AUTONOMY, TECHNOLOGY AND PRENATAL SCREENING

AUTONOMY, TECHNOLOGY AND PRENATAL SCREENING: WHAT A RELATIONAL UNDERSTANDING OF AUTONOMY AND A POSTPHENOMENOLOGICAL MODEL OF TECHNOLOGY CAN CONTRIBUTE TO THE ETHICAL DISCOURSE OF PRENATAL SCREENING.

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Abstract

This thesis explores the contribution that both a postphenomenological understanding of technology and a relational understanding of autonomy can make to the ethical debate over prenatal screening. Postphenomenological theories of technology make the surprising move of viewing artefacts as *actors* without agency. This move is useful because it allows artefacts to be socially embedded and able to convey intentionality in their relationships of mutual constitution with human subjects. The relational model of autonomy views autonomy as a capacity that is developed via our relations with others. Self trust is a key component of relational autonomy because in order to exercise autonomous capacity one has to have trust in oneself to make autonomous decisions. A key area of the ethical debate over prenatal screening can be articulated in terms of how prenatal screening interacts with and contributes to the identities of individuals, artefacts and social groups involved. Practices such as prenatal screening have a large influence on social identities because they overlap with significant social, ethical and political issues - such as the rights and value of women, people with disabilities and fetuses - and ethical values such as autonomy. Narratives that arise in our interactions with prenatal screening are particularly important because they have particular force of voice due to the authority that 'medicine' and 'science' imbue them. Prenatal screening provides a useful service and I am not arguing that prenatal screening should not be conducted but rather that we need to be aware of how the particular practice of prenatal screening interacts with both individuals and artefacts to contribute to a variety of social narratives, some of which are coercive, or harmful to particular social groups.

Acknowledgements.

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Introduction

Prenatal screening, a population based health initiative to screen the fetus for

Down's syndrome, Trisomy 18 and neural tube defects in early pregnancy is a topic in

bioethics that is the subject of continuous ethical debate. Until recently prenatal screening

was restricted to high risk subpopulations of pregnant women such as those over 35 years

of age; however a slew of "wrongful birth" lawsuits in North America has recently lead to

legislation in Canada mandating that all pregnant women be explicitly offered prenatal

screening as part of routine prenatal care.[1] Such legislation raises questions about cost

effectiveness, the legal liability of medical professionals and whether the requirements of

informed consent are met by women who undergo prenatal screening. However it also

raises questions about how well intentioned practices such as prenatal screening promote

problematic social values. Does requiring that pregnant women be offered screening

suggest to the disabled population that they are less important or less worthy? Although

offering screening increases choice, does this correspond to an increase in the autonomy

for women involved in the practice? How does prenatal screening impact on social

discourses of the fetus? In the leading medical journals current discussion of the ethical

problems with prenatal screening is limited to analysis of the informed consent process

for prenatal screening, a complex problem in its own right. However there is no

recognition of the more subtle and complex social issues that arise from the particular

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[1] Mark Pioro et al, "Wrongful birth litigation and prenatal screening" *Canadian Medical Association Journal* 179 no. 10 (2008), 1027-1029.

way in which we currently conduct the practice of prenatal screening especially how the widespread use of prenatal screening contributes to social beliefs about pregnant women, the fetus and people with disabilities.

This thesis will argue for an understanding of the ethical issues that arise from prenatal screening beyond informed consent as arising from the interaction of actors in the discourse, where both people and technological artefacts are conceived of as actors in the discourse whose identities are developed during the course of the interaction. Two concepts key to prenatal screening are 'technology' and 'autonomy', and providing an in depth analysis of these concepts, via a discussion of a postphenomenological understanding of technology and a relational understanding of autonomy, allows for a better understanding of the ethical issues. One significant aim of this thesis is to reject the idea of the technology of prenatal screening as inherently problematic, and rather argue that the ethical issues arise from the way such artefacts are embedded in social discourses and interact with individuals and groups. Changing the site of the ethical problem allows for the continued usage of prenatal screening. Both the postphenomenological account of technology and the relational account of autonomy use the notion of mutual identity construction; for autonomy this is the reciprocal development of the autonomous capacities of subjects in the relationships while for technology this is the way in which the interactions of subjects and objects, artefacts and technologies, create the social meanings and identities of both objects and subjects. These underlying concepts will allow in the fourth chapter an ethical analysis of prenatal screening in terms of how

prenatal screening contributes to three key identities; pregnant women, people with disabilities and the fetus.

This thesis is divided into four chapters. The first chapter will briefly introduce prenatal screening providing an overview of the practice of prenatal screening and an introduction to the conditions screened for. This first chapter will also briefly introduce what I perceive to be the key ethical issues in prenatal screening in order to provide a context for the following two chapters that discuss philosophical accounts of autonomy and technology which are key to the theoretical framework of the prenatal screening debate. The key argument of this chapter is that we need to re-conceive our understanding of prenatal screening as a social practice in order to better understand how several key ethical issues arise. The second chapter will examine a postphenomenological account of technology. The key ideas that will be drawn from this account are: artefact intentionality, the embeddedness of technology in social discourse and the specific types of relations that artefacts can have with people and groups. A postphenomenological account of technology can help clarify bioethical debate about particular biomedical technologies used to screen for disorders during pregnancy by understanding the artefacts as actors, that is, active contributors to the shaping of meaning and discourse. The third chapter will present an account of relational autonomy. The significant ideas in this account are; understanding autonomy as a capacity and a way of thinking and that being autonomous requires self trust. Self trust can be negatively impacted by oppressive socialisation, and a lack of self trust can affect the autonomy various participants in a social discourse. The final chapter will examine how the similarities in the underlying schemas of the accounts

presented in the second and third chapters allow a better understanding of some of the ethical issues arising from prenatal screening. There are two groups whose members are potentially harmed by the current prenatal screening discourse; women, particularly pregnant women, and people with disabilities. Furthermore prenatal screening promotes a problematic understanding of the fetus. Structuring the ethical concerns in terms of identity construction allows an understanding of these harms as arising out of the larger social discourses around women and people with disabilities and how that careful consideration of the particular practices of prenatal screening may allow some of these issues to be minimised.

Chapter one: Prenatal Screening in Canada

Introduction

This first brief chapter will describe the practice of prenatal screening, what it is

and how and why it is carried out. I will also examine the social discourse that structures

the current practice of prenatal screening in Canada before going on to discuss the

problematic contribution the practice of prenatal screening makes to discourses of

disability, fetus and pregnancy. Until recently prenatal screening was offered only to

those deemed high risk, such as those over 35 years of age, but in 2007 the Society of

Obstetricians and Gynaecologists of Canada clinical practice guidelines on prenatal

screening for fetal aneuploidy were updated.[2] The new guidelines recommended that

maternal age as the sole indicator of risk be abandoned and that the program be expanded

so that all pregnant women are offered prenatal screening, a decision that was justified

through emphasis on the relative non-invasiveness of the procedure.[3] Similar changes

have been made in other countries including New Zealand-Aotearoa, the United States of

America, Great Britain, and Australia.[4] Clinical practice guidelines outline the standard of

care that can be expected from any practitioner.[5] The change in the guidelines has two

outcomes. Firstly as Pioro notes, in recommending that all pregnant women be offered

screening, the guidelines establish a situation where any medical practitioner who fails to

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[2] Summers.
[3] Ibid, 147.
[4] Pioro, 1027.
[5] It should be noted that these guidelines only cover aneuploidy disorders (extra copies of chromosomes) such as Down's syndrome and Trisomy 18 not neural tube defects or any of the other disorders it is possible to screen for.

offer prenatal screening to a patient can be sued for wrongful birth if a child is born with a

screenable condition and the parents can show that they would have aborted had the

information been available to them.[6] Like Pioro, Nancy Press, in her interviews with

Californian women who underwent prenatal screening in the early 1990s, recognises how

prenatal screening is reinforced by the legal interest medical professionals have in not

wanting to be sued for malpractice or wrongful birth.[7] This can have a significant

influence on how prenatal screening is conducted because medical professionals are the

dominant group in setting prenatal screening policy, and concerns about being sued could

lead them to present prenatal screening more urgently and forcefully than they would

otherwise. This could be significant as women who are ambivalent or uncertain about

undergoing prenatal screening are extremely influenced by the opinions of their doctors.[8]

Secondly, medical narratives are extremely dominant in the construction of social

meanings and identities. The particular biomedical ways of understanding both objects

and subjects very strongly influence the wider understandings of both subjects and

objects. The biomedical way of understanding 'pregnant woman,' disabled person' and

'fetus' often overrides the contribution made by other relations to these identities. For

instance, the medical understanding of disability can unbalance the identities of people

with disabilities because medical relations to disability are structured in terms of the

health problems associated with having the disability. Biomedical relations are

authoritative in part because they draw on science, which is perceived to be a truth

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[6] Ibid, 1027.
[7] Press and Browner, "Risk, Autonomy and Responsibility" S11.
[8] Chiang, 276.

providing authority. This is problematic because the overall social discourses of these identities then becomes dominated by these singular understandings and other relations are ignored. Social practices such as prenatal screening influence how individuals involved in those practices are understood. The way in which a practice such as prenatal screening interacts with pregnant women can influence how 'pregnant woman' 'fetus' or 'disabled person' is valued in the abstract and how particular individuals are treated by others in everyday life. The model of mutual identity construction is reciprocal however, therefore not only does the current practice of prenatal screening influence the identities of pregnant women and people with disabilities but it also leads to prenatal screening being devalued and labelled an ethically 'bad' technology. The next section will examine prenatal screening as a policy and using a postphenomenological conception of technology examine both the social narratives that facilitated the uptake of prenatal screening and the social narratives that are promoted by our relations with prenatal screening.

Down 's syndrome and Neural Tube Defects: The conditions being screened for.

Prenatal screening is one aspect of the larger practice of prenatal testing that also includes prenatal diagnostic testing. Prenatal screening is a population health measure in which every pregnant woman is offered screening, via prenatal ultrasound and blood tests, to check for markers of fetal abnormality. It is only when these tests come back with a positive result – indication of a heightened risk of one of the screened for conditions – that a pregnant woman is then offered diagnostic testing such as amniocentesis or

chorionic villi sampling which provide a definitive diagnosis.[9] Hence, prenatal screening

should be understood "not [as] an isolated test but the first step in a filtering process of

multiple possible tests and decisions."[10] Down's syndrome is the most common disorder

screened for. A condition that results from having an extra copy of chromosome 21

(Trisomy 21), Down's syndrome results in a wide variety of health problems where

individual cases can greatly differ in both type and severity. The effects of Down's

syndrome include reduced cognitive ability in the form of mild to moderate retardation,

delayed physical development and characteristic physical features such as a flat face.

People born with Down's syndrome are also at increased risk of a variety of health issues

including congenital heart defects, intestinal blockages, cataracts and hearing difficulties.

Although there is no cure for Down's syndrome, individual health issues can be treated

and people's quality of life can be enhanced via therapies and extra support. [11]

The second most common form of abnormalities screened for are neural tube

defects. The most common neural tube defect is spina bifida which is caused by the tube

containing the spinal cord failing to close, causing damage to the exposed nerves. The

placement on the spine of the opening is the major determining factor of the degree of

damage caused as there is often nerve paralysis below the opening. Although surgery

after birth can close the opening this does not restore function to the damaged nerves. The

higher up the spinal column the opening, the more severe the effects of the neural tube

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[9] Summers et al, "Prenatal Screening for Fetal Aneuploidy" *Journal of Obstetrics and Gynaecology Canada* 29 no. 2, (2007). 148-149. -Amniocentesis and CVS are only offered to those with a heightened risk a precaution taken because both these more accurate procedures carry a risk of miscarriage.
[10] Seavilleklein, 7.
[11] National Institute of Child health and Human Development, *Down's Syndrome*, http://www.nichd.nih.gov/health/topics/Down_Syndrome.cfm (21 August 2009)

defect, which can cause problems walking and a lack of bladder and bowel control. The

most severe form of spina bifida, although more rare, causes the back part of the brain to

be displaced into the neck causing problems which may need to be relieved surgically and

can lead to permanent brain damage, learning disorders and delays in mental and physical

development.[12] Anencephaly is the most severe form of neural tube defect, which is

caused when the upper end of the neural tube fails to close resulting in a fetus without a

forebrain. Anencephalic fetuses are most often still born or spontaneously abort, and

those that are not die within hours after birth. There is no treatment for neural tube defects

although the incidence can be reduced by 75 percent given folic acid supplementation in

early pregnancy.[13] The third condition commonly screened for is Trisomy 18 which is

almost as deadly as anencephaly: 50 percent of foetuses with Trisomy 18 die in utero,

while only 5-10 percent of those that survive until birth will survive the first year.[14]

Trisomy 18, like Down's syndrome, is associated with a wide variety of physical and

mental problems, most commonly heart defects and kidney problems.[15] There is no way

to prevent or cure Trisomy 18.

These conditions thus vary from moderately debilitating, (Down's syndrome), to

lethal (anencephaly) where the most common conditions have the least debilitating

consequences, and the rarest the most severe. While Down's syndrome has an incidence

of 1/800 the more severe Trisomy 18 has an incidence of 1/3000. The incidences of

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[12] National Institute of Child health and Human Development, *Neural Tube defects,*
http://www.nichd.nih.gov/health/topics/neural_tube_defects.cfm (21 August 2009)
[13] Ibid.
[14] Genetic Home Reference Library, *Trisomy 18* http://ghr.nlm.nih.gov/condition=trisomy18 (21 August 2009)
[15] Medline Plus Encyclopedia *Trisomy 18* http://www.nlm.nih.gov/medlineplus/ency/article/001661.htm (21 August 2009)

neural tube defects are harder to calculate because of the recent introduction of mandatory

folic acid supplementation in many countries. Currently in Canada, Spina Bifida has an

incidence of 1/1,000 while the incidence of anencephaly is 0.55/10,000.[16]

Prenatal screening: a history.

Diagnostic testing for specific hereditary disorders became available in the 1950s

but was limited both in availability and scope, mainly limited to the provision of risk

assessment for pregnant women with family histories of disorders that follow simple

Mendelian inheritance patterns.[17] In the early 1970s prenatal diagnosis became available

on a wider scale due to a combination of events including the development of

amniocentesis, the legalisation of abortion in Canada, the United States of America, the

UK, and France, and the identification of prenatal karyotypes for Down's syndrome.[18]

Neither Down's Syndrome nor neural tube defects, the other disorder tested for at this

time, are hereditary but rather arise from a mischance in the early stages of fetal

development (neutral tube defects) or during fertilisation (Down's syndrome). In the late

1970s, a blood test that could detect the level of alpha-fetoprotein (AFP) in the maternal

blood serum was developed, and was first offered in Canada in 1985: the first time

prenatal screening was offered in Canada. High levels of AFP indicate a risk of neural

tube defects while low levels indicate a risk of Down's Syndrome. Maternal Serum AFP

testing is a low risk method to identify those fetuses with an elevated chance of NDTs or

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[16] Phillipe De Wals et al, "Reduction in Neural-Tube Defects after Folic Acid Fortification in Canada, *New England Journal of medicine,* 357 no.2 (2007), 135-142, 138.
[17] These disorders include Huntington's, Tay-Sachs, Muscular Dystrophy and Cystic Fibrosis and are still tested for today using more refined techniques.
[18] Seavilleklein, 27.

Down's syndrome. Pregnant women who have abnormal levels of AFP can then go on to

have diagnostic testing using amniocentesis.[19] Since the 1980's, new serum markers have

been introduced to both increase the accuracy of the risk assessment for neural tube

defects and Down's syndrome, and to test for other disorders.[20]

Current practice in Canada involves assessing the levels of three serum markers,

human chorionic gonadotrophin, unconjugated estriol and AFP. The level of deviation

from the norm in any of these markers indicates the level of risk for a disorder, with more

deviation indicating higher risk. This triple test is offered between 16 and 18 weeks of

gestation and has a risk threshold for Down's Syndrome of 1/385, meaning that any

pregnant woman who is assessed as having more than a 1 in 385 chance of having a child

with Down's Syndrome is said to have a positive result and encouraged to have further

testing. At this threshold rate the triple test will identify 71% of all cases of Down's

syndrome with a false positive result of 7.2%. An ultrasound is routinely performed

between 18-20 weeks of gestation, not only to examine the fetus for abnormalities but

also to measure fetal growth which then allows for further adjustment of the risk

assessment. It is also becoming increasingly common for first trimester screening to be

offered between 11 and 14 weeks of gestation using two serum markers, free β-human

chorionic gonadotrophin and pregnancy associated plasma protein A. Levels of these

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[19] Bridget Kuehn, "Study Downgrades Amniocentesis Risk," *Journal of the American Medical Association* 296 no. 22 (2006) 2663-2664, 2663. Amniocentesis is not routinely offered to all pregnant women because the procedure has a significant risk of inducing miscarriage. Rates of miscarriage for amniocentesis are given as between 1/200 and 1/400 depending on the study.

[20] Summers, 151. The introduction of human chorionic gonadotrophin increased the accuracy of screening for Down's syndrome and trisomy 18 while testing the level of unconjugated estriol increases the accuracy for neural tube defects Down's syndrome and Trisomy 18.

markers can be used to assess the risk of both Down's syndrome and Trisomy 18.[21]

Furthermore the use of first trimester ultrasound to assess the thickness of the nuchal fold,

another marker for Down's syndrome, is also becoming more common although its

availability is limited by a lack of trained practitioners in Canada.[22] It is becoming more

common now to offer integrated prenatal screening in which the results of all the

screening blood tests from both the first and second semesters and the nuchal ultrasound

are combined to give an even more accurate risk assessment. The screening blood tests

are offered within the sequence of routine prenatal care, as part of the greater sequence of

blood tests offered to pregnant women. Prenatal tests are also conducted for rubella,

syphilis, hepatitis B and anaemia, all of which are treatable conditions of the mother that

can harm a fetus if steps are not taken for protection.[23][24] We can thus draw clear

distinctions in kind between prenatal screening, which provides risk assessment of the

potential for Down's syndrome, NDT and Trisomy 18 in the fetus, and the maternal blood

tests which look for conditions in the mother that could affect fetal development. A

further distinction can be drawn between the risk assessment of prenatal screening and

later diagnostic testing via amniocentesis or CVS.

Ethical problems with prenatal screening

One reason I have included such a detailed description of the technical process of

prenatal screening and the variety of conditions being screened for is to indicate the

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[21] Ibid, 151-152.
[22] Ibid, 153-154.
[23] BabyCenter Canada, "Routine Blood Tests"
http://www.babycenter.ca/pregnancy/antenatalhealth/testsandcare/bloodtests/ (21 August 2009).
[24] The Society of Obstetricians and Gynaecologists of Canada, "Women's Health Information: Pregnancy:
Prenatal Diagnosis". http://www.sogc.org/health/pregnancy-prenatal_e.asp (21 August 2009).

complexity of the information that needs to be conveyed to pregnant women. Not only are there significant variations between the severities of the conditions being screened for; in the case of the aneuploidy conditions, Down's syndrome or Trisomy 18 there is the additional complexity that the range of possible severity within the condition is also wide. Another potential source of confusion is in understanding what exactly is being conveyed by the results of the screening because prenatal screening is not a diagnostic test but an indicator of risk : that there is a X% chance that your fetus will have Y condition, rather than a definitive positive or negative result. Problems with the informed consent process are a source of significant concern to bioethicists interested in prenatal screening. The problematic historical relationship women have had with autonomy and being considered autonomous will be discussed in later chapters. Because informed consent is a concept in biomedical ethics that derives from autonomy, any practice focused on women, particularly ones involving reproduction and pregnancy that has problems with obtaining, or fails to obtain, informed consent is particularly problematic.

This chapter briefly introduces the major ethical concerns being discussed by the bioethical community with regards to prenatal screening with particular emphasis on the Canadian context,. These concerns will be discussed in terms of the role that the discourse of prenatal screening plays in constructing the identities of pregnant women, people with disabilities and fetuses and the problems that arise from the particular ways prenatal screening currently constructs these identities. Not only does the current practice of prenatal screening reinforce and construct the self so as to negate or decrease the autonomous capacity of the particular pregnant women, but prenatal screening also

promotes, constructs, and reinforces problematic social discourses about people with

disabilities, pregnant women and fetuses.[25] These understandings are problematic in two

ways, first because they contribute to the oppression of women and people with

disabilities, thus making it more likely that people in these groups will not have the self

trust necessary to make many particular autonomous choices let alone be

programmatically autonomous.[26] Second they are problematic because prenatal screening

as it is currently practiced provides a single way of understanding the fetus that is

extremely dominant in current North American society.

Conclusions

Prenatal screening constructs the fetus as a patient and individual in its own right

and this is problematic because it increases tensions between the pregnant woman and her

fetus, understanding them as at odds or as competing. This can impede the autonomy of

pregnant women both directly and via reinforced problematic social narratives such as the

right to life anti-abortion movements. The fourth chapter will examine each of these

issues in depth. It will examine how the current practice of prenatal screening can harm

people with disabilities, the problematic contribution the current practice of prenatal

screening makes to the identities of pregnant women both directly via informed consent

and to the wider social identity of pregnant women. Finally it will examine prenatal

screening's contribution to social discourses of the fetus. In each section I will draw on

current bioethical literature which has identified these problems and I hope to strengthen

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[25] I understand social narratives to be the particular results of relations (either between objects and subjects or between subjects) that together contribute to forming the wider social discourse on any given identity.
[26] Programmatic autonomy is acting autonomously with regards to ones whole life.

their arguments by explaining the particular mechanisms in terms of the mutual construction of identities of the artefacts and pregnant women and the impact of these particular relations on the wider understandings of 'women', 'disability' and 'fetus.' First however I wish to provide detailed accounts of the models of autonomy and technology that I will use in my discussion, a postphenomenological understanding of technology and a relational understanding of autonomy. The implications of these particular models to understanding prenatal screening are not always obvious.

Chapter Two: Technology

Introduction:

The successful analysis of the ethical role of technology in debates on prenatal

screening requires a clear account of both how technology functions and how it interacts

with ethical subjects. One question to be kept in mind throughout this chapter is how

technologies involved in prenatal screening practices, such as ultrasound and

amniocentesis, interact with and inform the constructions of a subject, in particular how

such practices inform the autonomy of subjects, given a relational understanding of

autonomy, as will be explored in the next chapter. Although postphenomenology posits

an extensive philosophy of technology, this chapter will draw on only those aspects of the

theory central to the exploration of the interactions of artefacts and ethical subjects.[27]

Hence the focus of this chapter will be on two aspects: first, explaining artefacts to be

socially embedded actors, second, exploring the types of relations that can occur both

between subjects and artefacts and between artefacts and societies.

Historically, the philosophy of technology has been affiliated with the analytic

philosophical tradition and has thus focused on analysing technology in-and-of-itself,

rather than technology as embedded in, and contributing to society.[28] This tendency to

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[27] Postphenomenology is a branch of phenomenology that incorporates key ideas from postmodernism to analyse artefacts and their relations to people and each other. Major proponents include Don Ihde, Evan Selinger and Peter Paul Verbeek.

[28] Hans Achterhuis, "Andrew Feenberg: Farewell to Dystopia" in Achterhuis (ed.), translated by Robert P. Crease, *American Philosophy of Technology the Empirical Turn,* (Bloomington: Indiana University Press, 2001), 65.

focus on the abstract notion of technology stands in contrast to the postphenomenological approach, which draws upon Science and Technologies Studies and, specifically, its examination of particular technologies embedded in particular circumstances. One problem with focusing on technology in-and-of-itself as a site of study is a tendency to view technology as a singular monolithic object and consequently the desire to make generalisations about all technologies in an attempt to find common traits universal to all 'technology'.[29] A socially embedded understanding of philosophy of technology is superior to a monolithic account when discussing the normative implications and values of technologies because it more closely reflects everyday understandings that inform public debate including ethical dialogues about specific social practices such as prenatal screening which in turn allows the formulation of an ethical lattice upon which to discuss bioethical issues that involve technologies. The most relevant account of technology for providing this lattice is postphenomenology which arises out of the work of Don Ihde.

Postphenomenological technology studies draw on three main traditions: Science and Technology Studies, a social sciences sub-discipline which provides sociological accounts of the embedded existence and usage of specific technologies; phenomenology, which provides a method for understanding how specific embodied individuals and technologies interact; and pragmatist philosophy, which provides a normative framework in which the discussion can take place, specifically a discussion that is both anti-essentialist and anti-foundationalist.[30] In justifying the relevance of this particular philosophy, it is instructive to first briefly examine other approaches to understanding

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[29] Ibid, 68-69.
[30] It also draws on Hermeneutics for the account of scripts

technology and thereby account for the weaknesses of these alternate approaches, specifically as they relate to – or, indeed, fail to relate to – empirical data about the role and uptake of technologies in existing societies. Thus the first part of this chapter will provide the historical context in which the postphenomenological theory of technology developed, the second section will develop the idea of artefacts as actors while the third will examine the types of relations that artefacts can have. The final brief section will draw out what I see to be the ethical implications of the postphenomenological form of analysis.

Postphenomenology in Context: A History of Philosophy of Technology.

The historically dominant philosophical understandings of technology can be divided into three distinct eras: premodern, modern and contemporary. Premodern philosophers of technology, those who wrote before the Sixteenth century, examined the role of technology in shaping society, as "always guided by the symbolic cultural reality that preceded them and in which they were embedded."[31] In contrast, philosophers of technology in the modern era, the Sixteenth to Nineteenth centuries, focused on the "transcendental conditions" required of technology, looking for those characteristics shared by all technology. Both modern and premodern positions can be distinguished from contemporary philosophers of technology who rely extensively on empirical data and the examination of concrete manifestations of specific technologies in their

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[31] Hans Achterhuis "Borgmann, Technology and the Good Life? and the Empirical Turn for Philosophy of Technology" *Techné: Research in Philosophy and Technology* 6, no.1 (2002). http://scholar.lib.vt.edu/ejournals/SPT/v6n1/achterhuis.html (21 August 2009)

discussions of what technology is and its role in society.[32,33,34] With contemporary

philosophers of technology we find a return to the earlier understanding in which

technology is embedded and formed in particular socio-cultural discourses. However the

contemporary methodology is distinct from the premodern because of its incorporation of

empirical methodology in its exploration of 'technology'. It is from the work of 20th

century authors such as McLuhan, Kuhn and Latour that the start of the contemporary

approach can be dated and from when philosophy of technology began to examine the

implications of understanding technology as culturally embedded rather than a culturally

isolated self governing entity.[35]

Philosophers of technology in the modern period, from Francis Bacon to Martin

Heidegger, were profoundly influenced by what they saw as the power of new modern

technologies, such as the printing press, gunpowder and the compass, to transform reality.

Their philosophical understanding of technology was rooted in a concern with the

"transcendental condition that made technology possible" those traits and characteristics

that made something 'technology'.[36] Consequently, in the modern period technology

became understood to function as an autonomous domain, independent of the conditions

in other social spheres such as religion and politics. Key to the modernist understanding

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[32] Hans Achterhuis introduction to *American Philosophy of Technology the Empirical Turn*, edited by Hans Achterhuis (Bloomington: Indiana University Press, 2001), 3.
[33] 'Artefact' and 'technology' are used almost interchangeably throughout this paper however there is I think a small difference between the two more related to the mindset of the viewer rather than the specific object. Technologies can also be processes involving an array of artefacts.
[34] Focusing on the transcendental conditions of technology means they were looking for the necessary and sufficient conditions for technology e.g.: being a tool, in an attempt to find the essential identity of 'technology'.
[35] Ibid, 6, 68.What I term the contemporary approach Achterhuis calls the empirical turn and Feenberg terms 'critical theory'.
[36] Ibid, 3-4.

of technology was that technologies were a tool, both governable and controllable. This caused a belief that placing boundaries and restricting usage would allow full control of technology. This approach would constitute the intellectual base for the eventual development of the contemporary approach, including the central ideas that technology is more than mere applied science and that it can be understood as a system. As is noted by Hans Achterhuis, the debate over the modernist understanding of the nature of technology is often framed in terms of technology being either an 'instrumental' tool or 'substantive' and autonomous. The instrumental view asserts that technology is socially neutral and functions the same way in all societies: the only norms of technology, in this conception, are that it values efficiency above all else and assists us in realising our pre-established goals. Technology by this view cannot change either our goals or us. The substantive position holds that technology creates new cultural understandings that draw its users' sense of reality "under its logic of domination". Rather than dictating the terms of technology usage, users are reduced to interchangeable cogs in the greater machine.[37] Despite their differences, both these theories can be considered thoroughly modern: seeing technology, as they do, as a monolith unaffected by, and detached from, society.

This binary understanding of technology and culture is complicated, however, by the work of Andrew Feenberg, who offers an alternative 'critical theory'[38] position. It is from this view that the contemporary philosophical understanding of technology, as part

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[37] Ibid, 68.
[38] Feenberg terms this critical theory because it is critical of both the instrumental and substantive understandings of technology, yet it incorporates aspects of both.

of a cultural system, develops.[39] Contemporary and critical studies approach does not

view efficiency as the central determining force on the forms that technologies will take;

but, rather social interests, cultural values and sheer chance are understood as being

equally influential. The work of Latour is located within this new tradition. He

contributes several key concepts to the contemporary debate which extend the

understanding of technology beyond older, modernistic notions of efficiency as sole

motivating force. The notion of *underdetermination,* for example, posits that there are

always multiple reasons that one technology is preferenced over another. There is never a

single reason for why one particular form of a technology is used over any other: "the

final decision about [technological] alternatives ultimately depends on the 'fit' between

them and the interests and beliefs of the various social groups that influence the design

process."[40] There is no set or determined path towards a particular form of a technology

but rather the path of technological development is contingent.

Phenomenology becomes Postphenomenology

The main contribution of the work of Don Ihde is to incorporate phenomenology

into the contemporary approach to philosophy of technology. In doing so he provides a

method for analysing how the particular interactions of people and artefacts structure the

identities of the interactants. The third chapter of this thesis will show how useful such an

approach is to a discussion of the ethical issues in prenatal screening. Ihde's engagement

with technology, from a phenomenological perspective, examines both the roles of

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[39] Ibid, 72-73.
[40] Andrew Feenberg, Alternative Modernity: The Technical Turn in Philosophy and Social Theory. Berkeley: University of California Press, 1995), 4.

specific technologies in everyday life and how these various technologies influence human relations to the world. The phenomenological approach argues that subjects and objects, humans and artefacts, cannot be understood separately from one another: a form of connectedness that is termed *intentionality*. This interpretation of technology, and objects more generally, arises out of the work of Maurice Merleau-Ponty, who characterises objects as a means of experiencing the world. In this conception, objects provide enhancement and alternative means of perception. Thereby objects contribute to determining the manner in which we experience and exist in the world. From this perspective, not only are objects shaped by our desires and needs, but we are also shaped by them.[41] Things are never experienced as things-in-themselves, only as things-for-us, because 'objects' "are always revealed [to us] within a specific context of interpretation or praxis."[42,43]

Although the initial intention of those philosophers who would come to be associated with phenomenology was the description of reality itself, the work of thinkers such as Husserl, Heidegger and Merleau-Ponty has since been taken up as a method for analysing human relations with reality. Merleau-Ponty characterises this relation in terms of perception, Husserl in terms of consciousness and Heidegger in terms of "dasein," or

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[41] Peter-Paul Verbeek "Don Ihde: The Technological Lifeworld" in *American Philosophy of Technology the Empirical Turn,* (Bloomington: Indiana University Press, 2001),125-126.

[42] Ibid, 121.

[43] Merleau-Ponty's contemporary, Martin Heidegger, applies the phenomenological mode of philosophy directly to technology, arguing that technology is *the* primary mode of interpreting the world. This interpretation is at odds, with that offered by Ihde, for whom technology is simply a mode of interpretation that, while it may be currently dominant, is not ahistorically or universally so. Thus where Heidegger sees a technological form of world disclosure, Ihde, following Merleau-Ponty, examines the type of world made possible by specific technological artefacts and the different forms that relations to the world can take as made possible by artefacts.

being-in-the-world. Ihde follows Merleau-Ponty in conceiving of the human-reality relation in terms of perception but expands and adapts Merleau-Ponty's explanation, so as to identify "intentionality" as the key aspect of this relation and to assert that it is through various technologies that humans experience the world. Thus Ihde posits a relation considerably more complex than the classic phenomenological understanding in which the subject and object mutually constitute each other yet also serve to mediate perceptions of the world. In Ihde's modified understanding "human-world relationships should not be seen as relations between pre-existing subjects who perceive and act upon a world of objects, but rather as sites where both the objectivity of the world and the subjectivity of those who are experiencing it are constituted" thus rejecting a framework of stable identities, in which "subjects are active and intentional, and objects passive and mute."[44] The next section will focus on postphenomenological understandings of subjects and objects are actors in social discourses.

Actor Network Theory: Actors in Postphenomenology

Actor network theory is a critical approach to understanding the role of science and technology in social relations in which meaning is understood as being produced via relationships. Although not strictly philosophy of technology, actor network theory developed several key ideas that have been taken up by philosophical theories of technologies such as postphenomenology. Actor network theory holds that technological artefacts are actors with full agency, while postphenomenology holds a more limited

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[44] Peter-Paul Verbeek, "Obstetric Ultrasound and the Technological Mediation of Morality: A Postphenomenological Analysis." *Human Studies* 31 (2008) 13-14.

understanding of technological artefacts as actors (as not having agency). It is useful to briefly examine actor network theory because postphenomenological ideas about 'actors' flow from it. Actor network theory is a methodological approach to relational ontology that does not "make prior distinctions between entities and actors, or define in advance what kinds of entities might be granted agency and explanatory force."[45] Early actor network theory attempted to show how nature, natural facts and science are products of the relations between agents. They are products of social relations, rather than existing outside of social discourse.[46] Later actor network theory moves beyond this set of concerns to argue that there is no principled division between the technological, the social and the human at all, but rather that everything can be understood as "particular sociomaterial arrangement[s] of relations and ordering of practices that simultaneously produce the social, the technological, the embodied, the subjective and the human."[47] Actor network theory functions similarly to the semiotic postulate that the meaning of a text is the "effect of relations between signs," by applying the logic of the semiotic postulate to the wider reality to argue that it is not only texts that are produced in this way but also material objects and forms of embodiment. It is within this worldview that we can locate the postphenomenological understanding of subjects and objects.[48]

Incorporating the phenomenological understanding of subject-object relations is a key step in escaping the modernist subjective-instrumental divide and creating a new

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[45] Ingunn Moser, "Disability and the Promises of Technology: technology subjectivity and embodiment within an order of the normal" *Information, Communication and Society* 9 no.3 (2006) 373-395. 390.
[46] Ibid, 376.
[47] Ibid.
[48] Both actor network theory and postphenomenology use a loose poststructuralist understanding of 'subject' as "a location of consciousness, knowing, thinking or feeling."(Moser, 377)

philosophy of technology.[49] With this new understanding, intentionality can be understood to arise from the interaction of human and artefact rather than being a trait residing in the subject as previous understandings would hold. This continuous and interactive intentionality means that the ethical and moral aspects of a social discourse also arise from the continuing interaction, rather than any static aspect. Peter-Paul Verbeek, a postphenomenologist, argues that the idea of morality and moral decisions as even partially mediated by technology makes many uncomfortable because it allows for the possibility of partially non-human agency.[50] A similar position arises in actor network theory. Latour, a key instigator of actor network theory, argues that artefacts are legitimate full others: they are actors possessing agency in contrast to the quasi-other status of artefact assumed by Ihde's position. For Ihde the otherness of artefacts-as-actor is different from that of animal-as-actor in that animals have actual rather than just apparent autonomy. For Ihde, animals react in an importantly different way from artefacts and thus are quasi-other while artefacts are other. It is in this distinction between other and quasi-other that the difference between Ihde's position and that of actor network theory becomes apparent. This thesis will follow Ihde's position that technological artefacts are actors without agency unlike both human and animal actors who hold agency.

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[49] Early phenomenologists such as Heidegger and Merleau-Ponty sat on the edge between modernist and contemporary understandings of technology because they still took phenomenology as providing a description of reality itself rather than a method of describing relations.
[50] Ibid. A distinction can be drawn here between agency and autonomy that will be expanded in the next chapter.

Understanding the process by which objectivity and subjectivity are constituted can allow us both a better understanding of the role of technology in ethics and furthermore illuminate how we might approach those human-artefact relations that are deemed ethically problematic. Thus all subjects and objects interact within many social discourses to produce meaning, meaning that has ethical implications. Therefore one way to change problematic ethical implications is to change the interactions of actors in the discourse. Inguim Moser, an actor network theorist, discusses the general role of technologies in 'normalising' people with disabilities through the enhancement of their abilities to give them a standard range of actions and movement. Moser observes that it is only the person with disability who is seen as being produced in a fluctuating distributed network of agency while normal actors have "natural, inherent and bodily bounded agency."[51] Here, Moser is drawing attention to how agency for people with disabilities is perceived as a product of relations of mediation, rather than as an inalienable property of particular human bodies as it is for the able bodied. [52] Moser argues that in the case of the able bodied these distributions and arrangements disappear into the background while for the disabled they do not. This is because people with disabilities do not fit smoothly into standardised environments, whose design permits the agency of only abled bodies to flow without interruption. Society is organised so as to make the relations of a 'normal' person with both the world and artefacts in it fade into the background.

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[51] Ibid, 384.
[52] The types of relations that can take place, background, embodied, hermeneutic and mediated, will be discussed in the following section.

Pregnant women are similar to people with disabilities in that they often do not fit smoothly into standardised environments. If we are then to consider pregnant women, as an "other" similar to the disabled, then the usefulness of Moser's analysis to a discussion of prenatal screening becomes apparent. Both 'pregnant women' and 'people with disabilities', in particular instances and as group identities, are the product of a network of relations and one of these relations that contributes to their identities is prenatal screening. Unlike with the non-pregnant and non-disabled these relations do not fade into the background because such relations are not constituted with a non-standard body in mind. It is in this mutual constituting relation of people and artefacts that specific "objectivities" and "subjectivities" are created. One way to change problematic ethical implications is to change the interactions of actors in the discourse. To facilitate a better understanding of the different ways to make such changes the following sections will examine the categories of relation that postphenomenology posits.

Embodied and Hermeneutic Relations.

Technology mediates our relations to the world in various ways. It must thus be understood as non-neutral in that it functions to transform our perceptions and experiences in specific and particular ways, and thereby structure our understanding of reality. Ihde lists possible relations between humans and technological artefacts – alterity relations, background relations and relations of mediation – which will be discussed more extensively in the next section, specifically in terms of the extent to which technology may inflect one's perception of reality. In delineating forms that technological mediation can take Ihde creates a schema which could prove useful in analysing the role of

technologies in bioethical problems. Different types of ethical problems can be associated with different forms of technological mediation and thus examining and explicating the distinct types of mediation is directly relevant to an examination of the forms of technological mediation present in the case of prenatal screening. Thus the following sections will examine and explicate the four main types of relations posited by Ihde.

There are two levels on which we can examine technological artefacts within postphenomenology, the macro and the micro. The macro level consists of cultural relations with technologies and artefacts, and explores how particular technologies and artefacts exist within any given culture. Macro level relations will be taken up in the later section *macro-relations and ontological multistability*. On the micro level, Ihde proposes the dual notions of *embodiment relations*, which analyse the interaction of technologies and specific bodily sensory perceptions in terms of "broaden[ing] the sensitivity of their bodies to the world,"[53] and *hermeneutic relations*, wherein technologies are analysed in terms of representations of the world such that technology is thought to provide an alternative way of interpreting the world. Embodied relations are characteristically transparent in that they are aids to viewing the world, allowing the "reflexive transformation of my perceptual and body sense," rather than things that are consciously perceived in themselves.[54] For Ihde "the experience of one's 'body image' is not fixed but malleably extendable and/or reducible in terms of the material or technological mediations that may be embodied."[55] Embodied relations hold a particular kind of use-

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[53] Verbeek, *American Philosophy of Technology,* 126.
[54] Don Ihde, *Bodies In Technology,* (Minneapolis: University of Minnesota Press 2002), 72.
[55] Ibid, 74.

context in which the more transparent the technology the better, because they aim to make mediated perception as similar to unmediated perception as possible. Examples of this form of relation include the telescope and microscope in that they provide an image of something that is too far away or small to see with the unaided eye.[56] The bulldozer or digger would be other artefacts with strong embodiment relations; they become extensions of the body and increase one's ability to physically move things in the world, and the telephone which allows one to talk over large distances. Conversely, Hermeneutic relations create an alternative representation of reality rather than assisting and extending means of sensing, thus they are not transparent and require interpretation in order to understand. Ihde characterises this as textual interpretation that requires reading, although hermeneutic relations are not necessarily linked to the visual sense: "readable technologies call for the extension of my hermeneutic and 'linguistic' capacities *through* the instruments, while the reading itself retains its bodily perceptual location as a relation *with* or *towards* the technology."[57] Thus in the case of the technologies that establish hermeneutic relations, "it is the *difference* between what is shown and how something is shown that is informative"[58]. While a regular telescope provides a similar although magnified image of a star and can be understood to establish an embodied relation, a spectrogram provides an abstract representation of the light given off by the star over time that requires a significant degree of interpretation in order to understand what the image represents, and therefore constitutes a hermeneutic relation. Writing is another example

[56] Ibid, 86.
[57] Ibid, 88. His emphases.
[58] Ibid, 92.

of hermeneutic relations because it is a technologically mediated visual representation of language.[59] In hermeneutic relations the object itself [the telescope or writing] "becomes the object of perception while simultaneously referring beyond itself to what is not immediately seen...textual transparency is hermeneutic transparency, not perceptual transparency."[60] For example a window lets one see the cold outside (perceptual transparency), while a thermometer can indicate the external temperature, and thus represent the outside world in a different non visual way that nevertheless informs us of what is there (hermeneutic transparency).

Technologies that have embodied relations can be considered 'low contrast' in that they do not significantly transform how we perceive the world, while technologies at the hermeneutic end of the spectrum are 'high contrast' in that they significantly transform our perception of the world. Thus for Ihde, unlike Heidegger, technological mediation does not necessarily lead to a reduced and more specific understanding of the world, but rather can lead multiple, alternative transformations of the world depending upon the specific technology under consideration. Technology is not, therefore, an inherently controlling and dominating form but instead opens up new ways to see the world – new domains of possible interpretation. Different technologies offer different ways of perceiving the world; they each transform perception differently and perform

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[59] Ibid, 81. Arguably with all hermeneutic relations as one becomes more familiar with the mediation ones notice of the interpretation decreases and after a point the lack of conscious interpretation makes them in some ways more like a embodied relation. As one gets used to reading topological maps you cease to see a representation of the world and instead see the hills and depressions it represents, but in one way a map will never be anything but a series of lines on paper.

[60] Ibid, 82. Note that one can have both embodied and hermeneutic relations to things via different artefacts simultaneously.

different kinds of mediation via the way they extend our body in the world.[61] It should be kept in mind, however, that subject and technological object never exist separately but via the process of mediation mutually constitute each other, which is to say there is never a pure unmediated human access that exists prior to technological mediation.

The way in which an artefact makes possible the constitution of a world and a human in the very process of perception can be understood as the "access to reality" that an artefact offers. Humans and the world they experience are the products of technological mediation, and not just the poles between which the mediation plays itself out.[62] Embodied and hermeneutic relations are thus both *relations of mediation* in which a technological artefact mediates one's relation to the world. Moreover, Ihde recognises that perception is a form of interpretation, and that the goal of obtaining as close as possible an unmediated perception should be understood as a subset of interpretation that is characteristic of embodied relations, while hermeneutic relations hold for all other types of desired interpretation. The value of hermeneutic relations, contrary to embodied relations, therefore arises from the disjuncture between what is shown and how it is shown.

Alterity & Background Relations.

Other than relations of mediation there are two other more complex forms of technological relation that can be identified: *Alterity relations* are relations to an artefact as object and as other, rather than a means of accessing the world at large, while

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[61] Verbeek, *American Philosophy of Technology,* 128-130, Ihde, *Bodies In Technology,* 75.
[62] Verbeek, *American Philosophy of Technology* ,131.

background relations occur when artefacts shape our relation to reality in a non-noticeable manner.[63] Alterity relations are the relations between humans and particular technologies where the artefact becomes a quasi-other due to its apparent autonomy. An example of alterity relations is the racing car, in which one relates to the artefact as a thing in itself (car) although not to the same degree one relates to a live animal, like a horse, providing a similar function such as in a horse race.[64] In alterity relations one primarily holds a sense of relating to something else (the car), and only peripherally to the world. [65] The relationship is primarily concentrated upon the relation between I and the artefact or technology while the world is of secondary concern or interest. Ihde characterises alterity relations as "I$\rightarrow$technology-(-world)" where the -(- indicates that the world may or may not be peripherally involved in the relation.[66] In contrast, he characterises hermeneutic relations as being "Human $\rightarrow$(technology-world)" to indicate that we experience the world and the artefact as tightly bound. Ihde characterises embodiment relations as being "(human-technology)$\rightarrow$world" to show that we experience the world through a lens of technology in the case of embodiment relations. [67] Finally, Ihde characterises background relations as being different from these other relations in that the artefact is not focal and lacks self awareness.[68] In contrast to background

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[63] Don Ihde, *Technology and the Lifeworld* (Minneapolis: University of Minnesota Press 1990), 97-98 Ihde characterises alterity relations as positive rather than negative like first two forms of relations. Alterity from Levinas' term used to describe relations between humans in terms of the non reducible other.

[64] Ibid, 99. Here Ihde describes all the ways our relations to the horse and the racing car differ, including how we understand and react to malfunction/disobedience, and how a horse won't hit a brick wall when its driver is to drunk to steer properly. The horse is fully other while the car is only quasi other.

[65] Ibid, 100.

[66] Ibid.

[67] Ibid, 107.

[68] Verbeek proposes that background relations are "human $\rightarrow$ (technology-world)" but I would argue that, given the examples of horizon phenomena used by Ihde in *Technology and the Lifeworld,* background

relations, hermeneutic, alterity and embodied relations are all relations with technology that occur in the foreground.[69] However "[b]ackground technologies, no less than focal ones, transform the gestalts of human experience and, precisely because they are absent presences, may exert more subtle indirect effects upon the way the world is experienced."[70] An example of a background relation is the thermostat regulating room temperature where it is characteristically only noticeable when it is lacking. Many artefacts are specifically designed to function in the background like the thermostat, but others exist in the background because they are designated as junk and no longer function as designed, or because while once designed to be foregrounded they have now become so ubiquitous that they are background. For example, we hardly notice recorded music playing in stores.[71]

Ihde discusses how when technologies are new they can change the forms of relations they hold. Artefacts can have different forms of relation both over time and with different actors. A novel artefact is much more likely to be held in an alterity relation, then as it becomes commonplace will slip into a more long-term background relation.[72] For instance, if one has never come across a thermostatically regulated environment then one is much more likely to notice the change in temperature when one enters said environment: thus, despite the fact that the artefact itself is hidden from view, one might encounter the technology through an alterity relation. This situation would last until the

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relations can also take the form "human (-technology)→world. Verbeek, *American Philosophy of Technology,* 132, Ihde, *Technology and the Lifeworld,* 112-115.

[69] Ihde, *Technology and the Lifeworld* , 108.

[70] Ibid, 112.

[71] Ibid, 108.

[72] Ihde, *Technology and the Lifeworld* , 105.

thermostat technology became commonplace and slipped into a form of background relation. Similarly one can become so accustomed to an artefact such as glasses that they in effect become a background relation. Embodied, hermeneutic, alterity and background relations are all micro forms of relation, that take place between particular subjects and particular objects or artefacts. The following sections will examine

Macro Relations and Ontological Multistability

To return to the wider context, Ihde's understanding of macro relations is more closely aligned on the macro level with Feenberg's critical studies perspective than either instrumentalism or substantivism, each of which are contemporary understandings of technology and propose a different formulation of how technology "works" and interacts on the societal level. Substantivists argue that technology, once created, exists and works as an independent power that can substantively alter and control culture independent of human agency and intention. For substantivists, technology is as an autonomous agent that develops according to its own internal dynamic rather than something we control.[73] In contrast, instrumentalists argue that technology is a tool, a means used to human ends, which is neutral in-and-of itself and thus does not need to be judged, controlled or analysed.[74] For Ihde however it is meaningless to talk about technology as separate from culture and people, each of which only make sense when discussed in relation to the others, such that "not only does technology become what it is in and through the

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[73] Substantivist approaches to technology are trying to capture the way in which technologies seem to develop along unanticipated and undesired pathways. See the upcoming example of Mintel for an example of this phenomena.

[74] Instrumentalist approaches to technology are trying to account for those ways in which technology is of human creation and under human control.

interweaving of technology and culture, so does culture and the human beings using the technology."[75] The mutually constitutive nature of this relation is a consequence of the fact that technologies possess "ontological multi-stability", which is to say that "technologies are always technologies-in-use, and this use context is part of a larger cultural context. This contextuality makes technologies multistable."[76] Thus, technologies can have different "identities" in different contexts. These identities can also be understood as a script, the particular set of relations that will result from interactions with an artefact under particular circumstance.[77]

This does not mean, though, that multistability simply implies that technology can be understood instrumentally as artefacts or that technologies do not have inclinations towards particular trajectories/scripts (or groups of trajectories) be they intentionally sought by the designers or not. Rather, multistability can be best understood as defined by two aspects: first, the lack of any fixed singular trajectory that a technology will follow over time; and second, the fact that the same 'physical' artefact when placed in a different social-cultural milieu can follow a significantly different trajectory. An interesting analogy can be drawn here when we consider technological evolution in terms of the evolution of a species. Any given species [technology] does not remain static overtime, it changes in various and non-linear ways depending on environmental [socio-cultural] influences. Furthermore when moved to a different environment the species will often evolve significant differences and diverge from the parent population. In other words

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[75] Verbeek, *American Philosophy of Technology,* 133.
[76] Ibid, 134.
[77] The same artefact will have different scripts under different circumstances and with different people.

from the same temporal starting point a technology will change (non linearly) both over time and will interact and evolve differently when existing in a different socio-cultural context. I emphasise this point because the concept of technological multistability is central to my analysis of the social practice of prenatal screening and the practical and ethical consequences thereof, which will be discussed in-depth in chapter three.

Another way to examine the trajectories of artefacts is in terms of intentional and unintentional scripts. Artefacts and technologies can determine what scripts we follow, which is to say what decisions we make: for example cars with alarms that do not shut off until a seatbelt is put on will encourage passengers to wear seatbelts. Here making the decision is not exclusively the provenance of the human being, but also that of the car which influences the decision making process (even if it has been designed to do so by another human).[78] While acting in a manner that demonstrates how an artefact may exert agency, the car is also acting according to a script or program of action inscribed by the artefact designer. Although Latour is attempting to ascribe agency to the artefact, a controversial claim, it is enough for the purposes of my position to claim merely that the car acts, where acting is that the cars action, triggered by us, also influences what we do next. The car and human mutually construct a discourse of meaning, one that is not restricted to the immediate situation but situated within a wider network of meanings.

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[78] B. Latour. "Where are the Missing Masses? The Sociology of a Few Mundane Artefacts." Edited by W.E. Bijker and J. Law, *Shaping Technology/Building Society: Studies in Sociotechnical Change*, (Cambridge, MA: MIT Press, 1997), 225–258, 225-227.

A distinction meaningful for any ethical analysis can be drawn between intentional scripts such as seatbelt alarms and scripts unintended by the artefact designers. Whereas intentional scripts are designed into the artefact unintentional scripts occur as the accidental by-product of the interaction between artefacts, individuals and societies.[79] One unintentional script of prenatal screening is the message it sends about disability, as the selective abortion of otherwise wanted fetuses because they will have Down's syndrome, reinforces the idea that people with Down's syndrome are less valuable than 'normal' people.[80] Unintentional scripts also include when individuals use technologies for purposes other than those intended by the designer of the artefact. Examples include the use of peer-to-peer networks for decentralised information exchange on the internet, rather than the more asymmetric broadcast/hub based model that was presumed by designers.[81] It is not the 'deviant' use of the technology that creates unintentional scripts though, but rather once a deviant usage becomes normalised and the artefact is or systematically used in the 'deviant' manner.[82] An example well discussed by philosophers of technology is Mintel, a French telecommunications company which shows this well. Mintel developed a system of information terminals to be placed in people's homes with the intention of providing unrestricted access to and dissemination of a vast amount of information stored in a central archive. Mintel instead became primarily a tool used for social communication. Feenberg argues that it is the specific background of French

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[79] Unintentional here is used only to indicate that the use was not intended by the initial producer/inventor of the technology.

[80] This example will be examined in depth in the third chapter.

[81] Leslie Haddon et al., *Everyday innovators: researching the role of users in shaping ICT's,* (Dordrecht, The Netherlands: Springer 2006), 50.

[82] Deviant here simply means atypical and unintended, it is when these atypical usages become typical that normalisation occurs.

culture upon which the system developed which made the technology follow the path it did: "In defiance of the clear and explicit intention of Mintel's designers, its users in effect were able to socially "redesign" the technology"[83] The technologies in these examples did not develop along a pre-planned trajectory but rather, as posited by multistability, followed scripts that were the product of human-technology relations that were constantly developing and changing within a specific social-cultural milieu.

Ethical Implications

As noted by Verbeek, Foucault's discussion of the constitution of moral subjects fits well with any attempt to extend the postphenomenological analysis of technology and how it mediates reality into the realm of normative ethics. Foucault's view is that it is the constitution of the moral subject that is the beginning of the realm of ethical enquiry. Foucault argues that if we start with an idea of the constitution of the subject as the question about which ethics turns, then ethics becomes about what type of subject we want to be.[84] Foucault's analysis is less useful however if we wish to consider the ethics of social policy or social relations, rather than an ethics of the individual.[85] It is in determining 'good' social policy that ideas and values such as autonomy become significant. Thus, the next chapter will posit a theory of relational autonomy that understands autonomy as a capacity that we value in people. From this it becomes possible to argue that good social policy is that which promotes autonomy in people and that we should structure our social practices and policies so as to do so. A

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[83] Achterhuis, *American Philosophy of Technology*, 80.
[84] Verbeek, "Obstetric Ultrasound" 12, 18.
[85] Here I use social policy very broadly to include more than just laws and regulations but really any kind of behaviour intended (unintentionally or not) to regulate the behaviour of individuals within the group.

postphenomenological understanding of technology assists in this endeavour because it focuses on the relationships between artefacts, technologies and both individuals and societies. It allows for an understanding whereby ethics is not about what individuals do, but rather about relationships, between humans and technologies (subject-object) and between humans (subject-subject), and making ethical decisions is a matter of understanding these relationship and how they produce particular forms of moral subjects. Hence, societal level ethics becomes about structuring peoples experiences so as to promote forms of moral subjects that align with particular values such as autonomy, justice and characteristics that we, as a society, value in a good moral subject. The next chapter will examine one of these key values, autonomy.

If one accepts a postphenomenological analysis of technology then the notion of fixing ethical issues by restricting the usage of artefacts becomes problematic, because such a 'fix' assumes an instrumentalist understanding of technology. In such an understanding, "rather than taking the interwoven character of the human and the technological as a point of departure for ethical reflection, the technological is taken as a threat, which needs to be kept away from the human with the help of ethics."[86] Yet such an approach is clearly unsatisfactory in light of Ihde's postphenomenological account of technology. These frameworks begin with a mistaken assumption about the role of technology and also fail to understand how ethics and morality are dynamic socio-cultural

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[86] Verbeek, "Obstetric Ultrasound" 19.

artefacts in and of themselves.[87] Contrary to such an account, it is more productive, then, especially in the context of ethical considerations, to consider technology not as threat but rather as one of the factors that needs to be considered when we are evaluating a ethical issue to do with the constitution of subjects. To restrict ethics to merely protecting humanity from technology is a severe misunderstanding of both the nature of technology and the role technology plays in society. Rather, ethics should examine how technologies mediate and factor this into the design of heath care practices. Far too often a technology, rather than the relationship, is considered in bioethical discourse to be the source of the problem. Thus technology in healthcare ethics is often examined solely in terms of health benefits vs. safety risks, while little consideration is given to the wider social role of the technology. This will be seen in chapter four when I examine the current bioethical discourse on prenatal screening where many authors consider the technology to be the source of the problem, without pausing to consider the ways in which many of the problems can be mitigated by changing the particulars of how we engage with prenatal screening. Recognising that technologies will mediate our experiences in ethically relevant ways indicates a need to shape technological scripts into desirable paths and ensure that the inevitable unintentional scripts are not harmful.

Conclusions:

Three key ideas can be drawn from the postphenomenological account of technology. First, artefacts and technologies are best understood as actors in networks of

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[87] The particular form and content of ethical values is influenced by social discourse about the values. One way that this shift occurs is when many of the particular social narratives which pertain to that value represent or construct it in a novel manner.

meaning. Artefacts are constructed within a dynamic network of social meaning and they are as much the product of our interactions with them as we are the product of our relations with artefacts. This results in artefacts having intentionality beyond the immediate use value that is scripted into such objects and as such they should not be understood as passive and neutral but rather as actors that contribute to social discourse. Second, there are four particular forms that the relations of artefacts and individuals can take; embodied, hermeneutic, alterity and background relations. Each of these forms transforms our perception in a different way. The third key idea that can be drawn from the postphenomenological analysis of technology is ontological multistability whereby the particular form a technology takes and the particular scripts it promotes are contingent on the particular set of human-technology relations that contributed to its production. It is the ontological multistability of technology that allows the possibility of changing our relations with artefacts to minimise the harmful social discourses that arise from our interactions with prenatal screening.

Chapter Three: Autonomy

Introduction:

This chapter will focus on autonomy, a key concept in ethics which can be understood as a quality that constitutes the subject as a self-governing, integrated 'whole,' who is thus accountable for their actions. Within the biomedical realm autonomy is often emphasised as having particular importance, above and beyond other moral concepts, because it acts counter to problematic historical trends of social oppression in medical research and practice – including the idea that 'doctor knows best' and mistreatment of the subjects of medical research. Within philosophy, however, contemporary discussion of autonomy tends to focus on a narrow set of concerns centred on debates in philosophy of mind such as freewill, rationality and singular vs. multiple identities. These concerns focus on what can be termed the internal conditions of autonomy. It is, however, the external conditions of autonomy, those social practices and structures that construct and constrain the internal conditions that make autonomy possible, which are more pertinent in terms of my argument about prenatal screening. Autonomy is central to the debate on prenatal screening not only because autonomous choice for pregnant women is a key topic of ethical concern but also because the widespread practice of prenatal screening has wider consequences to the autonomy of other groups and individuals in society.

Technology, and our relations to it are external conditions of autonomy, albeit often overlooked. As argued in the previous chapter, interactions with technologies in the everyday world structure our identities and do so in ways that have ethical implications.

One thing that technologies often do is open up new possibilities and choices, which is generally regarded as a good thing; less recognised however is that opening up choices reshapes social narratives to remove previously existing choices as well. Prenatal screening is often justified in terms of how it increases both the knowledge and choices available to pregnant women, yet the way it is currently conducted in many countries problematises this claim. Findings across several countries show that not only do pregnant women not choose to undergo prenatal screening - thinking it a routine part of prenatal care - but those that do often fail to understand what they are agreeing to and also fail to comprehend the range of choices that a positive test result will force on them.[88][89] Beyond problems with the informed consent of pregnant women, current practices in prenatal screening also constrain autonomy in at least two other ways First, they restructure our understanding of the fetus – as a patient in its own right - casting it in opposition to the pregnant woman. This causes problematic social discourses in which the interests and autonomy of the pregnant woman are understood as opposing the interests of the fetus. Second, one outcome of prenatal screening is that pregnant women who test positive overwhelmingly choose to abort.[90] The selective abortion of otherwise wanted

[88] Nancy Press and Carole Browner, "Risk, Autonomy and Responsibility Informed Consent for Prenatal Testing," *Hastings Center Report* Special Supplement, 1995, S9-S12, S11.

[89] Hsien-Hsien Chiang, "Informed Choice of Pregnant Women in Prenatal Screening Tests for Down's Syndrome" *Journal of Medical ethics* 32 (2006), 273-277, 276.

[90] Nancy Press, "Assessing the Expressive Character of Prenatal Testing: The Choices Made or the Choices Made Available?" edited by Eric Parens and Adrienne Asch, *Prenatal Testing and Disability Rights*, (Washington, D.C.: Georgetown University Press, 2000).

fetuses creates a social narrative about the desirability and value of being disabled that can potentially influence disabled people in ways problematic to their autonomy.[91]

This chapter will examine the concept of 'autonomy' arguing for a relational understanding of autonomy as a capacity, which emphasises the ways in which an individual's social reality affects their autonomy. A relational understanding of autonomy is thus compatible with the idea used in the previous chapter of an individual's identity being constructed via their relations, where autonomy is understood as an integral aspect of one's identity. This will allow in the final chapter a discussion of prenatal screening in terms of relational or narrative identity construction, where the roles of technology and autonomy are particularly emphasised. The first section of this chapter will provide a general introduction to autonomy and why it is important to bioethics. This will be followed by an overview of relational autonomy divided into the internal and external conditions required for autonomy. Underlying relational autonomy is a narrative theory of identity, thus the third section will provide a brief account of narrative identity theory before the fourth and fifth sections go on to discuss the problem of oppression and how adding a requirement for 'self trust' to the relational model of autonomy negates this problem. The final section in this chapter will examine informed consent, presenting Sue Sherwin's critique of informed consent which emphasises the need to account for oppression and socialisation in any account of autonomy.

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[91] It also creates the possibility that this will lead to lower social status for people with disabilities and that this in turn will lead to diminished resources being available to them.

Why Relational Autonomy.

One key problem with in debate around autonomy is that the many particular

conceptions of autonomy such as; a right to freedom, informed choice, rational self-

legislation and voluntary rational choice, have become conflated with the concept

'autonomy'. McKenzie and Stoljar, editors of a definitive text on relational autonomy,

argue that the concept of autonomy is best understood as similar to self determination and

that all other conceptions of autonomy are derivative of this idea.[92] Confusion between

autonomy and its many particular conceptions has lead to everyday understandings of

autonomy that are based upon a murky and often contradictory conception that is

frequently left unexamined. False criteria of what is required of the properly autonomous

individual such as being an isolated, self transparent individualist who is both separate

from and unmoved by society, slip uncritically into the everyday or received conception

of autonomy, which in turn leads to a belief in problematic ideas about what is required

of individuals in order to meet the criteria of an autonomous being.[93] For example,

Loraine Code argues that in contemporary western culture, an autonomous man is seen as

one who is independent and self sufficient, yet neither of these traits is necessary for

'autonomy' as it is used in the philosophical sense. Rather emphasis upon such

normatively masculine traits leads to the devaluation of traits considered to oppose these

traits that instead align with interdependence such as loyalty, responsibility and

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[92] Catriona Mackenzie and Natalie Stoljar Introduction to *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* edited by Catriona Mackenzie and Natalie Stoljar, (New York: Oxford University Press, 2000), 5.

[93] The conception of autonomy that links ideas of the self as a transparent, isolated individualist shall be called the "received view" of autonomy – term from Jennifer Parks, *On the call for a feminist notion of autonomy in biomedical ethics*. (Ottawa: Library and Archives Canada 1996). Doctorial dissertation.

friendship.[94] In this way autonomy is often considered to be gendered as masculine as many of the traits the received understanding of autonomy opposes are those associated with feminine ways of being. New critiques, particularly those arising from feminist theory, thus challenge the received notion of autonomy and allow a new, more nuanced understanding of autonomy to arise, an understanding that reduces or resolves many commonly perceived problems in moral philosophy and bioethics.[95] It is not the goal of the feminist discussion of autonomy considered in this paper to reject the received notion of autonomy, but rather to critique the received notion and rebuild autonomy as a concept that is theoretically coherent, practically viable and does not inherently preference a white masculine way of being.

Autonomy in Bioethics

Although contemporary social and moral philosophy has provided extensive criticism of the received view of autonomy and the associated understanding of identity, there has been little uptake or even recognition of this in areas such as applied bioethics.[96] Informed consent, a key idea in bioethics, is derivative of autonomy. However when informed consent is equated with autonomy, which in turn has been understood as self sufficiency and independence, then only people who are, or have the capacity to be, self sufficient and independent can be autonomous and give an informed consent. It follows

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[94] Lorraine Code, *What can she know?: feminist theory and the construction of knowledge,* (New York: Cornell University Press, 1991), 78.

[95] Another author who makes this critique is Margaret Urban Walker in chapter 6 of *Moral Understandings* (New York: Oxford University Press, 2007).

[96] By 'applied bioethics' I mean practical bioethics as existing on the ground in biomedical practice in contrast to theoretical bioethics such as I am engaging in here. In the third chapter there will be a brief analysis of how autonomy is understood in biomedical journals addressing ethical concerns that will justify this claim.

from this that any person who is, or perceived as, interdependent or values traits associated with it cannot be autonomous. It is this misunderstanding that is especially problematic in bioethics as being able to give an informed consent is essential to almost all biomedical procedures and medical care is a central place in which the autonomy of a person is socially negotiated.[97]

In the twentieth century women were socialised to value and express traits of interdependence more than men and to a lesser degree this continues to be the case in many communities.[98] Thus in holding a conception of autonomy that associates it with traits of independence, bioethics as a discipline often continues to unintentionally comprehend as less autonomous those who value interdependence, where the majority of those who value traits of interdependence are women.[99] Furthermore during pregnancy a woman exists in a physical relationship with the fetus that presents her as not-independent from the fetus and thus less autonomous. Because of this historically problematic relationship between autonomy and women medical practices centring on reproduction need to be understood as particularly important for any discussion of autonomy in bioethics. Abortion and the 'right to choose' is the topic most often considered when autonomy is considered in terms of reproduction, yet by focusing on this one narrow aspect of reproductive autonomy what is often left out is any discussion of autonomy in a

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[97] A person's autonomy is the continuously evolving product both of social forces and internal beliefs and capacities which intersect in many ways both to reinforce and negate other out. Both large scale social forces and interpersonal relations act to reinforce, negate or remove a person's autonomy.
[98] Carol Gilligan, *In A Different Voice: Psychological Theory and Women's Development*, (Cambridge, MA: Harvard University Press, 1982), 22.
[99] I don't want to say women are more interdependent, rather that they have been socialised to believe that they should value these traits in a way men are often not. To be nurturing, caring, consider others needs.

'normal' pregnancy. With the rise of less invasive, increasingly accurate and more comprehensive testing processes, one aspect of pregnancy, prenatal testing, has risen to newfound prominence in the experience of pregnancy and many countries now offer prenatal screening routinely to all pregnant women.[100,101]

Relational Autonomy

Like the previous chapter's account of technology, the account of autonomy provided in this chapter is intended to build a foundation upon which to base the ethical analysis of the practice of prenatal screening that will occur in the third chapter. This section will present and defend an account of relational autonomy. Developed by Diana Meyers, the relational theory of autonomy provides a richly nuanced understanding of autonomy that recognises and emphasises the role of relationships, socialisation and social structures in both developing the skills required to "be autonomous" and in constraining the options and choices of those who do not have the skills required of autonomy. Meyers argues that personal autonomy should not be understood as the ability to make choices free of social influence; this would be incoherent as she adheres to a view of identity as partially constructed by social relations. Rather autonomy, in this context, is considered to be a capacity, and autonomous choices are those choices which have been subjected to critical reflection and found acceptable to the self.

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[100] Pioro et al. "Wrongful birth litigation and prenatal screening" *Canadian Medical Association Journal* 179, no.10 2008, 1027-1030, 1027.
[101] These countries include Australia, Canada, New Zealand, Taiwan, Sri Lanka, many US states and the majority of Europe.

Relational autonomy finds the middle ground between accounts that understand autonomy as a fully social construct, where our identity is purely the product of our external social relations, and those accounts that argue social relations have no contribution to our identity and that it is purely internal to the self. Thus there are two aspects to any theory of autonomy that posits a relational understanding of identity, the internal and external conditions of autonomy. The internal conditions of autonomy focus on questions that derive from the theory of identity posited while the external conditions of autonomy examine the role of socialisation and relationships in autonomy. One of the major advantages of a relational understanding of autonomy is the narrative model of identity it presumes in which the role of socialisation and relationships are built into the model of how identity develops.[102] An underlying premise of narrative identity theory, and therefore relational autonomy, is that the "true" self does not have an asocial core existing beyond the bounds of socialisation but rather the 'self' is developed, always changing, through the experience of life – via our relationships with other actors, both subjects and objects. Given this view of the self autonomy is thus better understood as a capacity, a repertoire of desirable skills gained via socialisation that allows a better understanding of the implications of choices in one's life which in turn allows for better life.[103]

Meyers asserts that relational autonomy is a procedural account of autonomy because it is a way of thinking, in which autonomy occurs via thinking in a particular way. In opposition to procedural accounts are substantive accounts where the attainment

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[102] A discussion of narrative identity will take place shortly.
[103] Diana Meyers, *Self Society and Personal Choice,* (New York: Columbia Press, 1989) 135.

of autonomy requires thinking specific thoughts.[104] In particular, Meyers argues that the capacity for autonomy arises from having well developed traits of self discovery, self direction and self definition all of which lead to an integrated yet dynamic self which can think in the ways required of an autonomous being.[105] The autonomous capacities of self direction, self discovery and self definition are the same as regular competencies in that they are a "repertoire of coordinated skills that enable a person to engage in a complex activity".[106] As Meyers argues;

> Autonomous people are not vouchsafed a glimpse of their inner selves that other people are denied, Rather, they possess and exercise skills that maintain a fluid interaction between their traits, their feelings, their beliefs, their values, their extended plans, their current possibilities for realising these plans, and their conduct.[107]

Furthermore the traits of self discovery, self direction and self definition are developed, and should thereby be understood, in terms of our social relations. The capacities of self - discovery, -definition and –direction are at once both the product of socialisation and the very aspects of the self used to analyse one's life and relations. Consequently, being autonomous requires being critically aware of the values one holds and recognising the way that your socialisation and particular situation contribute to those values. Only then can one analyse and accept or reject the various aspects of oneself as being more or less conducive to both being autonomous and being coherent with a life plan.

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[104] The difference between substantive and procedural accounts of autonomy will be taken up later when the problem of oppression is discussed.
[105] Ibid, 87.
[106] Ibid, 56.
[107] Ibid, 55.

Autonomy can also be programmatic, wherein considerations are not based on immediate preferences – "what I want now" – but rather on one's larger life plan, or "how do I want to live".[108] A life plan in this context is a larger conception of what one wants and values in life. Not a static ideal that requires unerring adherence, but rather a revisable flexible ideal of a worthwhile life that allows efficiency in that it means every decision doesn't have to be deeply weighted but only considered in light of how it aligns with one's life plan.[109] Consequently one can reject or accept a decision and/or modify one's life plan. The difference between heteronomous (non-autonomous) and autonomous decision making is procedural, whether one uses, or has the capacity to use the skills of autonomous capacities to evaluate the decision. For Meyers there is an authentic self – a self chosen identity that is rooted in one's most enduring values while also sensitive to autonomous capacities and thus critical self reflection, refinement and possibly radical change.[110] Here 'self chosen' must be understood within the limitations of the socially realised narrative self rather than a blank slate self and refers to a process by which one is continuously subjecting one's evolving self to critical consideration as guided by one's autonomous capacities and life plan. Each individual for Meyers will differently weigh various interests and considerations (health, wealth, friendship, family, power etc) in formulating their life plan and thus everyone will have a different authentic self.[111] But,

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[108] Ibid, 48.
[109] Ibid, 49-51.
[110] Ibid, 61.
[111] Ibid, 99-102.

regardless of the form that self takes, the autonomous capacities, for Meyers, provide the only possible access to the interests of the authentic self.[112]

Life plans, authentic selves and being procedurally autonomous are the components of the highest levels and ideals of 'being autonomous,' but Meyers is emphatic that autonomy is also obtainable for those who are less self aware, less critically engaged and have less developed autonomous capacities, regardless of the reason that those capacities are less developed. Autonomy as understood by Meyers can be both episodic and a matter of degree. According to Meyers autonomy can be episodic because an individual can be periodically autonomous, meaning they have the capacity to be autonomous with respect to only some aspects of their life, and/or for certain periods of their life. Autonomy can also be a matter of degree because people can also be autonomous in any given situation to a variety of degrees on a spectrum of autonomy ranging between minimal and full autonomy.[113] People with fewer areas where they enact episodic autonomy are towards the minimum end of the spectrum while those who have more areas in which they can act autonomously fall higher up the spectrum. The autonomy present in these situations can be understood as episodic, rather than programmatic, because in these situations the individual lacks the critical awareness derived from fully developed autonomous capacities and is autonomous only with regards to certain aspects of their life. By this account, nobody can be fully autonomous without being programmatically autonomous though it is plausible that one could develop

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[112] Ibid, 107.
[113] Ibid.

programmatic autonomy and still only be episodically autonomous with regards to some areas of one's life.

Meyer's version of relational autonomy is thus a procedural account in which autonomy is understood as a capacity that can be developed like any other capacity, a capacity we can hold with regards to some decisions while not others and also with a variety of degrees. However a purely procedural account of autonomy runs into problems when it attempts to deal with questions of oppressive socialisation. Consequently, the next sections will focus on the role and effects of socialisation, particularly oppressive socialisation, on autonomy and in doing so examine whether it is necessary to include a substantive component to autonomy in order to account for oppressive socialisation.

The External Conditions of Autonomy.

Central to Meyer's understanding of autonomy, is the assertion that the skills of autonomy are developed and learned through social experience.[114] Traditions, practices and institutions, which for the duration of this argument shall collectively be called socialisation, are the external conditions of autonomy, in that they shape, limit and enhance the ability of the self to develop autonomous capacities. An understanding of identity in terms of one's identity being a narrative helps to comprehend the temporal and continuously changing nature of identity. A narrative self, because it is always evolving, allows one to overcome the effects of problematic forms of socialisation that prevent or decrease the development of autonomous capacities. The fluidity of a narrative self

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[114] Ibid, 43.

identity, in which one is continuously developing and changing, means that the autonomous capacities can be developed at any stage of life. "Good" socialisation and social practices, institutions and norms, are thus those which enhance the range of available self understandings and increase an individual's autonomous capacities of self direction, definition and discovery. On the other hand, "bad" socialisation, practices, institutions and norms are those that limit potential understandings of the self and decrease the autonomous capacities. One often discussed example of "bad" socialisation is Twentieth century North American feminine socialisation where the way girls and women are socialised to be feminine is responsible for both decreased bodily abilities e.g. "throwing like a girl," and being strongly altruistic.[115,116,117] Although feminine socialisation is the most often discussed instance of socialisation that harms the development of autonomous capacities, the autonomous capacities model allows that other forms of socialisation, such as North American masculine socialisation can be equally detrimental. Any socialisation which disvalues the traits that assist in developing the autonomous capacities, or directs an individual towards a limited, static and particular self understanding can be understood as "bad" because it restricts autonomy. It is however worth noting that feminine socialisation, more so than masculine socialisation, often leads to minimal development of the autonomous competency. This is because

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[115] Ibid, 178.

[116] Iris Marion Young, *On female body experience: "Throwing like a girl" and other essays,* (New York: Oxford University Press 2005) 32-35.

[117] There is a tendency to use the terms masculine and feminine socialisation as shorthand for 20th century North American masculine and feminine socialisation. Masculine and feminine socialisation in North America differs not only with race and class inside North America but also substantially differs with regards to the middle classes of other western nations. The use of the terms masculine and feminine without conditionals serves to obscure this. That said, when the terms masculine and feminine are used in relation to socialisation they are henceforth referring to the North American 20th century socialisation.

masculine socialisation encourages the rejection of connection and dependence as something that is weak, while in contrast, women are more often socialised to be strongly altruistic. Meyers terms this "heteronomous altruism," the form of altruism where pleasing others, satisfaction of others' needs and preferences are paramount and she identifies it as one of three practices of conventionality that lead to heteronomity rather that autonomy.[118] Other than hyper altruism, the practices of conventionality also include those people who unreflectively accept prevailing beliefs and practices, and those who profess that their beliefs match those conventional beliefs and preferences when we know that is not the case.[119]

Questions about the role of socialisation in autonomy are at the root of almost all critiques of autonomy: this is true whether a critique concerns how and whether socialisation contributes to formation of the self or how social practices, institutions and structures affect 'autonomous' decision making. Some opponents argue that a critical problem with procedural accounts of autonomy is that they cannot deal with the problem of oppression because being oppressed both creates restrictive ways of thinking and decreases individuals self trust. Whether oppressive socialisation is a problem depends upon whether relational autonomy is required to be a procedural account. These questions will be taken up in a later section on oppressive socialisation, the possibilities of self trust being a substantive component of autonomy. The next section will focus on elucidating the relevant aspects of narrative identity theory, the theory of identity that underpins the relational model of autonomy.

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[118] Meyers, *Self, Society and Personal Choice,* 176-178.
[119] Ibid, 178.

Narrative Identity.

A relational conception of autonomy requires a narrative understanding of identity. Proponents of a narrative conception of identity argue that it can explain and provide the *synthetic strategies* required of dynamic and embodied subjects (as opposed to disembodied minds). [120] In other words narrative identity can explain the mechanisms by which people create and develop identities within a society, via particular social relations. For narrative theories of identity there are three perspectives that everyone holds; first personal psychological perspective, second personal relational perspective, third personal objective perspective and each perspective should be understood as an aspect of the self. [121] These first and second personal relations can be understood to loosely correspond with the internal (first personal) and external (second personal) conditions of autonomy previously mentioned. They argue that a narrative theory of identity provides a model of how the three aspects of identity are integrated in terms of relations of mutual implication and mutual explanation. [122] One's psychological state and social relations inform and construct each other within the ongoing process of the developing self identity. Identity is understood prescriptively as "a description under which you value yourself, a description under which you find your life to be worth living and your actions to be worth undertaking." [123] According to the narrative model, then, identity is composed of all interpersonal and socio-cultural aspects (ethnicity, gender occupation, religious and political beliefs) of a person as well as physical and

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[120] The term identity will mean narrative identity unless explicitly stated otherwise. Furthermore it should be kept in mind that identity and self are interchangeable concepts in narrative identity theory.

[121] Kim Atkins, *Narrative Identity and Moral Identity,* (New York: Routledge, 2008), 123.

[122] Ibid, 2-5.

[123] Christine Korsgaard, *The sources of Normativity,* (New York: Cambridge University Press, 1996), 101.

psychological capabilities.[124] Narrative identity theory provides a clear model for

selfhood that allows identity to be constituted via socialisation and relationships.

Furthermore narrative identity provides a clear model for the dynamic development of

identities via relationships, upon which both relational autonomy and the

postphenomenological model of technology are premised.

The Problem of Oppression:

The next sections will examine the requirements of informed consent; the aspect

of autonomy most often focused on in bioethics, and argues that many of the feminist

concerns about informed consent can be traced back to concerns over the role of

oppression in accounts of autonomy. A central question in debates over autonomy is

whether someone can be autonomous if they are socially oppressed. The answer to this

question depends on the particular understandings of oppression, autonomy and informed

consent being used. If we use a very broad definition of oppression as something that

happens to both individuals and groups who are systematically disadvantaged by the

structure of social relations, then a significant proportion of the population is potentially

oppressed. Oppression can impact someone's ability to develop autonomy by

disproportionately limiting the opportunities available to develop autonomous capacities

and it can also structure one's self understanding and awareness in ways detrimental to

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[124] Physical and psychological capabilities are not separate from socio-cultural attributes and capacities such as occupation, gender, religious and political values as each has the ability to impact others. E.g. throwing like a girl.

being able to act autonomously by creating a negative self-image.[125] A tension exists between the need to recognise that people are oppressed, and thus often socially disadvantaged, and a need to recognise other people as autonomous.

It is important to recognise both oneself and others as autonomous. Because according to Meyers recognising one's self as autonomous reaffirms your value and worth and thus creates the opportunity to expand your autonomy into areas where confidence was previously lacking.[126] Acknowledging others as autonomous recognises not only that they are capable self governing beings but also that this makes them similar to you, and thus of equal moral worth. In this manner, autonomy, or the capacity for it, is often posited, at least implicitly, as a requirement for being of full moral standing. By this logic any theory of autonomy that recognises a portion of the population as systematically lacking autonomy, either because they lack a valued trait, or hold an undesirable one, identifies these individuals as not being full moral agents. The question of whether individuals who are oppressed can be autonomous is thus very important, as we would be extremely reluctant to say that any person who is oppressed cannot make autonomous decisions and thus cannot give informed consent, in that they are not competent to make decisions. Therefore, one requirement of any theory of autonomy is an ability to acknowledge and recognise the consequences of oppression and difference, which is not overcome by them such that autonomy becomes meaningless. A theory of autonomy must be able to recognise whether an individual wanting, or not wanting, a given biomedical

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[125] For example internalising a commonly help belief that members of your group cannot do something both makes you believe that you cannot do it and disallows you the opportunity to practice the autonomous capacities.
[126] Meyers, *Self, Society and Personal Choice*, 85.

intervention has the capacity to autonomously decide whether they are right for them, or whether a person is oppressed such that autonomy with regards to this choice is not possible.

As set out above, oppressive social forces can impede autonomy in two ways. Firstly, oppressive social forces can determine and limit the formation of values, desires and attitudes, which is problematic, especially with respect to oneself, as oppressive forces can thereby decrease one's sense of self worth via the promotion of a negative self image. Secondly, such forces can limit opportunities to "exercise and develop one's cognitive, emotional and moral capacities."[127] The major strength of relational autonomy is that it recognises the role of oppressive social forces in autonomy and thus allows these theoretical problems that arise from their existence to be identified, addressed and potentially solved. The following section highlights the tensions that occur when talking about autonomy and oppression and which derive from attempts to balance ideas of how individual identities are formed and structured in relation to society with a requirement that groups of people are not systematically denied autonomy because they are oppressed.

Meyer's procedural account understands autonomy as a competency or skill: something that is learnt and developed and then applied to particular situations or content. Being autonomous is not about making the correct choices but rather about whether the skills of autonomy are applied in making the decision. Thus, no matter an individual's values and desires, because the content of their thoughts does not matter they can make an

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[127] Atkins, *Narrative identity,* 124.

autonomous decision given the opportunity and faculty for critical reflection.[128] Although removing content specific requirements can avoid many of the problems discussed with relation to the received account, one significant problem still exists: the irreconcilability of procedural accounts of autonomy with Stoljar's argument that those who make decisions informed by oppressive social circumstances cannot be fully autonomous.[129] Stoljar argues that although oppressed agents can be autonomous with regards to decisions in some areas of their life, with regards to those areas wherein their identity is influenced by oppressive social practices they will be less autonomous, or heteronomous. This is because a defining feature of oppressive social practices is that they constrain agent's understandings of what is possible, valuable and/or right.[130] Stoljar names this argument the feminist intuition.

Using Luker's study of contraceptive risk taking as an example. Stoljar argues that "their behaviour leading up to the unwanted pregnancy is both reasonable and logical given their own definition of the situation" and thus successfully meets the requirements of critical reflection.[131,132] Given Stoljar's argument that "preferences influenced by oppressive norms of femininity cannot be autonomous" - either this feminist intuition or

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[128] It is interesting to consider here whether particular values or sets of values are more compatible with the autonomous skill set than others.

[129] Natalie Stoljar, "Autonomy and the Feminist Intuition" edited by MacKenzie and Stoljar *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self.*, (New York: Oxford University Press, 2000), 95

[130] Ibid, 95.

[131] Ibid, 96.

[132] Luker interviewed 50 women in California during the 1970s examining why, when they presumably have access to contraceptives, they end up having unwanted pregnancies and abortions. Many of these women used either no birth control method or used them erratically. Luker's analysis focused on how their decisions about birth control leading up to the pregnancy can be understood as rational given their understanding of their circumstances but not always autonomous because their self understanding is distorted by incorrect norms of femininity. They are motivated by oppressive norms.

procedural autonomy must be rejected.[133] Given this, Stoljar opts to reject relational

autonomy as a procedural account in favour of reconfiguring it as a substantive account

by building in a requirement for self trust. She believes that doing so will successfully

exclude women, such as those found in Luker's study, from being understood as acting

autonomously with regards to their contraceptive choices. Stoljar argues that this example

can be separated from the acts of risk takers in other domains such as smoking or not

wearing a seatbelt because "Luker's subjects are motivated by oppressive and misguided

norms that are internalised as a result of feminine socialisation." Yet to single out

feminine socialisation as differently influencing risk taking socialisation in contrast to

other forms of problematic socialisation seems problematic.[134] What must be made clear

here is that Stoljar's version of relational autonomy is not arguing that oppressed

individuals can never be fully autonomous with regards to all decisions but rather that

achieving critical awareness via the autonomous capacities with regard to choices related

to feminine socialisation may be harder than for those whose internalisation of the norms

of feminine socialisation is more complete.

Self Trust – A substantive component of relational autonomy?

All members of our society are affected to varying degrees by the forces of

oppression and many have diminished ability to exercise autonomy as a consequence of

their experiences as members of oppressed groups.[135] Given a narrative understanding

where the current identities of individuals are always influenced by history the damage

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[133] Ibid, 95.

[134] Ibid, 96.

[135] I would argue that being a member of an unoppressed or oppressive group in an oppressive society also impacts on ones autonomous skills.

done by oppression may be so deep that the effects can never be completely erased, but being aware of and reducing oppressive circumstances can increase opportunities to repair some of the damage and minimise its occurrence in future generations.[136] Sherwin, in her discussion of the social conditions that can limit autonomy, recognises that many of the skills required to develop the autonomous capacity evolve out of one's unique personal relationships and thus differ even within a singular social group. Women are often forced to make catch-22 decisions, such that there are negative consequences no matter which option is chosen. For example, one source of women's oppression is that they are primarily valued by both themselves and others as mothers, a pronatalist ideology. Women desiring to have children who have problems conceiving spend substantial amounts of money and face significant health risks to become mothers. These women are both perpetuating the harmful pronatalist ideology and are at the same time victims of it because "it is not sufficient simply to offer a person an uncoerced choice; it is also necessary to ensure that she has had the opportunity to learn to exercise choice responsibly".[137] One way to decrease the occurrence of such catch-22 situations would be via the instigation of programs that assist people in developing the skills of autonomy. One of these skills is self trust, where self trust is the belief in one's ability to make decisions.[138]

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[136] Susan Sherwin and Caroline McLeod, "Relational Autonomy, Self-Trust and HealthCare for Patients who are Oppressed." Edited by Catriona MacKenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*, (New York: Oxford University Press, 2000), 259-279, 260.

[137] Ibid, 262.

[138] The concept of self trust will be examined in more detail in the following paragraphs.

In this vein, a later article by Sherwin and McLeod argues that "[i]t is essential in developing the capacity to be autonomous that the agent trusts her capacity to make appropriate choices, given her beliefs, desire and values" and that it is not possible to have and exercise the autonomous competencies without this self trust. This self-trust, however, is thought to be particularly affected by oppression. Sherwin and McLeod draw a distinction between big picture 'oppression' that is systematic and group based and interpersonal oppression, acts between individuals that result from oppressive beliefs and internalised [oppressive] norms: "When a group is oppressed, the society at large operates as if that group is less worthy and less competent than others." In turn, individual members of oppressed groups often go on to internalise these social norms and attitudes about themselves, particularly on an unconscious level, leading them to doubt their ability to make choices.[139] Sherwin and McLeod distinguish self trust from both self respect and self worth. They argue that self trust is distinct from Meyer's notion of self-respect- a "positive conception of one's own worth" - because self trust is rather a belief in one's own abilities.[140] Three aspects of self trust are drawn out in Sherwin and McLeod's account of self trust in relational autonomy. First, trust in one's capacity to choose effectively. Components of this form of trust are trust in one's autonomous competencies and also in the "accuracy and adequacy of the information available." However, trusting the information available with regards to medical research is much harder for members of oppressed groups, for several reasons, not the least of which is the role oppressed groups have historically played in medical research. For example, A variety of biomedical

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[139] Ibid.

[140] Ibid, 263.

research trials were conducted on oppressed minorities as late as the 1960s and 1970s, including the Tuskegee Syphilis research program in a rural poor black community in which research into the course of untreated syphilis was continued even after a cure for syphilis was found. The introduction of the Helsinki declaration in 1964 which provided an ethical code in research ethics caused further problems in that it unintentionally discouraged the inclusion of members of oppressed groups as research subjects, except when research was into conditions uniquely or predominately associated with that group. Thus from the 1970s until the late 1990s medical research into new treatments was conducted primarily on white [middleclass, educated] males, who were thereby assumed as the norm, and consideration about differential effects of treatments on women and other racial groups were not considered and neither were the confounding factors associated with poverty, such as poor nutrition and less education. After decades of mistreating oppressed groups medical research then ignored them altogether and the effect of this policy is that many medical treatments are unintentionally designed to work best on white males.

The second type of self trust required is trust in one's ability to act on a decision. There are two reasons an oppressed individual in particular may lack this form of self trust: a lack of courage or conflicting desires. Conflicting desires about a course of action are particularly common in oppressed individuals who are attempting to fight internalised oppressive norms. The third type of self trust Sherwin and McLeod identify is trust in the judgements that underlie one's choices. They argue that it is in this final form of self trust that the substantive component of autonomy can be located because it "requires some

confidence in the appropriateness of her values" and "[i]f her values have been shaped by oppression, it will not be easy for her to trust them because they will encourage her participation in practices and behaviour that undermine her moral worth and that may cause her severe suffering."[141] Sherwin and McLeod argue that although everyone has areas in which they lack the self trust required to make autonomous decisions, if we lack the self trust with regards to many or most areas of our lives then our autonomy can be affected. This is particularly true for oppressed groups, they argue, because a lack of self trust is more likely to occur in areas related to how one defines oneself or what one values most.[142,143]

Drawing on these different conceptions of self trust as offered by Sherwin and McLeod, it is possible to relate them to earlier considerations of helping oppressed individuals expand their autonomous capacities.[144] Although for the discussion of prenatal screening in the following chapter it does not matter whether the account of relational autonomy is substantive or procedural, Sherwin and McLeod's analysis of the importance of self trust and the role of oppression in autonomy does highlight the

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[141] Ibid, 264.

[142] Ibid.

[143] Sherwin and McLeod argue that it is sensible for us to have areas in which we lack self trust and cite the example of a philosopher making an engineering decision. I would argue however that knowing one does not have the relevant expertise and knowledge to make a decision is not a lack of self trust but rather an excellent example of self trust in the higher level decision about one's qualifications to answer a particular question. Thus in their example the philosopher exhibits perhaps the highest form of self trust, knowing the limits of your knowledge and expertise.

[144] The first form of assistance society can supply is in providing an environment and opportunities in which one can use the autonomous capacities and hence learn to trust one's exercise of them. A supportive environment by definition shows trust in the outcomes of someone's decisions and hence trust in them so this would also facilitate the development of self trust. This is something that could be considered as an additional goal when developing ethical guidelines to structure practices such as prenatal screening programs.

importance of recognising the profound impact of social dynamics in any discourse of autonomy in healthcare. By focusing on oppression they raise the question of whether oppressive socialisation should be privileged as more important than other, less malign, forms of socialisation as all forms of socialisation create preferences and values.[145]

Autonomy in Health Care – Informed consent

Discussion of autonomy in the context of healthcare typically focuses on the way specific factors such as ignorance, internal compulsion and coercion can interfere with a patient's autonomy in making particular decisions about their healthcare. For example when a patient is ignorant of a possible consequence of a treatment option, or they have internalised that a particular choice such as pain management while giving birth is bad, or they are making health care choices based on what they think others want you to do, then their autonomy can be affected. Consequently, discussion within the ethical discourse often focuses on what the medical practitioner can do to enhance the patient's autonomy with regards to making a specific decision. Sherwin and McLeod argue that, although coercion is recognised, oppression is a factor constantly overlooked by the discourse because, although it often involves all the conventionally discussed factors, oppression is a more ambiguous and invisible force that can affect a patient with regards to more than simply a specific decision and furthermore can affect entire social groups. Moreover, as a consequence of its complex nature, oppression is not a factor that can be accounted and

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[145] Meyers provides the example of the conventional person who unthinkingly follows his parent's desire for him to become a surgeon and who is happy and heteronomous despite a lack of critical consideration and autonomy (Self society and Personal Choice 176-178). When one is a member of the dominant social group and holds more power it can be harder to engage in self discovery of one's motives, because one has more freedom of choice and is less likely to be internally conflicted. This is not a question I have the space to examine further however.

adjusted for by an individual medical practitioner and as a result tends to be ignored in

discussions of autonomy in healthcare.[146] Having raised the issue of social oppression,

Sherwin and McLeod use relational autonomy to present an account of oppression in

healthcare which argues that "relational autonomy ... involve[s] explicit recognition of the

fact that autonomy is both defined and pursued in a social context and that social context

significantly influences the opportunities an agent has to develop or express autonomy

skills."[147] Central to this account is Sherwin's earlier work that focuses on the external

conditions of autonomy, what she terms "social location."

Sherwin analyses informed consent as an example of how one's ability to meet the

internal conditions of autonomy may be compromised if an agent faces external forces

that constrain their ability to exercise the autonomous capacity. She argues that, "the

paradigm offered for informed consent is built on a model of articulate, intelligent

patients who are accustomed to making decisions about the course of their lives and who

possess the resources necessary to allow them a range of options to choose among."[148] In

this line of argument, Sherwin, unlike Meyers, is focused upon the socially situated self

and provides less discussion of the particulars of how socialisation might contribute to the

development of an autonomous self. Instead, Sherwin focuses on how, in the specific

realm of healthcare, social and material conditions can limit the autonomy of women via

oppression. For example poor women who cannot afford to take time off work or who

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[146] The most often cited example of the conventional account of autonomy in health care is Tom
Beauchamp, James Childress *Principles of Biomedical Ethics,* (New York: Oxford University Press , 2001).
[147] Sherwin and McLeod, "Relational Autonomy, Self-Trust and HealthCare for Patients who are
Oppressed," 259-260.
[148] Susan Sherwin, "Relational approach to autonomy in Healthcare" edited by Elisabeth Boetzkes and
Wilfrid Waluchow *Readings in Health Care Ethics* (Toronto: Broadview Press, 2000), 72.

must pay for childcare during an medical appointment are much less able to obtain

preventative healthcare even when medical care is free. Sherwin notes the manner in

which, although autonomy is understood as a primary value in healthcare, it is often

reduced in practice to an understanding of patients giving informed consent for particular

medical procedures and choosing between a range of predetermined treatment options.

For example, a patient is seen as making an informed choice, and therefore being at least

episodically autonomous with regards to a medical choice, if they meet four conditions;

that the patient 1) be competent/rational, 2) be making a choice based upon a restricted set

of possibilities, 3) have adequate information and understanding, and 4) be free from

explicit coercion towards or away from any particular option.[149]

Sherwin argues that each of these conditions is deeply problematic and

successfully fulfilling them is much more difficult than generally understood.

Furthermore these criteria overly narrow the focus of any discussion of autonomy in

healthcare to enquiries into the abilities of particular patients to make particular decisions.

This is because the informed consent equals autonomy approach "discourages attention to

the context in which decisions are actually made" and thus the way in which social

conditions structure the options available to someone is discounted.[150] Sherwin argues

that one of the most significant features of current autonomy discourse in bioethics is its

exclusive focus on the autonomy of individual patients and that this is an extension of

medicine's tendency to approach illness as a problem with "particular patients" rather

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[149] Ibid, 73.
[150] Ibid. Take the example of a poor woman who has to pay for childcare while getting medical treatment and can't afford to.

than examining and providing solutions to the structural problems in society that underlie many healthcare issues.[151]

There are also problems with each of the specific criteria. Rationality is often constructed in opposition to traits considered as stereotypically feminine or belonging to oppressed minorities, such as the disabled, poor, and illiterate. Sherwin suggests that at a minimum healthcare providers should; "become sensitive to the ways in which oppressive stereotypes can undermine their ability to recognise some sorts of patients as being rational or competent" in order to reduce this conflation.[152] The set of options available to patients has been influenced by the research and policy agendas. Oppressed groups are underrepresented on the bodies that are involved in setting these agendas and it is plausible to assume that the particular needs of these groups are thus less considered. Thus healthcare providers should be aware of the way in which the set of available treatment options has been selected. What is considered "relevant information" is also determined by the research and policy agenda. Thus healthcare professionals should be aware that there is also probably a large gap in life experience between the relatively privileged physician and a seriously disadvantaged patient, which could lead to a corresponding gap both in what is considered relevant and having enough information to know the correct questions to ask.[153] Coercion is particularly hard to detect in oppressed individuals, particularly when the choice being evaluated is tied to their oppression. Sherwin argues that:

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[151] For example, it is much harder to eat healthy foods when one is poor for a variety of reasons such as long working hours and how many tastier healthy options such as fruit are expensive.
[152] Ibid.
[153] Ibid, 74.

> When a woman's sense of herself and her range of opportunities have been oppressively constructed in ways that (seem to) leave her little choice but to pursue all available options in the pursuit of beauty or childbearing or when she is raised in a culture that ties her own sense of herself to external norms of physical appearance, or fulfilment associated with childbearing or, conversely, when having a(nother) child will impose unjust and intolerable costs on her, it does not seem sufficient to restrict our analysis to the degree of autonomy associated with her immediate decision about a particular treatment offered.[154]

Sherwin makes a series of claims about the role of autonomy in healthcare that are relevant to a discussion of prenatal screening. Firstly that "medicine, despite the limits of its expertise and focus, is the primary agent of healthcare activity in our society and physicians are granted significant social authority to be the arbiters of health policy."[155] Medicine is about treating individuals, the majority of whom are already sick. Health policy overvalues medicine and thereby constructs healthcare as the treatment of disorders and disvalues, other areas of healthcare that are not about treatment, but are instead about prevention. This particular observation is important in the discussion of pregnancy because women are not being treated for the illness of pregnancy, but are rather, in most cases, being monitored to prevent the onset of one of the unique set of disorders associated with pregnancy. The second concern Sherwin brings up is that overly focusing on individuals "obscures our need to consider questions of power, dominance, and privilege in our interpretations and responses to illness and other health-related matters as well as in our interpretations of the ideal of autonomy."[156] Sherwin argues that "dismissing as outside the scope of healthcare many of the sources of illness that primarily affect the disadvantaged," such as malnutrition and fear of assault, privileges

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[154] Ibid.
[155] Ibid, 76.
[156] Ibid.

the wealthy.[157] For Sherwin this means that when talking about autonomy we need to look beyond the specific decisions of individuals and examine the contexts in which they are making a decision to look at what is influencing their decision:

> By focusing only on the moment of medical decision making, traditional views fail to examine how specific decisions are embedded within a complex set of relations and policies that constrain (or ideally, promote) an individual's ability to exercise autonomy with respect to any particular choice.

Sherwin's distinction between agency and autonomy allows for a better understanding of the relationship between autonomy and oppression, where exercising agency can be understood as making a reasonable choice under the circumstances and autonomy as the stricter notion that is harder for oppressed individuals to obtain. A woman's choice to use a risky form of reproductive technology can be considered, for Sherwin, the product of agency because it is rational given the individual's socialisation, situation and preferences. However, because the "behaviour accepts and adapts to oppression" it should not be described as an autonomous choice without first examining the degree to which the woman's autonomous competencies are engaged in this particular decision.[158] If a woman is aware of the ways in which her wish for children is the product of oppressive socialisation, and even if having children for her enhances her self-valuation, or how others value her, she can still make an autonomous choice. If she has critically engaged with these ideas via the competencies, even if she knows that she will value herself more (or her partner or family will value her more) and she still wants to have a child then she has made an autonomous decision because she has engaged in self discovery – to know what she is like, self definition – to establish her own values, and self direction –

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[157] Ibid.
[158] Ibid, 77.

choosing how these values will be expressed.[159] Although it is potentially harder to make an autonomous decision where the outcome of the choice aligns with the heteronomous desires of a similarly situated individual this does not mean it is impossible.

Conclusions:

The major strengths of relational autonomy are its ability to account for relationships and socialisation. A relational model of autonomy incorporates, or is compatible with, many ideas from contemporary theories of identity such as narrative identity theory and also ideas about the construction of identity. Relational autonomy posits autonomy as a capacity, one that is developed via self direction, self definition and self discovery, all of which are developed by having trust in oneself. A relational model of autonomy provides both a dynamism that allows oppressed individuals to develop autonomy with regards to all aspects of their life via critical awareness, and for people to be autonomous with regards to only some aspects of their lives. The relational model of autonomy emphasises the need to understand individuals as embedded in society and the role that socialisation can play in the development of an individual's identity. The discussion of informed consent in the fourth chapter will allow a greater understanding of problems with informed consent in prenatal screening and how this contributes to problematic social understandings and discourses with regards to pregnant women.

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[159] Even though these values can align with the values and choices of a woman who is heteronomous it is the process by which the decision has been reached not the actual decision that makes a decision autonomous.

Chapter Four: Prenatal Screening

Introduction:

When considered through the lenses of socially embedded, relational and interactively constructional understandings of autonomy, technology and identity, ethical concerns about prenatal screening, and their apparent solutions, appear in significantly different light. The earlier chapters of this thesis argued for very different understandings of autonomy, technology, and how they work, than that which is commonly assumed in bioethics. Building on these earlier arguments, this final chapter shall apply these previously developed philosophical concepts to the task of situating the ethical issues and problems apparent in discourses of prenatal screening. Each of the previous chapters presents an account of a concept key to the ethical discourse of prenatal screening. In exploring the nuances of these concepts it becomes apparent that a key idea is shared and presumed by both the postphenomenological understanding of technology and a relational model of autonomy, the mutual construction of objects and subjects via their relationships. That groundwork having been completed, this chapter will now take these concepts and examine how they are used and understood in the bioethical discourse of prenatal screening and ask how, and whether, the understandings gained in previous chapters about power relations and the role of socialisation allow for a better understanding of the ethical issues at play.

Jennings challenges bioethicists to consider the model of technology at play in their work and argues that there is an assumption made in 'conventional' bioethics that

"technology carries with it no intrinsic value commitments," instead operating as a morally neutral tool. Thus technology is "not [regarded as] an appropriate object of ethical evaluation in its own right."[160] He argues, then, that conventional bioethics is "blind to the background influence of the reality-constituting power of the technology itself."[161] In contrast to this conventional understanding, Jennings suggests that any bioethics framework ask of itself the following questions; "what understanding of 'technology' does the frame propose? What relationship is postulated between technology and those who make use of it? How are the conditions of choice and moral agency to be understood, and what is taken to be integral to those conditions and what is taken to be merely incidental?"[162]

Although often separately touched upon in the bioethical discourse of prenatal screening in terms of both autonomy and technology, what is seldom noted is that the mutual constitution of identity is a theme of both prenatal screening and many debates in bioethics. By explicitly recognising and elucidating the importance of the contemporary philosophical discourses on technology and autonomy I have proposed a way to illuminate problems with the current framework that underlies bioethical debate about prenatal screening. Although many, if not all, of my concerns with prenatal screening have been expressed by other authors, I hope that by presenting the concerns explicitly in terms of the way bioethical concerns about prenatal screening are at odds with the

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[160] Bruce Jennings, "Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability", Eric Parens and Adrienne Asch (eds.), *Prenatal Testing and Disability Rights,* (Washington, D.C.: Georgetown University Press, 2000), 130.
[161] Ibid, 126.
[162] Ibid, 129.

philosophical discussion of such topics it will make more apparent both the problems and potential solutions. Several contentious ethical claims are made about the current practice of prenatal screening. First, prenatal screening is coercive with regards to women, particularly pregnant women, and second, it discriminates against people with disabilities.[163] The third claim that is less commonly mentioned is that prenatal screening also problematically influences social understandings of the 'fetus.' The current practice of prenatal screening structures the fetus as a patient, and thus individual, in its own right. This is problematic not least because when such an understanding of the fetus becomes a forceful social discourse and leads to opposition to legalised abortion. This both limits the choices of women and encourages the criminalisation and unsafe practice of abortion.[164] Thus it is worthwhile to examine how the current practice of prenatal screening structures the identities of pregnant women, people with disabilities and the fetus. Although reinforcing problematic social discourses does not necessarily result in discrimination against these groups prenatal screening is one of the many activities that can reinforce problematic social attitudes.

Consumer demand or expert recommendation.

Although Schwartz-Cowan argues that the spread of prenatal screening was primarily driven by consumer demand from pregnant women who asked for such tests, others argue that pregnant women have such diverse opinions on the matter, depending on

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[163] Victoria Seavilleklein, *The Values and Practice of Prenatal Screening in Canada*, (Ottawa: Library and Archives Canada 2008). Doctorial dissertation.

[164] A recent study shows that in countries where abortion is illegal there are no less abortions but rather much higher rates of complications. Susheela Singh et al. *Abortion Worldwide a decade of uneven progress*, Guttmacher Institute New York 2009. http://www.guttmacher.org/pubs/AWWfullreport.pdf

their socio-economic status, religious values and the preferences of their health

professionals, that consequently demand from pregnant women is at best limited as an

explanation for the uptake of prenatal screening.[165] Instead, one could consider the

support of government and health care providers as the strongest influences on the uptake

of prenatal screening. Right from the introduction of prenatal screening in the 1970s,

governments have been supportive of such testing because of the economic benefits it

allows in terms of not having to pay the extra costs of care for children with DS and spina

bifida.[166] Government support in many countries is reciprocally strengthened by

healthcare providers support of the tests and "strong institutional or provider support is

the best predictor of women's acceptance" of prenatal screening.[167]

Vassy, who examines social mechanisms for the proliferation of prenatal

screening, argues that one often overlooked feature of new biotechnology is that not only

does the new technology shape individuals and societies but society (public opinion) and

individuals (particularly health professionals and health administrators) also shape the

technology.[168] This aligns with the postphenomenological understanding of technology

which conceives of the interaction of the relations between artefacts and people as

mutually constituting and with the idea of artefacts as actors with intentions. Vassy

explicitly denies that consumer demand is the primary driving force for the rapid uptake

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[165] Carine Vassy, "From a Genetic Innovation to Mass Health Programmes: The Diffusion of Down's Syndrome Prenatal Screening and Diagnostic Techniques in France" *Social Science and Medicine* 63(2006) 2041-2051, 2043.

[166] Ibid, 2043.

[167] Press and Browner "The Production of Authoritative Knowledge in American Prenatal Care" *Medical Anthropology Quarterly* 10(2) 1996. Pp141-156, p.152.

[168] Carine Vassy, "How Prenatal Diagnosis Became Acceptable in France" *TRENDS in Biotechnology* 23 no. 5 (2005) 246-249, calls this the "social shaping of the techniques" p.247.

of prenatal screening in France on the grounds that "the speed with which a technique spreads does not necessarily reveal its social acceptability."[169] Rather, she suggests that in the case of introducing prenatal screening in France "the experts promoted not only a technique but also a moral cause. In their view, the abortion of foetuses [*sic*] with DS [Down's syndrome] is the best way to relieve women from the social and economic burden of bringing up a disabled child."[170] Vassy argues that experts promoted prenatal screening because it aligned with their values and in turn these experts became 'moral entrepreneurs' in that they set new norms about abortion, disability, health, and set new standards about what women are expected to do in their quest for reproductive health.[171]

However it is problematic to call those who promoted prenatal screening *moral entrepreneurs* because they themselves did not intend to set new moral norms and did not do so via their direct relations with others. Rather the experts set a variety of new moral norms, intentional and otherwise, by facilitating the widespread use of a new technology [prenatal screening] which interacted with individuals and society such that new norms about women, people with disabilities and fetus were set. They believed that promoting prenatal screening would facilitate a different moral norm about the goodness of removing a particular burden of care from women. If one accepts a postphenomenological understanding of technology then all artefacts contribute to the construction of moral narratives, beyond those that humans intend them to contribute to because all artefacts are imbued with intentionality. Thus although Vassy makes a key observation about the role

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[169] Ibid, 248.
[170] Ibid, 247.
[171] Vassy, "From a Genetic Innovation to Mass Health Programmes" 2042, 2045.

of experts in facilitating the uptake of prenatal screening her argument that they set moral norms by doing so is mistaken. Although the experts' interactions with prenatal screening helped shape the trajectory of the technology, the experts encouraged its usage because they thought it would do a good thing, removing a social and economic burden from women. Although prenatal screening does this it is not the only narrative that prenatal screening facilitates. This shows the way that technologies can have different effects than those intentionally designed into them by humans and thus the way that technologies and objects can have intentionality in their own right.

Prenatal screening promotes a variety of social narratives, all of which have formed because of existing social discourse. This includes norms intended by the facilitators and designers of technologies and also unintentional norms. The current practice of prenatal screening promotes a problematic conception of disability, as will be examined in a later section, but the narratives that result from our interactions with prenatal screening occur because of previously existing narratives in society. This is what Ihde means by ontological multistability: the particular form a technology or artefact takes (including its particular intentionality) is a product of the particular society in which it exists. Thus if prenatal screening developed in a society that did not have already existing problematic social narratives involving women and people with disabilities then the particular problems that we currently have with prenatal screening would not necessarily exist. If the women and people with disabilities were not already disadvantaged then the discourse of prenatal screening could not reinforce problematic

understandings of them, however this does not preclude the possibility that a practice could introduce new harmful understandings of these identities.

Prenatal Screening and Fetal Identity.

Concerns about prenatal screening arise not just from analysing the individual choices of pregnant women but also "by considering the meanings and cultural tensions of the choices made available by the increasing number and routinization of prenatal testing."[172] This is the intentionality of the artefacts constraining the options available to both women and people with disabilities. Social narratives thus contribute to the construction of identities. However prenatal screening also contributes to a third social narrative, the fetus; but because 'fetuses' are not things that can make choices (while women and people with disabilities are) the contribution of prenatal screening to the social narrative of fetus is problematic because it constrains the choices of pregnant women rather than of fetuses themselves. Although tightly entangled in notions of 'pregnant woman' prenatal screening contributes to the wider social discourse of 'fetus.' In particular the current practice of prenatal screening promotes ideas about the fetus as a thing in itself – the fetus as a patient in its own right. This affects social discourses about the bodily autonomy of pregnant women because it promotes the idea that the interests of the fetus and pregnant woman exist in opposition. This is of particular concern for the United States of America where ideas about the fetus-as-person have created a very vocal movement opposed to abortion.

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[172] Press, "Assessing the Expressive Character of Prenatal Testing" 217.

Among almost all cultures, Jennings argues, folk wisdom develops about what women can know about their baby "from its movements and from her own emotions and bodily responses during pregnancy."[173] This makes understandable the dominance that prenatal screening, particularly ultrasound, has in determining the current cultural myth of 'pregnancy'. However, the "genetic imaginary" created when the fetus is understood and related to primarily via prenatal screening and antenatal care restricts potential parents' conceptions of the unborn.[174] This is problematic because the fetus-as-genetic-imaginary "structure[s] our moral perception of pregnancy, childbearing, and disability in particular [problematic] ways," something that is not often considered in ethical analyses of prenatal screening.[175] The next section specifically explicates the cultural scripts of ultrasound combining the analyses of a philosopher of technology, Verbeek, and several feminist authors, Rothman, Zechmeister and Petechsky to examine how fetal ultrasound contributes to problematic ideas of the fetus and how we can minimise these.

Although many authors engaging in the bioethical discourse on prenatal screening mention and then problematise technology, very few actually provide any sort of argument for why the technology is a problem in terms of it being a technology or in terms of the relationship between technology, society, and individuals. This is at least in part a result of the tensions between, and dominance of, two particular ways of understanding technology mentioned in the first chapter: technology as a tool and technology as an autonomous domain separate from the social. Understanding

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[173] Jennings, 125.

[174] The genetic imaginary is a term developed by Jennings in his argument that biomedical understandings of the fetus have come to dominant all other possible ways of understanding the fetus.

[175] Jennings, 126.

technologies as 'actors' enmeshed in networks that also include individuals, groups and policies, where the identity of all of these 'actors' is created by the networks that they contribute to, allows for a better understanding of the ethical impact of both the actors and their contributions to the network dynamics. Thus prenatal screening is an actor in its own right that can contribute to the network dynamic in ways unintended by its human creators and instigators. Understanding particular technologies as actors in social narratives also allows insight into how we can effect change upon the causes of ethical implications we do not like, not by removing an actor, but by changing the network dynamic.[176] We can reconfigure prenatal screening so that it does not contribute to and reinforce harmful ideas about particular identities once we unpack the mechanisms by which prenatal screening contributes to these identities. The majority of this chapter will be dedicated to the unpacking of these mechanisms and only brief general suggestions will be made about how to reconfigure prenatal screening.[177]

In her discussion of contemporary North American understandings of the pregnant body, Kukla claims that there is a cultural "mass hysteria" about what women do to their pregnant bodies. [178] Assumptions of an innocent, healthy and individual fetus are structured by technological practices such as prenatal screening and in particular the idea of a disembodied fetus constructed by obstetric ultrasound. The 'visual publicity' of the

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[176] Latour was the first to describe society in terms of more-than-human/non-human 'actors' and in terms of networks of these actors.

[177] This is because I feel I lack the expertise and necessary practical knowledge about prenatal screening to make practical suggestions that are useful and instead I restrict my recommendations to a general level.

[178] Rebecca Kukla, *Mass Hysteria Medicine, Culture, and Mothers' Bodies*. Oxford UK: Rowman & Littlefield Publishers, 2005, 107.

fetus, she argues, promotes the idea of the fetus as its own patient and person.[179] This can be seen in legislation that gives fetuses separate protection as research subjects, recognises fetal homicide as a separate crime from the killing of the pregnant woman, and gives the fetuses of low-income parents separate health coverage from the pregnant woman.[180] Similarly to Jennings, Kukla is concerned with the rigidity of the concept of 'fetus' produced by the visual dominance of contemporary technologies where the idea of "a *single*, canonical fetus who has become the inhabitant of each individual pregnant body" is promoted.[181] Both Jennings and Kukla problematise the idea of the fetus promoted by technologies like prenatal screening; however if we rephrase this understanding from being a problem with the technologies to being a problem with our particular current relations to prenatal screening then solutions become more possible. There is no doubt that prenatal screening is a useful technology to have; whether it should be routinely offered to all pregnant women is another issue. By resituating the problem it becomes apparent that we can keep using the technology but change the particular ways we interact with the artefacts of prenatal screening.

Ultrasound and Quickening: Conflicting narratives in fetal discourse.

This section examines obstetric ultrasound to illustrate how reconfiguring our particular relations to prenatal screening can change the social discourse of the 'fetus'

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[179] Where 'visual publicity' arises from the high number of fetal images that we are exposed to in contemporary society. These include ultrasound images.

[180] Kukla, 109.

[181] Ibid, 110. By single canonical understanding Kukla means that the way we understand 'fetus' has been reduced to a single ideal of 'fetus'. She is worried that something important is lost when all fetuses are perceived in terms of a singular ideal fetus.

promoted by prenatal screening.[182] Verbeek applies a postphenomenological analysis to

the practice of obstetric ultrasound in order to illuminate the roles of technology in the

narrative and its ethical function, where ultrasound is examined not simply as the making

visible of a fetus but also as contributing to shaping peoples' experiences with both the

particular fetus and ideas about the unborn in general.[183] He notes that in the Netherlands

two ultrasounds are routinely offered to pregnant women, at between 10-12 weeks and

around 20 weeks respectively. While for parents these scans are often an exciting and

new way of interacting with their unborn, the scans are done for several reasons beyond

novel interaction with the fetus. The first scan is to determine both fetal age and the risk

of Down's syndrome via nuchal fold analysis and the second scan is to check for

developmental defects.[184] According to the postphenomenological scheme, obstetric

ultrasound forms a hermeneutic relation with the unborn and the people examining it.

Importantly this relation will impact differently those parents who are looking at their

"baby" for the first time and the ultrasound technician who will be perceiving the fetus

with an eye more accustomed to looking at sonograms and checking for both deviations

from what is considered normal, and markers of age.[185] Rather than simply providing a

"window into the womb" Verbeek argues that ultrasound represents and constitutes the

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[182] Obstetric ultrasound is also known as a sonogram or fetal ultrasound.
[183] Peter-Paul Verbeek. "Obstetric Ultrasound and the Technological Mediation of Morality: A Postphenomenological Analysis. *Human Studies* 31 (2008) 11 - 26.
Verbeek, "Obstetric Ultrasound and the Technological Mediation of Morality"
[184] The second scan is done at 20 weeks in order to allow for time before the abortion deadline of 24 weeks.
[185] I recognise that it could be problematic to call the pregnant woman and her partner parents when they don't yet have a child; however it is linguistically unwieldy to call them anything else.

fetus in a number of specific ways that can be mutually contradictory.[186,187] Feminist critics of ultrasound, such as Rothman and Overall, have previously made similar observations and many of the concerns with obstetric ultrasound are similar or identical to those that arise with prenatal screening in general.

When applying a postphenomenological analysis to obstetric ultrasound a variety of aspects of the practice must be considered. First, the size of the screen on which the sonogram is displayed enlarges the fetus to the size of an average newborn, so as to better perceive the details. Verbeek argues that this enlarging potentially creates subconscious beliefs about the stage of development of the fetus, where parents may believe that it is more developed than it really is. Because it is newborn sized Verbeek argues that parents could mistakenly believe that the fetus is closer to viability than it actually is.[188] Second, ultrasound depicts the unborn as dissociated from the mother's body, "free-floating in space", isolated, independent and separate from its mother. This constructs the mother as an environment in which the fetus lives, because "women solely function as environment and space to be explored,"[189] rather than seeing the pregnant woman and fetus as enmeshed. Constituting the pregnant woman as a fetal environment is problematic in that it potentially constructs the mother's body as a place that needs to be guarded and controlled in order to protect the fetus and its rights. However the only way to do this is to

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[186] Christine Overall, *Ethics and Human Reproduction: A Feminist Analysis*. (Winchester, MA: Allen & Unwin, 1987) 44.

[187] The term "window into the womb" was coined by Overall to explain the popular understanding of the role of ultrasound.

[188] Verbeek "Obstetric Ultrasound and the Technological Mediation of Morality" 15.

[189] Zechmeister, Ingrid "Foetal Images: the Power of Visual Technology in Antenatal Care and the Implications for Women's Reproductive Freedom" *Health Care Analysis* 9 no.4 (2001). 387- 400. 391.

monitor the lifestyle and choices of the woman, both via internal surveillance by the mother and externally through legislation and social condemnation.[190] Obstetric ultrasound isolates and separates the fetus from its mother and thus changes the fetus's relations to others.[191]

Verbeek argues that obstetric ultrasound deprives a mother of her special relation to the unborn by "shifting the privilege of having knowledge about the unborn to healthcare professionals."[192,193] In terms of the fetus, obstetric ultrasound formulates congenital defects as preventable, presenting the unborn in terms of medical variables, and quantifying the fetus in terms of medical risks, while also transforming pregnancy into an abnormal thing, needful of medical intervention and quantification, requiring monitoring and professional care. This is a problematic claim for several reasons, primarily because it formulates the problem in terms of the technology of obstetric ultrasound, rather than in the more fluid and changeable idea of the constitution of relations between ultrasound, society and individuals. The type of knowledge a healthcare professional gains about the fetus cannot be derived by the mother through other means and obstetric ultrasound provides a service that women should not be denied because there is no other way a mother can determine whether an unborn has one of these conditions and obstetric ultrasound serves important functions other than those of prenatal

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[190] This can be seen in the current debate over the autonomy of pregnant women with addictions to illegal drugs. T Shivas, S Charles "Behind Bars or up on a Pedestal: Motherhood and Fetal Harm" in Sharon M. Meagher, Patrice DiQuinzio (eds.) *Women and Children First: Feminism, Rhetoric, and Public Policy.* SUNY Press 2005.
[191] Verbeek ""Obstetric Ultrasound and the Technological Mediation of Morality" 15-16
[192] Ibid.
[193] Margarete Sandelowski, "Separate, but less unequal: Fetal ultrasonography and the transformation of expectant mother/fatherhood." *Gender and Society*, 8, no.2 (1994). 230–245. 231, 239.

screening.[194] This does not necessarily mean that prenatal screening should routinely be offered to all pregnant women. It is problematic to place sole blame on the technology because obstetric ultrasound provides an important health service. Furthermore the conceptual framework underpinning the assumption that technology is solely at fault allows many other potential problems with the social narrative to be overlooked such as the role of pre-existing beliefs about other actors in the narrative such as women and the disabled.

Third, obstetric ultrasound can identify the sex of the fetus thereby facilitating the naming of the future baby and so transforming it more and more into an unborn person rather than a fetus. As Rothman argues "knowledge changes things, because with sex comes gender...Gender goes beyond the X and Y chromosomes, beyond genitalia, to our ideas about the kind of person the fetus will become."[195] The many scripts of obstetric ultrasound "generate a new ontological status" for the fetus "constituting it as an individual person:" a separate being from its mother rather than as being part of or in unity with its mother.[196] This idea of *fetal personhood* is further enhanced because obstetric ultrasound reinforces ideas of the fetus as a separate patient from the mother, one which can suffer from its own separate diseases and disorders which can be 'treated' or fixed.[197] For Verbeek this construction of the unborn, particularly the way parents understand the fetus, raises the most important ethical concern with obstetric ultrasound.

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[194] Ingrid Zechmeister "Foetal Images: the Power of Visual Technology in Antenatal Care and the Implications for Women's Reproductive Freedom" *Health Care Analysis,* (2001) 387-400. 387
[195] Barbara Rothman, *The Tentative Pregnancy: Amniocentesis and the Sexual Politics of Motherhood,* (London: Pandora 2nd ed. 1994) 119
[196] Verbeek "Obstetric Ultrasound and the Technological Mediation of Morality" 16-17.
[197] Ibid.

Obstetric ultrasound creates the potential for choice where there previously was none in that when a defect is detected, ultrasound transforms pregnancy from 'expecting a child' to 'choosing a child.' Obstetric ultrasound thus creates another level of choice because of the way it has become a standard or routine part of prenatal care and choosing not to have an ultrasound is consequently constructed as an irresponsible choice because it means "you deliberately run the risk to have a disabled or sick child."[198] As I have previously mentioned this is despite the 'cure' to these defects primarily being not treatment, but abortion. This has particular consequences for those who know in advance that they will not abort any fetus for religious or moral reasons.

Verbeek argues that "ultrasound inevitably and radically changes the experience of being pregnant and the interpretations of unborn life" and while this is unquestionably true, it is not necessarily a bad thing.[199] The ultrasound procedure changes how both we as a society, and particular individuals relate to fetuses from how it would be if the ultrasound did not occur, by the 'mutual constituting' of identity produced by the interaction of the pregnant woman and fetus. Obstetric ultrasound is not inevitably bad or ethically problematic under all possible conditions, only in the current circumstances. All of these seldom noted ethical consequences of obstetric ultrasound arise from the particular way we currently relate to ultrasound and could, in the event that the parents choose to abort a fetus with one of the 'conditions,' contribute to the stress and sadness

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[198] Ibid,16 .
[199] Ibid, 18.

they feel at doing so.[200] For instance, there is the increased possibility of mental distress because obstetric ultrasound simultaneously creates circumstances that facilitate abortion through identifying conditions deemed unhealthy, while also enhancing emotional bonding and encouraging ideas of fetal personhood.[201] Thus it would be useful to examine whether it would be beneficial to structure the experience of obstetric ultrasound differently to help decrease the stress. One possible way to mitigate ideas of fetal personhood could be presenting alternative images to the parents during the ultrasound in which the fetus is the actual size and embedded in the woman's body.[202] In the 1980's Petechsky recognised the potential problems that could arise from images of fetuses decontextualised from pregnant women and she suggests a solution similar to that discussed above when she suggests that, "we must create new images that recontextualize the foetus: that place it back into the uterus, and the uterus back into the woman's body and her body into its social space."[203]

Contrasting the social narrative of ultrasound to that of quickening, the first time the fetus is felt to move, makes apparent the role of perception in constructing moral narratives.[204] Historically, quickening has been regarded as a significant stage in a

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[200] Psychological distress is common to almost everyone who chooses to abort no matter what the circumstances of the abortion.

[201] Ibid, 17.

[202] Tests to see whether providing alternative images is useful would have to be conducted.

[203] Rosalind Petechsky "Foetal Images. The Power of Visual Culture in the Politics of Reproduction" in M Stanworth (ed.) *Reproductive technologies, Gender, Motherhood and Medicine.* Cambridge Polity Press 1987, 78

[204] Obstetric ultrasound and quickening are social narratives in their own right that contribute to social discourses about 'fetus' and 'pregnancy.' They are narratives however that often contribute to fetal discourse in ways that oppose and contradict. If the discourse of quickening was strengthen then the idea of a single canonical fetus arising from the ultrasound narrative could be overcome and a more complex discourse of the fetus could be developed.

pregnancy, taking place in the 18-21st week of pregnancy. In many periods of history

quickening marked the point at which the fetus gains moral significance.[205] When

understood as a way of perceiving the fetus, quickening provides an interesting, although

non-artefact mediated, way of understanding the role of perception in morality,

particularly when considered in contrast to the role of the sonogram in contemporary

society.[206] As the mechanisms of pregnancy and fetal development became better

understood during the nineteenth century, the right to life movement also grew in

strength, particularly in the United States of America and arguments against abortion at

any stage of pregnancy were developed.[207] Quickening was a method for perceiving the

fetus and the first point in development at which the fetus could be differentiated and

perceived as something other than part of the mother.

Quickening establishes a different experiential relation to the fetus than that of the

sonographic techniques, because perception of the fetus at quickening does not dissociate

the fetus from the body of its mother as an independent being, as obstetric ultrasound

does, because the movement still takes place within the mother's body. Thus quickening

allows a fetus to be understood as significantly alive, but not as a being that can be

separated from the mother or understood as independent. A further difference between the

sonograms and quickening as alternate ways of understanding a fetus, is that quickening

is understood as a biologically significant event in the process of pregnancy while the

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[205] In the 13th Century Pope Innocent III stated that after quickening abortion was homicide, 18th century lawyer William Blackstone argues that only after quickening is there fetal homicide a separate crime from the murder of the mother. See 22-25 of Luker for further discussion.

[206] I am not attempting to introduce a new idea about 'perception' here merely to apply the discussion of perception and technology developed in chapter two too the particular part of social reality that is morality.

[207] Also at this time the framework changes from "stages of pregnancy" to "stages of fetal development".

taking of a sonogram promotes an understanding or image of a fetus apart from the idea of physical stages in pregnancy. The sonogram image is perceived not as an event in itself, but rather as a snapshot of a continuously existing being. Visual perception tends to dominate other forms of perceiving and because obstetric ultrasound provides a visual image of the fetus, that others can see, it has become a key experience of pregnancy, particularly in the wider cultural symbology of pregnancy.

The key conclusion to be drawn from this analysis of obstetric ultrasound and its contrasting with quickening is the need to recognise the transformative power of technologies. Artefacts and technologies are productively understood as actors in society who contribute to social narratives both in ways their designers intend and in unexpected ways. Artefacts can contribute to unexpected social discourses just as much as they contribute to the discourses their designers intended and even then they can transform such discourses in ways the designer did not intend. The other conclusion to be drawn from the analysis of obstetric ultrasound is the way in which social narratives arising from biomedical practices can dominate other equally valuable ways of understanding the artefacts and people involved in a discourse. Particularly when they arise in areas of strong ethical tension such as pregnancy the social narratives that arise from our relations with particular artefacts and discourses have the potential for significant social and ethical impact such as obstetric ultrasounds' transformation of peoples' understanding of the unborn.

Disvaluing Disability.

The following sections will examine the way that the current discourse of prenatal screening is problematic in terms of reinforcing problematic social narratives of disability, and discuss how this is an ethical issue. The narratives produced by prenatal screening can be seen in the assumptions and language used by a variety of Canadian sources about prenatal screening. The new Canadian clinical practice guidelines for prenatal screening, introduced above, arose from a desire to reduce the use of amniocentesis when maternal age is the only risk factor being used and no screening tests have been conducted. The stated aim was to reduce "the numbers of *normal* pregnancies lost because of complications of invasive procedures."[208],[209] Implicit here, although probably unintentional, is a value judgement that it does not matter how many fetuses that have one of the conditions being screened for are lost [because they will be aborted anyway]. This presumption that fetuses that test positive will, in the majority of cases, be aborted, and that this is unreservedly a good thing, can be seen in the language used by another Canadian study, conducted by Gekas, which examines the cost effectiveness of various forms of prenatal screening. In the study, Gekas declares that the savings were "$C30 963 per additional birth with Down's syndrome averted"[210] and repeatedly uses the phrase "unnecessary terminations."[211] This reinforces the notion that fetuses with Down's syndrome should be aborted, and that such terminations are 'necessary.' The major audience for such literature is medical professionals, particularly obstetricians, the very

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[208] Amniocentesis is a diagnostic that takes a fetal cell sample and so can provide a definitive diagnosis.
[209] Summers, 146. (emphasis added).
[210] Jean Gekas et. al., "Comparison of different strategies in prenatal screening for Down's syndrome: cost effectiveness analysis of computer simulation" *British Medical Journal* 338 no. 138 (2009), 1-10.
[211] Gekas, 1, 5, 6, 8.

people who will be interacting with, and providing information to, pregnant women who are making choices about prenatal testing and whether to abort after a positive test result.[212]

Ralston, an obstetrician, brings up two other contributing factors for why in the biomedical realm disability is understood as a bad thing which help explain why such language is prevalent. Firstly, doctors are taught in medical school that disability is typically bad and should be avoided, and secondly that most obstetricians have very little contact with the disabled community.[213] Seavilleklein discusses how problematic the language surrounding prenatal screening can be both in terms of characterising the probability of a positive result in terms of 'risk,' when other 'risks' of pregnancy, such as gestational diabetes, are never expressed in terms of 'risk'.[214] The language used to describe the fetus is also problematic because terms such as "'affected', 'defective', 'mutated' or 'abnormal'" involve negative normative judgements.[215] Both the language of risk and the terms used to describe the fetus convey to pregnant women that a disabled fetus is undesirable without providing any information about what the actual disability is.

Although this language use is problematic, a strong argument could be made, on quality of life grounds, that aborting a fetus with anencephaly is the right thing to do given that most fetuses with anencephaly are stillborn and those that do survive birth die

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[212] Note that prenatal testing encompasses prenatal screening but also includes diagnostic tests in the event of a positive screening result.
[213] Steven Ralston "Reflections from the Trenches: One doctors encounter with disability rights arguments" 334-339 edited by David Parens and Adrienne Asch *Prenatal Testing and Disability Rights*, (Washington DC Georgetown University Press 2000), 335-336
[214] Seavilleklein, 246-248.
[215] Ibid, 248-249.

within hours. A quality of life argument cannot be made however for someone with Down's syndrome due to the relative mildness of suffering for the majority of people with Down's syndrome or spina bifida. Instead the selective abortion of fetuses with Down's syndrome is most justifiable on the basis of the extra burden of care, and lack of support services that parents face. However this argument does not focus on the wellbeing of the fetus but rather is primarily about the parents and the burden of care they face. Although, this could be considered a valid argument for abortion it changes the subject of value in the discussion from the potential person with a disability to the parents and, in doing so, could potentially reinforce an understanding that people with disabilities have lives that are not worth living. [216]

The clinical practice guidelines recommend that "screening for a disorder should be undertaken only when the disorder is considered to be serious enough to warrant intervention;" however, this is also problematic. [217] The use of code words for abortion such as 'intervention' has been noted by Press, who questions whether an informed consent can be given when abortion is only alluded to as a possible outcome of prenatal screening. Her study examines a Californian information booklet on prenatal screening from the early 1990s which states that in the event of a positive test result, "different options would be discussed" and that they would "support whatever decision the woman makes," yet nowhere in the booklet was the possibility of abortion mentioned despite it

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[216] David Parens and Adrienne Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations" 3-43, edited by David Parens and Adrienne Asch *Prenatal Testing and Disability Rights*. (Washington DC: Georgetown University Press, 2000), 27-28.
[217] Summers, 147.

being the most frequent outcome of a positive diagnostic test.[218] Regardless of widespread awareness in the bioethical community of this problem a similar problem still persists in Canada. The section of The Society of Obstetrics and Gynaecology of Canada's website dedicated to informing the public, does not mention the possibility of abortion once, despite up to 85 percent of women with a positive outcome choosing to abort.[219] The closest the website comes to mentioning abortion is the statement that "a couple should make a decision regarding Maternal Serum Screen after considering what they would do if the results suggested that there was a problem."[220] Seavilleklein argues that this problem is compounded by the fact that little to no information about the actual disorders being screened for is currently being provided.[221] This lack of information or knowledge can be seen in the way people with Down's syndrome are discussed by women who have a positive prenatal screening result, as documented in a study by Chiang. Two interesting associations are made by women interviewed in this study: Firstly that not having a child with Down's syndrome is "good for the child" and secondly they equate having Down's syndrome with being unhealthy.[222]

Both Seavilleklein and Parens and Asch recommend that disclosing information about the conditions being screened for helps "counter the assumption implicit in screening programs that it is undesirable to have a child with these conditions" and

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[218] Press, "Risk, Autonomy and Responsibility," S11.

[219] Nancy Press, "Assessing the Expressive Character of Prenatal Testing" edited by David Parens and Adrienne Asch, *Prenatal Testing and Disability Rights*. (Washington DC: Georgetown University Press, 2000), 214-233. 221.

[220] Society of Obstetrics and Gynaecology of Canada, "Women's Health Information, Pregnancy, Prenatal Diagnosis"

[221] Seavilleklein, 9.

[222] Chiang, 276.

enhances the informed consent process for prenatal screening.[223,224] Worries about the

disvaluing of people with disabilities should not, however, be situated as being causally

derivative of prenatal screening but rather should be understood as the product of

particular relations in a society which already has problematic narratives about disabled

people. If problematic discourses about disability and disabled people did not already

exist then prenatal screening could be less problematic in this regard. The three key

relations of prenatal screening; between the pregnant woman and the technologies of

prenatal screening, the healthcare provider and the technologies of prenatal screening and

the pregnant woman and the healthcare provider, would not be conducted against a

background hostile to disability, and people with disability. If prenatal screening could be

structured as a site such that it lessens problematic ideas about disability and instead

introduced pregnant women and their partners to the idea that people can live a good life

with a disability then prenatal screening instead of being problematic for disabled people

could be a site that promotes positive understandings of people with disabilities,

particularly those with Down's syndrome or Spina Bifida. [225]

In order to achieve this goal it would be necessary to change the understandings of

disability held by the healthcare providers. Not only would they provide an efficient

conduit in that they see many pregnant women everyday but they also are a source of

medical authority. As mentioned briefly above medical understandings of subjects (such

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[223] Seavilleklein, 239.

[224] Parens and Asch "The Disability Rights Critique of Prenatal Genetic Testing" 33.

[225] It is not enough to argue that education of potential parents and healthcare providers is the solution to the disvaluing of disability because education about the lives of people with disabilities is only part of the solution. The other key aspect is examining the social mechanisms that promote problematic ideas about people with disabilities and educating people about how they occur and ways to minimise such narratives.

as people with disabilities) are particularly dominant, thus if someone seen as a source of medical authority could introduce people to more positive understandings of disability then it would more strongly counteract problematic understandings of disability than many other sources. One of the easiest ways to do this would be to introduce people in medical school to people with disabilities who live good lives as Ralston suggests.[226] There would be two results if a more positive understanding of disability could be introduced. First, fewer women would choose to abort fetuses that tested positive for the less severe disorders if they felt that someone with Down's syndrome or Spina Bifida could live a rewarding and happy life. This possibility is alluded to in Press's interviews with women who had positive diagnostic test results and who had previous contact with people with disabilities and were subsequently much less likely to say that they would abort because they felt a child with a disability could not have a good life.[227] The second consequence would be that the general discourse about disability would be less problematic. Where disabled people were more positively valued, aborting on the basis of disability would be less likely to send a problematic message. As such there would be less reinforcement of a problematic understanding of an oppressed minority when women choose to abort a fetus with a disability. Consider the parallel with sex-based abortion: where male fetuses are aborted because of sex-linked disease it is unlikely that a negative message about males is sent, since there is no background social disvaluing of males.[228]

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[226] Ralston, 335-336.
[227] Press, "Assessing the Expressive Character of Prenatal Testing", 225-226.
[228] Dorothy Wertz and John Fletcher "Fatal Knowledge? Prenatal Diagnosis and Sex Selection" *Hastings Center Report*, 19 no.3 (1989), 21-27, 22.

Expressive Harm and Self Trust

I have talked frequently in the previous section about how the current practice of prenatal screening sends problematic messages or promotes problematic understandings of disability and I briefly wish to unpack why and how this is problematic. The idea that social practices can promote problematic ways of understanding things derives from the idea of expressive or symbolic harm; those harms that arise from unintended meanings or consequences of an action, social discourse or social practice. The harm arises not in the action depicted, but due to the social context, power relations and discourses, in which it is conducted. Many of the concerns with prenatal screening can also be understood in terms of expressive harm, the harms arise from the way in which the social narrative of prenatal screening contributes to the identities of others involved in the narrative. Social practices that are authoritative have been identified as being particularly problematic because they are regarded as a source of authority with regards to the narrative, and these particular understandings can come to dominate the identities of actors in the discourse.

Several authors who discuss the contribution of prenatal screening to the discourse of disability use the model of expressive harm to express their concerns, Eva Feder Kittay, James Lindeman Nelson and Press all discuss how prenatal screening, and the resulting selective abortions of fetuses with disabilities, express problematic 'messages' about the value of disabled people.[229,230,231] Although Kittay and Nelson both ultimately

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[229] Eva Feder Kittay, "On the Expressivity and Ethics of selective abortion for disability: Conversations with My Son" Edited by Eric Parens and Adrienne Asch *Prenatal Testing and Disability Rights*. (Washington, D.C.: Georgetown University Press, 2000) 165-195.

reject expressivism they still use the framework to explore why prenatal screening is problematic for disability. An expressive understanding of harm runs into problems when one attempts to analyse how expressive harms arise because they work with a restricted understanding of who counts as an actor in a social narrative. If one accepts both that things can be actors, and that social narratives are the production of the various identities of actors involved in the narrative then the expressive harm model is more comprehensible. The next step is to examine what about someone's identity is affected by a discourse such that they are harmed. I argue that one of the most obvious candidates for this is that social practices which cause expressive harms do so because they reduce someone's capacity for autonomy by promoting a social environment that decreases the self trust of people with disabilities.

As argued in the previous chapter self trust is a key component of being autonomous, because if you do not believe that you can make good choices then you cannot help but be heteronomous. Given that we value being autonomous, any social practice that decreases the autonomy of others, particularly in such a subtle way, is problematic. Note that practices that restrict autonomy are not ones that restrict or constrain choice but rather are those practices that restrict the development of one's autonomous capacity. This is a key distinction because all social discourses construct the choices available to us but only some particular social narratives act to constrain the development of one's autonomous capacity and these social narratives roughly map onto

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[230] James Lindeman Nelson "The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies" Edited by Eric Parens and Adrienne Asch *Prenatal Testing and Disability Rights*. (Washington, D.C.: Georgetown University Press, 2000), 196-213.
[231] Press "Assessing the Expressive Character of Prenatal Testing."

those practices we deem oppressive to particular groups in society. Thus the current practice of prenatal screening could be deemed oppressive for disabled people because the selective abortion of fetuses solely because they will have a disability promotes the social narrative that having a disability is so bad that it is a life not worth living. Casual contacts between people with disabilities and those whose sole, primary or dominant contact with disability has been in terms of this narrative in prenatal screening will be structured in terms of this or a similar belief about living with a disability and this will affect the self trust of people currently living with disabilities. This is because of the way a person's relations with others in society influence beliefs about themselves. Pregnant women because they are directly involved in the practice of prenatal screening can be harmed in two ways, indirectly via expressive harms promoting problematic social narratives about pregnant women as a group in a manner similar to that previously described for people with disabilities, and directly as individuals via particular relations with particular pregnant women.

Prenatal Screening and social discourse around 'pregnant woman.'

One reason many authors, particularly feminist authors, are concerned with prenatal screening as it is currently practiced is because they are in large part concerned with how it reinforces problematic idea(l)s associated with 'woman'. In particular the process of informed consent for prenatal screening is ignored in many countries and marginalised in the majority of others, particularly when prenatal screening is

incorporated into routine prenatal care.[232] Women as a group have many problematic

associations with the ideas of autonomy, which as previously discussed is the dominant

ethical principle that lies behind a belief in the importance of informed consent. Historical

understandings of autonomy existed in opposition with many of the traits considered

feminine and valuable in women. Consequently, women as a group have often been

considered to be less autonomous, and less able to be autonomous. Given the value placed

on autonomy by contemporary North American society it is detrimental to any social

group to be considered as less able to be autonomous.[233] Given historical discourses of

women, which include both significant oppression and discrimination, the identities of

individuals within the group 'women' are often regarded as vulnerable to harm because of

lingering, often tacit, assumptions surrounding them. Pregnant women in particular have a

history of being considered less able to be autonomous. This is because the particular

relations of everyday life will be influenced by problematic social narratives and

influenced by this pre-existing conception of 'pregnant women', even if either party in the

relation (pregnant woman and other person) don't believe that the particular pregnant

woman is less autonomous or even that any pregnant woman is less autonomous. This can

be illustrated by the example of pregnant women as research subjects. Current legislation

that details who can be a research subject in both the United States of America and

Canada states that pregnant women (along with prisoners and children) are a vulnerable

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[232] Studies from the Netherlands, where prenatal screening is not routine prenatal care (Garcia et al.) show a higher degree of informed consent than studies from countries like Canada and some US states where it is routine (Press).

[233] Being autonomous is often associated with being a person and being a person often equated with being a rights holder.

population and then go on to define 'vulnerable' as being less able to make choices.[234]

Although pregnant women might be vulnerable, they are not vulnerable because they are

less able to make autonomous choices but rather for four reasons. First pregnancy

involves changes to a person's pharmacokinetic profile, this means they can metabolise

and react to pharmaceuticals in ways that the non-pregnant population will not. Second

the fetus can be detrimentally affected by diseases that are not harmful to a non-pregnant

person. Third, the rapid and relatively short term physical changes can make them less

physically able to perform activities in their regular lifestyle. Fourth, 'pregnant women as

vulnerable' is a social discourse reinforced through a variety of social practices and

policies in society telling them they are vulnerable and less able to autonomously choose.

This is just one instance of the way in which 'pregnant woman' is constructed as an

identity that is less autonomous than other people.

Medical professionals set the "boundaries between the normal and the

pathological."[235] Attempting to provide insight into the cultural values that promote

prenatal and cancer screening in industrial countries Vassy argues that;

> Tests that provide information about the future health of an individual are
> considered to be beneficial at first sight. They become routine and standard in the
> name of powerful cultural values such as equal access to health care and patient
> autonomy...the process of making screening routine leads patients to consider that
> there is no active decision to be made and to undergo the tests because everybody
> does it.[236]

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[234] Nancy Kass, Holly Taylor and Patricia King, "Harms of Excluding Pregnant Women from Clinical Research: The Case of HIV-Infected Pregnant Women" *Journal of Law, Medicine & Ethics.* 24 no.1 (1996) 36–46. 39.
[235] Vassy, "How Prenatal Diagnosis Became Acceptable in France"246.
[236] Ibid, 248.

The applicability of such an argument to pregnancy is not immediately apparent, because, as Sherwin has previously noted, pregnancy is not illness. Usually patients are considered vulnerable because they are ill, and this needs to be considered in the doctor-patient dynamic; yet the pregnant woman undergoing routine prenatal care does not fit the typical patient-doctor dynamic. She is a healthy individual undergoing preventative screening to pre-empt any potential harms to her fetus.[237] When someone is vulnerable they are considered less able to consent and this is problematic with regards to pregnant women because there is a historical precedent for considering pregnant women as a group to be less able to make 'good' or 'correct' choices for themselves, though I will argue that there are few grounds on which to hold such a position.

When the idea of pregnant-women-as-vulnerable-because-they-are-a-patient-and-all-patients-are-sick is reinforced by the historical understanding of pregnant women as a vulnerable population, there is further reason to be concerned about external valuing/understanding of the autonomy of pregnant women and how this can result in pregnant women being less autonomous because it contributes to structuring their everyday relations in ways that impede the development of self trust.[238] Not only does the current practice of prenatal screening contribute to problematic relations and constructions of the general identity 'pregnant woman;' prenatal screening is also often troubled by problematic particular relations to pregnant women, especially with regards to the issue of informed consent. The problems that arise from particular relations reinforce

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[237] It is somewhat problematic to include prenatal screening under this understanding as prenatal screening is not preventative, but the first stage of checking for already existing conditions in the fetus.
[238] Levine et al. "The Limitations of Vulnerability as a Protection for Human Research Participants" *The American Journal of Bioethics* 4 no.3(2004) 44–49.

the problems with the construction of the general identity 'pregnant women' just as

problems with the general identity contribute to these particular issues. The next section

will examine informed consent in prenatal screening, focusing on how the biomedical

literature frames the problem. I will argue that in using an overly simplistic and

misleading conception of autonomy many authors analysing problems with informed

consent and autonomy fail to comprehend how many of the difficulties with informed

consent arise from wider structural problems in society that are related to wider

understandings of both 'pregnant women' and 'fetus'.

Informed consent in prenatal screening.

In addition to the previously noted points, the Society of Obstetricians and

Gynaecologists of Canada guidelines also require that "the program [for prenatal

screening in Canada] must include the provision of understandable information for both

patients and providers to ensure informed decision making."[239] There are two areas of

concern with regard to such a statement, first, the understanding of autonomy and

informed consent used in the health professional literature and second, whether such a

program actually enhances autonomy. Burgess, when providing an ethical overview of

genetic testing, characterises the autonomy-informed consent link in a way typical in

healthcare circles when he claims "informed consent promotes patient participation and

autonomy in health-care decisions by requiring the provision of information and

recognising that patients must voluntarily authorize interventions."[240] He then goes on to

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[239] Summers, 147.
[240] Burgess "Beyond Consent: Ethical and Social Issues in Genetic Testing" *Nature Reviews Genetics* 2 (2001), 147-152. 147.

define autonomy as important because it is "the capacity to be rational and self-directing. Autonomy creates the possibility of moral responsibility."[241]

This account is reinforced in the work of another author, Garcia, who provides the following account of autonomy; "Central to autonomy is the thought that persons are able to make informed decisions, in light of the available information. Elements considered to be necessary conditions for autonomous decision making are: the presence of valuable options, clear information about the alternatives and the absence of actual constraints."[242] Garcia, who possibly has the most sophisticated understanding of autonomy among those accounts from medical and science journals, later formulates the principle of autonomy as stating "that women must make their choice without being influenced by the opinion of other persons" yet cites how this principle conflicts with how the pregnant women they interviewed actually made the decision because "relationships do play a role in decision-making regarding pregnancy testing." Garcia then goes on to argue that these women 'do not want to shoulder all responsibility for these decisions" rather than understanding that considering-the-opinions-of-others is a practice compatible with autonomy.[243] This is complicated further though, when, in his conclusion, Garcia, briefly questions the model of autonomy previously used, querying whether it is accurate in the context of prenatal screening.[244] Thus despite some awareness of relational autonomy, there is still a pronounced difference between health professionals' understandings of autonomy and

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[241] Ibid, 148.
[242] Garcia "Rethinking autonomy in the context of prenatal screening decision-making" *Prenatal Diagnosis* 28, (2008) 115-120. 115
[243] Ibid, 118.
[244] Ibid, 119.

informed consent and the more nuanced understanding put forward in the previous

chapter. The discrepancy with regards to relational autonomy is pronounced and it is

because of this gap that many of the ethical issues surrounding prenatal screening cannot

be adequately confronted despite good intentions on the part of all parties.[245]

Many of the problems with valuing informed consent and using it as a substitute

for autonomy in health care have already been examined during the analysis of Sherwin

offered in the previous chapter: These include the way that an overly strong focus on

overt coercion decreases recognition of the effects of problems such as oppressive social

circumstances, and the way in which social conditions structure choices available.[246]

Press and Seavilleklein both provide excellent accounts of how prenatal screening can be

coercive and the next few sections will review and examine the studies by Press, Chiang,

Garcia and Green who interviewed pregnant women undergoing prenatal screening. All

of these studies raise serious concerns about prenatal screening in terms of the beliefs

held by many pregnant women; that prenatal screening is routine prenatal care; a general

lack of comprehension about what the test actually did; and not knowing what would

happen in the event of a positive diagnosis. The widespread lack of informed consent

with regards to prenatal screening indicates that there is a problem in the current practice

of prenatal screening deriving from more than just a problem with the obtaining of

informed consent in particular cases. Rather such widespread problems indicate that there

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[245] What is pronounced here is the gap in between what I term theoretical bioethicists, particularly those of a feminist bend, and the healthcare professionals concerned with bioethics. This can be seen in the different ways that autonomy and informed consent are characterised in bioethics articles in the mainstream biomedical journals such as *Nature* or *Prenatal Diagnosis* and the sociology or philosophy literature.
[246] Sherwin, 73.

are problems with the structure of current prenatal screening practice and also the way that other social discourses interact with it.

Seavilleklein argues that informed consent can be analysed in terms of four ideas: disclosure, comprehension, voluntariness and consent.[247] Considered in these terms, the first problem with informed consent in prenatal screening is finding the balance of how much detail it is relevant to disclose: not enough disclosure and one fails to provide relevant information, too much and one threatens to reduce the level of comprehension obtained. Potentially the most significant issue with finding this balance between these four factors is the lack of discussion of abortion in the process of informed consent. According to Press, there is good reason to require informed consent for prenatal screening, despite the lack of physical risk in the actual procedure (informed consent is not usually obtained for blood tests), because the event of a positive result initiates a complex chain of future possible actions that the pregnant women needs to be aware of, including the chance of miscarriage when obtaining definitive diagnosis via amniocentesis or CVS and the possibility of abortion.[248] Studies show that abortion is seldom mentioned when consent is being obtained for prenatal screening yet in the event of a positive screening result, followed by a positive diagnostic test, termination is

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[247] Seavilleklein, 112-113.
[248] Browner, Carole and Press Nancy. "The Production of Authoritative Knowledge in American Prenatal Care" *Medical Anthropology Quarterly*, 10, no. 2, (1996), 141-156. 145.

overwhelmingly the 'choice' made unless the pregnant woman has a strong objection to abortion.[249]

Studies that evaluate pregnant women's comprehension of prenatal screening overwhelmingly show that there is often a very low level of understanding of even such basic facts as what conditions are being tested for and what a positive screening result means. This lack of comprehension is common to both women who decline screening and those that desire it.[250,251] Moreover, although methods of facilitating information such as videos and pamphlets increase comprehension they fail to even come close to obtaining the level needed for informed consent, where informed consent is at a minimum a sufficient understanding of the process and possible consequences of what they are agreeing to.[252] Prime among the many concerns, is the finding of one study which indicated that many women when subsequently interviewed believed that the testing was mandatory.[253] The same study found a belief that the fetus could be harmed unless they obtained prenatal care because such testing was part of that care and was "to make sure your baby is healthy".[254] Implicit in these understandings of prenatal screening was often a belief that prenatal screening was preventative not diagnostic. It should be noted though that since this study was conducted, in the early 1990s, many countries and health agencies have put large amounts of effort into improving the consent process in prenatal

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[249] Over 90% of women with a positive result choose to abort. Press and Browner, "Risk, Autonomy and Responsibility," S10.
[250] Press and Browner "Risk, Autonomy and Responsibility" and Chiang.
[251] J.M. Green et al. "Psychosocial Aspects of Genetic Screening of Pregnant Women and Newborns: A Systematic Review" *Health Technology Assessment* 8 no.33 (2004) 1–109.
[252] Ibid, 69.
[253] Press, Nancy and Browner Carole, "Why Women Say Yes to Prenatal diagnosis." *Social. Science and Medicine.*45, no. 7 (1997) 979-989. 983
[254] Ibid, 984.

screening with a strong emphasis on comprehension and making sure that women understand that prenatal screening is something one can choose to do. For instance, the Canadian SOGC website provides all information in the third person passive voice in which all reference to the woman who 'may' undergo such a procedure is removed and instead presents the information as;

> Maternal Serum Screen (single screen, double screen or triple screen) is usually done at 15 to 16 weeks. Reports are available in one to two weeks. This testing cannot tell if the baby has or does not have a chromosomal problem but instead gives an estimate of risk, such as the risk of a 20 year-old or the risk of a 40 year-old. The couple is then faced with deciding whether or not to have more definitive testing and again must wait several weeks for the report of this testing.

Another recent study, conducted by Chiang in Taiwan, also examines women's reasons for undergoing Maternal Serum Screening, the standard form of prenatal screening offered in Taiwan.[255] Chiang's findings emphasise that almost all the women who underwent prenatal screening felt that they had not made a decision regarding prenatal screening because it was a presented by health professionals as a routine part of prenatal care, even though the test was not covered by their health insurance and they had to pay out of pocket for it.[256] Chiang also discusses the confusion and powerlessness the women felt when the "test result did not coincide with their expectations that the test would ensure the baby's health," an outcome which is also indicative of the level of comprehension.[257] Every study examined indicates that women's understanding of the risks and their knowledge of prenatal screening is insufficient and that they often did not

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[255] There are some cultural differences between Taiwan and North America, such as more deference to medical authorities, but with regards to comprehension and beliefs about what prenatal screening does to make a discussion of Chiang worthwhile.

[256] Chiang, 274-275.

[257] Ibid, 275.

feel fully informed about both the possible consequences and options available, when making choices regarding prenatal screening, nor did they realize that they had a choice as many thought the test was compulsory and routine.[258]

With the notable exception of Garcia, all the authors who examined the consent process of women undergoing prenatal screening argue that a serious investment of both time and resources is required to overcome deficiencies in the current process of informed consent for prenatal screening.[259] This is important because it may affect the economic cost-benefit argument that is the public health rationale for offering prenatal screening to all pregnant women. Studies such as these indicate that attention is being paid to the process of informed consent and that attempts are being made to both improve informed consent in terms of the four areas highlighted by Seavilleklein and also to remove any possible coercion on a structural and institutional level. However they also indicate that there are serious problems with the informed consent process in prenatal screening. One thing I believe the analysis presented here highlights is the way in which the debate about improving the informed consent process should be understood as derivative in part from wider social discourse about pregnant women. The particular narratives in the discourse of pregnant women promoted by the current practice of prenatal screening serve only to reinforce problematic ideas about the abilities and responsibilities of pregnant women and this feeds back into the existing individual level ethical problems both structurally via policy and the range of choices made possible by prenatal screening and in limiting the

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[258] Green, Press, and Chiang.
[259] Chiang, Green and Press. Garcia's study differed in several key ways as prenatal screening is not routinely offered to all pregnant women in the Netherlands.

autonomy of pregnant women, particularly with regards to self-trust, as discussed in the previous section on disability and self-trust.

Does increasing choice increase autonomy?

Many authors take discourses such as prenatal screening to task for being coercive. However if one accepts a postphenomenological model then all artefacts are coercive in that our interactions with them promote particular social narratives, one often unintended by the artefact designer. These narratives can harm both the particular individuals interacting with a technology, like pregnant women in prenatal screening, or the identities of whole groups such as 'pregnant women' or 'person with a disability.' A more limited and useful understanding of coercion can be obtained if we restrict 'coercive' to those affected by direct interaction with prenatal screening. Thus prenatal screening can be coercive with regards to both pregnant women and medical professionals but not with regards to people with disabilities. This is because the current practice of prenatal screening is only harmful to people with disabilities because it promotes a dominant and restricting social narrative into the general social discourse of 'disability', one that potentially restricts the development of self-trust in people with disabilities by impeding their interactions with others.

One way that prenatal screening has the potential to be coercive is that it purports to expand choice, and thus autonomy, by providing additional information about one's pregnancy. The current practice of prenatal screening forces on women a variety of choices that they may not necessarily want, and therefore prenatal screening can

potentially reduce autonomy.[260] Thus, while Chiang argues that "prenatal screening

provides options for women to control the pregnancy process," this control is, in many

ways, an illusion based on false understandings: as mentioned previously, many women

understand prenatal screening as ensuring the health of their fetus.[261] Given that all the

'conditions' currently screened for are untreatable if one has a positive diagnosis, this

"control" translates to little more than either increased knowledge of the rough probable

health and care needs for the future baby or abortion. Additional information does not

necessarily facilitate autonomy, especially considered relationally, because of the way

that the provision of information is always embedded in a social practice. It is often

assumed that enhancing the range of choices and the level and amount of information

available will increase autonomy: however this is not necessarily the case. As can be seen

in the discussion of women's comprehension of prenatal screening, it is possible that in

many cases offering prenatal screening actually reduces autonomy because although it

provides an opportunity for the exercise of the autonomous capacity in those operating at

a high level of autonomy who have a high degree of self trust and well developed

autonomous capacities, for the majority who are episodically autonomous pregnancy,

particularly those aspects of pregnancy that interact with the medical profession, are

likely to be the very areas where one lacks the autonomous capacity. While it is very

possible that prenatal screening does increase a woman's autonomy, it does not

necessarily do so on the grounds that it provides extra information. Given a relational

understanding where autonomy is about the way in which you make your decisions and

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[260] Garcia, 115.

[261] Chiang, 246. There is an interesting assumption that control equals autonomy here.

choices, then providing more choices for someone, does not necessarily increase their autonomy or even facilitate them using it. Even if the process of informed consent was and could be improved with regards to particular individuals to meet the standards of disclosure, comprehension, voluntariness and consent, this does not parry the larger criticism that increasing the information available does not increase an individual's autonomy.

Conclusion.

The first chapter of this thesis explored a postphenomenological understanding of technology, a socially embedded understanding of technology where the intentionality of the actor-artefact is derived in part from the intentional scripts designed into the object by the creators and also from the existing social discourses that interact with the artefact, its creation and design and its creators. The postphenomenological model of technology understands artefacts as existing in relationships of mutual constitution, the identities of both parties are informed by the particular relation. Thus one's identity is informed by the sum of one's relations. This model of identity fits well with the model of relational autonomy explored in the second chapter, where autonomy is understood to be a capacity, something one does. In order to exercise autonomous capacity one has to have trust in oneself that one can make autonomous decisions. Self trust is an aspect of one's identity that is developed via one's relations and thus problematic relations can greatly impact one's autonomy – where the postphenomenological discussion of technology provides a

model by which to consider those relations which we most often overlook, our relations to technology.

Many of the ethical concerns with regards to the current practice of prenatal screening can best be articulated in terms of how prenatal screening interacts and contributes to the identities of individuals, artefacts and structures involved in the social narrative of prenatal screening. Although this contribution is both mutual and continuous a practice such as prenatal screening has a large amount of influence on a variety of social discourses because of its connections to significant social, ethical and political issues - such as the rights and value of women, people with disabilities and fetuses - and ethical values such as autonomy. Narratives that arise in our interactions with prenatal screening are particularly important because they have particular force of voice due to the authority that 'medicine' and 'science' imbue in them. Prenatal screening provides a useful service and I am not arguing that prenatal screening should not be conducted but rather that we need to be aware of how the current particular practice of prenatal screening interacts with both individuals and artefacts to contribute to a variety of social narratives, some of which are coercive, or harmful to particular social groups. Using a postphenomenological analysis of the relationships and role of the technologies of prenatal screening it has become apparent over the third chapter how such harmful narratives arise.

Prenatal screening as it is currently practiced reinforces problematic social narratives of pregnant women, in many areas it is structured such that it reduces the opportunities for pregnant women to exercise their autonomous capacity, and it also promotes problematic notions of 'pregnant woman' in society. Others who interact with

pregnant women will be influenced by these problematic understandings of 'pregnant women' and in some cases this will structure the interactions of pregnant women with others so as to inhibit the development of self-trust in the pregnant woman. Another social narrative closely associated with that of 'pregnant woman' is that of 'fetus'. As can be seen in the example of obstetric ultrasound, prenatal screening contributes to understandings of the fetus in two key ways. Prenatal screening as it is currently practiced has a tendency to reinforce ideas of the fetus as a patient, and thus person, in its own right, hence contributing to a problematic social trend where fetal interests become understood as 'rights' seen as existing in tension and conflict with the interests of the pregnant woman. This again promotes problematic social narratives about pregnancy and pregnant women and further reduces the opportunities of pregnant women for autonomy. Thus the current practice of prenatal screening inhibits the development of autonomy in pregnant women for two reasons. The direct relations of pregnant women with the technologies of prenatal screening are structured such that they inhibit the opportunities of pregnant women to develop an autonomous capacity. Moreover the current practice of prenatal screening promotes social narratives that structure the relations of pregnant women such that the development of key components of autonomy, such as self-trust, are inhibited.

Discourses of 'disability' are the final area influenced by the social narratives of prenatal screening because prenatal screening promotes selective abortion, of otherwise wanted fetuses, because they will have a disability. Although terminating pregnancies in which the fetus will be either stillborn or die soon after birth is less problematic, the

current structuring of prenatal screening leads to the systematic abortion of pregnancies where the fetus will probably develop only minor disabilities. This is problematic for people already living with similar conditions as it reinforces negative ideas about their value both to themselves and others and this can inhibit the development of key components of autonomy such as self-trust. The technologies of prenatal screening are used in socially embedded practice and should be structured with the following question in mind. How can this practice be structured so as to minimize the reinforcement of problematic ideals about an already marginalised group? What should not be lost here is the particular notion that technologies are actors in social discourses along with people. Furthermore particular technologies can act in ways unintended by their human designers and implementers and can act with other social actors in unpredictable ways. However if we recognise that artefacts can be actors then it is possible to reposition our relations to these actors without removing them from the discourse altogether.

It should be the goal of any ethical analysis to consider ways to minimise such potential harms, however it should also be kept in mind that prenatal screening is not the only social discourse in which these actors are embedded. Questions still need to be asked about how big a contribution the discourse of prenatal screening makes to the identities of women, and ideas of the fetus and disability. For instance, could it be more effective to focus our efforts on analysing and reorganising other social narratives either because they are more problematic in terms of these identities or because prenatal screening provides an important healthcare service whose effectiveness would be diminished by intervention. When a practice is directed towards a particular group the practical particulars and

realities of their social situation should be taken into account in any ethical analysis. This does not however mean reducing things to stereotypes. In the case of pregnant women this means recognising the ways in which being pregnant is constructed, especially in relation with reproductive technologies, and thinking about the potential problems that arise from the routinization of technologies such as prenatal screening. This is the case also with regards to narratives of the fetus particular promoted by reproductive technologies, and also with consideration for how they influence discourses of disability. What should be included in the cost benefit analysis of policy decisions about prenatal screening along with the financial costs, liability risks and medical benefits, is the harder to quantify effects of the practice on pregnant women, as both individuals and as a group, on people with disabilities and on social discourses of the fetus. This way the real cost of conducting a social practice such as prenatal screening, where the harms have been minimised, can be assessed.

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