and Anita Stuhmcke, *Australian Principles of Tort Law* (The Federation Press, 2012) 403. In a Wrongful Life (WL) claim a person, usually while still being a child files a lawsuit against a defendant, because he or she was born as a result of the defendant's negligence.

[12] Ibid 408. In a Wrongful Birth (WB) action parents file a lawsuit against medical practitioners or other persons and they claim that if the defendants had not been negligent, their child would not have been born.

[13] *Waller v James* [2013] NSWSC 497.

with a known condition is harmed when the alternative would have been not to be born at all.

Due to the limited number of real-life cases, the scenarios I present here are fictional narrations of credible situations that could occur within an ART procedure in a real-life context. They explore decision-making points that come into play during the ART process and the legal and ethical issues that arise. Each scenario offers an alternate perspective on the ART process by substituting different contextual factors, such as the use of a male gamete donor in Scenario One, knowledge of inheritable genetic conditions in Scenario Two, and finally, an absence of knowledge of genetic profile in Scenario Three. In so doing, I identify several different aspects of a woman's reproductive autonomy. The scenarios are also situated in two different jurisdictions, New South Wales and Victoria, in order to show the varying effects of different legal regimes.

The scenarios explore the research question in two specific circumstances – 1) where donor gametes are used together with the woman's gametes and – 2) where the couple's own gametes are used. I chose these two variations to allow me to analyse how the decision making of the woman differs between these situations, and to allow me to examine whether the two situations are affected differently by ART legislation or guidelines and, finally, what this means for a woman's reproductive autonomy.

In the first circumstance, the scenarios explore, among other things, how the woman's decision to use technologies to detect a genetic condition can have a direct effect on the gamete donor's life. For example, the donor can suddenly be confronted with the knowledge that he or she has a genetic condition, with all the consequences which this knowledge involves. They also explore the different legal consequences where donated gametes are used. For instance, consent to use a gamete or embryo may, under some legislative regimes, be revoked by the donor for any reason up to a specified time. A woman's decision whether to undertake genetic testing can be inhibited or facilitated by the relevant legislation.[14] In the second circumstance, where the woman's own gametes are used, the scenarios explore the varying effects the disclosure or non-disclosure of a genetic condition can have. Disclosure by the woman may put into action clinical policies which modify or inhibit the woman's ART treatment, and may result in her forgoing the chance to become a parent. The woman's decisions may thus depend on clinical rules and policies.

1.2.2 DESCRIPTION AND CHALLENGES OF THE SCENARIOS

In what follows I briefly describe the scenarios, why I selected particular 'facts' for each, and the new challenges faced by women using ART that these scenarios demonstrate.

I based the first scenario on a real situation, described in the research of Millbank et al,[15] where an ART clinic refused the donation of genetically affected embryos by a woman who had two children with the genetic condition. In one of the surveys, an interviewee, Scarlet, wanted to donate her remaining genetically affected embryos. Scarlet and her two children had a genetic condition with a 100% transmission rate. Although the recipients were informed of the genetic condition and consented to accept Scarlet's embryos, the ethics committee of the donor's clinic stood by the clinic's refusal. The committee argued that the donation was not in the best interests of the future child.[16] This example shows how disclosure, that embryos are genetically affected, impacts on the reproductive autonomy of the donors and the recipients and that a clinical policy can be at odds with an individual's reproductive choice. In this case, the donors were understandably upset and angry at the clinic's refusal and its

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[14] The consent is analysed in chapter 3 section 3.3.1. *Assisted Reproductive Technology Act 2007* (NSW) s17(4). 4) A consent may be modified or revoked at any time up until:
(a) in the case of a donated gamete—the gamete is placed in the body of a woman or an embryo is created using the gamete, or
(b) in the case of a gamete other than a donated gamete—the gamete is placed in the body of a woman or an embryo created using the gamete is implanted in the body of a woman.

[15] Jenni Millbank et al, *ENHANCING REPRODUCTIVE OPPORTUNITY A Study of Decision-Making Concerning Stored Embryos* (Australian Research Council and University of Technology Sydney Faculty of Law, 2013).

[16] Ibid 152.

argument that the refusal was in the best interest of the child, demonstrating that the meaning of the phrase “the best interests of the child” is not necessarily the same for a clinic as it is for donors and potential recipients.

Inspired by this example, Scenario One examines the situation where male donor gametes are used to fertilise a woman’s own eggs to create embryos. Having had one successful pregnancy and birth from the embryos created, the woman wishes to have a second embryo from the same batch transferred. The woman chooses to disclose to the clinic that her first child has a genetic condition. She decides not to have her embryo tested, because she wants the embryo to be implanted with or without the inheritable condition, Mitochondrial Myopathy (MM).

Scenario Two is also inspired from the real-life situation used in the first scenario, but this time I opted for the woman’s non-disclosure of her genetic condition, and no donor involvement, to analyse how the ethical and legal issues arising differ from the first scenario. This scenario explores the circumstance where a couple uses artificial insemination (AI) and their own gametes to give rise to a pregnancy and birth, but fail to disclose the woman’s known genetic disorder. There is routine testing, but no special testing for known genetic issues in the family. The child is born with the condition. This scenario addresses concerns in connection with bodily integrity and invasive reproduction techniques which are all germane to a woman’s autonomy. I use this scenario to illustrate that the woman’s decision not to disclose her condition may have been made for various reasons affecting her autonomy. The reasons might include her fear that her choices might be affected, because she might feel pressured to undergo the more invasive IVF procedure instead of AI, and that she then might feel pressured to use preimplantation genetic diagnosis (PGD), potentially compromising the possibility of her becoming a parent (by the potential risk of destruction of the embryo in that procedure). In this context, Scenario Two also examines the question of whether the presence of a genetic condition is acceptable where a person or couple uses their own gametes compared to someone using donor gametes. Finally in this scenario, I also show that the woman’s decision not to disclose her condition might be motivated by a fear of being refused access to ART, because she has a genetic condition, indicating a need to think more complexly about how these issues are approached by legal and ethical governance structures.

As described in these two scenarios, a woman who wants to use ART and who has a genetic condition might face a double challenge. The first challenge is that, as a person with a genetic condition which could be considered as a disability, she might have to make choices that frame her own condition in negative terms. For example, she might feel pressured to use the technologies available to detect whether the embryo has the same genetic condition as herself, and if this is the case she might be expected to choose against the implantation. A second challenge is that she might be denied access to ART due to her condition, which may disadvantage her compared to a woman without a genetic condition. Or if she can access ART, she might be strongly encouraged to use donor gametes in order not to transmit her condition. In such a situation, Silvers claims, a person with a disability is considered to be biologically incapable of being 'permitted reproductive freedom'.[17] Scenario Two explores these challenges particularly focusing on the question of the reproductive autonomy of a woman, who has a genetic condition in these circumstances.

Scenario Three is based loosely on a real-life situation that occurred while I was working as a midwife. The case concerns a couple I will call A and B, undertaking IVF. The woman A was unable to produce viable eggs. A had already had two IVF treatments which both ended in miscarriages. For those two cycles the couple used the eggs from a cousin, called C. Because of the failure of these two cycles for the third IVF treatment, the couple used a donor egg from a friend, D, and the sperm from the husband B as before. No genetic testing was done, for either A, B, or D as there was no history of a genetic condition. This cycle resulted in a son for A and B. Their son was diagnosed a few weeks after birth with a genetic condition. It turned out that the father B and the egg donor D were carriers of the same condition. In this situation,

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[17] Anita Silvers, *Feminist Perspectives on Disability* (Spring 2015) The Stanford Encyclopedia of Philosophy <http://plato.stanford.edu/entries/feminism-disability/#Emb>. Silvers uses the words "reproductive freedom" instead of reproductive autonomy.

many questions were asked following diagnosis of the baby's condition. A and B wondered whether, if they had known that the father was a carrier, they would have asked for the egg donor to be tested as well, or whether they would have asked for PGD. Both A and B struggled with feelings of guilt. Egg donor, D, was suddenly confronted with a diagnosis of a condition of which she had been unaware. From this real-life situation, various questions arose, such as: should testing be done even if there is no genetic history? If not always, then in what circumstances would it be justified? For what conditions should the testing be done? What level of ignorance is acceptable where testing is available? When should counselling to undergo testing occur – before and during any ART treatment, or only when there is a history of genetic disease?

Scenario Three is developed with that background in mind. In this scenario the couple uses IVF due to unexplained infertility. This is one of the most common reasons for IVF and therefore is a realistic basis for the scenario. While there is no known history of genetic disorders the woman has experienced mild symptoms of balance problems and hearing problems prior to the IVF treatment and thought she had a flu-like virus. The clinic offered special testing and genetic counselling, but the woman declined. Upon aggravation of the symptoms after the birth of the child both mother and child are subsequently diagnosed with a genetic condition.

I use this Scenario Three to show the potential conflict a woman might face in such a situation. On the one hand, the woman's right to privacy, which is her right not to know of an existing or potential disorder when she declines testing and counselling for herself, can be at odds with the pressure she might feel to participate in testing and counselling on behalf of a future child. Her refusal may be considered as against the interest of the future child, who may be born with the condition. This is also a conflict between the interests of a person who actually exists in the world and a person who does not yet exist.

The scenarios show that ART is like a Pandora’s box, which has opened up a whole new world of challenges for the woman, her partner if present, and the health professionals involved in the reproduction process. These emerging challenges, linked to the research question, will be analysed closely in the following chapters (three to five) depicting the scenarios, focusing on the ethical and legal issues that arise, and whether the woman can be held responsible for them. Before I turn to the scenarios, in Chapter Two I analyse the key concepts necessary to address the research question.

2 CHAPTER TWO KEY CONCEPTS FOR WOMAN'S DECISION MAKING IN ART

Autonomy, choice and disability play a key role in a woman's decision-making process during her ART treatment. In order to understand how they impact on my research question it is first necessary to define and analyse these concepts.

2.1 DEFINITIONS OF AUTONOMY

2.1.1 AUTONOMY

A woman does not make a decision about reproduction in isolation from others, especially when she wants to conceive with ART. She is however, the main actor whose decisions are generally taken after being given information and offered guidance during various consultations with a multidisciplinary team of ART health professionals. Some of these decisions need to be made even before the start of an ART treatment. Some concern the future child, some concern the woman and her partner, and others apply solely to the woman. For instance, a woman and her partner may have to decide whether they want to undergo tests relative to their own health status, whereas only the woman has to decide whether she wants to undergo IVF techniques that involve her body. Autonomy is an important value in reproductive decision making because it ensures the woman can make decisions which are truly her own choices. It has also a significant meaning for many feminists because, as Nedelsky claims, 'feminists are centrally concerned with freeing women to shape our own lives, to define who we (each) are, rather than accepting the definition given to us by others (men and male-dominated society, in particular)'.[18]

My thesis takes the concept of autonomy as a central framing idea and argues that one of the underlying conditions of reproductive decision making is the presence of autonomy. Below I explore this concept of autonomy as it applies to reproduction,

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[18] Jennifer Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989) 1 *Yale Journal of Law and Feminism* 7, 8.

with a specific focus on the idea of relational autonomy, which I have found particularly useful in addressing my research question.

2.1.2 REPRODUCTIVE AUTONOMY

Major human rights instruments typically define 'reproductive autonomy' as a person being able to decide whether to have a child, when to have a child and with whom. The *Universal Declaration of Human Rights* (1948), to which Australia is a signatory, recognises the right of every human being of full age to have children. Article 16(1) states that

> men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.[19]

In contemporary westernised countries, it is generally accepted that a woman is free to choose whether she wants to reproduce or not. This reproductive freedom could be divided into negative and positive freedoms.[20] On the one hand, negative freedom means that a person is free to make decisions without interference or restrictions. For example, in the context of reproduction, a woman is free to choose whether she wants to have children or not, and she is free to become a parent via natural or assisted reproduction.[21] In Australia, it is only a recent freedom that a woman can choose to reproduce using ART. When the technology was first available, in many states women had to prove clinical infertility. However, if a woman wants to reproduce using ART, she needs to comply with ART legislation and regulations and this will have an impact on her reproductive autonomy. On the other hand, positive freedom means that the state is obliged to assist the person in the pursuit of these rights. Thus, the state supplies the means and conditions which are needed to 'exercise an autonomous

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[19] UN General Assembly, 'The Universal Declaration of Human Rights' GA Res 217A (III), UN GAOR, 3rd sess, 183rd plen mtg, UN Doc A/810, (10 December 1948) article 16(1).

[20] Swiss National Advisory Commission on BiomedicalEthics (NEK-CNE), above n 4, 27.

[21] Ibid.

reproductive choice' including medical assistance.[22] In Australia, public funding helps a woman to exercise her reproductive choice. It supports the acquisition of ART treatment for eligible women, and also allows the funding of certain contraceptive devices and partial funding for an abortion. The fact that public funding supports these various reproductive choices and, hence, a woman's reproductive autonomy in relation to them, suggests that the public considers this health expenditure appropriate for the government. Both negative and positive freedoms are crucial to the enjoyment of autonomy in this context. As Freedman and Isaacs put it, women's reproductive autonomy enables them 'to take control over their reproductive lives by entrusting to them both the authority to make decisions about reproduction and the ability to make those decisions based on access to adequate information and appropriate services'.[23] This is a fundamental premise that my thesis has taken as a given when addressing my research question.

In the domain of medicine and particularly in the context of ART reproduction, guaranteeing a woman's autonomy is of utmost importance, because as Rosamund Scott has put it, autonomy reinforces a 'patient's moral interest in self-determination and bodily integrity'.[24] A woman's autonomy in medical decision making, particularly in ART, is closely linked to the information she receives and the informed consent she has to give. Thachuk enumerates four criteria of autonomous decision making to guarantee informed consent, all of which are appropriate for the ART context. Those criteria include 'patient competency, a reasonable choice from a set of options provided, disclosure of relevant information and freedom from coercion'.[25]

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[22] Ibid.

[23] Lynn P Freedman and Stephen L Isaacs, 'Human Rights and Reproductive Choice' 24 *Studies in Family Planning* 18, 19.

[24] Rosamund Scott, *Rights, Duties And The Body: Law And Ethics Of The Maternal Fetal Conflict* (Hart Publishing, 2002) 7.

[25] Angela THACHUK, 'Midwifery, Informed Choice, and Reproductive Autonomy: A Relational Approach' (2007) 17 *Feminism & Psychology* 39, 44 quoting Sherwin, S. (1998) 'A Relational Approach to Autonomy in Health Care', in The Feminist Health Care Ethics Research Network, S. Sherwin (coordinator) The Politics of Women's Health: Exploring Agency and Autonomy, pp. 19–47. Philadelphia, PA: Temple University Press, 26.

The information given by health professionals to an ART patient should enable the patient to give informed consent to her treatment in a way that respects her autonomy. Information about tests and technologies can arguably be coercive, depending on the way the various options are presented to a woman. Yet at the same time, their availability constitutes a right and enhances reproductive autonomy. It allows her to make an informed decision to terminate her pregnancy or select not to have an affected embryo implanted, if she so desires. In medicine the term 'substantial autonomy' is used, meaning that the patient understands significant information, is not improperly influenced and is not manipulated or coerced.[26] For this project, this description of autonomy is the one I rely on. However, I also take a broad view of what constitutes coercion and manipulation. While the coercion and manipulation might not be intentional, a person's autonomy can be affected by social and economic factors and a cultural expectation of compliance with medical and routine procedures. The medical framing of ART procedures means that these social, economic and cultural pressures may not be adequately accounted for.

The Australian Medical Association's (AMA) position statement about reproductive health is relevant here. It states clearly that it 'supports the right of every woman to make her own decisions about reproduction and about her use of available and appropriate reproductive technology'.[27] However, although a woman can make her own decisions and choose or refuse procedures, it is clear that her autonomy is complicated by the context in which those decisions are made. Just as health professional and social expectations influence a woman's decision making, if a woman wants to use ART, she needs to decide in accordance with the legal framework and the policies and guidelines which regulate ART processes.

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[26] Mary Anne Warren, 'Is IVF Research a Threat to Women's Autonomy?' in Peter Singer et al (eds), *Embryo Experimentation* (Cambridge University Press, 1990) 125, 131.

[27] Australian Medical Association AMA, 'Reproductive Health And Reproductive Technology - 1998. Revised 2005' <https://ama.com.au/position-statement/reproductive-health-and-reproductive-technology-1998-revised-2005>. The Australian Medical Association (AMA) is a membership organisation representing registered medical practitioners and medical students of Australia. It exists to promote and protect the professional interests of doctors and the health care needs of patients and communities and it advocates on behalf of its members at the Federal, and State and Territory levels.

Emily Jackson reflects this more comprehensive approach to reproductive autonomy by arguing that a person is a social being whose capacity for autonomy progresses in a social context.[28] She argues that in order for a person to exercise his or her reproductive autonomy, the person must be able to 'act on preferences that are *already* fully formed and clearly articulated'[29] and it needs to be recognised that 'positive provision of resources and services may be necessary in order to assist people both to work out their own priorities and to realise them'.[30] As I will show in Chapters Three, Four and Five, Jackson's approach is crucial to an ethical outcome for women undergoing ART. Though the resources and services are not described by Jackson, it is clear that in order to truly benefit from reproductive autonomy, access to information, support networks, social and financial support is vital. In other words autonomy is never just simply an isolated act of will but must be a socially supported exercise of self-determination.

2.1.3 RELATIONAL AUTONOMY

This sense of autonomy arising from a particular social context is reflected in the scholarship on relational autonomy, which emphasises the relationships from which autonomy arises and is sustained. A woman lives in the middle of a network of relationships, even more so when she wants to have a baby and enters a reproduction process, and her reproductive choices and decisions are taken within this network. An ART process increases this network of relations and therefore the autonomy a woman exercises in this context may be described as relational autonomy.

According to Laufer-Ukelest, the aim of the literature on relational autonomy is to create a 'framework for enhancing and optimising autonomous decision making through dialogue and explicit recognition of social and contextual pressures involved in

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[28] Erin Nelson, *Law, Policy and Reproductive Autonomy* (Oxford and Portland, 2013) 35.

[29] Ibid.

[30] Ibid 36, quoting Emily Jackson, Regulating Reproduction: Law, Technology and Autonomy (Oxford, Hart Publishing, 2001.

choice'.[31] For Nedelsky, the various components to optimise the capacity for autonomy are 'comprehension, confidence, dignity, efficacy, respect, and some degree of peace and security from oppressive power are probably also components'.[32] Whereas Laufer-Ukelest writes that the aim of relational autonomy is to create a structure for optimal autonomous decision making, Nedelsky describes elements that are needed to ensure autonomy. On the one hand, there is autonomous decision making, which inheres in the individual's actions, while on the other hand, there is the capacity for autonomy, which encompasses a person's situation or context in which he or she lives. Thinking about it another way, Nedelsky's components for optimal capacity may be part of the range of components needed to create Laufer-Ukelest's framework.

In order to achieve relational autonomy, it seems that the creation of a favourable and constructive framework on a legal and social level is indispensable for the multiple components necessary to enhance the capacity for autonomy. This framework and these components should ideally be present in an ART institutional setting, where an open dialogue without any sense of coercion, between the woman and the health professionals is of utmost importance so that she can make autonomous decisions true to her values.

2.2 RELATIONAL REPRODUCTIVE AUTONOMY IN THE ART CONTEXT

In ART, a woman's autonomy may be challenged in particularly complex ways. When a woman makes a decision during her ART procedure, she obviously takes responsibility for that decision. However, does this mean that the more a woman exercises her autonomy when she makes that decision, the more she can be held ethically responsible for it? If the answer to that question is 'yes', then what is the significance of a decision to give birth to a disabled child? This question is likely to be asked in an ableist society, where disability is considered negatively. For Kumari Campbell ableism is defined as

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[31] Pamela Laufer-Ukelest, 'Reproductive Choices and Informed Consent: Fetal Interests, Women's Identity, and Relational Autonomy' (2011) 37 *American Journal of Law & Medicine* 567, 611.
[32] Nedelsky, above n 18, 11.

> a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human.[33]

However, throughout this thesis, I want to challenge the assumption that disability is always negative. I will return to this point in part 2.6 below.

For Laufer 'autonomy and women's health in reproductive choices should be about recognising the complexity involved in such choices and providing an appropriate framework for women to make such choices in their own best interests'.[34] With the proliferation of decision-making points in IVF and ART and the involvement of numerous third parties autonomous decision making is harder to ensure unless it is understood relationally.

If a non-relational approach is taken, the danger is that a woman will be subjected to an individualisation of accountability for preventive measures. It can mean that a woman and, if present, her partner, are given freedom of choice but also primary responsibility for making the decision whether to use genetic testing. A woman can choose to limit the chances she will give birth to a child with disability. She has at her disposal various tests like preconception testing, PGD,[35] preimplantation genetic screening (PGS), prenatal diagnosis (PND) and prenatal screening (PNS). If a very harsh view of the consequences of disability is accepted, the availability of these tests leads to pressure on a woman's decision making. According to Silvers, 'some bioethicists, including some who are feminists, have adopted medicalised views of disability and, in doing so, have argued that the prospect of bearing a disabled child justifies, or even

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[33] Fiona AK Campbell, 'Inciting Legal Fictions: "Disability's" Date with Ontology and the Ableist Body of the Law' (2001) 10 *Griffith Law Review* 42, 44.

[34] Laufer-Ukelest, above n 31, 623.

[35] Hans Galjaard, 'Draft Report on Pre-Implantation Genetic Diagnosis and Germ-Line Intervention', (Draft Report SHS/EST/02/CIB-9/2, United Nations Educational, Scientific and Cultural Organisation, International Bioethics Committee (IBC), 2002) 2.

obligates, termination of the pregnancy'.[36] Purdy and McMahan, referred to earlier as choice feminist, are among those feminist bioethicists. If this point of view is transposed into the ART domain, then that means a woman with a genetic condition, should do everything she can in order not to give birth to a disabled child. She would be expected to conceive her child via ART, and always go ahead with PGD in order to detect whether her embryo is affected and, if that is the case, she should select against its implantation or she should use donor gametes. This theoretical situation would effectively negate the woman's autonomy, because her genetic condition would not allow her to make her own choices. In medical practice, ethics preclude doctors from flagrantly violating a woman's autonomy, and she cannot be forced into using certain techniques and selecting only unaffected embryos. Indeed, this would come dangerously close to eugenics, if it was coerced. However, current testing technologies, along with a culture that is generally hostile to disability, leads to a lesser but still significant pressure on the woman.

A woman or a couple with a known genetic risk may opt for a pregnancy, which could end in a termination after prenatal diagnosis, because they are not allowed to (or cannot afford to) have an embryo examined using PGD prior to transfer to the uterus.[37] But not all women would choose PGD over prenatal testing. IVF and PGD can be viewed as more invasive and harmful than prenatal testing and abortion. Alternately, they may make a decision based on balancing of risks. For instance, they may not want to take the risk of accidental destruction of their embryo by PGD. All these factors make up the substance of autonomous decision making.

A woman's reproductive possibilities can also be limited depending on where she lives, especially in the ART domain, where access rights vary by jurisdiction. A woman may

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[36] Silvers, above n 17, 18. In the text Silvers refers to the following works of Mc Mahan and Purdy: Mc Mahan: 1998. "Wrongful Life: Paradoxes in the Morality of Causing People to Exist," in J. Coleman and C. Morris (eds.), Rational Commitment and Social Justice, Cambridge: Cambridge University Press, 208–247.
Mc Mahan 2005. "Causing Disabled People to Exist and Causing People to be Disabled," Ethics, 116(1): 77–99. Purdy, L., 1995. "Loving Future People", In J. Callahan (ed.), Reproduction, Ethics and the Law, Bloomington, IN: Indiana University Press.

[37] Swiss National Advisory Commission on BiomedicalEthics (NEK‑CNE), above n 4, 30.

be denied access to ART services due to her marital or social status depending on her geographical location. For example in Victoria, before the *Assisted Reproductive Treatment Act 2008* (VIC) changed the eligibility criteria for ART treatment, a woman was only eligible for access to ART services if she was married or in a de facto heterosexual couple.[38] Under such a regime a woman is likely to feel that her reproductive autonomy is curtailed if she has no access to an ART treatment.

It is important that a woman can exercise her relational autonomy, in order to implement her reproductive choices. The enjoyment of this relational autonomy comprises also various social, economic and cultural elements which contribute to the realisation of autonomy in the ART context. As set out above, some of those contextual elements consist of the quality of information, the fact that consent should not be coercive, a culture that is hostile to disability, and geographical constraints.

2.3 CONFLICT OF INTEREST BETWEEN THE WOMAN'S AUTONOMY AND THE INTEREST OF THE NOT-YET CONCEIVED CHILD

A woman's autonomous decisions are especially difficult in an ART process where there may be a perceived conflict of interest between the woman and her future or not-yet conceived child. Laufer-Ukelest, for example, claims that when a woman considers having a baby, woman and foetus are a relational unit and hence decisions cannot be made on a purely individual autonomous level but need to be made on a relational level.[39] Though this relational unit makes sense, sometimes the interests of the woman and those of the future child are placed in opposition.

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[38] Nelson, above n 28, 273. The current legislation of Victoria, Section 10 (2)(a)(i) and (ii) of the *Assisted Reproductive Treatment Act 2008* states: 10 Persons who may undergo treatment procedures. For subsection (1)(b)(i), the criteria applicable to a woman are
(a) a doctor is satisfied, on reasonable grounds, that—(i) in the woman's circumstances, the woman is unlikely to become pregnant other than by a treatment procedure; or (ii) the woman is unlikely to be able to carry a pregnancy or give birth to a child without a treatment procedure; or (iii) the woman is at risk of transmitting a genetic abnormality or genetic disease to a child born as a result of a pregnancy conceived other than by a treatment procedure, including a genetic abnormality or genetic disease for which the woman's partner is the carrier; and (b) a presumption against treatment does not apply to the woman.

[39] Laufer-Ukelest, above n 31, 611.

In ART processes the woman is placed in a position of primary responsibility for the health outcome of her future child. The decisions she must make relate to her concerns also for her future child. During an ART treatment, if the woman has a genetic condition, she needs to decide whether she wants her embryo tested. This decision is not made easier by the fact that before she gives genuinely informed consent, she has to digest the volume of information generated on each of the ART procedures. She lives in an environment of attendant pressure to comply with them, which makes her vulnerable to subtle coercion. Gates shares this view stating that:

> there is evidence that testing is, for some women, associated with a sense that control over important reproductive decisions is, to a degree, being usurped by family, by society, and by the medical profession.[40]

The autonomy of the woman has necessarily changed due to medical progress. Physicians have taken over, especially in reproductive medicine, the constellation of care has changed and pregnancy and childbirth have been treated more like pathologies, based on a medical model. The woman has been taken under the wing of doctors and other health care specialists.[41] Moreover, the increasing availability of preconception and preimplantation testing has altered how the woman's decisions, to use or not to use this testing, are viewed in regard to the future child's best interests. Karpin and Savell caution against focusing on the perceived welfare of the child, arguing that:

> [the] perceived welfare of the future child is problematic for two reasons. Firstly, it potentially constrains women's reproductive choices whatever they may be and, secondly, it tethers their reproductive decision to the idea that an objective statement about the undesirability of certain traits is being made.[42]

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[40] Elena A Gates, 'Prenatal Genetic Testing: Does It Benefit Pregnant Women?' in Karen H Rothenberg and Elizabeth Jean Thomson (eds), *Women & Prenatal Testing Facing the Challenges of Genetic Technology* (Ohio State University Press, 1994) 183, 188.

[41] Nicolette Priaulx, *The Harm Paradox: Tort Law and the Unwanted Child in an Era of Choice* (Routledge-Cavendish, 2007) 21.

[42] Isabel Karpin and Kristin Savell, *Perfecting Pregnancy : Law, Disability, and the Future of Reproduction* (Cambridge University Press, 2012) 348.

Medical language in the field has contributed to the depersonalisation of the woman in ways that potentially impact her autonomy. For example, although the AMA refers to the woman in its *Declaration of Maternal Decision-Making*, her interests are merged with those of the foetus. It says:

> [m]ost pregnant women strive to achieve the best possible health outcomes for both themselves and their unborn babies. Because of the inter-dependence of the maternal-foetal relationship, both the mother and the foetus have an interest in any health care decision. In this situation, "interest" refers to "optimal health and wellbeing".[43]

This suggests that the woman's actions necessarily will take into account the interdependent welfare of herself and her foetus. So if her decisions only take into account her interests and not those of the foetus, she is potentially subject to accusations that she is making unethical decisions.

The way that women are described in the medical language highlights the danger that a woman will not be acknowledged as an autonomous person at all but rather a means (a body capable of reproducing) to an end (the birth of a child). Van der Ploeg goes even further and blames medical progress in the domain of reproduction for the disappearance of the woman as a central person during the reproduction process and an individual patient. For her:

> the result of interventions on women's bodies (the construction of congenital disease and male infertility as a foetus's and a couple's medical problem) is changed into the reason for intervention in women's bodies. The inconspicuousness of this reversal is enhanced by hardly ever presenting interventions as interventions on female bodies, and hardly ever having women figure as individual patients.[44]

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[43] Australian Medical Association AMA, 'AMA Position Statement Maternal Decision-Making' <https://ama.com.au/position-statement/maternal-decision-making-2013>.

[44] Van der Ploeg, '"Only Angels Can Do Without Skin": On Reproductive Technology's Hybrids and the Politics of Body Boundaries' (2004) 10 *Body & Society* 153, 176.

With the woman’s disappearance in the medical terminology of ART, her choices give way to the interests of a hypothetical foetus, where ‘the foetus comes to exist prior to its actual incarnation’.[45] This disappearance can also be the consequence of a change in the woman’s role, which has subtly changed from an active to a passive role. For Ettorre, ‘women are more done to than the doers, as their foetuses’ performances are appraised over time through various technical procedures’.[46] The disappearance and the change in her role put into the equation the interests of the foetus or not-yet conceived child and can have an impact on whether the woman can be held responsible for her decisions. She can be held ethically responsible for her actions, because they can be considered as taking into account solely her wellbeing and harming or neglecting the wellbeing of the not-yet conceived child. Hence the dilemma between a woman’s interests and the interests of the not-yet conceived child has emerged and it has become even more accentuated when disability of the future child is involved. This concern arises, too, in the language used in ART legislation.

2.4 ART LEGISLATION AND WOMAN’S AUTONOMY

Although my scenarios are situated in the States of New South Wales (NSW) and Victoria (VIC) in Australia, these jurisdictions can be usefully contrasted with Canada, because the *Canadian Assisted Human Reproduction Act (AHRA)* from 2004 is one of the few such laws that puts the woman in the foreground. It states in its *Declaration*:

> while all persons are affected by these technologies, women more than men are directly and significantly affected by their application and the health and wellbeing of women must be protected in the application of these technologies.[47]

By directly referencing women, the Canadian legislation acknowledges the woman’s identity and individuality and indirectly her role as a decision-maker. By emphasising that women are, more than men, directly and significantly affected, the legislation also

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[45] Isabel Karpin, ‘The Uncanny Embryos: Legal Limits to the Human and Reproduction Without Women’ (2006) 28 *Sydney Law Review* 599, 619.
[46] Elizabeth Ettorre, *Reproductive Genetics, Gender and the Body* (Routledge London, 2002) 20.
[47] *Assisted Human Reproduction Act, SC 2004, c 2, s 2(c)*.

points out that the ART treatment occurs to the woman as a person and patient and not merely to a body part of the woman.

In Australia, the main form of regulatory control of ART is the National Health and Medical Research Council's *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* (*NHMRC ART Guidelines*).[48] All State legislation has adopted the *NHMRC ART Guidelines*, but some State legislation adds additional requirements. All clinics follow these guidelines in order to be accredited by the Reproductive Technology Accreditation Committee (RTAC)[49] as required under s10 and s11 of the *Research Involving Human Embryos Act 2002*.

The *NHMRC ART Guidelines* do not use the word 'woman' specifically in their description of ART procedures. Instead they use the neutral word 'participants'. They specify that these procedures must

> be conducted in a way that is respectful of all involved. Clinical decisions must respect, primarily, the interests and welfare of the persons who may be born, as well as the long-term health and psychosocial welfare of all participants.[50]

The *Assisted Reproductive Technology Act 2007* (NSW) refers directly to the woman by stating that one of the objects of the Act is 'to protect the interests of a woman undergoing ART treatment'.[51] It also refers directly to her in relation to counselling services when it is stated that 'an ART provider must ensure that counselling services are available to any woman who seeks ART treatment from the ART provider'.[52] However, the *Assisted Reproductive Technology Act 2007* (NSW) also makes indirect reference to the woman in ways that are less positive, for example, in its definition of the embryo which is defined as 'the single entity formed by the combination of a

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[48] National Health and Medical Research Council NHMRC, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (National Health and Medical Research Council, 2004 (as revised in 2007 to take into account the changes in legislation), 2007) <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e78.pdf>.

[49] The RTAC was founded by the Fertility Society of Australia (FSA).

[50] NHMRC, above n 48, 21.

[51] *Assisted Reproductive Technology Act 2007* (NSW) 2.

[52] Ibid s 9(2)(12)(1).

human sperm and a human ovum until the time it is implanted in the body of a woman'.[53]

The choice here of the words 'implanted in the body of a woman', instead of 'implanted in the woman', is notable because where else than her body would the embryo be implanted? While the definition could have referred to the woman as a person, instead it referred to her as a body. This is not a simple choice of interchangeable words with the same meaning. On the contrary, using the word "woman" implies that one talks about a human being capable of making informed and conscientious decisions, whereas a body is incapable of doing so. Kirejczyk and Van der Ploeg find also that the language can disadvantage women and they claim that:

> the medico technical language of IVF creates a disconnection between the female subjectivity and women's objectified bodies, which are visible only as disembodied organs and processes.[54]

In Victoria ART is regulated by the *Assisted Reproductive Treatment Act 2008* (VIC) which came into force on 1 January 2010. Similarly to the New South Wales Act, the Victorian Act refers indirectly to the woman via the definition of artificial insemination which 'means a procedure of transferring sperm without also transferring an oocyte into the vagina, cervical canal or uterus of a woman'.[55] Similarly to the definition of the embryo in the New South Wales Act, discussed above, the woman as person is absent in the definition, while her body parts are listed. Artificial insemination could have been described as a procedure of transferring sperm into a woman. This would have been a simple definition, without using any medical jargon, and it would not have separated the procedure from the woman as a person, capable of making decisions, and it would not have reduced the woman to anatomical parts.

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[53] Ibid s 1(4)(1).

[54] Marta Kirejczyk and Irma Van der Ploeg, 'Pregnant Couples: Medical and Social Constructions around Fertility and Reproduction' (1992) 5 *Reproductive and Genetic Engineering: Journal of International Feminist Analysis* 113, 125.

[55] *Assisted Reproductive Treatment Act 2008* (Vic) s 2(3).

In Victoria's better use of language, the woman is explicitly mentioned in the guiding principles of the Act where it says that in relation to her reproductive capabilities, 'at no time should the use of treatment procedures be for the purpose of exploiting, in trade or otherwise—the reproductive capabilities of men and women'.[56] Though the person described in the '[g]eneral requirements for treatment procedures'[57] is the woman, which shows the importance accorded to her, the Act does not give any information about the woman's decision-making capacity and her potential responsibility for her actions. If there is a risk of transmission of a genetic abnormality, a woman can proceed with an ART treatment as long as

> a doctor is satisfied, on reasonable grounds, that the woman is at risk of transmitting a genetic abnormality or genetic disease to a child born as a result of a pregnancy conceived other than by a treatment procedure, including a genetic abnormality or genetic disease for which the woman's partner is the carrier.[58]

Thus the Victorian *Assisted Reproductive Treatment Act 2008* (VIC) describes the situation where the woman has access to ART, so that she can use ART to avoid transmission of a disease, but the Act is silent about the woman's decision-making capacity and her potential responsibility in such a situation.

Neither in New South Wales nor in Victoria are the woman's decision-making rights and capacity clearly described or mentioned in the legislation. And yet Australian ART legislation does deal directly with the welfare of the child to be born, in language that leaves no doubt about the importance of the future child.

The Australian Health Ethics Committee (AHEC), for example, has stated in its *NHMRC ART Guidelines* that the 'welfare of people who may be born as a result of the use of ART is paramount'.[59] Those guidelines also state that ART procedures must be accomplished in a respectful manner for all involved and that 'clinical decisions must

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[56] Ibid s 5(5)(b)(i).

[57] Ibid pt 2 div(2)(10).

[58] Ibid s 10(2)(a)(iii).Ibid s 11 pt 2 div 2(10)(2)(iii).Ibid s 11 pt 2 div 2(10)(2)(iii).

[59] NHMRC, above n 48, 9.

respect, primarily, the interests and welfare of the persons who may be born'.[60] As for the states, New South Wales declares in its *Assisted Reproductive Technology Act 2007* (NSW) that one of its objects is the protection of the interest of 'a person born as a result of ART treatment'.[61] The same goes for South Australia (SA) where section 4A of its *Assisted Reproductive Treatment Act 1988* (SA) says:

> the welfare of any child to be born as a consequence of the provision of assisted reproductive treatment in accordance with this Act must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of this Act.[62]

The State of Victoria acknowledges also in the guiding principles of its *Assisted Reproductive Treatment Act 2008* (VIC) that 'the welfare and interests of persons born or to be born as a result of treatment procedures are paramount'.[63]

In Victoria there is a further legal intervention on behalf of a future child: the general requirements for ART treatment procedures must include a criminal record check and a child protection order check of the potential patient. The Act states that the consent given by the woman and her partner to an ART procedure

> must include a statement by the counsellor who provided counselling to the woman and her partner, if any, under section 13 that the counsellor has sighted a criminal records check in relation to the woman and her partner[64]

and that it

> must be accompanied by permission from the woman and her partner, if any, for a child protection order check to be conducted in relation to the woman and her partner.[65]

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[60] Ibid 21. This is stated in their ethical principles for clinical practice of ART.
[61] *Assisted Reproductive Technology Act 2007* (NSW) pt 1(3)(b)(i).
[62] *Assisted Reproductive Treatment Act 1988* (SA) pt 1(4a), ('*Assisted Reproductive Treatment Act*').
[63] *Assisted Reproductive Treatment Act 2008* (Vic) s 5(a).
[64] Ibid s 11(1)(c).

There is a presumption against ART treatment if the criminal record check shows that charges have been proven against the woman or her partner (if any) for a sexual offence; or that a woman or her partner (if any) has been convicted of a violent offence.[66]

A person may apply to the Patient Review Panel for a review against the presumption against treatment, but the Patient Review Panel must consider whether granting access to an ART treatment is 'consistent with the best interests of a child who would be born as a result of the treatment procedure'.[67] These checks can prejudice a woman's reproductive autonomy. A woman who has a criminal record of a sexual or violent offence but who can conceive naturally has the right to become pregnant and give birth to her child, whereas a woman who cannot conceive naturally and who has the same criminal record or has a partner who has such a criminal record can be denied access to services. Thus, she is twice disadvantaged: first she cannot conceive naturally and needs help to conceive, and second she cannot have access to ART because of her or her partner's criminal record.

The analysis of autonomy, in this section, has shown that autonomy plays a major role for the woman in her decision-making process during an ART treatment. Autonomy enables a woman to make choices according to her values. A woman's decision is composed of various decision-making points during an ART process. Her reproductive autonomy can also be characterised as relational autonomy as the decisions are taken within a network of various players who should provide information and counselling if needed. This section has also shown that the interests of the child, if present in the legislation, can have an impact on a woman's autonomy by emphasising those interests as fundamental and paramount, while the woman's interests are underplayed or absent. While a statute might spell out what the welfare of the child actually means, the fact that it is treated as of paramount importance makes it an

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[65] Ibid s 11(1)(d).

[66] Isabel Karpin, 'The Legal and Relational Identity of the "Not-Yet" Generation' (2012) 4 *Law, Innovation and Technlogy* 122, 129.

[67] *Assisted Reproductive Treatment Act 2008* (Vic) s 15(3)(b)(ii).

essential part of the legislation in ways that a woman's autonomy is not. Finally, in order to see whether a woman can be held responsible for her actions, it is necessary to acknowledge the complexity surrounding a woman's reproductive decision, especially when the decision involves a future child with a disability. And it is equally important to provide an appropriate social, medical and legal framework to guarantee that the woman can make genuine choices.

2.5 CHOICE

2.5.1 NEW REPRODUCTIVE TECHNOLOGIES AND THE MEANING OF CHOICE

Autonomy and choice are clearly linked because without autonomy a person cannot make a meaningful choice. In this section, however, I will focus on the kinds of choices a woman makes regarding testing for disability in the context of new reproductive technologies. This section explores the meaning of choice, its links with autonomy, what it means for the woman and the circumstances surrounding it.

Choice is defined as an ‘act of choosing between two or more possibilities’.[68] If reproductive choice was originally a choice between having, or not having, a child, it has now diversified with the emergence of new testing technologies and ART techniques. In Australia ART has enabled a woman to have a child irrespective of her fertility status or relationship status. Within ART technologies the choices have also multiplied with the advance of PGS and diagnosis, so that the choice is no longer simply between having or not having a child, but between selecting one child instead of another. Disability has become a central consideration in that choice.

For Purdy, assisted reproduction has thus become a source of controversial choice. She notes that the ‘new options’ for women have now become a standard of care, a routine, which women are not really free to reject. She claims that these new options are not necessarily in a woman’s best interest, because there are possible dangers and problems related to them.[69] Rehmann-Sutter shows that, though there has been a shift towards putting the woman at the centre of the decision, she is confronted with an underlying pressure to undertake all the tests and to terminate where there is an outcome of disability. Typically, she faces ongoing requirements of tests and assessment that are expected to be conducted during pregnancy and she needs to

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[68] Oxford University Press, *Dictionary* (2014) Oxford Dictionaries Language matters <http://www.oxforddictionaries.com/>.

[69] Purdy, above n 7, 225.

justify her decision if she does not want to go ahead with any of them.[70] She may feel that her decision is sometimes harder to make especially when the argument of the welfare of the future child is used.

There are new dimensions to the ethical dilemmas that arise as a consequence of these new technologies. Women now have to make choices that previously did not exist. An example is the woman who has a genetic condition, who wants to use ART and who chooses not to undergo tests to detect a disability, and who is then held ethically, if not legally, responsible for an adverse outcome. In the past such a woman would have been considered a 'victim of the natural lottery'[71], whereas now she is seen as someone who has made a risky and possibly adverse choice. This is the case even if she has attempted to avoid making difficult choices. In the presence of these new options, as Finger says, '[e]ven ignorance involves choice, because you also have to choose not to choose'.[72]

Therefore, by not acting in relation to testing for disability, a woman can be viewed as actively harming a future child. Pioro and Mykitiuk contend that the 'combination of this ability to choose and the legally sanctioned concept that the birth of a disabled child can constitute a harm, may cause a woman to be viewed as harming a child, simply by choosing to bring a disabled child to term'.[73] Rothman goes even further and warns that 'women may be considered bad mothers for bringing a disabled child into the world'.[74] This shows that increased testing choices have actually made it much harder for a woman to risk, or actively choose, proceeding with the birth of a child with a disability.

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[70] Christoph Rehman-Sutter, '"It Is Her Problem, Not Ours": Contributions of Feminist Bioethics to the Mainstream' in Laurel Baldwin-Ragaven, Petya Fitzpatrick and Jackie Leach Scully (eds), *Feminist bioethics : at the center, on the margins* (The Johns Hopkins University Press, 2010) 23, 32.

[71] John A Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton University Press, 1994) 231.

[72] DA Caeton, 'Choice of a Lifetime: Disability, Feminism, and Reproductive Rights' (2011) 31 *Disabilities Studies Quaterly* 10 <http://dsq-sds.org/article/view/1369/1501>.

[73] Mark Pioro, Roxanne Mykitiuk and Jeff Nisker, 'Wrongful Birth Litigation and Prenatal Screening' (2008) 179 *CMAJ: Canadian Medical Association Journal* 1027, 1028.

[74] Ibid quoting Katz Rothman B. The tentative pregnancy: prenatal diagnosis and the future of motherhood. New York (NY): Viking; 1986.

The new reproductive technologies therefore do not offer a real choice for the woman in any simple sense. Katz Rothman claims that 'new reproductive technologies are all being used to give the illusion of choice',[75] though she admits that on an 'individual level they certainly solve some very grave troubles'.[76]

One argument here, considering the relational view of reproductive autonomy outlined above, is to offer women more genuine choice. Thus if a woman chooses to use a detection technique for disability, and if a disability is detected, the alternative should not only be termination or non-selection, but the alternative should also be support to proceed with a pregnancy and ideally a social support network to rear a disabled child. Genuine alternatives are important so that the person does not feel compelled to 'choose the socially endorsed alternative'.[77]

While it is outside the scope of this project to analyse to what extent social, economic and financial considerations have an impact on reproductive choices, it is clear that these may strongly influence a woman's reproductive choice, especially when this decision involves a future child with a disability.

2.5.2 THE LANGUAGE OF ART BUSINESS AND ITS IMPACT ON A WOMAN'S CHOICE

ART is a business propelled by a consumer desire and massive financial profits. Australia, for instance, provides substantial government funding for fertility treatments, which has made fertility treatment in Australia more economically feasible. The industry is likely to generate a revenue growing from $575 million to $775 million over a five-year period. This corresponds to a projected growth of 34.8% between 2014-15 and 2019-20.[78]

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[75] Barbara Katz Rothman, *Recreating Motherhood* (W.W. Norton & Company, 1989) 200.

[76] Ibid.

[77] Ibid 199 quoting Ruth Hubbard, unpublished position paper on surrogacy, untitled.

[78] Media Team, 'On Fertile Ground: Industries Benefiting from the Coming Baby Boom' (Industry Report, IBIS World, May 2015) <http://media.ibisworld.com.au/2015/05/12/on-fertile-ground-industries-benefiting-from-the-coming-baby-boom/>.

Australian and New Zealand reported 66,347 ART treatment cycles taking place in their countries, 23.1% (15,319) of all ART treatments resulting in a clinical pregnancy and 17.5% (11,640) in a live delivery.[79] Prior to starting an ART treatment a woman can gather information via websites of ART clinics or institutions. A substantial part of these websites is dedicated to their success rates, which are often illustrated by colourful graphs and positive, enticing captions. These graphs present for example the '[c]linical pregnancy rate for each embryo transfer for patients with their own eggs'[80] or they compare a particular clinic's '[c]linical pregnancy rate per embryo transfer or live birth rate per embryo transfer'[81] with the average of other clinics. But these examples of success rates might not be considered as the most honest way to present success rates. For Hammarberg, the success rate of a live birth per IVF cycle is 'the only honest way of reporting chance of success because what people want and expect when they start an IVF cycle is a live birth'.[82] Her findings are based on the 2011 statistics about IVF success in Australia and New Zealand where the rate of success 'quoted as pregnancies per embryo transfer'[83] is higher than the 'chance of a live birth per started cycle'.[84] The websites also link their success rates to the age of the woman considering ART treatment, due to the broad 'belief that IVF can help overcome age-related infertility'.[85] In that context she also found that 'in women aged 40 or older 94 out of 100 attempts will not result in the birth of a baby'.[86] Hammarberg's findings show also that the language used can instil misleading beliefs and assumptions and potentially direct a woman to making decisions that she would not otherwise make.

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[79] Alan Macaldowie et al, 'Assisted Reproductive Technology in Australia and New Zealand 2011' (National Perinatal Epidemiology and Statistics Unit, the University of New South Wales, August 2013) 4 <http://npesu.unsw.edu.au/data-collection/australian-new-zealand-assisted-reproduction-database-anzard>. Of these clinical pregnancies, 13,790 (90%) were from Australian clinics and 1,529 (10%) from New Zealand clinics. There were 12,623 babies born (including 12,443 liveborn) following ART treatment in 2011

[80] IVF Australia, *IVF Australia* <http://ivf.com.au/about-fertility>.

[81] Genea Limited, *IVF Success Rates* (2013) Genea World Leading Fertility <http://www.genea.com.au/my-fertility/why-genea/ivf-success-rates>.

[82] Karin Hammarberg, *If IVF 'success' Is Judged on the Number of Live Births, the Figures Don't Look so Good* (2014) The Conversation Academic rigour, journalistic flair <http://theconversation.com/if-ivf-success-is-judged-on-the-number-of-live-births-the-figures-dont-look-so-good-29412>.

[83] Ibid.

[84] Ibid.

[85] Ibid.

[86] Ibid.

It is evident that ART clinics have an impact on a woman's choice by directing her needs and desires in a certain direction, where she might feel sometimes compelled to undergo certain tests or techniques. When a woman has a genetic condition, or when it is present in her family, or when choices need to be made in relation to her ART treatment or about her future child, then genetic counselling can be offered as part of her treatment. The aim of genetic counselling is not only to give information about how to prevent a genetic disease but also to raise awareness about a genetic risk.[87] Raising awareness about a risk means creating a need to know and increase decision-making points and it is questionable how these increased choices influence a person's autonomy. Even though patients are considered autonomous individuals making informed choices, it is crucial that ART clinics inform their patients in a responsible and adequate way so that the communication is as genuine and complete as possible, and so that my broader meaning of autonomy is respected.

Some commentators suggest that in order to attract customers ART related businesses and clinics are increasingly using a vocabulary that itself creates a need or a desire for their services, with persons who may or may not have an infertility problem, but nevertheless want to use ART techniques to gain more reproductive control. Hence it can be presumed, that if the clinics manage to attract more women to use ART, even if they do not have fertility problems, then the success rate will increase and the clinics might take advantage of that fact and also promote it. This consumer-friendly attitude is further sustained by using a positive, reassuringly scientific language, where the focus is unfortunately not on the woman, but mainly on techniques and tests which ensure that the foetus or baby is not disabled. It is important that those who consider ART treatment 'are given honest and realistic information about the chance of the treatment working for them'.[88]

ART business is not only a successful financial health industry business, but it has shaped and will continue to shape and transform the lives of numerous people, first

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[87] Nikolas Rose, *The Politics of Life Itself Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton University Press, 2007) 115.
[88] Hammarberg, above n 82.

and foremost of women. Therefore it is crucial that the ART business addresses and considers the woman as a key partner in their dealings with her. The language should be such that the woman can make an informed autonomous decision. This would require the clinic to treat her and refer to her as a person and not as an accessory of an ART technique, or a mere incubator for her future child.

Nevertheless, the reality is that, in approaching the significant business interests that shape how ART is packaged and offered as a service, a woman is exposed to pressures and influences which can undermine her autonomy. This is another factor that underpins women’s decision making in ART.

In the next section I analyse disability, which is the last key concept required to address my research question.

2.6 DISABILITY

Nowadays ART not only makes it possible for a woman to have babies with the help of technology, but it also allows women to access knowledge about a future child's possible genetic conditions at a very early stage of their reproductive treatment.[89] The decisions that women may face in relation to this new knowledge concern issues about disclosure of disability, the use of technologies to detect a disability, and the implantation or not of embryos that might have a disability. Questions can also arise concerning the welfare of the woman and the future child, and access for people with disabilities to ART services. The role that the concept of 'disability' plays in these various issues needs to be analysed, because it reflects on whether the woman can or cannot be held ethically or legally responsible for her decisions.

2.6.1 DEFINITION, REPORTS AND MODELS OF DISABILITY

Disability has a different meaning in different contexts and it is difficult to find and use a common language when issues arise in regard to disability. In my research question, where ART and disability are analysed together, I aim to give priority to the woman's perspective on disability, but the broader view on disability from society in general and distinct interest groups (like health professionals, disabled persons, religious groups or other) cannot be ignored.

A general and comprehensive definition of disability is given by the International Classification of Functioning, Disability and Health (ICF). It defines disability as:

> an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g.

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[89] In this thesis I use either disabled child/ woman/ person or child/woman/person with a disability, I use disability to refer to all aspects of disability, and I use condition (for example genetic condition) to highlight the biological or genetic anomaly over the social aspect.

> negative attitudes, inaccessible transportation and public buildings, and limited social supports).[90]

Disability impacts people in every part of society, and a report from the Australian Bureau of Statistics (ABS) underlines this. It shows that disability affected 4.2 million people in Australia (18.5%) in 2012. Amongst the persons with a disability, 3.7 million (88%) had a specific limitation or restriction; those persons were affected in their self-care, mobility, communication, schooling and employment. In 2012, more women than men had a disability (18% compared with 19%), but in the age group 5 to 14 years, more boys than girls had a disability (11.2% compared with 6.2%).[91]

To stress the importance of disability on a global level, the United Nations *Convention on the Rights of Persons with Disabilities* entered into force internationally on the third of May 2008. The first article of the *Convention* stipulates that '[t]he purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.[92] The purpose of the Convention is also relevant for a woman's decisions during an ART process in relation to disability, if she has a genetic condition herself, because concerns about her fundamental freedoms and respect for her inherent dignity can arise.

The various models of disability put a different emphasis on what they consider is the most important component of a definition of disability. The "medical model" and the "social model" of disability are two well-known models with a different approach to disability, and the difference between them can be very useful to understand and analyse ethical and legal issues around disability. In the "medical model" disability is

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[90] Media centre World Health Organisation (WHO), 'Disability and Health Fact Sheet No 352' <http://www.who.int/mediacentre/factsheets/fs352/en/>.

[91] Australian Bureau of Statistics(ABS), *4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings* (2012) <http://www.abs.gov.au/ausstats/abs@.nsf/lookup/3A5561E876CDAC73CA257C210011AB9B?opendocument>.

[92] United Nations (UN), *Convention on the Rights of Persons with Disabilities* (13 December 2006) <http://www.un.org/disabilities/default.asp?id=259>.

viewed as ‘an abnormality of form or function, the cause of which lies in the biology of the individual’.[93] Biomedicine quantifies this deviation from normality by referencing it to a ‘norm of physical or mental structure and function’.[94] The aim is to heal the patient or to correct or improve the patient’s health condition.[95] Medical treatment and the reform of health care policy are considered of utmost importance in the medical model.[96] This model is widely critiqued by disability activists who reject the proposition that the medical condition is what primarily characterises the life of a disabled person.

Besides the medical model of disability, there is the “social model”, where disability is determined by the ‘relation between an individual and her or his social environment: the exclusion of people with certain physical and mental characteristics from major domains of social life’.[97] In this model, society as a whole is responsible for ‘creating’ the disability by putting barriers in place of the person with a disability having full access to social life. Society, then, should also be responsible for making the necessary environmental changes, so that everybody can enjoy fully and equally all parts of social life and activities.[98] The environment fails persons with disabilities when they can participate only partially and unequally in social activities. Or, as Ouellette puts it, the ‘tragedy is the failure of social institutions to help people with physical impairments lead productive lives’.[99]

Apart from the medical and social model of disability there is the “empowering” model of disability which argues in favour of giving persons with a disability the possibility of making decisions about his or her own treatment and access to services. Professionals

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[93] Jackie Leach Scully, *Disability Bioethics : Moral Bodies, Moral Difference* (Rowman & Littlefield & Publishers, Inc., 2008) 23.

[94] Ibid.

[95] David Wasserman et al, *Disability: Definitions, Models, Experience* (Fall 2013) The Stanford Encyclopedia of Philosophy 5 <http://plato.stanford.edu/cgi bin/encyclopedia/archinfo.cgi?entry=disability>.

[96] Ian Langtree, *Definitions of The Models of Disability* (10 September 2009) Disabled World <http://www.disabled-world.com/definitions/disability-models.php>.

[97] Wasserman et al, above n 95.

[98] Langtree, above n 96.

[99] Alicia Ouellette, *Bioethics and Disability toward a Disability-Conscious Bioethics* (Cambridge University Press, 2011) 60.

provide the necessary services and guidance and endeavour to ensure that the client's decision becomes reality. Hence the model "empowers" the person to achieve his or her personal targets.[100] In ART related situations, similar to my scenarios, this model of disability is partially applied by taking into account a woman's autonomy. For example a woman, who has a genetic condition and wants to have a baby, may want to use ART to conceive instead of natural conception, so that she may know whether her future child has a genetic condition and hence make her decisions in light of that knowledge. This may be especially true if she wants her embryo to be tested via PGD before implantation. The role of the clinic, subject to the relevant laws and regulations, is to facilitate the woman's choice.

2.6.2 DISABILITY, DECISION MAKING AND ETHICAL CONSIDERATIONS

In this section I engage with scholarship on the ethics of ART which illustrates and analyses the choices a woman faces and the decisions she makes in relation to disability during the ART process. It is important to understand how a woman's reproductive autonomy is affected by these choices and decisions and hence to understand better whether it is appropriate to hold her responsible for them.

2.6.2.1 MODELS OF DISABILITY AND THEIR IMPACT ON ART

ART is a very medicalised domain, within which the desire to have a baby has become a matter for professional medical intervention. In relation to disability, issues that arise during ART are predominantly approached in a medical way, by focusing on medical techniques to detect or diagnose genetic conditions, so-called disabilities. The woman is involved on various levels. Firstly, she is involved on a psychological level when she makes the decision that she wants the genetic condition to be detected or diagnosed. Secondly her involvement becomes physical, for example, when she decides to go ahead with PGD and this requires the more invasive technique of IVF.

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[100] Langtree, above n 96.

The medical model of disability tends to put the woman in a position where she finds herself caught up in this tension between disability rights and women's rights and the cultural values and views of a society relating to disability. Each of these views potentially has an impact on a woman's individual decisions about prenatal screening and diagnostic tests.

Lippman claims that testing presents disability as if it were simply a medical problem, hides the social roots of handicaps, and distracts attention from prevailing social, economic, and political policies whose failure to account for a wide distribution of abilities converts impairments into handicaps.[101] She argues that 'testing reshapes the problem of disability so that it need not be *ours* collectively to solve (what will *we* do to embrace and accommodate those among us with disabilities?)'.[102] Instead it becomes the woman's responsibility to "solve the problem of disability" and she will be the person to be held responsible. For Lippman 'society does not truly accept children with disabilities or provide assistance for their nurturance. Thus, a woman may see no realistic alternative to diagnosing and aborting a foetus likely to be affected.'[103] In the same context, Asch 'challenges the view of disability that lies behind the social endorsement of such testing and the conviction that women will or should end their pregnancies if they discover that the foetus has a disabling trait'.[104] She argues that testing is intended not to prevent the disability or illness of a born or future human being but to prevent the birth of a human being who will have one of these undesired characteristics.[105] Gillot rejects the idea that parents who choose to do testing and who choose to terminate a pregnancy because of foetal abnormalities are making moral judgments about those who are living with these abnormalities already. Rather, they are making judgments about their own lives and the lives of their children in relation to this genetic disorder.[106] While some authors, like Gillot, argue

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[101] Abby Lippman, 'The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity for Women?' in *Women & Prenatal Testing Facing the Challenges of Genetic Technology* (Ohio University Press, 1994) 9, 23.
[102] Ibid.
[103] Lippman, above n 5, 32.
[104] Asch, above n 8.
[105] Ibid 1651.
[106] John Gillot, 'Screening for Disability: A Eugenic Pursuit?' (2001) 27 *Journal of Medical Ethics* ii21.

that the woman who undergoes these tests does not make a moral judgement about disabled persons, but rather about her own life, others like Asch and Lippman argue that her decision is coloured by a society that does not genuinely embrace disabled persons.

2.6.2.2 DECISION MAKING IN ART BY PEOPLE WITH DISABILITIES

Though ART treatments take place in a highly medicalised environment, the social environment also shapes a woman's reproductive decision making. These decisions can be in regards to genetic technologies or the woman's own disability. Anita Ho considers that when people with disabilities make their reproductive decisions, for example in relation to the use of genetic technologies, oppressive forces work on their decision making, arising from an ableist socio-cultural environment. For her, persons with a disability cannot exercise the realisation of their life-plans autonomously and fully in an ableist socio-cultural context, because of the marginalisation of their experiences and positions. She underlines that the restructuring of the social framework is essential for the promotion of autonomy of a disabled person, and that health professionals play an important role in that attempt.[107] Restructuring means either physical restructuring for example, transforming a workplace so that it is physically adapted to a person with a disability, or it can signify a change in attitude, for example, health professionals adapting their way of communicating with patients.[108]

For Ho, disabled persons cannot realise their life-plans fully in an ableist society. Interestingly, however, scholars Albrecht and Devlieger, have presented research demonstrating that disabled persons enjoy an excellent quality of life. They call it the 'disability paradox'[109].

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[107] Anita Ho, 'The Individualist Model of Autonomy and the Challenge of Disability' (2008) 5 *Bioethical Inquiry* 193, 205.

[108] Ibid 197.

[109] Gary L Albrecht and Patrick J Devlieger, 'The Disability Paradox: High Quality of Life against All Odds' (1999) 48 *Social Science & Medicine* 977. The authors developed their work about the disability paradox by building on the research of Sol Levine. In his sociological studies, Levine studied health related quality of life through health behaviour, the activities of medical professionals and the problems of medical

The disability paradox is the apparent paradox that ‘many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence’.[110] Albrecht and Devlieger explain the disability paradox with a qualitative approach while also using semi-structured interviews with 153 persons with disabilities. After analysing their interviews, they came to the conclusion that ‘a good or bad quality of life’ depends on the person’s equilibrium between the physical, mental and spiritual self and on creating and upholding a balanced set of relations within a social setting and an external setting.[111] From this conclusion it follows that the social model of disability offers the best chances for a high quality of life for a person with a disability, since this model focuses attention on the external social setting.

2.6.2.3 THE ROLE OF HEALTH PROFESSIONALS IN DECISIONS ABOUT DISABILITY

A woman who goes through an ART process is surrounded by a team of health professionals, whose influence on her decision-making is significant. Their close relationship with the woman can influence and guide her choice and decision in relation to testing or screening, or questions of disability. Her decision can be in conflict with the predominant medical opinion and given the power differential in that relationship, she can potentially feel that her decisions have less authority than her medical care providers. One possible response is to require that the education of health care providers in regard to disability includes a greater emphasis on receptivity to people with a disability, because this change will enrich the woman’s choice and consequently her reproductive autonomy. Health care providers’ information should enable future parents ‘to consider how a child's disability would fit into their own hopes for parenthood’.[112]

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care delivery, with a particular focus on those who were disadvantaged. See Sol Levine, ‘The Changing Terrains in Medical Sociology: Emergent Concern With Quality of Life.’ (1987) 28 *Journal of Health & Social Behavior* 1.

[110] Ibid 977.

[111] Ibid.

[112] Asch, above n 8, 1655.

Ouellette also underlines the important role played by health professionals. She suggests that health providers should be disability-aware and she comes to that conclusion by comparing first the disability rights perspective and the bioethics perspective. She notes that both groups are devoted to the same central values, which are 'respect for persons and ethical and fair medical decision making'.[113] However, conflicts between the disability specialists and the bioethicists occur because the former 'promote the protection of disabled persons as a group, even when the community interest might conflict with the choice of an individual member'.[114] The latter endorse, however, 'informed individual choice'.[115]

Ouellette underlines the importance for 'disability-conscious'[116] bioethicists to train health care providers to become disability competent. It is important that competent health professionals have excellent knowledge and training and a good understanding of disability and that they do not let disability define the person. Health providers should give care to a person as a full human being, attending to his or her vital needs, which define human life.

Ouellette's stance is important. A woman, who is cared for by a disability-competent health care provider, has the opportunity of receiving comprehensive and objective information relating to the disability, for example, where she can get necessary supports. She then can have a realistic picture of what it means to live or to care for her disabled child, or what life with a disability can look like for her future child. Thanks to this information, she should then be able to make an informed and autonomous choice.

While a woman needs guidance and patient-specific care during an ART process, in particular to ensure her decisions are informed, it can happen that this guidance can overwhelm her decision-making capacity. One of the reasons for this is that the expert

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[113] Ouellette, above n 99, 13.
[114] Ibid.
[115] Ibid.
[116] Ibid 14.

advice can be outside her realm of knowledge and understanding. For Gates another reason is that:

> A woman, valuing her relationship with her physician and being in a relatively less powerful position in the physician-patient relationship, may hesitate to go against her physician's recommendations.[117]

2.6.2.4 DISABILITY AND DECISIONS ABOUT ABORTION

With the medicalisation of reproduction, a woman is confronted with decisions, before or during her pregnancy, that are linked to disability. When she conceives via ART, these decisions are sometimes made, even before implantation of the embryo, because of the advent of technologies like PGD, which allow the embryo to be tested outside the woman's body. Depending on the test result, the woman can either choose not to implant her embryo if she undergoes PGD or, if she is already pregnant, she can choose to have an abortion. Her decision can have a medical, ethical, social or cultural reason, but should be made within the legal and regulatory framework.

Although the following report is not within an ART context, it is an interesting example of the link between disability and abortion. Abeywardana and Sullivan's Australian 2002-2003 report of congenital anomalies shows the trend in favour of termination after prenatal diagnosis of trisomy 21 (Down syndrome). Around 63.6% of the foetuses diagnosed with Down syndrome resulted in terminations of pregnancy or foetal deaths.[118] At 76%, the proportion of terminations of pregnancy and foetal deaths is even higher for foetuses affected with neural tube defects.[119] It is noteworthy, in light

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[117] Gates, above n 40, 193.

[118] Samanthi Abeywardana and Elizabeth A Sullivan, 'Congenital Anomalies in Australia 2002–2003. Birth Anomalies Series No. 3 Cat. No. PER 41.' (AIHW National Perinatal Statistics Unit, 2008) 165, vi <http://npesu.unsw.edu.au/surveillance/congenital-anomalies-australia-2002-2003>. This second report on congenital anomalies in Australia presents epidemiological data on 33 selected conditions because they are monitored internationally by the International Clearinghouse of Birth Defects Surveillance and Research. The data are based on notifications to birth defects registries in New South Wales, Victoria, Western Australia and South Australia, and on data collected by perinatal data collections in Queensland, Tasmania and the Australian Capital Territory.

[119] Abeywardana and Sullivan, above n 118.

of the Australian report noted above that similar approaches exist in the U.S. A U.S. population survey from 1990 illustrates social expectations are heading in the same direction as the Australian statistics. The U.S. survey showed that 39% of the interviewees felt that 'every woman who is pregnant should be tested to determine if the baby has genetic defects'[120] and 22% believed that 'a woman should have an abortion if the baby has a serious genetic defect'.[121]

Belcher finds that behind the statistics of terminations that would have become disabled children, lies 'an attitude which views that the life of a disabled child as of less worth, less importance and less potential than that of an able-bodied child'.[122] This statement could also be applied to disabled adults.

2.7 Conclusion

A woman's autonomy, her reproductive choice and disability are invariably linked. Since the medicalisation of reproduction, a woman faces many more choices and decisions about disability, concerning herself and her not-yet conceived future child. In ART new screening and diagnostic techniques have emerged. While the prevention of disability has been placed in the hands of an individual person, namely, the woman, she is not free to exercise that choice without societal pressure. As Lippman puts it, the question that is presumed is: 'what will *she* do to avoid having a baby with a disability?'[123] The fact that a woman is expected, or at least under pressure, to take action in order to prevent her from having a baby with a disability has an enormous psychological or physical impact on her autonomy. If she conceives via ART, she might be expected to undergo genetic testing or PGD and select against the implantation of

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[120] R Alta Charo and Karen Rothenberg, '"The Good Mother": The Limits of Reproductive Accountability and Genetic Choice' in *Women and prenatal screening: facing the challenges of prenatal testing* (Ohio State University Press, 1994) 105, 106.

[121] Ibid. Unfortunately I could not get hold of an Australian survey which analysed the same questions. There are studies about social expectations for genetic testing, but they were of a more general nature and not limited to women and/ or pregnancy.

[122] Diane Belcher, 'Denying Disability: The Increase in Disability Directed Terminations-A Parent's Perspective' (Conference presentation at the National Spina Bifida Conference orgnaixed by NSW Spina Bifida Collaborative Group, Sydney, 19 October 2012) 8. The Data was found on the website of International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) Annual Report 2010.

[123] Lippman, above n 101, 23.

an affected embryo or she might be expected to use donor gametes. Because of those societal expectations failure to prevent disability can be seen as irresponsible. Some argue the woman, in that case, should be held accountable. If so, this thesis argues, such an approach would be an unethical breach of autonomy for those women who want to give birth to a disabled child and should be legally construed.

In the scenarios which follow, I analyse, by referring to the three key concepts of autonomy, choice and disability, whether it is appropriate to hold a woman responsible for her decisions made during ART which have resulted in disability in the child subsequently born as such.

3 CHAPTER THREE

In the next three chapters, I analyse three hypothetical scenarios focusing on the woman's decision-making points in each of the scenarios as well as examining their ethical and legal implications. The first scenario, the subject of this chapter, is situated in the state of New South Wales (NSW). As I explained in the previous chapter (section 2.3) in NSW there is no statutory body to supervise regulatory issues and the legislation is largely silent about the provision of IVF services and genetic testing.

3.1 Story of the first scenario

The first scenario takes place in January 2014. Nell is a forty-year-old woman from NSW, who works as a part-time zoologist. She is a single mother who has a four-year-old daughter, Adalyne. Nell conceived Adalyne in December 2009 via IVF, at the age of 36, with her own egg and donated sperm from a known donor, John. The donor, who is a friend of Nell, had never donated sperm before. In her IVF treatment two embryos were created, and Nell decided to freeze her second embryo.

In 2012 Adalyne was diagnosed with a mild form of an inheritable genetic condition, Mitochondrial Myopathy (MM). Adalyne's doctors confirmed that it is not a life threatening condition and their prognosis is optimistic, as they do not think that her form of MM will aggravate.

MM is a 'group of neuromuscular disorders that result from defects in the function of the mitochondrion, a small organelle located inside many cells that are responsible for fulfilling energy requirements of the tissue'.[124] Persons affected with MM have muscle symptoms. Originally MM was diagnosed based solely on clinical findings, but current genetic tests supply additional information that is mostly consistent with the clinical

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[124] Bryan R Cobb, *Encyclopedia of Neurological Disorders: Mitochondrial Myopathies* (2006) EMDN (European Mitochondrial Disease Network) 1 <www.emdn-mitonet.co.uk/.../Encyclopedia_of_Neurological_Disorders_Mitochondrial_Myopathies.pdf>.

diagnosis and can sometimes determine the long-term prognosis.[125] Mitochondrial myopathies are caused by 'mutations in Deoxyribonucleic Acid (DNA) from the nucleus of the cell, which is known as nuclear DNA (nDNA) or by mutations in the DNA of the mitochondrial genome (mtDNA)'.[126] In our scenario Adalyne has an nDNA mutation, because her clinical symptoms have been developing during early childhood. Knowing that her condition is the result of an nDNA mutation, the genetic counsellors can assess the recurrence risks in her family. A person's body cell has 46 chromosomes, made up of 23 pairs. The chromosomes numbered 1-22 are called autosomes, and pair number 23 constitutes the two sex chromosomes X and Y.[127] On each autosome are located two copies of every gene. Being of nuclear origin, the condition is passed on by autosomal recessive inheritance, meaning that the faulty gene is positioned on an autosome.[128]

After Adalyne was diagnosed in 2012, Nell informed John of her daughter's condition and Nell and John underwent tests which showed that they are unaffected carriers. They have a faulty gene on one autosomal chromosome and a working gene on the other half of the autosomal pair.[129] Adalyne inherited copies of the faulty gene, one each from her mother and the donor.

While there is one chance in four (a 25% chance) that the child will inherit both copies of the faulty gene from the parents and the child will be affected by, or prone to develop, the condition, there is also one chance in two (50%) that any further child from Nell and the donor will be a genetically unaffected carrier for the condition, if he or she inherits a faulty copy and a working copy of the gene.[130] John voluntarily

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[125] Ibid.

[126] Ibid 4.

[127] Centre for Genetics Education, *Fact Sheet 1: Genes and Chromosomes - The Genome* (2013) 1 <http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/genes-and-chromosomes-the-genome-1>.

[128] Ibid. The gene is considered to be faulty if some variations in genes stop the gene from working properly.

[129] Centre for Genetics Education, *Fact Sheet 8: Autosomal Recessive Inheritance – Traditional Patterns of Inheritance 1* (14 November 2013) 2 <http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/autosomal-recessive-inheritance-2013-traditional-patterns-of-inheritance-1-2>.

[130] Ibid.

decided to put the information that he is a carrier of the genetic condition MM on the NSW Ministry of Health Central Register.[131]

Nell wants a second child and so wants to use the remaining embryo. She notifies the clinic of her daughter's condition, because she wants to be open about all aspects of her situation. The clinic advises Nell to consider PGD, to test whether the remaining embryo is affected with the genetic condition of MM. Nell refuses PGD, because she is afraid that she may be denied treatment by the clinic, if the embryo tests positive for the condition. This is because the clinic has told her that the NHMRC ART Guidelines do not allow them to select an embryo for implantation that is affected by a genetic condition. She tells the clinic that she wants the embryo to be implanted with or without the inheritable condition and therefore would prefer not to know. PGD is a '[t]echnique by which embryos fertilized in vitro are tested for genetic characteristics, particularly for specific genetic disorders'.[132] It is possible to perform PGD on frozen-thawed embryos.[133] PGD is not performed. The embryo is implanted and Nell subsequently gives birth to a son, Nicolas, who is affected with MM.

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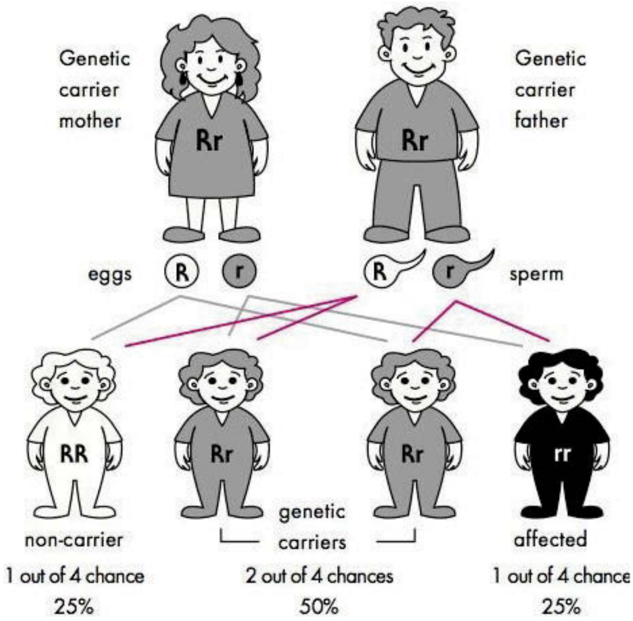
[131] NSW Ministery of Health, *I Was a Sperm, Egg or Embryo Donor before 1 January 2010* <http://www.health.nsw.gov.au/art/Pages/I-was-a-sperm-egg-or-embryo-donor-before-1-January-2010.aspx>.

[132] NHMRC, above n 48, 97.

[133] N Frydman et al, 'Première Naissance Après Un Diagnostic Génétique Pré-Implantatoire (DPI) Pratiqué Sur Embryons Décongelés [First Birth after Preimplantation Genetic Diagnosis Performed on Thawed Embryos]' (2003) 32 *Journal de Gynécologie Obstétrique et Biologie de la Reproduction [Journal of gynecology, obstetrics and biology of reproduction]* 363, 363.

Explanatory figure of recessive inheritance[134]



This figure illustrates autosomal recessive inheritance when both parents are unaffected genetic carriers for the condition. The autosomal faulty copy of the gene containing a recessive mutation is represented by 'r' and the working copy of the gene by 'R'. Four possible combinations of the genetic information are passed on by the parents, in every pregnancy. There is one chance in two (or 50%) that each parent will pass on the faulty copy of the gene. There is one chance in four (a 25% chance) that the child inherits both copies of the faulty gene from the parents and the child will be affected by or prone to develop the condition.[135]

3.2 Decision-making points of the first scenario

In this scenario I distinguish two decision-making points for Nell. Both relate to the broad question of the ethical and legal responsibilities of women and their impact on women's reproductive autonomy. The two decision-making points are:

1) Nell's disclosure of her daughter's inheritable condition to the clinic and the donor; and

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[134] Centre for Genetics Education, above n 129, 2.

[135] Ibid.

2) her refusal of post-conception but preimplantation testing and her wish to have the embryo implanted with or without the genetic condition.

In the following sections I analyse the legal and ethical implications of Nell's decisions, to see how they affect her reproductive autonomy and whether she can be held responsible for them.

3.3 Ethical and legal considerations of the decision-making point: disclosure of the inheritable condition

The main ethical and legal question raised by this scenario is whether Nell's decision to disclose her daughter's condition was the right decision for her to make. In order to answer this question, I analyse some ethical and legal reasons why Nell may not have disclosed the condition, and some reasons why, in fact, her decision to disclose may have been unethical although not illegal.

3.3.1 Legal considerations of disclosure treated in the NSW legislation, the *NHMRC ART Guidelines* and the *Code of Practice of the Fertility Society of Australia (FSA)*

Nell chose to disclose her daughter's inheritable condition to the clinic and the donor. She is located in NSW and is therefore subject to the *Assisted Reproductive Technology Act 2007* (NSW) and its regulations. In disclosing the information to the donor and the clinic, Nell acted freely as there was no legal obligation in the *Assisted Reproductive Technology Act 2007* (NSW) for her to do so. But if Nell had decided to inform the clinic, but not the donor, her decision could have been bypassed by the clinic, under section 15 of the existing NSW legislation. Section 15 deals with disclosure of medical information in case of donated gametes. A medical practitioner acting on behalf of the ART provider may have informed the donor if it was deemed necessary by the medical practitioner. Section 15(1)(b) states that:

> An ART provider may disclose medical information: …, (b) to a donor, about an offspring born as a result of ART treatment using the donor's donated gamete, if a registered medical practitioner has certified in writing that it is necessary to make the disclosure to save a person's life or to warn the person to whom the information is disclosed about the existence of a medical condition that may be harmful to that person or to that person's offspring (including any future offspring of the person).[136]

However there is no obligation for the ART provider to do so. Section 15(4) specifies that '[n]othing in this section requires an ART provider to disclose information to any person'.[137] Similar to the *Assisted Reproductive Technology Act 2007* (NSW) the *NHMRC ART Guidelines* do not oblige ART clinics to disclose medical information about the gamete recipients to the donor. Although guideline 6.12 of the *NHMRC ART Guidelines* proposes that a donor has an entitlement to information, it does not specify whether medical information about the gametes receivers or their offspring is included. Guideline 6.12 is titled 'Provide gamete donors with relevant information about their genetic offspring' and it states that '[g]amete donors are entitled to some information about the recipients of their gametes and the offspring born (in particular, to prepare them for future approaches by their genetic offspring)'.[138] The *NHMRC ART Guidelines* do neither specify whether the ART clinics have an obligation to provide information, nor whether this is about medical information.

Nell, therefore, acted autonomously when she chose to disclose her daughter's genetic condition, because there is no legal requirement in the Act or in the Guidelines for her to disclose. However, by disclosing her daughter's condition to the clinic and the donor, a woman in Nell's situation could also have put herself at risk of her reproductive autonomy being negatively affected. If Nell did not already have existing embryos at the time of her disclosure, John would have been entitled to withdraw his consent to any further use of his gametes something he may have chosen to do in light of receiving the information. This is because s 17(4)(a) of the *Assisted Reproductive Technology Act 2007* (NSW) specifies that:

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[136] *Assisted Reproductive Technology Act 2007* (NSW) Section 15(1)(b).
[137] Ibid Section 15(4).
[138] NHMRC, above n 48, 29 at guideline 6.12.

> A consent may be modified or revoked at any time up until:
> (a) in the case of a donated gamete—the gamete is placed in the body of a woman or an embryo is created using the gamete ….[139]

Fortunately for Nell the second embryo was already created and the donor could no longer withdraw his consent. According to the Act, since the creation of the embryo, ownership of the embryo belongs to her and Nell is therefore free to choose what to do with the remaining embryo. The *Code of Practice of the Fertility Society of Australia (FSA)* and the *NHMRC ART Guidelines* agree with the *Assisted Reproductive Technology Act 2007* (NSW) in relation to the donor's right to withdraw his consent and they highlight the woman's responsibility for her embryo where donor gametes are used. The *Code of Practice* affirms 'the right of donors to withdraw or vary the terms of their consent and specify limits, subject to any relevant legislation, at any time until the donated gametes or embryos are used'.[140] The *NHMRC ART Guidelines* state in regards to this subject that, '[a]t any time before insemination or fertilisation, gamete donors may vary or withdraw their consent to donation'.[141] But the *NHMRC ART Guidelines* clearly acknowledge the woman's responsibility in decision making for the embryo by stating that:

> [o]nce fertilisation has taken place, the persons for whom the embryo has been created have responsibility for decision making about its use in their own reproductive treatment and the medical care of the embryo (both before and after implantation into the uterus), storage and disposal.[142]

These legal considerations show that Nell's decision to disclose her daughter's genetic condition is an autonomous decision, which does not affect her choices in regards to

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[139] *Assisted Reproductive Technology Act 2007* (NSW) Section 17(4)(a).
The circumstances of modifying or revoking a consent are different when no donated gametes are used. Section 17(4)(b) of the NSW ART Act states that: A consent may be modified or revoked at any time up until: in the case of a gamete other than a donated gamete—the gamete is placed in the body of a woman or an embryo created using the gamete is implanted in the body of a woman.

[140] Fertility Society of Australia, above n 1, 24. This Attachment 2 about Donor Requirements does no longer figure in the CODE OF PRACTICE, revised March 2014.

[141] NHMRC, above n 48, 30.

[142] Ibid.

her remaining embryo. The fact that the remaining embryo is created with donated sperm and exists already does not restrict Nell's reproductive autonomy, because the donor can no longer revoke or modify his consent.

3.3.2 The right to privacy

One of the reasons why Nell may be held ethically responsible for disclosing her daughter's genetic condition could be because she breached her daughter's right to privacy, as well as the donor's right to privacy. There is a risk that, once the genetic information is revealed, not only Nell but the others that are affected lose control of what happens with that information and hence there is a potential threat to their privacy and autonomy.

Furthermore, once the ART provider receives from Nell genetic information about herself and her daughter, a permitted health situation emerges which is described in the *Privacy Act 1988.*[143] The Act covers *Australian Privacy Principles (APPs)* that regulate the collection, use, disclosure and handling of 'personal information' by Commonwealth government agencies and large private sector organisations.[144] The *Privacy Act 1988* does not define genetic information, but it is included in sensitive information or health information.[145]

> A *permitted health situation* exists in relation to the use or disclosure by an organisation of genetic information about an individual (the *first individual*) if the

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[143] *Privacy Act 1988* (Cth) Section 16B(4)(a).

[144] Commissioner for Privacy and Data Protection VICTORIA, 'Privacy Background Paper' 2 <https://www.cpdp.vic.gov.au/images/content/pdf/privacy_papers/Privacy_Background_paper.pdf>.

[145] Office of the Australian Information Commissioner (OAIC), *Chapter D: Permitted Health Situations* (2014) Australian Government Office of the Australian Information Commissioner Privacy 6 <http://www.oaic.gov.au/images/documents/privacy/applying-privacy-law/app-guidelines/APP_guidelines_complete_version_1_April_2015.pdf> D.26. Genetic information about an individual is included in the definition of 'sensitive information' (Privacy Act s 6(1)) and genetic information that is 'about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual' is covered by the definition of 'health information' (Privacy Act s 6(1)).

> organisation has obtained the information in the course of providing a health service to the first individual.[146]

A consequence of this permitted health situation is, that an organisation can use or disclose genetic information if it reasonably believes that it is 'necessary to lessen or prevent a serious threat to the life, health or safety of another individual who is a genetic relative of the individual'.[147] Hence there may be a risk, as previously mentioned, of a person in Nell's situation losing control of what happens to the information. A clinic may be required to comply with Federal and State privacy legislation. Whether they are caught by these Acts depends on their size and whether they are public or private clinics. The clinic must use and disclose information in accordance with the guidelines authorised under section 95 AA of the Guidelines for Australian Privacy Principles about genetic information.[148]

Some Australian States and Territories also have information or health privacy legislation that applies to the handling of genetic information. This legislation uses privacy principles analogous to those in the Commonwealth *Privacy Act* with regard to 'personal information', 'health information' or 'personal health information'. In New South Wales, The *Privacy and Personal Information Protection Act 1998* (NSW) regulates the privacy of health and other personal information handled by the New South Wales public sector.[149]

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[146] *Privacy Act 1988* (Cth) Section 16B(4). The term 'first individual' is used in relation to a 'genetic relative' of an individual. A genetic relative is another individual who is related to the first individual by blood, including but not limited to a sibling, a parent or a descendant of the first individual. (Section 6 of the Privacy Act).

[147] Office of the Australian Information Commissioner (OAIC), above n 145, 6 D.24.

[148] *Privacy Act 1988* (Cth) Section 16B(4)(a). Section 95AA allows the Commissioner to approve for the purposes of the Australian Privacy Principles guidelines that are issued by the National Health and Medical Research Council. For the purposes of paragraph 16B(4)(c), the Commissioner may, by legislative instrument, approve guidelines that relate to the use and disclosure of genetic information for the purposes of lessening or preventing a serious threat to the life, health or safety of an individual who is a genetic relative of the individual to whom the genetic information relates.

[149] Australian Law Reform Commission Australian Government, *07. Information and Health Privacy Law State and Territory Privacy Legislation* (2014) <http://www.alrc.gov.au/publications/7-information-and-health-privacy-law/state-and-territory-privacy-legislation>.

The donor's right of privacy is another reason why Nell's disclosure may be deemed unethical, because through her actions the donor is confronted with his own genetic status, even if he may not have wished to know about it. He finds himself in a situation where he is diagnosed as a carrier of MM, whether he wanted that information or not, and will need to disclose his knowledge of his condition in some circumstances where he did not previously, such as acquisition of life insurance, and on ART donor registers in some jurisdictions.

In NSW since the beginning of 2010 new legal requirements address this situation. If a donor donated after the first of January 2010, or if the previously donated gametes or embryo were used after the first of January 2010, the ART clinic must have collected mandatory information from the donor to include them on the Central Register. As John was a donor before the first of January 2010, he voluntarily provided information to the NSW Ministry of Health's Central Register. The donor's health information is closely linked to those persons who used or are born via his gametes. The information contains:

> any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of a person undergoing ART treatment involving the use of the donated gamete; any offspring born as a result of that treatment; any descendants of any such offspring.[150]

The aim of the Central Register is to allow access to identifying or non-identifying information to a donor conceived person, a donor, a parent or a sibling of a donor conceived person. Such information about genetic origin and inheritance is of crucial importance for donor conceived persons as its lack can cause medical or social

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[150] Health NSW Government, *The Central ART Donor Register* (6 June 2013) NSW Government Health Assisted Reproductive Technology Information sheets <http://www.health.nsw.gov.au/art/Pages/Forms.aspx> Since 1 January 2010 ART providers have been required to provide mandatory information regarding every child born as a result of ART treatment using donated sperm, eggs or embryos, or born through surrogacy, and whose conception occurred after 1 January 2010, to the NSW Ministry of Health for inclusion on the Central Register.

issues.[151] This information can have a significant impact for the future reproductive decision of a parent of a donor conceived child.

A second reason why Nell's disclosure could be seen as unethical could be the right of the child to maintain control over her personal information. It is arguable that Nell should wait to disclose this information until her daughter is no longer a minor. Her daughter could decide then for herself, as an adult, whether she wanted to disclose this health information to third parties, such as when she later applies for a job and would have to disclose medical information or if she wanted to access IVF or to apply for life insurance.[152]

3.3.3 Stigma associated with genetic condition

Disclosure could also be unethical, because it risks inappropriately reducing a person to his or her genetic condition. For Asch, a person should not be defined according to a single aspect of identity, such as his or her disability. She writes that there is a danger that '[p]hysicians, public health experts, and bioethicists let disability become the only relevant characteristic'[153] and these professionals 'fail to recognize that along with whatever impairment may be diagnosed come all the characteristics of any other future child'.[154] So, when a woman undergoes testing, ART health professionals should distinguish between the future child as a person and the disability. The disability does not define a person. Health providers should assist a woman and adapt their care, so that it enables her to make reproductive decisions that are more in keeping with her status as a fully autonomous person.

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[151] Health NSW Government, *Assisted Reproductive Technology* (15 June 2012) Assisted Reproductive Technology <http://www0.health.nsw.gov.au/hospitals/phc/art.asp>.

[152] Kristine Barlow-Stewart and David Keays, 'Genetic Discrimination in Australia' (2001) 8 *Journal of Law and Medicine* 250, 250.

[153] Asch, above n 8, 1652.

[154] Ibid.

3.3.4 Preserving autonomous decision making

Finally, if Nell had chosen not to disclose, this may have had a positive impact on her reproductive choice and freedom because she would remain independent of the clinic's influence on her, at least in relation to treatment of that disability. This independence may be necessary given that Nell's interests and the clinics are not necessarily aligned. Nell's interests are in having a child while the clinic is concerned with its reputation and legal liability. In Segal's words, a clinic is 'a professional entity measured by the expertise and technological prowess by which the risk of delivering a child with abnormality and/or disability is avoided'.[155]

In an ART process, health care professionals too play an important role in determining whether a woman can exercise her reproductive choices. The 'beliefs and objectives'[156] of health practitioners may influence a woman's decision and limit her autonomous decision making capacity regarding whether or not to give birth to a disabled child. If the woman exercises her autonomy in making choices about the use of an embryo, her choice might be questioned. De Lacey and Norman query whether in a situation where a future parent is willing to take the risk that their future child might have a congenital disability, health care professionals should recognise this as a completely rational choice. The authors criticise the viewpoint that a woman's competence and hence her judgment might be clouded by her desperation for a child, by social pressure and emotional vulnerability and that health professionals are ethically and legally bound to consider the best interest of a child.[157] This implies that future parents are not capable of making a sound judgment where they have decided to accept the outcome of either a disabled or an able-bodied child. According to this viewpoint, a woman would be expected to decide that not being disabled is in the best interests of the child and to forego her own choice in the circumstances. In this scenario, Nell, who already has a

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[155] Teresa M Segal, 'The Role of the Reproductive Technology Clinic in the Imposition of Societal Values' (2010) 3 *International Journal of Feminist Approaches to Bioethics Special Issue: Disability Studies in Feminist Bioethics* 90, 96.

[156] Ibid.

[157] Sheryl de Lacey and Robert J Norman, 'What Should We Do with Donated Embryos That May Be Genetically Affected?' (2004) 19 *Human Reproduction* 1065, 1066.

child with an inheritable condition, is experienced about what it means to be a parent of an affected child. Nevertheless, her ability to make a rational choice, and to have the remaining embryo implanted without testing the embryo, might be questioned by health care professionals.

The ethical considerations discussed above demonstrate that Nell’s disclosure could be considered unethical.

3.3.5 Reasons in favour of disclosure

The previous section shows that the disclosure may have a negative impact on her autonomous decision making. But Nell’s decision to disclose is an autonomous decision, reflecting her desire to be honest and transparent with the health providers. Her honesty and transparency about the existence of her daughter’s genetic condition should allow a sincere communication with the health professionals in regards to her ART treatment. It also shows that Nell feels confident that her openness may not lead to a denial of access to ART treatment, for example, that she may be unable to have her embryo implanted where there is a genetic condition present or not.

Since the birth of her first child, there may have been changes in the medical domain in regards to ART treatment or to the genetic condition MM, of which Nell is unaware. Hence it is important that the health professional can offer her the necessary and specific counselling support and provide her with the latest information. Nell needs the appropriate information to understand her options for testing and other procedures and to be able to make an autonomous decision. The *NHMRC ART Guidelines* state that ‘[t]he information discussed should allow participants to develop an accurate understanding of the following issues: any significant risks involved in the proposed procedures …’.[158]

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[158] NHMRC, above n 48, 41 at guideline 9.1.1.

3.4 Ethical and legal considerations of the decision-making point: refusal of pre-implantation testing of the remaining embryo with the genetic condition.

In this section I examine various arguments that Nell can make for refusing PGD, and having her affected embryo implanted on the basis of her reproductive autonomy, and bodily integrity.

3.4.1 Legal aspect of having an affected embryo implanted

To explore this decision-making point from a legal point of view, I first analyse what the legal implications are in the jurisdiction where Nell refuses PGD. Nell has only one embryo left. Could the clinic have refused to allow Nell to have the remaining embryo implanted?

In Australia neither the NSW ART legislation nor the *NHMRC ART Guidelines* prohibit the use of a remaining embryo, even when the mother and the sperm donor are carriers of a genetic condition, so that this is not a reason to deny the woman access to ART treatment. The clinic may have interpreted the *NHMRC ART Guidelines* as precluding them from knowingly transferring an affected embryo, because they viewed the embryo's implantation as, in effect, a deliberate selection of a genetic defect. The *NHMRC ART Guidelines* specify that 'PGD must not be used for selection in favour of a genetic defect or disability in the person to be born'.[159] However, in their empirical research Karpin and Savell found that

> the intention was only to limit *a preference* for an affected embryo and not to prohibit the transfer of an affected embryo where there were no unaffected embryos available'.[160]

Clearly there is ambiguity in the guidelines that leaves this question open. Karpin and Savell's research also suggests that health professionals are undecided about how to

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[159] Ibid 55.

[160] Karpin and Savell, above n 42, 214.

react to such a situation and that their uncertainty, along with the ambiguity in the *NHRMC ART Guidelines*, is an argument in favour of more precise regulations.[161] This lack of clarity shows that it was in the hands of the clinic to respect or not Nell's reproductive autonomy. If Nell had been refused the implantation, she would have foregone her chance to become a parent with her remaining embryo. In the legal issues that arise from this scenario, the best interests of the future child are again a decisive factor in shaping the potential consequences of Nell's decisions.

3.4.2 Could a woman be sued if she chooses to have her affected embryo implanted?

This scenario raises the question whether a woman, who knowingly had an affected embryo implanted, could be sued by her resulting child? Pickering Francis imagines a right to such a lawsuit when he says that:

> parental failure to undergo PGD given IVF and knowledge of a risk of serious genetic disease is a private wrong against the resulting child, giving rise to the child's right to sue the parent in tort. Presumably, in such a lawsuit the child would recover, as damages, the difference between the child in his/her actual state and his/her hypothesized state without the disorder not tested for.[162]

However, in Australia and most other jurisdictions a child does not, in fact, have an actionable right against his or her mother on the basis of implantation despite knowledge of an inheritable genetic condition. Although this scenario has not been properly tested in the courts to date, it is unlikely that such an actionable right would be found because in our hypothetical scenario the alternate state for the child would have been non-existence. Non-existence could have been the consequence if there was an accidental destruction of the embryo during PGD or if the clinic refused the implantation of an affected embryo. In a scenario such as this one, where there is no

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[161] Ibid 215.

[162] Leslie Pickering Francis, 'A Wrongful Case for Parental Tort Liability' (2012) 12 *The American Journal of Bioethics* 15, 16.

law or regulation, or there exists an ambiguity in the guidelines, the clinic should give priority to respecting the woman's autonomy.

3.4.3 The woman's potential loss of her embryo via PGD or prenatal testing and its effect on her.

In this scenario the clinic strongly advises Nell to go ahead with PGD, because of her daughter's genetic condition. The *NHMRC ART Guidelines* state that PGD 'is currently used to detect serious genetic conditions'.[163] Putting aside the question of whether the condition would be considered serious, Nell refuses PGD and along with it the risk of accidental destruction of the embryo by the procedure. A woman should not be held ethically responsible because she accepted PGD, in those cases where the embryo is lost. Rather a woman's autonomy may be affected where she is pressured into choosing the procedures or not.

3.4.4 Nell's decision and the interests of her future child and the seriousness of the condition

Nell refused PGD, and it remains open whether her decision was ethically responsible and in the best interests of the child and whether the seriousness of the condition has an impact on her ethical responsibility. Whether Nell can be held ethically responsible turns, to some degree, on the question of whether the potential disability, that triggers the suggestion of PGD, is grave or mild. To what extent, if at all, is the level of seriousness of the disability decisive?

Nell lives in a society where, as de Lacey and Norman point out, '[t]here is a widespread assumption that the best interests of children are to be born able-bodied (including intellectually abled)'.[164] In Western societies there is a strong cultural opinion that a responsible parent's choice in case of foetal disability would be termination or intervention in a pregnancy. It could be added that the same belief is

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[163] NHMRC, above n 48, 55 at guideline 12.1.
[164] de Lacey and Norman, above n 157, 1067.

valid for parental decision making within ART. In the ART context this could mean that a responsible parent's choice would be choosing PGD and selecting not to have an affected embryo implanted.

In a society where there is little tolerance for imperfection, it is likely that a woman faces criticism if she decides to give birth to a genetically affected child. She may be considered as an irresponsible and immoral person.[165] These statements show that disability is embedded negatively in the context of reproduction, where the medical model of disability seems to be dominant. And that, in such a context, a woman can be held ethically responsible for her decision to have an affected embryo implanted. There are also authors who argue that parents should act in the interest of their future child when they are using IVF and are at risk of transmitting a genetic condition. These authors claim that:

> it is reasonable for prospective parents to see themselves as acting for the wellbeing of "their child" in ensuring that any child they bear does not carry that genetic condition.[166]

Significant pressure to reject embryos with serious genetic disorders comes from feminist as well as non-feminist directions. One reason is a concern that the woman may not be able to cope physically, psychologically, socially or financially with a child who has a serious genetic disorder. Therefore, it is even more important to ensure that the woman lives in an environment where she gets the necessary support for the choice she has made. Therefore health providers and social workers need to inform the woman as best as possible about what life with the relevant genetic disorder may look like, before she can make an autonomous and informed decision.

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[165] Rosemarie Tong, *Feminist Approaches to Bioethics : Theoretical Reflections and Practical Applications* (Westview Press, 1997) 233.

[166] Malek, J., and J. Daar. 2012. The case for a parental duty to use preimplantation genetic diagnosis for medical benefit. American Journal of Bioethics 12(4): 3–11, cited in David Wasserman and Adrienne Asch, 'A Duty to Discriminate' 12 *The American Journal of Bioethics* 22, 22.

The seriousness of a future child's genetic condition is hard to define. The *NHMRC ART Guidelines* acknowledge in their section about the use of PGD that 'what counts as a serious genetic condition is controversial'.[167] Reproductive autonomy can be limited by an ethical or legal framework which draws a limit beyond which PGD is unacceptable. Scott claims that ART professionals and parents have differing views on seriousness, and health professionals and scientists acknowledge that there is a subjective component to seriousness.[168] They also think that 'there must be a limit to what could in any sense be regarded as a "serious genetic condition"'.[169] In this scenario the relative seriousness of the genetic condition could explain the clinic's strong recommendation to use PGD.

The seriousness of a condition also affects a woman's decision. It might be reasonable to suggest that it is wrong to bring a child into the world if the child is going to be born into a short life of excruciating pain. A woman does not make her reproductive decisions in isolation; her decisions are made and her autonomy is exercised in a social, medical and cultural context. Autonomy is only meaningful if there exist surrounding social supports. For Nelson, this means that 'conditions exist that actually permit (or foster) the meaningful exercise of reproductive choice'.[170]

The question also arises whether Nell's wish to have the affected embryo implanted, is similar to a couple's wish to adopt disabled children with special needs.[171] The similarity between both groups of parents is that they know and are aware that parenting a child with special needs involves different parenting. One difference is that adoptive parents might have the advantage of getting a more realistic picture of what parenting will be like, as the child exists already. Another difference is that Nell wants to bring a disabled child into existence, whereas the child exists already in the case of adoption. It raises the ethical question of whether it is ethically right to deliberately

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[167] NHMRC, above n 48, 55.

[168] Rosamund Scott, *Choosing Between Possible Lives Law and Ethics of Prenatal and Preimplantation Genetic Diagnosis* (Hart Publishing, 2007) 215.

[169] Ibid.

[170] Nelson, above n 28, 50.

[171] de Lacey and Norman, above n 157, 1066.

bring a disabled child into the world. The other ethical question is how the presence of an ART treatment may influence the outcome, due to the presence of laws, regulation and a proliferation of decision-making points for the future parent. Nell's wish to become a parent for a second time, albeit knowing that her child has an inheritable condition, is her right of autonomy, to live a life of her choice and to take responsibility for that choice.

Reproductive autonomy is, unfairly, more restricted for a person who needs ART to become a parent than one who does not, especially because her rights and parental capacities are questioned and compared mainly in relation to the future child's welfare. Scott defends a parent's decision and choice by claiming that, it is a judgment for parents to make in regards to 'the balance of rewards and demands in raising a disabled, as compared with a non-disabled, child'.[172] In this scenario Nell's ability to cope with her existing daughter's condition affects her reproductive decisions for any future child.[173] Having already a daughter with MM, she does not consider MM to be a very "serious" condition, otherwise she might have decided to undergo PGD and not to implant an affected embryo. Nell considers her daughter's and her future child's lives with this genetic condition worth living, therefore in her eyes her decision to implant her potentially affected embryo is not unethical.

3.5 Conclusion

In the past it was possible just to choose whether one wanted a child or not. Abstinence, giving away her child, or secret abortions were the only choices for a woman if she did not want to become a parent. Nowadays the capacity of choosing whether to become a parent cannot be separated anymore from the kind of child one will have. This is due to the medicalisation of reproduction, especially ART, the proliferation of testing and screening techniques and hence the proliferation decision-making points. A future parent can to some degree decide about the kind of child they want to have. If the parent does not want to decide he or she needs to decline all

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[172] Scott, above n 168, 217.

[173] Ibid 218.

testing. Here it is also worth providing some complexity to the idea of reproductive autonomy. For example, Scott considers whether

> the concept of reproductive autonomy or procreative liberty only concern an interest in being able to choose whether to become a parent or whether it also encompasses something about what kind of child one will have?[174]

The decision-making points of the scenario show that from a legal point of view the relevant legislation and regulatory framework keep silent about a woman's responsibility to disclose or not the genetic condition of her child. Nell was not legally obliged to disclose, hence there is no legal culpability. But after having disclosed, she was not legally obliged to implant an unaffected embryo. The clinic accepted Nell's openness about her daughter's condition, and Nell was not legally culpable for having her affected embryo implanted. Also the clinic had neither any legal reason to refuse the implantation of the embryo, nor to deny Nell access to ART treatment. In regards to her existing daughter's ownership of her genetic identity, Nell did not commit any legal wrongdoing in regards to her daughter's privacy.

This scenario shows that it is difficult to assign ethical responsibility to the woman in regards to her decision to have her potentially affected embryo implanted. This autonomous decision might be judged ethically irresponsible especially in a medicalised society where choosing not to give birth to a disabled child is expected. The future child's wellbeing challenges the woman's autonomy. A woman's reproductive rights and parental capabilities are not challenged in this way if the woman is able to conceive naturally. For Nell her remaining embryo is worth implanting and the future child is worth nurturing and raising with or without a genetic condition. If Nell were to be held ethically responsible for her decision to use her affected embryo she would have been prevented from living a life she considers worth living and exercising her reproductive choice. Nell is committed to raise her future child and to fulfil her parental duties, independent of the child's genetic condition.

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[174] Ibid 14.

4 CHAPTER FOUR

4.1 Story of the second scenario

Skyla and Pablo live in Victoria (Australia) and are both 37 years old. Skyla works as a musician and Pablo is a children's book writer. Their son Maurice was born three years ago in 2013. At the age of 30 Pablo had a car accident which left him paraplegic due to a complete spinal cord injury. Skyla and Pablo discussed their wish to have a baby with their general practitioner (GP), who advised them to go to an assisted reproduction technology specialist to seek help and advice for the conception of their baby. Skyla had ART treatment because she wanted to become a mother and the ART clinic helped her attend this 'valued life goal'.[175] She did not disclose to the clinic that she has a genetic condition called Neurofibromatosis type 1 (NF1). The couple used their own gametes to conceive and they agreed privately that they wanted to have a baby regardless of its health status.

They conceived their baby via artificial insemination (AI), which is a technique of transferring sperm without also transferring an oocyte into the vagina, cervical canal or uterus of a woman.[176] It is used in this scenario because Skyla and Pablo cannot achieve conception through natural means because of a mechanical difficulty with intercourse, due to Pablo's accident. Though Pablo has an injury he is still fertile so the couple can use Pablo's sperm.

In this scenario a form of AI, known as intrauterine insemination, was being used where Pablo's sperm was inserted through Skyla's cervix and into her uterus at or near the time of ovulation. This controlled and planned ART method can be performed during a natural menstrual cycle.[177]

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[175] Emily Jackson, *Regulating Reproduction : Law, Technology and Autonomy* (Hart Publishing Ltd, 2001) 182.

[176] *Assisted Reproductive Treatment Act 2008* (Vic) s 3.

[177] Victorian Assisted Reproductive Treatment Authority VARTA, *What Is Assisted Reproductive Technology? (ART)?* (2011) <http://www.varta.org.au/what-is-assisted-reproductive-technology-art/>.

Skyla has known since she was 15 that she had Neurofibromatosis type 1 (NF1) which is a genetic condition also known as Von Recklinghausen disease. It affects about 1 in 3,000 to 5,000 people.[178] The range of severity for NF1 is wide and the most common symptoms are having multiple, painless coffee-coloured ‘birth marks’ on the skin (cafe-au-lait patches); neurofibromas (harmless soft pink small lumps that can grow on nerves anywhere in the body; freckles in unusual areas that are normally unexposed to sunlight (groin, armpit, under the breast) and Lisch nodules (harmless small brown spots on the iris of the eye).[179] Other symptoms, to a lesser extent, can be learning and behavioural problems, high blood pressure, physical development effects (scoliosis, larger than average head, smaller size and weight) and effects on the brain and nervous system (migraines, brain tumours).[180] A very rare problem is a malignant peripheral nerve sheath tumour (MPNST), which is a type of treatable cancer, known for its aggressive nature, that develops within a plexiform neurofibroma.[181]

Everybody has two copies of the gene NF1 located on chromosome 17. A person affected with NF1 has one faulty NF1 gene copy and one working NF1 gene copy.[182] Neurofibromin works as a tumour suppressor protein and is encoded by the NF1 gene.[183] The condition follows a pattern of autosomal dominant inheritance. The effect of the mutation which causes the NF1 gene to be faulty is dominant over the working copy to produce the protein.[184]

In this scenario Skyla, who has a condition due to an autosomal dominant faulty gene, passes on to a child either the working, or the faulty copy, of the gene. Pablo is unaffected by NF1. When their son was conceived, each parent passed on one copy of

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[178] Centre for Genetics Education NSW Health, *Fact Sheet 37: Neurofibromatosis Type 1* (20 December 2013) 37 <http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/neurofibromatosis-type-1>.

[179] NSW Health, above n 178.

[180] UK National Health Service, *Neurofibromatosis Type 1* 4–5 <http://www.nhs.uk/Conditions/Neurofibromatosis/Pages/Introduction.aspx>.

[181] Ibid 7.

[182] Centre for Genetics Education., *Neurofibromatosis Type 1 FACT SHEET 37* (2012) 2 <http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets>.

[183] U.S. National Library of Medicin, *NF1* Genetics Home Reference <http://ghr.nlm.nih.gov/gene/NF1>.

[184] NSW Health, above n 178, 2.

each of his or her genes to the baby .[185] There is one chance in two that the autosomal dominant faulty gene will be passed on to the child by the affected or predisposed parent. The other parent can only pass on working copies of the gene.

This means that in every such pregnancy there is, as in Skyla's and Pablo's case, one chance in two that their child inherits the faulty copy of the gene and the working gene copy, and therefore is affected by, or at increased risk of developing the condition. Skyla is one of many people with the condition who is affected only mildly.

Maurice has started showing signs of NF1 since the beginning of 2014. There is a wide range of severity of symptoms, but to date Maurice is affected only mildly. A blood test was conducted and his health providers extracted DNA (Deoxyribonucleic acid) confirming that Maurice has NF1. In order to reach a diagnostic for NF1, most people do not need genetic testing. The reason for this is that the majority of people affected show sufficient symptoms of the condition by the age of five and hence a specialist can confidently make a diagnosis.[186]

Although genetic testing is not necessarily needed, Skyla knows that she could have asked for PGD before pregnancy or prenatal testing once pregnant, however she chose not to disclose her genetic condition. She also chose not to do testing to detect the possible genetic condition in her future child.

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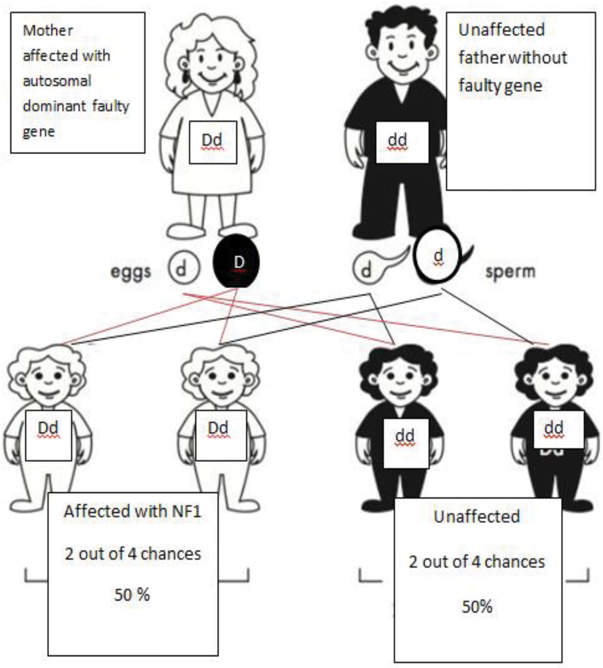
[185] Centre for Genetics Education, *Fact Sheet 9 AUTOSOMAL DOMINANT INHERITANCE–Traditional Patterns of Inheritance 2* <http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/Fact%20Sheet%209>.

[186] Kristine Barlow-Stewart, Jon Emery and Sylvia Metcalfe, *Genetics in Family Medicine: The Australian Handbook for General Practitioners* (The Australian Government Agency Biotechnology Australia, 2007) 252 <https://www.nhmrc.gov.au/your-health/egenetics/health-practitioners/genetics-family-medicine-australian-handbook-general-prac>.

Explanatory figure of autosomal dominant inheritance[187]



This figure illustrates autosomal dominant inheritance when one parent carries the autosomal dominant faulty NF1 gene copy. The autosomal dominant faulty gene copy causing NF1 is represented by 'D' and the working copy of the gene by 'd'.[188] This figure also shows the mother as the parent with the faulty NF1 gene copy; the same situation would arise if it was the father. NF1 usually affects men and women equally.

4.2 Decision-making points of the second scenario

In this scenario, as in the first, a woman gives birth to a genetically affected child and legal and ethical considerations arise in regard to her reproductive choice which question her right to risk giving birth to an affected child, and whether she should have acted differently. In the second scenario I distinguish two decision-making points for the woman and the legal and ethical considerations related to them, which are:

1) Skyla's decision not to disclose her health status to the clinic; and

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[187] NSW Health, above n 178, 2. Figure modified to correspond to this scenario.
[188] Centre for Genetics Education, above n 185, 2.

2) her decision to go ahead with AI and not to undergo preimplantation genetic testing, other prenatal testing or to use donor eggs.

4.3 Ethical and legal considerations of the decision-making point: non-disclosure of the genetic condition

The first decision-making point in this scenario is Skyla's decision not to disclose to the health professionals at the ART clinic that she is affected by Neurofibromatosis 1 (NF1), a genetic condition. In order to examine whether responsibility can be assigned to the woman for non-disclosure, various legal and ethical aspects are examined. This section looks into the respective legislation, guidelines and ethical reasons for keeping silent about one's genetic condition in Skyla's circumstances. The three ethical reasons which are analysed are the woman's autonomy and the interests of her future not-yet conceived child, the right to privacy and her status as a woman affected with a genetic condition.

4.3.1 Legal considerations of ART and AI for this scenario

As this scenario is situated in Victoria, I start the analysis of Skyla's situation with the *Assisted Reproductive Treatment Act 2008* (VIC)[189] and its impact on her reproductive autonomy.

Victoria was the first State in Australia and the first common law jurisdiction worldwide to regulate ART by statute.[190] The *Assisted Reproductive Treatment Act 2008* (VIC) regulates, amongst other things, the use of assisted reproductive treatment and artificial insemination, and came into effect on the first of January 2010. The *Assisted Reproductive Treatment Regulations 2009* (VIC)[191] accompany the *Assisted Reproductive Treatment Act 2008* (VIC) . ART clinics in Victoria must also observe the

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[189] *Assisted Reproductive Treatment Act 2008* (Vic).

[190] Malcolm Smith, *Regulating IVF and Pre-Implantation Tissue-Typing for the Creation of 'Saviour Siblings': A Harm Analysis* (Doctor of Philosophy (PhD), Queensland University of Technology, 2010) 38 <http://eprints.qut.edu.au/35798/1/Malcolm_Smith_Thesis.pdf>.

[191] *Assisted Reproductive Treatment Regulations 2009* (Vic).

Reproductive Technology Accreditation Committee’s *Code of Practice* and the *NHMRC ART Guidelines*.[192]

Due to her husband’s accident and the resulting mechanical difficulty in conceiving, Skyla’s circumstances were such that she was unlikely to become pregnant without ART. Skyla was eligible for ART treatment because a doctor was satisfied, ‘on reasonable grounds, that in the woman's circumstances, the woman is unlikely to become pregnant other than by a treatment procedure’.[193] Skyla fulfilled the general requirement for a treatment procedure as she and Pablo both agreed to go ahead with artificial insemination. The *Assisted Reproductive Treatment Act 2008* (VIC) specifies in Division 1 Section 8 that ‘a person may carry out artificial insemination of a woman only if the person is a doctor’[194] and is satisfied with the general requirements for treatment procedures, for donors, and respecting the provisions about consent. Nothing so far in the *Assisted Reproductive Treatment Act 2008* (VIC) limits Skyla’s reproductive autonomy, but arguably this is because she did not disclose that she had a genetic condition.

Before a first consultation at an ART clinic the woman should have had all the pre-pregnancy screening tests, including various blood tests and physical checks.[195] A doctor in an ART clinic cannot force a woman to divulge all the required information, nor can a doctor force a woman to undergo all available genetic tests, in order to make sure the patient is not a carrier of a genetic condition.

As I explained in Chapter Three, there is currently no legal avenue for a child to file a lawsuit against his or her mother in Australia. She cannot be taken to court if she fails

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[192] VARTA, above n 177.

[193] *Assisted Reproductive Treatment Act 2008* (Vic) s 10(2)(a)(i).

[194] Ibid s 8.

[195] IVF Australia, above n 80. On the website under First consultation the pre-pregnancy screening tests are published. For the women they include Pre-Pregnancy Screening Tests for rubella (German measles) immunity, chicken pox immunity, syphilis serology, full blood count, blood group and antibody status, hepatitis B and C ,HIV ,current pap smear and breast check (within last two years). For the men they include hepatitis B, hepatitis C and HIV.

to disclose any information about her health status, even if the child claims that the mother's actions were against his or her interests.[196]

4.3.2 Autonomy of the woman and the interest of the future child

Skyla is in a situation where there is no legal obligation to disclose, and she has thus made an autonomous choice not to do so. But one could also question whether Skyla has an ethical responsibility to disclose her condition, that is more important than her exercise of autonomy. Arguably if the answer to that question is yes, then this ethical responsibility would play in favour of the interest of the child and not in favour of her personal autonomy. It should be noted that unlike Scenario One there is no donor involved so there is no ethical issue around breach of the donor's privacy.

Based on the principles of autonomy and choice examined in Chapter Two, it becomes evident that a decision not to disclose may be perceived as the woman's autonomy conflicting with the interests of her future child, a person who does not yet exist. As seen in Chapter Two section 2.2, in order to guarantee a woman's autonomy, it is important to acknowledge that a woman makes her decision but within the complexity of a relational framework.[197] The potential conflict of interests between the woman and the future child is even more pronounced when disability is involved. Even before making choices about testing and screening about disability, she may already experience feelings of pressure and even guilt depending on the decisions she plans to make. This seems to apply especially when a woman considers or decides to give birth to a disabled child. Her action can be perceived as harming her future child, as Pioro and Mykitiuk put it.[198] Or the woman may be characterised as a bad mother.[199] However, based on the arguments canvassed in Chapter Two I argue that a woman's interests should be prioritised and she should not be held to account for making a

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[196] See Chapter Two 3.4.1.

[197] Laufer-Ukelest, above n 31, 623.

[198] Pioro, Mykitiuk and Nisker, above n 73, 1028.

[199] Ibid quoting Katz Rothman B. The tentative pregnancy: prenatal diagnosis and the future of motherhood. New York (NY): Viking; 1986.

decision that concerns first and foremost her health status. This is the case in this scenario.

In this scenario the interests of the future child concern the child's genetic health status and not the maintenance of control over his or her personal health information as in the first scenario. For example, Skyla could have been expected by society and the health professional to act as a 'responsible future mother', that is one, 'who does everything—takes all tests—to ensure foetal health'[200] and the health of the future child. In some jurisdictions she would have been 'subjected to rules, regulations, and duties established by those seeking to protect foetal interests'.[201] In these circumstances a woman can find herself in a situation where her choice and responsibility are questioned.

Skyla's choice, not to disclose her condition and consequently not do any testing, may be questioned as being unethical in regards to her future child's genetic status. However, her decision not to test may be prompted by the fact that testing is aimed at eliminating a condition, rather than treating an affected person, that is preventing the birth of a person affected with a condition. If a woman like Skyla feels that health professionals, if they knew about her genetic condition, would not want her to reproduce, or to give birth to an affected offspring, then her choice not to disclose her condition is understandable. Also the fact that Skyla is herself affected, gives her a different point of view of testing compared to somebody who has no genetic condition. She may consider that if she tests her future child for her own condition and if she decides not to have an affected embryo implanted or to give birth to an affected child, then she makes a negative judgement about her own existence, about her life with a genetic condition.[202]

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[200] Lippman, above n 101, 22.

[201] Ibid.

[202] Gillot rejects the idea that parents who choose to do testing and who choose to terminate a pregnancy because of foetal abnormalities are making moral judgments about those who are living with these abnormalities already: see Chapter Two, section 2.6.2.1. This scenario is different because here the parent is already living with an abnormality herself.

Before considering whether Skyla's decision not to disclose was ethical it is necessary to ascertain her reasons for non-disclosure. If Skyla had reproductive autonomy she would have felt free to disclose her condition and free to reject the testing 'without someone questioning her motives'.[203] This situation is similar to the pressure pregnant women may feel to undergo so-called routine prenatal testing and to make a particular decision depending on the result of the tests. For Lippmann

> prenatal testing may not only reduce a woman's liberty to refuse an abortion, but it allows geneticists and their obstetrician colleagues to impose a "choice" for abortion covertly, if not overtly, when they decide which fetuses are healthy, what defines healthy, and who should be born.[204]

Whatever the test result, based on the principles of reproductive autonomy elucidated in Chapter Two, the woman should feel free to choose whether she wants to continue her pregnancy or not. Women's choices are autonomous if society provides them 'with what they require to be able to continue a wanted pregnancy to term, whether or not a disability has been identified'.[205]

The clinic's information and counselling services may influence a woman's decision and Skyla may have wanted to make decisions free of this influence. This could be another reason for non-disclosure. One of the main topics discussed with the woman in genetic counselling is the wellbeing and the interests of her future child. Morrigan describes genetic counselling as a 'funnelling process that concentrates on the foetal body as the part of the self to be governed in an ethics of reproductive choice'.[206] Sometimes health professionals may use a 'risk discourse'[207] during genetic counselling to talk about foetal abnormality and the likelihood of its occurrence. The *NHMRC ART*

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[203] Lippman, above n 101, 29.
[204] Ibid 23.
[205] Ibid.
[206] Viviane Morrigan, *An Ethics of Reproductive Choice: Genetic Counselling and Prenatal Diagnosis* (PhD thesis, University of New South Wales, 2002) 49 <http://unsworks.unsw.edu.au/fapi/datastream/unsworks:597/SOURCE01>.
[207] Ibid 50.

Guideline 9.3.1 gives information about the characteristics of counselling services, specifying that:

> [c]linics should provide and discuss information in a way that is appropriate to, and sufficient for, informed decision making. The information should be given: verbally, supported by written information in plain language; with sensitivity to cultural diversity and religious beliefs; in a way that is accessible to those with low literacy or disability, and/or whose first language is not English; in a way that avoids any coercion or inducement.[208]

Had Skyla disclosed her condition, the counselling services should have given Skyla the option to discuss and explore any concerns, and to understand the impact on her, her partner and the future child. They could have looked also into Skyla's knowledge of the genetic condition and offered information about what it means to take care of a child with NF1 whose symptoms can be very different to hers, depending on the gravity of the condition. After Skyla had all this available advice, it would have been appropriate to leave the final decision to her, whether she wanted to go ahead with AI to conceive her child as planned. A woman should feel free to disclose her health status without apprehension. However in this scenario Skyla did not feel free to disclose her status. As a consequence, besides feeling forced into a situation of non-disclosure to preserve her autonomy, Skyla missed out on vital health care services she would otherwise receive, such as professional counselling.

The woman's autonomy and the interests of the future child can also be at odds because of the woman's choice of her reproductive treatment. Had Skyla disclosed her genetic status she might have been expected to put her choice of AI aside and undertake the more invasive IVF with PGD so that the future child could have been tested. It is worth considering whether Skyla can be held ethically responsible for her non-disclosure to ensure her choice of reproductive treatment, where that choice goes against the interest of the future child.

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[208] NHMRC, above n 48, 42.

Assuming Skyla's motivation not to disclose was due to her fear of being denied access to the wanted ART treatment namely AI, what is the basis for this fear? Clinics in Victoria have a paramount obligation to consider the welfare of the future child. The clinic could refer to the *VIC ART Act,* which indicates that 'the welfare and interests of persons born or to be born as a result of treatment procedures are paramount'.[209] The *NHMR*C *ART Guidelines* also state that

> clinical decisions must respect, primarily, the interests and welfare of the persons who may be born, as well as the long-term health and psychosocial welfare of all participants, including gamete donors.[210]

If the decision must respect the future child's as well as the participant's welfare, then theoretically Skyla did not need to be afraid that she would be refused AI, even if she disclosed her genetic condition. The *NHMRC ART Guideline 2.5* does not specify what welfare means, but arguably 'welfare of the persons who may be born' does not mean a life completely free of a genetic condition or a disability as that would exclude a very large number of people. Furthermore, if welfare included any genetic condition, a woman would be expected to disregard her own autonomous choices and instead undergo whatever testing was available to ensure that the future child did not have a condition. She would feel ethically pressured to comply with testing even if she felt no need of it and her compliance with testing would be less an expression of choice than an instance of conformity.[211] Instead of making an autonomous decision in regards of her future child, women might feel that testing involves around disability.

Another reason for Skyla's non-disclosure may have been based on her concern that she would be expected, by the ART provider to use IVF and either undergo PGD or use donor eggs. In her eyes, her reproductive autonomy would be restricted by these options. Firstly she would not receive the treatment that she wanted namely AI. Secondly, the treatment that she would be offered, would be more demanding and

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[209] *Assisted Reproductive Treatment Act 2008* (Vic) s 5(a).
[210] NHMRC, above n 48, 21.
[211] Lippman, above n 101, 19.

risky namely IVF with preimplantation testing. There is a risk of accidental destruction of the embryo during the PGD process, because of 'the handling, testing and manipulation of embryos in genetic technology procedures may expose them to significant risk of harm'.[212] Thirdly, Skyla may have been concerned that the clinic would insist she use donor eggs if no unaffected embryos were identified in which case she would not be able to have a genetically related baby. Fourth and finally, she may be concerned that the more onerous processes would ultimately result in her not having a baby at all. Consequently her reproductive choice could have been severely curtailed if she disclosed her genetic condition.

Skyla's non-disclosure may however be considered as ethically irresponsible if the condition she has is viewed as serious. Judging the seriousness of a condition is controversial regardless of its various degrees of severity. Even the *NHMRC ART Guidelines* concede this in their guideline for the use of PGD.[213] But being affected with NF1 herself, Skyla may not consider NF1 as very serious. For Skyla her life with a genetic condition is worth living and therefore she considers the life of her future child worth living. In that context Scott argues that 'if a person is born with a condition that leaves her with a life worth living there can be no question of a duty to prevent that life for *her* sake'.[214] In that context a woman, who finds her life with her condition worthwhile, cannot be held ethically responsible for not disclosing and allowing the birth of child with a potential condition and there is no conflict between her autonomy and the interest of the child.

Similar to the *Assisted Reproductive Technology Act 2007* (NSW)*, the Assisted Reproductive Treatment Act 2008* (VIC) does not give any information or guidance either to the woman or health professionals about what happens when a woman undergoing ART does not disclose her genetic condition. As the Act keeps silent about non-disclosure of a genetic condition by the patient, it is not possible to say that Skyla

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[212] NHMRC, above n 48, 91. Guideline 12.1 states: 'what counts as a serious genetic condition is controversial'.
[213] Ibid 55.
[214] Scott, above n 168, 37.

did anything that was legally wrong by not disclosing her genetic status. A woman can legally choose not to disclose having a genetic condition to the ART clinic.

The *NHMRC ART Guidelines* are also silent on what a woman who consults an ART clinic should disclose or whether some of the information she discloses is deemed compulsory, or what happens if she does not disclose certain information. They do, however, give advice on how ART procedures should be conducted. They specify that the clinics should record information which should include among other things the 'genetic conditions'[215] of the participants, but obviously this can only be done if the participants disclose them. ART procedures must be conducted in a way that is respectful of all involved. Clinical decisions must respect, primarily, the interests and welfare of the persons who may be born, as well as the long-term health and psychosocial welfare of all participants, including gamete donors.[216]

Neither the Victorian ART legislation nor the *NHMRC ART Guidelines* state that the existence of a genetic condition is a barrier for the clinics to go ahead with Skyla's treatment. But there can be a link between a genetic condition and access to ART. An Australian study of decision making concerning stored embryos found that, two participants who had genetically affected embryos, and who wanted to donate them, were prevented from doing so, even though recipients had been notified of the condition and still agreed to receive the embryos, on the ground that it was not in the best interests of the future child.[217] In this study the authors noted that there was no problem for participants who had affected embryos to access their own embryos. It was only where donor embryos were being offered that clinics would not allow their use. 'It is notable that no one in the study was denied access to IVF when they were being treated with their own gametes on the basis that it was not in the interests of their child to potentially be born with the relevant condition'.[218]

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[215] NHMRC, above n 48, 49.

[216] Ibid 21.

[217] Millbank et al, above n 15, 152–153.

[218] Ibid 153.

So far we have seen that on the one hand Skyla exercises her autonomy by non-disclosure of her condition which ensures she receives her preferred ART treatment (AI). On the other hand her non-disclosure deprives her of the material condition in which she would fully exercise her reproductive autonomy by being informed of all the various medical permutations. She left the health professionals in of ignorance of her genetic status and they could not act as they would have had they known about her condition. This means she missed out on additional counselling and information, to allow her to make an autonomous decision. Or, as Scott puts it:

> [t]he information process that is part of prenatal screening and diagnosis is intended to enhance and facilitate a woman's reproductive choices and, at the same time, not to burden them.[219]

This does not mean that a woman changes her initial reproductive choice but it gives her at least the opportunity to have a different view of her situation and the available options.

4.3.3 Right to privacy

Skyla's decision not to disclose her condition is also linked to her right to keep her health status private. This section analyses whether Skyla's decision is legally and ethically acceptable on these privacy grounds.

Arguably, a woman has a right not to disclose her own health status. This right to keep her genetic condition secret is part of her privacy rights, acknowledged as a fundamental human right in Article 12 of the *Universal Declaration of Human Rights* says that:

> [n]o one shall be subjected to arbitrary interference with his [sic] privacy, family, home or correspondence, nor to attacks upon his [sic]honour and reputation. Everyone has the right to the protection of the law against such interference or attack.[220]

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[219] Scott, above n 168, 157.

In Australian legislation there is no actual definition of privacy. In the Hon Michael Kirby's words:

> '[p]rivacy' is not defined in legislation, and providing a conclusive definition is difficult. Privacy relates to the principles of human dignity, human uniqueness, the importance of solitude, and has historically been described as 'the right to be left alone'.[221]

As in the first scenario, section 3.3.2 of the *Privacy Act 1988* is also relevant when a woman does not disclose her condition. The *Privacy Act 1988* specifies in section 16 that

> nothing in the Australian Privacy Principles applies to:
> (a) the collection, holding, use or disclosure of personal information by an individual or
> (b) personal information held by an individual;
> only for the purposes of, or in connection with, his or her personal, family or household affairs.[222]

The ART clinic is considered as an Australian Privacy Principle (APP) entity, an 'agency or organisation or a small business operator'[223] which 'must not do an act, or engage in a practice, that breaches an Australian Privacy Principle'.[224]

In Victoria the collection and handling of health information by the public and private is under the jurisdiction of the *Health Records Act 2001*. The Act keeps silent about a woman's responsibility of disclosure in the presence of a genetic condition; it merely

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[220] Commissioner for Privacy and Data Protection VICTORIA, 'Privacy Background Paper' 3 <https://www.cpdp.vic.gov.au/images/content/pdf/privacy_papers/Privacy_Background_paper.pdf>.

[221] Commissioner for Privacy and Data Protection Victoria, *What Is Privacy?* (2015) <https://www.cpdp.vic.gov.au/menu-privacy/privacy-what-is>, quoting the Hon. Michael Kirby AC CMG (2013) 2653 Griffith Journal of Law and Human Dignity 'Privacy: An elusive and changing concept.'

[222] *Privacy Act 1988* (Cth) s 16.

[223] Ibid s 6.

[224] Ibid s 15. An ART clinic is considered [a] small business operator is an individual, body corporate, partnership, unincorporated association or trust that: (a) carries on one or more small businesses; and (b)does not carry on a business that is not a small business: See *Privacy Act 1988* s 6D(3). A business is defined as a small business if in a current financial year its annual turnover for the previous financial year is not more than $3,000,000: See *Privacy Act 1988* s 6D(1).

mentions genetic information in its definition of health information. Health information is defined as:

> other personal information that is genetic information about an individual in a form which is or could be predictive of the health (at any time) of the individual or of any of his or her descendants.[225]

Moreover, the guidelines of the *Privacy Act 1988* do not give any information about the woman's responsibility to disclose personal genetic information, which may be relevant for her future child, though they detail that:

> [f]or the purposes of paragraph 16B(4)(c), the Commissioner may, by legislative instrument, approve guidelines that relate to the use and disclosure of genetic information for the purposes of lessening or preventing a serious threat to the life, health or safety of an individual who is a genetic relative of the individual to whom the genetic information relates.[226]

The legislation only applies to legal persons, and because persons who are not yet conceived, are not legal persons, the legislation cannot extend to them.

In the first scenario, the concern about privacy was related to the divulgence of information about a person's health condition, while in this second scenario it concerns the right of a person to keep this information private. Though both actions are autonomous actions of a person, Scenario One shows that the woman's action in divulging information involves other persons (her daughter and the donor), and might be therefore considered as unethical. In the second scenario her action, keeping the information secret, concerns foremost herself and a not-yet conceived person and so is arguably of diminished ethical significance.

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[225] *Health Records Act 2001* (Vic) s 3(d).

[226] *Privacy Act 1988* (Cth) s 95AA.

4.3.4 Fear that her own genetic condition will lead to denial of access to ART

Though Skyla is only mildly affected with NF1, she has a different view of what it means to live with a genetic condition, compared to somebody who is not affected. The question arises whether she can be held ethically responsible for non-disclosure because of her status as a woman affected with a genetic condition.

Skyla's reason for not disclosing may be her fear of being denied access to ART because she may be considered disabled due to her genetic condition. The fact that every person has genetic flaws should be a source of greater empathy, understanding and tolerance towards disability as a collective human experience. But in reality, having a genetic condition, or even being a carrier, remains a source of social stigmatisation. O'Connell describes this situation as follows: '[w]hile genetic technologies are being used as a means to eradicate disease and disability, they also show that we are all the bearers of biological "flaws".'[227] The stigmatisation of genetic risk stems from its association with disability and people's conceptions about disability. In the domain of reproduction the progress in genetic knowledge potentially reinforces a negative image of disability, which then has an impact on a woman's reproductive decisions. In that context Lippman argues that:

> increasing genetic knowledge will lead to a more rigorous definition of disability; in the increasing scrutiny of the embryo, there is the prospect that any and all disabilities will be viewed negatively.[228]

As long as the stigmatisation of a genetic condition exists, there will always be women like Skyla who prefer not to disclose their genetic condition when they want to have a child. This is because they are aware that they are treated differently to a woman who

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[227] Karen O'Connell, 'The Clean and Proper Body: Genetics, Stigma and Disability Discrimination Law' (2009) 14 *Australian Journal of Human Rights* 139, 151.

[228] Abby Lippman 'Prenatal genetic testing and screening: constructing needs and reinforcing inequities'(1991) 17 American Journal of Law & Medicine 15,45 in Karen O'Connell, 'The Clean and Proper Body: Genetics, Stigma and Disability Discrimination Law' (2009) 14 Australian Journal of Human Rights 139, 151.

has no genetic condition or who can conceive naturally. They choose non-disclosure to protect their reproductive autonomy and their identity.

Saxton argues that disabled women 'who choose parenthood are often targeted by assumptions both by medical professionals and the larger community'.[229] Pregnancy and parenthood in people with disability can cause concern, or even disgust and some medical professionals believe that disabled persons cannot deal with the responsibility and role of parenting.[230] Health professionals and relatives may also be biased in their judgement of a woman's decision making. One could imagine that, had Skyla disclosed, she could have been confronted with both professionals and relatives concerned that she might be unable to deal with a child affected with NF1, if the child turned out to have a more severe form of NF1 than herself.

For Saxton, genetic professionals 'should take responsibility to learn about and teach more accurate pictures of disability'[231] and they need to analyse society's view of ablebodiedness, their own values and apprehensions about disability and be aware of how they influence their work. She claims that a disabled woman knows more than any other person of her own 'life circumstances, goals and capabilities'[232] and therefore she should be considered the expert in any decisions about disability in a future child. A woman, like Skyla, who has a genetic condition, should not be held morally responsible for not disclosing it, because she was reasonably concerned that her disclosure might be met with incomprehension and misjudgement by the health professionals.

4.3.5 Is a genetic condition more acceptable if own gametes are used compared to donor gametes

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[229] Marsha Saxton, 'Born and Unborn: The Implications of Reprodcutive Technolgies for People with Disabilities.' in Rita Arditti, Renate Duelli Klein and Shelley Minden (eds), *Test-tube women : what future for motherhood?* (Pandora Press, 1984) 298, 304.

[230] Ibid.

[231] Ibid 308.

[232] Ibid 309.

For this scenario, it is important to analyse whether or not, the woman's or the couple's use of own gametes or donor gametes makes an ethical difference in regards of the acceptability of a genetic condition.

If in this scenario Skyla used a donor egg and donor sperm, her own genetic condition would not have an impact on the genetic condition of the embryo. Before the embryo is created, both donors undergo testing anyway as part of the routine procedure of an ART clinic. Ethically speaking a woman is not expected to disclose her own genetic condition. Routinely both donors have screening blood tests and other genetic tests, if requested, to exclude any condition of the future embryo. Basic testing at an ART clinic includes Cystic Fibrosis, Thalassaemia, Spinal Muscular Atrophy (SMA), Fragile X, HIV (AIDS), Hepatitis B & C, Syphilis, Cytomegalovirus, Human T-cell Lymphotrophic Virus (HTLV) and Karyotype).[233]

However if Skyla uses her own egg and her husband's sperm these kinds of routine tests will not be undertaken unless specifically requested. If donor sperm were involved, as in Scenario One, and Skyla disclosed her condition then that may change the clinic's approach. On the one hand, if she discloses her condition, the sperm donor will be tested for NF1. Admittedly the possibility that the donor is also affected with NF1, is slim but as I have mentioned in Scenario One section 3.3.2, it could happen and the donor would be confronted with health information whether he wanted it or not. On the other hand, if she does not disclose, her behaviour could be viewed as unethical in regards to the donor, because it does not give him the possibility to exercise his right to refuse consent to the creation of an embryo that will become a child with the condition. Maybe he would not have given his consent to donate his sperm to Skyla, if he had known that there was a possibility that the future child could be born with a genetic condition. Section 16 of the *Assisted Reproductive Treatment Act 2008* (VIC) specifies that:

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[233] IVF Australia, above n 80.

> [g]ametes donated by a person may be used in a treatment procedure only if the person who donated the gametes has consented to the use of the gametes in a treatment procedure of that kind.[234]

However if the presence of the condition is analysed from the perspective of the interest of the future child, one could argue that there is no ethical difference between own gametes and donor gametes. Assuming that genetic health is better, in such a situation the parents should undergo all the possible tests in order to prevent the child to be born with a genetic condition whether they use donor gametes or not. For Savulescu there would not be an ethical difference whether a parent uses their own or donor gametes. He argues that, '[c]ouples should employ genetic tests to have the child, of the possible children they could have, who will have the best opportunity of having the best life (subject to cost constraints)'.[235] When a woman makes a decision about giving her future child "the best opportunity of having the best life", she may not consider that "the best life" can be reached by doing genetic tests. A woman's reproductive decision is about her values and the meaning of disability or genetic condition for her. Parker criticises Savulescu's position by arguing that

> [i]n most cases of reproductive decision making however,—ie, those in which it might reasonably be argued that the conditions for the possibility of a good life have been met, these are choices that women should be free to make on the basis of their own values in the light of their own conceptions of what it means for a life to go well.[236]

In the context of ART where techniques are available to test for numerous conditions, Savulescu's argument would mean that parents were expected to use PGD and non-selection of an affected embryo. This position would compromise a woman's autonomy, if she felt pressured to act according to such expectations and it would also speak against a woman's wish to give birth to a disabled child. A negative attitude towards disability can influence a woman's decision making and shape a society's

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[234] *Assisted Reproductive Treatment Act 2008* (Vic) s 16(1).

[235] Julian Savulescu, 'Deaf Lesbians, 'Designer Disability, and the Future of Medicine' (2002) 325 *British Medical Journal* 771, 771.

[236] Michael Parker, 'The Best Possible Child' (2007) 33 *Journal of Medical Ethics* 279, 283.

treatment of disabled persons. The fact that a woman knows that there is support for her or her child to live with a disability, may have a positive effect on a woman's reproductive decisions, so that she feels more able to make her own testing decisions. Internationally the importance of support is recognised, the *Convention for the Protection of Human Rights and Dignity of the Human being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* which states in Article 14 that:

> [s]tates must guarantee the effectiveness of the duty of solidarity towards individuals, families and population groups that are particularly vulnerable to disease or disability linked to anomalies of a genetic character.[237]

In ART the woman's use of her own gametes or donor gametes when a genetic condition is present should not make an ethical difference, because in both cases the woman should feel free to make her reproductive decision without being pressured or fearing that her wish to become a parent might be compromised or being denied access to ART treatment. The woman's interests should be respected in comparison to the future child's interests. For all reproductive decisions where disability, the woman's or the future child's disability, is involved, it is crucial to guarantee a woman's social, financial, medical support.

4.4 Ethical and legal considerations of the decision-making point: decision not to undergo PGD, other prenatal testing or to use donor eggs

Skyla decided to become a parent and to welcome any child born to her and her partner. This decision was supported by the knowledge that she had the emotional and other resources to care for her child.[238] She decided to give birth to a child who might be genetically affected just like herself and clearly she would not have made that

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[237] Council of Europe COE, *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* (1997) 260 <http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm>.

[238] Saxton, above n 229, 310.

decision if she did not think she had a 'life worth living'.[239] Skyla's second decision-making point is to go ahead with AI and not to undergo preimplantation genetic testing, other prenatal testing, or to use donor eggs, although she is fully aware that there is one chance in two that her child will be affected with NF1.

The ethical issues at this decision-making point concern mainly a woman's right to make her own reproductive choices and the repercussions and significance of these decisions in relation to her welfare, disability and the use of ART.

4.4.1 The legal situation in Victoria as to whether a woman must proceed with PGD or donor gametes

In Australia there is no law or regulation which makes PGD or prenatal testing compulsory for a woman. The tests can merely be offered to a woman who is free to choose whether she wants to undertake them. Certain tests can only be accessed if specific conditions are fulfilled. Though there is no legal requirement, most of the ART clinics require their patients to attend pre-pregnancy screening tests and a basic fertility assessment before they start their treatment.[240]

The *NHMRC ART Guidelines* apply to Victoria, as they do to all Australian States. Assisted reproductive treatment, including PGD, is regulated in Victoria by the *Assisted Reproductive Treatment Act 2008* (VIC) , and section 5(a) and section 5(d) offer an ethical framework within which legislators, courts and policy-makers 'balance embryonic and reproductive interests'.[241] Section 5(a) states that 'the welfare and interests of persons born or to be born as a result of treatment procedures are paramount'[242] and section 5 (d) specifies that 'the health and wellbeing of persons

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[239] Scott, above n 168, 37.

[240] Melbourne IVF, 'Sperm Donation' <https://www.mivf.com.au/sites/mivf.com.au/files/attachments/miv_12ppa5_spermdonation_donorbooklet_web_0.pdf>.

[241] Kerry Petersen, 'Regulating Preimplantation Genetic Diagnosis: A Criminal Model versus a Professional Model.' (2009) 17 *Journal of Law and Medicine* 452, 456.

[242] *Assisted Reproductive Treatment Act 2008* (Vic) s 5(a).

undergoing treatment procedures must be protected at all times'.[243] Petersen points out that section 5(d) relates mainly to the woman's reproductive health and wellbeing, but the woman is not directly mentioned, instead the non-gender specific term 'persons' is used.[244]

ART clinics in Victoria perform PGD to reduce the risk of or avoid a range of conditions each year, consequently Skyla could have asked for PGD, as it can be used by couples who have a family history of a genetic disease or chromosomal abnormality that they risk passing on to their children.[245]

4.4.2 Impacts of Skyla's decision on autonomy and responsibility

In this decision-making point another ethical question is whether Skyla, being aware of her condition, should have done all she could to avoid giving birth to a possibly affected child. The answer to this question requires an examination of preimplantation techniques, disability, the child's and woman's welfare and the impact of these elements on the woman's autonomy.

Skyla's choice in conceiving a child was dictated by her partner's car accident which left him paraplegic and which made them opt for an ART treatment to conceive. The couple choose not to adopt or foster a child. For Jackson, infertile men and women should not be subjected to increased pressure to adopt or foster given that the fertile man and woman's wish to procreate is not considered selfish or immoral.[246] To do so would mean that the reproductive autonomy of persons who seek ART treatment would be less than those who do not need it and would be shaped by societal expectations of good behaviour in regard to child welfare in ways that people outside of ART are not.

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[243] Ibid s 5(d).
[244] Petersen, above n 241, 456.
[245] Melbourne IVF, above n 240.
[246] Jackson, above n 175, 174.

Skyla becomes pregnant with the help of ART, a treatment which has undoubtedly had an impact on society, nevertheless, these technologies are not necessarily as transformative as some have claimed. Katz Rothman argues that, while they make a society reconsider and challenge its values, beliefs and policies, they do not define them.[247] Technological challenges to the values a society expresses, have the potential to improve a woman's individual situation and make it easier for her to achieve her aims on a moral, cultural, social, religious and even financial level. For example, in Skyla's case thanks to the advance and normalisation of ART, her conception by way of AI is no longer a taboo subject in society. It is morally and culturally acceptable and it is affordable by her.

But Katz Rothman also warns that some reproductive technologies give power to some people at the cost of others, and can increase a person's control and choice as well as state/market/social control, so the issue in her eyes becomes power, not the technology.[248] By choosing not to undergo preimplantation testing, Skyla avoided a possible confrontation and power issue with health professionals about a choice among tests, to see whether the embryo is affected or not and finally the choice of electing or not to have that baby, that may have ultimately led to a refusal of implantation. Hence a woman's choice can be in conflict with the predominant medical opinion. For Skyla, disclosing her condition would have meant more choice, but not the choice she necessarily wanted and hence expanding her options would have lessened her reproductive autonomy.

Skyla's decision not to undergo testing is a positive sign of her reproductive autonomy. However, she might be held ethically more responsible than a woman who opts for testing her embryo, because she might be accused of acting against her child's welfare. Press and Browner question the 'extent to which choices to test are really informed and autonomous'.[249] They are concerned that a woman who chooses not to test 'may

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[247] Katz Rothman, above n 75, 197.

[248] Ibid 199.

[249] Rebecca Kukla and Katherine Wayne, *Pregnancy, Birth, and Medicine* (17 February 2011) The Stanford Encyclopedia of Philosophy <http://plato.stanford.edu/archives/spr2011/entries/ethics-pregnancy/>.

face diminished support and increased blame for their choice'.[250] Women who do not choose to test can be harshly judged by society for not acting in the best interest of her future child. Knoppers' statement about pregnant women can be also applied to a woman who needs to make decisions even ahead of conceiving. She argues that

> a pregnant woman who either does not comply with a referral for testing or decides to continue to carry a fetus in which a disability has been detected is viewed by others as irresponsible, irrational, and selfish'.[251]

As argued in Chapter Two, it is necessary, however, to take a more nuanced view of disability. It is not self-evident that being born disabled means being born harmed. Therefore, this thesis argues that a woman, like Skyla, who chooses to give birth to a disabled child, should be able to do so, and she should have the necessary financial, social, economic and emotional support. The more society offers this support, the more a child with a disability can have similar opportunities to an able-bodied person to gain a good quality of life, the more a woman's reproductive choice will become genuine, where the choice might be about the child and not about the disability.

By refusing testing Skyla missed out on seeing a counsellor. In that context, Mahowald claims that, when a woman chooses to see a counsellor or to be tested, she decides to participate in the process. In my view, a woman like Skyla, who has first-hand experience of the disability and who chooses not to see a counsellor participates in the decision-making process of her reproductive journey, on her own terms. Her decision not to attend counselling may have been intended to protect her from confronting a presumptive idea of a problem.

4.4.3 Interest of the future child and potential lawsuit

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[250] Ibid.

[251] Knoppers BM, Le Bris S. Reproductive genetics: Canadian and European perspectives in *Fetal Diagnosis and Therapy* 1993;8(1):189–201 quoted in Karen L Lawson and Roger A Pierson, 'Maternal Decisions Regarding Prenatal Diagnosis: Rational Choices or Sensible Decisions?' (2007) 29 *Journal of obstetrics and gynaecology Canada (JOGC)* 240, 7.

For some bioethicists, Skyla would have a parental duty to use PGD for the medical benefit of her future child, especially when she knows that there is a ‘significant risk for birthing a child with a serious genetic disorder’.[252] This stance is taken by Sandelowski and Barroso even if a positive prenatal diagnosis could lead to a paradox of choice, meaning that a parent is ‘forced to consider choosing against a wanted pregnancy’.[253]

Malek and Darr argue from a U.S. perspective that there could be legal consequences for the parents of an IVF conceived child born with a genetic condition, if the parents had refused to proceed with PGD. The child could sue the parents for prenatal harm based on elements of tort and statutory law. This argument is based on the principle that

> once a person demonstrates an intent to proceed with reproduction that individual has a duty to act as a reasonably prudent parent when taking all subsequent reproduction related actions.[254]

This duty arguably includes the obligation to maximise the wellbeing of any possible future child by preventing known risks. In those cases (the vast majority) where parental liability has been rejected, courts in the U.S. have concentrated on ‘the doctrine of parental immunity and a woman’s rights to bodily integrity and procreative liberty’.[255] Jurists are concerned that enforcing liability for negligent conduct during pregnancy unlawfully disrupts ‘a pregnant woman’s right to exercise physical autonomy’.[256] However, in the case of IVF embryos, a woman’s bodily integrity is not directly compromised by requiring the use of PGD, rendering this line of cases less applicable.[257] Malek and Daar are more concerned about the harm caused by the failure to investigate and select the healthiest embryos from among the group

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[252] Janet Malek and Judith Daar, ‘The Case for a Parental Duty to Use Preimplantation Genetic Diagnosis for Medical Benefit’ (2012) 12 *The American Journal of Bioethics* 3, 3.
[253] Margarete Sandelowski and Julie Barroso, ‘The Travesty of Choosing After Positive Prenatal Diagnosis’ (2005) 34 *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 307, 314.
[254] Malek and Daar, above n 252, 9.
[255] Ibid.
[256] Ibid.
[257] Ibid.

presented. They trust the law would favour the relatively negligible inconvenience in parental waiting time and expense which could considerably improve the future child's health profile.[258] I cannot support this view as it vastly underestimates the physical burden of IVF, the limited success of implantation and the scarcity of viable embryos. It also prioritises the welfare of the child over the welfare of the future mother, and it limits a woman's reproductive autonomy. Furthermore, there are harms that follow from PGD if the embryo is destroyed and the woman has to undergo further IVF procedures that impact directly her body. She thus would have to undergo potential invasive procedures in order to guarantee the wellbeing of a future child that may never come to exist.

4.4.4 Is the refusal of testing unethical because there may be an expectation to avoid the birth of a disabled child

Skyla's refusal may be considered unethical because she risks giving birth to a genetically affected child. There may be an expectation that it is a woman's duty not to give birth to a disabled child. On the other hand her decision may be deemed ethical because she considers that not giving birth to a disabled child would be a form of eugenics.

This brings into play the earlier discussion about disability. As Parker puts it:

> is there a moral duty to have a healthy child in situations where there is a choice? If so, what is to count as healthy and/or disabled and who is to decide in any particular case?[259]

Purdy argues that having the children that one wants is essential to human happiness and that denying people the capacity to carry through their choices contributes

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[258] Ibid.
[259] Parker, above n 236, 279.

significantly to human misery.[260] I agree with Purdy, and would add that the freedom to choose a future child, including with a disability, is a fundamental element of a woman's autonomy. Furthermore, it impacts directly on the disabled individual's sense of self-worth as in Skyla's case she is aware of the possibility of having a child affected with NF1 and as she is herself affected. She can relate to a life with NF1.

But there are authors who criticise this point of view. One author is Savulescu, who bases his arguments on two principles of reproductive ethics: procreative beneficence and reproductive autonomy albeit a form of autonomy differently conceived. He defines procreative beneficence as the 'selection of the best child of the possible children one could have'[261] and that parents should use genetic tests to achieve this result. For him reproductive decision making presupposes that people should be 'free to do what others disapprove or judge wrong, provided the exercise of freedom does not harm others'.[262] So for Savulescu, Skyla should have disclosed her condition, used PGD and then decided against implantation in the case of an affected embryo.

Parker objects to these principles, for him the principle of procreative beneficence is underdetermining, self-defeating and overly individualistic.[263] There are ways in which Skyla could have made a better decision particularly if one has the view that Skyla had an obligation as a parent to guarantee, insofar as possible, that her child has a reasonable chance of a good life. If she had opted for PGD the health professionals would have played a major role, their obligation would have been to help Skyla to ponder her choices and to discuss with her the 'moral dimensions'[264] of her choice. I concur with Parker when he challenges the view that the health professionals' attitude is as a violation of a patient's autonomy. He argues that it is more appropriate and useful to discuss the reasons for making a choice and to challenge them. In Skyla's case such a discussion could have led to a better understanding of what life for her child

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[260] Laura M Purdy, 'Children of Choice: Whose Children? At What Cost?' (1995) 52 *Washington and Lee Law Review* 197, 199.

[261] Julian Savulescu, 'In Defence of Procreative Beneficence' (2007) 33 *Journal of Medical Ethics* 284, 284.

[262] Savulescu, above n 235, 771.

[263] Parker, above n 236, 279.

[264] Ibid 283.

could be like if NF1 took a more severe form than her own and this discussion would have enabled her to change her opinion if there were factors she did not previously consider.

Any person with an inheritable condition, who wants to procreate is normally aware that his or her condition is likely to be passed on to their offspring.[265] But the possibility of passing on an inheritable condition should not require all those persons who are genetically affected to undergo preimplantation testing. To do so would be a major infringement of reproductive autonomy.

4.5 Conclusion

This scenario shows that there is no legal liability for a disability in a future child to a woman who decides not to disclose her genetic condition or who refuses preimplantation genetic testing. It is also inappropriate to assign her ethical responsibility. Skyla's decision not to disclose genetic condition before her ART treatment, is rational and even necessary to protect her autonomy. Skyla preferred not to disclose and have her baby without feeling pressured to undergo more invasive treatment with its potential flow on effects to her reproductive choices.

The fact that Skyla did not disclose her condition may also be interpreted as a sign of her fears about the reactions of health professionals to her own health status. ART health professionals have an impact on a woman's decisions and rights. Health professionals' approach to disability could not only redirect a woman's choice, but it could also in the longer term have an impact on how society sees disability and disabled persons. In that context, Asch argues that life with disability is worthwhile and she believes that a fair society must value and support the lives of all people, whatever the person's abilities.[266] I concur with Asch that ideally a society should establish the infrastructure and the social means to care for somebody who is not able-bodied and

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[265] Isabel Karpin, 'Choosing Disability: Preimplantation Genetic Diagnosis and Negative Enhancement' (2007) 15 *Journal of Law and Medicine* 89, 94.

guarantee that life (access to work, study, leisure) is the same whether one is able-bodied or not.[267] In such a society a woman's reproductive autonomy would be more likely to be fully realised because she would only have to decide whether she wants to have a child or not without having to worry about the attendant moral, social or financial support. And women like Skyla and Nell, from the first scenario, would not be held ethically responsible when they choose to risk having a child with a disability.

Skyla opted against a more intense medicalisation of her ART treatment by not disclosing her condition. But this scenario shows that a woman's autonomy is only genuine if she can disclose her condition without having to fear that she will be pressured to undergo a treatment she does not want and run the risk of not becoming a parent. On the one hand, ART allowed Skyla to become a parent and exercise her reproductive autonomy. On the other, Skyla did not disclose because she was afraid that ART could have potentially challenged and disputed this same right where it intersects with a clinical bias against disability.

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5 CHAPTER FIVE

5.1 Story of the third scenario

In this third scenario there is no third party and an unknown genetic history.

Alva and Irwin had their first baby Phyllis in December 2015. She was conceived by IVF, in NSW in March. At the time Alva and Irwin were 34 and 36 years old. Alva is a gardener and her partner is a community nurse. As they had been trying to conceive naturally for over a year and a half without success, they decided, on the advice of their GP to consult a fertility specialist. The World Health Organisation's (WHO) clinical definition of infertility is a 'disease of the reproductive system defined by the failure to achieve a clinical pregnancy after twelve months or more of regular unprotected sexual intercourse'.[268] In line with this, most ART clinics, and the one that Alva and Irwin chose was no exception, suggest that individuals should seek assistance after twelve months of trying if the woman is under thirty-five.[269]

Prior to the first visit, the couple read brochures provided by their GP, and consulted ART clinic websites to choose a clinic. From these sources they obtained information about fertility tests, ART treatments, and testing techniques. By the time they went to their first appointment they had a good idea of the steps in the IVF procedure, its duration, potential side effects of the treatment and of the medication, the chances of becoming pregnant and the clinics' success rates. They also looked at the treatment costs and out of pocket expenses. By consulting the websites, Alva was introduced to topics such as genetic testing and she became aware that this sort of testing was a significant feature of ART clinics' websites. In the brochures and on clinic websites, Alva read sentences like 'taking home a healthy baby'[270] and 'every couple wants to

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[268] F Zegers-Hochschild et al, 'International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) Revised Glossary of ART Terminology, 2009' (2009) 92 *Fertility and Sterility* 1520, 1522.

[269] IVF Australia, *About Infertility* (2014) <http://ivf.com.au/about-fertility/infertility-treatment#when-should-you-seek-help->.

[270] Limited Genea, *A 40% Better Chance of a Healthy Baby* (2013) Genea WORLD LEADING FERTILITY <http://www.genea.com.au/my-fertility>.

have a healthy baby'[271] which she felt transmitted a very specific message about disability. Alva gained the distinct impression from the repeated use 'healthy baby' that the clinics wanted to transmit the message that with ART only healthy babies are guaranteed and that they did not want future parents to think of the possibility of a disabled baby. Other testing techniques were also described in detail on the websites. The websites' medical language also gave Alva the impression that in addition to preventing the conception of a disabled baby, testing ought to be considered in order to 'have a healthy baby'.[272]

After a first consultation where the specialist took their medical history and assessed their general health, they underwent initial tests and investigations.[273] The specialist came to the conclusion that the infertility could not be explained, and he suggested that the couple proceed with IVF. When no cause of infertility can be detected, doctors term this "unexplained infertility". This event concerns in ten to twenty percent of couples,[274] experiencing difficulties in conceiving

After one cycle of IVF Alva became pregnant. Approximately a year and a half before Phyllis was born, in September 2014, Alva had been experiencing mild symptoms of affected balance and hearing and thought she had a flulike virus. She informed the IVF clinic about her symptoms before commencing IVF. The health professionals urged her to have additional tests, offered her preconception testing and genetic counselling. They informed her about Preimplantation genetic testing (PGT) which comprises two techniques, PGD and preimplantation genetic screening (PGS) and advised her that these tests could be performed within her IVF treatment. They explained that PGD is used for the detection of serious genetic conditions when the potential parent is known to be at risk, of carrying or being predisposed to a particular genetic condition,

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[271] The Centre for Genetics Education, 'Prenatal Testing Special Tests for Your Baby During Pregnancy' 2 <http://www.genetics.edu.au/Publications-and-Resources/PublicationsBrochuresandPamphlets/PrenatalTestingSpecialTestsforYourBabyDuringPregnancy.pdf>.

[272] *Understanding Preimplantation Genetic Diagnosis* (2013) Genea WORLD LEADING FERTILITY <http://www.genea.com.au/>.

[273] IVF Australia, above n 80.

[274] IVF Australia, *Female Analysis* (2014) <http://ivf.com.au/fertility-treatment/female-infertility-tests>.

whereas PGS is used to detect unspecified or chromosomal anomalies in embryos when parents have no diagnosed genetic condition.[275] They also advised her to consider the use of an egg donor which would exclude the possibility of having a child with a genetic condition, assuming that the preconception testing showed that Alva had a genetic condition. Alva felt quite overwhelmed by the provision of information by the health professionals and the information on the clinic's website. She felt that this was an over-reaction to what she thought was just a mild virus. She felt pressured to reconsider her decisions in regards to herself, her future child and her position towards genetic testing.

Alva and Irwin decided to go ahead with IVF, and Alva refused the offer to undergo further medical testing for herself and PGT for her embryo and she also made it clear that she did not want to use egg donation. There were several reasons why she declined testing. Alva refused further testing because her symptoms at the time were mild and, she believed, temporary. She did not see the need for genetic testing because there was no known family history of a genetic condition.

Though Alva accepted IVF, a highly medicalised procedure in her eyes, she still wanted her pregnancy to be as natural as possible. Alva also refused testing because it would have exposed her to risks inherent in those tests (for example implantation or not of an embryo, selection for or against an affected embryo). She also declined testing because she did not believe she had a genetic condition and viewed the process of testing as adding additional unnecessary stress, particularly given the potential costs to her professionally, socially and financially. Finally she was concerned it would have an impact on her ART treatment.

Alva's symptoms became stronger after the birth of Phyllis and at that point she underwent further investigation in 2014. She was finally diagnosed with the genetic condition Neurofibromatosis type 2 (NF2), caused by mutations in the NF2 gene that

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[275] National Health and Medical Research Council NHMRC, 'Draft Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research. Public Consultation' 41 <http://consultations.nhmrc.gov.au/files/consultations/drafts/artdraftethicalguidelines150722.pdf>. Preimplantation genetic testing (PGT) comprises two techniques PGD and PGS.

regulates the production of the merlin/schwannomin protein.[276] If the NF2 protein, which normally inhibits tumour growth, is defective the body's tumour protection does not work properly. The information for the protein NF2 is located on chromosome 22. Persons with NF2 have since birth a faulty copy of the NF2 gene and a working NF2 gene copy since birth. The estimated birth frequency of NF2 is 1 in 33,000 to 40,000. Neurofibromatosis type 1 (NF1) and Neurofibromatosis type 2 (NF2) are two different genetic conditions, though similarly named, with a different genetic basis.

The symptoms of NF2 are the 'development of swellings (non-cancerous tumours so-called schwannomas) on the nerves that control hearing and balance (auditory and vestibular nerves)'.[277] The onset of the symptoms is normally in late puberty but some people only develop problems in their 40s and 50s. The pattern of inheritance of the faulty gene causing NF2 in families is described as autosomal dominant inheritance. This means that a child has one chance in two to inherit a copy of the faulty NF2 gene and will therefore be affected by NF2 at some time in their life.[278]

Once Alva was diagnosed Irwin and Phyllis were tested to see if they were also affected. Amongst people with NF2, 'approximately 50% of NF2 cases are inherited and about 50% are due to new mutations in the NF2 gene'.[279] Irwin was unaffected. Their daughter Phyllis was affected because she received the faulty copy of the gene from her affected mother and a working copy of the gene from her unaffected father.

Explanatory figure of autosomal dominant inheritance[280]

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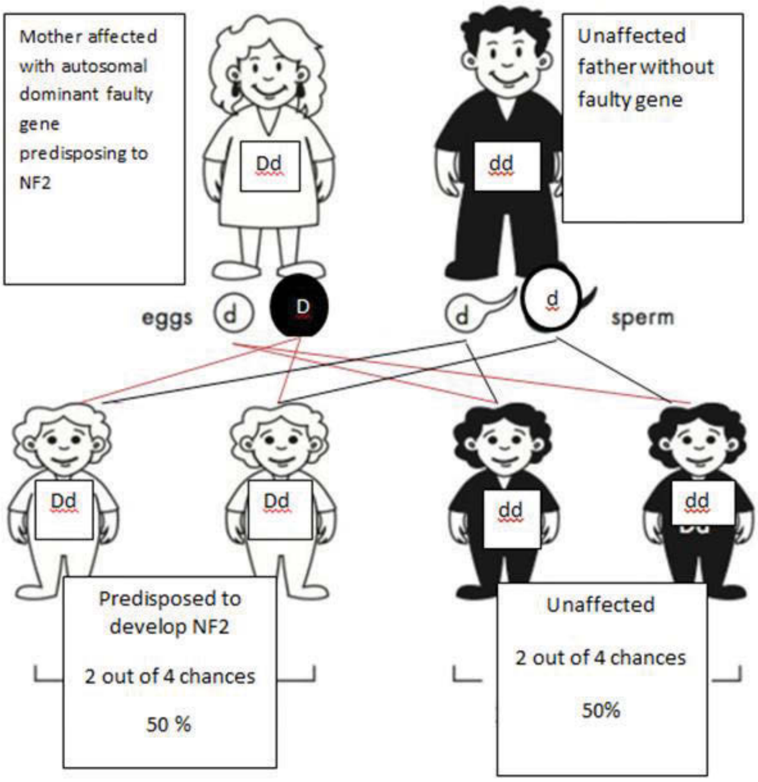
[276] Barlow-Stewart, Emery and Metcalfe, above n 186, 6. Neurofibromatosis chapter 14.

[277] Ibid.

[278] Ibid 2.

[279] Ibid 6.

[280] Centre for Genetics Education, *Neurofibromatosis Type 2 FACT SHEET 52* (20 December 2013) 2 <http://www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/neurofibromatosis-type-2>. Figure modified to correspond to this scenario.



This figure illustrates autosomal dominant inheritance where one parent has the faulty NF2 gene copy. This figure shows the mother as the parent with the faulty NF2 gene copy, the same situation would arise if it was the father. The faulty copy is represented by 'D', the working copy by 'd'. The autosomal dominant faulty gene causing NF2 is represented by 'D', the working copy by 'd'.

5.2 The ethical and legal implications of Alva's decision to decline the clinic's offer of preconception testing

In this scenario the health professionals recommended that Alva undertake additional investigations for herself and they offered her alternatives after she informed them about her symptoms of balance and hearing problems. In this decision-making point Alva refused the clinic's recommendation that she undertake preconception testing to check whether she might have a genetic condition, she also declined genetic counselling, and did not want to consider an egg donation. This section considers whether there was a legal or ethical obligation for Alva to request genetic testing for herself. Unlike Skyla, in Scenario Two, Alva does not know that she has a genetically inheritable condition and she has no reason to believe that it was more serious than a temporary condition. The legal and ethical implications of her decision are analysed with a view to determining whether, and if so, in what circumstances, a woman has a responsibility to be genetically tested. For instance, if Alva had had no symptoms would she have had no responsibility to undergo genetic testing?

These considerations associated with decisions made during an ART treatment can be the subject of intense deliberations for individuals, with differing conclusions. For this decision-making point, the relevant considerations are diverse and wide-ranging: they deal with the question of information, provision, medicalisation and commercialisation of reproduction and the role of the health professionals within ART treatments.

5.2.1 Decision to decline testing and its legal considerations

This section examines what the NSW legislation and the *NHMRC ART Guidelines* have to say in relation to this scenario and whether Alva can be held legally responsible for her decision. Before Alva started her ART treatment she did what a reasonable person would do in her situation. When she attended the ART clinic she informed the clinic staff about her symptoms. She did not conceal her symptoms and did not make a false representation of her health status, but she viewed them as mild and temporary. Informing the clinic about her symptoms is significant because depending on the information Alva gave, the health professional would have taken different approaches to her treatment.

During a first appointment at an ART clinic with a fertility specialist, the doctor examines the patient's medical history, assesses the general health of the patient and organises initial tests and investigations.[281] In Alva's case this initial check-up ensured that the clinic knew about her symptoms. The clinic advised her to investigate further, especially once it became clear that the couple would use IVF. The decisions a woman makes about giving information regarding her health and about having testing or

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[281] IVF Australia, *Your First Consultation* (2014) <http://ivf.com.au/fertility-treatment/first-fertility-consultation>.

counselling are arguably the same whether she wants to conceive naturally or via ART. Nevertheless, when a woman wants to have an ART treatment, those decisions can change the course of the treatment.

The *Assisted Reproductive Technology Act 2007* (NSW) and the *NHMRC ART Guidelines* give information about decision making and the importance of counselling and consent. Even before a woman has an ART treatment, the clinic must inform her that counselling services are in place. The *Assisted Reproductive Technology Act 2007* (NSW) specifies this in section 13(1)(a) relating to an ART treatment which does not involve donated gametes:

> [a]n ART provider must inform a woman of the following before providing ART treatment to the woman: (a) the availability of counselling services.[282]

The *NHMRC ART Guidelines* stress also the importance of information so that the patient can make an informed decision:

> [t]o make informed decisions about their treatment, participants in ART need to understand all the procedures involved, including any health risks and psychosocial consequences associated with them. Clinics must give up-to-date, objective, accurate information about treatment options and the procedures involved to all potential participants in ART procedures and discuss it with them.[283]

It is clear that this information is important for a woman's capacity to exercise autonomy and choice.

The *Assisted Reproductive Technology Act 2007* (NSW) and the *NHMRC ART Guidelines* deal with an ART clinic's requirements, but they do not compel a patient to undergo screening nor do they provide guidance about a patient's responsibility to undergo screening or diagnostic testing. Numerous tests and techniques are available to evaluate the health status and development of a baby before conception or birth. Each

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[282] *Assisted Reproductive Technology Act 2007* (NSW) s 13(1)(a).

[283] NHMRC, above n 48, 41.

of the tests has advantages and disadvantages and presents the woman with a decision.

In the ART context, the *Assisted Reproductive Technology Act 2007* (NSW) and the *NHMRC ART Guidelines* do not hold a woman responsible when she does not get genetically tested prior to conceiving. They do not require such an act from the woman, but, perhaps more interestingly, the ethical guidelines do not even suggest it is prudent. Alva therefore had no legal responsibility to accept the clinic's recommendation to investigate her symptoms further. The fact that Alva declines further testing is her right. Indeed, the *NHMRC ART Guidelines* note a woman's right to decide on all matters regarding the procedures which are directly related to her ART treatment, like IVF or PGD. Guideline 5.5 acknowledges that '[p]articipants in ART have the right to decide for themselves whether or not to take part in the proposed procedures'.[284]

In the context of this decision-making point, it is interesting to align it with the approach to prenatal testing, taking in relevant policy directives that acknowledge explicitly that the woman may not want to undergo testing and that testing is not an obligation. For instance, in the *NSW Policy Directive of Prenatal Testing/Screening for Down Syndrome & Other Chromosomal Abnormalities* it is acknowledged that not every woman wants to use prenatal screening or diagnostic tests.[285] In NSW the woman is not legally bound to have prenatal testing, as long as the woman receives objective information about the testing and information about what this decision involves, then she can make a conscientious and ethical decision. The woman's decision is a very personal one and depends, amongst other things, on her risk status. In fact everyone is at risk so a different view would suggest universal testing and screening. But it is important to remember that from a legal point of view, in Australia, a woman does not have to have prenatal testing.[286] A statement in the NSW Ministry of Health's Centre for Genetics Education information booklet for prenatal testing

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[284] Ibid 22 at guideline 5.5.

[285] Ministry of Health, 'Policy Directive Prenatal Testing/Screening for Down Syndrome & Other Chromosomal Abnormalities Space' 5 <http://www.health.nsw.gov.au/policies>.

[286] The Centre for Genetics Education, above n 271, 2.

reinforces also the right of the woman to refuse testing. It clarifies that 'it is important to remember that you do not have to have prenatal testing if you do not wish to'.[287] By acknowledging a woman's autonomy to decline testing, the statement frees her from any legal responsibility. It seems likely then that the same view prevails in the IVF context before conception.

The *NHMRC ART Guidelines* support a woman's autonomy by stating in their ethical principles for clinical practice of ART that '[p]articipants in ART are entitled to understand and participate in the decision making about their care'.[288] They are 'entitled to detailed information about proposed procedures and any alternatives and to receive counselling about the consequences of those procedures'.[289]

As far as information giving and counselling are concerned, the *NHMRC ART Guidelines* and the *Assisted Reproductive Technology Act 2007* (NSW) stress the importance of clinics providing counselling services by 'professionals who have appropriate training, skills, experience and accreditation necessary for their counselling role'.[290] In order to make an informed decision the clinic's staff would have to make sure that Alva understands 'all the procedures involved, including any health risks and psychosocial consequences associated with them'.[291]

The role and the aim of this multidisciplinary clinical team, composed of doctors, nurses, scientists and counsellors, is to support Alva and Irwin personally and emotionally and to offer them the possibility to discuss and raise concerns and to explore the personal and social implications for them and their future child of any issue that might arise.[292] Due to the emotional and challenging nature of the ART experience, according to the *NHMRC ART Guidelines* and the *Assisted Reproductive Technology Act 2007* (NSW), the clinic must offer services from accredited counsellors

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[287] Ibid.
[288] NHMRC, above n 17, 21 at guideline 5.3.
[289] Ibid 22 at guideline 5.4.
[290] Ibid 43 at guideline 9.3.1.
[291] Ibid 41 at guideline 9.1.
[292] Ibid 43 at guideline 9.3.1.

to support participants in their decision-making about their treatment, before, during and after the procedures.[293]

This section has shown that a woman such as Alva, accessing ART treatment, cannot be held legally responsible if she declines genetic testing for herself or the additional testing which may be necessary to detect a health condition. The *Assisted Reproductive Technology Act 2007* (NSW) and the *NHMCR Guidelines* deal with some of the topics related to Alva's decision, namely information for the patient, counselling and consent of procedures. But there is nothing in the legislation and the guidelines requiring a woman to have genetic tests or other medical tests in the presence of symptoms which may give rise to a suspicion of a condition.

5.2.2 Right to privacy and interests of the future child

Scenario Three shows the potential for conflict in a situation where the pressure a woman feels to participate in testing and counselling is at odds with the protection of her privacy. And her refusal of testing and counselling can also be at odds with her privacy in relation to a future child. Privacy rights include her right not to know of an existing or potential disorder in herself.

The right not to know is specifically mentioned in the joint report of the *Australian Law Reform Commission (ALRC)* and the *Australian Health Ethics Committee (AHEC) of the NHMRC.* The *ALRC Report* describes the importance of the right not to know in relation to privacy and the particular qualities of genetic information.

> The right not to know has been stated as the right people should have to be protected from information that their own bodies can yield, based on the ethical principle of respect for autonomy. This principle may be seen as having particular application to genetic testing because of the predictive power, or perceived predictive power, of

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[293] Ibid at guideline 9.3.

> genetic information in relation to a person's long-term health prognosis and other physical and behavioural characteristics'.[294]

The right not to know is also referenced in the *National Statement on Ethical Conduct in Human Research*, where in regard to genetic testing the participant must be able 'to decide whether they wish to receive the information and who else may be given the information'.[295]

Neither the *NHMRC ART Guidelines*, nor the NSW ART legislation mention the right not to know, and the right of a woman to decline testing for herself. Nevertheless it is likely that the view expressed in the ALRC report and the National Statement would be favoured in the ART context making it unlikely that responsibility to know could be assigned to a woman in a situation similar to this scenario.

Section 4.3.2 of the previous scenario dealt with the tension between the autonomy of the woman, an existing person, and the interest of the future child, a not-yet existing person. The actions of the former have an impact and are judged in relation to the latter. A similar tension exists here.

The difference between the two scenarios is that in Scenario Two the woman kept silent about her genetic condition, whereas in Scenario Three the woman declined testing about her health status and therefore remained ignorant of her condition. In both scenarios the woman's decision is linked to the interests of the future child's genetic health status. Similar to Skyla in Scenario Two, Alva might have been expected, just like Skyla, to act as a 'responsible mother', that is, one 'who does everything—

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[294] Australian Law Reform Commission (ALRC) and Australian Health Ethics Committee (AHEC) of the National Health and Medical Research Council (NHMRC), 'Essentially Yours: The Protection of Human Genetic Information in Australia.' (96 Volume 1, 2003) 636, 7.24, 240 <http://www.alrc.gov.au/publications/report-96>. The Report represents the culmination of a two-year inquiry by the ALRC and AHEC of the NHMRC and contains 144 recommendations for reform.

[295] NHMRC (National Health and Medical Research Council), Australian Research Council and Australian Vice-Chancellors' Committee, *National Statement on Ethical Conduct in Human Research 2007 (Updated May 2015)* (National Health and Medical Research Council, 2007) 42 at guideline 3.5.2 (a)(i) <www.nhmrc.gov.au/guidelines/publications/e72>.

takes all tests—to ensure foetal health'.[296] Nevertheless, Alva's reproductive autonomy and choice means she should be free to reject testing for herself 'without someone questioning her motives'.[297] The woman should feel free to choose whether she wants to conceive a child as planned or whether she wants to alter her plan. In an ableist society, however, the woman's decision may be judged as ethically wrong and damaging to the interests of their future child. In both scenarios the autonomous nature of the woman's choice would be enhanced if society supported persons with a disability equally with those who do not have a disability. As Asch writes

> our clinical and policy establishments must communicate that it is as acceptable to live with a disability as it is to live without one and that society will support and appreciate everyone with the inevitable variety of traits.[298]

5.2.3 Refusal to consider an egg donation

In this scenario there is a risk that a mere suspicion of a condition may lead to some external pressure on the woman who considers ART, to use methods and techniques which minimise the risk of having a child with a disabling condition. For instance, in this scenario it is the clinic's advice to consider egg donation where preconception testing shows that Alva has a genetic condition. While Alva would have no legal obligation to use an egg donor, some might argue there is an ethical obligation. The ethical obligation to use an egg donor will be dealt with in the next paragraphs and the ethical implications of a refusal of testing will be examined in the next section.

In New South Wales egg donation is allowed and the *Assisted Reproductive Technology Act 2007* (NSW) regulates the use of donor gametes and explains the various implications for those who might donate or receive donor eggs. It does not specifically regulate a woman's right to refuse egg donation because it is assumed that she must consent to all procedures. The *Assisted Reproductive Technology Act 2007* (NSW) also

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[296] Lippman, above n 101, 22.
[297] Ibid 29.
[298] Asch, above n 8, 1656.

is silent about whether a clinic may refuse to provide services to a woman who rejects the option of egg donation, where there is an inheritable condition. If a clinic refused, based on the health of the future child, the woman's autonomy may be compromised. The *NHMRC ART Guidelines* make it very clear that respecting the welfare of the future child is an obligation. They state that

> [a]ssisted reproductive technology (ART) procedures must be conducted in a way that is respectful of all involved. Clinical decisions must respect, primarily, the interests and welfare of the persons who may be born, as well as the long-term health and psychosocial welfare of all participants, including gamete donors.[299]

This obligation is also valid when gamete donations are used. The *NHMRC ART Guidelines* specify that '[i]n using gamete donations, clinicians must carefully consider the physical, psychological and social wellbeing of the person to be born and the participants'.[300]

The *Assisted Reproductive Technology Act 2007* (NSW) does not give any information about whether an egg donor needs to be tested. The *NHMRC ART Guidelines* do not give any specific information about testing, but in section 6.2 it is specified that 'in using gamete donations, clinicians must carefully consider the physical, psychological and social wellbeing of the person to be born and the participants.'[301] As clinics are required to provide gamete recipients with relevant medical history about the gamete donor, it can be deduced that they must make sure that they receive the appropriate information.[302] A typical information booklet about egg donation from an Australian ART provider explains that the egg donor will receive genetic counselling during the assessment process.[303]

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[299] NHMRC, above n 48, 21.
[300] Ibid 26.
[301] Ibid.
[302] Ibid 28 at guideline 6.10.
[303] Melbourne IVF, 'Egg Donation' 6 <https://www.mivf.com.au/sites/mivf.com.au/files/attachments/miv_20ppa5_eggdonationbooklet_web.pdf>.

This scenario raises the question of whether a woman's ethical obligation to use egg donation, when she has a genetic condition, is greater when she conceives by way of ART, as opposed to a woman who conceives naturally. Is she put under additional pressure because she has an ART treatment? A woman who conceives via ART is taken care of by a team of health professionals even before starting her treatment. The team offers medical information and advice related to her potential genetic conditions and the possible implications for her treatment and her future child. In light of all the information the woman receives, she may feel pressured to consider egg donation. If she does feel pressured, then her autonomy is at risk, because she is more likely to use a method which does not correspond to her initial reproductive choice. A woman who plans to conceive naturally is less likely to know these options and to experience any pressure to use them, because there is not the same medical engagement with her potential pregnancy.

5.2.4 Decision to decline testing and its ethical implications

Alva's various reasons to refuse testing included the mildness of her symptoms and the absence of a genetic condition. The question remains as to whether Alva should be held ethically responsible when she declines testing for herself and for her embryo. The ethical considerations of her refusal concern Alva's reproductive autonomy. Alva's refusal to further investigate her symptoms, concerns primarily her own health. Yet her behaviour seems to become ethically questionable the moment she plans to have a child. Suddenly her refusal is questioned, especially in an ableist society, where a woman is considered to be acting *responsibly* in the interest of a not-yet conceived child by accepting all testing to prevent the conception or birth of a disabled child. The medicalisation of reproduction encourages this attitude and hence a woman's reproductive autonomy is often subordinate to the woman's ethical responsibility for a not-yet conceived child. For Bonte, Pennings and Sterckx, a potential parent has a moral duty of 'non-maleficence, a duty not to harm others, often by passive abstention'.[304] The authors claim that

> [i]f some potential parent would only have to be non-maleficent in relation to her potential future child, more leeway should be given to her own right to autonomy: she should then be free to live her life as she sees fit without being duty-bound to procure the good (for someone else).[305]

In this scenario Alva's refusal could be characterised as non-maleficent behaviour in regard to herself.

The moment Alva disclosed her symptoms to the ART clinic's staff, it was their duty to provide their patient with appropriate information related to her situation. The *NHMRC ART Guidelines* specify which information can be provided, they say that '[p]articipants in ART are entitled to detailed information about proposed procedures and any alternatives'.[306] In this scenario the appropriate information included information about IVF, genetic testing and egg donation.

The *NHMRC ART Guidelines* detail also how the information should be given to the patient in order to make an informed decision. They state that:

> [c]linics should provide and discuss information in a way that is appropriate to, and sufficient for, informed decision making. The information should be given: verbally, supported by written information in plain language; with sensitivity to cultural diversity and religious beliefs; in a way that is accessible to those with low literacy or disability, and/or whose first language is not English; in a way that avoids any coercion or inducement.[307]

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[304] Pieter Bonte, Guido Pennings and Sigrid Sterckx, 'Is There a Moral Obligation to Conceive Children under the Best Possible Conditions? A Preliminary Framework for Identifying the Preconception Responsibilities of Potential Parents' (2014) 15 *BMC Medical Ethics* 1, 3.

[305] Ibid.

[306] NHMRC, above n 48, 22 at guideline 5.4.

[307] Ibid 42 at guideline 9.1.3.

Though they describe the characteristics of information, they do not define coercion and inducement.

The *Assisted Reproductive Technology Act 2007* (NSW) specifies that an ART provider has a duty to inform the participant and which information is compulsory within an ART treatment.

> Provision of information—ART treatment involving no donated gametes
>
> (1) An ART provider must inform a woman of the following before providing ART treatment to the woman:
>
> (a) the availability of counselling services,
>
> (b) any other matter that is prescribed by the regulations.[308]

Health professionals play a crucial role in the provision of information. Another ethical consideration of this decision-making point is whether the nature of the information or the way it is provided puts pressure on a woman and influences her decision. In an ART context the information should, theoretically, be nondirective. Alva stands by her decision to decline testing in accordance with her values which she reached after having been provided with the appropriate information.

In reality, health practitioners are conscious that it is impossible to be completely nondirective. In a study undertaken by Katz Rothman in which she interviewed health professionals, one participant admitted: ‘I am aware that I can do a very subtle thing, and make a decision for somebody, and I really work at not doing that - it’s really terrible. It’s not appropriate.’[309] Information does not need to be coercive to have an impact on a woman’s reproductive decision. The statement of the health professional shows that there may be a link, even only a subtle one, between provision of information, pressure and a woman’s autonomy. It underlines the importance of giving the appropriate information in the appropriate way. If the information is inappropriately delivered, the woman may be put off testing, which she may have

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[308] *Assisted Reproductive Technology Act 2007* (NSW) s 13(1).

[309] Barbara Katz Rothman, *The Tentative Pregnancy How Amniocentesis Changes the Experience of Motherhood* (W.W. Norton & Company Inc., 1993) 40.

chosen otherwise or she may misunderstand the application of testing or screening techniques. This link between information and pressure, can also explain why Alva refused genetic counselling. Though she knew that she would decline testing, she was afraid that she would be pressured into accepting genetic testing during a genetic counselling session.

Information provided by health professionals has become a powerful tool to influence a woman's decision, even if they follow the *NHMRC ART Guideline 9.1.3* about information. For Lippman, health professionals' offers of prenatal diagnosis, genetic testing and screening have been presented as responses to the needs of pregnant women.[310] This perception of a need can be extended to non-pregnant women who are considering having a baby. Lippman argues that establishing a need for testing to diminish the possibility that a woman gives birth to a child with a detectable condition 'rests on assumptions about the value of information, about which characteristics are or are not of value and about which risks should or should not be taken.'[311] A woman is supposed to act in a responsible way in her role as a caregiver and she 'may come to "need" prenatal diagnosis, and take testing for granted'.[312] A woman, like Alva, who resists the need for testing, considers whether the risks of testing outweigh the benefits. In her eyes, there is nothing to be gained from testing, but the possible risk is great, namely; the possible loss of her embryo.[313] The reasons why a woman refuses testing vary, they are not necessarily a 'rejection of and/or resistance to the offerings of science and technology'.[314] Markens and her colleagues found that women's perception of risk, generated by the information given by the health professionals about the testing, could be a reason for refusal and that women who refused testing did not perceive it as 'routine pregnancy care'.[315] Liamputtong found in her study that a woman does not think that the medical profession should impose their beliefs systems on the patient, because not everybody is afraid of having a child with a

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[310] Lippman, above n 5, 26.
[311] Ibid 27. For Lippmann these assumptions reflect almost exclusively a white, middle-class perspective.
[312] Ibid 28.
[313] Katz Rothman, above n 309, 77.
[314] Susan Markens, CH Browner and Nancy Press, '"Because of the Risks": How Us Pregnant Women Account for Refusing Prenatal Screening.' (1999) *Social Science & Medicine* 359, 360.
[315] Ibid 364.

disability, and not everybody believes that deciding not to carry a child to term is morally or spiritually right. [316]

For Hubbard a woman's rejection of testing represents a 'rejection of modern beliefs that women should do everything possible for the health of the future child'.[317] Lippman claims further that it is easier for a woman to go along with the testing than to refuse it, and that the technology 'perversely creates a burden of not doing enough, a burden incurred when the technology is not used'.[318] Wertz and Fletcher share her view by claiming that 'it is extremely difficult, if not impossible, for women to choose to reject technologies approved by the obstetrical profession'.[319] These statements show that information that appears benign may still be coercive in effect and that the woman's decisions about testing for a disability can be influenced by 'the decisions of those in the medical profession about normality and abnormality in children'.[320] It is important that a woman receives all the information needed about testing, before she can make an informed decision, but this information needs to be given in an objective non-directive manner. Only then can a woman preserve her autonomy and refuse testing, without having the impression that she made a questionable ethical decision.

5.2.5 ART websites and their potential influence on a woman's decision making

The information provided by the clinics' websites gave Alva and her husband the impression that testing is important in order to have a healthy child. Though it made them reconsider testing, they stood by their decision to refuse it. Testing would have been in conflict with their values.

Websites can be a convincing and powerful instrument and they are very often a woman's first point of contact with a clinic. Websites are more than the passive

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[316] Pranee Liamputtong et al, 'Why Do Women Decline Prenatal Screening and Diagnosis? Australian Women's Perspective' (2003) 37 *Women & Health* 89, 96.

[317] Markens, Browner and Press, above n 314, 360.

[318] Lippman, above n 5, 28.

[319] Markens, Browner and Press, above n 314, 360.

[320] Liamputtong et al, above n 316, 96.

provision of medical information to a potential user of ART. They can shape her decision making and act directly and indirectly on a woman's reproductive autonomy. They are also an integral part of the commercialisation of ART. The progress of IVF has undergone three stages since the first IVF birth in 1978. The first stage is described as scientific, because it was marked by scientists who worked hard to find answers to the physiology of reproduction.[321] The second stage was the clinical one where fertility institutions emerged and where indications for treatment multiplied. Currently IVF has reached the stage of commercialisation where ART centres, clinics, services, private equity funding and providers merge.[322]

Over time, the patient's role has changed gradually from a service recipient to a medical consumer. In order to make autonomous reproductive decisions a woman must be given information 'verbally, supported by written information in plain language'.[323] The clinics should avoid any pressure or enticement and the *NHMRC ART Guidelines* specify that the 'up-to-date, objective, accurate information about treatment options and the procedures involved'[324] should be given 'without emotive imagery (such as images of babies and young children) or emotive language'.[325]

Although the guidelines are very clear, the presentation of information in practice looks different to these specification and websites still use advertising with beautiful baby pictures and enticing words like dream or miracle. Hawkins finds that such advertising lacks informational content and the effects on potential clients can vary and can be negative.[326] He postulates that showing a baby can nourish both real and false hopes of a successful pregnancy.[327] The use of such images of an ideal outcome of an ART treatment may influence a woman's mindset and her decisions. Arguably at the very least the websites are designed to play with a woman's feelings and emotions

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[321] Brown, Simon, 'Business Is Booming' (2014) *Focus on REPRODUCTION ESHRE (EUROPEAN SOCIETY OF HUMAN REPRODUCTION and EMBRYOLOGY)* 24, 24.
[322] Ibid.
[323] NHMRC, above n 48, 42.
[324] Ibid 41.
[325] Ibid 42 at guideline 9.1.3.
[326] Jim Hawkins, 'Selling ART: An Empirical Assessment of Advertising on Fertility Clinics' Websites' (2013) 88 *Indiana Law Journal* 1147, 1155.
[327] Ibid 1156.

in a subtle way, as the woman who may already be in a vulnerable state is exposed to emotional visual stimuli. This does not however imply that a woman who seeks ART treatment acts purely on an emotional basis just that this material pressure exerts unnecessary pressure on her.

It is often via the websites that a woman tries first to find out more about ART and she often consults them even before an actual visit with a health professional. Websites can have a positive impact because they give her detailed information about ART. A woman like Alva, who consulted the websites, could take her time to reflect on the information about genetic testing. The websites allowed Alva to get to know more about her options, to complete her picture about testing and hence make a more informed decision. She preferred not to take the risk of losing her embryo via a testing procedure, when she trusted the results of her former medical investigations, which did not indicate that she had a genetic condition.

However the provision of information via clinic websites can also have a negative impact, as another woman in Alva's position could have been indirectly pressured into certain choices and decisions. Similar to society or health professionals, websites can lead the woman in a certain direction, so that she makes decisions which are expected of her, but which are not necessarily the decisions she really wants to make and which reduce her autonomy and self-determination.

In this scenario, a woman's ethical obligation to do everything so that her future child will not be born with a disability, can also be linked to ART clinics' websites. For example, after having consulted this virtual information about "healthy babies" and availability of testing procedures, the woman may have the impression that she is expected to fulfil her ethical obligation by complying with these procedures presented on the websites. The question highlights how a woman must develop resistance to these commercially based emotional approaches and appeals in order to retain her autonomy. In this case Alva is not seduced by all the available techniques and procedures, and she does not change her attitude towards disabled children and preconception testing.

5.3 Conclusion

Scenario Three, has shown, similar to the other scenarios, a woman should not be held responsible for harm to her future child, if she declines genetic testing for herself and additional testing, even if she is advised to do so. Neither the NSW ART legislation or the *NHMRC ART Guidelines* regulate the question of whether a woman is required to use preconception tests in a situation where a woman may have a medical condition. Nor do they establish the circumstances where a woman has a responsibility to get herself genetically tested. Therefore, no legal responsibility can be assigned to the woman if she refuses getting tested.

The fact that she declines testing is an autonomous decision where the woman shows that she wants her privacy to be respected, by exercising her right not to know about her health status. This decision brings up the woman's ethical responsibility in relation to the interests of her future child. Similar to Skyla in Scenario Two, by choosing not to undergo testing, Alva avoided a possible confrontation and power issue with health professionals about a choice among tests, to see whether the baby is affected or not and finally the choice of electing or not to have that baby, that may have ultimately led to a refusal of implantation. A woman's choice can be in conflict with the predominant medical opinion.

In this scenario, the actions would have been preconception screening and in case of a presence of a genetic condition, the actions would have been to consider PGD or an egg donation. A woman's autonomy and the best interest of the future child are claimed to be at odds, especially when disability or potential disability is at play. However this assumes that disability is always worse than being born. Therefore, it is important that a woman gets comprehensive information before she makes a decision, especially when disability is a possibility.

This scenario has underlined again that the medicalisation of reproduction and the role of health professionals have an important impact on a woman's autonomy. They influence her decisions, her perception of risk and or even her perception of need for certain tests. In addition, the ART clinics' commercial marketing material, specifically websites, can influence a woman's decision making and information collection. A woman can be held ethically responsible when she decides against the medical advice or routine. She can feel pressured to act in a particular way in her role as a caregiver that is not necessarily her own genuine preference. Although the woman is the one who ultimately decides, it is a fact that her decisions, especially during an ART treatment, are not taken in isolation but in interaction with a team of health professionals. The role of the health professionals is to ascertain that a woman can make an autonomous reproductive decision, provide her with counselling and show her alternatives.

6 CHAPTER SIX CONCLUSION

6.1 INTRODUCTION

The aim of this thesis has been to analyse whether it is appropriate, to hold a woman ethically or legally responsible, where, before the birth of her child created with ART, she acted, or omitted to act, in such a way that the child subsequently born from the procedure is born with a disability.

In order to answer this question, it was first necessary to ascertain what kind of decision making occurs in the ART context. I have used three hypothetical scenarios to map out the different kinds of decisions that are made in ART and that have an impact on disability. The three hypothetical scenarios describe plausible clinical situations and were subjected to a bioethical analysis which involved consideration of the ethical responses and responsibilities arising from the potential for disability in the future child specifically. Each scenario ends in disability but the circumstances of each couple differ. Variables include whether the woman knew about a genetic condition, whether she disclosed that condition, whether she had her own or donor gametes and in which jurisdiction she accessed ART. All these different permutations raised different ethical and legal questions. The scenarios cast various angles on the ART process and show the significance and possible impact on a woman's reproductive decision and choice.

In Chapter Two, I argued that women's reproductive autonomy and choice were paramount guiding principles in any discussion of responsibility and that ideas of disability differ depending on context. Therefore, it was important to look into the research question from a feminist perspective. Although the domain of reproduction and especially ART has been undergoing constant development it is still the woman who goes through pregnancy and she is still the one who gives birth to the child. She remains a key actor and a key decision-maker in reproduction and it is her body that is the primary subject of medical intervention and procedures. She is an embodied subject during the ART process and must be treated as a fully autonomous person.

ART, with its legal and regulatory framework has had an inevitable impact on the woman, potentially undermining her reproductive autonomy.

6.2 MAIN FINDINGS OF THE THESIS

After having analysed the research question through the three scenarios, it is evident that the advent of ART has had a significant impact on the woman's reproductive autonomy and yet because of the legal and regulatory silence around women's decision making in ART it is difficult to ascertain whether and when responsibility can or should be assigned to the woman. Every decision or choice a woman makes concerning her reproductive opportunities within ART, potentially gives rise to a corresponding ethical or legal responsibility. The birth of a disabled child thus raises complex questions of rights responsibility.

The main conclusions of this thesis are as follows.

1) There is an absence of direct reference to the woman in ART legislation and regulations This can have both positive and negative outcomes for the assignment of responsibility and preservation of reproductive autonomy. Legislative silence about a woman's autonomy or responsibilities in regards to the decision-making points in the scenarios can sometimes offer the woman protection where, for instance, she is not obliged to disclose her genetic status (Scenario Two). Sometimes, however, it will deny her a voice where, for example, she is deprived of counselling and advice to ensure she is not pressured to make a particular decision (Scenario Two). If a woman is included directly in a regulatory framework, this will not automatically ensure her autonomy and may in fact operate to her detriment. Therefore any future attempt to explicitly include the woman in ART legislation must be enacted with extreme caution.

2) The use of ART has resulted in a proliferation of decision-making points and this multiplies women's reproductive responsibilities along with expanding her choices. The effect is that she is potentially subject to a host of pressures, both direct and subtle, that a woman who naturally conceives is not. As seen in Chapter Two the woman must operate within a network of relationships when she enters a reproduction process. Within this network a proliferation of decision-makers can emerge and it can be challenging for a woman to exercise her relational autonomy.

3) Social attitudes, as they infiltrate medical and health practices around ART, can impact women's sense of responsibility and reproductive autonomy.

6.2.1 THE ABSENCE OF THE WOMAN IN THE LEGISLATION AND REGULATIONS

When a woman conceives by using ART she finds herself in a reproduction process which is necessarily within a framework which legalises and regulates the various aspects of her ART treatment. The lack of definition of certain terms in the legislation and regulations can make it difficult to assign ethical responsibility to a woman in regard to her reproductive decisions. For example, there is no definition of the seriousness of a disability or a condition. It is impossible to hold somebody responsible when it is not defined clearly what she is responsible for.

This thesis has shown that there is a silence in the regulations regarding the woman’s autonomy and her responsibilities. The absence of the woman as an autonomous subject within the regulatory framework of ART, makes her invisible as a key actor and decision-maker in the reproduction process. This absence is such that neither the word “woman” nor the word “responsibility” even appear in the legislation and are rarely used in the medical description of ART treatments. There is, therefore, no indication of a potential legal and/or ethical responsibility for the woman within the ART process. As the presence of the woman is essential, it is important to acknowledge her as a main actor in ART policies and guidelines. This will acknowledge her reproductive autonomy.

However, the various scenarios demonstrate that the silence and the absence in the legislation or regulations, in regard to the various decision-making points, can have positive as well as negative consequences for a woman’s reproductive autonomy and her assignment of responsibility. Hence any legislative and regulatory acknowledgment of the woman must be linked to her reproductive autonomy. This acknowledgment needs to be handled very carefully, since it needs to embed her autonomy to make decisions and protect her from legal claims in relation to those decisions.

In Scenario One the absence of the woman and the absence of legislation in regard to the impact of the presence of a genetic condition worked in the woman's favour. Nell was able to exercise her autonomy and openly disclose her daughter’s genetic condition and could not be held legally liable for her choice to proceed. She was still able to obtain the treatment she wished to have. But Nell might have ended up not receiving her desired treatment, if she had done PGD and her embryo had a genetic condition. Without doing PGD she was able to implant her remaining embryo, independent of whether the embryo was affected or not with MM. While Nell was able to use the legislative silence to exercise her autonomy, it would be better to have positive legislation that clearly removed any legal liability on the part of the woman for these decisions.

In Scenario Two, as in the first scenario, the legislation and *NHMRC ART Guidelines* are silent about a woman’s obligation to disclose her genetic disorder. There is no indication of what, if anything, Skyla would need to disclose about her genetic condition. Skyla chose not to disclose for fear that she would be pressured to undergo testing or denied access to some ART technologies. However it is evident that Skyla’s non-disclosure had both a positive and negative effect on her autonomy. The positive effect was that she could access the ART treatment she planned to have. It might be seen as an advantage for Skyla that neither the laws nor the guidelines require any disclosure from a woman. The negative effect was that she could not receive all the information she might have wanted and needed. Receiving comprehensive information allows a woman to make an informed choice in order to make a genuinely responsible and autonomous decision. However, because she felt she could not disclose, she had to forego counselling and the possibility of expressing and exploring any concerns in a way that might have enriched her decision-making process. Thus, her exercise of her reproductive autonomy was potentially compromised.

In Scenario Three, the absence of the woman in the law also had a positive consequence for the woman, because it allowed her to exercise her reproductive autonomy, and follow through with her choice not to undergo preconception testing. Again, the legislation in Australia and the *NHMRC ART Guidelines* do not prescribe any requirements in this situation and it is a woman's responsibility to accept or refuse preconception testing or counselling where there is evidence of a possible genetic condition. The absence of the woman in the legislation can be seen as an advantage for the woman's autonomy in this case just as it was in Scenario One and Two. However, it would also be possible to reinforce the reproductive autonomy of a woman by including an explicit legal acknowledgment of a woman's autonomy to decline testing in the ART legislation, rather than relying on the right to refuse treatment more broadly.

The absence of the woman in the legislation and guidelines can therefore have significant consequences for her autonomy. On the one hand it may allow her to make an autonomous decision, but on the other hand it can undermine her power, when she is forced to withhold information or is pressured to lie, because she is afraid that if she does not she will be denied access to ART. Nevertheless it is crucial to be very cautious when we include women explicitly in legislation and regulations, so that the autonomy of their decisions is preserved and that they are protected against legal actions in regard to those decisions.

Similar to the legislation and guidelines the woman is also absent in the language of medical procedures. In contrast is the surprisingly strong presence of the not-yet conceived child in the legal and medical discourse. Prenatal and preimplantation testing techniques have contributed to this respective disappearance of the woman and presence of the not-yet conceived child. Before the ultrasound and other technological advances pregnancy was defined as a 'condition of the woman'.[328] It was only when the mother felt the foetus move that it became socially 'visible'. It was via the mother's presence and experience of 'quickening' that the foetus communicated its existence to society.[329] A consequence of this visualisation is a physical separation between the woman and the foetus, which enables us 'to separate their interests, both conceptually and morally, in turn weakening those of the parent in comparison with those [of the future child]'.[330] As Katz Rothman wrote of ART, 'the mothering experience becomes narrowed to its physical side'.[331] This separation of the woman and her body leads to the gradual disappearance of the woman as the subject of the legislative language and the subject of the medical language. Now an embryo or foetus, conceived in vitro and visible on a screen, seems to have a separate existence of its own.

The medical and medico legal language of ART use the words "embryo" and "foetus" and stress the importance of their wellbeing and their interests in a way they do not for the woman. In this way the welfare of the woman can be diminished in relation to the welfare of the future child. Hence, if we regulate to explicitly include the woman in future legislation, we must be mindful to do so in a way that does not set their interests against those of the future child.

6.2.2 PROLIFERATION OF DECISION-MAKING POINTS

Due to the complexity of the reproduction process in ART, decision-making points proliferate. ART has made the process of conception, pregnancy and birth no longer limited to one or two people, the woman and her partner; rather it has divided the reproduction process into multiple separate acts, which are shared by the woman, her doctors, ART specialists, clinical staff, nurses, counsellors, donors and regulators

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[328] Katz Rothman, above n 309, 113.
[329] Ibid.

among others. As a consequence, decisions which would in the past have been made primarily by one person, the woman, now involve various additional actors in the reproduction process. In relation to the proliferation of decision-makers, the scenarios highlight that a woman's decision-making capacity is influenced by the attitude of persons who are involved or weigh in on the formation of a decision.

More people, more input, more information, and likely a wider range of technological possibilities lead to many more decisions than are encountered in natural conception. Even the most capable woman is put into a situation where she is confronted with challenging new situations and testing opportunities. She might feel that she has no choice but to make use of these opportunities, especially in a situation where she needs to decide about testing where a disabled child might be born. This proliferation of decision making around testing is also linked to the negative approach to disability which, as argued in this thesis and set out below, is embedded in the ART system, and both have an impact on a woman's autonomy and responsibility.

This research has shown that there is a constant negotiation between a woman's reproductive autonomy, the interests of the child and the influence of health professionals in shaping ethical considerations. With the proliferation of decision-making points it is crucial that a woman's choice should be considered carefully during an ART process, and health professionals play a key role in ensuring this is so. The scenarios have demonstrated that a woman's and the future child's interest can be set at odds, particularly because of the way that the legislation and guidelines are written to prioritise the latter. I have argued that the role of the health professionals should be to facilitate a woman's decision making as a matter of paramount concern.

For the woman's decisions to be autonomous, she needs to be comprehensively informed beforehand regarding what this decision involves. Therefore it is important that the clinics give the necessary support, counselling and follow-up to the woman throughout the ART process. A woman should not feel pressured to make a particular decision and she should be able to make it in accordance with her values and her capacities and the necessary support.

Scenario One described Nell making an autonomous decision to disclose her genetic condition while retaining her right to have a child that may be born with that condition. The potential consequences of such a decision were canvassed. First, it led to the birth of a genetically affected child for which, it was argued, she could be held ethically responsible within some bioethical frameworks, particularly in the context of an ableist society where '[t]here is a widespread assumption that the best interests of children are to be born able-bodied (including intellectually abled)'.[332]

Another consequence of her disclosure was that her privacy and the privacy of her daughter and the donor, in relation to each other and the IVF clinics, are compromised. Theoretically the risk exists that their privacy will be compromised further if the clinic fails to keep the records private. By disclosing the genetic information, she had an unintended impact on her future child's right to keep its genetic health status private. Disclosure, in the ART context, can mean that reproductive autonomy is more restricted for a person who needs ART to become a parent than one who does not. In this situation her rights and parental capacities may be subordinated to the future child's welfare.

By contrast Scenario Two examined what might happen if there had been non-disclosure. In that scenario Skyla was able to maintain control of what happened with this sensitive health information, for herself and her future child. Her decision not to disclose was also one way to manage the potential impact of the additional decision-makers on her choices. The health professionals did not have a significant impact on her reproductive choice, because she avoided being confronted with more advice and pressure to undergo further testing. She did not have to choose whether she wanted to have PGD, for example, or be afraid of being denied ART treatment on the grounds of the best interests of the future child. On the negative side, as mentioned above, she

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[332] de Lacey and Norman, above n 157, 1067.

also did not have access to the same information as she would have had if she had disclosed her condition.

Similar to Scenario One and Two, Scenario Three has shown that a woman, like Alva, who decides not to undergo any testing for herself, or her future child, is making an autonomous decision. Health professionals have a duty to give her advice and counselling during her ART treatment, and also to supply her with comprehensive information before she makes a decision, especially when disability is a possibility but they do not have a duty to pressure her into a particular decision. Alva's decision to refuse testing, has prevented a possible confrontation with health professionals about a choice among tests. It has also avoided any refusal of implantation that health professionals may have felt bound to make.

Alva's decision has underlined her determination to have her privacy respected by exercising her right not to know further information about her health status. Hence this Scenario has shown that a potential conflict can rise, when the pressure a woman feels to participate in testing and counselling is at odds with the protection of her privacy. Also in an ableist society, by defending her right to privacy, a woman's ethical responsibility is questioned, because her decision can be considered as acting against the interest of the child, when her child is born with a disability.

This Scenario has again emphasised the impact of the medicalisation of reproduction and the role of health professionals on a woman's decision making. In addition, it has shown that the ART clinics' commercial marketing material, specifically websites, can influence a woman's decision making and information collection. On the one hand, they can have a positive effect on her decision, because they provide her with a vast range of detailed information, on the other hand the provision of information via clinic websites can also have a negative impact. Similar to society or health professionals, the websites can lead the woman in a certain direction, so that she makes decisions which are expected of her, but which are not necessarily the decisions she really wants to make and which reduce her autonomy.

In order to help a woman make an autonomous decision despite all the various decision-making points, a complex balance is needed between the interest and rights of the woman, the interests of the future child, the interests of people living with a disability and the more general values of non-discrimination and diversity of life. All these factors are essential as they have an impact on a woman's decision-making process.

6.2.3 NEGATIVE ATTITUDES TO DISABILITY AND THEIR IMPACT ON A WOMAN'S DECISION MAKING

ART is a medical domain where research is promoted and new techniques are presented primarily as scientific breakthroughs. ART has expanded the possibilities for future parents, enabling many people to have babies who would not otherwise be able to become parents. However, some of these techniques are directed towards ensuring the birth of a so-called "healthy" baby and this means different things to different people. ART is driven by commercial as well as medical interests, and in order to be successful clinics need to promote new testing methods. Therefore, clinics need to be cautious that in their drive to succeed in both their scientific and commercial endeavours, they do not overwhelm the autonomous decision making of women, especially those who may choose unconventional paths and wish to continue with ART despite the presence of a possible disability.

This thesis has shown also that the fact that a child is born with a disability can lead to a potential conflict between disability rights feminists and feminist choice activists. As we saw in chapter one, some of the former, such as Lippman and Asch, argue that ART does not offer a woman a greater reproductive choice but rather places an onerous burden on her to create perfect children, whereas the latter, like Purdy and Andrews, argue the contrary: that a woman should have all possible options and more and better testing technologies only increase her choices.

With respect to disability itself, we saw in the scenarios that the women have to make their decisions in regard to a possible disability of her future child in an ableist environment, which can shape her decisions. Her decision can be influenced by the absence or insufficiency of social support and structures for persons with a disability. The scholarship has shown, that in order for the woman to make autonomous reproductive decisions related to disability, it would be desirable that an environment surrounds her, where a framework of social network and structures exists. Scholars, like Asch, argue that the presence of such framework can be decisive in a woman's decision-making process. In those cases where a woman makes a decision about giving birth to a disabled child instead of choosing termination of a disabled child, the existence of a social support network may be crucial to her decision.

Health professionals not only have an important role in regards to the proliferation of decision-making points in ART, as seen in section 6.2.2, but also in regard to questions of disability. They have an important role to play as expert or trusted advisor for a woman who wants to have ART treatment. They exercise responsible practice when they provide the material support for a woman to give informed consent and make a reproductive decision in accordance with her values, without feeling pressured or judged by health professionals. In that context, Asch suggests that potential parents should gain access to this information, because

> responsible practice that is concerned with genuine informed decision making and true reproductive choice must include access to this information, timed so that prospective parents can assimilate general ideas about life with disability before testing and obtain particular disability relevant information.[333]

Clinics should not operate from the perspective only of a non-affected person. This limited perspective could and does not result in a clinic considering it their duty to avoid the birth of a disabled person. A negative approach to disability pre-empts the question of responsibility, since it assumes the woman must avoid disability to act responsibly, however I have argued this is not the appropriate way to respond to

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[333] Asch, above n 8, 1655.

possible disability in a future child. In order to reinforce a positive approach towards disability, it is worth promoting support and comprehensive provision of genuine information about disability for women during their ART process. Real-life information about the quality of life of people with disabilities might illuminate a different perspective.

In all three Scenarios, the autonomy of the woman can be construed by some bioethicists as in conflict with the interest of the future child where the woman does not do all in her power to avoid disability. In Scenario One and Two, the disclosure and non-disclosure of the genetic condition and their attitude towards disability, put both women in a situation of conflict with the interests of their future child.

In Scenario One, although Nell decided to disclose her first child's condition, she might be considered as ethically irresponsible, because she decided to have her embryo implanted whether affected or not. Nell did not consider a possible disability impacting her second child as a reason not to have this embryo implanted. For Nell, her remaining embryo was worth implanting and being raised. Not having this embryo implanted would have prevented her from exercising her reproductive choice. Hence a future child's alleged wellbeing can challenge the woman's autonomy. This Scenario showed that it was in the hands of the clinic and its attitude towards disability, to respect or not Nell's reproductive decision to have her affected remaining embryo implanted.

In Scenario Two, Skyla did not disclose her genetic condition, and as a consequence she did not proceed with any testing for her embryo. Despite having a genetic condition herself, Skyla was able to exercise her reproductive autonomy because ART allowed her to become a parent on her own terms. However her non-disclosure showed that she was afraid that ART could have potentially challenged and disputed this same right where it intersects with a clinical bias against disability. The Scenario underlines the desirability role of health professionals being 'disability-conscious'[334], so

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[334] Ouellette, above n 99, 14.

that women, like Skyla, do not need to be afraid to disclose their condition because they are afraid of the reactions of health professionals to their own health status.

Scenario Three shows that a woman’s attitude towards disability has an important impact on her decision making. Alva declined testing for her future child, because she was prepared to risk having a child with a disability. She believed that she could cope with a disabled child and decided that she would rather not test and give birth to a child independent of the health status. As seen in Scenarios One and Two, the medicalisation of reproduction encourages an attitude that subordinates the woman’s values. However, if a more positive attitude to disability is accepted into clinical practice, Alva’s decision is both legal and ethical.

The ethical considerations of Alva’s refusal concern also her position towards disability. Her position seems to become ethically questionable the moment she plans to have a child, especially in an ableist society, where a woman is considered to be acting *responsibly* in the interest of a not-yet conceived child by accepting all testing to prevent the conception or birth of a disabled child.

The approach to disability and a woman’s ethical obligation to do everything so that her future child will not be born with a disability, can also be linked to ART clinics’ websites. In this Scenario, Alva consults all this virtual information about “healthy babies” and availability of testing procedures. Alva is not seduced by all the techniques and procedures, and she does not change her attitude towards disabled children and preconception testing.

6.3 CONCLUSION

This thesis aimed to analyse the appropriateness of holding a woman ethically or legally responsible, where, before the birth of her child created with ART, she acted, or omitted to act, in such a way that the child subsequently born from the procedure is born with a disability.

After having analysed what happens in practice, via the three hypothetical scenarios, a woman cannot be assigned legal responsibility under our current legislative and regulatory frameworks, because they are silent about such a responsibility. But the scenarios have shown that, while it would be preferable to explicitly acknowledge women's rights and responsibilities in legislative form, a simple inclusion of the woman in legal structures will not necessarily increase her reproductive autonomy. They showed, that leaving a woman out as a main actor in ART legislation and regulation, can have a positive effect and play in favour of a woman's autonomy. Hence if we want to include the woman and make her visible in the legislation, we need to proceed carefully. We need to be very cautious, in order not to reduce her autonomy in her decision making, so that she is protected from legal claims in relation to those decisions.

Before a woman can be held ethically responsible, systemic and structural protections around provision of information and treatment are required. Furthermore a positive approach to disability would need to be promoted on a societal and medical level, so that women who consider giving birth or raising a disabled child, can count on a support network. They would need to be encouraged particularly by health professionals, because the scenarios have shown the influence of these professionals on a woman's decisions. A woman should not feel pressured to make any particular decision and she should be able to make the decisions she does in accordance with her values. Unless these systemic and structural protections are in place and an openness to disability is developed woman's autonomous decision making cannot be protected and respected.

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