

The concept of prenatal screening as an enforceable parental duty

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PhD in Bioethics and Medical Jurisprudence

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School of Law

DEDICATION

To Granny Betty who is watching from above, my parents who have unknowingly taught me how to be a good parent, my wife, my soul mate, Gemma and our daughter Eliza, our *raison d'être*

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ABSTRACT

Name Of University: The University of Manchester

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Thesis Title: The concept of prenatal screening as an enforceable parental duty

The question of whether parents-to-be have a moral obligation to maximize the welfare of their future children before they are born has fuelled considerable debate and a multitude of contrasting opinions from within the philosophical, legal and medical academic literature over the last three decades. It is unsurprising that this burst of activity in the field has coincided with continuous and significant advances in the field of reproductive, perinatal and neonatal medicine. These advances perpetually re-set the bar as to what screening processes and therapies can be offered before birth to ensure that infants are born in the healthiest possible state. By extension, I argue, that our obligations towards the unborn should also change.

Within this thesis I explore philosophical and legal theories relating to responsibilities held to the unborn child by those wishing to be parents but also the State. In doing so, I approach the available literature from a more clinical viewpoint. I argue that in future, when screening processes and *in utero* therapies are likely to be safer and more effective, the duty of future parents to bring to life the healthiest child possible will become more compelling.

In my articles I employ a personhood view of the foetus and argue that eventual children can be harmed in the pre-personal stage. I carefully analyze what it means to be harmed and apply a comparative account of harm through the thesis in trying to answer the five main questions that permeate through the articles.

I question whether parents-to-be have a moral obligation to engage with antenatal screening services, I do not limit the screening processes to genetics alone but include foetal anomaly and microbiological information acquired antenatally in the process. I also explore what the obligations of parents-to-be are, once a screening process reveals a certain problem or risk. I elaborate on what circumstances they may be obliged to act upon, in a way that treats or minimizes the risks posed to the foetus. I argue that even in the absence of a cure, antenatally acquired information can be vital for the welfare of the child and this should compel parents to engage with the services on offer. I also purport that if there is a cure the parents are obliged to uptake it, provided it is safe and with good clinical outcomes.

Finally I question whether the State has a moral duty to increase uptake of such antenatal health programs and if so to what extent should it attempt to do so. By analyzing the moral limits of law I argue that impositions on individual liberties in the interest of the unborn may only be reasonable if our reproductive choices stand to significantly harm others. I argue that recent amendments in English and Welsh Law that prohibit the application of advanced reproductive technologies to select for disabled fetuses signify an important change in the way the State values the welfare of future children. I explore international legal cases that suggest that the foetus is increasingly afforded more legal protections and investigate possible ways in which we could objectively quantify harm caused antenatally in a manner that would help us decide if and when the State should intervene with reproductive choices of parents-to-be. Finally, I elaborate on the how State led medical paternalism can be stratified and what each stratum involves in terms of intervention. I put forth that the State ought to explore avenues of soft and moderate paternalism first but should stop short of hard paternalism for a number of reasons.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Date 24th of November 2016

Constantinos Kanaris

On the value of expert knowledge

“The way we got out of the caves and into modern civilisation is through the process of understanding and thinking. Those things were not done by gut instinct. Being an expert does not mean that you are someone with a vested interest in something; it means you spend your life studying something. You’re not necessarily right – but you’re more likely to be right than someone who’s not spent their life studying it.”¹

¹ Cox B. Being anti-expert is the way back to the cave . *The Guardian* 02/06/2016 <https://www.theguardian.com/tv-and-radio/2016/jul/02/professor-brian-cox-interview-forces-of-nature> accessed 23/06/2016

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I would like to express the deepest gratitude to my supervisor Professor Rebecca Bennett. No superlative is enough to express what a big role she has had in steadying me during numerous wobbles through the course, there is no doubt in my mind that this thesis would have been left unfinished without her infectious optimism, inherent pastoral qualities and unparalleled support. Her qualities as a teacher and work ethic are rare and she is a true asset to the University of Manchester. Becki has also supervised me before me during my intercalated undergraduate degree in Medical Ethics and Law so our friendship has spanned over a decade; I know that in her I have found a lifelong friend.

During my time at the University of Manchester and the Royal Manchester Children's hospital I have also greatly benefited from the backing of three individuals who have not been directly involved in my thesis but have always been there to support me in whatever fashion it was asked of them, sometimes with brutal honesty, sometimes by fighting my corner and always with a big serving of compassion and understanding about my

circumstances. Professor Margot Brazier, Dr Guy Makin and Dr Rob Yates, you have all had an integral role to play in the completion of this PhD, I am forever indebted to you.

Last but not least, I would like to thank my closest friends who have been there for moral, emotional and any other type of support that was asked of them during a very traumatic period of my life, during events that threatened to extinguish everything that I have worked for. James Higgins, Sarah Boehm, Niel Davis and Diane Adamson, I am blessed to have people like you as friends, I am forever grateful.

THE AUTHOR

I am a physician within the field of paediatric intensive care medicine; my vocation entails looking after critically ill children and often their end of life care. During my undergraduate years I had the opportunity to undertake an intercalated degree in Medical Ethics and Law and have maintained my interest in the field ever since. When I was given the chance to be part of the first cohort of students to undertake a Ph.D. Programme in Bioethics and Medical Jurisprudence at the University of Manchester I could not refuse, a decision made, perhaps, more with the heart rather than the mind. It has been a challenging, positive, educational experience that has allowed me to appreciate the value of perseverance as well as support from teachers, friends and family.

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PUBLICATIONS AND CONFERENCE PAPERS

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LIST OF ABBREVIATIONS

ART	Advanced Reproductive Technologies
BMA	British Medical Association
CHAOS	Congenital High Airway Obstruction Syndrome
CPS	Crown Prosecution Service
CVS	Chorionic Villus Sampling
DMD	Duchenne Muscular Dystrophy
DNA	Deoxyribonucleic Acid
DoH	Department of Health
EU	European Union
GBS	Group B Streptococcus
GMC	General Medical Council
GP	General Practitioner
HFEA	Human Fertilisation and Embryology Authority
HIV	Human Immunodeficiency Virus
HVS	High Vaginal Swab
ICF	International classification of functioning
ICF-CY	International Classification Of Functioning, Disability And Health: Children And Youth
ICIDH	International Classification of Impairments, Disabilities and Handicaps
MRI	Magnetic Resonance Imaging

NHS	National Health Service
NICE	National Institute for Health and Care Excellence (formerly Clinical Excellence)
OTCD	Ornithine transcarbamylase deficiency
SDS	Severity of Disabilities Scale
U.N	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund (formerly United Nations International Children's Emergency Fund)
UTI	Urinary Tract Infection
WHO	World Health Organisation

PREAMBLE

Ιθάκη

Σα βγεις στον πηγαϊμό για την Ιθάκη,
να εύχεται νάναι μακρύς ο δρόμος,
γεμάτος περιπέτειες, γεμάτος γνώσεις.
Τους Λαιστρυγόνες και τους Κύκλωπας,
τον θυμωμένο Ποσειδώνα μη φοβάσαι,
τέτοια στον δρόμο σου ποτέ σου δεν θα
βρεις,

αν μέν' η σκέψις σου υψηλή, αν εκλεκτή
συγκίνησης το πνεύμα και το σώμα σου
αγγίζει.

Τους Λαιστρυγόνες και τους Κύκλωπας,
τον άγριο Ποσειδώνα δεν θα συναντήσεις,
αν δεν τους κουβανείς μες στην ψυχή σου,
αν η ψυχή σου δεν τους στήνει εμπρός
σου.

Να εύχεται νάναι μακρύς ο δρόμος.
Πολλά τα καλοκαιρινά πρωιά να είναι
που με τι ευχαρίστησι, με τι χαρά
θα μπαίνεις σε λιμένας πρωτοειδωμένους•
να σταματήσεις σ' εμπορεία Φοινικικά,
και τες καλές πραγμάτειες ν' αποκτήσεις,
σεντέφια και κοράλλια, κεχριμπάρια κ'
έβενους,

και ηδονικά μυρωδικά κάθε λογής,
όσο μπορείς πιο άφθονα ηδονικά
μυρωδικά•

σε πόλεις Αιγυπτιακές πολλές να πας,
να μάθεις και να μάθεις απ' τους
σπουδασμένους.

Πάντα στον νου σου νάχεις την Ιθάκη.
Το φθάσιμον εκεί είν' ο προορισμός σου.
Αλλά μη βιάζεις το ταξίδι διόλου.
Καλλίτερα χρόνια πολλά να διαρκέσει•
και γέρος πια ν' αράξεις στο νησί,
πλούσιος με όσα κέρδισες στον δρόμο,
μη προσδοκώντας πλούτη να σε δώσει η
Ιθάκη.

Η Ιθάκη σ' έδωσε τ' ωραίο ταξίδι.
Χωρίς αυτήν δεν θά βγαινες στον δρόμο.
Άλλα δεν έχει να σε δώσει πια.

Κι αν πτωχική την βρεις, η Ιθάκη δεν σε
γέλασε.

Έτσι σοφός που έγινες, με τόση πείρα,
ήδη θα το κατάλαβες η Ιθάκες τι
σημαίνουν

Ithaca

When you set out on your journey to Ithaca,

pray that the road is long,

full of adventure, full of knowledge.

The Lestrygonians and the Cyclops,

the angry Poseidon -- do not fear them:

You will never find such as these on your path,

if your thoughts remain lofty, if a fine

emotion touches your spirit and your body.

The Laistrygonians and the Cyclops,

the fierce Poseidon you will never encounter,

if you do not carry them within your soul,

if your soul does not set them up before you.

Pray that the road is long.

That the summer mornings are many, when,

with such pleasure, with such joy

you will enter ports seen for the first time;

stop at Phoenician markets,

and purchase fine merchandise,

mother-of-pearl and coral, amber and ebony,

and sensual perfumes of all kinds,

as many sensual perfumes as you can;

visit many Egyptian cities,

to learn and learn from scholars.

Always keep Ithaca in your mind.

To arrive there is your ultimate goal.

But do not hurry the voyage at all.

It is better to let it last for many years;

and to anchor at the island when you are old,

rich with all you have gained on the way,

not expecting that Ithaca will offer you riches.

Ithaca has given you the beautiful voyage.

Without her you would have never set out on the road.

She has nothing more to give you.

And if you find her poor, Ithaca has not deceived you.

Wise as you have become, with so much experience,

you must already have understood what Ithacas mean.

In the very first draft of my introduction during the first year of my PhD I made reference to a poem that has been very close to my heart since I was a child. It was omitted from subsequent versions of the introduction but it seems fitting for me to include it again at the very beginning of this thesis proposal.

"Ithaca"² is based on Homer's account of Odysseus's voyage home. The poem reflects on the journey of life in all its complexity, outlining its inevitable setbacks and the lessons learnt, lessons necessary for survival. Cavafy's poem urges us to live for the journey rather than end-point, in order to have a flourishing and fulfilling life; the value of life is life itself, not the destination.

"Ithaca" suggests that we ought not to wish away our time, but "ask that (our) journey be long". We may have many problems on the way, health worries or lost loved ones, but when we eventually, and inevitably, overcome these troubles by the time we arrive to our own metaphorical Ithaca we will be much more resolute and better armored for future obstacles.

The course of this degree has unquestionably thrown its fair share of adventure my way and there is surely a case to be made that I would have, in retrospect, had a strong preference for less Cyclopes and Laistrygonians and more Phoenician markets on the way. What I can say with certainty is that I have emerged from the process wiser and stronger whilst appreciating those around me who have persistently shown that they will be supportive in any future journey. To those who have sailed with me, and they know who they are, I am forever grateful.

² Cavafy CP 'Ithaca' (1911), *The Complete Poems of Cavafy*, trans. Dalven R (1961). Hogarth, p36-7.

PART 1
INTRODUCTION

CHAPTER 1

PHILOSOPHICAL AND LEGAL BACKGROUND

CHAPTER 1

Introduction: The concept of prenatal screening as an enforceable parental duty

Aims

The aim of this thesis is to make a case in favour of the concept that prenatal genetic screening (and where available prenatal treatment) is a parental duty. It is argued that parents have a *duty to know* whether or not the child they are about to bear is healthy or not and how not exercising that duty might make them ethically culpable. I argue that screening is a necessary tool in making a parental moral choice, not only for parents-to-be that are liberal in their opinions on abortion, but also necessary in couples/single parents who oppose abortion. Once a reasonable case of the above is made I argue further that the state has a moral claim in promoting widespread prenatal screening for a number congenital and genetic conditions.

Clarifications

It needs to be addressed from the outset that the aim here is not to promote abortion, but rather to improve the quality of life of those that are to be born disabled and enhance parental education as well as choice. Nor is it my goal to imply that to be born with a genetic condition is a parental moral error, for that would devalue those with variable degrees of disability. Although I will focus at large on westernized societies, my arguments can also plausibly be extrapolated to safeguard against infanticide in countries where this is prevalent.^{3,4,5} I will advocate that the parental error would be not maximizing the quality of life of this potentially disabled child and how screening in

³ Mosher, S. (1984). Forced abortions and infanticide in Communist China. *The Human life review*, 11(3), 7-34.

⁴ James, W. H. (1997). The Validity of Inferences of Sex-Selective Infanticide, Abortion and Neglect from Unusual Reported Sex Ratios at Birth. *European Journal of Population/Revue européenne de Démographie*, 13(2), 213-217.

⁵ Sahni, M., Verma, N., Narula, D., Varghese, R. M., Sreenivas, V., and Puliyel, J. M. (2008). Missing girls in India: infanticide, feticide and made-to-order pregnancies? Insights from hospital-based sex-ratio-at-birth over the last century.

pregnancy can positively influence such a life. Emphasis will also be placed on how treatment of disability, *in* or *ex utero* (i.e. an enhancement that stands to improve the overall health of the resulting disabled child), is a possible derivative of this parental foreknowledge. I support that such therapy (be it an anatomical or genetic enhancement, or one resulting from advanced parental education), to an existence brought to life in a disadvantaged state, provided it is safe on future parents and the foetus, is also a moral pursuit.

I shall focus on genetic screening, rather than testing as the former applies to a broader population. Whilst both are used to predict the likelihood of a genetic condition, genetic testing is a parent/patient-targeted term, only clinically indicated in people with a collection of specific signs and/or symptoms and a positive family history⁶. Genetic screening is applicable in cases where there are neither signs, symptoms nor a clinically significant family history and as such encompasses a broader population. So whilst in genetic testing a parent must have a predisposition to a condition, and hence a greater need to gain insight on the genetic makeup of their potential offspring (or so may current clinical practice lead us to believe)⁷, screening poses no such limits and can encompass every parent-to-be.

I only refer to screening where the primary purpose is to benefit the foetus or newborn through *in utero* or early treatment (medical or social) and also touch upon the special considerations that engulf conditions whereby early neonatal death is the likeliest outcome. Any conditions that are late onset, are therefore excluded with the caveat that in the future, with gene therapy advances, some of the arguments I put forth may extend to include late onset conditions. I purport that the conditions that parents ought to screen for are disorders in which effective treatment is available and disorders where early medical, surgical and even educational intervention are proven to improve the health and by extension the quality of life of the resulting child. The conditions do not necessarily need

⁶ Goetzing, K. R., and Odibo, A. O. (2011). Statistical Analysis and Interpretation of Prenatal Diagnostic Imaging Studies, Part 1 Evaluating the Efficiency of Screening and Diagnostic Tests. *Journal of Ultrasound in Medicine*, 30(8), 1121-1127.

⁷ There's ample examples to this effect, current UK National Screening Committee guidelines for prenatal Down syndrome screening advises or targets gravid women over 30 years of age as the incidence of the condition exponentially increases with maternal age. Many more such targeted tests exist on <http://nscfa.web.its.manchester.ac.uk/> Accessed 12/12/2013

to be of a genetic nature, spina bifida (essentially an unfused spinal column), for example, is usually a result of complex environmental factors and genetic mutations are both sporadic and rare.⁸ The defect, however can be repaired *in utero* or prevented by the mother taking folic acid during pregnancy.⁹ Most of the conditions that involve amino acid, organic acid and fatty acid oxidation disorders, haemoglobinopathies as well as conditions where severe mental handicap exists would fall in the category that parents ought to screen for and a non-exhaustive but reasonably comprehensive list, albeit applicable to neonates, was published by the report by the American College of Medical Genetics (ACMG) urging screening for these disorders.¹⁰

I also need to clarify that I shall be referring to duty in terms of a moral responsibility or obligation rather than in a legal context and as such I will need to expand on why the foetus or the potential child may be worthy of such protections. Although the thesis has a philosophical character at large, a brief overview into the legal aspects of my proposal will be made.

Focus will be placed on how choices made with the power of knowledge, have a greater probability of being moral choices. I will argue that if prospective parents make decisions regarding the foetus without having previously tried to highlight any health problems the foetus will have, they will be committing a moral error. I will base a lot of my reasoning on the concept of knowledge as a virtue and of the need for these important choices to be informed choices. My opinions have been shaped by clinical experiences I have had as a paediatric critical care physician, working both within neonatal and paediatric intensive care units. The more senior I have become within the paediatric intensive care field, the more I have battled with the paradox that physicians leave no stone unturned to prevent harm (or often, averting further harm from happening) to the

⁸ Copp, A. J., Adzick, N. S., Chitty, L. S., Fletcher, J. M., Holmbeck, G. N., and Shaw, G. M. (2015). Spina bifida. *Nature Reviews Disease Primers*.

⁹ Greenberg, J. A., Bell, S. J., Guan, Y., and Yu, Y. H. (2011). Folic acid supplementation and pregnancy: more than just neural tube defect prevention. *Reviews in Obstetrics and Gynecology*, 4(2), 52.

¹⁰ Watson, M. S., Mann, M. Y., Lloyd-Puryear, M. A., Rinaldo, P., and Howell, R. R. (2006). American College of Medical Genetics Newborn Screening Expert Group Newborn Screening: Toward a Uniform Screening Panel and System-Executive Summary. *Pediatrics*, 117(5), S296-S307.

child and yet we fail to protect potential children in their most fragile state, with the same vigor.

The law, of course, demands of us to do so after birth but there are no such legal safeguards in antenatal period. As the welfare of children is paramount in my line of work, I explore how this can be better protected antenatally and whose responsibility it is to do so. I argue that more medical and parental antenatal knowledge, and the acquisition of information about the foetus before it is born will help more children to be born in a healthier state. I also believe that failure to engage with antenatal services, if provided, and on the proviso that the parents are planning to go ahead with the pregnancy raises serious moral questions. After all, without the acquisition of vital antenatal information (and there is a wide array of information to be acquired ranging from microbiological risks to genetic risks) there is little to no chance that the foetus will receive appropriate care to treat what puts it at risk in the first place; a crucial opportunity missed.

The incidence of disability and the impact of prior knowledge

Internationally, there is a 6% chance of any given newborn to have a genetic condition that will affect its health and wellbeing¹¹. Congenital disorders are common; the World Health Organisation (WHO) estimates that 7% of all neonatal deaths are caused by congenital anomalies (calculated to be in the region of 260,000 per year).¹²

This percentage is higher in countries where consanguineous marriages are prevalent^{13,14} and lower in more affluent, westernized nations where routine screening for a small

¹¹ Christianson, A., Howson, C. P., and Modell, B. (2005). March of Dimes: global report on birth defects, the hidden toll of dying and disabled children. *March of dimes: global report on birth defects, the hidden toll of dying and disabled children*. On <http://www.marchofdimes.com/MOD-Report-PF.pdf>

¹² World Health Organization. (2010). Birth defects: report by the Secretariat. *Sixty- (2) Third World Health Assembly A, 63* http://apps.who.int/gb/ebwha/pdf_files/WHA63/A63_10-en.pdf. Accessed 16 November 2015

¹³ Khlaf, M., and Khoury, M. (1991). Inbreeding and diseases: demographic, genetic, and epidemiologic perspectives. *Epidemiologic reviews*, 13, 28

¹⁴ Mokhtari, R., and Bagga, A. (2003). Consanguinity, genetic disorders and malformations in the Iranian population. *Acta Biologica Szegediensis*, 47(1-4), 47-50.

number of conditions is carried out¹⁵. It is a fact that there is still a stigma in having offspring with a certain genetic conditions in many societies. Parents of such children react in a multitude of ways, ways impossible to formulate and predict, reactions as diverse as the spectrum of cultures out there. Anyone who attempts to formulate parental reactions within individual cultures taking into consideration main influencing parameters such as religion and affluence is posed with a serious socio-philosophical challenge. This is because often the reaction of the individual may be ultimately molded in accordance to family politics and dynamics rather than consideration for what is the moral choice or the moral action.^{16,17,18}

What has, however, been noticed socially is that that parents of those with certain genetic conditions are more likely to either give up their child for adoption, foster care or abandon them in a specialized institution with minimal contact thereafter. This is especially true of some cultures, more so in the east than the west^{19 20}. This poses numerous ethical concerns about the prospective quality of life of the child but also that of the potentially guilt ridden parent.

A large proportion of those with a genetic condition or malformation have numerous psychosocial issues that predictably impair quality of life. Take a common condition, Down syndrome, for example . Children born with trisomy 21 have severe cognitive impairment and by extension arguably less chance of having the things that are so

¹⁵ Cunningham, S., and Marshall, T. (1998). Influence of five years of antenatal screening on the paediatric cystic fibrosis population in one region. *Archives of disease in childhood*, 78(4), 345-348.

¹⁶ Brown, N. A., Clegg Smith, K., Thornton, R. L., Bowie, J. V., Surkan, P. J., Thompson, D. A., and Levine, D. M. (2015). Gathering Perspectives on Extended Family Influence on African American Children's Physical Activity. *Journal of Health Disparities Research and Practice*, 8(1), 2.

¹⁷ Mandell, D. S., and Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental retardation and developmental disabilities research reviews*, 11(2), 110-115.

¹⁸ Kramer, E. J., Kwong, K., Lee, E., and Chung, H. (2002). Cultural factors influencing the mental health of Asian Americans. *Western Journal of Medicine*, 176(4), 227.

¹⁹ Su, B., and Macer, D. R. (2003). Chinese people's attitudes towards genetic diseases and children with handicaps. *Law and Human Genome Review*, 18, 191-210.

²⁰ Ravindranadan, V., and Raju, S. (2007). Adjustment and attitude of parents of children with mental retardation. *Journal of the Indian Academy of Applied Psychology*, 33(1), 137-141.

stereotypically linked with the socially imposed image of what construes “happiness”: parenthood, education, relationships and health. With respect to the latter especially, children with Down syndrome have very high incidences of congenital heart problems and leukaemias in addition to everything else. This is not to say that Down syndrome children do not have worthwhile lives but rather, given that they are born in a disadvantaged position they have a right to the optimization of their life, a life that is as good as can be and this, I argue, can be facilitated if parents are aware of their condition prenatally. Most would argue that good health is something the majority of us aspire to have, and deem it as something good and pleasurable. By extension, a cogent case can be made that the chances of parent ‘A’, parenting child ‘a’ without any congenital or severe genetic problem having a better quality of life than parent ‘B’ who fathers/mothers offspring ‘b’ with a debilitating condition, are likely to be much increased. I explore whether parents can harm themselves by their failure to screen antenatally and treat a disability accordingly, should a suitable therapy be available.

The Royal College of Paediatrics and Child Health’s²¹ guidance in withholding or withdrawing life-sustaining treatment for children, acknowledges the significant impact of disability in families and those around them. From personal clinical experience, my social observation is that in most cases, the greater the dependence of the eventual child on healthcare services and the more the child is reliant on carers for everyday functioning, the greater the degree of disability, and the greater the impact will be on his parents lives (and the immediate family). This observation has well documented evidence.²² Financially one can argue that parents will have less economic resources to invest in their own interests, albeit this could be said of parenthood in general. The magnitude of limitations in earnings in cases of severe disability has consistently been proven to be severe. Parents often have to stop work to provide carer duties; home

²¹Royal College of Paediatrics and Child Health (2004). *Withholding or withdrawing life saving treatment in children : A framework for practice*. http://www.gmc-uk.org/Withholding.pdf_40818793.pdf Accessed 25/08/2015

²² See for example one of the first studies to emerge on the subject in Piachaud, D., Bradshaw, J., and Weale, J. (1981). The income effect of a disabled child. *Journal of epidemiology and community health*, 35(2), 123-127.

adjustments are imperative to make accommodation functional, recurrent specialist health care appointments, and predictably large medication bills. The catalogue of sacrifices a parent of a disabled child has to make, as listed, is sizeable but not exhaustive.²³

In addition there are considerably higher stress²⁴ levels and higher depression and divorce rates²⁵ documented in parents of children with disability. Analysis suggests that these stem from a combination of reasons such as financial concerns and bearing witness to the inability of their child to flourish within the societal norm. It is thus feasible for an argument to be made that parents may harm themselves in opting out of antenatal services that may unmask certain disabilities that can be potentially treated.

On the opposite side of the argument, the consensus of numerous studies that focus on the impact on families with a disabled child found that despite the challenges posed, parents of disabled children have lives comparable to the general population²⁶. Similarly, arguments have been made on the negative impact on the psychology of families that had an abortion following antenatal test result that indicated a foetal anomaly. The reasoning is that the magnitude of the impact on the family's psychology may be far worse than the effect of having a disabled child would be.²⁷

I should point out that comparing the severity of impact on psychology between the theoretical occurrence of an abortion versus the theoretical birth of a disabled child is not accurately possible. It is no more possible to compare what my mood will be like before I

²³ Dobson, B., and Middleton, S. (1998). *Paying to care: The cost of childhood disability*. York Publishing Services. pp 1-4

²⁴ Keskin, G. (2010). The evaluation of anxiety, parental attitude and coping strategy in parents of children with mental retardation. *Anatolian Journal of Psychiatry*, 11(1), 30-37

²⁵ Cummings, S. T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically III children. *American Journal of Orthopsychiatry*, 46(2), 246.

²⁶ Ferguson, P. M., Gartner, A., and Lipsky, D. K. (2000). The experience of disability in families: A synthesis of research and parent narratives. in Parens, E., and Asch, A. (2000). *Prenatal testing and disability rights*. Georgetown University Press p. 73.

²⁷ Anstey, K. W. (2008). A critique of arguments supporting disability avoidance. *Disability and Society*, 23(3), 235-246.p.237

go for a swim to someone else that decides not to go for a swim. Furthermore, as my position is not one of disability avoidance but rather one of disability reduction, the arguments focusing on the secondary effects of abortion on families are not directly relevant.

On the basis of the above evidence I would deduct that with the exception of severe disability, whereby children have an extremely poor quality of life, the act of parenting, in itself, be it of a healthy or disabled child, is likely to be a worthwhile, fulfilling, stressful, rollercoaster venture regardless. The philosophical defence of the application of the harm principle antenatally, for the protection of *the parents* becomes easier the more severe the disability of the child is. With severe disability, evidence of the detrimental effects to the parents is much more clear but with milder disorders the evidence is not as compelling, by extension proving philosophically that parents can be harmed by their child having a less severe disability is difficult. I expand on the relative evidence in the second paper of the thesis.

Note that this is not to say that those that bear healthy foetuses do not have a duty to screen. This would be nonsensical, as one would only know if the foetus is healthy or not if and only if he/she engages with antenatal screening services. As such, everyone who wishes to become a parent has a moral duty to engage with antenatal screening services. The only way in which harm to parents and resulting child can be reduced is by up taking such services and any available therapies, on the proviso that early intervention (that is safe to both mother and child to be) can improve the degree of functioning of the resulting child.

I will suggest that the onus of “educated foresight” largely lies with the parent and what actions he/she/they have taken to ensure a good quality of life for their child. Extrapolating the Aristotelian dictum *οὐ το ζῆν, ἀλλὰ το εὖ ζῆν* (*ou to zein alla to eu zein*)²⁸: our object is not to stay alive but to live as we should (or live well depending on translation), one could argue that parental role and responsibility is not to ensure that that

²⁸ Aristotle *Nicomachean Ethics* (2002) Focus Publishing full ref needed

their offspring lives, but that it lives well and that parental contract does not begin with the passage of the foetus through the birth canal but 9 months before that. I argue that if prospective parents have the intention of bearing that specific foetus, then harming that foetus in the pre-personal state is morally wrong. By extension in an era where advanced reproductive technologies allow us better foresight into how healthy the foetus is, prenatal screening is increasingly necessary in order to help the forward planning of a healthier child. I put forward the argument that failure to engage with antenatal screening services and the subsequent failure to uptake effective, safe treatments that can treat any health issues highlighted by the obtained foreknowledge is a moral wrong.

Taking spina bifida for example, a parent whose child will be born with spina bifida can attempt to maximize the quality of life of his /her child by taking folic acid or allowing *in utero* repair of the defect.²⁹ This implies two positive actions. Firstly, the screening process, without which the vital information couldn't be gained and secondly, the repair/enhancement process. Both of these need to materialise if the parent is to act in a moral fashion, if either or neither happens a child that could have otherwise been born healthy is born severely debilitated without any real prospects of an *eu zein*. If we are to achieve a certain result we need to educate ourselves first (*x*), act on that education (*y*) and eventually achieve that aim (*z*). If our moral pursuit *z* is to ensure, or attempt to, have a good quality of life for our children the fore-education *x* and action on that education *y* are vital steps in achieving that. If *z* is not a viable option with current medical advances, e.g. when a child is born with anencephaly (complete lack of brain tissue) infanticide can be justified as the moral choice.

Is it wrong for the State to prefer non-disabled (or less-disabled) potential offspring to disabled ones?

The above question is an alternative take on two questions that John Harris compares and contrasts:

²⁹ Walsh, W. F., Bruner, J., and Tulipan, N. (2000). Neonatal outcome of the first 50 infants treated with in utero repair of spina bifida. In *Pediatric Research* Vol. 47, No. 4, pp. 439

- Is it wrong to prefer a nondisabled person to a disabled one?
- Is it wrong to prefer to produce (or even to prefer to be) a nondisabled individual rather than a disabled one?³⁰

Harris swiftly rejects the first, loaded question and rightly so. Preferring someone disabled to someone who is able-bodied would advocate a whole avalanche of social inequalities and injustices. Those disabled are not worthy of any less (or more) moral, political, social consideration than those without disability. The subtle, yet all-important difference in the questions is the word *person*. Whilst the former refers to already existing people, or persons in Harrisian terms, the latter refers to people yet to be born. Harris asks the above question with potential parents in mind, attempting to justify why it's not morally objectionable for parents to not want their potential children to be disabled in any way. He further elaborates that it is intuitive in most to wish the best for their children (those that already exist and those that come to exist) and how "it is better that my child be not disabled, but not that if it is disabled, a nondisabled child is a better child".³¹ In doing so he safeguards the dignity of those disabled, without devaluing disability in itself. By choosing, for example, to either vaccinate against an infection (such as the widely used pertussis vaccine in pregnancy given to the mother-to-be, proven to reduce the incidence of whooping cough in the infant)³²; or to give antibiotics to minimize the harm sustained to a patient is not to discriminate against those who are already infected. The entire medical profession is dedicated to harm minimisation in any disease process.

Disability rights activists take issue with the Harrisian account³³, a common argument is that disability is a social construct so instead of trying to reduce the incidence of

³⁰ Harris, J. (2010). *Enhancing evolution: The ethical case for making better people*. Princeton University Press. p88

³¹ *ibid* p89

³² Gall, S. A., Myers, J., and Pichichero, M. (2011). Maternal immunization with tetanus–diphtheria–pertussis vaccine: effect on maternal and neonatal serum antibody levels. *American journal of obstetrics and gynecology*, 204(4), 334-e1.

³³ See for example Asch, A. (1989). Reproductive technology and disability. In Cohen, S., and Taub, N. (1989). *Reproductive Laws for the 1990s* (pp. 69-124). Humana Press.

disability, the collective ought to make the world a more accepting and easily accessible place for them. I agree with Harris against this stance. It does not follow logically that people who encourage good antenatal health and practices in the interest of the eventual child by the application of reproductive technologies, wish to get rid of people with existing disabilities, *au contraire*. It is because disabled members of society are valued and the limitations to their everyday functioning (as perceived by those not disabled, at least) that such technologies exist, in order to help address those limitations. Ethicists, doctors, geneticists, lawyers that defend the application of reproductive technologies in parallel with the advancement of social and medical support in order to improve the health of our future children do not discriminate against those who are disabled. In Harris' words:

To decide not to keep a disabled neonate alive no more constitutes an attack on the disabled than does curing disability. To set the badly broken legs of an unconscious casualty who cannot consent does not constitute an attack on those confined to wheelchairs. To prefer to remove disability where we can is not to prefer non-disabled individuals as persons. To reiterate, if a pregnant mother can take steps to cure a disability affecting her foetus she should certainly do so, for to fail to do so is to deliberately handicap her child.³⁴

Harris' main focus, however remains the preference of *the parent* towards nondisabled offspring; but what about the preference of *the State*? In attempting to assess whether it is wrong for the *State* to prefer non-disabled (or less-disabled) potential offspring to disabled ones, two other questions are bound to be asked:

- To what extent should the State extend public policy to accommodate parental preferences?
- Why does the State have a vested interest in the parents-to-be in being responsibly aware of their potential offspring's health?

³⁴ Harris, J. (1993). Is gene therapy a form of eugenics? *Bioethics*, 7(2-3), 178-187. p182

Disability rights groups will be quick to point out that for the State to openly prefer non-disabled offspring to the extent where procreative liberties are being directly or indirectly limited, devalues or discriminates against the disabled.³⁵ Jonathan Glover elaborates on these “ugly attitudes towards people with disabilities”³⁶ and history (with the most obvious example of Nazi Germany) indeed makes us cautious of proverbial slippery slopes. The following extract, composed by parents of children with Down syndrome confers what an (openly expressed) State preference for non-disabled children may construe.

Does British society really want to make this statement to our children with the syndrome, and the many adults with it who are living independent, fulfilling and wonderful lives, that they shouldn't be here; they are such a burden that they should be eradicated before birth?³⁷

The above quote succinctly highlights the “expressivist objection” whose central claim is that the use of prenatal testing to select against disabling traits expresses a hurtful attitude about disability and sends a hurtful message to people who live with those very traits³⁸. The same argument stretched to its limit appears to also suggest that prenatal screening and subsequent selective abortion seems to imply that those disabled are unworthy of being born on the grounds that the DNA they possess is flawed or suboptimal.³⁹

Based on the above, on first instance, it may intuitively seem wrong and indeed indefensible for the State to openly promote screening programmes designed to treat and change these very disabilities it screens for. Is it not, however, also intuitive for parents to want the healthiest possible children and to expect the State to make this a possibility, to make this a reality? Are then, these two “intuitions” in direct opposition to each other? Seemingly they cannot both be true.

³⁵ See for example *Regulating eugenics*. (2008) *Harvard Law Review* 121(6): 1578-99. (No authors listed)

³⁶ Glover, J. (2006). *Choosing children: genes, disability, and design: genes, disability, and design*. Oxford University Press.p 29

³⁷ *ibid* p33

³⁸ Parens, E., and Asch, A. (2003). Disability rights critique of prenatal genetic testing: reflections and recommendations. *Mental retardation and developmental disabilities research reviews*, 9(1), and 40-47.

³⁹ Gonter, C. (2004). The expressivist argument, prenatal diagnosis, and selective abortion: an appeal to the social construction of disability. *Macalester Journal of Philosophy*, 13(1), 3.

The key in the above conundrum is the interpretation of the word disability. Harris defines this as “a condition that someone has a strong rational preference not to be in and one that is moreover in some sense a harmed position”.⁴⁰ I have preferred the Harrisian account over another frequently used definition, that of Daniels who suggests that disability ought to be seen as something that interferes with “normal species functioning”.⁴¹ The main problem with Daniels account is the word “normal”, which is at best, a term that eludes a consistently good philosophical definition. I may be disabled, relative to the population that surrounds me but still be normal. Under this definition it can be argued that a Caucasian 100m sprinter is disadvantaged when compared to his Black counterparts, as genetically they are blessed with having a higher proportion of "fast-twitch" fibres and more testosterone than white athletes, which in turn predisposes a black athlete to run faster.^{42,43} Granted fast twitch fibres are not the only piece of the jigsaw that fulfils a successful sprinting career, but assuming all else being equal, such as funding, graft, focus and a winning mindset the Caucasian athlete is still disadvantaged. The fact that the last Caucasian sprinter to win the 100m even at the Olympics was all the way back in 1980⁴⁴ is testament to this Caucasian “disability” under Daniels’ definition. The example may be race-specific but few would argue that a Caucasian athlete, fit to compete at the highest level is disabled. Disadvantaged perhaps, relative to his black counterparts but certainly not disabled or less healthy. Harris’ account precludes any consideration to normalcy and therefore anticipates possible pitfalls the “normal species functioning” definition might have had.

But where Harris gives a good account of disability, he is more cautious with his approach as to what the position of the State should be in terms of deciding whether to prefer disabled over non, or less-disabled offspring: “We have recognized the powerful

⁴⁰ Harris J. *op.cit.* p91

⁴¹ Daniels, N. (2007). *Just health: meeting health needs fairly*. Cambridge University Press.

⁴² Weston, A. R., Karamizrak, O., Smith, A., Noakes, T. D., and Myburgh, K. H. (1999). African runners exhibit greater fatigue resistance, lower lactate accumulation, and higher oxidative enzyme activity. *Journal of Applied Physiology*, 86(3), 915-923.

⁴³ Bosch, A. N., Goslin, B. R., Noakes, T. D., and Dennis, S. C. (1990). Physiological differences between black and white runners during a treadmill marathon. *European journal of applied physiology and occupational physiology*, 61(1-2), 68-72.

⁴⁴ Adam Wells of Great Britain in the Moscow Olympics when the US decided to boycott the venue

desire and the strong interest that people generally have in having children. Just as this desire should be exercised *responsibly*, (my emphasis) we should also be careful not to frustrate it without good reasons”.⁴⁵

It would be ideal for a State to be fully populated with Harris’ “responsible parents”. A world where in contrast to the current low childhood immunisation uptake rates⁴⁶ the uptake was one hundred percent minimising the spread of life threatening communicable diseases in childhood, a world where parents opted out of smoking in the interests of the welfare of their children,⁴⁷ a world where in general the children’s health and welfare was a prime concern for parents. In such a world the welfare of the child would be optimised, and that is an end in itself. However, utopian discourse, although attractive, is impractical for the formulation of social policy. In a country where non-accidental injury of children is on the rise⁴⁸ and in the advent of some very high profile child abuse cases across the UK and Europe (Baby P,⁴⁹ Victoria Climbié⁵⁰ and Josef Fritzl⁵¹ to name but a few) it is evident to see that the sense of parental responsibility is not universal and in some cases severely ailing. This is not to say that child abuse, *in utero* abuse and bringing a disabled child into the world are morally equivocal, far from it, but safeguarding child health (as applied to actual and potential children) and promoting “responsible parenting” merits special consideration by the State both *in* and *ex utero*. I shall elaborate.

⁴⁵ Harris J. *op cit* p95

⁴⁶ Harrington, P. M., Woodman, C., and Shannon, W. F. (2000). Low immunisation uptake: Is the process the problem? *Journal of epidemiology and community health*, 54(5), 394-394.

⁴⁷ Cook, D. G., and Strachan, D. P. (1999). Summary of effects of parental smoking on the respiratory health of children and implications for research. *Thorax*, 54(4), 357-366.

⁴⁸ Barlow, K. M., and Minns, R. A. (2000). Annual incidence of shaken impact syndrome in young children. *The Lancet*, 356(9241), 1571-1572.

⁴⁹ Baby P : The Whole Truth? http://news.bbc.co.uk/panorama/hi/front_page/newsid_8029000/8029126.stm Accessed 12/12/2014

⁵⁰ Victoria's parents welcome ‘progress’ <http://news.bbc.co.uk/1/hi/education/3091120.stm> Accessed 12/12/2014

⁵¹ Profile: Josef Fritzl <http://news.bbc.co.uk/1/hi/world/europe/7371959.stm> Accessed 12/12/2014

A State preference for widespread screening: Promoting responsible parenting and a preference for more functional disability.

If the public health department were to suggest that all pregnant women would have to undergo prenatal screening to identify congenital and genetic imperfections in the foetus, the likely justification would be along these lines:

- a) It may benefit the State financially.
- b) It may benefit a number of children with conditions where *in utero* or early *ex utero* therapies are available.
- c) It allows parents to make fully informed decisions about their offspring.
- d) It would advocate the advancement of foetal surgery and gene therapy.

On the other side of the coin the main two objections to a widespread prenatal screening government proposal would probably be:

- a) Parental autonomy is paramount and as such parents should not be coerced into tests they do not wish to have
- b) This is a eugenic proposal that discriminates against the disabled.
- c) Increased uptake of all screening services will increase abortion rates.

Let us analyse these arguments one by one to see if they stand up to scrutiny.

Constructing the arguments in favour of a State preference for widespread screening, the promotion of responsible parenting and a preference for more functional disability.

a) It may benefit the State financially.

Within the medical system disability has been viewed as a biological problem or a limitation.⁵² Physiological limitation is thought of as a substantial contributing factor to

⁵² Berkowitz, E. D. (1989). *Disabled policy: America's programs for the handicapped: A Twentieth Century Fund report*. Cambridge University Press.

high unemployment, low educational levels and by extension low socioeconomic status. This physiological limitation provides a financial burden to governments, other than not earning their dues; those disabled may come with “hidden extras”. The State needs to provide special schooling, income support, special carers, disability allowance, fund increased healthcare bills, invest in buildings for disabled access and parking and so on.

Unsurprisingly, this justification, referred to in the disability communities’ literature as “the medical model of disability”⁵³ receives widespread condemnation. According to Adrienne Asch, this sort of reasoning suggests, “Disability must be prevented because disabled people cannot function within existing society”⁵⁴ and brings us full circle to Glover’s aforementioned ugly attitudes towards disability. There may be enough financial incentives to promote widespread screening with a view to reducing overall disability, which in turn would in all probability save the government money but capitalist and financial reasoning are worlds apart from moral reasoning.

This type of financial utilitarianism is a poor argument in which to justify a widespread screening process, and I explore this in depth in my first article. It may be true that those who are disabled are more likely to have an inferior *financial* value to the State than someone able bodied, or even a negative financial value.⁵⁵ However, it would be a serious blow to human dignity; equality and respect to humanity to even suggest that a disabled person is of less moral worth to the State and a vast generalisation to say that all those classified as disabled are likely to be more of a financial drain than those classified as non-disabled. As a result I would argue that a disabled person is entitled to as much concern by the State as someone who is less disabled. Those disabled ought to be empowered and afforded equal opportunities for flourishing but there are socially determined walls, that can hinder them from doing so. According to the United Nations,

⁵³ Saxton, M. (2000). Why members of the disability community oppose prenatal diagnosis and selective abortion. *Prenatal testing and disability rights*, 147-164. Parens, E., and Asch, A. (2000). *Prenatal testing and disability rights*. Georgetown University Press.

⁵⁴ Asch, A. (1989). Reproductive technology and disability. In Asch, A., Cohen, S., and Taub, N. (eds) (1989). *Reproductive Laws for the 1990s*. Humana Press p.73

⁵⁵ Notable exceptions obviously do exist with the likes of Stephen Hawking (Motor neuron disease) John Milton (acquired blindness) Frida Kahlo (polio, anecdotally spina bifida)

barriers that exclude or restrict a disabled persons full integration in society can be physical, financial, social or psychological⁵⁶.

As a physician, I believe that the purpose of any screening process ought not be to eradicate disability, I believe in this emphatically. Nor is the purpose of screening to improve financial prosperity of the State. Rather; it is to aid parents and prospective parents assume their parental responsibilities and decide, in a more educated and informed fashion whether they are in a position to raise a disabled child, whether there are any early steps (*in* or *ex utero*) that allow any frustrations to the child's welfare to be reduced so as to improve the child's quality of life or at least to have its welfare more optimised. This is not to say, however, that there are no valid reasons to consider how societal welfare may also be frustrated financially if antenatal screening services are not engaged with. This merits some more clarification.

Some argue that the State has a vested financial interest in screening for case-specific conditions.⁵⁷ Firstly, a system whereby the onus of financially supporting those less healthy lies on the presumably healthier wider society seems to be primarily self-serving. There are bound to be situations where ascertaining whether a reproductive choice stands to increase or reduce the welfare of others is unclear. It can be suggested therefore, that it is in our collective best interests to fund such cases, in the event that we may require such assistance in the future.

This objection is pertinent in grey cases; it does little to illuminate the cases whereby the reproductive choices are black and white. Take foetal surgery and persisting with our example of *in utero* spina bifida repair. When the technique and outcomes are perfected, an easily diagnosed disability can be treated and the overall health of that resulting child will improve.

⁵⁶ U.N. World Conference on Human Rights, Vienna Declaration and Programme of Action, U.N. Doc. A/CONF.157/23 (1993) 64.

⁵⁷ Kurtz Z . Children and the State Tunstill, J. (Ed.). (1999). *Children and the State. Whose Problem?* A and C Black. p92-117

The mainstay of postnatal care of uncorrected spina bifida focuses on palliation of the existing neurological damage rather its reversal. Part of this limitation of postnatal care results from the deleterious effects that the *in utero* environment has on the neural elements. A recent prospective randomized multicenter trial showed that *in utero* repair significantly helps preserve neurological function, reverses hindbrain herniation and decreases the need for surgical ventricular shunting to alleviate hydrocephalus⁵⁸. Physicians argue that the procedure is likely to become safe and set the standard of care for the management of these congenital anatomical deformities in the near future.⁵⁹ I argue that apart from the more obvious harm that befalls the child by parental failure to screen, diagnose and uptake the appropriate therapy the reproductive choice in similar cases, there may be a collateral harm to society in general. My position is that a failure to repair the said malformation *in utero* is bound to result in otherwise avoidable significant neurodisability, frustrating thus the eventual child's welfare. The disabled child will need medication, physiotherapy, mobility equipment, recurrent hospital appointments and admissions and neurosurgery at the very least. It may be more relevant to those involved with healthcare economics rather that moral philosophy but apart from the obvious impact on the quality of life of the child, which is my prime concern, all these medical interventions will also accrue significant medical costs, a bill that in the UK at least, is publically funded.

In cases whereby one is unable to disentangle whether an antenatal decision can improve or minimize the child's health and the collective welfare, the application of the harm principle in an antenatal setting cannot be defended sufficiently. However, as in the case of spina bifida where the science is clearer and there is the possibility of safe therapies for disability *in utero*, we can argue that failure to engage with antenatal services and therapies results in true harm on both a child specific as well at a societal level.

⁵⁸ Adzick, N.S., Thom, E.A., Spong, C.Y., Brock III, J.W., Burrows, P.K., Johnson, M.P., Howell, L.J., Farrell, J.A., Dabrowiak, M.E., Sutton, L.N. and Gupta, N., (2011). A randomized trial of prenatal versus postnatal repair of myelomeningocele. *New England Journal of Medicine*, 364(11), 993-1004.

⁵⁹ Moldenhauer, J. S. (2014). In utero repair of spina bifida. *American journal of perinatology*, 31(7), 595-604.

b) The State justification for parental screening certain children with conditions in which in utero therapies or early ex-utero treatments are available stand to benefit

According to John Stuart Mill “The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant.”⁶⁰ There is of course a considerable opposition as to whether the harm to others principle can be applied to the antenatal setting. The juxtaposed arguments vary; some argue, citing the maternal/foetal conflicts⁶¹ of interest: parents should be autonomous and have little/no obligation toward a theoretical future child, a foetus after all is not a person (in Harrisian terms) and merits less moral consideration than actual persons. Others argue that the harm principle cannot be applied to the antenatal setting as parents-to-be have a right not to know about their own genetic makeup, even if it is to the detriment of a future child.⁶² My second paper explains how Mills’ harm principle can be appropriately used in the antenatal setting and addresses the various accounts of harm in moral philosophy. The third and final paper looks at how there is a trend within English and US law that has incrementally afforded the foetus more protection and investigates whether and to what extent, the State should promote antenatal screening services.

If we were to borrow Mills’ harm principle premise, that stems from political theory, and apply it to reproductive ethics we can advocate that reproductive liberties are worthy of our utmost respect, but the State’s respect for these liberties ends where the public peril begins.⁶³ In order to prove that the State has sufficient moral justification to frustrate these reproductive liberties we must first try and prove that to bring a child into the world that is more disabled than it would have been if antenatal screening and therapies had been up taken, is to harm or wrong it in some way. It is very important to note again that what I am purporting is not replacing disabled foetuses with other foetuses that are

⁶⁰ Glover J. *op. cit* p73

⁶¹For a good overview see: Harris, L. H. (2000). Rethinking Maternal-Fetal Conflict: Gender And Equality In Perinatal Ethics. *Obstetrics and Gynecology*, 96(5, Part 1), 786-791.

⁶² Takala, T. (1999). The right to genetic ignorance confirmed. *Bioethics*, 13(3-4), 288-293.

⁶³ This is wordplay on a verdict on the famous Tarasoff case, which moulded confidentiality laws across in the U.S, see Buckner F and Firestone M. (2000) "Where the Public Peril Begins": 25 Years After Tarasoff. *The Journal of Legal Medicine*. 21 (2): 187-222 and *Tarasoff v. Regents of University of California*, 17 Cal. 3d 425, 551 P.2d 334, 131 Cal. Rptr. 14 (Cal. 1976)

healthier, but rather exploring if the State has a moral duty to promote safe (and only safe) *in utero* enhancement of foetuses with health risks to make them more healthy/less disabled giving them thus a chance at a better quality of life than they would have otherwise had.

Let's take an example of two doctors who attempt to treat a pregnant woman for a common urinary tract infection (UTI). Dr G erroneously prescribes trimethoprim to a pregnant woman, which is currently the first line treatment for a simple uncomplicated UTI,⁶⁴ but dangerous in pregnancy because it can cause neural tube defects such as spina bifida.⁶⁵ In this instance the physician would be deemed negligent (in law), careless (at best) by his peers and be blamed for exposing the child to be to unnecessary risk in developing structural abnormalities. Whether the child develops structural abnormalities or not is irrelevant, the fact that a child's future chance of being as healthy as possible has been jeopardised makes the physicians action a morally harmful one. Obviously the parents, and the State, would feel more aggrieved if the potential child had come to actual harm from the medication but the physicians' culpability would have been no bigger.

Dr T decides to prescribe the pregnant dysuric patient thalidomide. The State and parental grievance would have been even bigger with Dr T's actions when compared to Dr G's actions not only because thalidomide is of no use in urinary tract infections but because the likelihood of foetal deformity and eventual harm is much bigger.⁶⁶ It is fair to say that both physicians were in a position of responsibility to safeguard and improve the health of the child bearer and the foetus. If the justification for their actions was that they were unaware of the effects the medicines had on gestation, it would be improbable that they would get any sympathy in the court of law because of legal liabilities attached to

⁶⁴ Raz, R., Chazan, B., Kennes, Y., Colodner, R., Rottensterich, E., Dan, M., Lavi, I. and Stamm (2002). Empiric use of trimethoprim-sulfamethoxazole (TMP-SMX) in the treatment of women with uncomplicated urinary tract infections, in a geographical area with a high prevalence of TMP-SMX-resistant uropathogens. *Clinical infectious diseases*, 34(9), 1165-1169.

⁶⁵ Hernández-Díaz, S., Werler, M. M., Walker, A. M. and Mitchell, A. A. (2001). Neural tube defects in relation to use of folic acid antagonists during pregnancy. *American journal of epidemiology*, 153(10), 961-968.

⁶⁶ Brook, C. G. D., Jarvis, S. N., and Newman, C. G. H. (1977). Linear growth of children with limb deformities following exposure to thalidomide in utero. *Acta Paediatrica*, 66(6), 673-675.

prescription errors.⁶⁷ In addition, the fact that they both allowed their knowledge shortcomings to (potentially) endanger a foetus renders them culpable not only in the legal sense but also in a moral one. The court is, however, more likely to look at Dr G's case more kindly, as he at least exhibited some basic *knowledge* of medicine by prescribing an antibiotic rather than a sedative/hypnotic unlike Dr T who exhibited utter lack of knowledge. So whilst Dr G may have some chance of being excused in the moral court for having some knowledge, Dr T will have no chance. Knowledge is the main determinant as to how much relative professional (and perhaps moral) guilt can be ascribed to Drs G and T. Ignorance is a jaundiced justification in the moral court, and it would be hard to argue that the State, and indeed the parent, would benefit from ignorant physicians.

What seems to me as a double standard, however, is that a physician who, through his oversight has risked a foetus, is likely to be condemned, professionally and perhaps morally by State and parents alike; but a gravid mother-to-be who carries on smoking and drinking alcohol in the first trimester of pregnancy exposing the foetus to unnecessary risks of lung and heart defects is spared by the State. The State recognises that the physician is in a position of responsibility that needs to be coupled with knowledge to avoid any wrongdoing and the view on parental responsibilities should be no different. According to Harris "Should she (the mother) stop these things and modify her behaviour so as to maximize the chances of her child not being thereby injured? Again I believe she should and that she would be wrong not to, wrong because to fail to modify her behaviour would be to deliberately risk injuring her child".⁶⁸ It can therefore be argued that all of us have a moral obligation to act to prevent harm to others, even when those others are future children, provided there is every parental intention to turn that specific foetus into a child.

The onus, according to the above account seems to lie with the parent-to-be; he/she should stop smoking and drinking, *he/she* should modify her behaviour. Again, in the

⁶⁷ Edersheim, J. G., and Stern, T. A. (2009). Liability associated with prescribing medications. *Primary care companion to the Journal of clinical psychiatry*, 11(3), 115.

⁶⁸ Harris J *op.cit* p 90

utopia of responsible parenting the State could rely on future parents' drive to sacrifice certain aspects of their lives that would benefit their children, but individual variations as to how responsible parents are will never cease to exist, in the same way variation of how responsibly people drive will never exist. In the same fashion that the State has a moral duty to implement safe driving to minimize harm that results from reckless driving, it could be argued that the State also has a moral duty in implementing safe, responsible, educated parenting. My autonomy, my driving liberties as a driver are frustrated because according to State law I am not allowed to go through a red light or drive at 80 mph on a residential road, but they are, according to Mill, frustrated for a good reason, the safety of others. The same can be applied to State implemented widespread screening policies, parental responsibility to *gain knowledge* prenatally and act responsibly with that knowledge so as to benefit and minimize the wrongdoing on the resulting child.

This is not to say that a couple who become aware that they are bearing a child with trisomy 21 would be doing anything morally wrong by deciding to give birth to a baby with Down Syndrome, far from it. The moral error, however would be if, once bestowed with that fore-knowledge they failed to provide early steps in stimulating, educating and providing adequate physiotherapy to that child (all of which are means that have been proven to raise the IQ of children with Down Syndrome) so as to maximize his/her quality of life. In a similar way, the moral wrong would be if they declined the offer of screening from the outset; ignorance, as I have argued, is a poor justification for an injustice to the eventual child. In the same way in which Dr's G and T could not be morally defended for simply "not knowing" that the drugs they prescribed could harm the foetus, the same rule of thumb ought to be applied to the parents who are in a position of at least as much responsibility, if not more.

These opportunities for improving the potential offspring's quality of life can only be grasped if the parents somehow become aware of the syndrome/deformity/disability in advance. Small measures like early physiotherapy and education of the child can make a big difference but also on some occasions more grandiose opportunities will arise. Spina

bifida and tracheal atresia⁶⁹ can be repaired *in utero* for example. The former repair would enable a child that would otherwise be born destined to be a wheelchair user, to run and walk and do sport, the latter would allow the child to live. It is hard to imagine a parent that would decline having its child's structural defect repaired if the proposed procedure was safe and effective, for refusing to do so would be to deny the eventual child to be fully mobile once born. It would also be hard to justify, in a moral sense, parents that would decline a repair of spina bifida and deny full mobility to their prospective child. This consequentialist approach is not a new concept. According to Julian Savulescu parents have strong obligations to choose the best child they possibly can⁷⁰ and extending the argument seems to purport that parents have an obligation to provide their children with the best upbringing they possibly can. While Savulescu's claim may be controversial⁷¹ what is much less controversial is that we have an obligation to future children that they be born in a condition that maximizes their welfare. Advocates of procreative beneficence theories use the widely accepted premise that one is obliged to cure (or try to cure) serious disease in children and extend this obligation to the foetal environment, i.e. the requirement for parents (and doctors) to use advanced reproductive technologies in order to avoid serious diseases. The theories however fall short on advocating mandates of prenatal testing or selective abortion as a means of disability or serious disease control and avoidance. The main cited considerations are related to women's rights to their bodies, religious freedom and discrimination against disability.^{72,73,74}

⁶⁹ Kanaris C, Cooper Hobson G. Ofoegbu B Neonatal Airways: A B C; It's (not Always) Easy As 1, 2, And 3: Looking Into The Future Of Neonates With Severe Upper Airway Compromise. (2015) World Airway Management Meeting, November <http://www.epostersonline.com/wamm2015/node/1683?sections=true>

⁷⁰ Savulescu, J. (2001). Procreative beneficence: why we should select the best children. *Bioethics*, 15(5-6), 413-426.

⁷¹ For an opposing view see Bennett, R. (2009). The fallacy of the principle of procreative beneficence. *Bioethics*, 23(5), 265-273.

⁷² Glover, J. (2006). *Choosing children: genes, disability, and design: genes, disability, and design*. Oxford University Press.

⁷³ Green, R. M., and Wood, D. (2007). *Babies by design: The ethics of genetic choice* (p. 33). New Haven and London: Yale University Press.

⁷⁴ Agar, N. (2008). *Liberal eugenics: In defence of human enhancement*. John Wiley and Sons.

I agree in part with Savulescu, at least in terms that the parents have strong obligations to safeguard their prospective child's good health and flourishing, but the term "choose the best" seems impractical in terms of a nationwide screening program. It would also be difficult to implement this in certain religious states and although Savulescu does not expressly advocate this, the stance has been criticized of inferring a compulsory abortion of foetuses that are in some way imperfect. It also implies one should prefer perfect foetus A over imperfect foetus B. That, on a larger scale would advocate selecting against disability on a large scale. My premise is that the State's and the parents' obligation is rather to optimize the *existing foetus*, thereby creating the best possible child that *that* foetus could be; provided the existing foetus has a predisposing risk or a congenital abnormality that renders itself to be safely treated. The mode of either risk reduction or therapeutic interventions to reduce the disability burden to a specific foetus is less relevant, but it is pertinent that whatever the mode, it is safe to both foetus and parent. Risk reduction can be by means of antibiotics (if the risk is a congenital infection) foetal surgery (in congenital anatomical foetal anomalies) or even genetic means by *in utero* gene therapy⁷⁵ when this becomes available. It is of course, self-evident, without antenatal screening, the risks cannot be known so the appropriate treatment options cannot be explored.

It is important also to highlight that I do not advocate a widespread abortion policy for disabled foetuses; my aim is not to eradicate disabled foetuses and replace them with other, healthier ones but rather to improve the health of existing foetuses. My premise allows abortion to be optional without deducting from the fact that parents ought to *make* the healthiest child possible. Abortion of a child with spina bifida is still a viable option under my premise, and one that can be defended with Richard Brandt's reasoning that "no person is frustrated or made unhappy or miserable by not coming to exist"⁷⁶ but a pre-person only becomes worthy of moral consideration from the specific point-in-time that the parents decide to have that specific child. Only then is there a firm (assumed)

⁷⁵ Schneider, H, Coutelle, C. (1999). In utero gene therapy: the case for. *Nature medicine*, 5(3), 256-257.

⁷⁶ Brandt R.B 'The Morality of Abortion' (1974) in Perkins R.L (ed.), (1974) *Abortion: Pro and Con* Schenkman Publishing Co, p.163

contract between foetus and parent that at some stage this potential will be met and the child will come into existence. If the parents chose to abort, that potential will never be met and there cannot be said to be moral value in potential that has no chance of being met. The parental and State duty in itself is to *make* the resulting child as healthy as possible. If the possibility exists to produce a child that will be in a less harmed condition by parental/medical or any other sort of intervention, then it is to the benefit of the resulting child and in the moral interest of the parent and State alike to pursue that.

c) Screening allows parents to make fully informed, educated decisions about their offspring.

It can be argued that most of us could hazard an *educated* guess of what the likely outcome of our actions would be, but the resulting outcome would not necessarily be the desirable one. Many of us would have a valid case in expecting to be judged by our actions and not their outcomes. History is full of medical examples where actions with good intentions end up having bad outcomes. The true story of Mary Mallon⁷⁷ (nicknamed Typhoid Mary) springs to mind whereby the aforementioned cook an asymptomatic carrier of *Salmonella Typhi* caused a typhus outbreak in the early 1900's (and the death of 3 people) in New York including the homeless shelter where she used to volunteer. A well-meaning action with a disastrous outcome.

The following excerpt from Bernard Williams clarifies my point further.

Mette looked into the eyes of her husband, but could find no flicker of remorse.

‘You tell me you want us back,’ she said to him. ‘But how can we do that when you won’t even admit that you did the wrong thing when you left me and the children?’

Because in my heart I don’t think I did wrong, and I don’t want to lie to you,’ explained Paul. ‘I left because I needed to get away to follow my muse. I went in the name of art. Don’t you remember when we used to talk about Gauguin and

⁷⁷ Leavitt, J. W. (2014). *Typhoid Mary: captive to the public's health*. Beacon Press.

how he had to do the same? You always said that he had done a hard thing, but not a wrong one.’

‘But you are not Gauguin,’ sighed Mette. ‘That’s why you are back. You admit you failed’

‘Did Gauguin know he would succeed when he left his wife? No one can know such a thing. If he was in the right, then so was I.’

‘No,’ said Mette. ‘His gamble paid off, and so he turned out to be right. Yours didn’t, and so you turned out to be wrong.’

‘His gamble?’ replied Paul. ‘Are you saying luck can make the difference between right and wrong?’

Mette thought for a few moments. ‘Yes. I suppose I am.’⁷⁸

Mette argues that two individuals may behave in exactly the same way, one being labeled as moral, and one as immoral depending on the outcome. Gauguin left his family and on doing so succeeded in becoming a great artist and is hence being applauded; whereas Paul replicated the same, initial action, but failed in his artistic endeavors and as such is being condemned for it. In extrapolating the above conundrum I will argue that a State that bases the welfare of its population on luck (for it is luck that generates outcomes from decisions stemming from genetic ignorance) does so on ethically shaky grounds. I will also aim to prove that the State has an overwhelming interest in educating responsible parents to maximize the welfare of the resulting children; wishful thinking for a good life of the State’s children is not sufficient. As in Gauguin’s case, luck can mean the difference between success and failure, life and death. I will argue that luck should not play a role in determining whether parents are moral agents or not, parental actions and the reasoning behind them should be used as determinants. If I can prove the above then it will be easier to justify how the State has an interest in promoting, even enforcing, widespread genetic screening as this will enhance parental decisions based on knowledge

⁷⁸ Baggini, J. (2010). *The pig that wants to be eaten*. Granta.p289 adapted from Williams B. (1981). *Moral luck: philosophical papers 1973-1980*. Cambridge University Press.p20-39

and limit parental decisions based on wishful thinking which are less likely to have the desired outcome of a healthier infant.

The term morality, and for the purposes of this thesis morality of the parental actions is associated with control, choice, responsibility, and by extension praise and blame. The term luck, on the other hand is immune to praise or blame as it implies complete lack of control, unpredictability and chance. In deontological terms Gauguin's act to abandon a family that he was morally bound to cater for may be characterized as callous and on par with Paul's action. The fact that the former was fortunate in his artistic endeavors diverts attention from the initial decision. In contrast, hedonistic utilitarianism may label Gauguin's action as a moral one as his art has led to the most pleasure for the greatest number resulted in him giving lots of joy to thousands.

Whether one subscribes to deontological, utilitarian, or even Machiavellian theories to justify the morality of his actions, inadvertently luck will influence the outcome. Kantian deontology projects morality as something immune from the influences of luck but rather depends on autonomy, choice, freedom and so on:

...consequently the ground of obligation must be looked for, not in the nature of man nor in the circumstances in which he is placed, but solely a priori in the concepts of pure reason; and that every other precept based on principles of mere experience – and even a precept that may in a certain sense be considered universal, so far as it rests in its slightest part, perhaps only in its motive on empirical grounds- can indeed be called a practical rule but never a law⁷⁹

The idea of morality ought not be judged purely on the outcome and by extension good or bad fortune. Moral assessment should be based on whether one has taken the option that ex-ante had a good expected outcome rather than whether it actually brought about good or bad results.

To accept that fortune is a major player in ascertaining if an action is moral or not would imply that humans have no control over their own moral agency. Intention based

⁷⁹Kant, I. (1785). *Groundwork of the Metaphysics of Morals*. (1998) Translated by Gregor M. Cambridge University Press.

moralism implores us all to have good intentions and be in control of the moral worth thereof, fortune based moralism has no expectations of us as we have no control if our actions (and their moral worth) will be graced by good fortune.

A good driver who drives below the speed limit but runs over a child who jumped onto the road chasing his red striped beach ball, resulting in the child's death may be labeled as unlucky, unfortunate, or clumsy at its harshest but not immoral. Similarly, the alcohol and cannabis intoxicated driver who does not run over a child whilst driving twice over the national speed limit may be fortunate but few of us would describe him as being moral. His action to drive in an inebriated state had significant risks to others, the chances of harming others had substantially increased as a result of his intoxication, and in acting in a fashion that endangered others, whether these others have resulted in harm or not, he is morally blameworthy.

According to Thomas Nagel "Prior to reflection it is intuitively plausible that people cannot be morally assessed for what is not their fault, or for what is due to factors beyond their control."⁸⁰ It is not, after all my fault if I am a heterozygous beta thalassaemia carrier, nor is it my parents' fault for giving me that gene. This is where the value of genetic screening comes in. The quality of life of the offspring is no longer beyond parental control, the nine gestational months need not be spent in the dark waiting for the day of delivery to deal with any health problems the child may have. The effect that "moral luck" will have on the eventual outcome is greatly diminished (although still palpable and this is unavoidable) and the parent stands to turn from a passive beneficiary or victim (the *laissez-faire*, "letting nature take its course" attitude) to an active one. And there's a moral distinction to be made between the terms passive to active.

Waiving the chance for foreknowledge, when there is such an option, may harm the resulting child when in fact it could have been made healthier *in utero*, *nota bene* not less-disabled, not less valuable but healthier and by extension with foreseeably better quality of life. The child may be born unhealthy not because of "bad luck" but because of parental inaction. That inaction translates to an opportunity to maximize the child's

⁸⁰ Nagel T. (1976) Moral Luck, *Proceedings of the Aristotelian Society* Supplementary vol. 50, pp. 137-55

quality of life missed, and as such the parents' omission may result to harm of the eventual child.

In bioethical terms, parenting and gestational ethics are complex as they introduce a binary dimension in ones actions. Parenting, by nature implies that actions inadvertently no longer affect oneself, singular, but ones child as well, dual. Few would argue that ensuring good health of one's children is not a moral pursuit, endeavor, aspiration or duty. Each of those words implies different connotations as to the depths one needs to go to ensure a child's wellbeing. Whilst an aspiration needn't really materialize as long a decent effort was put in, a duty implies that (within the moral norm whatever that may be socio-culturally) a parent must ensure that their child remains healthy. Parenthood has many obligations, but at its core, rests the optimization of welfare of one's offspring. Once parentage is established, strong financial, emotional and practical duties are placed upon parents in order to safeguard the welfare of the child.

I prefer the use of the term duty, and I aim to prove that pursuing your children's welfare is a moral right,⁸¹ something that is worth pursuing, or aspiring to, and as such not attempting to attain it would be a moral wrong. If I succeed in proving that then it would follow that a parent-to-be that chooses genetic ignorance with the self-justification that he/she is acting autonomously and finds solace in literature on ethical justification of acts and omissions would be jeopardizing the health and quality of life of his/hers potential child on doing so, and as such the primordial parental duty of the welfare of the offspring would be trumped from the outset.

With the advent of medical research and *in utero* surgical advancements screening has the capacity of improving the health of the child substantially. This is not only applicable to anatomical, congenital disorders that are not necessarily of genetic origin (spina bifida and oesophageal atresia for example) but also genetic disorders that will have the possibility to be remedied through advances in gene therapy.⁸² Already successful

⁸¹ Right in the sense that it's correct not in the sense that it's a legal right.

⁸² Cavazzana-Calvo, M., Thrasher, A., and Mavilio, F. (2004). The future of gene therapy. *Nature*, 427(6977), 779-781.

treatment in some single gene disorders such as severe combined immunodeficiency⁸³ and Leber's congenital amaurosis⁸⁴ causing congenital blindness have been made, and promising literature exists on the treatment of Huntington's⁸⁵ and Parkinson's disease.⁸⁶ Single gene disorders such as cystic fibrosis, haemophilia, muscular dystrophy and sickle cell anemia are currently untreatable and have serious implications on the affected individuals quality of life. Further advances in *in utero* therapies for these conditions will make my proposition even more relevant. It will be hard to argue that the parental right for genetic ignorance overrules the benefits that these potential children may have once the knowledge that they will be plagued by a potentially treatable serious genetic disorder is uncovered. Harder yet will be to justify how the State will be willing to place parental ignorance above the welfare of the potential offspring once the ethical pros and cons are placed on the moral balance.

Admittedly, my core assumption that the aim for healthy offspring is always the best alternative is not, however universally accepted. Vehmas has argued that showing preference to a healthy child over a disabled one is a form of discrimination.⁸⁷ On the other hand, Bennett has purported that a child is not necessarily worse off if it is born in a diseased state in choosing between two embryos, one with an impairment and one without– the impaired embryo is not rendered better or worse off by our choice to implant the non-impaired one.⁸⁸ I oppose these arguments in the main body of this thesis. Regarding the former assertion, I argue that true harm can befall the child-to-be in the

⁸³Cavazzana-Calvo, M., Hacein-Bey, S., de Saint Basile, G., Gross, F., Yvon, E., Nusbaum, P., Selz, F., Hue, C., Certain, S., Casanova, J.L. and Bousso, P (2000). Gene therapy of human severe combined immunodeficiency (SCID)-X1 disease. *Science*, 288(5466), 669-672.

⁸⁴ Maguire, A.M., Simonelli, F., Pierce, E.A., Pugh Jr, E.N., Mingozzi, F., Bennicelli, J., Banfi, S., Marshall, K.A., Testa, F., Surace, E.M. and Rossi, S. (2008). Safety and efficacy of gene transfer for Leber's congenital amaurosis. *New England Journal of Medicine*, 358(21), 2240-2248.

⁸⁵Holmes, B. (2003). Gene Therapy May Switch Off Huntington's. *New Scientist* 3, 80-1.

<http://www.newscientist.com/article/dn3493-gene-therapy-may-switch-off-huntingtons.html>

⁸⁶ Ananthaswamy, A. (2003). Undercover Genes Slip into the Brain. *New Scientist*, 3, 11-14.

<http://www.newscientist.com/article/dn3520-undercover-genes-slip-into-the-brain.html>

⁸⁷ Vehmas S. Assent and selective abortion: a response to Rhodes and Häyry. (2001) *Cambridge Quarterly of Healthcare Ethics*; 10: 433–440.

⁸⁸ Bennett, R. (2001). Antenatal genetic testing and the right to remain in ignorance. *Theoretical medicine and bioethics*, 22(5), 461-471.

prepersonal state. Our aim should be one of maximizing the welfare of our eventual offspring, not one of widespread disability wipeout. Our provision of a prosthetic limb to an amputee in order to optimize his mobility and welfare does not constitute discrimination against other amputees; giving antibiotics to neonates with group B streptococcal infections, does not make us discriminators against the neonates that have come to harm by the disease and did not receive antibiotics. Medicine is there to treat and promote a healthier life. In response to Bennett I hold firmly that my argument does not involve choosing between children, quantification of harm can only be done with the same (pre-) person in mind. I argue in favour of harm reduction to the very child that is going to be born, the *same* foetus. This goes some way in answering Vehmas's argument too; if we are not choosing between a disabled foetus and a non-disabled foetus, and rather rendering a disabled foetus healthier then my preference in having the same eventual child, healthier, does not constitute discrimination.

d) It would advocate the advancement of foetal surgery and gene therapy.

The last justification as to why the government has an interest in making prenatal screening more widespread than current practice, is also the least controversial and easiest to put forth. There is a lot to be said on the dictum "practice makes perfect" within the field of medicine, even more so when practical skills are in question, and more evidently in the field of surgery. Current foetal surgical practices remain limited to a handful of tertiary specialist centers worldwide. The practice of caesarean sections have evolved from highly risky procedures, with high mortality rates in the 1960's into a perfected operation used on 10% of all births with minimal complications in the modern era⁸⁹. It takes but a small imaginative leap to apply the same to foetuses that stand to benefit from corrective spina bifida surgery or gene therapy if the government employs a widespread screening policy. The numbers of various repairable or conditions amenable to treatment uncovered by these policies will be substantial and the wealth of surgical

⁸⁹ Gabert, H. A., and Bey, M. (1988). History and development of cesarean operation. *Obstetrics and gynecology clinics of North America*, 15(4), 591-605.

experience to be gained and by extension the improvement in the quality of life of the receiving child is evident.

A similar line of reasoning can be used to answer questions to those who oppose screening tests, especially invasive ones such as chorionic villus sampling and amniocentesis on the grounds that they carry a small risk of miscarriage (in the region of 1-2%)⁹⁰ The principle remains the same: the bigger the number of patients the more physicians can practice their trade and by extension the procedures will be exponentially perfected, and the numbers of peri/post-procedural complications will decrease. There is good clinical evidence to support this for many surgical fields.^{91,92} I maintain that unless the proposed procedure is safe for both child to be and the parent(s) then there can be no obligation to screen and treat, so a widespread promotion of these services in the interests of promoting surgical and genetic advances alone is a poor justification. It is, however, evident that if screening and treatment uptake is higher, this will be a secondary benefit, but should not be our (or any public policy's') primary target.

Deconstructing the arguments against a State preference for widespread screening, the promotion of responsible parenting and a preference for more functional disability.

a) Parental autonomy is paramount and as such parents should not be coerced into tests they do not wish to have

A stumbling block for many, in terms of agreeing with me on my proposal is autonomy. This is an obvious objection and I aim to prove that prenatal screening as a tool for

⁹⁰ Tabor, A., Vestergaard, C. H. F., and Lidegaard, Ø. (2009). Fetal loss rate after chorionic villus sampling and amniocentesis: an 11-year national registry study. *Ultrasound in Obstetrics and Gynecology*, 34(1), 19-24.

⁹¹ Sosa, J. A., Bowman, H. M., Tielsch, J. M., Powe, N. R., Gordon, T. A., and Udelsman, R. (1998). The importance of surgeon experience for clinical and economic outcomes from thyroidectomy. *Annals of surgery*, 228(3), 320.

⁹² Gordon, T.A., Bowman, H.M., Bass, E.B., Lillemoe, K.D., Yeo, C.J., Heitmiller, R.F., Choti, M.A., Burleyson, G.P., Hsieh, G. and Cameron, J.L. (1999). Complex gastrointestinal surgery: impact of provider experience on clinical and economic outcomes. *Journal of the American College of Surgeons*, 189(1), 46-56.

advancing parental foreknowledge, not only does not limit parental autonomy (and if it does it only does so transiently) but also rather enhances it.

Autonomy can be understood as the capacity to reflect critically and rationally on one's wishes and desires, one's plans and projects, one's commitments and therefore to be able to revise (at least) aspects of one's self which constitute one's identity to act, that is, only on those desires that one endorses after critical, *educated* reflection⁹³.

When it comes to this broad subject, the lion's share of the literature focuses on a philosophical tug-o-war as to whose definition of autonomy we should use, the Kantian account or John Stuart Mill's account. In very basic terms Kant believed that we have an obligation to be autonomous and act in accordance to the best information available to us at the time.⁹⁴ Mill believes that autonomy also involves uninformed choices, to the extent of self-destruction, provided others are not significantly harmed.⁹⁵

When philosophical discourse takes place trying to resolve the question of whether one has a right not to know about his/her *own* genetic make-up, one's stance can be largely influenced on which of these contrasting notions he/she believes in. I will argue both accounts of autonomy are in-line with my reasoning and as such cannot be used to disprove it. In brief, I will discuss as follows.

Kant, on the one hand, believes that we need to act based on the best information available to us,⁹⁶ hence the moral choice would be to act after we obtain genetic information on the child-to-be; refusing to obtain that information would automatically suggest that we are, or will be acting, without the best available information therefore not exercising our autonomy to its full extent. In other words, that vital step in obtaining the information is vital and forms the basis of any subsequent autonomous choices. By extension it wouldn't be wrong to suggest that the true autonomous choice is the educated

⁹³ Rössler, B. (2002). Autonomy. Problems and Limits Introduction. *Philosophical Explorations*, 5(3), 162-166. p 163

⁹⁴ Kant I (1995) (translated by Ellington J.W) *Ethical Philosophy: The Complete Texts of "Grounding for the Metaphysics of Morals" and "Metaphysical Principles of Virtue"* Hackett Publishing Co 2nd Revised edition

⁹⁵ Mill J S (2006) *On Liberty and the Subjection of Women* Penguin Classics

⁹⁶ Kant I. *Metaphysische Anfangsgründe der Rechtslehre* (1797). Translated by Ladd J. (1999) reprinted in Kant I. *Metaphysical Elements of Justice*. Second edition. Hackett.

one, the one that allows effective “self-rule”, and that uneducated choices are not truly autonomous. So to imply that parental autonomy is limited by forceful education would be paradoxical and nonsensical, if anything the reverse can be said to be true, parental fore-education is certain to enhance parental autonomy even if, paradoxically perhaps, that acquired knowledge is received with a degree of reluctance and skepticism by the educatee.

In Millian terms, once uninformed, autonomous actions are allowed provided no harm is inflicted on others. So whilst many may argue that we have a right not to know genetic information about ourselves, when the information in question is about a third party that could potentially be harmed when that information is not obtained then, acquisition of the information to maximize the safety of others would be the moral thing to do. Even if the harm is a potential harm, on an arbitrary moral scale an action that may allow harm is less morally permissible than one that may prevent or minimize harm.⁹⁷

If we are to follow these stereotypical views of autonomy how can we go a step further and prove that the parent-to-be who opts out of the genetic screening, or “genetic fore-knowledge” does something morally wrong? How can we prove that education, and the pursuit of knowledge is a moral duty?

Knowledge is used on a daily basis to ensure that a desirable outcome has a better probability of success. We use our knowledge of driving to get us safely into work and once we get there we use our skill and knowledge to make a living and improve our quality of life. When our knowledge on a particular subject has reached its limit we try and dip our feet in someone else’s fountain of knowledge, we go to the doctor to have our funny rash down below treated; we go to an architect to design our new house and so forth.

What is certain is that, one wouldn’t have a job to go to if he didn’t have the knowledge to do that particular job, the ramifications to the employer would be much greater as the “probability of error” would be greater, i.e. the chances of someone trained to do the job making a mistake would be much smaller of someone not having been trained to do the job. From this we can extrapolate that one would not choose to show his “funny rash

down below” to his architect, not only because that would be embarrassing and socially inappropriate but mainly because the “probability of error” or the chances of a wrong diagnosis would be much higher than if he had chosen to go to a knowledgeable physician. In simple terms, knowledge diminishes error. It is true that error is sometimes inevitable and cannot be avoided, but the only way of minimising the occurrence of errors is through knowledge and education. If a parent’s aim is to achieve a moral goal, maximize the health of his/her child, he can only optimise the chances of this materialising by acting through knowledge and information obtained about the child to be. Waiving the opportunity to be informed of that valuable knowledge is it actively or passively, decreases the chances of that child being born as healthy as possible. And by extension, a State that does not promote this acquisition of prenatal knowledge by the parent can be said to be diminishing the chances of healthier offspring being born, with all the moral ramifications that that may imply.

At risk of laboring over the same point, placed into context, when I refer to “error” in the context of my thesis I do not imply that parents choosing to bring into life a disabled child are committing a moral wrong, neither do I imply that all foetuses proven to have a genetic error in their make up must be aborted. To do so would devalue disability and that is not my aim or my conviction. This notion needs to be reinforced if the reader is to be able approach my viewpoint with an open mind. The aim of my argument is not to swap a foetus with a new, healthier foetus, but rather to keep the same foetus and instead of trying to render it healthier *ex utero*, to acquire enough information antenatally to enable parents (and us as a collective term for healthcare professionals) to treat, where safely treatable, any health risks/disabilities *in utero*. For example to give antibiotics to the mother to treat infection and reduce transmission rate antenatally, repair anatomical anomalies *in utero*, should these be repairable in a manner that is safe and has good outcomes for both mother and child, or even to allow the child to be born in a tertiary hyper-specialized center should it have a congenital heart problem (as there is compelling

evidence that outcomes are poorer if these children are not born in such centers due to delayed diagnosis).⁹⁸

The moral wrong comes into place when parents who could have been informed in advance about their children's condition and opted not to, allowing thus a reduction in their child's quality of life as a result is causing harm, is reducing net happiness and all through the choice "not to know". With the choice of "not knowing" and with the fallacious opinion that by doing so they are expressing their autonomy in the most effective way, parents miss out on vital time to prepare for what will be a lifelong challenge should they opt to raise the challenge (or rise to it).

Early education and physiotherapy has been proven time and time again to improve outcome and quality of life of many disabled children.^{99,100, 101} Cogent frameworks for pharmacological and nutritional therapies for cognitive and behavioural issues are also evolving.¹⁰² Without advanced notice, parents invariably fail to recognize early what local health authorities have in place so as to support disabled children with the result of these resources not being used to their optimal potential and a resulting worse outcome in disabled children.¹⁰³

This line of thinking should also satisfy pro-life and anti-abortion viewpoints. Many may have jumped to reject the proposal on the grounds that if parents don't believe in abortion, undergoing genetic screening is unlikely to be beneficial as their resulting choice will be the same. Again, I disagree with this view as my arguments are not pro-

⁹⁸ Brown, K. L., Ridout, D. A., Hoskote, A., Verhulst, L., Ricci, M., and Bull, C. (2006). Delayed diagnosis of congenital heart disease worsens preoperative condition and outcome of surgery in neonates. *Heart*, 92(9), 1298-1302.

⁹⁹ Mahoney, G., Robinson, C., and Fewell, R. R. (2001). The effects of early motor intervention on children with Down syndrome or cerebral palsy: a field-based study. *Journal of Developmental and Behavioral Pediatrics*, 22(3), 153-162.

¹⁰⁰ Woods E. (1984) *The effect of early home teaching on the child with Down syndrome* (1984) (MPhil Thesis) Portsmouth, UK: University of Portsmouth;

¹⁰¹ Bird, G., and Wood, A. (2003). Supporting children and families through Early Development Groups. *Down Syndrome News and Update*, 3(3), 74-81.

¹⁰² Capone, G. T. (2004). Down syndrome: Genetic insights and thoughts on early intervention. *Infants and Young Children*, 17(1), 45-58.

¹⁰³ Buckley S. Early Support – new materials and services for families with babies and children with Down syndrome (2006) *Down Syndrome News and Update*.5 (3); 124-126

abortion arguments, my justification for antenatal screening is not to terminate a pregnancy where the foetus is disabled in order to replace it with another, healthier one. My argument is pro-foreknowledge; for even if there is little or no *in utero* treatment for the specific anomaly that a screening test will reveal, then there is considerable evidence that early education/physiotherapy (services that will need to be planned in advance for it is self evident if diagnosis is made postnatally there will be greater delay) can greatly benefit children with disabilities.

Foreseeably, a further objection to the quality of life justification is that it may be speculative and unproven, it can be argued that it may not be clear that foreknowledge of all these conditions is likely to enable an increase in welfare of the children in question. I needn't look too deep to respond to these objections, for there are numerous, more tangible examples from the world of paediatrics, neonatology and clinical genetics for me to prove my point. Some answers have already been given above in the context of current advances in foetal surgery and (current and future) advances in gene therapy. In situations where it is not clear if there is an effective *in* or *ex utero* treatment early after birth that can promote the eventual child's welfare, then it cannot be said that prospective parents have a duty to screen and engage with the available therapies. It is however more and more clear that in keeping with the pace at which antenatal therapeutic research is advancing that more and more conditions will stand to benefit from interventions before or early after birth.

For example, a handful of conditions that have been either lethal *in utero* or given rise to children with severe disabilities or a minimal life span can now be repaired *in utero*. Conditions such as diaphragmatic hernia, oesophageal atresia, myelomeningocele, tracheal stenosis and severe cases of spina bifida but to name a few can now be repaired surgically in the intrauterine environment, allowing children to survive, have a good lifespan and in cases when spinal surgery is needed, have better mobility and less neuromotor problems.^{104,105} Many of these conditions can be lethal within hours of birth;

¹⁰⁴ Bebbington, M. W., Danzer, E., Johnson, M. P., and Adzick, N. S. (2011). Open fetal surgery for myelomeningocele. *Prenatal diagnosis*, 31(7), 689-694.

¹⁰⁵ Hirose, S., Farmer, D. L., Lee, H., Nobuhara, K. K., and Harrison, M. R. (2004). The *ex utero* intrapartum treatment procedure: looking back at the EXIT. *Journal of pediatric surgery*, 39(3), 375-380.

others are associated with severe neurodisability. Survival is only possible with in utero therapy in conditions such as tracheal stenosis.¹⁰⁶ In some of the listed conditions above (a non-exhaustive list), foetal surgery provides outcomes that are so superior to the overall prognosis and outcome than when compared to post-birth surgery that clinically, the former is by far the better choice if we are to maximize the welfare of the eventual foetus. Part of the reason is that healing of foetal tissue is flawless as opposed healing of tissue after birth.¹⁰⁷

Self-evidently such treatments will only be available to the parent if they agree to prenatal screening; that is the vital crossroad in the chain of events. Should the parents-to-be choose ignorance the resulting a child whose leg function could have been restored *in utero* will be confined to using a wheelchair for life. This is because the surgical option that could have restored normal neurology was never offered, since the advance diagnosis wasn't made. Should the same parents-to-be choose knowledge however, the recommended *in utero* therapy can be offered and the resulting child can have a chance for functional restoration of his/her gait.

This suggests an obligation not only to screen for various conditions and by extension an obligation to act positively to either treat any abnormalities (surgically for example) or minimize the risks posed to the foetus (by taking antibiotics for example) revealed by any antenatal tests. I make no secret that as a paediatrician; my primary concern is the welfare of children, present and future. So although such parental obligations may seem too much of a burden on parental autonomy, I will argue that provided the available therapies are safe to both foetus and mother, provided the intended clinical outcomes of the intervention are consistently proven to be beneficial to the eventual child, and provided

¹⁰⁶ Kanaris C, Cooper Hobson G. Ofoegbu B Neonatal Airways: A B C; It's (not Always) Easy As 1, 2, And 3: Looking Into The Future Of Neonates With Severe Upper Airway Compromise. (2015) World Airway Management Meeting, November
<http://www.epostersonline.com/wamm2015/node/1683?sections=true>

¹⁰⁷ Longaker, M.T., Whitby, D.J., Adzick, N.S., Crombleholme, T.M., Langer, J.C., Duncan, B.W., Bradley, S.M., Stern, R., Ferguson, M.W. and Harrison, M.R., (1990). Studies in fetal wound healing VI. Second and early third trimester fetal wounds demonstrate rapid collagen deposition without scar formation. *Journal of pediatric surgery*, 25(1), 63-69.

that the parents have decided to have *that specific* child, then parental obligations towards the unborn should supersede parental autonomy.

With the above provisions, I will argue that true autonomous choices can only be made in the company of medical information acquired antenatally, failing to acquire this information can indirectly harm the foetus (that will come to exist) as the chances of intervening in advance in order to safeguard the eventual child's welfare will be diminished.

b) This is in essence a eugenic proposal that discriminates against the disabled.

My premise is one of optimization of welfare of future children that would otherwise be born in a worse off health state, and not one of rejection of disability.

The values behind Hitler's dream of an Aryan German race in Mein Kampf¹⁰⁸ and parental will of a healthy future child could not be any more different. What I suggest in this thesis is not a social policy in order to improve the gene pool. Parents who aspire to have healthy children do not think in terms of eradicating a specific genetic condition such as spina bifida or deafness.

Minimizing future children's suffering does not imply aborting the foetus itself. What it does mean is repairing the defect *in utero* where possible or furthering parental education on the early identification of resources that can maximize the resulting child's quality of life would be the moral thing to do. Not doing so would result in a failure to avoid foreseeable suffering and thus implies two things:

- i. Parents who do have prenatal screening have a further duty to advance their knowledge about available treatments or therapies of the specific condition that has been uncovered by the screening process, but also to engage with these therapies if the results are clinically effective and safe for both the mother-to-be

¹⁰⁸Hitler A. Mein Kampf ("My Fight") (1926), Reissue edition (1998) Mariner Books

- and the fetus. The scope of this is to minimize the foreseeable suffering of the potential child. Not doing so would be a moral wrong via parental inaction at the “second hurdle”. This implies the need of a continuum in parental education as a means to reasonably ensure the offspring’s well being.
- ii. Parents who decline prenatal screening gamble with a possibility of giving birth to a suffering infant, whose malaise could have been reduced if foreknowledge had been sought. Through their inaction these parents have committed a moral wrong at the very “first hurdle”.

There are of course instances where parents are not offered prenatal screening opportunities by their midwife or obstetrician. The onus in these cases lies with the physician or the health authority that fails to provide such services. An obstetrician who does not screen patients in routine pregnancy or who fails to offer screening tests may invite a malpractice action should the patient deliver a child that has come to harm as a result of the omission. For example, if a high vaginal swab to ascertain whether or not the mother is an asymptomatic Group B streptococcus (GBS)¹⁰⁹ carrier or not is not offered and the newborn is infected with GBS (the most lethal pathogen in the neonatal period, as a result), then the parents may have a clinical negligence claim against the physician. This would not be the case if

- a) Screening had taken place
- b) Prophylactic antibiotics were given to both mother and child as a direct result of the screening findings.

If there are no screening results to act upon, there is no resulting action, so the neonate is exposed to potential harm. The health care providers inaction or failure to offer the option of advanced knowledge to the pregnant woman is professionally (at least) but also morally indefensible. Similarly, the child with the neural tube defect could have had the deformity repaired *in utero*, and avoidable suffering could have been prevented.

¹⁰⁹ Rodriguez-Granger, J., Alvargonzalez, J.C., Berardi, A., Berner, R., Kunze, M., Hufnagel, M., Melin, P., Decheva, A., Orefici, G., Poyart, C. and Telford, J (2012) "Prevention of group B streptococcal neonatal disease revisited. The DEVANI European project." *European journal of clinical microbiology and infectious diseases* 31.9 (2012): 2097-2104.

Marsha Saxton argues however that “...physician’s fear of wrongful life and wrongful birth suits became a ‘reason to test’ and routine prenatal testing is built into the standard of care as a way to protect physician interests unrelated to patient concerns”¹¹⁰

Cynical as this viewpoint may be it highlights one important misconception, and misguided contraposition to my proposal. The ethical justification of prenatal screening is not the avoidance of wrongful life, for with the exception of some debilitating conditions such as Tay-Sachs syndrome that form the exception to the rule, the vast majority of disabled children brought into existence do not have a wrongful life or a life that most would consider ‘unworthwhile’. I explore this notion further in my second paper, highlighting that only in extremely rare situations, children with certain uncommon syndromes that entail short, pain filled lives with rapid neurocognitive deterioration, making their lives of “sub-zero “quality may be better off, never to have been born.

According to Abby Lippman, an epidemiologist by trade “Rare cases make bad policies”.¹¹¹ Even if we focus on the conditions that receive the bulk of the attention in screening programs such as Down syndrome, spina bifida, cystic fibrosis and Fragile X Syndrome, all have clinical outcomes that usually have moderately disabling phenotypes. So to screen for “wrongful life prevention” purposes would be firstly unethical as it would automatically dictate discrimination against disability and secondly impractical for public policy purposes. The ethical justification of screening therefore does not lie in the realm of preventing a wrongful life but rather enhancing one that is to be brought into this world in a disadvantageous position.

c) Increased uptake of all screening services will increase abortion rates

Chapter 3 is dedicated to answering this question more extensively as it merits special consideration. In brief, my objection is based on the assumption that is made is that (a) increased screening uptake would (b) increase the number of abortions. Current,

¹¹⁰ Saxton M. “ Why members of the disability community oppose prenatal diagnosis and selective abortion” In Parens E. Asch A. “Prenatal Testing and Disability Rights (Hastings Center Studies in Ethics)” Georgetown University Press; (2000) p 153

¹¹¹ Lippman, A. (1991). Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *American Journal of Law and Medicine* 17: 15-50

empirical evidence suggests otherwise, that (b) does not follow (a).¹¹² A recent systematic review looking at the period between 1996-2011 is the largest review of data termination rates in the U.S following a prenatal diagnosis of Down syndrome. The authors conclude that the data analysis suggests that, even at a time where Down syndrome screening has increased uptake termination rates are lower. I therefore argue that the objection that more screening will lead to more abortions is not backed by current evidence. It is rather, more likely that increased screening will enable more future parents to uptake the therapeutic interventions available, which range from simple treatments such as taking antibiotics to more complex therapy such a foetal surgery, in a way that benefits the eventual child.

To what extent would my proposal be applicable in a legal sense?

Based on the title of the thesis most people with a basic conception of healthcare ethics and medical law have been quick to point out some very obvious legal and philosophical objections.

As alluded to earlier the objective and focus of the thesis is the promotion of pre- parental education and to have closer look at the duties parents have to maximize the welfare of that specific foetus should they choose to complete the pregnancy cycle. I purport that parents have a *duty* to inform themselves about the nature of their potential children and act in a favourable (to the potential child) manner based on the acquired information. This is not in order to abort any potentially disabled children but more to allow parents to make an *informed choice* whether they can cater for the needs of a disabled child or not. Those who can, will have advanced knowledge into the specific disability and a few months to prepare themselves on how to optimise the child's quality of life, how to educate it from early on and to identify local health authority services that are in place that help children with specific disabilities. Others may even be able to enhance, or ameliorate their child's disability *in utero*.

¹¹² Natoli, J. L., Ackerman, D. L., McDermott, S., Edwards, J. G. (2012). Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995–2011). *Prenatal diagnosis*, 32(2), 142-153.

A section of the thesis focuses on the value of education, how the State has a vested interest in having educated citizens, and how the term education needs to be seen under a broader light, and not just in a schooling context but also in this one. In bioethical terms many will focus on how enforcing any sort of treatment (which screening isn't) or prenatal tests on a patient ultimately trumps on their autonomy. My aim is to highlight the "autonomy paradox" how one's autonomy, one's ability to self-rule can only be optimised through knowledge, for knowledge allows us to make educated choices and educated choices stand more chance of reaching our desired outcome than non-educated choices. By extension, if we desire a moral outcome then an educated choice will stand a better chance to be a moral one as well.

The law in its current state strictly prohibits any physical form of examination, invasive or not without patients' consent¹¹³ so seemingly; from a legal perspective the suggestion that antenatal screening may in some cases be enforced upon parents is out of line with the current law in this area. Additionally, the Disability Discrimination Act (1995),¹¹⁴ the Sex Discrimination Act (1975),¹¹⁵ and the Race Relations Act (1976)¹¹⁶ are just a few of the many Acts deeply embedded into UK law that also render my proposition impermissible in a legal context.

On an international context, UNESCO's Universal Declaration on the Human Genome and Human Rights, that is applicable to legal person of which the foetus is not, states that: "The right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected."¹¹⁷ This shows how the "right not to know" is valued under certain international guidelines, and although not a true right in the legal context of the word, many can argue that there is a legal *interest* in not knowing.

¹¹³ There are of course exceptions when considering competency issues or medical emergencies but these are tangential to the bigger picture and I shall not be veering into them

¹¹⁴ Disability Discrimination Act (1995)

¹¹⁵ Sex Discrimination Act (1975)

¹¹⁶ Race Relations Act (1976)

¹¹⁷ UNESCO *Universal Declaration on the Human Genome and Human rights article 5c* on http://portal.unesco.org/en/ev.phpURL_ID=13177andURL_DO=DO_PRINTPAGEandURL_SECTION=201.html

The idea that there is a right to refuse to know relevant genetic information is also recognized by the Council of Europe. The Oviedo Convention states that: “Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.”¹¹⁸

Much of the “right not to know” literature is focused around parental autonomy; few take a step back to consider that congenital conditions, such as bronchial atresia and diaphragmatic hernia, both lethal in neonates, may now be repaired *in utero*^{119,120}. This modern-day trend of a quest for autonomy at all costs can be judged as being blindfolded at times. Advances in foetal and antenatal genetic medicine are gaining momentum but the more parental ignorance is defended the more foetuses that could have been potentially saved will be born in a condition that is worse off than if they had received any available *in utero* therapies. It is imperative of course that these therapies are safe to both child and mother and are proven to have consistently good outcomes, otherwise the argument to educate and treat *in utero* becomes problematic; it is self-evident however that with time more and more safe, successful therapies will be available and the argument against parents foregoing any interaction with the offered antenatal services will become, philosophically at least, more compelling.

It is with good philosophical and legal reason that consent provides lawful justification for treatment. If valid consent is not given, any treatment which involves touching would amount to a battery. It is neither my objective, nor my belief to convince that law ought to be changed to allow the doctor to undertake prenatal tests on pregnant women without their consent. I do however explore whether the State has a vested interest, and to what

¹¹⁸ *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 Medicine*. Oviedo, 1997. Article 10.2. <http://conventions.coe.int/Treaty/en/Treaties/html/164.htm>

¹¹⁹ DeKoninck, P., Gomez, O., Sandaite, I., Richter, J., Nawapun, K., Eerdeken, A., Ramirez, J.C., Claus, F., Gratacos, E. and Deprest, J., (2015). Right-sided congenital diaphragmatic hernia in a decade of fetal surgery. *British journal of obstetrics and gynaecology: An International Journal of Obstetrics and Gynaecology*, 122(7), 940-946.

¹²⁰ Peranteau, W.H., Moldenhauer, J.S., Khalek, N., Martinez-Poyer, J.L., Howell, L.J., Johnson, M.P., Flake, A.W., Adzick, N.S. and Hedrick, H.L. (2014). Open Fetal Surgery for Central Bronchial Atresia. *Fetal diagnosis and therapy*, 35(2), 141-147.

extent, to promote the uptake of the said services.

The 1990's saw no less than seven cases in England and Wales whereby it was declared lawful to perform Caeserean sections on pregnant women without their wishes,¹²¹ these cases served as eye openers to the legal system and made the legal academia reconsider what ethical and legal responsibilities parents-to-be owe towards the unborn. Then followed the decision in *St George's Healthcare NHS Trust v S* where it was held that having regard to the right of an individual to autonomy and self-determination was paramount to the extent that, a compos mentis person is entitled to refuse medical treatment, even when his or her own life depended on receiving such treatment. This respect for individual autonomy remains unaltered pregnancy, merely because her decision to exercise it might appear morally repugnant.

The decision saw a halt in the emerging trends of enforced caesareans in the UK with only the case of *Bolton NHS Trust v O* [2003] 1 FLR 824 reported between 1998 and 2003¹²². Over the last 3 years there has been a re-emergence of caesarean section performed against maternal wishes, under the protection of the Mental Health Act 1983 with at least five more such cases having made UK headlines at the time of writing¹²³

When considering the legal and ethical issues raised by maternal and parental responsibility for foetal health, Brazier argues that:

¹²¹ *Re S (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 671; *Rochdale Healthcare (NHS) Trust v C* [1997] 1 FCR 274; *Norfolk and Norwich (NHS) Trust v W* [1996] 2 FLR 613; *Re L (An Adult: Non Consensual Treatment)* [1997] 1 FLR 837; *Tameside and Glossop Acute Services Trust v CS* [1996] 1 FCR 753; *Re MB (Caesarean Section)* [1997] 2 FLR 426, CA; *St George's Healthcare NHS Trust v S, R v Collins, ex parte S* [1998] 3 WLR 936, CA.

¹²² *Bolton NHS Trust v O* [2003] 1 FLR 824.

¹²³ *Re AA* [2012] EWHC 4378 (COP); *In the matter of P* [2013] EWHC 4581 (COP); *Great Western Hospitals NHS Foundation Trust v AA* [2014] EWHC 132 (Fam); *NHS Trust 1, NHS Trust 2 v FG* [2014] EWCOP 30. Press Association, 'Judge gives permission for a caesarean section on mentally ill woman' *The Guardian* (London, 31 January 2014) <<http://www.theguardian.com/society/2014/jan/31/judge-caesarean-section-mentally-ill>>; Patrick Sawyer, 'Judge orders mentally ill woman to have forced caesarean' *Daily Telegraph* (London, 1 February 2014) <<http://www.telegraph.co.uk/health/healthnews/10611575/Judge-orders-mentally-ill-woman-to-have-forced-caesarean.html>>; BBC News, 'Judge approves forced Caesarean for mentally-ill woman' <<http://www.bbc.co.uk/news/uk-england-london-25996231>> all accessed 16 January 2015.

¹²³ *CP (A Child) v First-Tier Tribunal (Criminal Injuries Compensation)* [2014] EWCA Civ 1554 and *CICA v First-Tier Tribunal and CP (CIC)* [2013] UKUT 638 (AAC).

Mothers-to-be have especial responsibility to their children *in utero*. The absolute dependency of the future child on its mother increases, not diminishes her *moral* responsibility for its welfare. She can no more morally justify causing injury to that child than to any of her born children, or any other woman's children.¹²⁴

Brazier is clear however that moral responsibility ought not translate into a legal responsibility due to the impact on individual autonomy, liberty and privacy being too great.¹²⁵ Until recently the involvement of the courts in foetal welfare has been limited. Not least because practically speaking if foetal health was to be paramount in UK law then many pre-parental actions preceding conception would somehow need to be regulated since certain behaviours could affect the health of the foetus and by extension that of the eventual child should that come to exist. A plausible example would be sexual promiscuity. One's sexual orientation and preferences are and should remain free from external interference. However, if the law was to protect foetal health it would be plausible to imagine that the government may want to regulate that to minimise the transmission of many sexually transmitted diseases such as syphilis from person to person, on the off chance one is impregnated and gives birth to a child with congenital syphilis; a condition associated with considerable neurodisability but preventable if pre-conception diagnosis is made.¹²⁶

Furthermore, policing peri- or ante-natal behaviour in order to enable conformity to medical advice, aside from being intrusive and an insult to individual autonomy is also both impractical and (more importantly) stands to erode the physician-patient relationship in a way that sends us back to the ages of quackery and back street abortions.¹²⁷

¹²⁴ Margaret Brazier, 'Parental responsibilities, foetal welfare and children's health' in Caroline Bridge (ed.), *Family Law Towards the Millennium: Essays for PM Bromley* (Butterworths 1997) p 272

¹²⁵ *ibid* p273

¹²⁶ Walker, D. G., Walker, G. J. (2002). Forgotten but not gone: the continuing scourge of congenital syphilis. *The Lancet infectious diseases*, 2(7), 432-436.

¹²⁷ Goodhart, C. B. (1964). The frequency of illegal abortion. *The Eugenics review*, 55(4), 197.

There are, however, signs that the law both in the U.K is beginning to afford more legal protection to the foetus. Whilst criminal responsibility of a third party for harm incurred to the foetus *in utero* was debated in the House of Lords as early as 1998¹²⁸ when it was held that a man who stabbed the woman carrying his child causing an early live birth and a subsequent early neonatal death could be charged with manslaughter.

Furthermore child destruction charges; the crime of killing an unborn and viable foetus, before it's "separate existence" that had been exceedingly rare have seen a re-emergence in the last decade. Child destruction offences are created by section 1(1) of the Infant Life (Preservation) Act 1929¹²⁹ but have historically been uncommon. There have been at least three reported charges since 2007. *R v Maisha Mohammed*¹³⁰ was the first reported criminal conviction of a woman for the offence of child destruction for the destruction of her unborn child at 34 weeks gestation. In 2012 in *R v Carl Anthony Whant*¹³¹ there was a double conviction for murder and child destruction of a man who murdered his partner who was eight months pregnant at the time. The Crown Prosecution Service stated that: "Child destruction is...a very rarely used charge (and that the courts were) not aware of another case like this one in Wales" and also emphasized how vital it was to mark the death of the unborn child with a separate charge. Finally, in December 2015, Kevin Wilson was found guilty of Child Destruction after attacking a heavily pregnant woman causing her to miscarry; he was sentenced to life in prison.

Intuitively, policing pre-parental behaviour by resorting to criminal law is not the way to influence responsible antenatal behaviour in a way that maximises the welfare of the eventual child. Although I do not dispute the need for a custodial deterrent for wilful acts of bodily harm against pregnant women resulting in a miscarriage or an early neonatal death, employing the criminal prosecution service to regulate the womb and interfere with the autonomy of parents-to-be would do society a disservice for the reasons I have already touched upon, not least for considerably intruding on private life and eroding the doctor-patient relationship, as it would change the role of the doctor to that of a law

¹²⁸ *Attorney-General's Reference (No 3 of 1994)* [1998] AC 245, HL.

¹²⁹ Infant Life (Preservation) Act 1929:

¹³⁰ *R v Maisha Mohammed* (2007)

¹³¹ *R v Carl Anthony Whant* (2012) EWCA Crim 2457

enforcer. This in itself would be at the detriment of future mothers and future babies alike as it would lead to the patients being selective to when he/she presents for medical attention but also selective to what he/she choose to divulge to the physician, Both of these would lead to a delay in diagnosis and management, likely to negatively affect the clinical outcome.

The stark difference between the law relating to child destruction charges and the application of criminal law to legislate against harm incurred to the foetus *in utero* as a result of irresponsible pre-parenting, such as the example of foetal alcohol syndrome given above, can be seen in the landmark case of *CP (a child) v first-tier tribunal & CICA [2014] EWCA CIV 1554*¹³². The courts were asked to consider whether maternal alcohol misuse leading to *in utero* foetal harm and resulting in foetal alcohol syndrome could be viewed as a crime. The objective of this was to award the child compensation under the Criminal Injuries Compensation Scheme. The case highlighted that the foetus does not have distinct legal personality before birth and as the foetus was not ‘another person’ at the time of the administration of alcohol, the *actus reus* could not be made out and the child was therefore not entitled to compensation for harms incurred *in utero*.

I argue that whilst it is important for individual maternal autonomy to be enshrined in law, there are worrying trends in other countries, such as certain U.S states where chemical endangerment and foeticide charges on pregnant women who harm their foetus are becoming more frequent. My position is that society has an interest in having the healthiest children possible. Not by replacing “defective” or “disabled” foetuses with new, healthier ones, but rather by optimising the health of those foetuses already conceived. I purport that whilst there are examples across the globe whereby the law interferes with pregnancy so as to penalise the perpetrator (be it the parent or someone else) for a harm incurred to the foetus, the best way for the State to maximise the welfare of children is to educate parents and promote screening services. This has to be done in way that helps parents make educated decisions and empowers them to engage more with

¹³² *CP (a child) v first-tier tribunal & CICA [2014] EWCA CIV 1554*

treatments , both old and new (provided these are safe and effective) so as to optimise foetal and by extension child health.

In the words of Brazier:

...foetal welfare is most likely to be maximised if society concentrates, not on using the law to pursue the occasional “bad” mother-to-be, but on ensuring that all those who may become parents grow up themselves and reproduce in a society which ensures that parental health maximises foetal health.¹³³

But whilst I am against the use of legislation that forces parents to behave responsibly in a way that benefits their future children, I maintain that the State has a duty to use non-coercive methods in order to encourage responsible pre-parental behaviour. I argue that lack of engagement with screening services and available treatments can harm the resulting child, and although it cannot be said that the parents have done anything legally wrong by their actions or lack thereof, they cannot be free from moral judgement.

In ‘The Limits of Medical Paternalism’¹³⁴ Heta Häyry highlights the differences between hard and soft paternalism. Whilst the former entails direct intervention with the actions of third party, the latter type of paternalism entails interventions that educate and change pre-conceptions of agents; thereby affecting choices that agents make for themselves, in hope that they will be in keeping with the choice desired by the State. An example of soft paternalism is campaigns that are designed to promote health. Their purpose by design is to modify behavioural patterns or increase the uptake of specific healthcare services (such as vaccination uptake or reducing alcohol intake) and improve overall health. Intervention in the family context (by any means ranging from antibiotics to foetal surgery) in cases of foetal health may be viewed under a similar prism. I do not assume that the interventions considered ought to be towards the hard end of the spectrum, involving forced intervention upon the choices of parents in the interests of the eventual child. There might be more compelling reasons for hard paternalism, once these

¹³³ Brazier M Parental responsibilities, foetal welfare and children’s health’ in Caroline Bridge (ed.), *Family Law Towards the Millennium: Essays for PM Bromley* (Butterworths 1997 p 293.

¹³⁴ Häyry H. (1991) *The Limits of Medical Paternalism*. Routledge.

technologies are nearly perfected. Even when that becomes the case I will argue that softer interventions ought to be exhausted first in order to accomplish the intended benefit. Providing pregnant women with free folic acid supplements; incentivising increased uptake of antenatal screening and foetal welfare clinics, offering better information to reduce consanguinity and the considerable foetal abnormality risks that accompany same marriage partnerships¹³⁵ are paradigms of how the State can act in a non-invasive fashion to achieve the intended outcome. Such softer interventions are justified as long as up to date evidence is used to modify how parents behave in an educated responsible manner in relation to their future children.

It is easier to suggest that parents refusing these sorts of tests can be morally, not legally, blameworthy. In a social context for example, the mothers of children born with foetal alcohol syndrome are inadvertently judged by members of the public, healthcare staff and labeled as “bad mothers” by their own families¹³⁶. So as a society we criticize the action of maternal drinking that in effect caused this condition to the resulting child and deem the mothers-to-be morally culpable. Would we, however judge an omission (such as an omission to have prenatal tests) any differently given that the end result may be the same? Should the mothers of children born with conditions that can be otherwise repaired *in utero* and that decline prenatal tests not be judged under the same light given that the end result is similar? The moral finger may well be pointed at in the same fashion but legally at least the mothers are not found guilty of any wrongdoing.

Can children born in a worse off condition than they otherwise would have been if an antenatal intervention had taken place have a legal claim against their parents?

The English Congenital Disabilities Act excludes claims of children against their mothers in respect to damage incurred to them during pregnancy; a notable exception is injuries

¹³⁵ Sheridan, E., Wright, J., Small, N., Corry, P.C., Oddie, S., Whibley, C., Petherick, E.S., Malik, T., Pawson, N., McKinney, P.A. and Parslow, R.C (2013) Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. *The Lancet*, 382(9901), 1350-1359.

¹³⁶ Toutain, S., and Lejeune, C. (2008). Family management of infants with fetal alcohol syndrome or fetal alcohol spectrum disorders. *Journal of Developmental and Physical Disabilities*, 20(5), 425-436.

sustained after a road traffic accident. Other countries however have contrasting laws. Whilst the Scottish constitution allows such claims Canadian tort law applies *in utero* just as it does *ex utero*. Parents have no greater right to harm their children than they do their children soon to be born. This is not to imply that giving birth to a disabled child is a moral wrong, (and I categorically reject that) but rather to highlight that given the chance to repair potentially lethal genetic or congenital condition *in utero* and opting, through ignorance not to is. What may be seen as a double standard within English law however is the wrongful birth claims by parents. Double standard on the grounds that if a physician or medical institution is party to a poor decision that leads to the birth of a disabled child, then the parents can claim compensation as a result; whilst if a parent is the reason for the child being born with foetal alcohol syndrome for example, the courts do not allow any such claims against the parents by the resulting child. Wrongful birth claims can be made in instances of:

- a) Pregnancy as a result of failed sterilization or vasectomy surgery
- b) Pregnancy as a result of a failure to provide sufficient information regarding contraception
- c) Pregnancy as a result of a failure to counsel parents regarding transmission risks of genetic disorders
- d) Birth of a child as a result of a failure to diagnose pregnancy or to provide appropriate information regarding termination of pregnancy;
- e) Birth of a child as a result of a failure to identify a foetal anomaly, which, if diagnosed, would have contributed to a decision to terminate the pregnancy.¹⁴²

Where a child has been harmed as a result of negligent clinical care received by their mother during pregnancy, the child may bring a claim for the injuries, which he/she has sustained (pursuant to the Congenital Disabilities (Civil Liability) Act 1976).¹⁴³

¹⁴² Farg S. (2014) Recovering damages in wrongful life cases *Personal Injury Law Journal* Sept. p 4-6

¹⁴³ Congenital Disabilities (Civil Liability) Act 1976

Notably, however, wrongful conception and wrongful birth cases are not injury claims but rest on the premise that the child ought not have been born. It was held in *McKay v Essex AHA (1982)*¹⁴⁴ that children themselves cannot bring claims for losses arising in consequence of their own existence, even if they are born with severe disability, but the parents are not prohibited from filing their own claim.

In *AD v East Kent Community NHS Trust (2002)*¹⁴⁵ the claimant was impregnated whilst she was a detainee at a psychiatric unit where the defendant was working. As the claimant had a psychiatric illness she could not appropriately care for her child who was instead brought up by other family members. The Court of Appeal applied the ruling from *McFarlane v Tayside Health Board (2000) 2 AC 59*¹⁴⁶ and held that costs in lieu of bringing up the infant could not be recovered.

In contrast, it was held by the Court of Appeal in *Parkinson v St James and Seacroft University Hospital NHS Trust (2001) EWCA Civ 530*¹⁴⁷ that there is a clear distinction in law if, as a result of antenatal negligence the resulting child is disabled. This specific case claim related to sterilization surgery that failed, contributing to the conception and eventual birth of a disabled infant. It was held by the court that as per *McFarlane v Tayside Health Board (2000) 2 AC 59* damages could not be awarded for the usual childcare costs but costs related to raising a disabled child could be recovered. The court clarified this rule by restricting its application to cases of ‘significant disability’ (entailing both mental and physical impairment) but excluded its application in cases of ‘minor defects’. The court used the definition of disability from s17 (11) of the Children Act 1989¹⁴⁸ as its basis. A similar case where the eventual child had Down syndrome but there was failure to diagnose it antenatally is *Rand v East Dorset Health authority*.¹⁴⁹

Also importantly, failure to diagnose disability whereby that disability has a genetic root is not the only source of parental claims against a physician or health authority. Claims

¹⁴⁴ *McKay v Essex AHA (1982) QB 1166*

¹⁴⁵ *AD v East Kent Community NHS Trust (2002)*

¹⁴⁶ *McFarlane v Tayside Health Board (2000) 2 AC 59*

¹⁴⁷ *Parkinson v St James and Seacroft University Hospital NHS Trust (2001) EWCA Civ 530*

¹⁴⁸ Children Act 1989 s17 (11)

¹⁴⁹ *Rand v East Dorset Health Authority (No 2). (2000) Lloyd's Rep Med 377*

have been made where a maternal infection was not diagnosed antenatally (or when the results were not acted upon to prevent transmission to the foetus). Examples of such cases are *Groom v Selby (2001)*¹⁵⁰ and *Hardman v Amin (2001)*.¹⁵¹ In the former case the neonate contracted salmonella of which the mother was a carrier, the child developed meningitis and septicaemia with a resulting long-term neurodisability.¹⁵² In the latter case the mother had rubella in pregnancy; the responsible physician did not diagnose this. The resulting child suffered from a well-known manifestation of this pathogen; congenital rubella syndrome whereby the infant is born with significant disability and anatomical problems.¹⁵³ In both cases the courts compensated the families in lieu of care costs incurred for a child with disability. Such cases highlight that it is not only genetic information that is important antenatally, but also various other markers of good maternal and foetal health, of which microbiological screening is one. I argue that there is nothing intrinsic about genetic information that makes it more or less relevant than microbiological or sonographic evidence; so the term antenatal screening is all encompassing to include all these screening modalities, the information of which can help us improve the health of the resulting child.

Similar cases permeate through U.S and Canadian legislature. The *Procanik v Cillo*¹⁵⁴ was a case based in the State of New Jersey in the U.S. A child sought damages for birth defects caused by the doctor's failings in the antenatal diagnosis of rubella in the mother during the first trimester of gestation. The court recognized that he could rightfully sue for wrongful life on the grounds that the physicians were deemed negligent in not allowing the child's parents, the choice of terminating the pregnancy. The parents' claim for wrongful birth was barred under the statute of limitations and the boy was awarded medical expenses costs for the rest of his life. It is worth noting also that the claims for compensation for emotional stress and impaired childhood in this specific case were

¹⁵⁰ *Groom v Selby (2001) EWCA Civ 1522*

¹⁵¹ *Hardman v Amin (2000) Lloyd's Rep Med 498*

¹⁵² Mason, J. K. (2007). *The Troubled Pregnancy: Legal Wrongs and Rights in Reproduction* (Vol. 5). Cambridge University Press.

¹⁵³ Gross-Galiano, S. (2011). Rubella and Congenital Rubella Syndrome Elimination: Lessons Learned for the Future. *Journal of Infectious Diseases*, 204(suppl 2), ii-ii

¹⁵⁴ *New Jersey, and Court Supreme. "Procanik by Procanik v. Cillo." Atlantic reporter 478 (1984): 755.*

unsuccessful. This case is relevant in what I am purporting as the tortfeasor in this case was the physician and I argue that onus for a healthy foetus ought not lie with the physician alone but also with the parents-to-be. In this case, an omission led to a child being born with significant health problems, the risks could have been minimized *in utero* but were not. A simple effective, almost risk free course of antiviral treatment during pregnancy could have cured the disease antenatally reducing the harmful effects the virus had on the foetus.

Another key international case was *Duval v. Seguin*¹⁵⁵, which reformed Canadian Law in the 1930s. The Supreme Court of Canada ruled that a permanently handicapped infant plaintiff could recover damages from a negligent third party motorist for pre-natal injuries. This paved the way for Canadian law that has allowed persons born with damages suffered while a foetus to bring a tort action with respect those damages. Again the fact that the foetus was injured by a third party motorist and not the parent should not matter, at least in philosophical realms. Parents have no greater right to harm their children than anyone in the general public has to harm anyone else. Despite the Duval case, actions against a birth mother for injury caused *in utero* have not been recognized in Canada, except for *Dobson v Dobson*.¹⁵⁶ This reflects the fact that even where the law is set out to protect the health of the potential child, parental autonomy is usually protected first. It may also be that while in some tort cases there may be questions as to whether the victim was foreseeable to the tortfeasor, it is unlikely to be the case between parent and child, particularly mother and child. Admittedly, most tort cases turn on the issue of remoteness or *foreseeability* of the damages. The term foreseeability needs to be emphasized since prenatal genetic checkups would make many life-threatening conditions foreseeable, and open the avenue and possibility in some cases for *in utero* repair or gene therapy.

With current limitations on neonatal surgery and gene therapy many may feel a limitation on parental autonomy resulting from a legally imposed screening process is too big a price to pay. The more that science advances however, the more relevant these legal

¹⁵⁵ *Duval v. Seguin*, (1972) 2 O.R. 686 (H.C.), affirmed (1973), 1 O.R. (2d) 482 (Ont. C.A)

¹⁵⁶ *Dobson (Litigation Guardian) v. Dobson* (January 20, 1997), (N.B.Q.B.)

“impositions” will become for the benefit and health of future generations. As outlined above, the trends of increased legal protection of foetuses in law both in England and Wales as well as the U.S, raise numerous ethical questions. It is beyond the remit of this paper to answer them all, nor do I attempt to elaborate whether criminal law is the appropriate way to legislate to ensure foetal protection, although intuitively I hold that that would be wrong on numerous grounds. Not least that expecting physicians to act as healthcare police would erode the doctor patient relationship considerably which would risk patients lives in itself. I will however, mindful of what foetal surgery and *in utero* gene therapies will be able to deliver in future, address whether, in-keeping with the 2008 HFEA amendments prohibiting the implantation of gametes with known parental genetic defects and “deliberately screening in a disease or disorder”¹⁵⁷, when foetal surgery outcomes become better, in future there might be a further imperative for State wide promotion of such practices.

As I have shown, the existing literature and current legal position is usually reluctant to interfere with individual autonomy to put pressure on women during pregnancy and expectant parents to take measures to find out about their future child’s health state before it is born. However, it seems that a strong case can be made to say that just as obstetricians and paediatricians have a duty to ensure that a foetus is brought to birth in the most optimal state they possibly can, women must also have a similar moral obligation to their future child’s welfare. The papers that follow this introduction and build this thesis argue strongly for this premise and take this moral duty further in arguing that if it is morally right that we try and maximise the welfare of our future children then there is a strong case to be made that the State has a role in enabling this obligation by ensuring a high uptake of antenatal screening and any effective treatments in pregnancy.

However, before we get to these papers there are two further issues that require further exploration and explanation in order to be really clear about the foundations of these papers and this thesis more generally. These further issues focus around two questions:

¹⁵⁷ Department of Health “Review of the Human Fertilisation and Embryology Act: Proposals for Revised Legislation London: The Stationary Office, 2006 s2.43

‘Do *in utero* therapies significantly change the personal identity of future children?’ And ‘Is increased screening likely to increase abortion rates and if so where does this leave my position?’. Addressing these two important questions will help me to provide essential background to the papers that follow in part 2 of this thesis and thus this will be the job of the next two chapters.

CHAPTER 2

**DO *IN UTERO* THERAPIES SIGNIFICANTLY CHANGE THE PERSONAL
IDENTITY OF FUTURE CHILDREN?**

CHAPTER 2

Do *in utero* therapies significantly change the personal identity of future children?

Through this thesis I employ a comparative account of harm. I argue that we cannot ascertain the degree harm or benefit between an action unless the same eventual child is implicated, i.e. we cannot measure harm to a potential person if that potential person has been discarded and replaced by a separate entity. Instead we must ensure that that eventual child whom we claim is harmed is the *same person* upon which the harm occurred to

As a result the question of how we define personal identity over time is an important one for my thesis, as, in relation to person affecting ethical judgement, our individual moral compasses will point in different directions depending on which of the personal identity theories we ascribe to. In this section I explore the notion of personal identity to justify why the account I apply through this thesis is the most appropriate one. I also argue that opinions that oppose *in utero* therapies citing objections on personal identity grounds are misguided. My main objection is that *ex utero* genetic “sameness”¹⁵⁸ (in cases of genetic therapy) or bodily “sameness” (in cases of foetal surgery/antibiotic therapy) does not equate to one’s personal identity being preserved, as what defines our personal identity is neither our genes nor our bodily integrity but rather psychological connectedness and continuity. Objections to *in utero* therapies are made on the grounds that different genes or better functioning body parts as a direct result of an *in utero* therapy designed to make the eventual child healthier change one’s personal identity are poorly founded as , I argue, neither influence psychological connectedness nor continuity.

The two main approaches to personal identity

There are numerous accounts of personal identity and in order to ascertain if a specific person is the same person as it was in the past we need to determine what gave that

¹⁵⁸ i.e sameness of *ex utero* and *in utero* genetic or anatomical constitution.

person his/her own identity fingerprint to begin with. There are two useful accounts to this.

The Psychological Approach: What is important in defining personal identity over time is being psychologically continuous with past and future entities. Thus a person x existing at time t is identical to a person y that exists another time, t^* , if and only if x can remember, at t , an experience y has at t^* or y can remember, at t^* , an experience x has at t .¹⁵⁹

The Biological/Physical Approach: What is important in defining personal identity over time is *physical continuity*. Thus, with respect to persons, one's being the same numerical entity over time consists in one's being the same physical entity over time and as persons are living organism's if x is a particular numerical person at time t and y is a particular numerical person at t^* , x can be said to be y only if y 's biological organism is continuous with x 's biological organism.¹⁶⁰

The Psychological approach, intuitively at least, is more in keeping with the persistence of personal identity over time when the subject matter is human beings with the ability to feel, process, have emotions and possess all those characteristics that separate us from other mammals.

I disagree with the Biological/Somatic approach because, whilst my own own identity or the identity of my friends and family may change though time as we age and grow, it is not the physical continuum that defines us collectively as persons but rather our character, our psychological existence. If I were to lose a limb today I would not be a different person tomorrow than I am now. I encounter similar experiences in my clinical

¹⁵⁹ Brueckner, A. (2005). Branching in the psychological approach to personal identity. *Analysis*, 65(288), 294-301.

¹⁶⁰ Olson, E. T. (1999). *The human animal: Personal identity without psychology*. Oxford University Press. p125-153

practice that validate my preference of the psychological approach to the biological one. If a child has endured a catastrophic brain haemorrhage because of a saccular brain aneurysm, families take little solace in the child's bodily integrity, whilst externally at least, physically the child is the same, psychologically he/she is no longer that same person.

In *Reasons and Persons*, Parfit indulges us in his famous "teletransporter"¹⁶¹ thought experiment. His machine puts the traveller to sleep, then breaks him down into atoms, copies the information and rapidly transports it to Mars. The receiving machine re-creates the traveller in such a way that he/she is identical to the one that stepped into the teletransporter in the first place. Parfit inquires if the teletransporter is a method of travel—is the person recreated by the receiving machine on Mars the *same person* as the person who was copied by the teletransporter on Earth? If I were to wake up on Mars, *I* would feel like myself and *I* would recall entering the teletransporter, I would still have all the memories and life experiences that moulded my identity into what it was at the time of transport.

Parfit continues the thought experiment by enhancing the teletransporter, turning it into a machine that can make numerous replicas of the traveller without destroying the "original", all of the copies would remember entering the machine in the first place¹⁶². The relevance of this enhancement in Parfit's argument is that, according to him, this serves a philosophical evidence that any attempts to determine the sameness of a person are likely to fail, because there is no further fact; all that matters is "Relation R"^{163,164} the psychological connectedness and continuity between mental events as the essence of a person. From this conclusion Parfit extrapolates that it is morally wrong for one person to harm or interfere with another person and a societal responsibility to prevent such

¹⁶¹ Parfit, D. (1984). *Reasons and persons*. Oxford University Press Oxford. p199-200

¹⁶² *ibid*

¹⁶³ *Op.Cit* Parfit D p 215

¹⁶⁴ Belzer, M. (1996). Notes on relation R. *Analysis*, 56(1), 56-62.

interference. He further concludes that it is also imperative that society protects our "Future Self" from such interferences. In the end what matters to Parfit is not personal identity, but rather mental continuity and connectedness.

My real life example of the child with the haemorrhagic stroke is in keeping with Parfit's ideology, I suspect most of us would have a preference for our child's personality and memories to remain unaffected even if it is at the expense of the loss of bodily integrity if a perverse thought experiment asked us to choose between the two.

Memory is important for personal identity, but it is not enough

Memory according to Locke is a necessary criterion¹⁶⁵, if one remembers having done an action, then it would follow that he/she is the person that did that action in the first place. Memory alone, however, does not seem sufficient to grant continuity in personal identity. The best-known objection to this perhaps is Reid's "Brave officer" example¹⁶⁶.

A young boy is flogged for stealing an apple; later in life, as a young officer, he recalls the flogging. The young officer ages further, becoming an old general that remembers acting bravely during his early years at the service but has no recollection at all of being flogged during childhood. If Locke's theory were to be valid, according to Reid, the young officer is the same person as the small boy, and the old general is the same person as the young officer. Paradoxically the old general would not be same person as the small boy, even though intuitively] identity is transitive (if $x = y$ and $y = z$, then $x = z$). A further flaw in Locke's memory criterion was posed by Butler¹⁶⁷ that criticises Locke's

¹⁶⁵ Locke J. *Concerning Human Understanding* (Oxford: Oxford University Press, 2008), book II, chapter X p37-39

¹⁶⁶ Reid T., 'Of Identity', in J. Perry (ed.), *Personal Identity* (1975) Berkeley: University of California Press, pp. 107-112, for a thorough analysis see Shoemaker, S. S. (1959). Personal identity and memory. *The Journal of Philosophy*, 56(22), 868-882.

¹⁶⁷ Slors, M. (2001). Personal identity, memory, and circularity: An alternative for q-memory. *The Journal of Philosophy*, 98(4), 186-214.

theory for being circular. The crux of this criticism is the notion of memory it employs presupposes the notion of personal identity.

The above objections make it clear that for the psychological account to be plausible, relations of psychological continuity must consist of memories, but not memories alone. A more direct psychological connection “which holds between an intention and the later act in which this intention is carried out”¹⁶⁸ and the connections required for the holding over time of a belief, a desire, a goal or any other psychological feature as well as indirect psychological relations which will allow the young officer to be, can be the same numerical person at times x, y and z despite a lack of memory at the later point z. After all what, without a doubt what happened at x influenced the young officers character and course of events in his/her life in a way that help mould his personal identity. We can therefore argue that in the presence of psychological continuity, where this is defined as “the holding of overlapping chains of strong connectedness”. If A is a particular numerical person at time T1 and B is a particular numerical person at T2, then A= B if A is uniquely psychologically continuous with B¹⁶⁹

The psychological approach has also been criticized for lacking the ability to credibly respond to binary situations such as cases of fission. If, for example someone (lets call him Tarquin) somehow divides by binary fission at a particular point in time resultant in in two identical persons, having undergone the same past life experiences and are therefore both psychologically continuous with Tarquin, then the psychological approach would dictate that both candidates could be Tarquin’s successor. A well-trodden example is that of a person having his two brain hemispheres separated and transplanted in two separate bodies that prior to the transplant had been anencephalic¹⁷⁰. This scenario would suggest that whilst under the psychological approach the survival of an individual if one

¹⁶⁸ Parfit, D. (1984). *Reasons and persons*. Oxford University Press Oxford. p205

¹⁶⁹ *ibid*, p. 206.

¹⁷⁰ Sperry, R. W. (1985). Consciousness, personal identity, and the divided brain. In : Frank Benson F , Zaidel E (Eds.) *The Dual Brain Hemispheric Specialization in Humans* , The Guilford Press (1985) p11-27.

hemisphere of the brain is transplanted is possible. It does not allow for the idea that the individual could exist as both persons after the dual transplant, as personal identity is necessarily singular; myself, you, Tarquin, none of us can be two people. Medically of course, hemispheric separation and transplant may one day be possible, mammalian experiments with brain grafts have already taken place¹⁷¹. And yet while it may be medically possible one day to exist as 2 separate people the above thought experiment, leads us to the nonsensical conclusion that whilst we would survive if one brain hemisphere was transplanted and the other destroyed, we would die if both hemispheres had been transplanted.

The fission objection to the psychological approach has therefore led me to employ the following approach to my thesis. With respect to matters relating to personal identity of future children, it is not identity itself that matters for survival, but rather psychological connectedness and continuity that provide it with significance. Whilst after fission in two identical parts it cannot be said that a person exists as two separate entities, the collective existence of his identical successors is equivalent to his survival. So if my right and left cerebral hemispheres were transplanted in two separate bodies, as, presumably my psychological connections, experiences, memories and all that make me myself have been split up, I do not exist as two different people, I exist as two halves, just in two separate bodies, when put together those two halves still add up to make me who I am.

By grounding connectedness and continuity as the major determinants of what constitutes personal identity (as opposed to the relation of identity itself) we would be consistent in saying that our Brave Officer is the same person at time x, y and z because he has strong intertwined bonds of continuity and connectedness, and this would hold true even if he was to have a split hemispheric transplant into two separate bodies. Furthermore, if our Brave Officer were to age and get dementia then the lines of continuity and connectedness would become blurred. In this situation we may hold that that depending on how much these lines have been blurred, i.e. how much psychological continuity and

¹⁷¹ Look at, for example, the seminal paper by Krieger *et al*: Krieger, D. T., Perlow, M. J., Gibson, M. J., Davies, T. F., Zimmerman, E. A., Ferin, M., Charlton, H. M. (1982). Brain grafts reverse hypogonadism of gonadotropin releasing hormone deficiency. *Nature* Jul 29;298(5873):468-71

connectedness remains, then the officer may or may not be (or even merely “be a fraction of”¹⁷²) the person that he was before the illness.

Do foetal interventions affect the resulting child’s personal identity?

A defining feature of *in utero* interventions is that by design they bring about changes that will (hopefully) make changes *in utero* that will improve the welfare of the child the fetus will become. Questions may therefore arise as to whether this therapy might bring about a change in the resulting child’s personal identity and, if it did, would this be significant or problematic from a moral standpoint.

I have argued above that it is psychological connectedness and continuity that are the main determinants of personal identity. Although there is some evidence that foetuses may have a degree of awareness or consciousness¹⁷³ and may be able to hear¹⁷⁴ or and feel pain¹⁷⁵, it is unlikely that any of us have any recollections of our life *in utero*. It is unlikely, therefore that it can be said that we have a personal identity in the pre-personal state. Foetuses have not developed a biographical life yet, they are not persons yet, they have no life experiences, no memories, have yet to meet any family to forge relationships with, they have yet to experience the joys, frustrations disappointments that mould every single one of us to the persons that we are, each of us with a unique personal identity that is the sum of all we are and what we have been through, good and bad. Personal identity is developed sometime after birth, at about the same time that we become

¹⁷²This notion was inspired by the following article Sabat, S. R., Harré, R. (1994). The Alzheimer's disease sufferer as a semiotic subject. *Philosophy, Psychiatry, and Psychology*, 1(3), 145-160.

¹⁷³ Chamberlain, D. B. (2003). Communicating with the mind of a prenat: Guidelines for parents and birth professionals. *Journal of Prenatal and Perinatal Psychology and Health*, 18(2), 95.

¹⁷⁴ Arya, R., Chansoria, M., Konanki, R., Tiwari, D. K. (2012). Maternal music exposure during pregnancy influences neonatal behaviour: an open-label randomized controlled trial. *International journal of pediatrics*, 2012.

¹⁷⁵ Derbyshire, S. W. (2010). Foetal pain?. *Best Practice and Research Clinical Obstetrics and Gynaecology*, 24(5), 647-655.

persons¹⁷⁶, so to say that an *in utero* therapy may alter a personal identity that at the time of the intervention is yet to exist is paradoxical in itself. *In utero* interventions that are by design there to improve foetal health do not seem to frustrate connectedness and continuity enough to alter ones personal identity as these occur pre-personal (identity) state.

Furthermore, with respect to foetal surgery, the objective is to improve an anatomical abnormality so that the eventual child is healthier when/she is born. That is a purely physical alteration, so for example a child that would have otherwise been born with a congenital diaphragmatic hernia, a condition with a considerable mortality, can have it repaired before he is born. As elaborated above, the biological/physical approach to personal identity is a poor one, even if the entire body is exchanged with a new one, provided the connectedness and continuity remain the same, the personal identity remains the same. Similarly, foetal interventions in the guise of giving medication antenatally, for example to prevent a neonatal infection cannot be said to frustrate personal identity claims. A neonatal septicaemia or meningitis, apart from death can lead to cerebral palsy, severe developmental delay or even to loss of limbs¹⁷⁷. Screening against such infections and accepting safe, effective antibiotic therapy is likely to prevent such sequelae, and aside from the reality that the eventual child may have a strong interest in not being born with meningitis for obvious reasons, it can not be said that should he/she survive his personal identity is different because had he/she not been treated antenatally, his bodily integrity or cognitive ability would have been lacking..

¹⁷⁶ For a definitive Harrisian account of personhood employed through the thesis see Harris, J. (2006). *The value of life: an introduction to medical ethics*. Routledge. and Harris, J. (1999). The concept of the person and the value of life. In Thomasma, D. C., Weisstub, D. N., Hervé, C. (Eds.). (2013). *Personhood and health care* (Vol. 7). Springer Science and Business Media. (pp. 99-111).

¹⁷⁷ Weston, E. J., Pondo, T., Lewis, M. M., Martell-Cleary, P., Morin, C., Jewell, B., Lynfield, R. (2011). The burden of invasive early-onset neonatal sepsis in the United States, 2005–2008. *The Pediatric Infectious Disease Journal*, 30(11), 937.

Identical twins and existential worries: special considerations in relation to *in utero* gene therapy

Whilst foetal surgery or antibiotics change the physical aspect of one's health, *in utero* gene therapy merits special consideration as its purpose is to facilitate a change at the genetic level, which may in turn influence or alter one's personal identity. Are we our genes? Are we just our genes? And is our personal identity dependent on our genes? Although a literature review of the above questions would be enough to fill numerous books, I will focus on a few pertinent points.

We are more than a sum of our DNA. Case in point is identical twins. So whilst identical twins are made of exactly the same genetic material, they have distinctly different personal identities. So genes alone are not enough to pre-define our personal identity. The case of identical twins has led to questions of when our individual life stories begin. Bernard Williams has formulated the Zygotic principle to try and answer this question "a story is about A if it about an individual who developed from the earliest item from which A in fact uniquely developed".¹⁷⁸

Certain genes code for certain character traits. This may be true, an extra Y chromosome for example may predispose one to more aggressive behaviour¹⁷⁹ or the DRD4 gene may predispose to delinquency¹⁸⁰. The evidence is that the genes provide exactly that, a predisposition, they do not cause the various character traits but they may contribute or unmask them if the right circumstances arose. The question then arises to what extent do

¹⁷⁸ Williams, B. (1995). *Making sense of humanity: and other philosophical papers 1982-1993*. Cambridge University Press. p230

¹⁷⁹ Price, W., Whatmore, P. B. (1967). Behaviour disorders and pattern of crime among XYY males identified at a maximum security hospital. *British Medical Journal*, 1(5539), 533.

¹⁸⁰ Dmitrieva, J., Chen, C., Greenberger, E., Ogunseitan, O., Ding, Y. C. (2011). Gender-specific expression of the DRD4 gene on adolescent delinquency, anger and thrill seeking. *Social Cognitive And Affective Neuroscience*, 6(1), 82-89.

our genes determine our character? Miller¹⁸¹ cites three answers that may be applicable to this question and relate to different degrees of determinism. He concludes that traits that we are genetically predisposed to serve as parameters within which we mould our own character and develop our personal identity. DNA is therefore important for the development of the said identity but is not the only significant determinant and we oughtn't conflate its importance. According to Miller, other parameters such as free will, responsibility and determinism are of at least, equal importance. Using the identical twin example above Miller argues that personal identity cannot exist in the DNA as identical twins do not have identical personal identity¹⁸², so whilst the DNA is an important encoder one should not exaggerate its importance in terms of personal identity development.

Following Miller's conclusion, Chadwick¹⁸³ has identified that since personal identity consists of something other than our DNA, it is possible, at least in theory, to change our DNA in a way that does not change our personal identity. By using gene therapy as an example she sees three different scenarios.

- (1) That any change in the DNA brings about an identity change;
- (2) that a change in a certain proportion brings about an identity change;
- (3) that a change in a key part brings about an identity change.¹⁸⁴

Regarding the 1st scenario, Chadwick argues that an argument that any change in DNA brings about an identity change is implausible to accept, as humans share 99% of their genes and yet we all have different personal identities. Even in cases of identical twins, as

¹⁸¹ Miller III, H. (1998). DNA blueprints, personhood, and genetic privacy. *Health Matrix*, 8, 179-221

¹⁸² For a good account of external determinants of character and personal identity see Cohen, D. B. (1999). *Stranger in the nest: do parents really shape their child's personality, intelligence, or character?*. J. Wiley and Sons.

¹⁸³ Chadwick, R. (2000). Gene therapy and personal identity. In G. K. Becker (ed.) *The Moral Status of Persons: Perspectives on Bioethics*. Atlanta, GA: Rodopi, p187

¹⁸⁴ *ibid* p 187

explained above, when exact copies of the DNA are found in two separate human beings, twins have distinctly different personal identities. Our personal identities are therefore not identical to our complete set of genes so objections to changing DNA for therapeutic reasons citing personal identity objections are weak. Regarding the 2nd scenario, since a change in a proportion of genes would reflect a physical change Chadwick cites similar objections that I have touched upon above relating to why the physical account of personal identity is poor¹⁸⁵. Finally, Chadwick acknowledges that the answer to the 3rd question can only be given if we know which aspects of the person are essential to his identity and which genes control it. At the time of writing there is some, but very limited evidence as genes controlling any character traits at all. The two examples given above (XYY and DRD4 gene) are not *known* to cause any character attributes, they are merely associated with them, they are not implicated in causation of aggressive behaviour but merely correlate with it. This is an important distinction, if everyone who has gone to the moon has eaten beef, there is a correlation with beef eaters having gone to the moon but eating beef does not result (or cause) in one going to the moon. In the absence of solid evidence it is more likely that our personal identities are moulded by nurture, more than by nature¹⁸⁶.

On evidence of the above arguments DNA has a part to play in the development of our personal identity. However, in the absence of confounding evidence of specific genes being causative of particular character attributes, objections that a change in some genes *in utero* in order to confer a welfare benefit to the eventual child will result in a change in his/her personal identity remain weak, and the role of the DNA in the evolution of our personal identity should not be exaggerated.

¹⁸⁵ *ibid* p190

¹⁸⁶ Cattell, R. B., Blewett, D. B., Beloff, J. R. (1955). The inheritance of personality: A multiple variance analysis determination of approximate nature-nurture ratios for primary personality factors in Q-data. *American Journal of Human Genetics*, 7(2), 122.

Somatic versus Germ Line therapy, does the distinction matter in terms of personal identity objections?

There are attempts in the literature to try and differentiate whether personal identity can be affected depending on the type of gene that is treated¹⁸⁷¹⁸⁸. The distinction is that germ cells affect reproductive cells so are likely to have a knock on effect to future generations that result from the individual that has received treatment, whereas somatic therapy only affects body cells of the individual. With respect to the latter, again the objections cited above with regards to the shortcoming of physical accounts of personal identity would be relevant.

The distinction between the two types of gene therapy is unhelpful where trying to settle personal identity objections. This is because of two scientifically reasons, firstly any somatic cell can now be used to become an embryo¹⁸⁹ and secondly, viruses can infect somatic cells which then contaminate germ cells by transferring somatic DNA onto them¹⁹⁰. So the debate of whether personal identity can be affected by *in utero* gene therapy cannot be settled by focusing on what type of genes are being treated. Instead it may be more useful to look at what objections, if any, future person may have by having received foetal therapies, including *in utero* gene therapies.

¹⁸⁷ See : De Wachter, M. A. (1993). Ethical Aspects Of Human Germ-Line Gene Therapy. *Bioethics*, 7(2-3), 166-177 and Chadwick, R. F. (2001). Genetic interventions and personal identity. In : Ten Have, H. A., Gordijn, B. (Eds.). (2013). *Bioethics in a European perspective* (Vol. 8). Springer Science and Business Media (pp. 339-349).

¹⁸⁹ Tachibana, M., Amato, P., Sparman, M., Gutierrez, N.M., Tippner-Hedges, R., Ma, H., Kang, E., Fulati, A., Lee, H.S., Sritanaudomchai, H. and Masterson, K., (2013). Human embryonic stem cells derived by somatic cell nuclear transfer. *Cell*, 153(6), pp.1228-1238.

¹⁹⁰ Spence, S. E., Gilbert, D. J., Swing, D. A., Copeland, N. G., Jenkins, N. A. (1989). Spontaneous germ line virus infection and retroviral insertional mutagenesis in eighteen transgenic Srev lines of mice. *Molecular and cellular biology*, 9(1), 177-184.

What legitimate objections may a future child have regarding possible changes in personal identity?

So far I have argued that personal identity of the eventual child is unlikely to be affected by either *in utero* treatments that improve bodily integrity (such as foetal surgery) or gene therapy. This is for two main reasons, firstly because *in utero* treatments fail to change one's psychological continuity and connectedness. Secondly I have argued that it is paradoxical to claim that one's personal identity has changed before one has become a person. One's anatomical identity may change if his/her heart defect is repaired *in utero* as that is pre-defined before he/she becomes a person, but his/her personal identity will not change as that foetus does not have a personal identity one yet.

However, if a resulting child that has directly benefited, at least in a medical sense, from an *in utero* therapy may have a grievance on the grounds of personal identity. In this section I will examine what legitimate grievances, if any, regarding personal identity future children in receipt of *in utero* treatments may have.

There are many positions a child may take if he/she finds out that they have benefited, at least medically, from a treatment before they had been born. "I should not have had *in utero* treatment", "I should have been born as someone less healthy", "I should have been born as someone else", "I should have had the genetic disorder I was treated for", "I should have been born with neonatal meningitis" or "I should have had the set of genes I was initially conceived with" may be legitimate grievances but they are not personal identity grievances. The children with these grievances may believe that they are different to what they would have otherwise been had an intervention not taken place. They may even, as a result, suffer from psychological harm. But believing in something does not make it valid, in the words of Shaw

"... We would have to try to disabuse them from their mistaken beliefs. Children are not intellectuals: if they have two loving caring parents, then the fact that the

symbolistic and filiative intermingling of the genes of mother and father is missing from their conception, is unlikely to trouble them a great deal”¹⁹¹.

Shaw makes his position clear, although he negates arguments that cite the toll on a clone’s psychological wellbeing as a reason to prohibit cloning his stance is very relevant in the wider setting of *in utero* gene therapy and foetal surgery. If a child is born healthier as a result of an intervention, he/she is unlikely to object much, and if they do have existential concerns, uncertain as to who they are or that they are not who they ought to have been it is our responsibility to dispel that falsely held belief. Any changes made to a foetuses genome or anatomy were done so before that foetus was a person, that foetus is yet to be born, so has yet to develop a personal identity. As such it cannot be a legitimate grievance to say *my* personal identity has changed because of something that happened to me *in utero*. Those changes contributed to who I am today and if they had not occurred I would not be here today, someone else would.

The only legitimate grievance that deals with the (presumed) sameness of that child’s personal identity is that he/she believe that they should have been born as someone else. But this stance is self-defeating, they could not have been someone else, they are who they are and if they were not who they are then someone else would have existed in their place instead. Similar objections are pointed out by Chadwick:

“The person who says 'I should not have had my genome altered' may have a coherent grievance but not one that lies in a personal identity issue. The statement of the grievance presupposes that identity has been preserved. Nevertheless it may be *perceived* as a personal identity issue”.¹⁹²

¹⁹¹ Shaw, D. M. (2006). *Genetic morality*. Peter Lang. p176

¹⁹² Chadwick R “Gene Therapy” in Kuhse, H., Singer, P. (Eds.). (2013). *A companion to bioethics*. John Wiley and Sons. p207-2015

Chadwick explains that this falsely perceived identity issue can be found in the question “I don't know who I am”, inferring that one is unsure of what his/her (genetic) origins are. This brings us full circle to the argument touched upon above, that whilst our genes and our DNA play a role in defining our personal identity, their role in the development of the said identity should not be exaggerated as the evolution of one's identity is influenced more by psychological connectedness and continuity.

By grounding psychological connectedness and continuity as the major determinants of what constitutes personal identity we can not say that *in utero* therapies, be it surgical, microbiological or genetic affects the personal identity of the resulting child in a way that he/she may have a legitimate grievance later on in life. Personal identity depends on life experiences, interpersonal relationships, family dynamics, schooling, culture, genetics and so on. Our memories, successes failures, prejudices and emotional attachments are all building blocks into what gives me my personal identity. *In utero* therapies are designed to create healthier infants, and infants need all of the above and more before they form their own personal identities as adults. Any attack on such therapies on the grounds that they threaten personal identity are bound to fail because as shown above, they are based on a misconception of the starting point of personal identity as well as its major determinants.

CHAPTER 3

**A DUTY TO OUR FUTURE CHILDREN –
IS INCREASED SCREENING LIKELY TO INCREASE ABORTION RATES
AND IF SO WHERE DOES THIS LEAVE MY POSITION?**

CHAPTER 3

A duty to our future children – is increased screening likely to increase abortion rates and if so where does this leave my position?

I argue that from the point in time that prospective parents decide to allow a specific foetus to meet its potential to become a child, they have a moral responsibility to protect that eventual child's welfare before it is born. Not doing so would be to harm that future child in the pre-personal, foetal stage. In order to behave in a way that does not impair the specific future child's welfare, I put forward that parents-to-be would need to abstain from risk taking behaviour such as smoking, taking recreational drugs (provided these are not essential for parental health reasons)¹⁹³ and take the appropriate dietary supplements that stand to benefit the future child. There would need to be firm scientific evidence that the type of risk taking behaviour engaged in consistently and predictably contributes to poor foetal and neonatal health in order to be grounded as parental duty. So for example, whilst being a passenger or driving a car whilst pregnant may in theory result in a catastrophic accident that results in the mother, foetus and by extension the eventual child being hurt, provided the car was being driven in a safe manner then it cannot be said that parents-to-be have a duty not to commute, as these events are sporadic and unpredictable. We can however claim that mothers-to-be have a duty not to drink excessive amounts of alcohol during pregnancy as excessive alcohol is consistently reported to cause foetal alcohol syndrome. The estimated rates of up to 29.9 per 10,000 live births depending on race have been reported in reviews analysing the prevalence of the syndrome¹⁹⁴.

Similarly, if a parent-to-be does not engage with the antenatal screening process, and misses the opportunity to treat antenatally (if such treatment exists) resulting in

¹⁹³ For example a mother-to-be dependent on opiates or alcohol would only be able to wean off alcohol or drugs with a step-down plan and under supervision by a medical team, stopping these on her own is likely to cause life-threatening withdrawal symptoms which will compromise both maternal and foetal life. See Bhat, A., Hadley, A. (2015). The management of alcohol withdrawal in pregnancy—case report, literature review and preliminary recommendations. *General hospital psychiatry*, 37(3), 273-e1 and Sheehan, M., Sheehan, M. G. (2013). Management of the pregnant substance abusing woman. *Clinical obstetrics and gynecology*, 56(1), 97-106.

¹⁹⁴ May, P. A., Gossage, J. P. (2001). Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research and Health*, 25(3), 159-167.

irreversible damage to the eventual child then I argue that such parents fail the eventual child in the pre-personal stage. Although I look at new, exciting, scientific advances that have the potential to significantly improve child health in future such *in utero* therapies, the argument is relevant now with much simpler medical treatment that is safe and effective for both mother and child. Antenatal screening for maternal infections for example give the physician the opportunity to offer antibiotics to the mother-to-be so that there is less risk of a life threatening meningitis or septicaemia to the newborn¹⁹⁵. It also allows for advanced planning of the immediate time after birth in terms of how intense the monitoring of both mother and child is, so whilst routinely a mother and child with a normal delivery may be sent home within six hours of birth if no known risk factors for infection are known; the same mother and child would need to stay in hospital for monitoring and antibiotics for a minimum of two days if a maternal high vaginal screen had come back positive for a maternal infection that could be passed on to the newborn. Treatment in such cases is simple, effective, well tolerated and advanced planning helps improve the outcomes of bacterial meningitis or septicaemia in the neonatal period, but the wheels for this type of management are set in motion in the antenatal setting, i.e. when the infant is still in a pre-personal stage. If parents do not engage with the above process then the outcomes for the newborn are likely to be far worse as there will be a delay in receiving antibiotics; after all, early administration of antibiotics has time and time again been proven to improve outcomes in the management of sepsis¹⁹⁶. I argue that this lack of engagement with the screening process, in cases where the evidence suggests that an early intervention is safe and effective, equates to the parents not exercising their parental duty towards their future child, a duty that can only be upheld if they have decided to go through with the pregnancy.

¹⁹⁵ Okike, I. O., Johnson, A. P., Henderson, K. L., Blackburn, R. M., Muller-Pebody, B., Ladhani, S. N., Cameron, J. C. (2014). Incidence, etiology, and outcome of bacterial meningitis in infants aged < 90 days in the United Kingdom and Republic of Ireland: prospective, enhanced, national population-based surveillance. *Clinical Infectious Diseases*, 59(10), e150-e157.

¹⁹⁶ Dellinger, R. P., Levy, M. M., Rhodes, A., Annane, D., Gerlach, H., Opal, S. M., Osborn, T. M. (2013). Surviving Sepsis Campaign: international guidelines for management of severe sepsis and septic shock, 2012. *Intensive care medicine*, 39(2), 165-228.

Continuing with the scenario of neonatal sepsis above, the intention here is not to screen in order to abort a foetus that has a risk factor that will render it disabled, although neonatal sepsis can have catastrophic sequelae and long term neurodisability. The objective is to maximise the chances of the infant to be born in a good condition and to have a better quality of life than he/she would have otherwise had if the screening and therapy process had not happened. It is unlikely that future parents would choose to abort a foetus if they had found out that the mother-to-be carries an infection that can be passed on to the child. It is more likely that they would engage with the antibiotic treatment offered, as it is simple, safe and effective. With respect to emerging technologies however and screening for various anatomical abnormalities or syndromes my position may be criticised, as an increase in screening uptake would also have the potential to increase the abortion rate, and that, for some may be ethically problematic. That is in part an inherent problem with most emerging technologies, they may be able to cure but the outcomes are not consistently good yet and the risks posed to the mother and child are likely to be more, so many parents may opt to abort instead. Time will probably iron out these difficulties to allow *in utero* therapies to be consistently safe and allow reliably good clinical outcomes¹⁹⁷ but at the time of writing this is not the case.

Objections against the theoretical increase in abortion rates following an abnormal anatomy scan are placed within a wider sphere of ethical issues relating to abortion and how such societal pressures influence motherhood. As an in depth analysis of the philosophical pros and cons of abortion would need several doctoral theses to be adequately addressed I focus on what I view to be most pertinent objection. Those condemning abortion as a result of an abnormal antenatal scan often employ a pro-life viewpoint. Pro-life advocates interpret abortion as a life-taking practice¹⁹⁸ and would therefore object to anything that could systematically be shown to increase abortion rates. Such objections assume that increased screening equates to more abortions and since even one abortion is morally problematic, multiple abortions are even more so. Whilst the

¹⁹⁷ For a detail account of you surgical outcomes improve with time see Freischlag, J. A., Kibbe, M. R. (2014). The evolution of surgery: the story of “Two Poems”. *The Journal of the American Medical Association*, 312(17), 1737-1738.

¹⁹⁸ Tribe, L. H. (1992). *Abortion: The clash of absolutes*. WW Norton and Company.

theoretical increase in abortion rates as a result of increased screening uptake may be a valid objection, it is an objection I take issue with on three fronts.

Firstly, assuming that abortion is in some way ethically questionable, the doctrine of double effect argument can be invoked to argue that this “harm” is permissible if our objective of increased welfare of children (rather than net welfare worldwide) can be achieved. The increased, alleged “harm” of abortion uptake is a side effect to the intended outcome of the action. This argument, in itself does not; however suffice so let us look at the evidence. The assumption made is that (a) increased screening uptake would (b) increase the number of abortions. Current evidence would suggest that (b) does not follow (a).¹⁹⁹ The systematic review published in 2012 spanning over 15 years between 1996-2011 presents the largest compilation of United States data on termination rates following a prenatal diagnosis of Down syndrome and suggests that termination rates are lower than noted in a previous reviews, and this is at the time when Down syndrome screening has increased uptake. So the objection that more screening will lead to more abortions is not necessarily valid or backed by current evidence, and is at the very least negated by the argument that increased screening (for anything from maternal infections to anatomical abnormalities) will inevitably lead to more engagement with therapeutic interventions which will benefit the eventual child

My second, objection reflects, to an extent John Harris’ “argument from Beethoven”.²⁰⁰ It is well known that Beethoven was deaf, and according to Harris, to abort a foetus with ‘Beethoven syndrome’ is not to abort Beethoven, but rather it is just to abort a foetus. Clarifying Harris’ position, if prospective parents prefer to have a non-deaf child to a deaf child and screen against that disability and subsequently abort any non-deaf foetuses, then no one has been harmed as no one has come to exist. Creating the healthiest possible children is what prenatal diagnosis is all about, according to Harris, and the notion that such practice is offensive to people who are deaf is misplaced. Harris

¹⁹⁹ Natoli, J. L., Ackerman, D. L., McDermott, S., Edwards, J. G. (2012). Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995–2011). *Prenatal diagnosis*, 32(2), 142-153.

²⁰⁰ Harris, J. (1998) *Clones, Genes and Immortality*, Oxford: Oxford University Press. p215

ascribes, little to no moral value to the foetus. I believe that foetuses are worthy of moral protection from the point in time when their future parents decide to go through with the cycle of pregnancy. If they do not wish to complete the pregnancy, then, like Harris' viewpoint discarding them oughtn't be morally objectionable. My proposition does open other possibilities to the parents though, many of the conditions that can be picked up by routine antenatal screening test may benefit from either *in utero* therapy or early *ex utero* treatment. These may either be entirely treated or the disability load to the specific child reduced. A child with a congenital diaphragmatic hernia may for example be entirely cured by foetal operative procedure, a foetus with Down syndrome and a cardiac defect will benefit from a birth in a tertiary cardiac centre so as to receive high level cardiac care immediately after birth. The real harm, I argue, is not how many non-persons have been discarded, but how many children that will come to exist in future have failed to benefit from therapeutic interventions in the perinatal environment; interventions that could only have been pre-planned had the parents engaged with the screening services and engaged with the treatment offered.

There is no straightforward answer when ascertaining how many children may benefit from these interventions and antenatal screening, but a possible approach is looking at EUROCAT (European Surveillance of Congenital Anomalies) evidence. EUROCAT is the network of population-based registers of congenital anomaly in Europe; member states have a common protocol and common data quality review. There are 22 state members covering 1.5 million annually. Over the four-year period between 2003 and 2007 EUROCAT recorded a total prevalence of major congenital anomalies of 23.9 per 1,000 births²⁰¹. This is *not* a negligible figure.

Of those 80% were live births and 2.5% of live births with a congenital anomaly were reported to have died in the first week of life. Only 2.0% were stillbirths and 17.6% of all cases were terminations of pregnancy following prenatal diagnosis. On this evidence it is clear that congenital anomalies in their majority concern newborns that survive the early

²⁰¹ Dolk, H., Loane, M., Garne, E. (2010). The prevalence of congenital anomalies in Europe. In de la Paz, Manuel Posada, and Stephen C. Groft, eds. *Rare diseases epidemiology*. Vol. 686. *Rare diseases epidemiology* (pp. 349-364). Springer Netherlands.

neonatal period and that less than a fifth of such fetuses get aborted. One could argue that the 80% of those live births could benefit by a type of intervention *in utero*, but this is unlikely to be the case. Foetal surgery is a speciality in its infancy so at the time of writing only specific congenital abnormalities can be repaired and with variable results. There is some early success with congenital cardiac anomalies²⁰² being the most common non-chromosomal subgroup of defects according to EUROCAT, at 6.5 per 1,000 births. These could benefit alongside fetuses with spina bifida²⁰³ (1 per 1000 births), diaphragmatic hernias²⁰⁴ (1 in 2000) and congenital upper airway anomalies²⁰⁵ (incidence unknown). The list is not exhaustive but at the very least, these congenital anomalies can be made less burdensome for the eventual child, a child that will have rights and interests and provided that the parents want to carry on with the pregnancy, a foetus that is worthy of moral protection. If fetuses are aborted, as is my main premise, these will never exist, so they are not worthy of moral protection and we cannot claim a moral wrong has been done by such an action. The rights and interests of a single eventual child that have been protected in the pre-personal stage are worth more than any theoretical rights and interests (if these exist at all) of a foetus that never came to exist.

It is worth remembering that the above figures relating to congenital abnormalities do not include the number of children born with congenital infections, by far the single biggest reason of neonatal death and, as I argue, the duty to screen is not limited to genetic disease. This duty extends to screening for infection and abnormal anatomy as well as genetic disease. According to UNICEF's Maternal and Newborn health review:

²⁰² McElhinney, D. B., Tworetzky, W., Lock, J. E. (2010). Current status of fetal cardiac intervention. *Circulation*, 121(10), 1256-1263.

²⁰³ Cragan, J. D., Roberts, H. E., Edmonds, L. D., Khoury, M. J., Kirby, R. S., Shaw, G. M., Krishnamurti, D. S. (1995). Surveillance for anencephaly and spina bifida and the impact of prenatal diagnosis--United States, 1985-1994. *MMWR. CDC surveillance summaries: Morbidity and mortality weekly report. CDC surveillance summaries/Centers for Disease Control*, 44(4), 1-13.

²⁰⁴ Langham Jr, M. R., Kays, D. W., Ledbetter, D. J., Frentzen, B., Sanford, L. L., Richards, D. S. (1996). Congenital diaphragmatic hernia. Epidemiology and outcome. *Clinics in perinatology*, 23(4), 671-688.

²⁰⁵ Joshi, P., Satija, L., George, R. A., Chatterjee, S., D'Souza, J., Raheem, A. (2012). Congenital high airway obstruction syndrome—antenatal diagnosis of a rare case of airway obstruction using multimodality imaging. *Medical Journal Armed Forces India*, 68(1), 78-80.

“...86 per cent of newborn deaths globally are the direct result of three main causes: severe infections – including sepsis/pneumonia, tetanus and diarrhoea – asphyxia and preterm births. Severe infections are estimated to account for 36 per cent of all newborn deaths....”²⁰⁶

Thirty-six percent of all neonatal death being related to severe infection is a compelling figure. Neonatal infections are almost always due to pathogens found in the maternal vaginal tract, which highlights the importance of a high vaginal swab as a screening tool. As antibiotics given to the mother antenatally in conjunction with antibiotic therapy immediately after birth, before infection has had the chance to manifest itself in the child is the gold standard of treatment and has consistently shown to improve outcomes of newborn sepsis²⁰⁷. On this evidence, the parental “right not to know” cannot be defended as in the context of early newborn infection remaining in ignorance can directly be linked to a poorer outcome for the child.

There will, of course, be objections focusing on the syndromes or anatomical abnormalities whose early diagnosis “cannot change anything”²⁰⁸. Medically speaking this objection refers to the inability of the test to change prognosis, i.e. if the child has trisomy 21, one cannot delete the spare chromosome so the disease isn’t cured *per se*. Therefore the prognosis may be said to be the same. This in itself is a wrongly founded objection, and I explain why. Firstly, prognosis is defined as a forecast of the likely course of a disease or ailment²⁰⁹, and whilst prognoses and disease progression are obviously important aspects of medicine, they are not the *only* important aspects. Patient

²⁰⁶ UNICEF. (2009). *The State of The World's Children 2009: Maternal and Newborn Health*. Unicef. p 13

²⁰⁷ Wilson, C. B., Nizet, V., Maldonado, Y., Remington, J. S., Klein, J. O. (eds) (2014). Antenatal antibiotics, for intraamniotic infection prevention *Remington and Klein's Infectious Diseases of the Fetus and Newborn*. Elsevier Health Sciences. p60-63

²⁰⁸ This is a common lay response by parents-to-be not wishing to undergo antenatal screening as cited by Siegel, B., Milunsky, J. (2004). When should the possibility of a genetic disorder cross your radar screen?. *Contemporary Pediatrics*, 21(5), 30-41.

²⁰⁹ Oxford English Dictionary online
http://www.oxforddictionaries.com/us/definition/american_english/prognosis accessed 22/6/16

comfort, adequate analgesia, protecting quality of life (even if there is little left) are central features of my everyday practice.

I am frequently involved in palliation or end-of-life discussions with parents whose children have terminal illnesses and without exception (at least at the time of writing) their main wish is for the medical team to do everything they can in order to not let their child suffer. The literature suggests that this is an overriding wish, not only within palliative care specialities but also specialities that deal with chronic conditions, including those with a life-limiting prognosis²¹⁰. Furthermore, curing people from a specific syndrome is almost never realistic; I have never read a case report whereby someone cured Down's syndrome or Klinefelter Syndrome or Cystic Fibrosis to name but a few. Genetic disease is not there to be cured, at least not at present, it is there for us to find ways to circumvent the disease process, make the patient more functional (the role of occupational health and surgeons), minimise the frequency they need hospitalisation (the role of the physician), optimise their education so that their disability doesn't exclude them socially (the role of the community paediatrician) and so on, the list is vast. So as a paediatrician I cannot, in good conscience accept the objection that there's no value in antenatal screening because "we can not do anything" about the syndrome. There are lots of things that we can do to make that child as comfortable as possible, minimise suffering and (with the exception of palliative care where the focus is maximising comfort at the end of life) help them integrate in society as well as they possibly can in order to maximise their happiness. In my second article I explain how early interventions in a "non-curable" condition such as Down Syndrome can help improve the child's welfare, justifying therefore the need to be aware that he child will be born with the condition before he/she is born.

²¹⁰ See for example Borneman, T., Stahl, C., Ferrell, B. R., Smith, D. (2002). The concept of hope in family caregivers of cancer patients at home. *Journal of Hospice and Palliative Nursing*, 4(1), 21-33. , Brajtman, S. (2003). The impact on the family of terminal restlessness and its management. *Palliative Medicine*, 17(5), 454-460 and Márquez-González, M., Romero-Moreno, R., Losada, A. (2010). Caregiving issues in a therapeutic context: New insights from the acceptance and commitment therapy approach. *Casebook of clinical geropsychology: International perspectives on practice*, 33-53.

PART 2
THE PAPERS

CHAPTER 4

OVERVIEW OF THE PAPERS

CHAPTER 4

Introduction

In part one of this thesis I aimed to give an account of the legal and philosophical background to the research questions I have explored in this thesis and the particular philosophical approaches I have taken to these questions. Part two of this thesis is made up of three papers, written for publication, that address my chosen research questions. In this section that precedes the papers I provide an overview of the papers and their contents.

Overview of the papers

The purpose of this thesis is to explore philosophical and legal theories that deal with the subject of responsibilities held to the unborn child by those wishing to be parents (primarily). A review of the literature raised further questions in my mind; primarily what responsibilities are held by wider society towards future children? I make no secret of the fact that I am a pediatric intensivist so my opinions have been in part moulded by what I come across daily on the paediatric intensive care unit. What has always baffled me is the paradox whereby the law protects existing children from harm or future harm from the point of birth²¹¹, even to the extent that newborns are removed by court order (a trend that is becoming more and more commonplace)²¹² should the parents be deemed to be unfit for carrying out their parental duties²¹³; and yet it fails to protect future children at their most medically fragile state, whilst they are still embryos.²¹⁴ The desire to develop this thesis has therefore stemmed in part from looking after children who have been born in a worse off state than they otherwise would have, if and only if the parents

²¹¹ Paris, J. J., Schreiber, M. D., and Moreland, M. P. (2007). Parental refusal of medical treatment for a newborn. *Theoretical medicine and bioethics*, 28(5), 427-441.

²¹² 'Huge rise' in newborn babies subject to care proceedings <http://www.bbc.co.uk/news/uk-35088794>
Accessed 15/12/2015

²¹³ Saunders, T. D. (1994). Banning Motherhood: An RX to Combat Child Abuse.. *Mary's Law Journal*, 26, 203-258

²¹⁴ Behnke, M., and Eyler, F. D. (1993). The consequences of prenatal substance use for the developing fetus, newborn, and young child. *Substance Use and Misuse*, 28(13), 1341-1391.

had received non-coercive guidance and medical advice as to what could have been done antenatally to improve the overall state of health of their baby.

I have therefore sought clarification in answering the following five questions:

1. Is there a moral obligation by parents-to-be to engage with antenatal screening services?
2. If the antenatal screening tests uncover a potential risk to the foetus do parents-to-be have an obligation to act in a way that reduces that risk?
3. In what circumstances are they obliged to do so?
4. Does the State have a vested interest in promoting antenatal screening and uptake of antenatal therapies?
5. If so how should the State increase uptake of such antenatal health programs?

A great deal of the ethical literature in this area focuses on the idea of a right to remain in ignorance of one's future child's genetic make up and health state in pregnancy. This argument is founded on the belief that harm cannot be avoided by knowledge of most conditions in pregnancy and thus the autonomy of the parents is often seen to trump the obligation to gain information about these disorders. For me this is an important and costly oversight and one that will detrimentally affect the welfare of future children. Thus, the papers that follow aim to build a case that, even where conditions are not curable in pregnancy, information gained by screening and testing is important to maximize the welfare of these children and thus, if parents are upholding their parental duties effectively, they should be availing themselves of this information. Further, I argue that the State has a role in enabling the fulfilment of these parental obligations even though this may seem to go against our usual reverence for respecting individual autonomy. In cases of antenatal screening and even some surgical intervention, I argue, that child welfare trumps parental autonomy.

Outline of The Three Articles

First Article:

Do prospective parents have a moral duty to undergo antenatal genetic screening and should this be reflected in the way that screening programs are offered?

This article argues against positions that hold that if there is a right to remain in ignorance of information about our genetic health, then this right is unaltered by pregnancy, at least until treatments emerge that can reverse genetic impairment.²¹⁵

I put forth that parents-to-be have a moral duty to access antenatal screening; the reason for this is the optimization of welfare of the specific child they plan to have. I argue that there is a strong case to be made for this moral duty to become more prevalent in policy and practice in the arena of perinatal medicine *in future*. I stress the term in future as at present, only a handful of conditions are effectively treatable *in utero*. It is foreseeable that on the current trajectory of scientific advances in the field, perinatal medicine will allow *in utero* treatment with relative safety and good outcomes to both the pregnant woman and the foetus with more consistency, something that can not be said of this relatively new field at the time of writing.

I argue that the harm principle is applicable in the pre-personal stage as long as future parents have the full intention of giving birth to that very foetus. I suggest that the acquisition of relevant antenatal information is not a limitation of individual freedom but rather an important adjunct to the Kantian perception of autonomy. It is argued that any results acquired before the birth of a child, including data of genetic nature, can minimize the risk of the future child and maximize that specific child's welfare, provided future parents use the attained information to intervene a positive way that benefits the eventual child before it is born. Central to this argument is the important distinction of the intention of the parents-to-be on whether the foetus will come to exist as a child or not, only then can an *in utero* harm be caused in the pre-personal stage. An *in utero* harm can be pro-active (for example by taking recreational drugs during pregnancy) or passive (for

²¹⁵ Bennett, R. (2001). Antenatal genetic testing and the right to remain in ignorance. *Theoretical medicine and bioethics*, 22(5), 461-471.

example by not taking antibiotics even if made aware that the child will be at significant risk of infection after birth).

Since some of the most promising, recent advances in *in utero* therapies such as foetal surgery have limitations; i.e. inconsistent outcomes and variable safety profiles for both mother and foetus, my argument cannot realistically be applicable in practice at the time of writing. This is because it is of vast clinical importance that for any treatment or screening process to be built into policy it should be safe, accurate and with good clinical results. With this in mind, I argue that the duty to know and intervene will become applicable and more pressing in future, once advances in antenatal care allow better surgical, medical and genetic intervention.

The article also responds to arguments made against parental duty to genetic screening in cases whereby the underlying disease process has no cure. I answer these objections by focusing on Down syndrome; a syndrome that readers are likely to be familiar with. I stress that the objective of the screening process for trisomy 21 ought not be termination of pregnancy, with the understanding that parents are entitled to abort should they wish, but rather to enable parents to forward plan with the early management. Non-invasive measures such as early physiotherapy²¹⁶ and early education²¹⁷ for the infant have been shown to be of benefit to the eventual child with Down syndrome.

²¹⁶ Capone, G. T. (2004). Down syndrome: Genetic insights and thoughts on early intervention. *Infants and Young Children*, 17(1), 45-58.

²¹⁷ Buckley S. Early Support – new materials and services for families with babies and children with Down syndrome (2006) *Down Syndrome News and Update*.5 (3); 124-126

Second Article:

How Antenatal Genetic Ignorance and Parental Failure to Engage with Screening Services Can Harm Us All

This article explores the question of whether ignorance of one's future child's genetic constitution before the child is born causes harm, and if so whether there is a moral obligation to avoid such ignorance by engaging antenatal screening and *in utero* therapies made available to us.

In the paper I argue against those in favour of the alleged "right not to know", the reasoning often employed to defend one's so called right to genetic ignorance. Such justifications hold that in a liberal society respect for individual autonomy is vital; on these grounds people should not have information about their own genetic make-up "inflicted" upon them even if it is intelligence deducted from antenatal screening. Those supporting the right not to know also question if Mill's harm principle is at all relevant in the antenatal setting. The paper aims to analyse these positions and argue against them.

In doing so I elaborate on different accounts of the harm principle and explain my preference for a comparative account of harm similar to Feinberg's subjunctive historical account. I rely on this definition on the grounds of biological continuity; it is nonsensical to compare harm to a person if that person has never come to exist. I maintain that harm can only be assessed with respect to future children by comparing between the health outcome on a specific child if an intervention has occurred *in utero* and what it is if the intervention has not.

Furthermore, I explain my views on the subject of potential *in utero* harms incurred to future children. I review the special situations where disability avoidance may be preferable, and maintain that in certain *very rare* conditions that inflict children with a "sub-zero" quality of life, the parental duty to screen ought to be coupled with a merciful decision to terminate the pregnancy. I make it clear that these syndromes are extremely rare and the argument suggesting that these children are better off to not have been born

should only be applied for the handful of wrongful life cases alone; it is not a blanket argument against disability.

I also explore the reasons why parents have a moral imperative to screen antenatally in situations of non-wrongful life by using examples from the arena of paediatrics. I focus on conditions whereby the newborn can suffer irreversible harm if the appropriate medical treatment is not offered immediately after birth or cases where the sole treatment that offers chances of meaningful survival are *in utero* therapies. With the expanding field of foetal surgery and genetic therapies it is likely that the catalogue of conditions that can be repaired antenatally will expand with time. I also ask the question if failure to engage with antenatal services can cause harm to others and not just the resulting child. I explore if parents, siblings, other dependents and wider society in general can come to harm if a foetus is born in a worse off condition that it would otherwise have been.

Finally I explain on how educating oneself with antenatal foreknowledge is supported by the Kantian definition of autonomy. I opine that if the moral worth of our actions can be assessed based on the outcome, then we have better chance of reaching the desired result if an educated decision is made compared to an uneducated one. The only way of improving our probability of success in avoiding harm is by evaluating the information available to proceeding and us in an educated manner.

Third Article:

Foetal surgery and using *in utero* therapies to reduce the degree of disability after birth. Could it be morally defensible or even morally required?

The third and final paper evaluates if the HFEA 2008 amendments²²¹ can be viewed as a safeguard that aims to regulate how healthy a state future generations of children are born in. Parts of the 2008 amendments have outlawed the use of advanced reproductive technologies in order to achieve deliberate selection of specific disabilities.

I evaluate the main modifications to the Code of Practice that imply a change in attitude towards whether it is right or wrong to use advanced reproductive technologies for the conception of disabled foetuses; in doing so I assess whether in future where *in utero* therapies are more robust and effective there ought to be further legislation to promote their uptake. Special consideration is given to the Welfare of the Child Principle that is evident throughout the HFEA's code. I purport that the purposeful selection and implantation of embryos with a genetic disorder is in violation of that principle. I indicate that by limiting the positive selection of disabled embryos (and by extension disabled children or children with genetic disorders) the HFEA suggests that the application of reproductive technologies for what they were initially designed (i.e. to help infertile couples and to allow the production of healthier children) is for some reason, more important now. The position of HFEA stance invites us to question as to why in liberal societies legal limitations protecting foetuses from genetic disease are in place if a couple wants to procreate with the aid of advanced reproductive technologies but no extrinsic legal limitations are placed on parents who wish to have children in the conventional way. There are for example no quality checks the embryo needs to pass before it is allowed to be born.

I aim to answer the question by focusing on recent attitudes of the law in the U.S, England and Wales, whereby there is a clear trend where foetuses are afforded more and more legal protection. Bearing this in mind I then assess what conditions need to be

²²¹ HFEA 8th Code of Practice 2008

satisfied if the State is to justify the promotion of *in utero* therapies in the future, I put forth that three provisions need to be met and analyse each of them. The conditions are first; a parental intention to carry the pregnancy to term. Second; the recommended procedure is safe to both foetus and mother-to-be, and finally; that unless repaired, the *in utero* disability will affect the eventual child's welfare in a severe fashion. This begs other questions with respect to what defines severe harm and how this is to be quantified. I explore the philosophical views of how harm is evaluated as well as the medical assessment tools that are in use as an aide to stratifying disability in order of severity. I do so in order to try and find an answer as to how pre-natal harm should be assessed. Finally, I investigate if State led paternalism could in future be the answer to promoting antenatal screening and interventions in the name of safeguarding future children's welfare and good health. The different magnitudes of paternalism are assessed and I put forth that although soft and moderate paternalism may warranted in some cases, hard paternalism can not be the answer for fear of eroding the patient doctor relationship, and because in numerous cases it may be unclear as to what the interests of future children may be.

CHAPTER 5
THE FIRST PAPER

CHAPTER 5

Paper 1

How Antenatal Genetic Ignorance and Parental Failure to Engage with Screening Services Can Harm Us All

Introduction:

This paper explores the question of whether ignorance of your future child's genetic make up in the antenatal setting causes harm and thus we have a moral obligation to avoid it by utilising all accurate and safe screening available in pregnancy. I focus particularly on the arguments put forward by Tuija Takala²²² in favour of one's right to genetic ignorance. Takala argues that in liberal societies respect for individual autonomy is seen as central, people have a right to genetic knowledge but that people also ought to have a right to remain in the dark regarding their own genetic information including information about fetuses they may carry. Takala dismisses the idea that harm to others can be used to override this right to remain in ignorance particularly in the context of information about fetuses in pregnancy. This paper argues against this stance provided an expectant person (or couple) is planning to carry the pregnancy to term.

Furthermore, as information about the foetus can only be obtained before the foetus becomes a child, I argue that parents-to-be have a moral obligation to utilise the information acquired by the said screening tests provided there is a safe (to mother and foetus), effective early intervention after birth or an *in utero* intervention that can significantly improve the welfare of resulting offspring.

So long as these the first criterion is fulfilled there can be no such right as to remain in ignorance with respect to the fetuses (and by extension ones own) genetic information and I argue that expectant parents have a moral obligation to avail themselves of most safe antenatal screening and treatment options in order to maximize the welfare of their future children.

²²² Takala, T. (1999). The right to genetic ignorance confirmed. *Bioethics*, 13(3-4), 288-293.

Takala's argument

Takala's main objections are that firstly the harm to others principle cannot be used as justification to restrict ones freedom. In this context she explores whether true harm can be caused to future children if a pregnant woman opts not to find out the foetuses (and by extension her own) genetic makeup. Takala takes a further step in saying that the knowledge itself can even cause harm if the foetus is aborted as a result of the unearthed information, thereby denying a future child a life.²²³

Secondly Takala argues against the application of Kantian principles, a philosophical stance often employed by those supporting the "duty to know" genetic information.²²⁴ Her argument in this respect is that full "and all available information" can never be known in most decisions we take in life, therefore at least in Kantian terms we can never be truly autonomous. I will explore these two arguments in more detail below.

Antenatal Application of the Harm principle, different approaches:

Takala states that the harm principle is poor justification for the duty to know genetic information about oneself, even during gestation, when genetic information about the foetus will inadvertently reveal genetic information about the parents. She argues that the term harm cannot be applicable to future children as information acquired antenatally only stands to have two effects, either to abort the child, or carry the child to term. In the case of abortion, Takala argues that "if A is never born A is not harmed as A never came into existence".²²⁵

In the instance where parents-to-be decide to follow through with the pregnancy, Takala argues that no harm can be said to have been done as the foetus will have received the

²²³ *ibid*

²²⁴ *ibid* p 292

²²⁵ *ibid* p 290

gift of life; if however the acquired genetic knowledge results in an abortion, then that may even be classed as an injustice²²⁶.

I will focus on two possible derivations of potential harm by exercising Takala's "right to ignorance". Firstly I will argue how harm to the foetus can come to exist by choosing to remain in ignorance, and secondly how that very ignorance may come to harm the expectant mother/couple.

Different accounts on the moral significance of harm have fuelled philosophical discourse for centuries. The Hippocratic oath has harm avoidance to its core "I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous...into whatever houses I enter, I will go into them for the benefit of the sick, and will abstain from every voluntary act of mischief and corruption".²²⁷ Mill's harm principle casts similar assertions and expects of moral agents "...liberty of tastes and pursuits; of framing the plan of our life to suit our own character; of doing as we like, subject to such consequences as may follow: without impediment from our fellow-creatures, so long as what we do does not harm them, even though they should think our conduct foolish, perverse, or wrong".²²⁸ One of the strongest principles in medicine and morality is generally to avoid harm to others. While most accept the importance of allowing individuals to have control over their life choices, wherever possible, this is usually tempered by a need to ensure that these choices do not cause significant harm to others.

In order to explain why I believe that the harm principle does apply to antenatal screening, even where screening cannot prevent the genetic disorder I need to first define what I consider to be a harm to others.

There are, broadly speaking two versions of state-based harm within literature, non-comparative and comparative accounts.

²²⁶ *ibid* p 290

²²⁷ Hippocrates, 'The Hippocratic Oath', in Brannan S. Chrispin E. Davies M. English V .Mussell R. Sheather J .Sommerville A., (2012) *Medical Ethics Today: The BMA's Handbook of Ethics and Law* third edition ,Blackwell App. A.

²²⁸ Mill, J. S. (1989). *On Liberty and Other Writings*, ed. Stefan Collini. Cambridge University Press

Non-comparative accounts hold that to suffer harm is to *just be* in a bad state. Non-comparative accounts have been championed by the likes of Shiffrin, Harris and Harman. Shiffrin holds that “To be harmed primarily involves the imposition of conditions from which the person undergoing them is reasonably alienated or which are strongly at odds with the conditions she would rationally will”²²⁹ whilst Harris purports that an individual is harmed when he has been put in a harmful position, a situation in which one sustains a disability or suffers in a way in which his/her interests or rights are frustrated²³⁰. Harman’s criteria of harm are simpler, to be said for *a* to have harmed *b*, *a* must be culpable for *b*’s pain, physical discomfort, disease, deformity, disability or death.²³¹

Comparative accounts of harm assume that *a*’s action or inaction puts *b* in a consonantly worse off state or situation, a situation that *b* would otherwise have not been in if *a* had not acted negatively (or omitted to act positively). Two main theories within this class exist, the subjunctive historical account of harm championed by Feinberg and the temporal account.

According to Feinberg an action (or inaction) done at *t*₁ is harmful for one only if it causes one to be worse off at *t*₂ than they would have been at *t*₂ if that specific action (or inaction) hadn’t occurred.²³² What Feinberg therefore feels qualifies a state of affairs as harmful is the difference between what (out of a number of counter-outcomes) would have been the case for *the harmed* if the act or omission that harmed him/her hadn’t occurred, and what the end state of affairs is now that the individual has actually been harmed. If for example I had been poked in the eye at *t*₁, what determines if I have been harmed or not is not that I was better off at *t*₁ (pre-poke) when compared to *t*₂ (post-

²²⁹ Shiffrin, S. V. (1999). Wrongful life, procreative responsibility, and the significance of harm. *Legal Theory*, 5(02), 117-148.

²³⁰ Harris, J. (1992). *Wonderwoman and Superman: the ethics of human biotechnology*. Oxford University Press p. 88

²³¹ Harman E., 'Harming as Causing Harm', (2009) in Roberts M. A. and Wasserman D. T. eds. (2009), *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem* Springer, p. 149.

²³² Feinberg, J. (1986). Wrongful life and the counterfactual element in harming. *Social Philosophy and Policy*, 4(01), 145-178. pp. 148-150

poke) but because by evaluating different possible outcomes we would deduce that I will be better off at t2 had I not been poked.²³³

The temporal account²³⁴ is more straightforward as it doesn't depend on assessing a variety of possible outcomes to determine if harm has been done or not, but rather by looking at the state of affairs before a certain act or omission. If I've been poked in the eye at t1 which leads me to being worse off at t2 then, harm has been done as I am worse off post-poke than when compared to pre-poke.

When it comes to trying to ascribe harm incurred *in utero* to a foetus *that will come to exist* (that is a foetus that will be brought to birth as opposed to one that will be aborted) the comparative account of harm is philosophically more sound and applicable rather than a non-comparative stance, simply because we rely on a comparison between the projected health of the very child that will result from the current gestation. This assumes a biological continuity²³⁵ that cannot be afforded by the non-comparative accounts; it is impossible to compare harm in a specific child if that specific (resulting) child never comes to exist or is replaced by a different (resulting) child.

For this reason when I refer to harm in this paper I have elected to ascribe to a definition more closely related to Feinberg's subjunctive historical accounts, within the definition I refer to interests, in doing so when I define them as distinct parts of one's welfare.

Harm: *b is harmed when b's interests have been stymied or failed to be changed in a positive manner improved by an action or omission as such that b is worse off than he would have otherwise been had a not occurred and some other action or omission taken place instead*

²³³ *Ibid.*

²³⁴ See for example Foddy, B. (2014). In defence of a temporal account of harm and benefit. *American Philosophical Quarterly*, 51(2), 155-165.

²³⁵ See Olson, E. T. (1999) *The Human Animal: Personal Identity without Psychology* Oxford University Press, pp.125-153.

A) *Harming of a potential child*

Takala argues that “if A is never born, A is not harmed either, as A never existed”.²³⁶ To this extent I agree but opine that trying to apply the harm principle to those that will never be born can be deceptive. Instead, let us focus on the woman who plans to carry the foetus to term. Barring any perinatal catastrophes that deprive prospective parents of their child, there is a strong case to be made in certain situations as to why they have no right to remain in ignorance.

The moral duties of the pregnant woman toward the foetus multiply when the decision to actually go through with the birth is made as the unwritten contract of allowing the foetus to maximize its potential by coming into existence is made. This is no longer a potential that will be discarded but rather an *understanding* that the potential will be met. This understanding can be reversed of course (up to the point of foetal viability), in the sense that the mother can change her mind about whether she will give birth or not, but whilst the decision is active and the parents wish is to procreate, then it is not unreasonable to deem it a moral and worthy cause that they should alter their behaviour and risk taking in a way that will ensure that the specific foetus becomes the healthiest possible infant.

I employ a personhood view of the moral status of the foetus. I assume that infants only have interests and a right to life some time after birth but purport that while embryos and foetuses may not have a right to life at this stage of their development, our treatment of embryos, foetuses and newborns oughtn't be without moral scrutiny; it is wrong to harm future persons in their pre-personal state. If we intend to bring a child to birth we have certain duties to protect that child's welfare, and if avoidable harm befalls that child as an embryo or a foetus. We have a duty to protect that future child in this early stage of its existence in order to safeguard its future welfare. The view implies that childbearing women deciding to bring their foetus to birth have different obligations and duties to those opting to abort. Those who decide not to bring their foetus to birth have no

²³⁶ Takala *Op Cit* p290

obligations to protect that foetus from harm so long as they ensure that the said foetus does not become a person.

In keeping with this stance we can subdivide foetuses, all of which are in the pre-personal stage,²³⁷ in two categories: Potential persons (or pre-persons) and borne persons, this will help us elucidate how obligations of parents-to-be vary in depending on which category their foetus lies in. Employing a Harrisian viewpoint, LaFollette writes:

“The human individual comes into being before it acquires personhood. This individual will gradually move from being a potential or a pre-person into an actual person when she develops whatever characteristics are thought to be distinctive of personhood”²³⁸

Sticking to Harris’ personhood view²³⁹ it would follow that no one is harmed or aggrieved by not being born, it is logical that if one doesn’t exist and has never existed he/she cannot have a legitimate grievance. If, however, one *will* exist in future the junction at which parents-to-be decide that the specific embryo will be brought to birth is philosophically a very important crossroad; not least because the foetus becomes worthy of moral consideration thereon in. Once born, having fulfilled thus its potential as a person, the eventual child can have legitimate grievances for any harm he/she has incurred before birth, during the pre-personal stage.

If an expectant couple opts to abort on the welfare of the foetus realistically does not merit similar moral obligations or antenatal safeguards as no person will ever come to exist out of that pregnancy; there will be no child who can have his/her interests frustrated in the antenatal setting.

Any parental act or omission that has harmed the eventual child the *in utero* environment can be said to have frustrated and harmed the welfare of that *specific* child in the pre-

²³⁷ Harris J. *Clones Genes and Immortality: Ethics and the Genetic Revolution* Oxford, Oxford University Press (1992) p 76

²³⁸ LaFollette, H. (2003). *The Oxford handbook of practical ethics*. Oxford Handbooks Online. p117

²³⁹ Harris, J. (1999). The concept of the person and the value of life. *Kennedy Institute of Ethics Journal*, 9(4), 293-308.

personal stage. I suggest that antenatal screening has a key purpose in bettering the welfare of the *specific* child (in contrast to maximization of net welfare a stance employed by Harris and Savulescu).²⁴⁰ With this in mind, in the interests of welfare of specific future children, I argue that parents-to-be have a duty to their future child to engage with the antenatal services provided by their local health authority.

My argument is thus; not that parents have a duty to acquire genetic (and other) information about their foetus in the interests of disability avoidance (i.e. so that they can abort and/or replace the foetus with an entirely new one conceived at a later stage) but rather one of disability reduction. Disability reduction in the sense that harm can only be said to have been done if an omission by *a* has harmed the *same* future child *b* (and not another), and a disability that could have otherwise been entirely prevented, improved or treated by early (or *in utero*) intervention was not.

There are of course rare exceptions where disability avoidance could be philosophically defended, such as situations of wrongful birth. I will defend why the application of the harm principle to the unborn that *will* come to exist is appropriate by looking at both cases of wrongful and non wrongful birth.

a) Wrongful birth

The term Wrongful birth stems from medical jurisprudence where a parent (or parents) claims for damages against a healthcare professional in cases where the said professional:

- a. Failed to diagnose a serious medical problem with an unborn foetus or,
- b. Failed to warn the parent of the risk of conceiving or giving birth to a child with a serious medical problem or

²⁴⁰ Arguing on the premise of maximisation of net welfare has other connotations, such as exchanging a disabled foetus for a healthy one and justifies selective abortion. Under this view one could make the case that all disabled foetuses should be aborted and replaced were possible by healthy foetuses. This introduces an unpalatable, indefensible position towards disability and one that I do not agree with, not least as it devalues people with disability, it would discriminate against them and would send a clear message that society as a general would be better off if they had not existed. It is for these reasons that I find arguments of maximisation of net welfare lacking in ethical merit. Maximisation of individual welfare has no such connotations, no person is replaced with a different individual that is healthier, and rather that same person is simply made healthier.

- c. Deprived the parent of making an informed decision about whether to terminate the pregnancy because of a significant medical problem with the foetus.²⁴¹

Steering away from the legal remit, the wrongful birth argument in medical ethics literature explores if true harm can be caused to someone by being brought into life. In a handful of conditions children can be so severely debilitated whereby their lives are short, filled with pain and repeated agony. Such conditions are rare and include the oft quoted Tay-Sachs syndrome²⁴² and epidermolysis bullosa.²⁴³ Intuitively, it would be challenging by one with no experience of the disease in question to cast aspersions as to whether a certain condition is disabling enough whereby one would be better off never to have existed. Glover alludes to this by urging us to question rather if there is a “serious risk of a life not worth living”²⁴⁴, a life whereby only pain can be felt with no capacity for any pleasure. These extremes of paediatric conditions raise the question whether parents ought to avoid bringing such children into existence.

In practice we can only raise this question if the pregnant woman has found out if her foetus will have Tay Sachs or not when he/she is born: for if we don't know of this information one might inadvertently harm the born child by bringing it into existence anyway. A foetus can only become one specific child, it can only have one possible genetic identity, if that identity affords him/her a life that is of “sub-zero” quality²⁴⁵ we need to inquire if his/her birth will be against his/her interests.

²⁴¹ Wolff, R. E. (1978). Wrongful Life: A Modern Claim Which Conforms to the Traditional Tort Framework. *William and Mary Law Review*, 20, 125.

²⁴² Tatar, S. E., and Caskey, C. T. (1977). Evaluation of a genetic disease education program for Tay-Sachs screening. *Progress in clinical and biological research*, 18, 367.

²⁴³ Silva, L. C. P., Cruz, R. A., Abou-Id, L. R., Brini, L. N. B., and Moreira, L. S. (2004). Clinical evaluation of patients with epidermolysis bullosa: review of the literature and case reports. *Special Care in Dentistry*, 24(1), 22-27.

²⁴⁴ Glover, J. (2006). *Choosing children: genes, disability, and design: genes, disability, and design*. Oxford University Press. p59

²⁴⁵ Scott R *Choosing Between Possible Lives: Law and Ethics of Prenatal and Preimplantation Genetic Diagnosis* (2007) Hart Publishing p34

Unquestionably, once born a child will have interests, both in legal and ethical terms: do those interests include never to have been born in certain situations, in certain medical conditions? I argue that yes, in a very rare handful of diseases some children are harmed by coming into existence, and if the expectant couple have risk factors and are aware of any such predisposing risks, genetic or otherwise, then they have a duty not to remain in ignorance antenatally and find out if the foetus carries a disorder that confers a “sub-zero” life.

Borrowing a phrase from Bonnie Steinbock and Ron McClamrock²⁴⁶ a child deserves a “decent chance of a happy life”. They argue that it is morally impermissible to voluntarily and knowingly bring child a into existence whose quality of life will fall below the zero line, that it would have been mercy if he or she had not been born.

It is not unreasonable to purport that parental responsibilities and duties in these rare cases would be to be merciful and not harm such a child by bringing it into existence. This is for the benefit of (at least) the child that the foetus stands to become and even the parents themselves (I explore this notion later).

Currently, health authorities are responsible for withholding fertility treatments to couples with a prior history of child neglect, abuse or sexual exploitation, in part perhaps because any resulting children may be at a serious risk of not having a life worth living; similarly there is an increasing trend of newborn babies being subject to care proceedings for comparable reasons²⁴⁷. In an analogous manner, we should also hold responsible, couples that are unaware of genetics risks of giving rise to offspring with lives at a serious risk of having a life not worth living, as doing so would be to allow for a great deal of harm. The only way of avoiding this harm is to ensure that they become aware of their own collective genetic background risks and practice “pre-parental” responsibility (I

²⁴⁶ Steinbock, B., and McClamrock, R. (1994). When is birth unfair to the child? *Hastings Center Report*, 24(6), 15-21 p18

²⁴⁷ 'Huge rise' in newborn babies subject to care proceedings <http://www.bbc.co.uk/news/uk-35088794>
Accessed 15/12/2015

use the word pre-parental as an inclusive term to denote couples or women that are wanting or are in the process of procreating from the point of conception onwards).

The challenge is this though. As aforementioned, since conditions that confer sub-zero quality of living are rare, is it reasonable to expect of prospective parents to screen for these conditions? There are two parental categories to consider.

In the first category that merits special consideration, lie parents with no previous risk factors for such conditions. Although it is improbable that scientific agreement in conjuring up an exhaustive list of these conditions will ever be reached, in general they may be genetically inherited, completely sporadic or randomly unmasked by perinatal exposure to radiation or other potentially harmful substances without parental insight. In these cases it would be difficult to argue that it is the parents' duty to show initiative to find out in advance if their foetus will be affected by a *specific* rare condition that confers a sub-zero quality of life once born. It would be unreasonable to expect everyone to screen for everything. Within the realms of a publically funded healthcare service however, the argument could be made that the onus to offer screening services to these potential children lies with the family physician, obstetrician or midwife. Wrongful life claims on negligent non-disclosure stem from such duties of the physician to warn. If screening services are declined by the family and harm is caused by the birth of a child with an unbearable life, then the moral blame should rightfully be shifted back to the parents.

The second category consists of prospective parents fully aware that such conditions run in the family or that the foetus was exposed to a known teratogen *in utero*. In these cases the avoidance of screening services has a more premeditated aspect; for although the healthcare service would still have to offer screening services, perhaps even services more tailored to that couples needs, the probability of potential harm in this cohort of prospective parents, i.e. the chances of the birth of a child with a sub-zero quality of life are much higher, and by extension the probability of harm is much higher. Wilful avoidance of such screening services cannot be defended morally since they *de facto*

increase the probability that children will be harmed by the curse of a joyless existence, as less of them will be aborted.

b) Cases of non-wrongful life

Harm, as defined earlier can also be caused by an omission to change a course of events in a way that will frustrate the welfare of the eventual child. In this section I aim to disprove Takala's assertion that the harm principle cannot be used as a justification to impose genetic knowledge onto parents of prospective children by focusing on those with disabilities that although significant, do not render their existence as unbearable or wrongful. I argue that in situations where intervention can benefit the potential child in a way that his/her disability is reduced then clear harm can be caused by foregoing antenatal screening services and choosing to remain in ignorance.

In the majority of common genetic or congenital disorders there is clear evidence and reports by both physicians and patients, that people with these conditions have worthwhile lives, lives very much worth living. Take for example a common disorder that severely affects the patient's quality of life: Duchenne muscular dystrophy (DMD) is a recessive X-linked form of muscular dystrophy, affecting around 1 in 3,600 boys, which results in muscle degeneration and premature death. Judgements by third parties about the standard of living with a certain condition and disability are sensitive in nature and very challenging. An example of this relating to DMD is the contrast of opinions given by the professional panel at a number of ethics discussion groups and that of the patients with DMD. Whilst calling the condition a severe disease, scientists divulged that the patients "gave their rating of quality of life the same as a healthy controlled sample. And the parents gave them the lowest quality and the clinicians gave them, somewhere between the two".²⁴⁸

²⁴⁸ Scott *Op Cit* p 212, p 222

Glover warns us to interpret the opinions “with alertness to possible biases”.²⁴⁹ In this instance there seems to be negative bias from the parent’s side and a positive bias from the patient’s side: but neither of the expressed opinions seem to suggest that the child has come to harm by his parents that have brought him into existence. I would agree with this and despite the progressive and debilitating nature of the disease, the accounts of these patients are evidence that they have fulfilling and worthwhile lives. I argue however that they might still be antenatally harmed by their parents in certain circumstances.

The same principles apply, if the parents know that they carry the DMD gene, and then real harm may be done in not trying to detect this antenatally or immediately after birth: again assuming that such provisions are catered for by the local health care authority. Quinlivan²⁵⁰ argues that early diagnosis of DMD is essential and it improves long-term outcomes. He argues that recent advances in therapy, especially the variable regimes of corticosteroids seems to improve outcomes, the earlier they are started the better, and those that start the said therapy later miss a “window of opportunity”²⁵¹ rendering the treatment less efficacious. He refers to a study²⁵² that highlights the issue of delayed diagnosis over the last 30 years with no signs of improvement on how early the conditions are diagnosed.²⁵³ He ends on an advisory note “there has never been a more important time of early diagnosis of DMD, we can now inform parents of newly diagnosed boys that they should expect their son to live well into adulthood”.²⁵⁴

There are a myriad of conditions where intervention in the neonatal period or shortly thereafter can have a substantial positive impact on the quality of life and the potential for flourishing of the (eventual) child. Metabolic disorders such as ornithine

²⁴⁹ Glover, J. (2006). *Choosing children: genes, disability, and design: genes, disability, and design*. Oxford University Press. p9

²⁵⁰ Quinlivan, R. (2014). Early diagnosis of Duchenne muscular dystrophy is essential to improve long term outcomes. *Archives of disease in childhood*, 99(12), 1061-1061.

²⁵¹ *Op Cit* p1061

²⁵² van Ruiten, H. J., Straub, V., Bushby, K., and Guglieri, M. (2014). Improving recognition of Duchenne muscular dystrophy: a retrospective case note review. *Archives of disease in childhood*, 99(12), 1074-1077.

²⁵³ The caveat to this is that the study’s exclusion criteria ruled out any children with a prior family history of DMD)

²⁵⁴ Quinlivan *Op Cit* p1061

transcarbamylase deficiency (OTCD) can, for example, present with severe neonatal encephalopathies in the first few days of life and often lead to coma and death because of high ammonia load.²⁵⁵ In the small, surviving population the early brain injury, sustained because of toxic levels of ammonia in the bloodstream, the resulting disability is severe with significantly impaired higher functioning skills, a damage that is alas, permanent²⁵⁶. Real harm can result if those wanting to procreate and are aware of a positive family history and/or risk factors to such conditions choose to remain in ignorance or in Takala's words, exercise their so called "right not to know".²⁵⁷ The acquisition of the knowledge that the foetus is affected by this condition, will allow the appropriate, low protein diet, and therapies for these future children to be set in place in advance so that the early ammonia damage doesn't happen; allowing thus normal to near normal higher functioning, mobility and by extension, much improved opportunities to flourish.

Screening early will become even more relevant in the future, as the future may well hold a gene therapy cure; to quote the eminent, late, Professor Ed Wraith "The gene has been cloned, it is a relatively common disorder, there is a very good animal model and current therapy is unsatisfactory. In addition the evidence that liver transplantation normalises the metabolic dysfunction suggests that a liver based gene transfer approach could be successful".²⁵⁸ Should this educated prophecy be fulfilled and genetic engineering allows us to cure such conditions *in utero*, the antenatal parental duties to screen for such conditions will become even stronger.

In such cases, the exercise of one's "right not to know" would either lead to early death or severely diminished cognitive and motor skills with minimal prospects of flourishing. To paraphrase Buchanan such cases confer examples whereby an actual person has been

²⁵⁵ Maestri, N. E., Clissold, D., and Brusilow, S. W. (1999). Neonatal onset ornithine transcarbamylase deficiency: a retrospective analysis. *The Journal of pediatrics*, 134(3), 268-272.

²⁵⁶ Braissant, O. (2010). Current concepts in the pathogenesis of urea cycle disorders. *Molecular genetics and metabolism*, 100, S3-S12.

²⁵⁷ Takala *op cit* p288

²⁵⁸ Wraith, J. E. (2001). Ornithine carbamoyltransferase deficiency. *Archives of disease in childhood*, 84(1), 84-88.

inflicted with a disability that would otherwise have been avoidable, or at the very least changed via some intervention to a much milder form.²⁵⁹

A possible point that may be raised about the specific management of OTCD is that given the risks associated with antenatal screening and that there are no *in utero* therapies at present that alter the phenotype or path of the disease, then screening needn't happen prior to birth. This point is only attractive in theory but not in practice, I explain why. On dealing with a time critical clinical condition there are numerous practical and logistical issues to consider, such the availability of genetics/metabolic laboratories immediately after birth, appropriate samples being sent (also implying the need for experienced staff trained to do so) and the rapid processing of the said samples in order for the results to be available before the child's first feed. Assuming that the practical issues are ironed out, which is improbable as the tests for the condition can only be undertaken in a handful of very subspecialised labs, this solution may be very reasonable for this specific illness as it would still minimize harm and decrease the degree of suffering in the newborn. The 1%²⁶⁰ risk of miscarriage associated with amniocentesis or chorionic villus sampling may be avoided in this case, if all the above human factor and logistical issues have been sorted out. Since there is a way to avoid harm and reach diagnosis immediately post birth (at least in theory) the parent would not be any more duty bound to carry out screening *in utero* than they would be *ex utero* provided this was done as soon as the baby is delivered.

Whether it is antenatally or immediately after birth, the parents would in these cases have found out what their genetic make up is "by-proxy"; as if the child has the condition it is quite likely that either or both of the parents are carriers depending on the Mendelian mode of inheritance. If it is therefore safe without any prospect of long term harm to the new born child to find out immediately after birth about whether she/he is affected by the

²⁵⁹ Buchanan, A., Brock, D. W., Daniels, N., and Wikler, D. (2001). *From chance to choice: Genetics and justice*. Cambridge University Press p .202

²⁶⁰ Human Genetics Commision (2006) *Making Babies: Reproductive Decisions and Genetic Technologies* para 3.15

disorder, then it cannot be said that they have harmed the child, but that they have a further obligation to continue to follow the recommended therapy.

This solution would not be suitable for conditions where perhaps the availability could only be reduced *in utero* (such as surgical repair of spina bifida).

Bennett argues that:²⁶¹ “If there is a right to remain in ignorance of information about our genetic health, then this right is unaltered by pregnancy, at least until treatments emerge that can reverse genetic impairment.” She is noting that where antenatal treatments exist or emerge that can drastically reduce the impact of a disorder on the child to be born then any right to remain in ignorance of these genetic disorders in any foetuses we aim to bring to birth is then on very shaky ground.

Bennett talks of the “reversal” of genetic impairment but this may be an unrealistic, at present, benchmark. Technologies are, however, fast emerging for treatments not just for genetic disorders but also anatomical abnormalities, to be *changed, treated* or *minimized in utero*, procedures that can improve the eventual child’s welfare. In addition to spina bifida repair, tracheal atresia or congenital high airways obstruction syndrome²⁶² (CHAOS) can be surgically repaired *in utero*. Gene therapies are also emerging that can modify disabilities *in utero*.²⁶³ Failure to engage with screening services translates to a missed opportunity in diagnosing a disease or condition that may be treatable *in utero*, the lack of parental awareness of what the foetus’s state of health is can in itself lead to a failure of the appropriate treatment to be sought and administered (if and only if such treatment exists). Using the definition of harm set earlier, child *b* has been harmed as *b*’s interests have failed to be changed in a positive manner improved by the parents omission

²⁶¹ Bennett R *op cit* p463

²⁶² Glynn, F., Sheahan, P., Hughes, J., and Russell, J. (2006). Successful ex utero intrapartum treatment (EXIT) procedure for congenital high airway obstruction syndrome (CHAOS) owing to a large oropharyngeal teratoma. *Irish medical journal*, 99(8), 242-243.

²⁶³ MacKenzie, T. C., David, A. L., Flake, A. W., Almeida-Porada, G. (2015). Consensus statement from the first international conference for in utero stem cell transplantation and gene therapy. *Frontiers in pharmacology*, 6.

to screen and treat, as a result *b* is worse off than he would have otherwise been had the omission and failure to treat not occurred and the parents had screened and treated instead.

There will be a very strong case to be made that if we can dramatically improve the outcome for the child born with *in utero* treatments of genetic and other conditions, that we will have a strong moral obligation to be informed about these conditions in good time to make these interventions. But, as we have said this state of affairs is, in most cases, some way in the future. However, this does leave open the issue that if we have a strong moral obligation to protect our future children's welfare by availing ourselves of any effective treatments *in utero*, if we can improve our future children's welfare in other ways by gaining information about their health status in pregnancy, that there is a strong case to be made that we should do so.

B) Harm to others

Various arguments have been forward in academic literature that explore the application of the harm principle with respect to antenatal parental duties. I will focus on whether, harm, as defined above, can be inflicted on others by a parental failure to screen antenatally and positively change a disability accordingly, should a suitable therapy is available. I will focus on three groups that may, in theory, be harmed in such situations, parents themselves, siblings (plus other dependants) and the wider society.

a) Harm to parents

The Royal College of Paediatrics and Child Health's²⁶⁴ guidance in withholding or withdrawing life-sustaining treatment for children, acknowledges the significant impact of disability in families and those around them. It seems reasonable to deduce that the greater the dependence of the eventual child on healthcare services, the more the child is dependent on carers for everyday functioning, the greater the degree of disability, the

²⁶⁴ Royal College of Paediatrics and Child Health, London (United Kingdom); (1997). *Withholding or withdrawing life saving treatment in children a framework for practice.*

greater the impact will be on his parents lives (and the immediate family). Evidence of this is well documented.²⁶⁵ From an economical viewpoint, one can argue that parents will have less financial resources to invest in their own interests; this can of course be said of parenthood in general, whether the offspring are healthy or not, and the degree of limitations in earnings. However in cases of severe disability, this has systematically been proven to be severe. One or both parents often have to stop work and be a carer, major home adjustments need to be done to make accommodation functional, frequent specialist health care appointments, expensive medication, the list is sizeable.²⁶⁶

Coupled with the considerably higher stress²⁶⁷ levels and higher depression²⁶⁸ and divorce rates documented in parents of children with disability, stemming from multifactorial reasons including financial worries and bearing witness to the inability of their child to flourish within the societal norm, it is feasible for an argument to be made that parents may harm themselves in opting out of antenatal services that may unmask certain treatable disabilities.

There are of course two sides to the argument, with evidence to the contrary. A review of a number of studies that focused on the impact on families with a disabled child found that despite all the challenges posed, parents of disabled children have lives comparable to the general population.²⁶⁹ Similarly, arguments have been made on the negative impact on the psychology of families that had an abortion following antenatal test result that indicated a foetal anomaly. The line of reasoning is that the severity of the impact on the

²⁶⁵ See for example one of the first studies to emerge on the subject in Piachaud, D., Bradshaw, J., and Weale, J. (1981). The income effect of a disabled child. *Journal of epidemiology and community health*, 35(2), 123-127.

²⁶⁶ Dobson, B., and Middleton, S. (1998). *Paying to care: The cost of childhood disability*. York Publishing Society. pp1-4

²⁶⁷ Keskin, G. (2010). The evaluation of anxiety, parental attitude and coping strategy in parents of children with mental retardation. *Anatolian Journal of Psychiatry*, 11(1), 30-37

²⁶⁸ Cummings, S. T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically III children. *American Journal of Orthopsychiatry*, 46(2), 246-255.

²⁶⁹ P. M. Ferguson, A. Gartner, and D. K. Lipsky, 'The Experience of Disability in Families: A Synthesis of Research and Parent Narratives', in A. Asch and E. Parens (eds.), *Prenatal Testing and Disability Rights* (2000) Washington: Georgetown University Press, p. 73.

family's psychology may be far worse than the effect of having a disabled child would be.²⁷⁰

A point of contention perhaps is that a comparison between the severity of impact on ones psychological well-being between the theoretical event of a termination of pregnancy versus the theoretical birth of a disabled infant is not accurately possible. It is no more likely that we can predict and contrast what my spirits will be like before I have a dram of single malt whisky and someone else that decides not to drink. In addition, as my position is not one of disability avoidance but rather one of disability reduction, the arguments relating to the secondary effects of abortion on individuals are not directly relevant.

What is clear is that with the exception of severe disability, whereby children have “sub-zero” quality of life, as addressed above, the act of parenting, in itself, be it of a healthy or disabled child, is likely to be a worthwhile, fulfilling, stressful, rollercoaster venture regardless. Although the philosophical defence of the application of the harm principle antenatally, for the protection of *the parents* seems sound, comparative evidence seems to be contradictory, making its defence difficult, bar cases of severe disability, where evidence of the detrimental effects to the parents is clearer cut.

With this in mind, it is implausible that in situations where those wishing to become parents and are aware of certain *severe* (but not milder) genetic risks within the family, that they have a right not to know provided there is an early intervention that can improve the degree of functioning of the resulting child. This is the only way in which harm to parents can be reduced, and it seems to me the only situation whereby the harm principle can be applied with respect to harm caused to the parents by their antenatal omissions.

²⁷⁰ Anstey, K. W. (2008). A critique of arguments supporting disability avoidance. *Disability and Society*, 23(3), 235-246.

b) *Harm to siblings (and other dependants)*

Procreative decisions we make, do not just affect ourselves and the (un) born child, the choices we make have a ripple effect to those closest to us, our families, children, dependants and indeed the wider society. These ripples stand to have side effects that may unintentionally harm (or benefit) others apart from the parents or potential offspring. Whether such procreative acts or omissions are moral or not will depend, in part, on these side effects.

The most obvious harm than can be bestowed upon other members of that family by the birth of a child whose disability could have otherwise been reduced/improved *in utero* is that of unequal resource redistribution. The term resource is applied both with respect to time spent and attention given to each child but also financial investment.

The financial impact disabilities have on families are well researched and the evidence is compelling. The annual cost to families to provide the bare necessities to a disabled child was estimated to be nearly triple than when compared to non-disabled children.²⁷¹ In a different study the same authors found that the average overall spend (minus food costs) is double for disabled offspring versus non-disabled. These costs are also coupled with the nearly tenfold cost in education for children in special needs schools as opposed to mainstream facilities.²⁷² The available resources for the dependents of that family are significantly more scanty if a newborn with a potentially treatable disability is added to the group and the reallocation of the said funds (and time) is likely to be diverted towards the new addition.

This re-allocation of resources to those who need it the most is not necessarily morally problematic, as charity and safeguards for those less fortunate are certainly needed in a modern society. Nagel explores this notion and puts forward the argument that provided

²⁷¹ Dobson, B., and Middleton, S. (1998). *Paying to care: The cost of childhood disability*. York Publishing Society.p.1

²⁷² Seven to nine times more expensive has been quoted in Mattingly J and McInerney L. (2010) Education for Children with Disabilities - Improving Access and Quality (Guidance Note) Human Development Resource Centre on Behalf of the Department for International Development p.5

that the welfare of the healthy child does not fall below a certain (arbitrary) level that renders him/her worse off than the disabled child then the redistribution of resources ought to be made by placing the interests of the disabled child first²⁷³.

There are two possible answers to Nagel's position. Firstly, if the disability is treatable *in utero* (and prospective parents can only find out if its is amenable to treatment or not if screening services are taken up), and the appropriate therapy is opted for, then cost of rearing the newborn will be less, and the redistribution of resources is also very likely to be less. All other things being equal, the input, in terms of healthcare resources, time and money needed for a legless child, are likely to be more than a child with one or both legs. In such a scenario, if there are more funds (and time) to begin with and a less austere/uneven redistribution of said resources, due to an improved disability then not only is the newborn a beneficiary of better health, but the existing siblings/dependants are less harmed as they have more at their disposal to allow them a better opportunity to flourish.

The second argument against Nagel is that in fact there are two parental choices here worthy of independent moral scrutiny. Firstly is the choice to forego antenatal services and by extension any *in utero* therapies that the result of said services merit, and secondly the choice to reallocate the various resources between their various dependants. So even if Nagel is right in his assertion, and there is no moral objection to the second parental choice which entails the redistribution of resources in favour of those less fortunate, this does not undo the moral wrong of the first parental choice which is bringing an impaired child (that could have otherwise been unimpaired or less impaired) into the world. Melinda Roberts has a similar stance and argues that in order to determine whether parental procreative choices are morally permissible or impermissible then what needs to be weighed up is "(1) the effects of that choice on each person, against (2) the effects of

²⁷³ Nagel, T. (1978). The justification of equality. *Crítica: Revista Hispanoamericana de Filosofía*, 3-31.p.22

each alternative choice, including those that exclude bringing (the impaired child) into existence."²⁷⁴ .

Roberts concludes in saying that prospective parents opting to have a disabled child will often, by extension, create less wellbeing (i.e. more harm) to their dependents than had they chosen otherwise. Although I do not ascribe to disability avoidance, as the definition of harm I ascribe to is an entirely comparative one, her arguments can be extrapolated to apply in cases of disability reduction.

It is evident therefore, that in a society that expects the role of the parent-to-be protectors of their children's interests and welfare and the providers of education, nutrition and healthcare amongst other things, Takala's so called "right" to genetic ignorance cannot have a moral standing, as real harm can befall both the disabled child that may result by opting out of antenatal services but also existing dependents as their own welfare can be said to be frustrated or harmed.

c) *Harm to the wider society*

Whether or not wider society can be harmed by parents that opt out of screening services and subsequent potential therapies depends on what our idea of distributive justice is. Whilst Nagel's position, as explored above, is that social inequalities have to be balanced whereas natural inequalities need not,²⁷⁵ Nozick purports that the "burden" of raising children (be it disabled or not) ought not be borne by the wider society as health, education, intellect and capacity lie outside the boundaries of distributive justice.²⁷⁶

Whether society can be placed in a worse off position by a parental failure to reduce *in utero* disability is largely dependent to resource redistribution and finances. Societies

²⁷⁴ Roberts, M. A. (2009). What is the wrong of wrongful disability? From chance to choice to harms to persons. *Law and Philosophy*, 28(1), 1-57.p 22

²⁷⁵ Nagel, T. (1997). Justice and nature. *Oxford Journal of Legal Studies*. 17, p 303-21

²⁷⁶See for example Nozick R *Anarchy State and Utopia* (1974) Blackwell

depend on a renewal of personnel, a younger population that is healthy and educated and stands to flourish, adding further to art, education and the prosperity of each healthcare state. The less unhealthy the individual, the greater the likelihood of flourishing, and the greater the earning potential. This is not to say that there are no exceptions to that dictum, but exceptions are exactly that, exceptional (Professor Stephen Hawking coming to mind).²⁷⁷ It has also been argued that (failure to diminish) disability,²⁷⁸ (where such an option exists), can also contribute to faster depletion of money allocated for healthcare and therefore reduce the resource availability per person in the specific health care authority. The added costs of special schooling for such children, outlined above, adds to the argument. A UK based study in 2012 showed that 76.4% of working age non-disabled people were in employment in comparison to an age matched 46.3% disabled population, making the contribution to national revenue of each cohort significantly uneven²⁷⁹. With this in mind, it can be put forward that societal members itself may have an interest on adequate uptake of antenatal services and *in utero* therapies by others, so as to maximize their *own* welfare.

There are, however, two distinct arguments against the application of the harm principle in such cases:

i) Firstly, a system whereby the onus of financially supporting those less healthy lies on the presumably healthier wider society seems to be primarily self-serving. There will undoubtedly be situations whereby determining whether a certain reproductive choice will increase or reduce the welfare of the eventual child may be unclear. So it may be said that it is in our collective interest to fund such cases, just in the eventuality that we may require such help in the future.

²⁷⁷ White, M., and Gribbin, J. (1992). *Stephen Hawking: a life in science*. Penguin Books India.

²⁷⁸ Vallentyne, P. (2002). Equality and the Duties of Procreators. In Archard, D., and Macleod C. M. (Eds.). (2002). *The moral and political status of children*. Oxford University Press. p205 Vallentyne refers to disability itself rather than *in utero* disability therapy but the argument is equally effective.

²⁷⁹ Labour Force Survey, Quarter 2 (2012) as quoted in Disability facts and figures (2014) Office for Disability Issues <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures#fn:5> accessed 28/12/2015

This objection does not however answer the cases whereby the reproductive choices are more straightforward. Take for example situations whereby an *in utero* foetal procedure (for example spina bifida repair, once the technique and outcomes be perfected) stands to treat an easily diagnosed disability and improve the overall health of that resulting child. Postnatal care of spina bifida (the most common congenital malformation of the central nervous system) focuses on palliating the existing neurological damage rather than reversing it. Part of this limitation of postnatal care results from the deleterious effects that the *in utero* environment has on the neural elements. A recent prospective randomized multicenter trial showed that *in utero* repair significantly helps preserve neurological function, reverses hindbrain herniation and decreases the need for surgical ventricular shunting to alleviate hydrocephalus.²⁸⁰ Medical academics and surgeons argue that the procedure is likely to become safe and set the standard of care for the management of these congenital anatomical deformities in the not too distant future.²⁸¹ Apart from the *obvious* (as argued above) harm that befalls the child itself by parental failure to screen, diagnose and uptake the appropriate therapy, the reproductive choice in this case can (or will in the near future) be logically followed in a way that can forward welfare of both the prospective child and the society as a whole. A failure to repair the said malformation *in utero* will predictably result in otherwise avoidable significant neurodisability, which, additional to the overall frustration to child's welfare, it will also dictate the need for significant public expenditure by means of healthcare (antiepileptic medication, physiotherapy, mobility equipment, recurrent hospital appointments and admissions and so on). So whilst cases whereby one is unable to decipher whether an antenatal decision can improve or minimize the child's and the collective welfare, the harm principle cannot be defended sufficiently, and the opposite holds in cases where the science is more clear cut and there is the possibility of reducing the degree by which an eventual child is affected by a specific disability.

²⁸⁰ Adzick, N.S., Thom, E.A., Spong, C.Y., Brock III, J.W., Burrows, P.K., Johnson, M.P., Howell, L.J., Farrell, J.A., Dabrowiak, M.E., Sutton, L.N. and Gupta, N., (2011). A randomized trial of prenatal versus postnatal repair of myelomeningocele. *New England Journal of Medicine*, 364(11), 993-1004.

²⁸¹ Moldenhauer, J. S. (2014). In utero repair of spina bifida. *American journal of perinatology*, 31(7), 595-604.

ii) The second objection is that whilst the increased costs of early life disability and poor health to the public are well documented, in “some disabilities...lifetime consumption of health and welfare resources is at or below the national average”.²⁸² This is in reference to many late onset disabilities, or cases where death ensues at a much younger age than the average life expectancy, thereby limiting the length of time that society has to subsidize the healthcare costs for the said population. The healthcare bill for a healthy 90 year old may overall be more expensive than that of an unhealthy (or disabled) 20 year old. In late onset disabilities or health problems, it is also possible that the patient has had a number of productive years, thereby contributing to overall societal welfare and the shared “money-pot” and his/her early demise has come before a pensionable age. It is plausible, it is therefore argued, that patients with health problems and disabilities that arise in adulthood may in fact contribute more to public funding and receive far less by virtue of their life-limiting conditions. My response to this argument is twofold; firstly some of those that are disabled will work only part-time or not at all. Even those who work full time are more likely to pay in less tax over their lifetime than the average citizen if their disability means they have to retire early. Secondly, even if we entertain the above objection to be correct, the juxtaposition focuses solely on late onset and early demise situations. In the theoretical occasion where failure to antenatally diagnose and treat a late-onset life limiting condition, whereby the resulting child will be healthy enough to contribute to public revenue in early adulthood on a full time basis and does not retire early on the grounds of his/her disability, then no harm can said to have been done to wider society (alone). The conditions set in this argument against the applications of the harm principle are, however very restrictive, to the extent of irrelevance as my focus is one of treating disability and harm avoidance in (usually) *in utero* manifesting syndromes and anatomical abnormalities. It is rather, more likely, as with the spina bifida example above, that an anatomical disability that could otherwise have been offered treatment *in utero* but has not, accrues more costs over time, costs covered by public

²⁸² Wilkinson, S. (2010). *Choosing tomorrow's children: the ethics of selective reproduction. (Issues in Biomedical Ethics)*, Oxford University Press p101

revenue (in the context of publically funded healthcare), thereby harming, in economic terms, the wider public.

C) Application of the Kantian definition of autonomy

The other objection Tuija Takala has to the duty of genetic knowledge is one against Kantian justifications to the said duty, as used by Rosamond Rhodes.²⁸³ Kant dictates that we have an obligation to be autonomous and act in accordance to the best information available to us at the time.²⁸⁴ Rhodes adds to this that true self-determination requires one to make informed decisions and by extension obliged to pursue *all* (my and Takala's emphasis) relevant information and not to be distracted by emotions of fear or a false sense of security.²⁸⁵ Takala finds two main arguments as to why the Kantian model of autonomy cannot be used to justify a duty of parental genetic knowledge. Firstly by focusing on the word *all* available information and secondly by arguing that in practical terms, knowledge cannot be forced upon individuals.

a) The all available information objection:

Takala claims "No-one can ever possess all the knowledge in the world, yet even in everyday decisions would, in this line of thought require full knowledge of psychology, biology, culture studies, economics and the law to say the least".²⁸⁶ The objection seems to be a semantic one and hinges on the word *all*, which is an exhaustive term. Takala suggests that since we cannot have all knowledge in any decision we make in life, or even all-available knowledge, and then any decision we make cannot be truly autonomous. The justification of the duty to know in order to promote autonomy and

²⁸³ Rhodes, R. (1998). Genetic links, family ties, and social bonds: rights and responsibilities in the face of genetic knowledge. *Journal of Medicine and Philosophy*, 23(1), 10-30.

²⁸⁴ Kant I (translated by Ellington J.W) (1995) *Ethical Philosophy: The Complete Texts of "Grounding for the Metaphysics of Morals" and "Metaphysical Principles of Virtue"* Hackett Publishing

²⁸⁵ Rhodes, *op cit* (1998) 18

²⁸⁶ Takala *op cit* (1999) 293

self-rule seems counterintuitive to her, as only supreme deities such as R.M Hares Archangels²⁸⁷ are all knowing.

I would agree to an extent with Takala and say that the acquisition of “all knowledge” as the benchmark as to what determines ones’ autonomy and a morality is a difficult starting point. Philosophically, most absolutist terms, such as all, everyone, no one, never and so on, are hard to defend. They only need one successful counter argument, one flaw in order to be disproved. Certainly if all knowledge had been available and easily accessible, the duty of pre-parents would be easier to defend. If all knowledge had been bestowed upon me, and on the proviso that I wanted to be as morally responsible as I possibly could, my acts, and my omissions, would have a maximum probability of being morally intact choices and I would be maximally autonomous. The result of my choices need not necessarily be the desired one as one cannot realistically eliminate luck, good or bad fortune from ones actions, but the moral gravitas of my behaviour would be judged on the intended outcome of my actions and not the actual one.

‘All’ knowledge is an unrealistic benchmark, “full *available* (my emphasis) information”²⁸⁸, is a more appropriate one, not least as it affords a more pragmatic human dimension. I will follow the Kantian dictum and argue that the best available knowledge is needed to make a fully moral and autonomous choice, whilst *all* available knowledge would be ideal, this is unattainable and as such some knowledge will suffice and is better than none.

We rely on knowledge to achieve a desirable result with a higher probability of success. Once our knowledge falters we rely on someone else’s knowledge and experience to guide us into achieving what is necessary. On the balance of probability, getting advice and guidance from an experienced person is more likely to help us reach our desired endpoint than if we take on a venture entirely on our own.

Knowledge minimises error, collective knowledge diminishes more error than no knowledge at all. An experienced mechanic would have a better chance of repairing my

²⁸⁷ Hare R.M (1981) *Moral Thinking: Its levels, Method and Point* (1981) Clarendon Press Ch. 3 as used by Takala *op cit* (1999), 293

²⁸⁸ Takala, *op cit* (1999) 293

car successfully than a novice like myself. And whilst end results are affected by other external factors such as fortune and butterfly effects,²⁸⁹ I maintain that the only way of having any control on positively influencing the probability that our actions will reach the desired goal is through the employment of knowledge, our own and that of others.

If we agree that a parental duty, and by extension a pre-parental one is the welfare of ones child, then, that duty is a moral goal. The only way with which a moral goal would have a better chance of coming to fruition is by diminishing the “probability of error”. Waiving, thus, the opportunity to be informed of valuable knowledge, provided that such an opportunity exists, would decrease the chances of that child being born in a condition that is as healthy as possible, in a condition that optimises its welfare.

In Kantian terms, a refusal of attaining antenatal information concerning a pre-person would automatically suggest us acting without the best available information, thus not exercising autonomy at its fullest. It becomes obvious then that the vital step is obtaining that very information as this forms the basis of our subsequent choice and effective “self-rule”. So, to imply that a “duty to know” limits parental autonomy is paradoxical and nonsensical.

The reverse can even be said to be true as parental fore-education is certain to enhance parental autonomy, even if paradoxically the acquired knowledge is received with a degree of reluctance and scepticism. By choosing to exercise the so called “right to ignorance” under the fallacy that this is the most effective way to express autonomy, parents miss out on vital time needed to prepare for what will be a lifelong challenge should they choose to rise to it.

This advanced knowledge, is not only beneficial in conditions where a surgical or medical intervention is available. Early education and physiotherapy has been proven repeatedly to improve the quality of life of many disabled children.^{290,291} Without

²⁸⁹ Dooley, K. J. (2009). The butterfly effect of the " butterfly effect". *Nonlinear dynamics, psychology, and life sciences*, 13(3), 279.

²⁹⁰ Woods E. *The effect of early home teaching on the child with Down syndrome* (1984) (MPhil Thesis) Portsmouth, UK: University of Portsmouth;

advanced notice, parents inevitably fail to recognise early what local health authorities have in place so as to support their disabled child, resulting in a delay in accessing these resource, and a subsequent failure of optimisation of their child's' welfare.²⁹²

b) The Impracticality of Kantian Autonomy

The second objection that Takala has with respect to using Kantian ideology to justify the “duty to know” is a more practical one “... the fact remains that knowledge cannot be forced upon people and thus to say that there is a duty to know would be contradictory to human psychology and thus practically impossible”²⁹³

I would agree with Takala that knowledge cannot (in most cases) legitimately be forced upon anyone, neither can dental hygiene, neither can good manners, neither can most things. The impracticality of the situation, however, offers little solace in philosophical realms. It is impossible for one to force me to brush my teeth, I may have a preference towards rotting, and bacteria infested teeth and halitosis. The impracticality or failure one has to make me look after my teeth does not grant me immunity to being pointed at or being judged as being unhygienic. In the same (bad) breath, parents cannot be forced legally to undergo antenatal screening, or to harm the foetus in other ways such as smoking. That does not make them immune to moral judgement, or a collective finger being pointed in their direction for failure to maximize their future child's' welfare.

²⁹¹ Bird G, Wood A. Supporting children and families through Early Development Groups. (2003) *Down Syndrome News and Update.*; 3(3); 74-81.

²⁹² Buckley S. Early Support – new materials and services for families with babies and children with Down syndrome (2006) *Down Syndrome News and Update.* 5(3); 124-126

²⁹³ Takala T. *Op cit* (1999), 292

What of the parents Right Not to Know?

*The Ostriches are On the March*²⁹⁴: Arguments in favour of the Right Not To Know

Antenatal screening tests may also reveal extraneous information, some of which may be relevant to parental health. Some of the findings may be directly relevant to the test carried out for the foetus. For example if a family screened to see if the foetus is affected by an autosomal recessive condition and the foetus is affected it would (normally) follow that he/she would have inherited one gene from each parent, which would confirm that both parents are carriers of that gene. Some other findings may be incidental²⁹⁵, such an example is conferred by case reports of maternal cancer diagnoses made on a number of women using the antenatal screening blood test MaterniT21 PLUS²⁹⁶

Incidental findings may be clinically relevant pieces, and in some situations, such as the maternal cancer example above, there may be a medical course of action that can help treat the recipient of the said information. Ethically speaking, however, these incidental findings are beyond the original purpose for which the antenatal test was conducted.²⁹⁷ The problem of what a physician should do when he/she encounters such incidental findings has been a major source discussion in bioethical realms.²⁹⁸

The right not to know dictates that people ought to have the ability to control genetic information about themselves to which they are exposed, and, it is argued that this so

²⁹⁴ The idea of an ostrich sticking his head in the sand to describe those in favour of the right not to know was taken from Harris, J., Keywood, K. (2001). Ignorance, information and autonomy. *Theoretical medicine and bioethics*, 22(5), 415-436. p416

²⁹⁵ Presidential Commission for the Study of Bioethical Issues (Anticipate and Communicate: Ethical Management of Incidental and Secondary Findings in the Clinical, Research, and Direct-to-Consumer Contexts 27 (2013) http://bioethics.gov/sites/default/files/FINALAnticipateCommunicate_PCSBI_0.pdf

²⁹⁶ Surprising Cancer Diagnosis After Non-invasive Prenatal Genetic Test <http://www.medscape.com/viewarticle/843917>

²⁹⁷ See Wolf, S. M., Lawrenz, F. P., Nelson, C. A., Kahn, J. P., Cho, M. K., Clayton, E. W., Illes, J. (2008). Managing incidental findings in human subjects research: analysis and recommendations. *The Journal of law, medicine and ethics*, 36(2), 219-248.

²⁹⁸ Leigh Jackson Et Al., *Incidental Findings In Genetic Research And Clinical Diagnostic Tests: A Systematic Review*, 158a AM. J. MED. GENET. 3159 (2012).

called right remains unaltered by pregnancy or parenthood. The notion was initially explored with the emergence of early screening tools for breast cancer, in an era when being linked with the condition was stigmatizing²⁹⁹. Under such circumstances it is evident why some patients might not want to be the recipients of such information. These arguments have been mirrored in cases of conditions of Huntington's and Alzheimer's disease, conditions where at the time of writing there is still no definitive cure.³⁰⁰

The problem that a paediatrician like myself (or an obstetrician that would be in charge of the antenatal screening process) is that the right not to know causes friction between two of the guiding principles we have been indoctrinated with in medical school, those of beneficence and autonomy.³⁰¹

We hold patient wishes and autonomy in high regard, but we also strive to do what is medically best for our patient. When these two principles collide it places the physician in an untenable position, respect patients wishes and the patient will unknowingly forego the opportunity for treatment, or go against their wishes inform them that their antenatal screening test (like the example above) picked up cancer and they may have a chance at surviving and seeing their child grow.

Proponents of the right not to know argument fervently defend that respect for autonomy should supersede beneficence in such scenarios. They are also quick to point out that there is a legal right to refuse medical treatment and this right should enable the patient to refuse medical information, even if it is to his/her detriment^{302, 303}. Other arguments in

²⁹⁹ Bloom, J. R., Kessler, L. (1994). Emotional support following cancer: A test of the stigma and social activity hypotheses. *Journal of Health and Social Behavior*, 118-133.

³⁰⁰ Chadwick, R., Levitt, M., Shickle, D. (2014). The right to know and the right not to know: the emerging debate. *The Right to Know and the Right Not to Know: Genetic Privacy and Responsibility*, Cambridge University Press. p13-23

³⁰¹ Ost, D. E. (1984). The 'right' not to know. *Journal of Medicine and Philosophy*, 9(3), 301-312.

³⁰² Laurie, G. T. (2000). Protecting and promoting privacy in an uncertain world: further defences of ignorance and the right not to know. *European Journal of Health Law*, 7(2), 185-191.

³⁰³ Emerson, T. I. (1976). Legal foundations of the right to know. *Wash. ULQ*, 1.

favour of the right not to know include the various ways in which patients may be harmed by receiving the said information, the commonest concerns being psychosocial repercussions such as depression secondary to societal stigma or discrimination.³⁰⁴ Concerns about the financial impact on the individual and the general public directly resulting from medical treatment and follow up arising from this information have also been cited.³⁰⁵

Another common argument used in defence of the right not to know cites qualitative objections about genetic information; they advise caution in interpreting and sharing information whose relevance, phenotypically at least, is not clear cut.³⁰⁶ Genes associated (but not found to cause) certain cancers³⁰⁷, ³⁰⁸ are examples of genetic information translating into little or no clinical relevance. These gene associations may in future become more relevant, but at the time of writing they simply, reveal a risk factor, muddying the waters of what is clinically relevant and what is not. According to Wilson “since being a carrier is not something that can be averted by informing, it is not clear why there should be an onus on individuals to know, or to facilitate others being told, about their genetic constitution.”³⁰⁹

Another significant argument in favour of the right not to know is that the paternalistic notion of “doctor knows best” is no longer relevant in this day and age, even if the

³⁰⁴ Lázaro-Muñoz, G., Conley, J. M., Davis, A. M., Van Riper, M., Walker, R. L., Juengst, E. T. (2015). Looking for trouble: Preventive genomic sequencing in the general population and the role of patient choice. *The American Journal of Bioethics*, 15(7), 3-14.

³⁰⁵ Klitzman, R., Appelbaum, P. S., Chung, W. (2013). Return of secondary genomic findings vs patient autonomy: implications for medical care. *Jama*, 310(4), 369-370.

³⁰⁶ Weaver, K. D. (1997). Genetic screening and the right not to know. *Issues in Law and Medicine* 13, 243.

³⁰⁷ Toyota, M., Suzuki, H., Sasaki, Y., Maruyama, R., Imai, K., Shinomura, Y., Tokino, T. (2008). Epigenetic silencing of microRNA-34b/c and B-cell translocation gene 4 is associated with CpG island methylation in colorectal cancer. *Cancer research*, 68(11), 4123-4132.

³⁰⁸ Xu, B., Feng, N. H., Li, P. C., Tao, J., Wu, D., Zhang, Z. D., Hua, L. X. (2010). A functional polymorphism in Pre-miR-146a gene is associated with prostate cancer risk and mature miR-146a expression in vivo. *The Prostate*, 70(5), 467-472.

³⁰⁹ Wilson, J. (2005). To know or not to know? Genetic ignorance, autonomy and paternalism. *Bioethics*, 19(5-6), 492-504.

principle of beneficence is the driving force behind the wish to share relevant medical information with the patient:

“If a person’s own judgment can be overridden by considerations of the ‘reasonable’, as defined by the profession, or by ethicists for that matter, we must forget the principle of autonomy at the outset, or at least find its applications extremely limited. It seems that by accepting the rhetoric of ‘what the reasonable person would do’, we re-introduce the practice of paternalism to medical ethics.”

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Takala, a fervent defender of a right not to know argues that “reasonable paternalism” has no place in modern practice. By separating the principles of beneficence and non-maleficence she puts forward the idea that whilst being aware of our genetic makeup, may , in some cases, allow for some meaningful treatment , lack of knowledge of a genetic malady would not necessarily harm the person as the defect has been present for a long time anyway.

The Anti-Ostrich Movement: The case against the right not to know

There are of course criticisms of the so-called right not to know, it is after all a way of hiding one’s head under the sand. Hottois is perhaps takes the hardest stance against the right not to know as he argues that the principle is “directly opposed to human rights philosophy and to ethics.”³¹¹. Most opponents of the notion have more moderate injections.

Harris and Keywood have labelled this practice as “passing the buck”³¹². Whilst acknowledging the interest that people have in genetic privacy, as well as their desires to be protected from information that may upset them, they conclude that there is no such

³¹⁰ Takala, T. (2001). Genetic ignorance and reasonable paternalism. *Theoretical Medicine and Bioethics*, 22(5), 485-491.

³¹¹ Hottois, G. (2000). A philosophical and critical analysis of the European Convention of Bioethics. *The journal of medicine and philosophy*, 25(2), 133-146.

³¹² Harris, J.,Keywood, K. (2001). Ignorance, information and autonomy. *Theoretical medicine and bioethics*, 22(5), 415-436.

thing as a moral right to remain in ignorance. They reach this conclusion by expanding whether the refusal of information about oneself can be done so on autonomy grounds and cite that this is illogical as the principle of autonomy supports the giving rather than the withholding of information in most circumstances. There is no basis to the argument that information alone restricts autonomy because there's a clear line between receiving relevant information relating to my or my future child's health and using that clinically relevant information upon which I base any subsequent decisions. They conclude "any claims to be shielded from information about the self must compete on equal terms with claims based in the rights and interests of others".³¹³

Laurie's also argues that trying to defend the right not to know by using autonomy as a core argument is a poor defence, not least because there is no such thing as choice free from external limitations.³¹⁴ There are numerous things I would like to do (or not do) or know (or not know) but have to resort to non-ideal choices and conform to laws and societal norms. I'd like for example to use my neighbourhood as a racing track and drive my 1972 Alfa Spider around the block as fast as I can, I am salient enough however to make a non-ideal choice and limit my autonomy not least because I know speeding in a residential area may result in someone being hurt but also because there are laws limiting my autonomy from doing so. I do not begrudge this reasonable limitation to my autonomy however as I understand that autonomy is not without limits; public policy needs to prohibit some of my actions in my own interest and that of the greater good, examples of such prohibition include suicide or selling myself as a slave.³¹⁵

Laurie does, however, offer of an alternative approach to defending the right not to know " [the right not to know is] better characterized as a privacy issue that is related to, and yet distinct from, autonomy claims that we each might have as individuals worthy of respect."³¹⁶ His rationale is based on the notion that we must ensure that an individual is afforded spatial privacy. He defines special privacy as something that includes one's separateness in both the physical and psychological sense. He argues that psychological

³¹³ *Op Cit* Harris J, Keywood K p434

³¹⁴ *ibid* p 415

³¹⁵ *ibid*

³¹⁶ *Op Cit* Laurie p54

privacy allows one to safeguard his/her own sense of self from external stressors . Following this line of thinking he argues that receiving unwanted information would violate ones' psychological spatial privacy.

If the right not to know is defended on privacy rather than on autonomy terms however, he joins Harris and Keywood in questioning whether the right not to know is a right at all. Laurie concedes that for someone to decide to violate one's psychological privacy he/she would need to weigh up numerous competing factors and assess the situation on an *ad hoc* basis, but the right not to know should not be upheld as a strict ethical rule. So whilst the divulging of information (if disclosed to the person against hid his/her wishes) might equate to an invasion of their private sphere; it may be justifiable under certain circumstances. Things that need to be taken into consideration for violating one's private sphere include the availability of curative interventions, disease severity, and the probability that the disease will manifest itself phenotypically.

Wilson³¹⁷ and Räikkä³¹⁸ are in agreement with the above, in that autonomy based arguments are not best used in defending a right not to know. Wilson concedes that receiving information against one's wishes may somehow impinge on their personal choices, but argues that whilst in situations where the information is nebulous and of little clinical benefit to the patient the right not to know may be defended. She accepts, however, that there should be certain circumstances (such as situations where the welfare benefits to the individual outweigh the welfare costs) then due consideration is needed on whether to breach the right not to know as in these cases it may be ethically justifiable to do so.

In addition to the above criticism of the autonomy based defence of the so called right not to know, Malpas³¹⁹ cites that if we are to follow traditional, Kantian, accounts of autonomy, one would need more rather than less amounts of information in order to make

³¹⁷ Wilson, J. (2005). To know or not to know? Genetic ignorance, autonomy and paternalism. *Bioethics*, 19(5-6), 492-504. p502

³¹⁸ Räikkä, J. (1998). Freedom and a right (not) to know. *Bioethics*, 12(1), 49-63.

³¹⁹ Malpas, P. (2005). The right to remain in ignorance about genetic information--can such a right be defended in the name of autonomy?. *The New Zealand Medical Journal (Online)*, 118(1220).

an informed decision. Rhodes reaches the same conclusion “respect for autonomy actually leads to the opposite conclusion, the obligation to pursue genetic knowledge”³²⁰

Knowledge is a core element in self-determination, if we starve ourselves of knowledge and information relating to ourselves we cripple ourselves of the ability to make informed decisions in order to exercise autonomy. Lack of knowledge can more often than not lead to poor decisions, and in the context of antenatal screening, these poor decisions may frustrate not only one’s future self, but also one’s future children.

Ost³²¹ has even gone so far as to criticise those choosing to remain in ignorance of relevant information about their health as being irrational in their actions. His rationale is that as no one has a crystal ball, one can not know whether or not the information they refuse to receive will be relevant or not to any future decision making process. He concludes that if someone is so firmly positioned on his or her refusal to receive information that no amount of rational conversation would sway them to reconsider then this would be equivalent irrational obsession; one cannot be truly autonomous if he/she is irrational as self-determination requires rationality.

The latter point Ost makes is very relevant in our analysis as he seems to take the criticism of the right not to know a stage further and imply that there is a duty to inform ourselves about pertinent clinical information relating to ourselves “we can say that the right of informed consent is a mandatory right, and that receiving information about one’s diagnosis, alternative treatments, etc., is both a right and a duty”³²².

Rhodes is on a similar wavelength also support there is a duty to know. Her point of view nicely summarizes the objections already summarised above. Rhodes purports that autonomy creates a duty to know as in the absence of relevant knowledge we simply cannot make autonomous decisions. She limits this duty to know where information “ is

³²⁰Rhodes R. Genetic Links, Family Ties and Social Bonds p419-438 in Sherlock, R., Morrey, J. D. (Eds.). (2002). *Ethical issues in biotechnology*. Rowman and Littlefield Publishers. p.425

³²¹ Ost, D. E. (1984). The ‘right’ not to know. *Journal of Medicine and Philosophy*,9(3), 301-312.

³²² *ibid* p309

likely to make a significant difference in my decisions and when the relevant information is obtainable with reasonable effort.”³²³

Conclusion

In this article I oppose the right not to know. I purport that lack of knowledge in the antenatal setting can harm the eventual child. Knowledge needn't be *just* of genetic nature, but include relevant anatomical and microbiological screening tests relating to the health of the mother and foetus. Citing the autonomy-based objections raised above, I argue that autonomous choices, at least in the Kantian sense, cannot be made in the absence of knowledge. I also argue that there is a duty to know relevant information about the foetus (if and only if the decision has been made to carry the pregnancy to term), provided that information can influence (by means of a proven therapy) in a positive way the health of the future child.

I have examined if parents-to-be have a moral obligation to engage with antenatal screening services and foetal therapies, where these exist, in the interest of the welfare of future children. I have argued that it is appropriate to apply the Millian harm principle to the *in utero* environment provided that those planning to have a child have every intention to bring the specific child to birth and the available screening processes and interventions are both safe and effective. I support that a comparative account of the harm principle is the one that is most applicable in the foetal setting. I conclude that it is the only account that seems to logically allow us a comparison between the net health of the same child, i.e. one theoretically born without an antenatal intervention that could improve his/her health and one that is born having had appropriate therapy.

After identifying a concept of harm that fits this context, I explored systematically whom the birth of future children born in an untreated diseased state may harm. I examined if the children themselves, parents, other dependents and wider society may be harmed in these situations. With careful review of medical and bioethical literature I have put across that in some *very rare* cases, termed as wrongful life cases, situations that very much

³²³ *Op. Cit* Rhodes p426

form the exception rather than the rule, disability may be so debilitating and severe that parents may harm their newborns by foregoing antenatal screening and not terminating pregnancy early. With respect to non-wrongful life situations, which form the vast majority of the disabled population, I have demonstrated that where there is a safe and effective screening process and therapy for a specific disorder, parents that fail to engage with antenatal services, stand to harm the eventual child before it is born. I concede, however, that where the therapy or screening process is unsafe (to either the foetus or the pregnant woman), or where no available medical or non-medical intervention exists that can benefit the future child *in utero* or soon after birth, then no such duty can exist.

I also analysed whether future parents can themselves be harmed by not engaging with antenatal screening services. On close inspection of literature assessing the impact of disabled children on parenthood, there seems to be considerable contradiction as to whether parental quality of life is significantly affected or not. What is clear however is that the more severe the disability, the more compelling the evidence that it has a deleterious effect on the wellbeing of parents. It is therefore logical to support that parents who have failed to engage with antenatal services in a way that has in some way harmed the eventual child, will have only harmed themselves as well in only the most severe forms of disability.

I also argue that the evidence of the impact of even moderate disability on other siblings is more persuasive. Therefore in a world that stereotypically holds parents as guardians of the welfare of their present and future children, foregoing the chance to treat a disability *in utero*, should such a treatment exist, stands to also frustrate the welfare of their other dependents.

With respect to whether wider society can be harmed or not by poor uptake of antenatal services and potential therapies I have looked at statistical and financial data relating to the impact of disability on a societal level as well as different accounts of distributive justice. On balance, this is a more difficult argument to settle due to limitations of science at the time of writing. What can be said is that in situations where we can accurately predict that an antenatal choice can improve the welfare of the child, then the wider society also stands to benefit. If the available medical technology cannot give us a clear

answer as to whether an antenatal choice will harm or benefit the eventual child in the long run, then we cannot claim that failure to engage with antenatal technologies can harm society in general.

In the final section, I answer to critics opposing the application of the Kantian definition of autonomy in the antenatal setting. I argue, along Kantian lines, that we are morally bound to act in accordance with the best information available to us for only then can it be said that we have acted in a truly autonomous way. That knowledge gives us better control of our actions and the desired outcome, which in this case, is the welfare of future children.

We cannot dispute that scientific knowledge and expertise in the arena of genetic and perinatal medicine is growing at an alarming rate. In the words of Rouvroy:³²⁴

Suggesting that one is today on the cusp of piercing the veil of genetic ignorance also implies that it is high time to renegotiate our social contract for a post-genomic era when genetic causes of inequalities in health and capabilities will become visible.

It is highly likely that at this rate of scientific evolution, the number of available procedures designed to improve the welfare of the eventual child will continue to become safer and more effective. In the interests of future generations of children, the duties and responsibilities of parents-to-be towards the unborn will need to transform as well in a way that accommodates these scientific advances.

³²⁴ Rouvroy, A. (2007). *Human genes and neoliberal governance: A Foucauldian critique*. Routledge. p175

CHAPTER 6

THE SECOND PAPER

CHAPTER 6

Paper 2

Do prospective parents have a moral duty to undergo antenatal genetic screening and should this be reflected in the way that screening programmes are offered

Introduction:

It has been argued that: If there is a right to remain in ignorance of information about our genetic health, then this right is unaltered by pregnancy, at least until treatments emerge that can reverse genetic impairment.³⁶⁶

This argument put forward by Bennett and others claims that pregnant women do not have a duty to find out about the genetic make up or health state of their foetus in cases where no effective treatment or cure for these impairments exists. Often such arguments focus on conditions like Down syndrome where, while a test will identify this condition, the test cannot enable this particular child to be born without Down syndrome. If we accept this kind of argument; that this information does not prevent harm to third parties but is information that may or may not be useful to prospective parents, then this will impact on how we feel that antenatal screening should be delivered. If having information about the genetic make up of our future child is unable to help us to prevent harm to our future child, then it seems we do not have any justification for putting pressure on individuals to be tested for these disorders.

In this paper I take issue with this claim for a number of reasons. I argue that not only do we have a duty to find out about any treatable genetic and other impairments our future child may have, but that we also have a duty to find out about incurable conditions, including conditions such as Down Syndrome. I argue that even where these conditions are untreatable knowledge of these impairments will enable prospective parents and the healthcare professionals caring for them to make better and more informed decisions which are likely to improve the welfare of these future children. I argue that not only do prospective parents have a strong moral duty to access all antenatal screening available in order to maximize the welfare of their future child, but that this strong moral duty should influence policy and

³⁶⁶ Bennett, R. (2001). Antenatal genetic testing and the right to remain in ignorance. *Theoretical medicine and bioethics*, 22(5), 461-471.

practice in antenatal screening, allowing screening programmes to be implemented that encourage this moral obligation.

A right to remain in ignorance?

A lot has been written, about a so-called right to remain in ignorance of our genetic and health states. It is often argued, for instance, that the principle of respect for individual autonomy dictates that individuals should be able to refuse to gain information via screening and testing and other means if this is their considered choice. This would also seem to be in line with current law and policy in healthcare. Even where such choices concern the health state and genetic make up of future children, there are those that argue that prospective parents still have this so-called right to ignorance. For instance, Bennett³⁶⁷ and Takala³⁶⁸ purport that while there may be good reason to suppose any right to remain in ignorance is diminished if it can be shown that this ignorance is likely to cause serious harm to third parties, such reasons are not applicable in antenatal genetic screening during pregnancy. Their reasoning is that most genetic disorders cannot be prevented by antenatal detection and thus screening would only provide information that might be helpful to the prospective parents in order to help them to decide to continue with the pregnancy or not rather than providing information that would prevent serious harm to a third party. As a result it has been suggested that where genetic disorders are not preventable prospective parents have a right to remain in ignorance of their future child's genetic make up.

I challenge this stance arguing that prevention of a genetic disorder is not the only way to prevent harm to the person a genetically compromised foetus will become. I argue that while the foetus may not have moral status at this stage, it can still be harmed in this pre-personal stage of its development. Further, I suggest that there is no intrinsic quality within genetic information that makes it less or more relevant to the prospective foetus than other types of antenatal information, such as microbiological or anatomical information and thus this information should be treated in a similar way. Ultimately I argue that, not only is there no right to remain in ignorance of our future child's *genetic* make up and health status, but prospective parents have a strong moral duty to find out this information in order to maximize their future child's welfare.

³⁶⁷ Bennett, R. (2001). Antenatal genetic testing and the right to remain in ignorance. *Theoretical medicine and bioethics*, 22(5), 461-471

³⁶⁸ Takala, T. (1999). The right to genetic ignorance confirmed. *Bioethics*, 13(3-4), 288-293.

Personhood and harm in the pre-personal state

It can seem strange to posit a duty to antenatal screening in order to maximize the welfare of future children when the same stance also claims that access to termination of pregnancy, on the basis of the pregnant woman's sufficiently autonomous choices, should be stridently defended. However, this apparent conflict can be dispelled when we pick this issue apart a little.

In this paper I employ a personhood view of the moral status of the foetus, meaning that I assume that infants only have interests and a right to life some time after birth. It is, of course, this notion that the embryo and foetus does not have interests and a right to life until after birth that underlies our legal approach to pregnancy, IVF and embryo experimentation and, at least up to the point of viability, abortion. I argue, however that while embryos and foetuses may not have a right to life at this stage of their development this does not mean that we can treat embryos, foetuses and newborns as we wish without any moral scrutiny, as it is wrong to harm future persons in their pre-personal state. If we intend to bring a child to birth it seems we have certain duties to protect that child's welfare, and if harm done to that child as an embryo or a foetus will harm its future welfare then it seems we have a duty to protect that future child in this early stage of its existence.

This view implies that pregnant women who have decided to bring their foetus to birth have different obligations and duties than those who have decided to terminate their pregnancy. So those who decide not to bring their foetus to birth have no obligations to protect that foetus from harm so long as they ensure that this foetus does not become a person.

In line with this we can separate embryos and foetuses into two camps; potential persons (or according to John Harris's account, *pre-persons*),³⁶⁹ that is where there is an intention to bring this fetus to birth, and non-potential persons where the intention is to terminate this pregnancy. In an attempt elucidate the how parental moral duties differ, if at all, with respect to each. John Harris states:

“The life cycle of a given individual passes through a number of stages of different moral significance. Once a new human individual comes into existence she will gradually move from being a potential or a preperson into an actual person when she

³⁶⁹ Harris J. (1992) *Clones Genes and Immortality: Ethics and the Genetic Revolution* Oxford University Press p76

becomes capable of valuing her own existence; it is very difficult to say precisely when this is”³⁷⁰.

From a pragmatic perspective, on this personhood view, if we hold the premise that no one is harmed by not coming to existence, (this seems to be at least logically true as there is literally no-one to be harmed by not being brought into existence) then a pre-person only becomes worthy of moral consideration from the specific point-in-time that the parents decide to bring that foetus to birth. Only then is there a firm (assumed) contract between foetus and parent that at some stage this potential will be met and the child will come into existence. If the parents choose to terminate the pregnancy, on this view, that entity never gained a life it could value and the interests that go with that and protecting the welfare of such an entity does not seem to be the same kind of moral duty.

It follows that any damage incurred *in utero* of the said pre-person would foreseeably frustrate the future welfare and wellbeing of that very foetus as that foetus will at some point be born. This damage can take many forms and can result from some parental action or inaction; the actions of the parent during pregnancy will foreseeably affect the newborn child and the individual that child will become. My thesis, and concern, is safeguarding that very welfare of these future children. I argue that antenatal screening has an important role to play in optimizing the welfare of the *specific* child (and not maximization of net welfare as others such as Harris and Savulescu have argued)³⁷¹ and as such parents have a duty to their future child to use antenatal services provided by their local health authority.

Why focus just on antenatal *genetic* screening?

Debates around a so-called right to remain in ignorance often centre on genetic screening. In this paper I will argue that while genetic screening is an important source of information, there is nothing intrinsically special about genetic information. There are clear instances where information about other conditions in pregnancy can help prospective parents protect their children from serious harm and it seems thus that these parents have a strong obligation to accept this information. I will argue that genetic screening should be seen in a similar

³⁷⁰ Harris, J. (2003). Consent and end of life decisions. *Journal of medical ethics*, 29(1), 10-15 p13

³⁷¹ Arguing on the premise of maximisation of net welfare has other connotations, such as exchanging a disabled foetus for a healthy one and justifies selective abortion. This introduces an unpalatable, indefensible position towards disability.

way. If this information is likely to enable the improvement of our future child's welfare then genetic or not we have a duty to access this information.

However, before we can equate these different types of information we first need to analyse if there is anything that sets genetic information acquired antenatally apart from other types of antenatal information. I argue that there is not.

The purpose of antenatal medicine is to inform and support parents and guide them as to how they will proceed with their pregnancy, if at all. If the parents decide to see the pregnancy through, antenatal services have another role, to allow an opportunity to optimise the condition the baby is born in by flagging up any potential complications that may occur at birth as well as pre and post labour. It is easy enough to classify the obtained information by genre or medical subgroup, but trying to elucidate what type of information is more relevant than the other is an impossible task.

Antenatal medicine covers numerous aspects of foetal and maternal health; the spectrum encompasses genetic disease, foetal anatomy and microbiology. It is hard to envisage how there can be any intrinsic qualities within genetic information that makes it any less, or any more relevant to the welfare of the foetus than information on anatomy or bacteriology. All types of antenatal information may be used to predict, with variable degrees of certainty, whether or not the child will be born in a diseased state, and if the reasoning behind the pursuit of these antenatal services is the welfare of the eventual child, then parents have as much an interest to find out about potential infections as they do about potential genetic problems. This is provided that the test is accurate enough and the information may signal an intervention that allows the welfare of the eventual person to be optimised. Whether or not there is an intervention to be made, however, can only be known retrospectively. The screening service in itself can help reduce the probability that that child's welfare will be frustrated. Quite simply, if we do not know of the presence of a certain foetal risk or anomaly that merits a certain therapy, we will not be able to offer it as treatment option.

Microbiological antenatal screening is currently easier to justify as a parental duty; antibiotics are cheap and effective, and minimize the risk of disease transmission to the newborn. A high vaginal swab (HVS) taken from the pregnant woman for example, can flag up a potentially lethal bacterium, Group B Streptococcus which is usually asymptomatic in the pregnant woman and does not cause her any long-term harm if untreated. The latter is the leading

cause of term infant mortality in the West³⁷² and can lead to meningitis in the first few days of life with significant lifelong neurological deficit and even death. Mortality and morbidity significantly drops if the pregnant woman has a short course of antibiotics prior to delivery, which treats the maternal infection and makes it considerably less likely to be passed on to the child. The HVS is still a type of screening, but unlike genetic screening the duties of pregnant women in this instance seems less controversial. Declining an HVS screen and treatment by a colonised pregnant woman intending to continue her pregnancy would be very likely to cause significant harm to the infant. In such an instance it seems clear, that the pregnant woman, has a moral obligation to act to avoid this significant and avoidable harm.³⁷³

The merits of early microbiological screening are evident, it is however also becoming increasingly easier to justify screening for non-microbiological information such as anatomical abnormalities. There are emerging foetal surgical procedures that can be carried out *in utero* that can improve the eventual child's welfare such as cases of spina bifida, or even save the newborn's life such as in cases of tracheal atresia or congenital high airways obstruction syndromes³⁷⁴ (CHAOS). It is also easy to justify why screening for any cardiac abnormalities is necessary. Congenital heart disease may cause immediate compromise to the newborn's health. If these cardiac anomalies are flagged up antenatally it allows forward planning that would allow the baby to be born in tertiary neonatal centres that are better suited to dealing with these time critical complex neonatal pathologies and would allow timely reparative surgery and a better long-term outcome for the baby.³⁷⁵

Treatable and untreatable conditions?

Bennett has claimed the following

“If there is a right to remain in ignorance of information about our genetic health, then

³⁷² Shet, A., and Ferrieri, P. (2004). Neonatal and maternal group B streptococcal infections: a comprehensive review. *Indian Journal of Medical Research*, 120, 141-150

³⁷³ Rejecting an HVS is not morally questionable if one is not planning to go through with the pregnancy, practically this is difficult as testing happens after the 24th week of gestation after which termination becomes illegal.

³⁷⁴ Glynn, F., Sheahan, P., Hughes, J., and Russell, J. (2006). Successful ex utero intrapartum treatment (EXIT) procedure for congenital high airway obstruction syndrome (CHAOS) owing to a large oropharyngeal teratoma. *Irish medical journal*, 99(8), 242-243.

³⁷⁵ Levey, A., Glickstein, J. S., Kleinman, C. S., Levasseur, S. M., Chen, J., Gersony, W. M., and Williams, I. A. (2010). The impact of prenatal diagnosis of complex congenital heart disease on neonatal outcomes. *Pediatric cardiology*, 31(5), 587-597.

this right is unaltered by pregnancy, at least until treatments emerge that can reverse genetic impairment”³⁷⁶.

This is perhaps the main distinction made between the subdivisions within antenatally acquired screening services: a distinction made between treatable and non-treatable conditions. Whilst microbiological information can be (cost-) effectively acted upon and the potential infection treated, most genetic conditions cannot be treated. Lets assume momentarily that Bennett is correct and the sole value of antenatal genetic knowledge is the treatment of the condition alone.

With advances in gene therapy one can only predict that more genetic disorders will be able to be remedied through advances in gene therapy³⁷⁷ and by extension there will be increasing reason to assume that antenatal genetic screening is a duty. Already successful treatment in some single gene disorders such as severe combined immunodeficiency³⁷⁸ and Leber’s congenital amaurosis³⁷⁹ causing congenital blindness have been made, and promising literature exists on the treatment of Huntington’s³⁸⁰ and Parkinson’s disease.³⁸¹ Thus, if we justify a parental duty to screen on the basis of treatability and the ability, therefore, to avoid harm, then one could justify a parental duty for antenatal screening for these specific *genetic* conditions on this basis.

Although I do not agree that only treatable conditions ought to be screened for, there is a certain cause for optimism. Further advances in *in utero* therapies for currently untreatable single gene disorders such as cystic fibrosis, haemophilia, muscular dystrophy and sickle cell anaemia will, in future, make claims to the right of parental genetic ignorance even weaker. These are conditions that significantly impact on patients’ quality of life, welfare and long-

³⁷⁶ Bennett R *op cit*

³⁷⁷ Cavazzana-Calvo, M., Thrasher, A., and Mavilio, F. (2004). The future of gene therapy. *Nature*, 427(6977), 779-781.

³⁷⁸ Cavazzana-Calvo, M., Hacein-Bey, S., de Saint Basile, G., Gross, F., Yvon, E., Nusbaum, P., Selz, F., Hue, C., Certain, S., Casanova, J.L. and Bousso, P., (2000). Gene therapy of human severe combined immunodeficiency (SCID)-X1 disease. *Science*, 288(5466), 669-672.

³⁷⁹ Maguire, A.M., Simonelli, F., Pierce, E.A., Pugh Jr, E.N., Mingozzi, F., Bennicelli, J., Banfi, S., Marshall, K.A., Testa, F., Surace, E.M. and Rossi, S. (2008). Safety and efficacy of gene transfer for Leber's congenital amaurosis. *New England Journal of Medicine*, 358(21), 2240-2248.

³⁸⁰ Vagner, T., Young, D., and Mouravlev, A. (2012). Nucleic Acid-Based Therapy Approaches for Huntington's Disease. *Neurology research international*, 2012.

³⁸¹ Howard, K. (2003). First Parkinson gene therapy trial launches. *Nature biotechnology*, 21(10), 1117-1118.

term survival, and not curing them antenatally or soon after birth where this is possible would seem indefensible and cruel; denying a particular child a chance of life without these welfare inhibiting conditions.

While many (but not all) of these treatments are currently science fiction for most conditions, there is evidence that we are not light-years away from the ability of treating more genetic disorders than we are able to do now. With the capacity and potential of improving the welfare of a number of children, and once the ethical pros and cons are placed on the moral balance,³⁸² it is improbable that one could justify placing parental ignorance above the welfare of the potential offspring.

Perhaps evidence that the tides might be changing is the recent vote by British parliament in February 2014 to allow the creation of three parent babies in order to spare children-to-be from being brought into a (short and painful) life with a mitochondrial disorder.³⁸³ Instead, 0.1% of the DNA make up of a *specific ovum* is altered via introduction of healthy mitochondrial DNA from a donor parent. I highlight the term specific ovum as it is an important distinction. The unhealthy ovum is not replaced or discarded it is simply cured and thereby allowed to be implanted and eventually result in a healthy child with a chance of a healthy, fulfilling life. The fact that the U. K has become the first country to approve laws to allow the creation of children from three “parents” is evidence that legislation and with it public policy will eventually have to change to keep abreast with scientific developments in medicine, in order to allow the eventual child a better, healthier quality of life.

Down Syndrome and the justification of screening for untreatable genetic conditions.

As mentioned above, Bennett³⁸⁴ argues that there’s no duty to obtain antenatal information unless there is a definite cure for the specific genetic condition. Although we can safely say that the number of curable genetic conditions will increase with time, at present most cannot be cured. However, I will argue that even though they cannot be cured, there are still good reasons to access this information. Often further medical complications that can be anticipated and dealt with if a genetic disorder is identified during pregnancy; and there are

³⁸² Arguably, greater uptake of antenatal screening services would also uncover more treatable cases, allowing more clinical exposure to these procedures, improving medical training and would hence help deliver better clinical outcomes.

³⁸³ MPs say yes to three-person babies <http://www.bbc.co.uk/news/health-31069173> accessed 12/2/15

³⁸⁴ Bennett R *Op Cit*

other, non-medical, interventions that can be planned if this knowledge is obtained early enough that will significantly increase the welfare of a child with a genetic disorder.

Bennett's objection is a common one and has frequently been mirrored by those arguing in favour of the so-called "duty to genetic ignorance".^{385,386} Although one can see a case of philosophically justifying a parental duty to antenatal screening in cases or conditions where there is an antenatal intervention available that would improve the welfare of the eventual child, they feel it is harder to justify this duty in conditions where there is no obvious intervention, and Down syndrome is the condition mentioned more frequently than not. It is not that Down syndrome merits any more consideration than any other genetic condition, but rather that it is arguably the most commonly known genetic syndrome.

Justifying the duty to parental antenatal knowledge, even in cases of Down syndrome where no cure is yet possible is, I argue, an easy one. As benefits are manifold I will only focus on a handful. Despite the widespread awareness of Down syndrome by lay members of the public, what is less known is that half of all children born with this condition are likely to have an associated congenital heart disease, and up to a third may have life threatening gut abnormalities (such as duodenal atresia). There are of course a myriad of other anatomical problems that babies with this syndrome are predisposed to but the two immediately most life threatening are heart and gut problems.

Especially in the case of congenital heart disease, many types merit neonatal intervention in the first week of life. Without it the infant's life is put at significant jeopardy. There is no treatment currently available that improves the course of structural heart disease *in utero*. The value of foetal diagnosis is that it allows redirection of confinement to tertiary centres prior to delivery, allows influence over timing and mode of delivery, and initiation of appropriate perinatal treatment whenever indicated³⁸⁷. Evidence also exists highlighting the increased morbidity and mortality associated with postnatal (and therefore delayed) diagnosis of specific time critical lesions such as hypoplastic left heart syndrome and transposition of the

³⁸⁵ Takala, T. (1999). The right to genetic ignorance confirmed. *Bioethics*, 13(3-4), 288-293

³⁸⁶ Weaver, K. D. Genetic screening and the right not to know. (1997). *Issues in Law and Medicine* 13, 243.

³⁸⁷ Jaeggi, E. T., Sholler, G. F., Jones, O. D. H., and Cooper, S. G. (2001). Comparative analysis of pattern, management and outcome of pre-versus postnatally diagnosed major congenital heart disease: a population-based study. *Ultrasound in obstetrics and gynecology*, 17(5), 380-385 p384

great arteries; when compared to when transport happens *in utero* so that foetomaternal care can be provided in tertiary, specialized units.^{388,389,390,391,392}

With the advent of six hour discharges from maternity ward, where newborns are sent home six hours after birth³⁹³ without the customary examination of the newborn by a paediatrician (or at the very least a doctor with basic knowledge of paediatrics) as well as the increase of home births,³⁹⁴ the possibility of a delayed diagnosis of Down syndrome has become more tangible.

Couple that with the increased uptake of In Vitro Fertilisation (IVF) services which allow mothers to give birth way past their mid thirties, as well as increasing maternal age globally, or at least in the UK³⁹⁵, Western Europe³⁹⁶, USA³⁹⁷, New Zealand³⁹⁸ and Australia³⁹⁹ then it

³⁸⁸ Lamont, R. F., Dunlop, P. D. M., Crowley, P., Levene, M. I., and Elder, M. G. (1983). Comparative mortality and morbidity of infants transferred in utero or postnatally. *Journal of Perinatal Medicine-Official Journal of the WAPM*, 11(4), 200-203.

³⁸⁹ Forbess, J. M., Cook, N., Roth, S. J., Serraf, A., Mayer, J. E., and Jonas, R. A. (1995). Ten-year institutional experience with palliative surgery for hypoplastic left heart syndrome risk factors related to stage I mortality. *Circulation*, 92(9), 262-266

³⁹⁰ Chang, A.C., Huhta, J.C., Yoon, G.Y., Wood, D.C., Tulzer, G., Cohen, A., Mennuti, M. and Norwood, W.I., (1991). Diagnosis, transport, and outcome in fetuses with left ventricular outflow tract obstruction. *The Journal of thoracic and cardiovascular surgery*, 102(6), 841-848.

³⁹¹ Soongswang, J., Adatia, I., Newman, C., Smallhorn, J. F., Williams, W. G., and Freedom, R. M. (1998). Mortality in potential arterial switch candidates with transposition of the great arteries. *Journal of the American College of Cardiology*, 32(3), 753-757.

³⁹² Bonnet, D., Coltri, A., Butera, G., Fermont, L., Le Bidois, J., Kachaner, J., and Sidi, D. (1999). Detection of transposition of the great arteries in fetuses reduces neonatal morbidity and mortality. *Circulation*, 99(7), 916-918.

³⁹³ Fears for health of new mothers: Women are being sent home from maternity hospitals too quickly, with many leaving just six hours after giving birth The Observer 29/05/2005 <http://www.guardian.co.uk/uk/2005/may/29/politics.health1> (accessed 03/2014)

³⁹⁴ MacDorman, M. F., Declercq, E., and Mathews, T. J. (2011). United States home births increase 20 percent from 2004 to 2008. *Birth*, 38(3), 185-190.

³⁹⁵ Statistical Bulletin for Births and deaths in England and Wales 2008, Office for National Statistics <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=14408> (accessed 04/2014)

³⁹⁶ Atlas of Health in Europe (2008) 2nd edition, World Health Organization <http://www.euro.who.int/Document/E91713.pdf> (accessed 05/2014)

³⁹⁷ Martin, J. A., Hamilton, B. E., Sutton, P. D., Ventura, S. J., Menacker, F., and Kirmeyer, S. (2009). National Vital Statistics Reports. Births: final data for 2006. Volume 57, Number 7. 2009.

³⁹⁸ Zealand, S. N. (2012). *Demographic trends: 2011* (pp. 1177-8075). Wellington: Statistics New Zealand ISSN.

is evident that the probability of having a child with Down has never been higher. The single biggest risk factor for Down syndrome (see graph 1)⁴⁰⁰ is, after all, maternal age, the risk increase with age is not linear, it is exponential.

As I have already discussed, this duty to know is only applicable where the parent has decided to go through with a specific pregnancy. The moral harm in these cases would not arise from bringing an infant with Down syndrome to birth. There is no moral wrong in having a child later in life, nor with having a disabled child⁴⁰¹ provided one has tried to maximize his/her welfare beforehand. A child with Down syndrome is as likely as any other child to have a life that it values, a life worth living. The harm comes from jeopardising the infant's welfare and life in the early stages, before a postpartum diagnosis has been made. Had there been an antenatal diagnosis the risks of gut perforation with inevitable sepsis, or the risk of severe hypoxia with probable long term neurological damage or even the risk of early death secondary to the above would have been foreseen by the antenatal physician and (hopefully) acted upon shortly after birth. In the absence of a diagnosis prior to birth, the diagnosis is delayed, more so in cases of home birth or six hour discharges. A delayed diagnosis unnecessarily puts the child at risk of the above, a parental omission failing to reduce the risk of harm to the child. This, I feel, considerably frustrates the welfare of the infant with Down syndrome.

Many will argue in return that, if the risk of congenital heart disease in a child with Down syndrome is 50% then only half of the foetuses with Down syndrome would have had their welfare frustrated by a lack of antenatal diagnosis⁴⁰². Superimpose the risk of severe gut malformations and the risk becomes much higher. Even if that had not been the case, unless a pregnant woman finds out whether her foetus has Down syndrome or not, she doesn't know whether her child will also have a congenital heart problem as well. The moral weight of parental acts or omissions are not settled by the outcome but rather by the intended outcome,

³⁹⁹Births 2007, Australian Bureau of Statistics [http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/DC32A0611500BAA0CA2574EF00142139/\\$File/33010_2007.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/DC32A0611500BAA0CA2574EF00142139/$File/33010_2007.pdf) (accessed 05/2014)

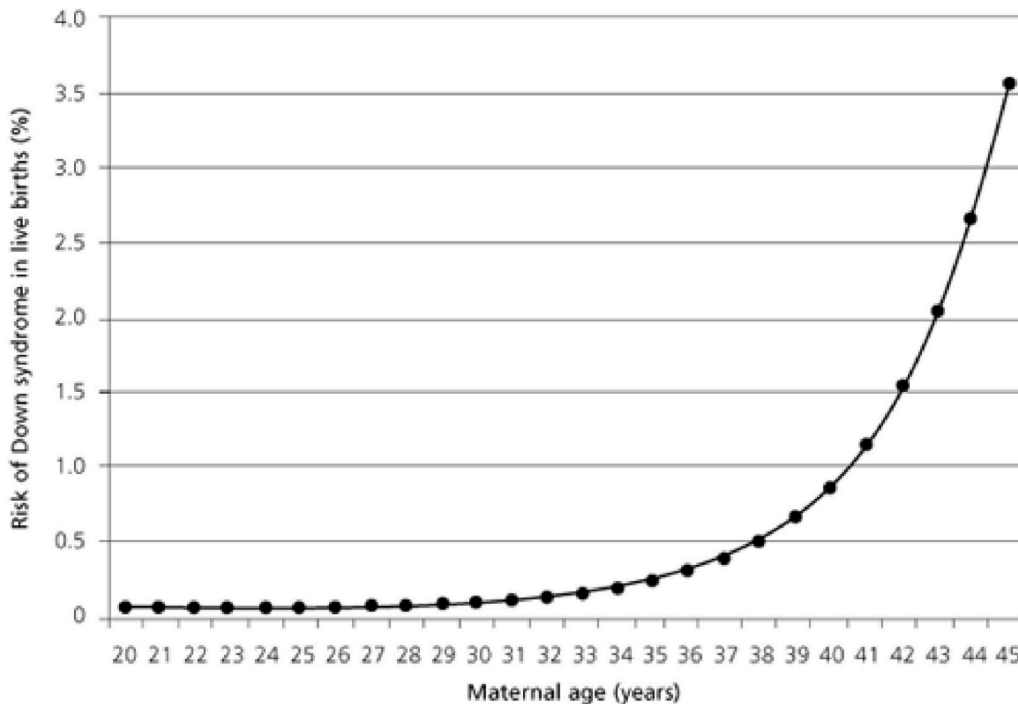
⁴⁰⁰ Newberger, D. S. (2000). Down syndrome: prenatal risk assessment and diagnosis. *American family physician*, 62(4), 825-32 p826.

⁴⁰¹ In rare, exceptional cases such as Tay-Sachs syndrome, harm could be done by being brought into existence. Usually these are neurodegenerative conditions whereby babies feel mainly pain and die soon after birth.

⁴⁰²National Down Syndrome Society Website <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/The-Heart--Down-Syndrome/>

otherwise luck, good or bad would be the main determinant if one is a moral agent or not, and this would, I fear, absolve all of us of any control over the moral worth of our actions.

Graph 1: Estimated risk of Down syndrome according to maternal age. (From Newberger, D. S. Down syndrome: prenatal risk assessment and diagnosis. (2000) *American family physician*, 62(4), 825-32 p826.



But for the sake of argument, let us assume that a child with Down is fortunate enough to be born with no associated anatomical abnormalities, and has a very mild phenotype with very dampened features of the syndrome. Would antenatal diagnosis benefit that child's welfare as well? I would argue a resounding 'yes'. Early education and physiotherapy has been proven repeatedly to improve the quality of life of many disabled children.^{403,404} Without advanced notice, parents inevitably fail to recognise early what local health authorities have in place to support their disabled child, resulting in a delay in accessing these resources, and a subsequent failure of optimisation of their child's welfare⁴⁰⁵. Specifically with respect to Down syndrome, early, targeted education and audio-visual stimulation of the infant has been

⁴⁰³ Woods E. *The effect of early home teaching on the child with Down syndrome* (1984) (MPhil Thesis) Portsmouth, UK: University of Portsmouth;

⁴⁰⁴ Bird, G., and Wood, A. (2003). Supporting children and families through Early Development Groups. *Down Syndrome News and Update*, 3(3), 74-81.

⁴⁰⁵ Buckley S. Early Support – new materials and services for families with babies and children with Down syndrome (2006) *Down Syndrome News and Update*. 5(3); 124-126

proven to improve the eventual intellect of the child⁴⁰⁶, and although a higher intellect does not necessarily equate to a better quality of life, it is at the very least an aide of optimising flourishing and by extension welfare. Thus delaying the diagnosis would frustrate their eventual welfare. Other examples exist with Down syndrome children, such as early physiotherapy and play therapy helping children reach their developmental milestones earlier and so on⁴⁰⁷.

If we look at the impact of a surprise diagnosis on parents and ability to bond/cope, affecting emotional well being most of all concerned with higher stress levels have been reported in parents of children with Down Syndrome.⁴⁰⁸ The timing of when the news of such a diagnosis is broken to parents by healthcare professionals has been looked upon extensively, and although studies mainly focus on the postnatal diagnosis of the condition, parental preferences seem to be in favour of knowing as early as possible. A recent review carried out by Skotko *et al*⁴⁰⁹ which aimed at developing a guideline on how the news of Down syndrome was broken to families had found the following across a series of studies that reflected on parental emotions and opinions:

“By delaying the conversation or waiting for a confirmatory karyotype result, physicians cause unnecessary anxiety in parents.”⁴¹⁰

Furthermore, with an eye into the future, there is sufficient evidence in animal models whereby there have been successful treatments *in utero* of mice with Down syndrome that has allowed an optimisation of brain development in the antenatal setting, which resulted in significant improvement in the postnatal cognitive outcomes in mice⁴¹¹. Key to this treatment is early prenatal diagnosis (28 week mark) and has been highlighted in numerous studies with

⁴⁰⁶ Spiker, D., and Hopmann, M. R. (1997). The effectiveness of early intervention for children with Down syndrome. *The effectiveness of early intervention*, 13, 271-305.

⁴⁰⁷ Connolly, B., Morgan, S., Russell, F. F., and Richardson, B. (1980). Early Intervention with Down Syndrome Children Follow-up Report. *Physical Therapy*, 60(11), 1405-1408.

⁴⁰⁸ Most, D. E., Fidler, D. J., Laforce-Booth, C., Kelly, J. (2006). Stress trajectories in mothers of young children with Down syndrome. *Journal of Intellectual Disability Research*, 50(7), 501-514.

⁴⁰⁹ Skotko, B. G., Capone, G. T., and Kishnani, P. S. (2009). Postnatal diagnosis of Down syndrome: synthesis of the evidence on how best to deliver the news. *Pediatrics*, 124(4), e751-e758.

⁴¹⁰ *ibid* p752

⁴¹¹ Mégarbané, A., Ravel, A., Mircher, C., Sturtz, F., Grattau, Y., Rethoré, M. O., Mobley, W. C. (2009). The 50th anniversary of the discovery of trisomy 21: the past, present, and future of research and treatment of Down syndrome. *Genetics in Medicine*, 11(9), 611-616.

variable *in utero* treatment options as highlighted in the thorough review by Guedj *et al.*⁴¹² It may be a matter of time when such studies are applied to the human model, which would make early screening for Down syndrome more pertinent.

If there is a syndrome whereby the antenatal test was grossly inaccurate, and where no associated, treatable features that frustrated the child's welfare existed, my argument could stand that in those cases, the parents wouldn't have a duty to screen. Such a syndrome may exist, but is most definitely the exception rather than the rule.

An unachievably high standard of parental obligation?

In response to my argument it might be argued that having a moral obligation to do everything we can to maximize the welfare of our future children is not only unreasonable but also unworkable as a guide for policy and practice. Such an obligation would seem not only to require prospective parents to avail themselves of every possible antenatal screen but also to make other choices and take other precautions. A duty to maximize our future children's welfare might mean that all women of reproductive age who are not averse to the idea of reproducing would need to watch their diet and lifestyle constantly in case they do become pregnant. Such a duty may also seem to require that prospective parents sell their sports car and other indulgences in order to give their children the best start possible and continue to make huge sacrifices, both financial and in their lifestyles in order that their future child's welfare be maximized.

In response to these claims I would argue that such obligations can only be philosophically applied if, and only if, the gestating person (and to an extent all people with future parental responsibility) decide to go through with the pregnancy. This is key as only then will the products of conception eventuate into an actual person, and therefore stands to have his/her future wellbeing frustrated or diminished. This can be done either actively (for example by substance misuse and similar risk taking behaviour that significantly risks causing damage that did not pre-exist in the foetus) or passively (whereby a parental lack of action, such as omitting to take folic acid fails to decrease the background risk of the foetus being born with a neural tube defect). My argument is that in an era of scientific revolution and exponential

⁴¹² Guedj, F., Bianchi, D. W., and Delabar, J. M. (2014). Prenatal treatment of Down syndrome: a reality? *Current Opinion in Obstetrics and Gynecology*, 26(2), 92-103.

advances in perinatal and fertility medicine, the wellbeing of foetuses and future children can be frustrated. Failure to plan in advance and act upon available information can have a major impact on the eventual child's health and welfare. To this argument, screening, testing, scanning and sampling is central. As long as the information gathered is proven to be safe (procedurally speaking) to both mother and foetus; the information gathered has high sensitivity and specificity and can be reasonably be relied upon by the parent and the advising clinician then, at the very least parents-to-be that have access to such medical care can to an extent be morally blameworthy if they fail to take up such services and act upon the resulting information in a way that benefits the eventual child. I stress, again, that if the information gathered results in an early abortion, then again, no one has been harmed as no one has come to exist, and that is morally acceptable, but this is not the focus of my argument, rather a possible side effect.

Furthermore, should *in utero* gene therapy prove effective in treating genetic disease in future, I feel, a grave injustice and insult to the welfare of the specific child if his/her parents did not, firstly engage with antenatal screening services for genetic disorders where such treatments are available (especially in the presence of a family history of such disorders), and secondly if they failed to take up the available *in utero* remedies provided by the healthcare system.

Conclusion:

While prospective parents do not have any moral obligation to protect the foetus if they are planning a termination, from the moment a decision is made to bring the pregnancy to term then the bioethical contractual dynamics change. Parents then become obliged to protect this future person by protecting the foetus and the newborn it will become. In ethical terms, they have a responsibility to protect the future person it will likely become in its pre-personal state.

Once a couple or individual have made the decision to become parents and bring a new person into the world, their rights to remain in ignorance of that new person's health state or genetic make up disappear as their obligations to enhance and optimize the welfare of their child-to-be override these. It is this justification that has led to calls for mandatory screening

for serious diseases such as Group B Streptococcus in pregnancy and has led to routine antenatal screening in most developed countries.

If screening tests are available to future parents by the local health authority, then pre-parental duties to antenatal screening include the uptake of all available antenatal services. This is because there is nothing intrinsic in the antenatal provision package that makes antenatal information of one genre more or less important than the rest. Microbiological information is as relevant to genetic information, which is as important as information obtained from anatomy scans. Every morsel of information can unravel potential health risks to the foetus, which if positively acted upon can maximize that specific child's welfare.

The reality that only a handful of genetic conditions can be treated in or *ex utero* has been used as an argument in favour of the duty to genetic ignorance. As antenatal medical science is a rapidly evolving field, this premise will become more difficult to defend as time goes by, as we will be able to treat more and more genetic conditions. Regardless, the duty to parental antenatal screening measures should be taken not only for diseases and disorders where prevention is possible but also for those where knowledge allows improvement in child welfare. By focusing on Down syndrome, I have argued that the condition and its associated features can be medically acted upon in such a way as to prolong the child's life and maximize its welfare, even if immediately life-threatening features do not exist.

In the same way that an obstetrician or a geneticist has a duty of care towards the pregnant woman and her future child, and would be held accountable if they misinformed the parent or misdiagnosed a severe condition antenatally, the same should apply to parents declining to acquire that information; or in Ruth Chadwick's words

“... the lack of knowledge can cause harm: decisions taken in ignorance in reproductive matters for example, have the potential to lead to harm that could have been avoided...”⁴¹³.

⁴¹³ Chadwick R., *The philosophy of the right to know and the right not to know* (1997) in Chadwick, R., Levitt, M., and Shickle D (eds)(1997) *The Right to Know and the Right not to Know* Avebury p18.

CHAPTER 7

THE THIRD PAPER

CHAPTER 7

Paper 3

Foetal surgery and using *in utero* therapies to reduce the degree of disability after birth. Could it be morally defensible or even morally required?

[An amended version of this paper was accepted for publication in *Medicine, Healthcare and Philosophy* on 30th May 2016, and published online in September 2016 its published version can be found in the Appendix of this thesis]

Introduction:

In 2008 the Human Fertilisation and Embryology Act extensively amended the original 1990 act in an attempt to "keep pace with new avenues of scientific research and reflect wider change in our society".⁴⁸⁶ The amended version was significantly more extensive and moved to accommodate ethical considerations that arose from a rapidly evolving world of perinatal medicine and assisted reproductive technologies. Some of the amendments moved to liberally modernise the act to keep abreast with social changes, such as the legal recognition of both parents in a same sex partnerships that conceived by means of donated gametes. Some other amendments were more limiting however, notably in the prohibition, with criminal sanctions, of the use of advanced reproductive technologies in selecting for a particular disability.

If deliberately choosing to bring disability into the world is now considered to be a legal wrong, punishable by the criminal law, then what might this change in law be inferred to say about the new possibilities in foetal surgery and *in utero* gene therapy? If we have a legal duty to avoid disability in one context should this influence our avoidance of disability in this other context? This paper aims to investigate whether the State might have a stake in wider promotion of practices to reduce the degree of disability in foetuses that will come to exist (as opposed to those that will be aborted).

Not selecting for disability does not affect the welfare of any future individual, whereas treating an *in utero* abnormality in such away as to optimize the eventual child's welfare; either by means of foetal surgery or any other antenatal intervention stands to improve clinical outcomes and welfare should that specific child be born. I will explore the reasons

⁴⁸⁶ HC Debate, 12/05/2008 c1066

that the State may want to intervene in the antenatal setting and to what extent, if at all; the State should implement these new technologies select for a specific disability.⁴⁸⁷

Prohibition against disability selection; is the HFEA aiming to produce the best children possible from these treatments?

Over the last half a century, scientific advances in the fields of perinatal medicine have meant that prospective parents were met with increasingly more complex reproductive choices. The main antenatal screening tools from ultrasonography to amniocentesis, chorionic villus sampling and maternal blood screening have been developed to help enhance parental insight into how healthy their foetus is prior to the projected expected delivery date. Advanced reproductive technologies such as in vitro fertilization, pre-implantation genetic diagnosis and foetal surgery have been developed in part to create healthier foetuses and by extension healthier children.

The Abortion Act in 1967⁴⁸⁸ was the first piece of legislature in the UK that was produced to accommodate the avalanche of reproductive choices that cascade as a result of new information acquired by antenatal screening tools, allowing for legal termination for foetal abnormalities.

But whilst the intended benefits of the above scientific advances were to help families to broadly speaking, either reproduce and create children without genetic disease and associated disabilities or allow families to forward plan for the eventuality of such a condition, a minority of prospective parents have moved to employ such technologies to positively select *for* a specific disability.

Such minorities come from small communities of specific disabilities themselves; examples include the deaf community or those with achondroplasia. Some members of these (relative) microcosms have such strong preferences in having offspring with the same disability as them that they have resorted to employing advanced reproductive technologies to create

⁴⁸⁷ Human Fertilisation and Embryology Act 1990 (amended by the Human Fertilisation and Embryology Act 2008, Sch. 2.3. 1ZA. s. (1).

⁴⁸⁸ Abortion Act 1967 s1 (d)

children that are “deaf like them”⁴⁸⁹ or have “achondroplasia like them”⁴⁹⁰; these examples are well publicized and have resulted in public outcry.^{491,492} From a sociological standpoint, it is well founded that parents have a preference for their children to be created in their image, some have even gone to the extent of describing communities with specific disability as a separate ethnic group on the grounds that they have shared customs, language and social structure.⁴⁹³ It is unsurprising therefore that such communities may wish to choose to bring to birth a child with the same condition they have as they would like him/her to experience the world in exactly the same way as them.

Whilst the patient’s wishes are paramount in a good physician-patient relationship, serious ethical objections have been raised in the application of advanced reproductive technologies for the positive selection of disabled fetuses. An intuitive, over simplified, objection finds root in the very first piece of advice offered to me in medical school, *primum non nocere*⁴⁹⁴, first of all do no harm. Medical literature is inundated with new technologies and ground breaking surgery that serves to raise the level of physical functioning of patients either born with or acquired medical ailments that hinder their degree of functioning and limit their potential. Cochlear implants for the deaf⁴⁹⁵, spinal surgery⁴⁹⁶ (to avoid paralysis) and limb lengthening⁴⁹⁷ for those with achondroplasia. The notion that medical advances can, and

⁴⁸⁹ Spriggs, M. (2002). Lesbian couple create a child who is deaf like them. *Journal of Medical Ethics*, 28(5), 283-283.

⁴⁹⁰ Braude, P. (2001). Preimplantation genetic diagnosis and embryo research-human developmental biology in clinical practice. *International Journal of Developmental Biology*, 45(3), 607-612.

⁴⁹¹ 'Choose' to Have Deaf Baby, BBC News (Apr.8, 2002) <http://news.bbc.co.uk/1/hi/health/1916462.stm> accessed 5/12/15

⁴⁹² Aviles, S. (2012). Do You Hear What I Hear: The Right of Prospective Parents to Use PGD to Intentionally Implant an Embryo Containing the Gene for Deafness. *William and Mary Journal of Women and the Law*. 19, 137.

⁴⁹³ Lane, H. (2005). Ethnicity, ethics, and the deaf-world. *Journal of Deaf Studies and Deaf Education*, 10(3), 291-310.

⁴⁹⁴ Smith, C. M. (2005). Origin and uses of *primum non nocere*—above all, do no harm! *The Journal of Clinical Pharmacology*, 45(4), 371-377.

⁴⁹⁵ Bond, M., Mealing, S., Anderson, R., Elston, J., Weiner, G., Taylor, R.S., Hoyle, M., Liu, Z., Price, A. and Stein, K., (2009). The effectiveness and cost-effectiveness of cochlear implants for severe to profound deafness in children and adults: a systematic review and economic model. *Health technology assessment*, 13(44), 1-330.

⁴⁹⁶ Thomeer, R. T., and van Dijk, J. M. C. (2002). Surgical treatment of lumbar stenosis in achondroplasia. *Journal of Neurosurgery: Spine*, 96(3), 292-297

⁴⁹⁷ Schiedel, F., and Rödl, R. (2012). Lower limb lengthening in patients with disproportionate short stature with achondroplasia: a systematic review of the last 20 years. *Disability and rehabilitation*, 34(12), 982-987.

have been used to create children with the very disabilities that the medical world has vested so much in trying to cure or improve in order to appease parental preference alone is a counterintuitive one and has been looked through the ethical microscope by the HFEA.⁴⁹⁸ Although a full review of arguments in favour and against such practice is beyond the scope of this paper I will expand on the welfare of the child provision, which is core to the HFEA's reasoning in limiting such procreative liberties.

The Welfare of the Child Provision

In trying to better regulate the practices in fertility clinics in England and Wales the Human Fertilization and Embryology Authority has adapted the Welfare Principle from criminal and family law. In brief the principle dictates that the courts take in to consideration the welfare of the child in situations whereby the courts decision may affect that child's interests. The principle permeates through numerous Acts (and their subsequent amendments), namely the Adoption Act 1976⁴⁹⁹, the Child Support Act 1991⁵⁰⁰ and the Children Act 1989,⁵⁰¹ the latter defining it as such:

“When a court determines any question with respect to (a) the upbringing of a child; or (b) the administration of a child's property or the application of any income arising from it, the child's welfare shall be the court's paramount consideration”.⁵⁰²

Whilst the initial HFE Act in 1990 was less prescriptive and directive as to how the welfare provision should influence treatments by fertility clinics, leaving its directive open to interpretation:

“A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of treatment... and of any child who may be affected by the birth”.⁵⁰³

⁴⁹⁸ For a thorough analysis see Lee, E.J. *Designer Babies: Where Should We Draw the Line?* (2002) Hodder Arnold,

⁴⁹⁹ Adoption Act 1976

⁵⁰⁰ Child Support Act 1991

⁵⁰¹ Children Act 1989

⁵⁰² Children Act 1989 s.1 (1)

⁵⁰³ HFEA 1990 s.13 (5)

The 2008 amendments are firmer and more explicit allowing much less abuse and commercial mis-application of advanced reproductive technologies by fertility clinics:

“... the center should consider factors... likely to cause serious physical, psychological or medical harm, either to the child to be born or to any existing child of the family. These factors include...any aspect of the patient’s (or where applicable their partner’s) medical history which means that the child to be born is likely to suffer from a serious medical condition”.⁵⁰⁴

Whilst there is no consensus within the HFE Act or Code of Practice as to what constitutes serious harm, it seems reasonable to argue that the purposeful selection and preimplantation of embryos with a genetic disorder could constitute serious harm and thus violate the welfare provision, making it unlawful practice.

Similar safeguards against the production of embryos with various genetic conditions exists within the HFEA code of practice prohibiting the donation of gametes from those known to be affected by genetic disease or be carriers of “deleterious recessively inherited”⁵⁰⁵ genes. The codes of practice further advocate that based on phenotype, past medical or family history, if a couple has a significant probability to transmit a genetic condition to their future child then “ all reasonable steps should be taken to prevent the transmission of serious genetic disorders”.⁵⁰⁶

Whilst the application of the Welfare Principle allowed some leeway to fertility clinics as to what constitutes serious harm was in part open to interpretation, the HFE Act amendments in 2008 provide an extensive list of the accepted purposes of preimplantation genetic diagnosis and gamete donation making the legal selection of a foetus with a known disability almost impossible:

“...persons or embryos that are known to have a gene, a chromosome or mitochondrion abnormality involving a significant risk that the person with the abnormality will have or develop (a) serious physical or mental disability, (b) a serious illness or (c) any other serious medical condition must not be preferred to those that are not known to have such an

⁵⁰⁴ HFEA “code of practice 7th edition London: HFEA 2008 para G 3.3.2

⁵⁰⁵ HFEA Code of Practice 4th Edition (London: HFEA, 1998) para3.59-3.60

⁵⁰⁶ HFEA Code of Practice 6th Edition (London, HFEA 2003) para 4.10

abnormality.”⁵⁰⁷

By limiting the positive selection of disabled embryos and by extension disabled children or children with genetic ailments the HFEA indicates that it is increasingly more concerned in the application of reproductive technologies and subsequent screening for what they were initially designed for, to help infertile couples and to allow the production of healthier children. Regulating what qualities the implantable gametes or embryos possess within the assisted reproductive technology setting is unique. It is unique in that (for good reason) no extrinsic legal limitations exist on parents wishing to procreate in the conventional way, there are no quality checks the embryo needs to pass before it is signed off as being free from genetic disease, and yet legal limitations protecting foetuses from genetic disease exist if a couple wants to procreate with the assistance of reproductive technologies.

How the law is changing to offer the foetus more protection.

In English law courts generally hold that a foetuses need for medical treatment does not supersede maternal autonomy. Mothers-to-be can decline therapy or *in utero* treatment even if it is at their own risk and at the jeopardy of the foetus. For example in *St George's Healthcare NHS Trust v S; R v Collins and Ors, ex parte S*⁵⁰⁸ the court held a trespass to the person when obstetricians performed a Caeserean section against the patients' will, on the grounds that the mother was diagnosed with severe pre-eclampsia, a condition known to cause severe repercussions on both mother and child^{509,510}

There are signs that the tides are changing globally and the law both in the U.K and the U.S is beginning to afford more legal protection to the foetus (irrespective of the mode of conception).

In England and Wales, Child Destruction is the crime of killing an unborn and viable foetus, a foetus before it's "separate existence".⁵¹¹ Child destruction charges are uncommon but

⁵⁰⁷ HFEA 1990 (as amended in 2008) s.13 (8.9)

⁵⁰⁸ *St George's Healthcare NHS Trust v S; R v Collins and Ors, ex parte S* (1998) 3 All ER

⁵⁰⁹ de Souza Rugolo, L. M. S., Bentlin, M. R., and Trindade, C. E. P. (2011). Preeclampsia: effect on the fetus and newborn. *Neoreviews*, 12(4), e198-e206.

⁵¹⁰ Voto, L. S., Lapidus, A. M., and Margulies, M. (1999). Effects of preeclampsia on the mother, fetus and child. In *Gynaecology forum* (Vol. 4, pp. 25-27).

⁵¹¹ Knight, B. (1998). *Lawyers Guide to Forensic Medicine*. Routledge.p 70

since 2007 there have been three reported charges. *R v Maisha Mohammed*⁵¹² saw the first reported criminal conviction of a woman for the offence of child destruction for the destruction of her own unborn child at 34 weeks gestation. In 2012 in *R v Carl Anthony Whant*⁵¹³ there was a successful conviction of murder and child destruction of a man who murdered his 8-month pregnant partner. The CPS statement on the case admitted that “Child destruction is...a very rarely used charge (and that the courts were) not aware of another case like this one in Wales” highlighting also the importance of marking the death of the unborn child with a separate charge.⁵¹⁴ More recently in December 2015, two men were found guilty of Child Destruction charges at the Old Bailey for attacking a 32-week pregnant woman causing her to miscarry.⁵¹⁵

US courts have been more vociferous in their attempts to protect the foetus in some guise, most often in an attempt to restrain mothers-to-be from risk taking behaviour such as taking glue, sniffing cocaine and methamphetamine consumption.⁵¹⁶ According to one journalist “Since the late 1980’s, . . . at least 200 women in more than 30 states have been prosecuted for behaviour while pregnant that posed danger to their foetuses.”⁵¹⁷ An early, much publicised case was *Johnson V. State*, 578 So.2d 419, 420. (Fla. 5th DCA 1991)⁵¹⁸, whereby Jennifer Johnson was sentenced to prison for delivering cocaine to her newborn child on the grounds that she had cocaine detected in her blood shortly prior to delivery.

In 2006 Chemical endangerment laws were introduced in the State of Alabama.⁵¹⁹ The charge refers to the crime of exposing a child to a controlled substance or the environment in which that substance is produced or distributed. Its addition to the Alabama legal code in 2006, was done with a scope of affording legal protection to children exposed to methamphetamine fumes. To be charged with chemical endangerment of a child, a person must "knowingly,

⁵¹² *R v Maisha Mohammed Manchester (2007)*

⁵¹³ *R v Carl Anthony Whant [2012] EWCA Crim 2457*

⁵¹⁴ www.cps.gov.uk/news/latest_news/cps_statement_on_carl_whant_conviction/ accessed 22/9/2015

⁵¹⁵ Man guilty of killing unborn baby by kicking mum's stomach <http://www.bbc.co.uk/news/uk-england-35125394> accessed 21/12/2015

⁵¹⁶ Gallagher, J. 'Collective Bad Faith: "Protecting" the Fetus', in Callahan, J. C. (1995). *Reproduction, ethics, and the law: feminist perspectives*. Indiana University Press. P 343-355)

⁵¹⁷ Terry D. (1996) In Wisconsin, a Rarity of a Fetal-Harm Case, *New York Times*, Aug.17, <http://www.nytimes.com/1996/08/17/us/in-wisconsin-a-rarity-of-a-fetal-harm-case.html> Accessed 12/09/2014

⁵¹⁸ *Johnson V. State*, 578 So.2d 419, 420. (Fla. 5th DCA 1991)

⁵¹⁹ Code of Alabama 26-15-3.2. Chemical endangerment of child.

recklessly, or intentionally cause or permit a child to be exposed to, to ingest or inhale, or to have contact with a controlled substance, chemical substance, or drug paraphernalia.”⁵²⁰

In its original phrasing, the law did not specify the inclusion of fetuses; prosecutors have increasingly, however, argued that the term "environment" should extend to include the *in utero* environment, and that by extension the definition of "a child" should also encompass unborn children leading to a rise in child endangerment charges brought to new mothers. An estimated 60 cases were prosecuted between 2006 and 2012.⁵²¹

Increased legal protection of the foetus is also seen in a controversial new law passed in 2014 in Tennessee, affording the unborn similar safeguards as those of chemical endangerment discussed above. As enacted the law provides that a woman may be prosecuted for assault for the illegal use of narcotics while pregnant if the child is born addicted or harmed by the said narcotic.⁵²² The first woman to be charged and prosecuted for the offence was Mallory Loyola who admitted to taking methamphetamines three days prior to delivery; her newborn tested positive for the substance.⁵²³

The signing of the Unborn Victims of Violence Act in 2004 saw an upsurge in criminal charges against mothers partaking in risk taking behaviour antenatally, signifying that fetuses were merited further legal protection. The Act allowed the recognition of the foetus as a legal victim in the U.S if it is injured or killed during the commission of any of 68 existing federal crimes of violence. Of the 38 States that recognise foetal homicide as a crime, the majority apply the principle throughout gestation, whereas a minority of States afford such protections at various different stages of foetal development, which vary from State to State.⁵²⁴

Foetal homicide laws, have since 2004 been increasingly used to prosecute pregnant women that either intentionally or through reckless behaviour damage the foetus leading to a miscarriage or a stillbirth. In 2006 for instance, the State of Mississippi charged Rennie Gibbs with murder for damaging her unborn child *in utero* by taking cocaine whilst being pregnant,

⁵²⁰ Code of Alabama 26-15-3.2. Chemical endangerment of child.

⁵²¹ Calhoun A. (2012). "The Criminalization of Bad Mothers". *The New York Times Magazine* 25th of April http://www.nytimes.com/2012/04/29/magazine/the-criminalization-of-bad-mothers.html?_r=0 accessed 21/12/2015

⁵²² Tennessee Code Annotated, Title 39 www.tn.gov/sos/acts/108/pub/pc0820.pdf accessed 23/09/2015

⁵²³ www.abnews.com/US/woman-charged-controversial-law-criminalizes-drug-pregnancy/story?id=24542754 Accessed 21/12/2015

⁵²⁴ Pedone, J. (2009). Filling the Void: Model Legislation for Fetal Homicide Crimes. *Columbia Journal of Law and Social Problems* 43, 77-116

an addiction that led to a stillbirth. The charges were later dismissed. 2011 saw the Indiana authorities charge Bei Bei Shuai, with murder and foeticide after her suicide attempt was unsuccessful but directly contributed to the death of her unborn child; Shuai eventually pleaded guilty to a criminal recklessness and was released, having been sentenced to time served.⁵²⁵ More recently, in 2015 Purvi Patel became the first woman in the United States to be charged, convicted, and sentenced on a foeticide charge. She had allegedly consumed abortifacient medications that led to a stillbirth of a foetus that would have otherwise been born alive. An appeal has been filed by the defence since the conviction, the outcome of which is pending at the time of writing.⁵²⁶

These early indications that foetuses are better protected by the law both in England and Wales as well as the U.S, in conjunction with the HFEA's prohibition for disability selection raises numerous ethical questions. It is beyond the remit of this paper to answer them all, nor do I attempt to elaborate whether criminal law is the appropriate way to legislate to ensure foetal protection. In view of what foetal surgery and *in utero* gene therapies are likely to be able to deliver in future, I shall address whether, in-keeping with the 2008 HFEA amendments prohibiting the implantation of gametes with known parental genetic defects and "deliberately screening in a disease or disorder",⁵²⁷ there might in future be a further imperative for public promotion of such practice by the HFEA. It could be argued that not engaging with such technologies may fail to positively influence the health of the foetus in a way that it improves its welfare, and hence once born may constitute serious harm and a violation of the welfare provision. We can only argue this with any conviction provided these conditions are met: the embryo has a disorder that can be repaired *in utero*, the parents-to-be are planning to have that very child and that foetal surgery (or other advanced reproductive *in utero* interventions) outcomes are better and safer on both mother-to-be and child to be.

⁵²⁵ *Bei Bei Shuai v. State*, 966 N.E.2d 619 (Ind. Ct. App. 2012).

⁵²⁶ Dyer, O. (2015). Woman is sentenced to 20 years in prison for feticide after death of baby. *British Medical Journal* 350, h1895.

⁵²⁷ Department of Health "Review of the Human Fertilisation and Embryology Act: Proposals for Revised Legislation London : The Stationary Office, 2006 s2.43

What conditions must be met for the State to justify promotion of *in utero* therapies in future?

Legislating against both the positive selection of an embryo with a genetic disorder or disability, and antenatal harm caused to the foetus by the mother (or a third party) places limitations on the degree of parental self-control. This self-control may relate (not exhaustively) to addiction, substance misuse, risk taking behavior, a misguided volition for creating a disabled infant or mere whimsy. Legislating to promote the uptake (and even in some situations to enforce) foetal surgery upon mothers-to-be would involve imposing an invasive, surgical procedure on a person in the interests of the unborn.

Similarities with such legislation can be drawn with laws relating to involuntary caesarean sections or involuntary blood transfusions. In 2012 for example, *Re AA (Mental Capacity: Enforced Caesarean)* (2012) EWHC 4378 (COP) Alessandra Pachierri^{528,529} was given the diagnosis of a schizophrenic disorder; she came to Britain whilst 39 weeks pregnant to attend a training course. After she stopped taking medication she suffered a panic attack and was sectioned under the Mental Health Act. The court of protection gave the Mid-Essex NHS Trust permission to subject her to a caesarean section; the newborn child was taken into care by Essex social services and has since been adopted.⁵³⁰ This is of course a Mental Health Act issue whereby the mother was deemed to lack capacity to consent to treatment both by the medical team and the courts, and that was used as the grounds for the ruling to allow for an enforced caesarean section. Since the landmark case of *St George's Healthcare NHS Trust v S* (1998)⁵³¹ the legal mandate in the UK has been clear that “(An unborn child’s) need for medical assistance does not prevail over (the mother’s) rights. She is entitled not to be forced to submit to an invasion of her body against her will, whether her own life or that of her unborn child depends on it.”⁵³²

⁵²⁸ Dyer, C. (2013). Court approved caesarean section for mentally ill woman because of two previous caesareans. *British Medical Journal*, 347.

⁵²⁹ *Re AA (Mental Capacity: Enforced Caesarean)* (2012) EWHC 4378 (COP)

⁵³⁰ Baby in Alessandra Pacchieri forced caesarean case adopted 15/04/2014 <http://www.theguardian.com/uk-news/2014/apr/15/pacchieri-baby-adopted-forced-caesarean-case-uk> accessed 23/09/2015

⁵³¹ *St George's Healthcare NHS Trust v S; R. v Collins, ex parte S* (1998) 3 All ER 673.

⁵³² *ibid.*

Similarly in the U.S, since 1980, there are over half a century of cases with reported court ordered caesarean sections⁵³³ and until the early 1990's most applications made to the courts for involuntary treatments in the interests of the foetus have been successful.⁵³⁴

The trident of the legal, medical and bioethical academic worlds have raised serious concerns about non-voluntary medical treatment in pregnancy. The Royal College of Obstetrics and Gynaecology for instance stipulate "Obstetricians must respect the woman's legal liberty to ignore or reject professional advice, even to her own detriment or that of her foetus"⁵³⁵, whilst in a similar vein the courts of appeal in *Re MB (Medical Treatment)* stated that: "The law is, in our judgement, clear that a competent woman who has the capacity to decide may, for religious reasons, other reasons or no reasons at all, choose not to have medical intervention even though the consequence may be the death or serious handicap of the child or her own death"⁵³⁶. The primary ethical objections to this particular foetal-maternal conflict that form the foundations of these policy and legal stances are based around safeguarding of maternal autonomy and respect for individual freedom and a woman's right related right to bodily integrity.⁵³⁷

Academic literature suggests that pregnant women are under considerable social pressures to undergo prenatal screening and diagnosis.⁵³⁸ It may be argued that such social pressures frustrate women's autonomy and may be seen as a form of coercion. There is evidence that women who agree to partake in HIV antenatal testing for example, do so as a knee jerk reaction to a recommendation or request made by a physician.⁵³⁹ Another study identified the

⁵³³ Robertson, J. A. (1996). *Children of choice: Freedom and the new reproductive technologies*. Princeton University Press. p. 87.

⁵³⁴ Kolder, V. E., Gallagher, J., and Parsons, M. T. (1988). Court-ordered obstetrical interventions. *Obstetrical and Gynecological Survey*, 43(1), 41-43.

⁵³⁵ Royal College of Obstetricians and Gynaecologists Ethics Committee(1994) A Consideration of the Law and Ethics in Relation to Court Authorised Obstetric Intervention p. 14.

⁵³⁶ *Re MB (Adult, medical treatment) (1997) 38 BMLR 175 CA* quoted from Jones RS Jenkins R (2004) *The Law and the Midwife* Second ed. Blackwell p116-117

⁵³⁷ Hornstra, D. (1998). A Realistic Approach to Maternal-Fetal Conflict. *Hastings Center Report*, 28(5), 7-12.

⁵³⁸ Ford N.(2002) *The Prenatal Person: Ethics from Conception to Birth* Wiley-Blackwell p134

⁵³⁹ de Zulueta, P., and Boulton, M. (2007). Routine antenatal HIV testing: the responses and perceptions of pregnant women and the viability of informed consent. A qualitative study. *Journal of medical ethics*, 33(6), 329-336.

commonest reasons why women undergo prenatal screening tests for Down syndrome;⁵⁴⁰ in order of frequency these were firstly an assumption that the test offered was routine antenatal procedure, secondly avoidance of giving birth to a child with Down Syndrome, and finally a trust in modern technology and medical authorities. Further evidence of the pressures that women are under to uptake antenatal tests offered to them can be found in literature criticizing the advertising of pro-screening campaigns by local healthcare authorities. Such campaigns having been criticized as being coercive and not in keeping with the spirit of patient autonomy.⁵⁴¹

I argue that in future, if antenatally acquired information reveals a treatable disability that the State has a strong imperative to promote foetal surgery for the disability to be repaired on three conditions:

- a) The parents have every intention of carrying the pregnancy to term.
- b) Foetal surgery is safe to both foetus and mother with good post surgical outcomes.
- c) Unless repaired *in utero* the disability can severely affect the eventual child's welfare.

I will now explain why these conditions are so important and lead to the conclusion that fetal surgery should be promoted where such conditions exist.

a) The provision that parents have the intention of carrying the pregnancy to term (and the causation of actual harm)

When it comes to trying to ascribe harm incurred *in utero* to a future child *that will be brought to birth* (as opposed to one that will be replaced by another or aborted) comparative accounts of harm are applicable and philosophically more sound. Whilst non-comparative arguments hold that to suffer harm is to *just be* in a bad state,⁵⁴² comparative accounts rely on a comparison between the projected health of the very child that will result from the current

⁵⁴⁰ Chiang, H. H., Chao, Y. Y., and Yuh, Y. S. (2006). Informed choice of pregnant women in prenatal screening tests for Down's syndrome. *Journal of medical ethics*, 32(5), 273-277.

⁵⁴¹ Flessel, M. C., and Lorey, F. W. (2011). The California Prenatal Screening Program: "options and choices" not "coercion and eugenics". *Genetics in Medicine*, 13(8), 711-713.

⁵⁴² For different accounts of non-comparative harm see Shiffrin, S. V. (1999). Wrongful life, procreative responsibility, and the significance of harm. *Legal Theory*, 5(02), 117-148.p. 124. , Harris, J. (1992). *Wonderwoman and Superman: the ethics of human biotechnology*. Oxford University Press p. 88 and Harman E, (2009) Harming as Causing Harm. in Roberts M. A. and Wasserman D. T. (eds.), (2009) *Harming Future Persons: Ethics, Genetics and the Non-identity Problem* Springer, p. 149.

gestation. This assumes a biological continuity⁵⁴³ that cannot be afforded by the non-comparative accounts; it is impossible to compare harm in a specific child if that specific (resulting) child never comes to exist or is replaced by a different (resulting) child. Harm can therefore be defined as:

Harm: *b is harmed when b's interests have been stymied or failed to be changed in a positive manner improved by an action or omission as such that b is worse off than he would have otherwise been had a not occurred and some other action or omission taken place instead.*⁵⁴⁴

The very same foetus (i.e. excluding the possibility of choosing the healthiest out of a number of foetuses) can in many cases have two possible phenotypes depending on parental behavior, genotype and treatment options; a phenotype of crippling, life limiting disability or that of a healthier child. I argue that it makes clear sense to view an act or omission that amounts to the former over the latter as amounting to harm. If we can chose the same child to be born in a healthier state as a direct result of something we do (e.g. take folic acid)⁵⁴⁵ or do not do (e.g. smoke),⁵⁴⁶ provided what we do or do not do is effective and safe to us and the child to be, then surely not acting in a way that benefits the eventual child constitutes a harm.

b) The provision that foetal surgery and *in utero* gene therapy will be safe to both foetus and mother with good post surgical outcomes.

At the time of writing foetal surgery is an evolving speciality but results have mixed outcomes with considerable risk to mother and foetus.⁵⁴⁷ *In utero* stem cell and gene therapy has had some success in lab animals but not humans. Somatic gene delivery *in utero* is a new approach to gene therapy for genetic disease. The practice assumes that prenatal intervention may avoid the development of severe manifestations of early-onset disease, allow targeting of otherwise inaccessible tissues and induce tolerance against the therapeutic transgenic

⁵⁴³ See Olson, E. T. (1999). *The human animal: Personal identity without psychology* Oxford University Press, pp.125-153.

⁵⁴⁴ This is a modified version of Feinberg's account of harm; see Feinberg, J. (1986). Wrongful life and the counterfactual element in harming. *Social Philosophy and Policy*, 4(01), 145-178. pp. 148-150

⁵⁴⁵ Scholl, T. O., and Johnson, W. G. (2000). Folic acid: influence on the outcome of pregnancy. *The American journal of clinical nutrition*, 71(5), 1295s-1303s.

⁵⁴⁶ Luciano, A., Bolognani, M., Biondani, P., Ghizzi, C., Zoppi, G., and Signori, E. (1998). The influence of maternal passive and light active smoking on intrauterine growth and body composition of the newborn. *European journal of clinical nutrition*, 52(10), 760-763.

⁵⁴⁷ Willyard, C. (2008). Tinkering in the womb: the future of fetal surgery. *Nature medicine*, 14(11), 1176-1177.

protein. This in turn provides permanent somatic gene correction.^{548,549} *In utero* gene therapy trials have been performed on mice and sheep foetuses and long term therapeutic effects on Crigler Najjar Disease, Leber's congenital amaurosis, Pompe's disease and haemophilia B have thus far been noted. The surgical risks in such therapies are in theory much reduced compared to conventional foetal surgery as the vector proteins are introduced with minimally invasive ultrasound and vector technologies; unfortunately much higher incidence of liver tumours in the mammalian foetuses have been reported.⁵⁵⁰ If and only if a specific *in utero* procedure can be deemed safe and successful enough, with good clinical outcomes for both mother and (eventual) child, can there be an imperative by the State to promote such clinical practice. As our objective is to avoid harm, it is self evident that we need to have clinical evidence and by extension clinical confidence that these procedures are likely to improve welfare, not cause more harm.

c) The provision that unless repaired *in utero* the disability can severely affect the eventual child's welfare.

Currently there is discordance amongst the medical profession as to which anatomical abnormality is severe enough to justify placing mother and child under such risk.⁵⁵¹ There is no universal agreement as to what criteria should be fulfilled in order to aid physicians to differentiate whether foetal syndrome X is more or less severe than foetal syndrome Y. Such deductions can only be reached by extrapolating guidance from various classifications of disability (which I discuss later in the paper) and with the help of clinical paediatric geneticists. For all the HFEA's amendments in 2008, the new code of practice has faced

⁵⁴⁸ Coutelle, C., Themis, M., Waddington, S., Gregory, L., Nivsarkar, M., Buckley, S., Cook, T., Rodeck, C., Peebles, D. and David, A. (2003). The hopes and fears of in utero gene therapy for genetic disease—a review. *Placenta*, 24, S114-S121.

⁵⁴⁹ McClain, L. E., and Flake, A. W. (2015). *In utero* stem cell transplantation and gene therapy: Recent progress and the potential for clinical application. *Best Practice and Research Clinical Obstetrics and Gynaecology*.

⁵⁵⁰ Coutelle, C., Themis, M., Waddington, S.N., Buckley, S.M.K., Gregory, L.G., Nivsarkar, M.S., David, A.L., Peebles, D., Weisz, B. and Rodeck, C. (2005). Gene therapy progress and prospects: fetal gene therapy—first proofs of concept—some adverse effects. *Gene therapy*, 12(22), 1601-1607.

⁵⁵¹ Willyard *C op cit*

criticism that the term “serious harm” is too open to interpretation.⁵⁵² In the amended 2008 code of practice the welfare principle is core to the guidance below.⁵⁵³

The centre should consider the following factors when deciding if PGD is appropriate in particular cases:

- (a) The views of the people seeking treatment in relation to the condition to be avoided, including their previous reproductive experience
- (b) The likely degree of suffering associated with the condition
- (c) The availability of effective therapy, now and in the future
- (d) The speed of degeneration in progressive disorders
- (e) The extent of any intellectual impairment
- (f) The social support available, and
- (g) The family circumstances of the people seeking treatment.

Although I do not aim to conjure up an exhaustive list of what conditions meet the criteria of constituting serious harm to the foetus, a cogent case can be made, based on my personal clinical experience of what types of conditions we should strive to find antenatal cures for. Rapid, neurodegenerative conditions whereby the child has little to no higher function and is destined to have a short life, most of which is supported within a hospital setting with numerous surgical interventions such as percutaneous entero-gastric tubes for feeding (to aid nutrition due to unsafe swallowing), surgically inserted intravenous lines (to enable long term intravenous access - often seen as less painful than numerous venepuncture attempts) and surgical tracheostomy insertion (to enable breathing due to a floppy tongue and a poor upper airway control) are the type of conditions whereby we can say that should there be an *in utero* cure, then the child has been seriously harmed by being deprived of it antenatally.

A prime example is postnatal care of spina bifida (the most common congenital malformation of the central nervous system). The main focus in treatment after birth is on palliation of the existing neurological damage rather than reversing it. Part of this limitation of postnatal care results from the deleterious effects that the *in utero* environment has on the neural elements. A recent prospective randomized multicenter trial showed that *in utero*

⁵⁵² See for example McLean, S. A., and Elliston, S. (Eds.). (2012). *Regulating pre-implantation genetic diagnosis: a comparative and theoretical analysis*. Routledge.p109-117

⁵⁵³ HFEA 8th Code of Practice 2008 10.7

repair significantly helps preserve neurological function, reverses hindbrain herniation and decreases the need for surgical ventricular shunting to alleviate hydrocephalus.⁵⁵⁴ It is evident that these type of disabilities are severe, and if the outcomes of *in utero* therapies are much better there is a solid argument to be made that harm befalls the eventual child if they are denied such treatments.

What magnitude of harm must befall the eventual child before birth to justify State intervention or coercion?

John Stuart Mill states that causing harm to others is a necessary condition to justify State intervention in a person's life, but it is not sufficient in itself to do so: "It must by no means be supposed that because damage or probability of damage, to the interests of others, can alone justify the interference of society, that it always does justify such interference"⁵⁵⁵.

When can the State justify the imposition of an antenatal intervention X on mother-to-be M to prevent harm to the eventual child C? In public policy, when the imposition on the individual is small (such as not smoking in an enclosed public space) and the harm to others may be big (such as second hand smoking and all the health sequelae associated with it) it may seem prudent and even morally important that we require the State to prevent this harm. If we regard respect for individual autonomy and enabling individuals to have control over their lives as important, then protecting others from harm is analogously important, as to do otherwise would imply disrespect towards their ability to have control over their lives. Similarly, if the personal cost and effort in engaging in a specific activity is nominal (such as picking up our dogs' mess) and the potential preventable harm to others is sizeable (hygiene, various zoonoses etc.) then the State may legislate accordingly to promote the uptake of the said activity. An instance of the application of this within a healthcare policy is for example the minor imposition of hand washing before and after contact with different patients upon healthcare workers. The correct hand washing technique is imprinted in their memories during the induction process at the new workplace, there are yearly compulsory refresher sessions and every corridor, and ward; hospital toilets have posters reminding them to carry

⁵⁵⁴ Adzick, N.S., Thom, E.A., Spong, C.Y., Brock III, J.W., Burrows, P.K., Johnson, M.P., Howell, L.J., Farrell, J.A., Dabrowiak, M.E., Sutton, L.N. and Gupta, N., (2011). A randomized trial of prenatal versus postnatal repair of myelomeningocele. *New England Journal of Medicine*, 364(11), 993-1004.

⁵⁵⁵ Mill, J. S. (1884). *Principles of political economy*. Appleton.p150

out this very simple duty. This is a basic and nominal infringement on their personal autonomy but is one of proven immense clinical benefit and significance and it reduces cross-infection and by extension morbidity and mortality of patients.⁵⁵⁶ Such an imposition is so easy to adhere to and the benefits so significant that it led to the introduction of a nationwide “Clean your Hands” campaign to promote hand washing, which has resulted in much lower death rates caused by cross infection.⁵⁵⁷

If we accept these paradigms then it seems that for X to be justifiably imposed by the State, then the harm to C must be significant. As Mill dictates above, this is not in itself enough for a State intervention. The State cannot expect a pregnant woman to give up her life entirely in the interests of a future child. One could also argue that if we believe that the State should have such expectations of pregnant women, then these expectations should extend to all women of fertile age as there is considerable evidence showing that healthy mothers give rise to healthier babies.⁵⁵⁸ There are for example cases where a mother needs to act in a way that may predictably damage the foetus. Epileptic mothers-to-be for example may only be sensitive to sodium valproate, an epileptic drug that has teratogenic effects on the foetus and can cause anatomical abnormalities and severe developmental delay as part of the spectrum of foetal valproate syndrome.⁵⁵⁹ If however there is an alternative effective non-teratogenic anti-epileptic therapy that the woman knows of and declines to take then the eventual child, and the State may have good reason to be aggrieved. In a myriad of possible scenarios and permutations pertaining to maternal and foetal health, one thing is certain; that the severity of harm sustained to either the mother or eventual child is relevant in ascertaining the appropriateness of a State intervention in any given situation; i.e. it is not unreasonable to posit that the greater the magnitude of the potential harm the greater the incentive for a State intervention to prevent the said harm. Savulescu alludes to three possible ways of describing

⁵⁵⁶ Pittet, D., Hugonnet, S., Harbarth, S., Mourouga, P., Sauvan, V., Touveneau, S., and Perneger, T. V. (2000). Effectiveness of a hospital-wide programme to improve compliance with hand hygiene. *The Lancet*, 356(9238), 1307-1312.

⁵⁵⁷ Gould, D. J., Hewitt-Taylor, J., Drey, N. S., Gammon, J., Chudleigh, J., and Weinberg, J. R. (2007). The Clean Your Hands Campaign: critiquing policy and evidence base. *Journal of Hospital Infection*, 65(2), 95-101.

⁵⁵⁸ See for example Atrash, H. K., Johnson, K., Adams, M. M., Cordero, J. F., and Howse, J. (2006). Preconception care for improving perinatal outcomes: the time to act. *Maternal and child health journal*, 10(1), 3-11.

⁵⁵⁹ Clayton-Smith, J., and Donnai, D. (1995). Fetal valproate syndrome. *Journal of Medical Genetics*, 32(9), 724.

the magnitude of harm in such settings,⁵⁶⁰ the threshold view, the maximizing view and the benefit view. These views merit some consideration if we are to attempt to find which one is most applicable in our quest to ascertain how to best measure harm incurred in the antenatal setting.

a) The Maximizing View: This view requires that the harm to M is less than that to C to justify an intervention. This view is too restrictive in a liberal society to be acceptable as a blueprint for social policy; it places too little value on parental autonomy and individual liberties. Under this view for example the State could imprison someone for nine months to preclude them from any risk taking behavior, simply because this would allow for (in theory) a healthier foetus and child.

b) The Threshold View: The harm to M is below some empirical threshold value. The view has two variants according to Savulescu,⁵⁶¹ the net harm or the single harm variants. On applying these two versions on real clinical events⁵⁶²; the former view would allow a physician to transfuse a Jehovah's Witness in labour who has had a life threatening placental abruption, as she will die without it. Her deeply held belief that she would rather die than receive blood is trumped, this amounts to a small harm; M and C's lives have been saved by the intervention so net harm has been avoided. The single harm variant places much greater weight on personal beliefs and less weight on any offsetting benefits. The theory dictates that it is only justifiable to inflict one harm to a person up to a certain threshold, despite any foreseeable benefits that may be incurred. Applying this view would morally permit the death of the Jehovah's Witness mother, as according to her beliefs being transfused is a far worse affliction than death.

c) The Benefit View: The harm to M is balanced by a benefit to M, so whilst an intervention might harm M in some way the way in which she profits by the intervention amounts to net benefit for both M and C. This view is the one most adhered to in US and English law to justify the authorization of enforced caesarean sections as the decision to grant such court

⁵⁶⁰ Savulescu, J. (2007). Future people, involuntary medical treatment in pregnancy and the duty of easy rescue. *Utilitas*, 19(01), 1-20.

⁵⁶¹ Savulescu *op cit* p 10

⁵⁶² Graffeo, C., and Dishong, W. (2013). Severe blood loss anemia in a Jehovah's Witness treated with adjunctive hyperbaric oxygen therapy. *The American journal of emergency medicine*, 31(4), 756-e3.

order was thought to be in the collective best interest of both mother and foetus.⁵⁶³ This view casts no assertions on how big the harm to the mother or eventual child needs to be before we can justify a State intervention. A forced intervention to avoid a nominal harm would, on this view be permitted, but in a liberal society such practice cannot be adhered to, the harm, in my opinion needs to be substantial in order for State intervention to be justified.

I opine that the net harm variant threshold view is the most relevant in justifying a State intervention. The reason for this is simply that avoidance of net harm is a larger scale version of individual physician's duties of non-maleficence, so a collective prevention harm is in-keeping with the principle of *primum non nocere*⁵⁶⁴ found in ethical decision making in everyday medical practice; a principle whose virtues are self-evident. Although I accept that the above principle is a person affecting one, and some philosophers recommend the abandonment of such person affecting principles with respect to the unborn⁵⁶⁵, I argue that harm incurred in the pre-personal state is a true harm in both philosophical and medical realms on the proviso that the specific child is born.

Definitions of thresholds of harm and grading of severity of harm have been elusive in the legal context even though, as discussed above, the HFEA tried to address this issue in 2008.⁵⁶⁶ On the provision that parents have full intention of carrying a specific pregnancy to term and that the procedure the State has an interest in promoting is effective and safe on both mother and child, then a severe disability is one that significantly inhibits both their potential of flourishing⁵⁶⁷ and their open future.⁵⁶⁸

Glover argues that certain disabilities are barriers to flourishing, because they hinder "safe navigation through the world," and sufferers fail to perceive "a whole dimension of enriching

⁵⁶³ For more in depth analysis of such cases see Weaver J. (2002) Court-Ordered Caesarean Sections ≈ Chapter 13 Bainham, A., Sclater, S. D., and Richards, M. (Eds.). (2002). *Body Lore and Laws: Essays on Law and the Human Body*. Bloomsbury Publishing p229 -247

⁵⁶⁴ Gillon, R. (1985). "Primum non nocere" and the principle of non-maleficence. *British medical journal (Clinical research ed.)*, 291(6488), 130-131.

⁵⁶⁵ See for example Brock, D. W. (1995). The non-identity problem and genetic harms—the case of wrongful handicaps. *Bioethics*, 9(3), 269-275.

⁵⁶⁶ HFEA 8th Code of Practice 2008 10.7

⁵⁶⁷ Glover, J. (2006). *Choosing children: genes, disability, and design: genes, disability, and design*. Oxford University Press, p 23

⁵⁶⁸ Feinberg J. The Child's Right to an Open Future. In Aiken W and LaFollette H.(eds.) (1980) *Whose Child?* Totowa, NJ: Rowman and Littlefield 124-53.

experience”.⁵⁶⁹ Although important, flourishing potential and scoring high enough on a quality of life scale isn’t sufficient reason to justify a State intervention. For one, quality of life accounts vary depending on the viewpoint of the person measuring the quality of life. There is even disagreement between medical professional bodies as to how disability severity ought to be defined.⁵⁷⁰ Take for example a common life limiting illness Duchenne muscular dystrophy (DMD). DMD is a recessive X-linked form of muscular dystrophy, affecting around 1 in 3,600 boys,⁵⁷¹ which results in muscle degeneration and premature death. Judgements by third parties about the standard of living with a certain condition and disability are sensitive in nature and very challenging. An example of this relating to DMD is the contrast of opinions given by the professional panel at a number of ethics discussion groups and that of the patients with DMD. Whilst calling the condition a severe disease, scientists divulged that the patients “gave their rating of quality of life the same as a healthy controlled sample. And the parents gave them the lowest quality and the clinicians gave them, somewhere between the two”.⁵⁷² Although important, quality of life assessment, that underpins Glover’s potential of flourishing argument, cannot in itself be sufficient to grade the severity of a severe disability. Which is why the child’s right to an open future should also be taken into account.

Originally explored by Feinberg, the right to an open future pertains to a set of moral rights children arguably possess that derive from the autonomy rights of adults.⁵⁷³ These rights, it is argued, protect children, or in this case future children against having important life choices decided by others before they have the ability to make them for themselves. The said right to an open future, if accepted, can be employed to assert restrictions on what parents (and others) are allowed to do to their children, and obligations as to what parents (and others) ought to provide to them with. Feinberg’s theory has been cited in numerous ethics and social

⁵⁶⁹ Glover, J. (2006). *Choosing children: genes, disability, and design: genes, disability, and design*. Oxford University Press p. 23

⁵⁷⁰ O'Donovan, M. A., and Good, A. (2010). Towards comparability of data: using the ICF to map the contrasting definitions of disability in Irish surveys and census, 2000–2006. *Disability and rehabilitation*, 32(sup1), S9-S16.

⁵⁷¹ Liew, W. K., and Kang, P. B. (2013). Recent developments in the treatment of Duchenne muscular dystrophy and spinal muscular atrophy. *Therapeutic advances in neurological disorders*, 6(3), 147-160.

⁵⁷² Scott R (2007) *Choosing Between Possible Lives: Law and Ethics of Prenatal and Preimplantation Genetic Diagnosis* Hart Publishing, p 222

⁵⁷³ See for example the analysis by Bredenoord, A. L., De Vries, M. C., and van Delden, H. (2014). The right to an open future concerning genetic information. *The American Journal of Bioethics*, 14(3), 21-23.

policy contexts varying from vaccination ethics,⁵⁷⁴ surgery ethics⁵⁷⁵ and genetic ethics.^{576,577} These “rights in trust”⁵⁷⁸ protect children from key parental decisions that the children themselves are likely to want to make when they grow up. These rights pertain to potentially harmful parental decisions such as early withdrawal from school, refusing life saving treatment (e.g. on religious grounds) or refusing medical treatment that can improve a child’s disability (e.g. refusing a cochlear implant in a deaf child). Similarly, in law, but rather for actual children rather than future children, similar rights are found in the capacity of the State to act as *parens patriae*. Cases such as *Re S*⁵⁷⁹ and *Re R*⁵⁸⁰ concerned a lack of parental consent for life saving treatment on religious grounds. The courts ruled that the children were not yet of age to have developed their own religious beliefs and the parents’ choice to decline treatment against medical advice would deprive them of a long enough life to do so.⁵⁸¹ As long as there is every intention by the parents to carry through with the specific pregnancy, similar harms can be inflicted upon the foetus and eventual child in the pre-personal state. Such harms have the potential to severely frustrate the eventual child’s right to an open future; by considerably narrowing the range of options and experiences that child will have when and if it grows up. Compare a foetus that has purposefully had the single gene whose sole function is to regulate hearing deleted *in utero* so that he/she is born deaf (whilst all his/her other characteristics remain unchanged) and the newborn who is deaf but whose parents refuse consent to restorative cochlear implants. Both entities, once they grow up may have a legitimate frustration against their parents for limiting the way in which they enjoy the world, for limiting their open future. I argue that in both cases “liberalism requires us to intervene to support that child’s future ability to make her own choices about which of the

⁵⁷⁴ Hasman, A., and Holm, S. (2004). Nicotine conjugate vaccine: is there a right to a smoking future? *Journal of medical ethics*, 30(4), 344-345.

⁵⁷⁵ Nunes, R. (2001). Ethical dimension of paediatric cochlear implantation. *Theoretical medicine and bioethics*, 22(4), 337-349.

⁵⁷⁶ Buchanan, A., Brock, D. W., Daniels, N., and Wikler, D. (2001). *From chance to choice: Genetics and justice*. Cambridge University Press. P170–175.

⁵⁷⁷ Kopelman, L. M. (2007). Using the Best Interests Standard to decide whether to test children for untreatable, late-onset genetic diseases. *Journal of Medicine and Philosophy*, 32(4), 375-394.

⁵⁷⁸ Feinberg, J. (1994). *Freedom and fulfilment: Philosophical essays*. Princeton University Press. P76-78

⁵⁷⁹ *Re S (A Minor) (Medical Treatment) (1993) 1 F.L.R 377*

⁵⁸⁰ *Re R (A Minor) (Blood Transfusion) (1993) 2 F.L.R 757*

⁵⁸¹ Heywood, R. (2012). Parents and medical professionals: conflict, cooperation, and best interests. *Medical law review*, 20(1), 29-44.

many diverse visions of life she wishes to embrace”⁵⁸².

It is evident that neither Glovers potential of flourishing dictum nor Feinberg’s open future argument in themselves suffice in determining the magnitude of foetal disability, that would allow us to apply the net harm threshold principle above so as to evaluate if it would be acceptable to advocate an antenatal State intervention.

If modified, a template of the now out-dated International Classification of Impairments, Disabilities and Handicaps⁵⁸³ (ICIDH) may be used in conjunction with the above to help apply the threshold principle in practice. The ICIDH is a structured framework for disability assessment that was endorsed by the World Health Organization. Disability was described in three dimensions Impairment, Disability and Handicap:

a) *Impairment*: In relation to health experiences an impairment is defined as any loss or abnormality of psychological, physiological or anatomical structure or function.

b) *Disability*: In relation to health experiences a disability is defined as any restriction or lack (resulting from impairment) of ability to perform an activity (or activities) in the manner or within the range considered normal for a human being.

c) *Handicap*: In relation to health experiences a handicap is defined as a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual.⁵⁸⁴

The ability of the ICIDH allows a classification of patient’s personal circumstances and provides an objective platform that can weigh disability severity that can be applied for a multitude of clinical (and non clinical) scenarios including (but not exclusively): “clinical diagnosis and rehabilitation assessment, record keeping in health and rehabilitation settings, the development of medical and rehabilitation monitoring systems, program evaluation and development, the promotion of linguistic agreement, debate and conceptual development in

⁵⁸² Davis, D. S. (2001). *Genetic dilemmas: Reproductive technology, parental choices, and children's futures*. Psychology Press. p 11

⁵⁸³ World Health Organisation (WHO). *International Classification of Impairments, Disabilities and Handicaps*. World Health Organisation: Geneva, 1980 (reprinted in 1993).

⁵⁸⁴ Van Buuren, S., and Hopman-Rock, M. (2001). Revision of the ICIDH Severity of Disabilities Scale by data linking and item response theory. *Statistics in medicine*, 20(7), 1061-1076.

the interdisciplinary field of disablement studies, development of research programs, the formulation of disability policy and the planning measures for equalisation of opportunity, data collection in survey research and database development”.⁵⁸⁵ It would not be unreasonable to extend its uses as an appropriate template on which to apply the Threshold principle to help ascertain the degree of foetal (and eventual child) disability.

A core part of the ICIDH Disability section was the Severity of Disabilities Scale (SDS). The SDS consisted of a set of seven severity codes, and was meant to mirror the extent to which an individual’s ability to perform a certain activity is restricted. (Table 1).

The benefits of applying a template akin to the SDS is that a numerical value in ascending order is used to grade disability severity, allowing for clinicians to speak the same language. The SDS was of course designed to assess and grade disabilities in existing patients and extrapolation of it to future children will prove a challenge, not least as it fails to classify the functional characteristics of developing children. Different grades may be needed in the first years of growth and development in order to give a true reflection of disability.⁵⁸⁶ Relevant to this point is the introduction of the International classification of functioning, disability and health: children and youth⁵⁸⁷ (ICF-CY) in 2007 that addresses the shifting of disability severity with maturity and progressive disease. It was a publication that supplemented the International classification of functioning (ICF) that was introduced as a direct replacement of the ICIDH in 2002.⁵⁸⁸ The ICF focuses less on disease consequences that predominates in the ICIDH, to a classification of human functioning and disability. The document is neutral with respect to aetiology of disability and pays much more weight to social and medical support available. The ICF template would be much more challenging and complex to stratify and apply in an antenatal setting. Although wealth and social support is important, it may create scenarios whereby, all things being equal, it is morally acceptable to forego *in utero* repair of spina bifida in a well-off family, but morally impermissible to do so if the family is socio-economically deprived. The main focus of any disability severity scale would therefore need to shift to measure the degree of disability in medical terms rather than base so much

⁵⁸⁵ Badley, E. M. (1993). An introduction to the concepts and classifications of the international classification of impairments, disabilities, and handicaps. *Disability and Rehabilitation*, 15(4), 161-178.

⁵⁸⁶ Ogonowski, J. A., Kronk, R. A., Rice, C. N., and Feldman, H. M. (2004). Inter-rater reliability in assigning ICF codes to children with disabilities. *Disability and rehabilitation*, 26(6), 353-361.

⁵⁸⁷ World Health Organisation (WHO). International classification of functioning, disability and health: children and youth version: ICF-CY 2007

⁵⁸⁸ World Health Organisation (WHO). Towards a Common Language for Functioning, Disability and Health: ICF The International Classification of Functioning, Disability and Health. ICF 2002

Table 1: Former severity of disabilities scale of the International Classification of Impairments, Disabilities and Handicaps⁵⁸⁹

Code	Label	Includes
0	Not disabled	No disability present (the individual can perform the activity or sustain The behaviour unaided and on his own without difficulty)
1	Difficulty in Performance	Difficulty present (the individual can perform the activity or sustain the behaviour unaided and on his own but only with difficulty)
2	Aided Performance	Aid and appliance necessary (the individual can perform the activity only with a physical aid or appliance)
3	Assisted Performance	The need for a helping hand (the individual can perform the activity or sustain the behaviour, whether augmented by aids or not, only with some assistance from another person)
4	Dependent Performance	Complete dependence on the presence of another person (the individual can perform the activity or sustain the behaviour, but only when someone is with him most of the time). Excludes: inability
5	Augmented Inability	Activity impossible to achieve other than with the help of another person, the latter needing an aid or appliance to enable him or her to provide this help (for example, the individual cannot get out of bed other than by the use of a hoist); behaviour can be sustained only in the presence of another person and in a protected environment.
6	Complete Inability	Activity or behaviour impossible to achieve or sustain (for example, an individual who is bed-bound is also unable to transfer)
8	Not Applicable	
9	Severity Unspecified	

⁵⁸⁹ World Health Organisation (WHO). International Classification of Impairments, Disabilities and Handicaps. World Health Organisation: Geneva, 1980 (reprinted in 1993).

weight on socioeconomic status and support. What is needed perhaps is a modified SDS scale that is formulated to account for the degrees of disability through growth and development of each specific condition, taking into account the potential of flourishing and an open future with and without a successful, minimally risky *in utero* procedure. Formulating such a scale would need significant work, funding and consideration albeit with a word of warning that clinical medicine is not an exact science, so in the absence of a crystal ball one can never be one hundred per cent certain of exactly how severe a genotype will translate into a phenotype.^{593,594}

Is State led paternalism in the antenatal setting the answer?

Paternalism is not normally seen in a positive light in the practice of modern medicine.^{595,596} I argue that if we closely analyse the different levels of paternalism there may be an acceptable version of paternalism that can help formulate a State wide policy to bolster uptake of antenatal screening and therapies

Häyry⁵⁹⁷ distinguishes between hard and soft paternalism. The former demands direct intervention with the actions of a third party whereas the latter type of paternalism is limited to interventions that educate the healthcare beliefs of agents, in order to influence choices that agents make for themselves, the goal being the realignment of these choices to mirror the choices desired by the State. Examples of soft paternalism include campaigns to promote health. These are designed to change behavioural patterns or increase the uptake of specific healthcare services (such as vaccination uptake or reducing alcohol intake) and improve overall health. Intervention in the family context of cases of foetal health may be viewed under such light. In the discussion above, it has implicitly been assumed that the interventions considered ought to be towards the hard end of the spectrum, involving forced intervention upon the choices of parents in the interests of the eventual child. There will likely be, once these technologies are nearly perfected, a place for the State to implement more direct intervention but not until softer interventions are better employed to attain the intended

⁵⁹³ King, L. S. (1952). Is Medicine an Exact Science? *Philosophy of Science*, 131-140.

⁵⁹⁴ Evidence that exceptions to clinical norms exist, especially with respect to disability are case reports of young adults with trisomy 21 getting accepted for university education: <http://www.cbsnews.com/news/rion-holcombe-college-hopeful-recvies-letter-of-his-dreams/> accessed on 23/09/2015

⁵⁹⁵ Buchanan, A. (1978). Medical paternalism. *Philosophy and Public Affairs*, 370-390.

⁵⁹⁶ Thomasma, D. C. (1983). Beyond medical paternalism and patient autonomy: a model of physician conscience for the physician-patient relationship. *Annals of internal medicine*, 98(2), 243-248.

⁵⁹⁷ Häyry H. (1991) *The Limits of Medical Paternalism*. Routledge

benefit. Providing pregnant women with free folic acid supplements, incentivising increased uptake of antenatal screening and foetal welfare clinics; offering better information to reduce consanguinity and the considerable foetal abnormality risks that accompany consanguineous partnerships⁵⁹⁸ are just a handful of ways in which the State needs to non-invasively act to achieve the intended outcome. Such softer interventions are justified as long as they do not cast more aspersions on parental responsibility than is suggested by up to date evidence.

Once the soft paternalism has been applied by the State, there are other ways of attaining the desired effect that stop short of hard paternalism (enforced intervention); I shall call this moderate paternalism. Moderate paternalism is an intervention that stops short of forcing a couple from employing certain behaviours that may be detrimental to foetal health but ensures that their actions will be merited with enough consideration by the couple to elicit a responsible behaviour. Moderate paternalism also include safeguards passed in law that ensure that should a couple require procreative help, the agencies assisting them will not do so recklessly by willingly allowing for disability selection. As elaborated above, such forms of moderate paternalism already exist within the HFEA amended Code of Practice⁵⁹⁹. Examples of moderate paternalism include the fortification of potable water with fluoride to improve dental health,⁶⁰⁰ the fortification of flour with folic acid in some countries to help reduce the incidence of congenital anomalies⁶⁰¹ and also Thalassaemia Prevention schemes.⁶⁰² With respect to the latter, in the 1970s pilot population programs directed to reduce the incidence of β -thalassaemia major by carrier screening, counselling, and prenatal diagnosis were started in several at-risk communities in Mediterranean populations.^{603,604} Several countries have comprehensive national prevention programs, which include public awareness

⁵⁹⁸ Sheridan, E., Wright, J., Small, N., Corry, P.C., Oddie, S., Whibley, C., Petherick, E.S., Malik, T., Pawson, N., McKinney, P.A. and Parslow, R.C (2013) Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. *The Lancet*, 382(9901), 1350-1359.

⁵⁹⁹ HFEA amended Code of Practice 2008

⁶⁰⁰ Petersen, P. E., and Lennon, M. A. (2004). Effective use of fluorides for the prevention of dental caries in the 21st century: the WHO approach. *Community dentistry and oral epidemiology*, 32(5), 319-321.

⁶⁰¹ De Wals, P., Tairou, F., Van Allen, M.I., Uh, S.H., Lowry, R.B., Sibbald, B., Evans, J.A., Van den Hof, M.C., Zimmer, P., Crowley, M. and Fernandez, B. (2007). Reduction in neural-tube defects after folic acid fortification in Canada. *New England Journal of Medicine*, 357(2), 135-142.

⁶⁰² Cao, A., and Kan, Y. W. (2013). The prevention of thalassaemia. *Cold Spring Harbor perspectives in medicine*, 3(2), a011775.

⁶⁰³ Angastiniotis, M. A., and Hadjiminias, M. G. (1981). Prevention of thalassaemia in Cyprus. *The Lancet*, 317(8216), 369-371.

⁶⁰⁴ Loukopoulos, D. (1996). Current status of thalassaemia and the sickle cell syndromes in Greece. In *Seminars in hematology* (Vol. 33, No. 1, pp. 76-86). Elsevier.

and education, carrier screening, and counselling, as well as information on prenatal diagnosis and preimplantation diagnosis.⁶⁰⁵

In most programs, carrier screening and counselling are implemented on a voluntary basis, these interventions would therefore be classed as soft paternalism. Cyprus, however, differs as the Orthodox Church has significant political and societal influence and as such requires certificated evidence that screening for β -thalassemia has been performed before marriage. This ensures that the decision of two heterozygotes getting married is not taken lightly, with the final decision on marriage and reproductive matters being left to the couple.⁶⁰⁶ It was not until 2004 when Cyprus became a member State of the European Union, that pre-marital certification requirement became obsolete for civil (but not religious) unions.⁶⁰⁷ These long-established prevention programs have succeeded in achieving 80%–100% prevention of beta thalassaemia major.⁶⁰⁸ If done sensitively and without casting any blame on parents who are carriers of a specific gene (or related between them) through no fault of their own moderate paternalism may in practice empower couples to make the right decision for them and their families as the procreative choices still stay firmly within their hands, but with more significant safeguards placed by the State and healthcare authorities. Such interventions are likely to affect pre-conception and antenatal behaviours in a way that allows for the creation a far healthier foetus and eventual child.

The big question is: if the State can ever have a moral duty to enact hard paternalism in the interest of future generations, should the government, in keeping with the HFEA 2008 amendments and on the basis of the ethical principles outlined above, have enough reason to impose such therapies in the womb to allow for better welfare and societal functioning? At the point of writing there are enough intrinsic safeguards that make this question self-evident. Foetal surgery and *in utero* genetic therapies are in their infancy, the risks to the mother and foetus vary from the uncertain to the unsafe and outcomes are far too variable to base any

⁶⁰⁵ Godard, B., Ten Kate, L., Evers-Kiebooms, G., and Aymé, S. (2003). Population genetic screening programmes: principles, techniques, practices, and policies. *European Journal of Human Genetics*, 11, S49-S87.

⁶⁰⁶ Kalokairinou, E. M. (2008). The experience of beta-thalassaemia and its prevention in Cyprus. *Medicine and law*, 27(4), 825-841.

⁶⁰⁷ Kolnagou, A., and Kontoghiorghes, G. J. (2009). Advances in the prevention and treatment are changing thalassaemia from a fatal to a chronic disease. experience from a Cyprus model and its use as a paradigm for future applications. *Hemoglobin*, 33(5), 287-295.

⁶⁰⁸ Angastiniotis, M., and Modell, B. (1998). Global epidemiology of hemoglobin disorders. *Annals of the New York Academy of Sciences*, 850(1), 251-269.

concrete medical recommendations on, let alone public policy guidelines. There may be a time when these technologies are safe for all parties with concrete clinical outcomes. Should that time come I still have considerable reservations as to whether hard paternalism should be employed to promote the welfare of the unborn, even if the intention is for that specific foetus to come to existence. For one, it is extremely difficult for the best interest of the child principle to override parental interests and autonomy. The interests of other family members almost invariably play a significant role and in many cases what the best interest of the child is will be unclear.⁶⁰⁹ Secondly, routine enforced interventions for the interests of the foetus are likely to erode the physician-patient relationship and trust in a way that takes us back to the dark, unsafe ages of backstreet abortions and similar quackery amounting to more maternal death and grief. Thirdly, the State clearly has both an interest and a responsibility in having children born in the healthiest possible state, or in disallowing foetuses to be born in an otherwise less-healthy state. This does not imply the State should abort unhealthy foetuses and replace them with healthy ones, this would create entirely new children and the harm principle can only be applied as a continuum. Instead it implies that society has an interest in existing foetuses to be born in their healthiest possible state. Before soft and moderate paternalistic approaches are exhausted, thereby proving that the optimum conditions for the creation of healthier children have been employed, making parents more educated and aware of their reproductive choices in the meantime, the State cannot claim moral authority to surgically intervene in the life of *compos mentis* citizens.

Conclusion

It is evident from the HFEA's amendments in 2008 to safeguard against disability selection there is a move towards legislation that ensures that advanced reproductive technologies are applied for what they were initially intended, helping couples procreate healthy children. Central to these amendments is the welfare of the eventual child. This, in conjunction with legal systems in the West seemingly more intent on affording the foetus with more legal protection raises possibilities that, in future, when foetal surgery and *in utero* gene therapies are much safer to both mother and foetus, with consistent positive clinical outcomes, the State is also likely to need to legislate to safeguard the birth of healthier children. As long as the parents have decided to carry on with a specific pregnancy, and not abort due to a specific

⁶⁰⁹ Harris, J., and Holm, S. (2003). Should we presume moral turpitude in our children? Small children and consent to medical research. *Theoretical Medicine and Bioethics*, 24(2), 121-129.

disability of the foetus, then not engaging with such therapies in order to maximize the eventual child's health and potential to flourish would leave the child with a grievance as it will have been harmed by his parents omission whilst he/she was in the pre-personal state. It is clearly a challenge as to when the State should promote such technologies. I have made a case that if a threshold of harm befalls the foetus then it would be in society's interest for the State to do so. Assessing the magnitude of harm antenatally is a challenge, there is wide variation of accounts of disability and assumptions on one's quality of life is rarely accurate. The task is further magnified by the variable degrees of disability in progressive conditions that become more severe when children grow and develop. I have suggested that whilst consideration needs to be given to Glover's potential of flourishing dictum and Feinberg's open future argument, perhaps a modified ICIDH scale for the developing child, focusing purely on the objective medical aspects of the disease may be of use once these technologies become less experimental and more mainstream. I maintain that whilst the State should promote these therapies via soft and moderate paternalistic avenues that allow the parents to make their own, albeit better educated, reproductive choices, hard paternalism is a path best avoided and unlikely to be implemented.

PART 3
CONCLUSION

CHAPTER 8

SUMMARY AND CONTRIBUTION OF THE ARTICLES

TO THE LITERATURE

CHAPTER 8

Conclusion

In this thesis I have explored the nature of parental responsibility when it comes to enhancing the welfare of future children when these children are yet to be born. My background as a physician dealing with childhood diseases and disorders has informed and motivated this area of study. My primary goal as a paediatric intensivist has to be to aim to maximise the welfare of the children in my care. This, of course, is also the primary interest of parents of sick children. This thesis has explored how the State might enable this goal of maximising the welfare of future children by giving prospective parents the information they need to make decisions that, I argue, will be in the interests of their future child and their wider family.

In this final section of the thesis I will bring out the conclusions I have reached in answer to the research questions I have addressed and aim to identify how I hope to have added to the literature in this area.

Summary and contribution of the articles to the literature

Introduction

The introduction has explored the general background to the philosophical and legal literature providing an overview to current arguments, which consider the complex dynamics of the foetal-maternal relationship. I have also explored in what way recent advances in antenatal medicine may benefit the foetus in the pre-personal stage, which by extension will benefit the eventual child. With the trajectory of current research in advanced reproductive technologies in mind, and whilst acknowledging the limitations of foetal therapies at the time of writing this thesis; I have argued that advanced reproductive technologies are likely to, in the not too distant future, be able to treat or even reverse certain conditions in ways that are safe to both mothers-to-be and the foetus.

The introduction also explores current philosophical attitudes towards disability, clarifying that my position is not one of disability avoidance, but rather one of treating disability for individual children to be. I have purported that the aim of antenatal screening services ought not be to abort or replace a disabled foetus with another, healthier one (although I acknowledge that this may be a plausible side-effect as no foetus is harmed by not coming into existence) but rather to improve the condition the same foetus is born in so that its

welfare as a child is optimized. As this implies a medical intervention in the pre-personal state in order to benefit the eventual person, I examined the situations in which it can be expected for parents to protect the foetus before it is born. I argue that, parents can only have a duty to do right by their future child, if and only if they have a full intention of carrying that very same foetus to term. I have argued that on three grounds. Firstly, because if the said foetal abnormality (or risk) can be therapeutically changed in a way that offers better clinical outcomes than doing so postnatally then, provided it is safe (for mother and child) to do so, then not doing so would be to harm the eventual child in the pre-personal state. One cannot take folic acid during pregnancy retrospectively for example; it has to be done prospectively if the chances of the foetus being born with neural tube defects are to be reduced.⁶¹⁰ Secondly, because if the objective is to make foetuses that have already been conceived into healthier children, the only account of harm that we can follow is a comparative account, i.e. one that allows us to ascertain if the harm (absence of appropriate treatment) incurred is on the very same child. It is nonsensical to try and compare net harm to a child if the disabled foetus is aborted and another healthier one is created instead.

The introduction also aimed to investigate what the common arguments against and in favour of a State preference of less disabled offspring and by extension responsible pre-parenting. The analysis concluded that whilst financial reasoning may be pertinent for public policy making in a free healthcare settings, it settles very little in philosophical or ethical realms. Instead, the justification for the promotion of antenatal services should be done on the grounds of the interests of future children and the interests of the advancement of pre-parental autonomy through education. The value of educated decisions in enhancing autonomous choices was highlighted and that uneducated choices cannot be fully autonomous, especially where they might harm others. On these grounds, I have argued that if we are to protect the interests of future children that *will* come to exist as opposed to *might* come to exist, seeking fore-education on the state of health the foetus is the only way in which the post-natal outcome can be positively influenced. The screening process is crucial in dictating how best to maximize the eventual child's welfare.

⁶¹⁰ MRC Vitamin Study Research Group. (1991). Prevention of neural tube defects: results of the Medical Research Council Vitamin Study. *The Lancet*, 338(8760), 131-137.

The final part of the introduction focused on the legal aspects of my proposal, in an attempt to elucidate what the legal protections the foetus is afforded in law and to see if any legal rights a foetus might have are invariably superseded by parental autonomy rights, with the exception of enforced treatments where the parent-to-be is deemed to lack capacity. I have noted however that both in English and U.S law there seems to be a trend whereby the foetus is afforded more legal rights. This is indicated by child destruction charges being on the rise in England and Wales, the introduction of the Unborn Victims of Violence Act in 2004 in the U.S, and the rise of foetal homicide and chemical endangerment charges for mothers abusing drugs during pregnancy. Although I deem criminalization of substance abuse in pregnancy a step too far, I explore how and to what extent the State might try and promote engagement of future parents with antenatal services by means of soft or intermediate paternalism. I argue that hard paternalism cannot be justified in a competent parent-to-be for numerous reasons including on the grounds that such a strategy stands to significantly frustrate the doctor-patient relationship with all the clinical repercussions that would accompany such an erosion in trust.

Chapter 2

The second chapter aims to address in more detail the relevant literature surrounding personal identity, as this is not done in depth in the articles. I explore the different accounts of personal identity and justify why the psychological approach is the one most applicable for my position. I explore whether non-DNA altering foetal therapies can change the future persons personal identity and go on to assess whether *in utero* gene therapy has any significant effect on the said identity. I postulate that although our genes and our DNA play some role in moulding our personal identity, their overall function in the formation of our identity is generally overstated since the sculpting of one's identity is influenced to a much greater extent by psychological connectedness and continuity, the pillars of the psychological approach to the personal identity conundrum.

I conclude that by grounding psychological connectedness and continuity as the main determinants of what constitutes personal identity, it cannot be argued with any conviction that *in utero* therapies, affect the personal identity of the eventual child in any meaningful way. Nor do these therapies affect ones personal identity in a way that the child may have a legitimate grievance when he/she grows older. This is because personal identity depends

more on life experiences, nature, nurture, memories, emotional bonds and so on. Since the purpose of *in utero* therapies is to create healthier infants, and infants need all of the above (and more) before they develop their own personal identities as adults; attacks on such therapies on personal identity grounds are destined to fail. This is because such objections are based on a fallacy as to when personal identity actually begins, as well as a misapprehension of what the major determinants in the formation of one's personal identity are.

Chapter 3

The third chapter gives special consideration if to the argument that increased uptake of antenatal screening services may in theory increase abortion rates, a commonly cited objection in pro-life circles.

I argue that, even if abortion is, in some way morally wrong, the doctrine of double effect could be deployed as a response to such criticism. As our objective is to improve welfare of future children any disallowing non-persons from coming into existence is an unfortunate side effect. I do concede however that, in isolation, this argument is in itself insufficient to answer the objection cited above.

I therefore look into recent scientific evidence relating to rates of congenital disease as well published data comparing the association between screening uptake rates and abortion rates. I posit that the real harm ought to be measured by how many children that have come to exist in future without benefitting from therapeutic interventions in the perinatal environment and not by how many non-persons have not come to exist, after all if no one has come to exist no person has been harmed.

By looking at evidence from EUROCAT (European Surveillance of Congenital Anomalies), that covers 1.5 million births a year across Europe nearly 0.25% of all births have some sort of congenital anomaly, nearly 375000 births a year in Europe alone⁶¹¹, a significant number of births that may benefit from antenatal diagnosis. And this is not including the number of newborns born with congenital infections, which would also be more likely to be detected and treated up if parents engage with the available screening services. According to UNICEF's Maternal and Newborn health review, severe infections are estimated to cause

⁶¹¹ Dolk, H., Loane, M., Garne, E. (2010). The prevalence of congenital anomalies in Europe. In de la Paz, Manuel Posada, and Stephen C. Groft, eds. *Rare diseases epidemiology*. Vol. 686. *Rare diseases epidemiology* (pp. 349-364). Springer Netherlands.

36% of all newborn deaths⁶¹² , this is in addition to the above number of newborns with congenital anomalies. This serves as solid evidence of the sheer numbers of newborns that are likely to benefit from antenatal screening and therapy.

The last piece of evidence I rely upon to make my case a U.S based systematic review published in 2012 spanning over 15 years between 1996-2011 that forms the largest compilation data on abortion rates following a prenatal diagnosis of Down syndrome. The paper suggests that termination rates are on the decline despite an increased uptake in Down syndrome screening. This would suggest that, scientifically at least, increased screening rates do not necessarily equate to increase abortion rates.

⁶¹² UNICEF. (2009). *The State of The World's Children 2009: Maternal and Newborn Health*. Unicef. p 13

The Three Articles: Outline of findings and contribution to literature

First Article

How Antenatal Genetic Ignorance and Parental Failure to Engage with Screening Services Can Harm Us All

This paper explores the question of whether ignorance of one's future child's genetic make up in the antenatal setting causes harm, and if so whether we have a moral obligation to avoid it by employing antenatal screening and *in utero* therapies available to us.

Special consideration is given to refuting arguments in favour of the so-called "right not to know", and justifications used often to defend one's so called right to genetic ignorance. Such a justification holds that in liberal societies respect for individual autonomy is paramount and as such people should not be forced to find out information about their own genetic information, even if it is information extrapolated from antenatal screening. Proponents of the right not to know also dispute whether Mill's harm principle can be applied in the antenatal setting. The paper sets out to dissect these arguments and disprove them.

In the first section I explore different accounts of the harm principle and settle for a comparative account of harm closely related to Feinberg's subjunctive historical account. The reason for this is biological continuity; it is nonsensical to compare harm to a person if that person has never come to exist. Harm can only be assessed with respect to future children by contrasting what the health outcome is on a specific child if an intervention has occurred *in utero* and what it is if the intervention has not materialized.

The second section focuses on harms incurred to future children. I initially analyse special considerations where disability avoidance may be preferable, implying that in certain very rare conditions whereby children have a "sub-zero" quality of life, it may be argued that the parental duty to screen ought to be coupled with a merciful decision to terminate the pregnancy. I do stress these syndromes are extremely rare and the argument purporting that these children are better off never to have existed should only be applied for these sporadic tragic wrongful life cases alone.

I then expand on why parents have a duty to screen antenatally for cases of non wrongful life, I do so by using examples from the field of paediatrics whereby irreversible harm can befall the newborn if either the appropriate medical treatment is not offered immediately after birth

and cases where the only available treatment that offers chances of survival are *in utero* therapies. It is plausible that with the expanding field of foetal surgery and genetic therapies, the collated list of conditions that can be rectified antenatally will become even bigger.

The third section assesses whether failure to engage with antenatal services can harm others and not just the resulting child. I assess whether parents, siblings (or other dependents) and wider society in general can be harmed by a foetus being born in a worse off condition that it would otherwise have been.

The final section expands on how the acquisition of antenatal foreknowledge is in keeping with the Kantian definition of autonomy. I argue that if the moral worth of our actions can be quantified based on the outcome, then we have a better probability of having a good result if an educated decision is made as opposed to an uneducated one. The only way of improving our chances of harm avoidance is by analysing the information at hand and acting appropriately.

Contribution of the first paper to the literature:

This paper served as an amalgamation between a review of current philosophical theories as to what constitutes true harm, as well as current clinical advances that can improve the health of future children. There are two novel ideas put forward.

The first contribution is a re-iteration to my argument in the first paper that highlights the importance of the pre-parental intention to carry the course with that specific pregnancy. Through employing personhood view of the moral status of the foetus I argue that the only way in which we can harm the foetus antenatally, i.e. harming it in the pre-personal stage, is if that foetus comes to exist later on. This implies that pregnant women who plan to abort, do not have duties of similar gravity towards the unborn, simply because their embryo will never be born and therefore it will never be a person that can be harmed. By extension, any damage that is incurred *in utero* (and the term damage implies harm either by an act or an omission) will foreseeably frustrate the welfare and wellbeing of the child that the specific foetus will turn into.

The second point that can be seen as a new addition to existing literature is a new take on Feinberg's subjunctive historical perception of harm. I define harm as *b is harmed when b's*

interests have been stymied or failed to be changed in a positive manner improved by an action or omission as such that b is worse off than he would have otherwise been had a not occurred and some other action or omission taken place instead.

This definition allows the application of Mill's harm principle in the antenatal setting as it implies a continuum of the same pre-person (foetus) to the person it becomes after birth. Unless we compare harm incurred on the same entity, pre and post birth, we cannot plausibly defend a duty to uptake antenatal screening services without frustrating those with a current disability. Non-comparative accounts measure a net harm, which would imply a duty to screen out every disabled foetus, an idea I disagree with as my objective is one of bettering welfare rather than eradicating those that are disabled.

Second Article

Do prospective parents have a moral duty to undergo antenatal genetic screening and should this be reflected in the way that screening programs are offered?

In this paper I argue that future parents have a strong moral duty to access antenatal screening as an aide to maximizing the welfare of the specific child they plan to bring to life and that this moral duty should be reflected in policy and practices in this area in future as perinatal medicine advances and allows us to offer *in utero* treatment with relative safety.

I make a case that the harm principle can be applied as long as the parents have full intention of having the child and that far from being a limitation of individual freedom, the acquisition of relevant antenatal information, including; that under the genetic umbrella, can minimize the risk on the future child and maximize that specific child's welfare. This is provided the parents use the attained information to intervene in such a way as to benefit their child. I purport that the distinction of the intention of the parents-to-be on whether the foetus will come to exist as a child or not is a very important one, since then, and only then can an *in utero* harm be caused in the pre-personal stage. I purport that an *in utero* harm can be proactive (for example by drinking excessive alcohol during pregnancy) or passive (for example by not taking antibiotics even if made aware that the child will be at significant risk of infection after birth).

Whilst acknowledging that some of the more recent advances in *in utero* therapies such as foetal surgery have limitations, both in terms of outcomes and safety to mother and foetus, I argue that the duty to know and intervene will become even more pressing once advances in antenatal care allow better surgical, medical and genetic intervention.

The paper also answers arguments against parental duty to genetic screening in cases when the underlying genetic disorder is incurable. I answer such arguments by focusing on Down syndrome; a syndrome, readers are likely to familiar with. I argue that the objective of the screening process for trisomy 21 ought not be termination of pregnancy, although parents are entitled to do so if they wish to, but rather to allow parents to plan ahead with where the baby should be born as well as set in place early physiotherapy and education for the infant. The medical evidence of how both these things benefit the eventual child with Down syndrome is presented.

Contribution of the second paper to the literature:

There are four notable contributions in this paper:

Firstly, I argue that harm can be incurred in the pre-personal state if the parents are planning to have that specific child and not replace it with another. I argue that this assumes an almost contractual relationship between a foetus and a parent-to-be; that at some stage the foetus's potential will be met as that child will come into existence. On this view, a choice to abort, although not the objective of my position, would imply that the entity would never have a life to value, so the interests that would accompany that potential life would merit far less protection.

The second argument is making the distinction from what the main literature in favour of screening and human enhancement purports. Whilst Harris and Savulescu argue in favour of the maximization of *net* welfare I argue rather on the maximization of welfare of a *specific* child. The distinction is important as it is less discriminatory against already disabled children as the rationale for screening and treating antenatally is not to replace the same collection of embryos with other, healthier ones but rather to make the existing ones, healthier.

The third argument is one whereby I put forth the notion that there is nothing intrinsic about genetic information acquired *per se* to make it more or less relevant to other types of antenatally acquired information that are more likely to be offered as standard. There seems to be very little literature on objections of the acquisition of microbiological information antenatally for example, and if a high vaginal swab from the mother-to-be shows a pathogenic growth then she would pre-emptively receive antibiotics to reduce vertical transmission to the newborn. The eventual child would also be kept in hospital for observation 24 to 48 hours depending on local protocols to ensure that he/she does not also need antibiotics. I argue that similar beneficial therapies can result from other information acquired antenatally; as such the principles applied to justify the acquisition of such information should be the same provided the screening results are accurate and the available therapies are safe to both mother and child to be.

The final argument that adds to the literature is my reasoning as to why the acquisition of antenatal information in situations where there is no cure *in utero* should be a moral pursuit by parents. I used Down Syndrome as an example, not because of special merits of the condition but rather because of familiarity of the reader with trisomy 21. I argue that early education and physiotherapy input in such children has been shown to improve intelligence, mobility and quality of life and the acquisition of said information *in utero* will allow parents to put plans in place early to meet those requirements. Furthermore, I have highlighted the association of the syndrome with congenital anomalies alongside clinical evidence that prove that better surgical outcomes, with less risk to the eventual child's life, are achieved if the birthing process occurs in a tertiary centre with the appropriate expertise; a plan that can only materialize if the diagnosis is known before birth.

Third Article

Foetal surgery and using *in utero* therapies to reduce the degree of disability after birth. Could it be morally defensible or even morally required?

The third and final paper assesses if, in line with the HFEA 2008 amendments that preclude the application of advanced reproductive technologies to deliberately select for a specific disability (such as deafness), questions whether these changes to the code of practice is a legal safeguard to control how healthy future generations of children are born. I analyse the main alterations to the Code of Practice that signify a change in attitude towards whether it is right or wrong to use advanced reproductive technologies for the conception of disabled foetuses, and examine whether in future where *in utero* therapies are more robust and effective there may be further legislation to promote their uptake. Special consideration is given to the Welfare of the Child Principle that permeates through the HFEA's code, acknowledging how the purposeful selection and preimplantation of embryos with a genetic disorder violates that principle. I put forth that by limiting the positive selection of disabled embryos, and by extension disabled children or children with genetic ailments, the HFEA send the message that it is more concerned with the application of reproductive technologies for what they were initially designed; to help infertile couples and to allow the production of healthy children. The HFEA stance then beckons the question as to why in liberal societies legal limitations protecting foetuses from genetic disease exist if a couple wants to procreate with the assistance of reproductive technologies, but there no extrinsic legal limitations on parents wishing to procreate in the conventional way. There are, no quality checks the embryo needs to pass before it gets the all clear for being genetic disease free if the parents are procreating naturally , and there are no ramifications for prospective parents wanting to select for a specific disability via natural conception; and yet deliberately selecting for disability in one's offspring using the advanced reproductive technologies under the amended HFEA regulations is deemed as a criminal act⁶¹³.

I attempt to answer the question by expanding on recent attitudes of the law in England and Wales but also in the certain States of the U.S, whereby foetuses are afforded increased legal protections. With this in mind I then analyse what conditions need to be met if the State is to justify the promotion of *in utero* therapies in the future. I argue that three provisions need to

⁶¹³ Human Fertilisation and Embryology Act 1990 (as amended by the Human Fertilisation and Embryology Act 2008, s. 13 (9)).

be met and analyse each of them; namely a parental intention to carry the pregnancy to term, the recommended procedure is safe to both foetus and mother-to-be, and that unless repaired, the *in utero* disability will severely affect the eventual child's welfare. This poses other questions with respect to what is meant by or what defines severe harm and how do we quantify it? I analyse the philosophical views of how harm is appraised as well as the medical assessment tools that are most commonly used in stratifying disability in order of severity to try and reach a solution as to how pre-natal harm should be assessed. Finally, I explore whether State led paternalism may in future be the answer to promoting antenatal screening and interventions for the purpose of safeguarding future children's good health. The different stages of paternalism are identified and I argue that whilst soft and moderate paternalism may be justified in certain cases, hard paternalism can not for fear of eroding the patient doctor relationship, and because in many cases what the interests of future children are, may in numerous situations be unclear.

Contribution of the third paper to the literature:

There are three points made in this paper that are arguably new additions to the existing literature:

Firstly, the argument that certain conditions can only be repaired *in utero* such as spina bifida; whereby *in utero* intervention can reverse the condition whilst surgical interventions after birth are largely palliation of existing neurological damage, not least because of the special qualities of foetal cells to heal without scar tissue. I argue that in these situations true harm can befall the eventual child if the *in utero* therapy is declined (provided it is safe for the parent-to-be). Such a declination would make the potential parents morally culpable.

Secondly, I highlight one of the shortcomings by the HFEA's code of Practice, the lack of a definition of "severe harm". Although this has been highlighted before I have defended a new plausible solution by suggesting the development of a modified scale extrapolated from the Severity of Disability Scale published by the World Health Organization in their International Classification of Impairments and Handicaps document. A modified Severity of Disability Scale that is designed to account for the degrees of disability through growth and development of each specific condition may be developed in future to aid with the complexity of such antenatal decisions.

The final argument to be added to existing literature is the idea of moderate paternalism and what that entails. I opine, and justify why, in the context of antenatal screening and antenatal therapies, it is morally permissible for the State to practice soft or even moderate paternalism. I have also argued however that it is hard to see, bearing in mind the significant clinical limits and safety profiles of such therapies at the time of writing, how hard paternalism can be morally acceptable, at least at present.

FINAL THOUGHTS

Maximization of the wellbeing and welfare of children has always motivated me in my daily practice as a paediatric intensivist and through my earlier training as a paediatrician. Of course I recognize the need and imperative to respect both the interests and choices of parents and parents-to-be. I am, however, also cogent in the fact that that parents or future parents usually have vested interests in the maximization of the welfare of any children they may have as well. Parents-to-be may have many reasons to refuse or avoid antenatal screening or treatments that might allow them to be more informed, information or therapies that may even improve the physical welfare of their future child either during pregnancy or shortly after birth. An apparent respect for parental autonomy may well stand in the way of these other interests regarding the welfare of children. Parents may not have the information that allows them to access the treatments and other provisions that may help them to benefit their children in their early stages of development.

I hope that I have brought my experience as a physician to this work to give a unique perspective on these ethical and legal issues. It is important that the ethical and legal debate in this area is informed by clinical practice and a consideration as to what the advances, and limitations of these advances are, in the field of reproductive, perinatal and neonatal medicine. Not only do I experience the effects of lack of information on children born without the benefit of early interventions on an alarmingly frequent basis but I also bear witness to the suffering of parents and children alike. In my line of work, good communication skills with parents of children with chronic or life-threatening illness are a valuable skill to have. Such discussions are often with parents whose child ends up in intensive care because of a disease process that could have been avoided, for example parents of children who refused to be immunized or parents of children that declined to engage with basic low-risk antenatal screening tests such as foetal anomaly scans. A common theme that transpires through such discussions is one of regret and frustration. Parents express both these emotions and in retrospect wish they could have done more to help their child and healthcare professionals mirror the feelings of frustration by the failure to prevent avoidable suffering of young patients. My clinical experience gives me insight not only into these human perspectives but also the reality of certain physical conditions and new possibilities. I am grateful to have been given the opportunity to bring my clinical skillset together with my interest and understanding of the ethical and legal aspects of this area to bring a different viewpoint to this debate.

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APPENDIX

Foetal surgery and using in utero therapies to reduce the degree of disability after birth. Could it be morally defensible or even morally required?

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Abstract In 2008 the Human Fertilisation and Embryology Act amendments made deliberately choosing to bring disability into the world, using assisted reproduction, a criminal offence. This paper considers whether the legal prohibition above, should influence other policy areas concerning the welfare of future children such as new possibilities presented by foetal surgery and in utero gene therapy. If we have legal duties to avoid disability in one context should this influence our avoidance of disability in this other context? This paper investigates whether the State might have a stake in wider promotion of practices to reduce the degree of disability in fetuses that will come to exist (as opposed to those that will be aborted). Not selecting for disability does not affect the welfare of any future individual, whereas treating in utero abnormalities can optimize the eventual child's welfare; antenatal interventions stand to improve clinical outcomes and welfare should that specific child be born. I explore why the State may want to intervene in the antenatal setting and to what extent, if at all; the State should implement these technologies. I argue that if the State is justified in intervening to outlaw the choosing to create disabled lives using assisted reproductive techniques, it is also justified in putting pressure on prospective parents to accept therapies in utero to help their child be born less disabled. However, I qualify this with the argument that the State is not

justified in using force or the criminal law in this situation during pregnancy.

Keywords Foetal rights · Foetal therapy · Foetal surgery · In utero gene therapy · Parental · Responsibility · Advanced reproductive technologies · Human enhancement · Disability · Disability rights · Genetics · Genetic screening · Public healthcare policy · Pregnancy

Introduction

In 2008 the Human Fertilisation and Embryology Act extensively amended the original 1990 act in an attempt to “keep pace with new avenues of scientific research and reflect wider change in our society” (Human Fertilisation and Embryology Act 1990). The amended version was significantly more extensive and moved to accommodate ethical considerations that arose from a rapidly evolving world of perinatal medicine and assisted reproductive technologies. Some of the amendments moved to liberally modernise the act to keep abreast with social changes, such as the legal recognition of both parents in a same sex partnerships that conceived by means of donated gametes. Some other amendments were more limiting however, notably in the prohibition, with criminal sanctions, of the use of advanced reproductive technologies in selecting for a particular disability.

If deliberately choosing to bring disability into the world is now considered to be a legal wrong, punishable by the criminal law, then what might this change in law be inferred to say about the new possibilities in foetal surgery and in utero gene therapy? If we have a legal duty to avoid disability in one context should this influence our avoidance of disability in this other context? This paper aims to

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investigate whether the State might have a stake in wider promotion of practices to reduce the degree of disability in fetuses that will come to exist (as opposed to those that will be aborted). Not selecting for disability does not affect the welfare of any future individual, whereas treating an in utero abnormality in such a way as to optimize the eventual child's welfare; either by means of foetal surgery or any other antenatal intervention stands to improve clinical outcomes and welfare should that specific child be born. I will explore the reasons that the State may want to intervene in the antenatal setting and to what extent, if at all; the State should implement these new technologies.

Prohibition against disability selection; is the HFEA aiming to produce the best children possible from these treatments?

Over the last half a century, scientific advances in the fields of perinatal medicine have meant that prospective parents were met with increasingly more complex reproductive choices. The main antenatal screening tools from ultrasonography to amniocentesis, chorionic villus sampling and maternal blood screening have been developed to help enhance parental insight into how healthy their foetus is prior to the projected expected delivery date. Advanced reproductive technologies such as in vitro fertilization, pre-implantation genetic diagnosis plus more recently mitochondrial donation (Reznichenko et al. 2015; three person IVF) and foetal surgery have been developed in part to create healthier fetuses and by extension healthier children.

The Abortion Act in 1967 (Abortion Act 1967) was the first piece of legislature in the UK that was produced to accommodate the avalanche of reproductive choices that cascade as a result of new information acquired by antenatal screening tools, allowing for legal termination for foetal abnormalities.

But whilst the intended benefits of the above scientific advances were to help families to, broadly speaking, either reproduce and create children without genetic disease and associated disabilities or allow families to forward plan for the eventuality of such a condition, a minority of prospective parents have moved to employ such technologies to positively select *for* a specific disability.

Such minorities come from small communities of specific disabilities themselves; examples include the deaf community or those with achondroplasia. Some members of these (relative) microcosms have such strong preferences in having offspring with the same disability as them that they have resorted to employing advanced reproductive technologies to create children that are “deaf like them” (Spriggs 2002) or have “achondroplasia like them”

(Braude 2001); these examples are well publicized and have resulted in public outcry. (BBC 2002; Aviles 2012). From a sociological standpoint, it is well founded that parents have a preference for their children to be created in their image, some have even gone to the extent of describing communities with specific disability as a separate ethnic group on the grounds that they have shared customs, language and social structure (Lane 2005). It is unsurprising therefore that such communities may wish to choose to bring to birth a child with the same condition they have as they would like him/her to experience the world in exactly the same way as them.

Whilst the patient's wishes are paramount in a good physician-patient relationship, serious ethical objections have been raised in the application of advanced reproductive technologies for the positive selection of disabled fetuses. An intuitive, over simplified, objection finds root in the very first piece of advice offered to me in medical school, *primum non nocere* (Smith 2005), first of all do no harm. Medical literature is inundated with new technologies and ground breaking surgery that serves to raise the level of physical functioning of patients either born with or acquired medical ailments that hinder their degree of functioning or that limit their potential. Cochlear implants for the deaf (Bond et al. 2009), spinal surgery (Thomeer and van Dijk 2002) (to avoid paralysis) and limb lengthening (Schiedel and Rödl 2012) for those with achondroplasia. The notion that medical advances can, and have been used to create children with the very disabilities that the medical world has vested so much in trying to cure or improve in order to appease parental preference alone is a counterintuitive one and has been looked through the ethical microscope by the HFEA.¹ Although a full review of arguments in favour and against such practice is beyond the scope of this paper I will expand on the welfare of the child provision, which is core to the HFEA's reasoning in limiting such procreative liberties.

The welfare of the child provision

In trying to better regulate the practices in fertility clinics in England and Wales the Human Fertilization and Embryology Authority has adapted the Welfare Principle from criminal and family law. In brief the principle dictates that the courts take into consideration the welfare of the child in situations whereby the courts decision may affect that child's interests. The principle permeates through numerous Acts (and their subsequent amendments), namely the Adoption Act 1976 (Adoption Act 1976), the Child Support Act 1991 (Child Support Act 1991) and the

¹ For a thorough analysis see Lee (2002).

Children Act 1989 (Children Act 1989a, b), the latter defining it as such:

When a court determines any question with respect to (a) the upbringing of a child: or (b) the administration of a child's property or the application of any income arising from it, the child's welfare shall be the court's paramount consideration (Children Act 1989s.1 (1)).

Whilst the initial HFE Act in 1990 was less prescriptive and directive as to how the welfare provision should influence treatments by fertility clinics, leaving its directive open to interpretation:

A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of treatment... and of any child who may be affected by the birth (HFEA 1990 s.13 (5)).

The 2008 amendments are firmer and more explicit allowing much less abuse and commercial mis-application of advanced reproductive technologies by fertility clinics:

... the center should consider factors... likely to cause serious physical, psychological or medical harm, either to the child to be born or to any existing child of the family. These factors include...any aspect of the patient's (or where applicable their partner's) medical history which means that the child to be born is likely to suffer from a serious medical condition (HFEA Code of practice 2008).

Whilst there is no consensus within the HFE Act or Code of Practice as to what constitutes serious harm, it is seems reasonable to argue that the purposeful selection and preimplantation of embryos with a genetic disorder could constitute serious harm and thus violate the welfare provision, making it unlawful practice.

Similar safeguards against the production of embryos with various genetic conditions exists within the HFEA code of practice prohibiting the donation of gametes from those known to be affected by genetic disease or be carriers of "deleterious recessively inherited" (HFEA Code of Practice 1998) genes. The codes of practice further advocate that based on phenotype, past medical or family history, a couple has a significant probability to transmit a genetic condition to their future child the "all reasonable steps should be taken to prevent the transmission of serious genetic disorders" (HFEA Code of practice 2003).

Whilst the application of the Welfare Principle allowed some leeway to fertility clinics as what constitutes serious harm was in part open to interpretation, the HFE Act amendments in 2008 provide an extensive list of the accepted purposes of preimplantation genetic diagnosis and

gamete donation making the legal selection of a foetus with a known disability almost impossible:

...persons or embryos that are known to have a gene, a chromosome or mitochondrion abnormality involving a significant risk that the person with the abnormality will have or develop (a) serious physical or mental disability, (b) a serious illness or (c) any other serious medical condition must not be preferred to those that are not known to have such an abnormality (HFEA 2008 s.13 (8.9)).

By limiting the positive selection of disabled embryos and by extension disabled children or children with genetic ailments the HFEA indicates that it is increasingly more concerned in the application of reproductive technologies and subsequent screening for what they were initially designed for, to help infertile couples and to allow the production of healthier children. Regulating what qualities the implantable gametes or embryos possess within the assisted reproductive technology setting is unique. It is unique in that (for good reason) no extrinsic legal limitations exist on parents wishing to procreate in the conventional way, there are no quality checks the embryo needs to pass before it is signed off as being free from genetic disease, and yet legal limitations protecting foetuses from genetic disease exist if a couple wants to procreate with the assistance of reproductive technologies.

How the law is changing to offer the foetus more protection

In English law courts generally hold that a foetuses need for medical treatment does not supersede maternal autonomy. Mothers-to-be can decline therapy or in utero treatment even if it is at their own risk and at the jeopardy of the foetus. For example in *St George's Healthcare NHS Trust v S; R v Collins and Ors, ex parte S (St George's Healthcare NHS Trust v S 1998)* the court held a trespass to the person when obstetricians performed a Caeserean section against the patients' will, on the grounds that the mother was diagnosed with severe pre-eclampsia, a condition known to cause severe repercussions on both mother and child (de Souza Rugolo et al. 2011; Voto et al. 1999).

There are signs that the tides are changing globally and the law both in the U.K and the U.S is beginning to afford more legal protection to the foetus (irrespective of the mode of conception).

In England and Wales, Child Destruction is the crime of killing an unborn and viable foetus, a foetus before it's "separate existence" (Knight 1998). Child destruction charges are uncommon but since 2007 there have been

three reported charges. *R v Maisha Mohammed* (*R v Maisha Mohammed* 2007) saw the first reported criminal conviction of a woman for the offence of child destruction for the destruction of her own unborn child at 34 weeks gestation. In 2012 in *R v Carl Anthony Whant* (*R v Carl Anthony Whant* 2012) there was a successful conviction of murder and child destruction of a man who murdered his 8-month pregnant partner. The CPS statement on the case admitted that “Child destruction is...a very rarely used charge (and that the courts were) not aware of another case like this one in Wales” highlighting also the importance of marking the death of the unborn child with a separate charge. (CPS statement 2012). More recently in December 2015, two men were found guilty of Child Destruction charges at the Old Bailey for attacking a 32-week pregnant woman causing her to miscarry (BBC News 2015).

US courts have been more vociferous in their attempts to protect the foetus in some guise, most often in an attempt to restrain mothers-to-be from risk taking behaviour such as sniffing glue and cocaine, and methamphetamine consumption. (Gallagher 1995). According to one journalist “Since the late 1980’s,... At least 200 women in more than 30 states have been prosecuted for behaviour while pregnant that posed danger to their foetuses.” (Terry 1996). An early, much publicised case was *Johnson v. State*, 578 So.2d 419, 420. (Fla. 5th DCA 1991) (*Johnson v. State*, 578 So.2d 419, 420. (Fla. 5th DCA 1991)), whereby Jennifer Johnson was sentenced to prison for delivering cocaine to her newborn child on the grounds that she had cocaine detected in her blood shortly prior to delivery.

In 2006 Chemical endangerment laws were introduced in the State of Alabama (Ala. Code § 26-15-3.2 2012). The charge refers to the crime of exposing a child to a controlled substance or the environment in which that substance is produced or distributed. Its addition to the Alabama legal code in 2006, was done with a scope of affording legal protection to children exposed to methamphetamine fumes. To be charged with chemical endangerment of a child, a person must “knowingly, recklessly, or intentionally cause or permit a child to be exposed to, to ingest or inhale, or to have contact with a controlled substance, chemical substance, or drug paraphernalia” (Ala. Code § 26-15-3.2 2012).

In its original phrasing, the law did not specify the inclusion of foetuses; prosecutors have increasingly, however, argued that the term “environment” should extend to include the in utero environment, and that by extension the definition of “a child” should also encompass unborn children leading to a rise in child endangerment charges brought to new mothers. An estimated 60 cases were prosecuted between 2006 and 2012 (Calhoun 2012).

Increased legal protection of the foetus is also seen in a controversial new law passed in 2014 in Tennessee, affording the unborn similar safeguards as those of chemical endangerment discussed above. As enacted the law provides that a woman may be prosecuted for assault for the illegal use of narcotics while pregnant if the child is born addicted or harmed by the said narcotic. (Tennessee code Annotated § 39-13-107). The first woman to be charged and prosecuted for the offence was Mallory Loyola who admitted to taking methamphetamines three days prior to delivery; her newborn tested positive for the substance (Wahowiak 2014; ABC News 2014).

The signing of the Unborn Victims of Violence Act in 2004 saw an upsurge in criminal charges against mothers partaking in risk taking behaviour antenatally, signifying that foetuses were merited further legal protection. The Act allowed the recognition of the foetus as a legal victim in the U.S if it is injured or killed during the commission of any of 68 existing federal crimes of violence. Of the 38 States that recognise foetal homicide as a crime, the majority apply the principle throughout gestation, whereas a minority of States afford such protections at various different stages of foetal development, which vary from State to State (Pedone 2009).

Foetal homicide laws, have since 2004 been increasingly used to prosecute pregnant women that either intentionally or through reckless behaviour damage the foetus leading to a miscarriage or a stillbirth. In 2006 for instance, the State of Mississippi charged Rennie Gibbs with murder for damaging her unborn child in utero by taking cocaine whilst being pregnant, an addiction that led to a stillbirth (*Gibbs v. State* 2010). The charges were later dismissed. 2011 saw the Indiana authorities charge Bei Bei Shuai, with murder and foeticide after her suicide attempt was unsuccessful but directly contributed to the death of her unborn child; Shuai eventually pleaded guilty to a criminal recklessness and was released, having been sentenced to time served (*Bei Bei Shuai v. State* 2012). More recently, in 2015 Purvi Patel became the first woman in the United States to be charged, convicted, and sentenced on a foeticide charge, she had allegedly consumed abortifacient medications that led to a stillbirth of a foetus that would have otherwise been born alive. An appeal has been filed by the defence since the conviction, the outcome of which is pending at the time of writing (*Purvi Patel v. State of Indiana* 2015; Dyer 2015).

These early indications that foetuses are better protected by the law both in England and Wales as well as the U.S, in conjunction with the HFEA’s prohibition for disability selection raises numerous ethical questions. It is beyond the remit of this paper to answer them all, nor do I attempt to elaborate whether criminal law is the appropriate way to legislate to ensure foetal protection. In view of what foetal

surgery and in utero gene therapies are likely to be able to deliver in future, I shall address whether, in-keeping with the 2008 HFEA amendments prohibiting the implantation of gametes with known parental genetic defects and “deliberately screening in a disease or disorder”, (Department of Health 2006 s2.43) there might in future be a further imperative for public promotion of such practice by the HFEA. It could be argued that not engaging with such technologies may fail to positively influence the health of the foetus in a way that it improves its welfare, and hence once born may constitute serious harm and a violation the welfare provision. We can only argue this with any conviction provided these conditions are met: the embryo has a disorder that can be repaired in utero, the parents-to-be are planning to have that very child and that foetal surgery (or other advanced reproductive in utero interventions) outcomes are better and safer on both mother-to-be and child to be.

What conditions must be met for the State to justify promotion of in utero therapies in future?

Legislating against both the positive selection of an embryo with a genetic disorder or disability, and antenatal harm caused to the foetus by the mother (or a third party) places limitations on the degree of parental self-control. This self-control may relate (not exhaustively) to addiction, substance misuse, risk taking behavior, a misguided volition for creating a disabled infant or mere whimsy. Legislating to promote the uptake (and even in some situations to enforce) foetal surgery upon mothers-to-be would involve imposing an invasive, surgical procedure on a person in the interests of the unborn.

Similarities with such legislation can be drawn with laws relating to involuntary caesarean sections or involuntary blood transfusions. In 2012 for example, *Re AA (Mental Capacity: Enforced Caesarean)* (2012) EWHC 4378 (COP) Alessandra Pachierri (*Re AA (Mental Capacity: Enforced Caesarean)* 2012, Dyer 2013) was given the diagnosis of a schizophrenic disorder, she came to Britain whilst 39 weeks pregnant to attend a training course. After she stopped taking medication she suffered a panic attack and was sectioned under the Mental Health Act. The court of protection gave the Mid-Essex NHS Trust permission to subject her to a caesarean section; the newborn child was taken into care by Essex social services and has since been adopted. (The Guardian 2014). This is of course a Mental Health Act issue whereby the mother was deemed to lack capacity to consent to treatment both by the medical team and the courts, and that was used as the grounds for the ruling to allow for an enforced caesarean section. Since the

landmark case of *St George's Healthcare NHS Trust v S* (1998) (*St George's Healthcare NHS Trust v S* 1998) the legal mandate in the UK has been clear that “(An unborn child's) need for medical assistance does not prevail over (the mother's) rights. She is entitled not to be forced to submit to an invasion of her body against her will, whether her own life or that of her unborn child depends on it.” (*St George's Healthcare NHS Trust v S* 1990).

Similarly in the U.S, since 1980, there are over half a century of cases with reported court ordered caesarean sections (Robertson 1996) and until the early 1990's most applications made to the courts for involuntary treatments in the interests of the foetus have been successful (Kolder et al. 1988).

The trident of the legal, medical and bioethical academic worlds have raised serious concerns about non-voluntary medical treatment in pregnancy. The Royal College of Obstetrics and Gynaecology for instance stipulate “Obstetricians must respect the woman's legal liberty to ignore or reject professional advice, even to her own detriment or that of her foetus” (The Royal College of Obstetrics and Gynaecology Ethics Committee 1994), whilst in a similar vein the courts of appeal in *Re MB (Medical Treatment)* stated that: “The law is, in our judgement, clear that a competent woman who has the capacity to decide may, for religious reasons, other reasons or no reasons at all, choose not to have medical intervention even though the consequence may be the death or serious handicap of the child or her own death” (Re: MB (Adult Medical Treatment 1997). The primary ethical objections to this particular foetal-maternal conflict that form the foundations of these policy and legal stances are based around safeguarding of maternal autonomy and respect for individual freedom and a woman's right related right to bodily integrity (Hornstra 1998).

Academic literature suggests that pregnant women are under considerable social pressures to undergo prenatal screening and diagnosis (Ford 2002). It may be argued that such social pressures frustrate women's autonomy and may be seen as a form of coercion. There is evidence that women who agree to partake in HIV antenatal testing for example, do so as a knee jerk reaction to a recommendation or request made by a physician (de Zulueta and Boulton 2007). Another study identified the commonest reasons why women undergo prenatal screening tests for Down syndrome; (Chiang et al. 2006) in order of frequency these were firstly an assumption that the test offered was routine antenatal procedure, secondly avoidance of giving birth to a child with Down Syndrome, and finally a trust in modern technology and medical authorities. Further evidence of the pressures that women are under to uptake antenatal tests offered to them can be found in literature criticizing the advertising of pro-screening campaigns by local healthcare

authorities. Such campaigns having been criticized as being coercive and not in keeping with the spirit of patient autonomy. (Flessel and Lorey 2011).

I argue that in future, if antenatally acquired information reveals a disability amenable to an effective in utero treatment that the State has a strong imperative to promote foetal surgery for the disability to be repaired on three conditions:

- 1 The parents have every intention of carrying the pregnancy to term.
- 2 Foetal surgery is safe to both foetus and mother with good post surgical outcomes.
- 3 Unless repaired in utero the disability can severely affect the eventual child's welfare.

I will now explain why these conditions are so important and lead to the conclusion that foetal surgery should be promoted where such conditions exist.

A) The provision that parents have the intention of carrying the pregnancy to term (and the causation of actual harm)

When it comes to trying to ascribe harm incurred in utero to a future child *that will be brought to birth* (as opposed to one that will be replaced by another or aborted) comparative accounts of harm are applicable and philosophically more sound. Whilst non-comparative arguments hold that to suffer harm is to *just be* in a bad state, (See Shiffrin 1999; Harris 1992; Harman 2009) comparative accounts rely on a comparison between the projected health of the very child that will result from the current gestation. This assumes a biological continuity (Olson 1999) that cannot be afforded by the non-comparative accounts; it is impossible to compare harm in a specific child if that specific (resulting) child never comes to exist or is replaced by a different (resulting) child. Harm can therefore be defined as:

Harm b is harmed when b's interests have been stymied or failed to be changed in a positive manner improved by an action or omission as such that b is worse off than he would have otherwise been had a not occurred and some other action or omission taken place instead.²

The very same foetus (i.e. excluding the possibility of choosing the healthiest out of a number of foetuses) can in many cases have two possible phenotypes depending on parental behavior, genotype and treatment options; a phenotype of crippling, life limiting disability or that of a healthier child. I argue that it makes clear sense to view an

act or omission that amounts to the former over the latter as amounting to harm. If we can choose the same child to be born in a healthier state as a direct result of something we do (e.g. take folic acid; Scholl and Johnson 2000) or do not do (e.g. smoke; Luciano et al. 1998), provided what we do or do not do is effective and safe to us and the child to be, then surely not acting in a way that benefits the eventual child constitutes a harm.

The provision that foetal surgery and in utero gene therapy will be safe to both foetus and mother with good post surgical outcomes

At the time of writing foetal surgery is an evolving speciality but results have mixed outcomes with considerable risk to mother and foetus (Willyard 2008). *In utero* stem cell and gene therapy has had some success in lab animals but not humans. Somatic gene delivery in utero is a new approach to gene therapy for genetic disease. The practice assumes that prenatal intervention may avoid the development of severe manifestations of early-onset disease, allow targeting of otherwise inaccessible tissues and induce tolerance against the therapeutic transgenic protein. This in turn provides permanent somatic gene correction (Coutelle et al. 2003, McClain and Flake 2016). *In utero* gene therapy trials have been performed on mice and sheep foetuses and long term therapeutic effects of Crigler Najjar Disease, Leber's congenital amaurosis, Pompe's disease and haemophilia B have thus far been noted (Coutelle et al. 2003). The surgical risks in such therapies are in theory much reduced compared to conventional foetal surgery as the vector proteins are introduced with minimally invasive ultrasound and vector technologies; unfortunately much higher incidence of liver tumours in the mammalian foetuses have been reported (Coutelle et al. 2005). If and only if a specific in utero procedure can be deemed safe and successful enough, with good clinical outcomes for both mother and (eventual) child, can there be an imperative by the State to promote such clinical practice. As our objective is to avoid harm, it is self evident that we need to have clinical evidence and by extension clinical confidence that that these procedures are likely to improve welfare, not cause more harm.

There may of course be objections to in utero gene therapy on personal identity grounds. The purpose of such of such therapy is to facilitate a change at the genetic level, which may in turn influence or alter one's personal identity. Are we our genes? Are we just our genes? And is our personal identity dependent on our genes? Although a literature review of the above questions is beyond the scope of this paper and would be enough to fill numerous books, I will focus on a few pertinent points.

² This is a modified version of Feinberg's account of harm; see Feinberg (1986).

We are more than a sum of our DNA. Case in point is identical twins. So whilst identical twins are made of exactly the same genetic material, they have distinctly different personal identities. So genes alone are not enough to pre-define our personal identity. The case of identical twins has led to questions of when our individual life stories begin. Bernard Williams has formulated the Zygotic principle to try and answer this question “a story is about A if it is about an individual who developed from the earliest item from which A in fact uniquely developed” (Williams 1995).

Certain genes code for certain character traits. This may be true, an extra Y chromosome for example may predispose one to more aggressive behaviour (Price and Whatmore 1967) or the DRD4 gene may predispose to delinquency (Dmitrieva et al. 2011). The evidence is that the genes provide exactly that, a predisposition, they do not cause the various character traits but they may contribute or unmask them if the right circumstances arose. The question then arises to what extent do our genes determine our character? Miller (Miller 1998) cites three answers that may be applicable to this question and relate to different degrees of determinism. He concludes that traits that we are genetically predisposed to serve as parameters within which we mould our own character and develop our personal identity. DNA is therefore important for the development of the said identity but is not the only significant determinant and we oughtn't conflate its importance. According to Miller, other parameters such as free will, responsibility and determinism are of at least, equal importance. Using the identical twin example above Miller argues that personal identity cannot exist in the DNA as identical twins do not have identical personal identity,³ so whilst the DNA is an important encoder one should not exaggerate its importance in terms of personal identity development.

Following Miller's conclusion, Chadwick (Chadwick 2000) has identified that since personal identity consists of something other than our DNA, it is possible, at least in theory, to change our DNA in a way that does not change our personal identity. By using gene therapy as an example she sees three different scenarios.

- (1) That any change in the DNA brings about an identity change;
- (2) that a change in a certain proportion brings about an identity change;
- (3) that a change in a key part brings about an identity change (Chadwick 2000 p. 187).

³ For a good account of external determinants of character and personal identity see Cohen (1999).

Regarding the 1st scenario, Chadwick argues that an argument that any change in DNA brings about an identity change is implausible to accept as humans share 99 % of their genes and yet we all have different personal identities. Even in cases of identical twins, as explained above, when exact copies of the DNA are found in two separate human beings, twins have distinctly different personal identities. Our personal identities are therefore not identical to our complete set of genes; thus those who have objections to curative DNA changes to a foetus, citing personal identity objections have a fundamentally flawed argument. Regarding the 2nd scenario, a change in a proportion of genes would reflect a physical change. I disagree with the biological/somatic/physical approach to personal identity; I shall elaborate. Whilst my own identity or the identity of my friends and family may change though time as we age and grow, it is not the physical continuum that defines us collectively as persons but rather our character, our psychological existence. If I were to lose a limb today I would not be a different person tomorrow than I am now. I encounter similar experiences in my clinical practice that validate my preference of the psychological approach to the biological one. If a child has endured a catastrophic brain haemorrhage because of a saccular brain aneurysm, families take little solace in the child's bodily integrity, whilst externally at least, physically the child is the same, psychologically he/she is no longer that same person.

Finally, Chadwick acknowledges that the answer to the 3rd question can only be given if we know which aspects of the person are essential to his identity and which genes control it. At the time of writing there is some, but very limited evidence as genes controlling any character traits at all. The two examples given above (XYY and DRD4 gene) are not *known* to cause any character attributes, they are merely associated with them, they are not implicated in causation of aggressive behaviour but merely correlate with it. This is an important distinction, if everyone who has gone to the moon has eaten beef, there is a correlation with beef eaters having gone to the moon but eating beef does not result (or cause) in one going to the moon. In the absence of solid evidence it is more likely that our personal identities are moulded by nurture, more than by nature (Cattell et al. 1955).

On evidence of the above arguments DNA has a part to play in the development of our personal identity. However, in the absence of confounding evidence of specific genes being causative of particular character attributes, objections that a change in some genes in utero in order to confer a welfare benefit to the eventual child will result in a change in his/her personal identity remain weak and the role of the DNA in the evolution of our personal identity should not be exaggerated.

The provision that unless repaired in utero the disability can severely affect the eventual child's welfare

Currently there is discordance amongst the medical profession as to which anatomical abnormality is severe enough to justify placing mother and child under such risk (Willyard 2008). There is no universal agreement as to what criteria should be fulfilled in order to aid physicians differentiate whether foetal syndrome X is more or less severe than foetal syndrome Y. Such deductions can only be reached by extrapolating guidance from various classifications of disability (which I discuss later in the paper) and with the help of clinical paediatric geneticists. For all the HFEA's amendments in 2008, the new code of practice has faced criticism that the term "serious harm" is too open to interpretation (McLean and Elliston 2012). In the amended 2008 code of practice the welfare principle is core to the guidance below (HFEA 2008).

The centre should consider the following factors when deciding if PGD is appropriate in particular cases:

1. The views of the people seeking treatment in relation to the condition to be avoided, including their previous reproductive experience.
2. The likely degree of suffering associated with the condition.
3. The availability of effective therapy, now and in the future.
4. The speed of degeneration in progressive disorders.
5. The extent of any intellectual impairment.
6. The social support available, and.
7. The family circumstances of the people seeking treatment.

Although I do not aim to conjure up an exhaustive list of what conditions meet the criteria of constituting serious harm to the foetus, a cogent case can be made, based on my personal clinical experience of what types of conditions we should strive to find antenatal cures for. Rapid, neurodegenerative conditions whereby the child has little to no higher function and is destined to have a short life, most of which is supported within a hospital setting with numerous surgical interventions such as a percutaneous entero-gastric tubes for feeding (to aid nutrition due to unsafe swallowing), surgically inserted intravenous lines (to enable long term intravenous access—often seen as less painful than numerous venepuncture attempts) and surgical tracheostomy insertion (to enable breathing due to a floppy tongue and a poor upper airway control) are the type of conditions whereby we can say that should there be an in utero cure, then the child has been seriously harmed by being deprived of it antenatally.

A prime example is postnatal care of spina bifida (the most common congenital malformation of the central nervous system). The main focus in treatment after birth is on palliation of the existing neurological damage rather than reversing it. Part of this limitation of postnatal care results from the deleterious effects that the in utero environment has on the neural elements. A recent prospective randomized multicenter trial showed that in utero repair significantly helps preserve neurological function, reverses hindbrain herniation and decreases the need for surgical ventricular shunting to alleviate hydrocephalus (Adzick et al. 2011). It is evident that these types of disabilities are severe, and if the outcomes of in utero therapies are much better there is a solid argument to be made that harm befalls the eventual child if they are denied such treatments.

What magnitude of harm must befall the eventual child before birth to justify State intervention or coercion?

John Stuart Mill states that causing harm to others is a necessary condition to justify State intervention in a person's life, but it is not sufficient in itself to do so: "It must by no means be supposed that because damage or probability of damage, to the interests of others, can alone justify the interference of society, that it always does justify such interference" (Mill 1884).

When can the State justify the imposition of an antenatal intervention X on mother-to-be M to prevent harm to the eventual child C? In public policy, when the imposition on the individual is small (such as not smoking in an enclosed public space) and the harm to others may be big (such as second hand smoking and all the health sequelae associated with it) it may seem prudent and even morally important that we require the State to prevent this harm. If we regard respect for individual autonomy and enabling individuals to have control over their lives as important, then protecting others from harm is analogously important, as to do otherwise would imply disrespect towards their ability to have control over their lives. Similarly, if the personal cost and effort in engaging in a specific activity is nominal (such as picking up our dogs' mess) and the potential preventable harm to others is sizeable (hygiene, various zoonoses etc.) then the State may legislate accordingly to promote the uptake of the said activity. An example of the application of this within a healthcare policy is the minor imposition of hand washing before and after contact with different patients upon healthcare workers. The correct hand washing technique is imprinted in their memories during the induction process at the new workplace, there are yearly compulsory refresher sessions and every

corridor, and ward; hospital toilets have posters reminding them to carry out this very simple duty. This is a basic and nominal infringement on their personal autonomy but is one of proven immense clinical benefit and significance and it reduces cross-infection and by extension morbidity and mortality of patients (Pittet et al. 2000). Such an imposition is so easy to adhere to and the benefits so significant that it led to the introduction of a nationwide “Clean your Hands” campaign to promote hand washing, which has resulted in much lower death rates caused by cross infection (Gould et al. 2007).

If we accept these paradigms then it seems that for X to be justifiably imposed by the State, then the harm to C must be significant. As Mill dictates above, this is not in itself enough for a State intervention. The State cannot expect a pregnant woman to give up her life entirely in the interests of a future child. One could also argue that if we believe that the State should have such expectations of pregnant women, then these expectations should extend to all women of fertile age as there is considerable evidence showing that healthy mothers give rise to healthier babies (Atrash et al. 2006). There are for example cases where a mother needs to act in a way that may predictably damage the foetus. Epileptic mothers-to-be for example may only be sensitive to sodium valproate, an epileptic drug that has teratogenic effects on the foetus and can cause anatomical abnormalities and severe developmental delay as part of the spectrum of foetal valproate syndrome (Clayton-Smith and Donnai 1995). If however there is an alternative effective non-teratogenic anti-epileptic therapy that the woman knows of and declines to take then the eventual child, and the State may have good reason to be aggrieved. In a myriad of possible scenarios and permutations pertaining to maternal and foetal health, one thing is certain; that the severity of harm sustained to either the mother or eventual child is relevant in ascertaining the appropriateness of a State intervention in any given situation; i.e. it is not unreasonable to posit that the greater the magnitude of the potential harm the greater the incentive for a State intervention to prevent the said harm. Savulescu alludes to three possible ways of describing the magnitude of harm in such settings (Savulescu 2007), the threshold view, the maximizing view and the benefit view. These views merit some consideration if we are to attempt to find which one is most applicable in our quest to ascertain how to best measure harm incurred in the antenatal setting.

The maximizing view

This view requires that the harm to M is less than that to C to justify an intervention. This view is too restrictive in a liberal society to be acceptable as a blueprint for social policy; it places too little value on parental autonomy and

individual liberties. Under this view for example the State could imprison someone for nine months to preclude them from any risk taking behavior, simply because this would allow for (in theory) a healthier foetus and child.

The threshold view

The harm to M is below some empirical threshold value. The view has two variants according to Savulescu (Savulescu 2007 p10), the net harm or the single harm variants. On applying these two versions on real clinical events (Graffeo and Dishong 2013); the former view would allow a physician to transfuse a Jehovah’s Witness in labour who has had a life threatening placental abruption, as she will die without it. Her deeply held belief that she would rather die than receive blood is trumped, this amounts to a small harm; M and C’s lives have been saved by the intervention so net harm has been avoided. The single harm variant places much greater weight on personal beliefs and less weight on any offsetting benefits. The theory dictates that it is only justifiable to inflict one harm to a person up to a certain threshold, despite any foreseeable benefits that may be incurred. Applying this view would morally permit the death of the Jehovah’s Witness mother, as according to her beliefs being transfused is a far worse affliction than death.

The benefit view

The harm to M is balanced by a benefit to M, so whilst an intervention might harm M in some way the way in which she profits by the intervention amounts to net benefit for both M and C. This view is the one most adhered to in US and English law to justify the authorization of enforced caesarean sections as the decision to grant such court order was thought to be in the collective best interest of both mother and foetus.⁴ This view casts no aspersions on how big the harm to the mother or eventual child needs to be before we can justify a State intervention. A forced intervention to avoid a nominal harm would, on this view be permitted, but in a liberal society such practice cannot be adhered to, the harm, in my opinion needs to be substantial in order for State intervention to be justified.

I opine that the net harm variant threshold view is the most relevant in justifying a State intervention. The reason for this is simply that avoidance of net harm is a larger scale version of individual physician’s duties of non-maleficence, so a collective prevention of harm is in-keeping with the principle of *primum non nocere* (Gillon 1985) found in ethical decision making in everyday medical practice; a principle whose virtues are self-evident. Although I accept that the above principle is a person

⁴ For more in depth analysis of such cases see Weaver (2002).

affecting one, and some philosophers recommend the abandonment of such person affecting principles with respect to the unborn (Brock 1995), I argue that harm incurred in the pre-personal state is a true harm in both philosophical and medical realms on the proviso that the specific child is born.

Definitions of thresholds of harm and grading of severity of harm have been elusive in the legal context even though, as discussed above, the HFEA tried to address this issue in 2008 (HFEA 2008, 10.7). On the provision that parents have full intention of carrying a specific pregnancy to term and that the procedure the State has an interest in promoting is effective and safe on both mother and child, then a severe disability is one that significantly inhibits both their potential of flourishing (Glover 2006) and their open future (Feinberg 1980).

Glover argues that certain disabilities are barriers to flourishing, because they hinder “safe navigation through the world,” and sufferers fail to perceive “a whole dimension of enriching experience” (Glover 2006 p. 23). Although important, flourishing potential and scoring high enough on a quality of life scale isn’t sufficient reason to justify a State intervention. For one, quality of life accounts vary depending on the viewpoint of the person measuring the quality of life. There is even disagreement between medical professional bodies as to how disability severity ought to be defined (O’Donovan and Good 2010). Take for example a common life limiting illness Duchenne muscular dystrophy (DMD). DMD is a recessive X-linked form of muscular dystrophy, affecting around 1 in 3600 boys (Liew and Kang 2013), which results in muscle degeneration and premature death. Judgements by third parties about the standard of living with a certain condition and disability are sensitive in nature and very challenging. An example of this relating to DMD is the contrast of opinions given by the professional panel at a number of ethics discussion groups and that of the patients with DMD. Whilst calling the condition a severe disease, scientists divulged that the patients “gave their rating of quality of life the same as a healthy controlled sample. And the parents gave them the lowest quality and the clinicians gave them, somewhere between the two” (Scott 2007 p. 222). Although important, quality of life assessment, that underpins Glover’s potential of flourishing argument, cannot in itself be sufficient to grade the severity of a severe disability. Which is why the child’s right to an open future should also be taken into account.

Originally explored by Feinberg, the right to an open future pertains to a set of moral rights children arguably possess that derive from the autonomy rights of adults (Bredenoord et al. 2014). These rights, it is argued, protect children, or in this case future children against having important life choices decided by others before they have

the ability to make them for themselves. The said right to an open future, if accepted, can be employed to assert restrictions on what parents (and others) are allowed to do to their children, and obligations as to what parents (and others) ought to provide to them with. Feinberg’s theory has been cited in numerous ethics and social policy contexts varying from vaccination ethics (Hasman and Holm 2004), surgery ethics (Nunes 2001) and genetic ethics (Buchanan et al. 2001, Kopelman 2007). These “rights in trust” (Feinberg 1994) protect children from key parental decisions that the children themselves are likely to want to make when they grow up. These rights pertain to potentially harmful parental decisions such as early withdrawal from school, refusing life saving treatment (e.g. on religious grounds) or refusing medical treatment that can improve a child’s disability (e.g. refusing a cochlear implant in a deaf child). Similarly, in law, but rather for actual children rather than future children, similar rights are found in the capacity of the State to act as *parens patriae*. Cases such as *Re S* (Re S (A Minor) 1993) and *Re R* (Re R (A Minor) 1993) concerned a lack of parental consent for life saving treatment on religious grounds. The courts ruled that the children were not yet of age to have developed their own religious beliefs and the parents’ choice to decline treatment against medical advice would deprive them of a long enough life to do so (Heywood 2012). As long as there is every intention by the parents to carry through with the specific pregnancy, similar harms can be inflicted upon the foetus and eventual child in the pre-personal state. Such harms have the potential to severely frustrate the eventual child’s right to an open future; by considerably narrowing the range of options and experiences that child will have when and if it grows up. Compare a foetus that has purposefully had the single gene whose sole function is to regulate hearing deleted in utero so that he/she is born deaf (whilst all his/her other characteristics remain unchanged) and the newborn who is deaf but whose parents refuse consent to restorative cochlear implants. Both entities, once they grow up may have a legitimate frustration against their parents for limiting the way in which they enjoy the world and for limiting their open future. I argue that in both cases “liberalism requires us to intervene to support that child’s future ability to make her own choices about which of the many diverse visions of life she wishes to embrace” (Davis 2001).

It is evident that neither Grovers potential of flourishing dictum nor Feinberg’s open future argument in themselves suffice in determining the magnitude of foetal disability, that would allow us to apply the net harm threshold principle above so as to evaluate if it would be acceptable to advocate an antenatal State intervention.

If modified, a template of the now out-dated International Classification of Impairments, Disabilities and

Handicaps (WHO 1980) (ICIDH) may be used in conjunction with the above to help apply the threshold principle in practice. The ICIDH is a structured framework for disability assessment that was endorsed by the World Health Organization. Disability was described in three dimensions Impairment, Disability and Handicap:

1. *Impairment*: In relation to health experiences an impairment is defined as any loss or abnormality of psychological, physiological or anatomical structure or function.
2. *Disability*: In relation to health experiences a disability is defined as any restriction or lack (resulting from impairment) of ability to perform an activity (or activities) in the manner or within the range considered normal for a human being.
3. *Handicap*: In relation to health experiences a handicap is defined as a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual. (Van Buuren and Hopman-Rock 2001).

The ability of the ICIDH allows a classification of patient's personal circumstances and provides an objective platform that can weigh disability severity that can be applied for a multitude of clinical (and non clinical) scenarios including (but not exclusively): "clinical diagnosis and rehabilitation assessment, record keeping in health and rehabilitation settings, the development of medical and rehabilitation monitoring systems, program evaluation and development, the promotion of linguistic agreement, debate and conceptual development in the interdisciplinary field of disablement studies, development of research programs, the formulation of disability policy and the planning measures for equalisation of opportunity, data collection in survey research and database development" (1993). It would not be unreasonable to extend its uses as an appropriate template on which to apply the threshold principle to help ascertain the degree of foetal (and eventual child) disability.

A core part of the ICIDH Disability section was the Severity of Disabilities Scale (SDS). The SDS consisted of a set of seven severity codes, and was meant to mirror the extent to which an individual's ability to perform a certain activity is restricted. (Table 1).

The benefits of applying a template akin to the SDS is that a numerical value in ascending order is used to grade disability severity, allowing for clinicians to speak the same language. The SDS was of course designed to assess and grade disabilities in existing patients and extrapolation of it to future children will prove a challenge, not least as it fails to classify the functional characteristics of developing children. Different grades may be needed in the first years

of growth and development in order to give a true reflection of disability (Ogonowski et al. 2004). Relevant to this point is the introduction of the International classification of functioning, disability and health: children and youth (WHO 2007) (ICF-CY) in 2007 that addresses the shifting of disability severity with maturity and progressive disease. It was a publication that supplemented the International classification of functioning (ICF) that was introduced as a direct replacement of the ICIDH in 2002 (WHO 2002). The ICF focuses less on disease consequences that predominates in the ICIDH, to a classification of human functioning and disability. The document is neutral with respect to aetiology of disability and pays much more weight to social and medical support available. The ICF template would be much more challenging and complex to stratify and apply in an antenatal setting. Although wealth and social support is important, it may create scenarios whereby, all things being equal, it is morally acceptable to forego in utero repair of spina bifida in a well-off family, but morally impermissible to do so if the family is socio-economically deprived. The main focus of any disability severity scale would therefore need to shift to measure the degree of disability in medical terms rather than base so much weight on socioeconomic status and support. What is needed perhaps is a modified SDS scale that is formulated to account for the degrees of disability through growth and development of each specific condition, taking into account the potential of flourishing and an open future with and without a successful, minimally risky in utero procedure. Formulating such a scale would need significant work, funding and consideration albeit with a word of warning that clinical medicine is not an exact science, so in the absence of a crystal ball one can never be one hundred per cent certain of exactly how severe a genotype will translate into a phenotype. (King 1952).⁵

Is state led paternalism in the antenatal setting the answer?

Paternalism is not normally seen in a positive light in the practice of modern medicine. (Buchanan 1978; Thomasma 1983). I argue that if we closely analyse the different levels of paternalism there may be an acceptable version of paternalism that can help formulate a State wide policy to bolster uptake of antenatal screening and therapies.

Häyry (Häyry 1991) distinguishes between hard and soft paternalism. The former demands direct intervention with the actions of a third party whereas the latter type of

⁵ Evidence that exceptions to clinical norms exist, especially with respect to disability are case reports of young adults with trisomy 21 getting accepted for university education: CBS News 2014.

Table 1 Former severity of disabilities scale of the International Classification of Impairments, Disabilities and Handicaps (WHO 1980)

Code	Label	Includes
0	Not disabled	No disability present (the individual can perform the activity or sustain The behaviour unaided and on his own without difficulty)
1	Difficulty in performance	Difficulty present (the individual can perform the activity or sustain the behaviour unaided and on his own but only with difficulty)
2	Aided performance	Aid and appliance necessary (the individual can perform the activity only with a physical aid or appliance)
3	Assisted performance	The need for a helping hand (the individual can perform the activity or sustain the behaviour, whether augmented by aids or not, only with some assistance from another person)
4	Dependent performance	Complete dependence on the presence of another person (the individual can perform the activity or sustain the behaviour, but only when someone is with him most of the time). Excludes: inability
5	Augmented inability	Activity impossible to achieve other than with the help of another person, the latter needing an aid or appliance to enable him or her to provide this help (for example, the individual cannot get out of bed other than by the use of a hoist); behaviour can be sustained only in the presence of another person and in a protected environment
6	Complete inability	Activity or behaviour impossible to achieve or sustain (for example, an individual who is bed-bound is also unable to transfer)
8	Not applicable	
9	Severity unspecified	

paternalism is limited to interventions that educate the healthcare beliefs of agents, in order to influence choices that agents make for themselves, the goal being the realignment of these choices to mirror the choices desired by the State. Examples of soft paternalism include campaigns to promote health. These are designed to change behavioural patterns or increase the uptake of specific healthcare services (such as vaccination uptake or reducing alcohol intake) and improve overall health. Intervention in the family context of cases of foetal health may be viewed under such light. In the discussion above, it has implicitly been assumed that the interventions considered ought to be towards the hard end of the spectrum, involving forced intervention upon the choices of parents in the interests of the eventual child. There will likely be, once these technologies are nearly perfected, a place for the State to implement more direct intervention but not until softer interventions are better employed to attain the intended benefit. Providing pregnant women with free folic acid supplements, incentivising increased uptake of antenatal screening and foetal welfare clinics; offering better information to reduce consanguinity and the considerable foetal abnormality risks that accompany consanguineous partnerships (Sheridan et al. 2013) are just a handful of ways in which the State needs to non-invasively act to achieve the intended outcome. Such softer interventions are justified as long as they do not cast more aspersions on parental responsibility than is suggested by up to date evidence.

Once the soft paternalism has been applied by the State, there are other ways of attaining the desired effect that stop short of hard paternalism (enforced intervention); I shall call this moderate paternalism. Moderate paternalism is an

intervention that stops short of forcing a couple from employing certain behaviours that may be detrimental to foetal health but ensures that their actions will be merited with enough consideration by the couple to elicit a responsible behaviour. Moderate paternalism also include safeguards passed in law that ensure that should a couple require procreative help, the agencies assisting them will not do so recklessly by willingly allowing for disability selection. As elaborated above, such forms of moderate paternalism already exist within the HFEA amended Code of Practice (HFEA 2008). Examples of moderate paternalism include the fortification of potable water with fluoride to improve dental health, (Petersen and Lennon 2004) the fortification of flour with folic acid in some countries to help reduce the incidence of congenital anomalies (De Wals et al. 2007) and also thalassaemia prevention schemes (Cao and Kan 2013).

The flour fortification example is the type of moderate paternalism that can positively influence the health of the foetus once a couple has conceived; if the pregnant mother-to-be feels strongly enough against ingesting flour fortified with folic acid, specifically designed to reduce neural tube defects of the foetus, she can buy unfortified flour, a relatively minor inconvenience for her yet an inconvenience that most are unlikely to have an objection to hence allowing the State to positively influence foetal health. The thalassaemia prevention example is different and less relevant to post-conception, in utero ethics (which is my focus) and more to do with pre-conception ethics, but it is important to elaborate on it as it is, perhaps the best example of how moderate paternalism may work in a way that can influence the behaviour of couples wanting to

procreate in a way that offers better chances of having a healthy foetus.

In the 1970s pilot population programs directed to reduce the incidence of β -thalassemia major by carrier screening, counselling, and prenatal diagnosis were started in several at-risk communities in Mediterranean populations. (Angastiniotis and Hadjiminias 1981; Loukopoulos 1996) Several countries have comprehensive national prevention programs, which include public awareness and education, carrier screening, and counselling, as well as information on prenatal diagnosis and preimplantation diagnosis (Godard et al. 2003).

In most programs, carrier screening and counselling are implemented on a voluntary basis, these interventions would therefore be classed as soft paternalism. Cyprus, however, differs as the Orthodox Church has significant political and societal influence and as such requires certificated evidence that screening for β -thalassemia has been performed before marriage. This ensures that the decision of two heterozygotes getting married is not taken lightly, with the final decision on marriage and reproductive matters being left to the couple (Kalokairinou 2008). It was not until 2004 when Cyprus became a member State of the European Union in 2004, that pre-marital certification requirement became obsolete for civil (but not religious) unions (Kolnagou and Kontoghiorghes 2009). These long-established prevention programs have succeeded in achieving 80–100 % prevention of beta thalassaemia major. (Angastiniotis and Modell 1998) If done sensitively and without casting any blame on parents who are carriers of a specific gene (or related between them) through no fault of their own moderate paternalism may in practice empower couples to make the right decision for them and their families as the procreative choices still stay firmly within their hands, but with more significant safeguards placed by the State and healthcare authorities. Such interventions are likely to affect pre-conception and antenatal behaviours in a way that allows for the creation of a far healthier foetus and eventual child.

The big question is: can the State ever have a moral duty to enact hard paternalism in the interest of future generations; and if so should the government, in keeping with the HFEA 2008 amendments (and on the basis of the ethical principles outlined above), have enough reason to impose such therapies in the womb to allow for better welfare and societal functioning? At the point of writing there are enough intrinsic safeguards that make this question self-evident. Foetal surgery and in utero genetic therapies are in their infancy, the risks to the mother and foetus vary from the uncertain to the unsafe and outcomes are far too variable to base any concrete medical recommendations on, let alone public policy guidelines. There may be a time when these technologies are safe for all parties with

concrete clinical outcomes. Should that time come I still have considerable reservations as to whether hard paternalism should be employed to promote the welfare of the unborn, even if the intention is for that specific foetus to come to existence. For one, it is extremely difficult for the best interest of the child principle to override parental interests and autonomy. The interests of other family members almost invariably play a significant role and in many cases what the best interest of the child is will be unclear. (Harris and Holm 2003). Secondly, routine enforced interventions for the interests of the foetus are likely to erode the physician-patient relationship and trust in a way that takes us back to the dark, unsafe ages of backstreet abortions and similar quackery amounting to more maternal death and grief. Thirdly, the State clearly has both an interest and a responsibility in having children born in the healthiest possible state, or in disallowing foetuses to be born in an otherwise less-healthy state. This does not imply the State should abort unhealthy foetuses and replace them with healthy ones, this would create entirely new children and the harm principle can only be applied as a continuum. Instead it implies that society has an interest in existing foetuses to be born in their healthiest possible state. Before soft and moderate paternalistic approaches are exhausted, thereby proving that the optimum conditions for the creation of healthier children have been employed, making parents more educated and aware of their reproductive choices in the meantime, the State cannot claim moral authority to surgically intervene in the life of *compos mentis* citizens.

Conclusion

It is evident from the HFEA's amendments in 2008 to safeguard against disability selection there is a move towards legislation that ensures that advanced reproductive technologies are applied for what they were initially intended, helping couples procreate healthy children. Central to these amendments is the welfare of the eventual child. This, in conjunction with legal systems in the West seemingly more intent on affording the foetus with more legal protection raises possibilities that, in future, when foetal surgery and in utero gene therapies are much safer to both mother and foetus, with consistent positive clinical outcomes, the State is also likely to need to legislate to safeguard the birth of healthier children. As long as the parents have decided to carry on with a specific pregnancy, and not abort due to a specific disability of the foetus, then not engaging with such therapies in order to maximize the eventual child's health and potential to flourish would leave the child with a grievance as it will have been harmed by his parents omission whilst he/she was in the pre-

personal state. It is clearly a challenge as to when the State should promote such technologies. I have made a case that if a threshold of harm befalls the foetus then it would be in society's interest for the State to do so. Assessing the magnitude of harm antenatally is a challenge, there is wide variation of accounts of disability and assumptions on one's quality of life is rarely accurate. The task is further magnified by the variable degrees of disability in progressive conditions that become more severe when children grow and develop. I have suggested that whilst consideration needs to be given to Glover's potential of flourishing dictum and Feinberg's open future argument, perhaps a modified ICIDH scale for the developing child, focusing purely on the objective medical aspects of the disease may be of use once these technologies become less experimental and more mainstream. I maintain that whilst the State should promote these therapies via soft and moderate paternalistic avenues that allow the parents to make their own, albeit better educated, reproductive choices, hard paternalism is a path best avoided and unlikely to be implemented.

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