The Ethics of Consent and Choice in Prenatal Screening

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TABLE OF CONTENTS

INTRODUCTION

> ‘This technology turns every user into a moral philosopher as she engages her fears and fantasies on the limits of mothering a fetus with a disability’ (Rapp, 2000, p.128).

The title of this work firmly positions it as applied ethics research. The questions raised by the routine implementation of prenatal screening are ethically significant because they potentially have an impact on human being and becoming that reaches beyond the obvious individual consequences. Prenatal screening impacts ethically upon the status of new human life, on the lives of mothers, couples and families, and on society generally in terms of the human values that are supported or denied by its practice.

If the moral form of life is intimately entwined with a sense of the indisputable uniqueness and ‘*inalienable preciousness’* and dignity of each human being as Raymond Gaita (1999, p.4) suggests, then the critical questions raised by prenatal screening technologies such as, who is permitted to be born, under what circumstances and conforming to which pre-conditions of entry to the human race are imposed, are inherently ethical in nature because they strike at the heart of our understandings of what it is to be human. To be allowed to exist (or not), for life to be valued in all its diverse forms solely because it is human life (or not), to be given the chance to grow and become, to live an embodied, embedded life (or not) may not be a presumed human good. With the advent of prenatal screening technologies, the creation of life may no longer be regarded as a matter of biological chance or of divine mystery, but increasingly in the mechanical, biological model, viewed through the reductionist lens of science, nascent human life may become objectified, leaving it open to technological manipulation and control. This previously untouchable and seemingly random natural process now falls under human scrutiny, judgement and control.

Consequently, notions of personal ‘choice’ and preference have become further entrenched into our reproductive expectations. Not only can we choose when or how many children we have, there is now a growing expectation that we can also choose which type of child we are willing to accept. Such choices, framed in socially entrenched prejudices governing which traits are desirable or undesirable in our offspring create a moral space in which the destruction or removal of such a life seems the technically and philosophically rational thing to do. When the ethical nature of 'choice' is considered within an analytical philosophical framework, rationality becomes the ultimate arbiter of which choice is better, or more rational, than another, but whose rationality should we privilege? In trying to forge humane and ethically responsible use of this technology, will we make the realisation as Kass (2002, p.17) does that '*not all human dignity consists of reason or freedom'*.

The choices offered or denied, however, are not ours alone to pursue. In order to make these technologically mediated choices a practical reality, individuals are dependent upon the technical expertise of others. Clearly technology has brought significant gains to our understandings of the human condition; however the potentially dehumanising gaze of technology, driven by a pursuit for perfection and the rejection of the imperfection of disability, cuts to the core of human dignity and is already blurring the boundaries of the sanctity, or preciousness, of human life. We now have the knowledge to detect and diagnose certain disabilities prenatally and the power to 'prevent' the presumed pain and suffering that accompanies them. Tentatively 'wanted' and 'planned' children may become unwanted and unplanned on the strength of a test result (Asch and Wasserman 2005; Katz - Rothman 1986). While some limited conditions may be treatable prenatally, couching prenatal screening as a means of promoting such early intervention is disingenuous because the genetic anomalies targeted are, as yet, inherently 'unfixable'.

With pregnancy and parenthood taking on the overtures of a well executed project, Kass remarks, ' *a society that when it does procreate, that sees its children as projects rather than gifts is unlikely to be open to the question of meaning and dignity of procreation'*(Kass 2002, p.20). Through technology, we have been invited to redefine our understandings of what a suitable body is, and for some, the expectations of what constitutes a suitable body for our children to be born into have been significantly influenced by access to prenatal and genetic screening. Indeed some commentators argue that we parents have a moral obligation to choose children with the best genetic prospects, or even intentionally enhance the genetic makeup of their future children where technically possible (Green 1997; Aldred, Savarirayan, and Savulescu 2003;

Savulescu 2001). Rather than accepting the wholeness of humanity as incorporating differences, we are perhaps swayed by the promise of technologically mediated perfection for our children. However, as previously discussed, our bodies are not merely objects or machines; they are the site of our human being in the world. As such, any purely mechanistic view of disease, illness or imperfection detached from the ontological realities of being, will fail to incorporate the essential humanistic understandings, of the deeply connected, embedded and relational realities that define the human condition. When mechanistic understandings of the body are coupled with a similarly mechanistic approach to ethics, the creation of the required open reflective moral space will be stifled.

While Kass (2002, p.10) was commenting on the use of human embryos as raw materials for use in medical research when he stated, '*we are desensitised and denatured by a coarsening of sensibility that comes to regard these practices as natural, ordinary and fully unproblematic'*, his comment could similarly apply to prenatal screening technologies. We should be equally wary of embracing 'soft' technologies, such as the non-invasive forms of prenatal screening that encourage us to judge who is worthy of being born because as Ruth Hubbard (1988, p.234) notes,

> 'We do ourselves an injury, as individuals and as a society, if we let fear of difference tempt us to decide "who should and should not inhabit the world" because it is hubris to pretend that we have the knowledge and foresight to make such judgments well'.

We are faced with the ethical reality of balancing the indisputable goods that medical technology can offer through the prevention of disease with the potential harm that human life may be dehumanised and disrespected in the process. Charles Taylor (1989) further observes that the difficulty in pursuing the 'good life' is often not the need to discern good from bad, but rather negotiating the moral conflict that arises when judging between competing goods. The questions of how we ought to consider and respond to these competing goods are ethical questions, thus they invite ethical answers, but what kind of ethics and how should we consider these competing potentials for good? While medical science asks 'can we', ethics uniquely challenges us to decide whether what we are doing is affirming or damaging. Thus the ethical landscape we create and the ethical legacy we leave doesn't depend upon free rational choice so much as it depends on which choices are made, or made available. Therefore, the role of ethics in our society is to provide a framework through which the moral dimensions of our daily lives may be articulated and understood, then incorporated into a constructive response to shape better lives.

CHAPTER ONE

CONSENT, CHOICE AND THE CONTEXT OF PRENATAL SCREENING

> ‘Women are situated on the research frontier of the expanding capacity for prenatal genetic diagnosis, forced to judge the quality of their own foetuses, making concrete and embodied decisions about the standards of entry into the human community’ (Rapp 2000, p.3).

The development of prenatal screening technologies has been described as ‘*simultaneously liberating and eugenic’* (Rapp 2000, p.2). They are liberating in that they can provide a means by which some parents may conceive or give birth to the healthy child they desire, but may be considered eugenic as, in the absence of the ability to ‘cure’ or treat certain physical or genetic conditions that may be diagnosed, choice is predominantly realised through the selective termination of those foetuses judged to be physically or genetically undesirable. Whichever interpretation is adopted, it is evident that the burgeoning practice of prenatal screening straddles an ethical divide.

The presumption that the technologically mediated goal of preventing disability is ‘*desirable and defensible’*, and a worthy pursuit that in no way passes judgement on existing people with disabilities is widely disseminated and claimed to be generally shared in society (Parker, Forbes, and Findlay 2002, p.10; Savulescu 2001). However, the means by which such prevention is achieved, the entrenched social prejudice it can instil, and the eugenic stance within are strongly contested by many commentators writing from a disability rights perspective (Shakespeare 2001, 1999; Hubbard 1988; Shakespeare 1998; Parens and Asch 2000; Newell 2003; Bridle 2004; Newell 2007; Kenen 1999). James Lindemann-Nelson (2003, p.3) further cautions,

> ‘According people the respect they are due is a matter of general importance, and we ought be especially scrupulous when people who have endured a history of negligence and abuse claim that they are yet again being demeaned’.

When the nature of the much hoped for ‘prevention’ comes in the form of terminating an existing foetus or embryo, ‘prevention’ takes on a radically different and increasingly controversial meaning; clearly a more extreme form of prevention than a measles inoculation for example.

Thus, in being invited to embrace the technology of prenatal screening, women are placed in the unenviable position of making ‘*concrete and embodied decisions about standards of entry in the human community*’ as Rapp (2003, p.3) noted earlier. Markens, Browner and Press (1999, p.367) similarly describe this choice as *‘engag(ing) in risk assessment which can determine the life and birth of future generations’*. The factors that shape this ethical divide between the culturally endorsed views of technology as irrefutably ‘choice enhancing’ and good, and the moral unease of prejudicial, discriminatory and stigmatising practices directed against people with disabilities, expose complex ethical questions that challenge our most fundamental understanding of what it means to be a human being. These questions are fundamentally ethical in nature and they form the social and cultural backdrop of this work.

Generally across all forms of medical intervention, the widely accepted and favoured safeguard against possible ethical impropriety, or in the case of prenatal screening accusations of coercion and eugenic intent, has been to focus on obtaining a patient’s informed consent prior to any proposed intervention (Marteau and Dormandy 2001). A prior consideration to our reliance on informed consent as a legal and ethical safeguard is that the intervention in question is not contrary to the accepted public order or shared sense of moral good. Only when an action does not breach the law, or breach codes of moral action in a society can a person be considered at liberty to give their voluntary consent. While prenatal screening is widely practiced and accepted in our society, and provided by public health institutions which convey societal endorsement of this practice, some disagreement lingers as to the inherent ethical acceptability of selective termination on the grounds of disability (Wertz 1998; Wertz and Fletcher 1998; Lippman 1991; Caplan 1999; Hubbard 2001; Asch and Wasserman 2005; Clapton 2003). The tensions surrounding the ethical acceptability of prenatal screening are acknowledged throughout this work; however, a definitive answer to these divisions will not be provided. Rather, the ethical tensions inherent within current practices will be explored, and some practical responses which may support all women to act within their own moral frameworks when confronted with the moral choices inherent within the offer to undergo prenatal screening will be considered.

When a proposed intervention is legal, conform to public policy and community standards of ethical behaviour, the conditions of informed consent prior to any medical intervention articulated in the medical ethics literature generally embrace the following five[1] criteria;

- that a patient must be competent to decide,
- that all material information about the proposed intervention must be disclosed,
- that participation in proposed intervention is optional and voluntary,
- that the patient fully understands the nature and potential benefits, risks and alternatives to the proposed intervention,
- that consent is active, and given freely without coercion

(Beauchamp and Childress 2001; Mitchell, Kerridge, and Lovat 1996; Jonsen 1998; Manson and O'Neill 2007).

Hence, a patient giving their informed consent, granted freely from a position of knowledge and understanding to undergo a particular 'treatment', has come to represent that any proposed intervention is ethically robust as the above mentioned conditions of competence, voluntariness and understanding are presumed to be implicit within its application. The routine seeking informed consent by health care professionals is further regarded as proof that patient autonomy has been respected, while the realisation of informed consent in practice is presumed to support individuals in their capacity to intentionally make important decisions and pursue their own individual goals in a way that is consistent with personal moral frameworks, free from control or manipulation.

The pre-conditions of voluntary and knowledgeable participation are believed to be inherent within prenatal screening protocols. However, research from around the globe into the motivations and understandings of women engaging in prenatal screening suggests that while many women do indeed participate in screening regimes, a significant number cannot articulate the purpose or potential outcomes of testing. This well established research into the motivations and experiences of women participating in prenatal screening programmes commonly reveals a lack of reflective understanding, passive compliance with a routine normative

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[1] In law, three pillars are generally cited being competence, information and voluntariness, however, the ethics literature commonly cites the five listed above.

pathway and an apparent inability to articulate the purpose, justifications or potential problems of the testing they have participated in (Santhalahti et al. 1998; Stapleton, Kirkham, and Thomas 2002; Press and Browner 1997; Markens, Browner, and Press 1999; Williams, Alderson, and Farsides 2002; Bernhardt et al. 1998; Harris, Connor et al. 2004; Santhalahti 1999; Kohut 2002). The tacit expectation of participation that routine screening conveys further obscures the optional nature of screening while the poor knowledge levels reported significantly challenges any comfortable presumption of 'informed' engagement. The belief that participation may be equated to ethical integrity as claimed by some commentators (Cuckle 1995; Whynes 2002) thus seems exaggerated.

As informed consent protocols have gained precedence primarily through the courts, a significant barrier to fulfilling the ethical intentions of informed consent in an institutional setting is the strong defensive legal bias which has influenced the organisational implementation of consent protocols. The ethical standard of informed and understood consent cannot be presumed to be inherent within the minimal legal criteria for informed consent in the area of prenatal screening. The legal bias which permeates practice often engulfs the more subtle moral or ethical negotiations required from the patient – physician exchange (Wear 1998). Indeed some commentators openly describe existing informed consent protocols as merely "empty bureaucratic rituals" (ibid), the main purpose of which is to provide a defensive legal document or form of insurance against malpractice suits, while paying superficial concern to the moral dimensions of care (Gillott 2001; Kenen 1999; Press and Browner 1995). When the motivation to procure consent is primarily driven by the legal goal of averting litigation, or fulfilling organisational policy requirements, rather than proactively equipping the patient with the necessary understandings to make decisions that are medically and morally coherent for that individual, the clash of motivation between those seeking consent and those giving it can create a conflict of interest that may further widen the existing ethical divide.

There are a number of practical problems in actualising informed consent in the clinical context of antenatal care. Entrenched institutional pathways such as the routine nature of screening may obscure voluntariness; overt and covert counselling may be subtly coercive while the predefining of certain outcomes as unacceptable may limit possibilities and narrow the boundaries of tolerance. Additionally the lack of genuine access to alternative pathways delimits which choices are permissible; limited time for consultations often prevents the formation of effective communication partnerships and poor access to adequate education and knowledge building converge to create a situation in which women's individual agency may be profoundly constrained.

Within the wider context of health care, low levels of informed consent are commonly observed across many fields of medical intervention and compelling evidence of failure to achieve 'informed consent' persists across an extensive variety of medical interventions and disciplines. Disturbingly low figures in meeting the ethical requirements of informed consent have been reported at 0.5 % success for 'complex' decisions, defined as having extensive effect on the patient with uncertain and multiple outcomes, and reaching a mere 26% success for simple decisions where the effect is minimal and the outcomes are clear and singular (Braddock et al. 1999, p.p.2315-7). Using Braddock et al's (ibid) descriptors, the decision to undergo prenatal screening may be regarded as complex, as the potential outcomes are numerous and uncertain, and the consequences may indeed be personally significant. Although the accepted protocols may meet the minimum legal or administrative requirements, evidence suggests that they commonly struggle to fulfil their ethical purpose of preserving patient autonomy and empowering the patient with the right to intentionally embrace or reject the intervention on offer (Braddock 2002; Braddock et al. 1999; Wear 1998; Bottrell et al. 2000). The potential consequences of ill informed compliance with prenatal screening for women include short and long term anxiety or depression; alienation and feelings of coercion (Goel, Glazier, Summers, & Holzapfel, 1998; Kowalcek et al., 2002; Watson et al., 2003). The failure to implement robust informed consent protocols that genuinely uphold and promote individual capacity for morally coherent decision making therefore has real potential to harm.

These observations invite further consideration of the underlying presumptions, conventions and ethical intentions inherent within 'informed consent'. Critically, they also raise questions about the role that 'informed consent' may play in preserving individual autonomy via the right to decide about treatment options, of protecting individuals from coercion and manipulation. The historical roots of requiring a patient to give 'informed consent' to participate in medical research were first outlined with respect to medical research in the Nuremberg Code (Manson and O'Neill 2007; Beauchamp and Childress 2001, p.77), and later in the

Declaration of Helsinki[2]. These Codes significantly position informed consent as a process of ensuring patient autonomy and freedom ‘from’ control, rather than their freedom ‘to’ pursue independent and intentional goals. It is the protective ‘freedom from’ stance that appreciably defines respect for autonomy in the medical ethics literature, although as outlined above, this appears not to be commonly achieved in clinical practice either generally or with respect to prenatal screening protocols.

Despite the mounting evidence that ‘informed consent’ protocols in their current form have enjoyed limited practical success to date (Manson and O'Neill 2007; Wear 1998; Braddock 2002), or that broader philosophical concerns exist about the defining features of autonomy or the merit of elevating individual agency and personal choice as the privileged means of shaping our collective moral direction, the ethical ideals of informed consent and autonomy hold considerable merit within broader Western social frameworks. Thus, ways to promote their actualisation, by seeking fuller understandings of the numerous and complex overlapping and interwoven constraints embedded within the broader social, institutional and personal domains that have stifled their realisation in practice need to be identified and incorporated into a more functional and responsive framework. It is proposed in this work that the problems observed in actualising informed consent do not entirely with the conceptual foundations per se, but more likely within the thin, reductionist, often cursory and inadequate support and organisational infrastructure directed at achieving ethically coherent informed consent in practice. The ethically adequate and socially inclusive ‘process’ of negotiating informed consent, as opposed to the minimal legally adequate administrative ‘event’ of obtaining consent, has the potential to equip patients with the necessary understanding to make ethical decisions in accordance with their own moral frameworks. Thus informed consent and respect for autonomy remain desirable and necessary prerequisites to ethically robust medical intervention. The critical question remains how we may support their actualisation in practice.

Flowing from the observations above, the questions posed in this work were founded on the combined observations that:

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[2] See World Medical Association. Ethics Unit Declaration of Helsinki. 2007. http://www.wma.net/en/30publications/10policies/b3/index.html. Retrieved 20-08-10. See also (Goodyear, Krleza-Jeric, and Lemmens 2007) for comment on the most recent changes to the Declaration.

- Prenatal screening, with its invitation to judge which characteristics are desirable in our future children, raises deeply complex and sensitive ethical issues which strike at the heart of individual and collective understandings of human being and becoming. Robust ethical standards must therefore be applied to this increasingly routine, but potentially ethically contentious, pregnancy intervention.
- While respecting patient autonomy through eliciting informed consent is valuable in preserving individual capacity and diminishing coercion or manipulation, current protocols as described in the published literature appear to have significantly failed to support patients in achieving a voluntary, understood and active participation in medical interventions both generally, and in the specific case of prenatal screening. The lack of informed consent does not automatically suggest that the patients' wishes have been violated (Schneider 1996); rather, it flags that the presumed ethical safeguard, in its current actualisation, may be less effective than believed.
- Developing robust informed consent protocols to support the humane, ethically inclusive and transparent use of prenatal screening technology may require us to rethink the current individualistic, legalistic and ethically reductionist approaches to consent. This will require a reorientation of collective understandings of autonomy as unencumbered individual choice, towards acknowledging autonomy as deeply relationally embedded and constrained, socially contextualised and subjectively interpreted. It also requires explicit recognition of the multiple underlying social, personal, institutional and philosophical constraints that impinge upon the practical realisation of autonomy, consent and choice. If these obstacles are to be meaningfully addressed and minimised, they must first be openly articulated.
- If informed consent is based upon patient understanding, any commitment to strengthen informed consent protocols demands that we address the question of 'how' to effectively inform. Furthermore, we must remain cognisant that 'what' information becomes worthy of informing is significantly pre-filtered through various cultural, historical and institutional interpretive lenses. As becoming informed, and gaining reflective understanding, is a process of learning, the insights offered through educational philosophy and cognitive theory may provide a suitable platform to strengthen informed consent. The crucial ethical distinction between minimalist forms of information disclosure and the fuller moral requirement of reflective understanding of the personal implications of any proposed intervention may then be

supported within the organisational infrastructures that women encounter during pregnancy.

- The ethical transformation of practice must be acknowledged as occurring simultaneously at the individual and institutional levels, as in reality they are interdependent, each partially defining, constraining or supporting the other.

This work sought to examine the deeply embedded social and ethical elements that shape the burgeoning practice and unspoken presumptions fuelling the rise of prenatal testing. While the applications and inventions of this technology have been described as a ‘new’ revolution, they are arguably influenced by some very old, historically significant and deeply entrenched prejudices and practices. As collective (mis) understandings of new technologies colonise our expectations of the controls we imagine can be imposed on the human condition, the criteria of what is an ‘acceptable’ life, and ultimately the choices we make of what constitutes a suitable body for our children to be born with permeate our judgements. Against a cultural backdrop in which the value of individual choice is privileged, in which an unborn child has no recognised legal status[3] and in which consumer demands drive individual and collective expectations of clinical care, careful consideration of how and why such tests are developed, offered and accepted demands further exploration.

As women and their unborn children are the sole recipients of these prenatal interventions, this research sought to illuminate how the ethical dimensions of existing prenatal screening practices and procedures were received specifically by women locally. As women’s experiences may be critically shaped by the presumptions, prejudices and attitudes of their health care practitioners, the motivations, experiences and beliefs of a cohort of health care providers was also canvassed. The combined consideration of a range of experiences collectively illuminated many social, cultural, historical and philosophical presumptions that inform practice today.

As the underlying tenets of ‘informed consent’, voluntary and understood participation, are broadly accepted as representing a high standard of ethical care in medical practice, genuinely facilitating informed decision making remains a critical concern in the practice of ethics across all forms of medical care.

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[3] In Australia.

Within the realm of prenatal screening the constraints that shape and mould how choice is constructed and whether informed consent is supported may be loosely categorised into four porous groups being:

> *Philosophical* constraints arising from the often thin and narrow interpretations of the ethical as realised through the exercising of personal autonomy, choice and informed consent. Further compounding these issues, the atomistic connotations implicit in the dominant interpretations of the philosophical concept of autonomy entrenches an individualistic view of the self which undermines the deeply related and embedded nature of decision-making. As outlined in Chapter Two, the danger in adopting an intellectual commitment to externally imposed philosophical reason at the expense of hermeneutically aware, collaborative negotiation may potentially narrow the view of what is permissible as an 'ethical' issue. Finally, by representing moral decision making as a detached and singular event rather than an ongoing, evolving, embodied and embedded process with far reaching relational consequences, the ethical considerations that precede clinical intervention may have become undermined.
>
> *Institutional* constraints include the routine nature of testing which obscures voluntariness, hierarchical power dynamics within institutional settings both inter-professionally and between patient/carer, and overt and covert counselling. Additional institutional constraints include poor educational opportunities for practitioners and patients, blurred accountability amongst various practitioner groups for informing, inequity of access to testing and the ever present time constraints of production-driven models of institutional care.
>
> *Social* constraints emanate from the realisation that the choices made available to women are significantly delimited by societal and peer expectations of '*responsible pregnant behaviour*' (Lippman 1991). Trust in science to deliver a healthy child becomes enmeshed with maternal and practitioner feelings of blame and responsibility if a disabled child is undetected, as embracing technology may abrogate blame. Poor understanding of disability, the predefining of certain physical/intellectual conditions as unacceptable, and inadequate social support for disabled persons further shape behaviour, behaviour that is deeply influenced by the political, legal, historical and cultural contexts in which such practices evolve. These social precursors to how

screening is developed, presented and interpreted remain under acknowledged in the dominant and de-contextualised account of ethics.

Personal constraints include the socially constructed ‘need’ to be re-assured, the ‘self evident’ need to screen to reduce the increased levels anxiety that flow from the discourse of risk that surrounds pregnancy, poor understanding of the probabilistic and statistical language of risk, and a lack of familiarity with the medical procedures, processes and terminologies that the mother may encounter.

These multiple and potentially choice constraining considerations overlap and interweave, mutually feeding each other in the complex web of constructive and destructive interactions that ultimately direct individual perception, behaviour and ‘choice’. Additionally, the critical combinations that culminate in a woman experiencing constrained agency or diminished choice occur differently for different people. Consequently these constraining features cannot be rigidly considered as linear or hierarchal. Rather, they are subjective, inter-subjective and interplaying, further invoking Gilligan et al’s (2003) notions of simultaneously co-occurring and contrapuntal threads that may create a unique pattern of either resonance or dissonance. However, if our aim is to understand and support ethical decision making in antenatal care locally, we need firstly to understand the various sources and potential consequences of these constraining factors, to articulate their role in the shaping the actual practice encountered by pregnant women and their practitioners, and to assess whether the constraints identified in overseas research are echoed locally. Each of these four areas will be considered in more detail in chapters 4-7.

Chapter Summary

Based on an initial literature review, it is suggested that the current response of incorporating legally driven, administratively framed and ethically reductionist informed consent protocols into existing routines has failed to create an environment in which the individual and communal ethical concerns about the potentially socially divisive or eugenic outcomes of prenatal screening technologies may be meaningfully considered. Numerous overseas studies have revealed that, while up to 90% of women in developed nations are believed to undergo some form of prenatal screening to assess the health if their unborn child, significant numbers do not understand the purpose or potential outcomes of the testing received. The presumption that participation alone equates to informed consent, which in turn assures ethical probity, is therefore flawed as the espoused ethical standards required within the biomedical definitions of ‘informed consent’ of voluntariness and reflective understanding appear to be rarely achieved in practice.

When the ethical principle of autonomy, realised through the exercising of informed consent, is applied in a clinical and bureaucratic context that is unresponsive to, or perhaps unaware of, the personal, institutional and social constraints that exist, a persons’ capacity to engage fully in the moral decision making process may become eroded. Indeed, entrenched modes of treatment may leave little room to examine why certain interventions have become favoured or recommended at the expense of other options, such as the option not to screen, an alternative which may remain undisclosed (Pilnick 2004). Inadequate educational opportunities coupled with the lack of appropriate organisational infrastructure to support the deeply related, situationally dependent and embedded process of decision making may therefore undermine individual capacity to give considered and informed consent. Additionally procedurally entrenched discriminatory attitudes towards disability may promote narrowly defined constructions of normalcy that ultimately undermine a patient’s capacity for full moral consideration and active decision making in the context of prenatal screening. The subsequent harms which potentially flow on to women include avoidable anxiety, depression and possibly long term psychological trauma (Goel et al. 1998; Kowalcek et al. 2002; Watson et al. 2003).

The predominant ethical considerations that emerge in the discussion of prenatal screening often centre upon whether this technology is eugenic in its gaze (Parens and Asch 2000; Asch and Wasserman 2005; Lippman 2003), whether treatment offers of termination are ethically contentious or whether this is yet another discriminatory form of social gate keeping aimed at selecting what ‘type’ of people are worthy of birth (Shakespeare 1998, 2001; Reinders 2000; Hubbard 1988). These questions certainly frame the broader context of why we as a society have pursued the development of such technologies. We are increasingly challenged by the ethical reality of balancing the indisputable goods that medical technology may offer through the prevention of disease, with the very real potential harm that human life, or potential human life, may be dehumanised, devalued and disrespected in the process. As Kass (2003, p.3) notes ‘*distinguishing well from bad thus intermixed is often extremely difficult*’.

While embracing the ‘technological imperative’ may hold great promise for the relief of pain and suffering, for improving quality of life, and for enhancing choice and well being for many, the challenge remains of how to promote the humane and ethical use of such technologies in ways that do not further re-enforce discriminatory, stigmatizing or de-humanising practices. As the capacity to prenatally diagnose continues to outstrip the capacity to cure, a commitment to openly reflect upon the inevitable ethical dissonance created will shape the ethical landscape we create and the ethical legacy we leave.

CHAPTER TWO

AN ETHICAL ORIENTATION

> 'Ethicists tend to leave the 'facts' of clinical medicine to the doctors; their task is then to apply elegant and compelling arguments drawn from first principles of ethics to these undisputed and indisputable facts. Unfortunately when the relationship between clinical medicine and ethics is conceived in this way, the result is a very sterile discourse' (Hoffmaster 1991. p.213).

Prior to exploring the emergent ethical issues presented by the routine institutional practice of prenatal screening, or considering the role of ethics in shaping a response to the perceived moral challenges within, a clear account of 'ethics' as it is understood for the purposes of this work must first be articulated.

According to Beauchamp and Childress (2001, p.1), ethics is best understood as a *'generic term for* ***various ways*** *of understanding and examining moral life'*. Within these 'various ways' there are many conflicting and competing accounts of 'ethics' based on different starting presumptions, offering differing explanations of what ethics is, how it ought to be practised and what its purpose and potential is. Clearly, the starting presumptions, expectations and understandings we have of 'ethics' critically influence how we attempt to 'do' ethics, yet as Isaacs (Isaacs 2003) notes, the most fundamental question of 'how ought one to understand ethics?' is largely unarticulated and simply taken for granted as a generally shared and unproblematic view. However, as flagged by Beauchamp and Childress (2001, p.1) above, ethics is not so simply categorised as *one* way of thinking, but rather incorporates multiple perspectives and foundational assumptions.

Within the multiple definitions and prescriptions of what ethics is, the understanding that arguably dominates the medical and bioethics literature is that of a 'theory centred', knowledge based, abstract and generalisable application of moral principles. Such principles[1] or theories may be held as points of reflection and guidance when considering ‘cases’ that present an ethical dilemma or quandary (Beauchamp and Childress 2001), and may be applied to reveal a consistent, considered and rational response to the ethical question ‘what ought I do?’ [2]. While this notion of ethics appears to have permeated collective understandings[3] and expectations in the field of medical ethics and bioethics, deep problems emerge when ethics is practised as an epistemological quest for moral knowledge and abstract truth. Most notably perhaps, is the attendant need to reduce the multifaceted and complex realities of ethical engagement to the sterile prescriptions of what Caplan (1982, p.8) describes as ‘*moral engineering’*, an approach which seeks to overlay moral theories and principles onto the (unproblematic?) ‘facts’ to reveal a dependable and generalisable moral truth.

A further criticism of practising ethics as a form of detached intellectual and scholarly inquiry, is that this approach segregates ethics as yet another expert specialty, beyond the grasp of clinicians and patients who may lack the prerequisite analytical skills or philosophical language deemed necessary to contribute to such specialised discussions (Pellegrino 2003; Komesaroff 1995). In an era of increasing pressure to embrace collaborative decision making between practitioner and patient and to implement more ‘patient-centred’ practices (Stewart et al. 2003), perpetuating the separation of ‘ethics’ as another expert outsider discourse is ultimately unsustainable, as it potentially distances and excludes practitioners and patients from full participation in ethical decision making. This familiar approach to ethics, while firmly entrenched, remains disconnected from the ‘*micro – ethical’* concerns (Komesaroff 1995) of the everyday clinic, and hence continues to attract criticism.

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[1] In western medicine and bioethics, the most commonly referred to principles of medical ethics are those proposed by Beauchamp and Childress (2001); autonomy, beneficence, non- maleficence and justice. It should be noted that Beauchamp and Childress do not regard the four principles as coherent ‘theory’, or prescriptive requirement, but rather a framework to initiate broader contextualised discussion**.** While this ‘Georgetown mantra’, as it is often referred to, has been heavily critiqued in North America and Canada, it still permeates the majority of professional codes of practice and conduct, and dominates the medical ethics discourse in Australia.

[2] It should be noted that the ‘I’ of medical ethics literature predominantly refers to the practitioner ‘I’, rarely the patient ‘I’(Dodds 2000).

[3] And notably numerous health care professional Codes of Ethics.

An ontologically grounded approach to ethics of the everyday defines the ethical as situated within a foundational framework of understanding that reflects the fundamentally social and relational, subjective and engaged nature of human encounters. While the former approach seeks to articulate those rational theories and principles that might anchor the ethical form of life as one of rational deliberation and decision making, the latter phenomenological account with its emphasis on acknowledging the hermeneutics of making meaning, seeks to intentionally embrace the deeply embedded and subjective nature of being that shapes individual moral decision making. Once we embrace the particular ontology of the self as related, dialogical, interpretative, and embedded in multiple contexts of history, culture, language, relationships, biology, time and spiritual horizons it becomes apparent that, while there may be shared moral frameworks, each individual has a unique and particular moral experience. The unique culmination of these layers of embeddedness shape individual moral frameworks for patient and practitioner alike and subsequently defines the plurality of 'goods' we affirm. It is the fusion of these multiple goods that determines how we interpret the ethical significance and meaning of life events. While strong individual moral frameworks are formed, these inextricably overlap with the shared social and moral space. It is therefore through accessing these multiple layers that fuller ethical understandings may be built and transformative ethical response may be forged at both the individual and societal levels.

If, as Arthur Caplan remarks, '*the resolution of moral issues demands more than the ability to marry moral theory with the facts*' (Caplan 1982, p.2), we must challenge ourselves to define and actualise the 'more' Caplan refers to. An approach to ethics such as that proposed by Isaacs and Massey (1994) recognises that interdependence and interconnectedness, as well as detached academic analysis, is both the starting point and the goal of any ethical conversation. As '*the individual is whole only in a world of others*' (Cassell 1991, p.26), an ethical framework that is founded on this most basic human understanding may provide a more resonant and accessible framework from which to respond to the shared ethical consequences of individual and communal choices such as those inherent with the practice of prenatal screening.

Isaacs and Massey (1994), propose that engaged ethical encounters have four dimensions; the appreciative, the appraisive, the hermeneutical (interpretive) and the transformative. While traditional philosophical approaches seek theoretical solutions, Isaacs and Massey (ibid) propose that applied ethical questions are invariably social, not solely intellectual, and therefore invite practical, not solely theoretical responses. Through embracing the four dimensions above the ethical question considered becomes ‘how can we respond?’, rather than the detached individualistic ‘what ought I do?’ that emerges from the analytical model.

As perceptions and judgements are not value free, but rather reflect prior contextualised understandings and experiences, the hermeneutical dimension invites us to develop understanding of the multiple interpretive lenses that each stakeholder brings. The appreciative dimension seeks to promote appreciation of each stakeholder by actively recognising the others’ humanity, dignity and unique presence. Isaacs and Massey (ibid) further note that it does not automatically follow that we agree with, or endorse, every perspective. Rather the aim of any human encounter is to appreciate and understand the multiple histories that shape it. The appraisive dimension recognises that ethical engagement ultimately involves judgement or evaluation. Finally, the transformative dimension calls upon us to take action to prevent the unethical and respond with strategies for reform from an informed position of appreciation and understanding. Thus applied ethics research is focused on *‘continuing enhancing of the other and the self within the social condition as it is actualised within specific situations, roles, practices, institutions and cultures’* (ibid, p.2). The applied ethics framework proposed by Isaacs and Massey (1994) thus provides a theoretically coherent and practically functional structure from which to explore, describe, understand, explain and potentially transform the ethical dimensions of clinical practice, in this case the particular practice of prenatal screening.

In applied ethics research such as this, if we hope to understand individual moral concerns and respond in a meaningful way, the importance of entering into dialogue with another as a way of appreciating their unique perspective becomes paramount. Hence, there is a critical link between the embedded, embodied, related and dialogical view of ontology offered by the phenomenologists and the importance of narrative as means of opening the moral space of shared understanding that underpins ethical care. As narrative invites us to enter and appreciate each other’s understandings, conversation and dialogue provides an appropriate entry portal into the world of another’s experience and knowledge. Charles Taylor (1989, p.38) further explains, ‘*the nature of our language and the fundamental dependence of our thought on language makes interlocution in one or other of these forms inescapable for us*’. The philosophical orientation adopted is supported by the use of a narrative research methodology as the most appropriate mode of ethical inquiry. As the aims of this research were not only to observe and describe, but rather to understand with a view to transform, the Isaacs and Massey (1994) engaged approach to ethics, coupled with a narrative method of inquiry is the most appropriate vehicle to critically explore the complex, subjective and inter-subjective factors which shape the ethical dimensions of prenatal screening.

Narrative and Ethics

> ‘Narratives in moral thinking come before, during, and after moral generalities (whether of theory, principle, or basic moral concept). They permit and invite full exploration of what often seems neglected or devalued on the engineering model: specific histories of individual commitment, of relationship and responsibility, of institutional practices and evolving moral tradition…...Emphasis on narrative construction pulls in the opposite direction--from premature or coercive streamlining of cases toward enrichment of context and detail’ (Walker, 1993, p.35).

The Moral Significance of Narrative

A significant feature of applied ethics research is that it recognises individual participants as having unique personal moral values and experiences, all of which are embedded in their particular historical, cultural, political, economic and social contexts. Consequently, there is not *one* rational way to be, but rather a wide plurality of ways, hence the ‘goods’ we seek are not singular but rather pluralistic. From a research perspective, if we hope to hermeneutically and appreciatively engage in another’s story, we may only access this unique perspectival stance through listening to their voice. Thus if ethics is fundamentally embedded in relationships, and if we are as Taylor (1989) and Bruner (1991) claim essentially narratively constructed and dialogical beings, then voice[4] must lie at the heart of ethics (and ethical) research because language underpins our ontological understandings as moral beings. As *shared* understandings are sought, the language and discourse that shapes meaning in this context becomes a central focus of ethical enquiry. Therefore, dialogue and narrative analysis form the central strategies of this approach which seeks

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[4] Among the various voices, the ‘voice of reason’ is just *one* of the many contributing voices to be heard, rather than the dominating voice.

to uncover tacit meanings and understandings within the broader social and particular individual contexts.

Isaacs (2007) explores the link between language, context and moral engagement saying,

> 'Language makes possible our being and becoming. Language mediates the good life. But language is itself mediated through others. And such encounters are only possible because we are, or stand in conversations with these others. We are, accordingly, dialogical beings and our being and becoming is significantly that of a dialogical being and becoming' (Isaacs, 2007, p.7).

In considering how human beings construct meaning from the experiences that weave the fabric of their everyday lives, Bruner makes the point, '*we organise our experience and our memory of human happenings mainly in the form of narrative – stories, excuses, myths, reasons for doing and not doing, and so on'* (Bruner 1991, p.4). Andrews further reiterates this point claiming that, *'if we are constructed by stories, or are storytellers by nature, or perhaps both, then narrative must surely be a prime concern of social research' (*Andrews 2000, p. 1).

Thus narrative invites us to enter into the being and becoming of the other in the totality of their embodied and embedded realities. It opens the possibility of sharing, understanding and appreciation of the complex and unique lived reality and plural moral frameworks that are unique to each human self. It further enables the expression of experiences of loss, suffering, or oppression to be voiced, especially by those who may feel disempowered or silenced. Finally, narrative opens up new meanings, new possibilities and new sensibilities for collective and individual moral insight and growth. Therefore, narrative methods of research complement the ethical orientation of this work, opening a fitting way to explore the richness, particularity and uniqueness of individual experiences. In other words, dialogue opens a moral space to particular ontology, and as this research is concerned with exploring particular experiences as shaped by broader social contexts, a narrative method of inquiry practically and theoretically supports the ethical orientation of this research.

Importantly though, narrative is widely recognised as significant in enhancing ethical understandings (Urban - Walker 1993, 1998; Tomlinson 1997; Brody 2002; McMillan and Gillett 2002). As sharing experiences through dialogue may improve our common understandings and open us to the rich complexities of each others lives, our ethical judgements may be better informed. Tomlinson (1997) further notes that narrative awakens our moral sensibilities, so that we can better appreciate any perceived 'wrongfulness' of the story being told. Thus narrative and dialogue are pivotal in shaping the ethical agenda (Taylor 1989; Widdershoven and Smit 1996).

Narrative Methodology

(From Latin narrāre, narrāt - from gnārus, knowing)

> '(We cannot underestimate) the importance of having research strategies that can work with the narratives people use to understand the human world. Although this perspective presents a problem for the research models to which we have grown accustomed and in which we take pride, it opens up a realm for understanding human beings that will, I believe, make our research considerably more successful' (Polkinghorne, 1988, p.xi).

This work sought to explore a range of critical ethical questions emerging from individual stakeholder's experiences with prenatal screening. In terms of the applied ethics framework proposed earlier by Isaacs and Massey (1994), this research may be seen as attending to the hermeneutic, appraisive and transformative dimensions of the ethical encounter. It is not therefore specifically concerned with finding 'the' definitive answer to specific research questions, or as Darbyshire suggests to '*lay out causal explanations in theoretical terms'* (Darbyshire, 1994, p.860). Rather, the aim of this project is to embrace a hermeneutic approach which fosters deeper understanding of the lived experiences of individual participants as a conduit to uncovering the ethically problematic aspects of the prenatal screening protocols and practices. In turn, new insights and possibilities from which to transform and strengthen the ethically challenging aspects of prenatal care may be gleaned and potentially relevant sites of future inquiry may be identified.

In understanding the hermeneutically layered nature of human being and becoming, the phenomenological account of ontology embraced throughout this work further acknowledges the core importance of language and narrative in the construction of the self as essentially a dialogical self (Taylor, 1988, 1989). Language and narrative significantly mediate the plurality of goods we affirm individually, but importantly, they also mediate and define the communal ethical encounter. Inviting participation in a shared moral space, narrative accommodates the pluralities of understandings of what is ethically 'good' and thus promotes the emergence of collectively negotiated, respectful and inclusive ethical conversations. As it is through such shared understandings that a more appropriate and inclusive moral response may be sought when navigating the ethical tensions inherent within the burgeoning practice of prenatal screening, a narrative research methodology is most fitting to this research as it provides an ontologically coherent and ethically inclusive means of hearing, appreciating and responding to the individual stories offered.

Why Narrative?

> 'Our ultimate goal as social scientists is to learn about the substance, make theoretical claims through methods and learn about the general from the particular. Individual action and biography must be the starting point of analysis, not the end' (Riessman, 1993, p.70).

Human beings are inherently storytellers, we interact with, and construct meaning from, the narratives we create around our lives every day (Bruner, 1991; Lindemann-Nelson, 2001; MacIntyre, 1984; Mishler, 1986; Taylor, 1989). We craft our own narratives and appear in others' narratives, co-authoring the larger collective cultural narratives of which we are all a part (Bruner, 1991; Lindemann-Nelson, 2001; MacIntyre, 1984). It is through narrative, therefore, that we reveal our moral evaluations, create meaning in our lives and construct our own and others identities (Andrews, 2000; Bruner, 1986; Lindemann-Nelson, 2001; Taylor, 1989). Taylor (1989, p.47) further remarks that the *'basic condition of making sense of ourselves is that we grasp our lives in narrative'*, concluding that narrative represents an '*inescapable structural requirement of human agency*' (ibid, p.52). The central importance of narrative and language in constructing and mediating the human condition is echoed by Mishler (1986) and further reinforced by Bruner (1991, p.5) who claims that narrative not only represents reality, but constitutes it as well. Indeed for Bruner *'a life as lived is inseparable from a life as told … not "how it was"… but how it is interpreted and reinterpreted, told and retold'* (1987, p.31). Thus individual experience, our narrative accounts of such experience and the ethical significance of narrative in framing our being and becoming are inextricably linked. Indeed, narrative lies at the core of the ethical.

Educationalist John Dewey (1938, cited by Clandinin and Connelly 2000, p.2), suggests that understanding is grounded in experience and prior learning, making the further observation that such experience and prior knowledge always have both a personal and a social dimension. The