

**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.

29<sup>th</sup> of February 2016

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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 Lymphotropic 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).<sup>1</sup> 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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<sup>1</sup> 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.