



# Reflecting the ‘human nature’ of IVF embryos: disappearing women in ethics, law, and fertility practice

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## ABSTRACT

Many laws and ethical documents instruct us that disembodied embryos created through IVF processes are not mere tissue; they are ‘widely regarded’ as unique objects of serious moral consideration. Even in jurisdictions which disavow any overt characterization of embryonic personhood, the embryo, by virtue of its uniqueness and orientation toward future development, is said to have a ‘special status’ or command ‘respect’. The woman whose desire for a child or children created this embryo, and who inhabits the body to whom it may one day be returned, is an omission or at best an afterthought in such frameworks. This paper engages in an historical analysis of this conundrum in the Australian context. It argues that the institutional structure of foundational ethics bodies (made up of a mandated mix of scientific and religious representation, in practice dominated by men, and absent any requirement of the participation of women patients) has produced the embryo as an object of ideological compromise: ‘not mere cells’ and ‘not life’, but a poorly bounded and endlessly contested something-in-between. The paper then turns to engage with the narratives of a selection of women patients about their sense of connectedness to their stored or discarded embryos, drawn from a larger study on decision making concerning patient’s experience of decision making about IVF embryos. I draw on these narratives to ask how we could reorient law and policy toward the concerns, needs and desires of such women.

**KEYWORDS:** human embryos, IVF, reproductive technology, ethical guidance, embodied relationality, feminist challenges to the disembodied embryo

## INTRODUCTION

I've only just started thinking about all of this, because ... I've been in this tunnel of young children — it's a dark, dark tunnel... and I'm just coming out of that and I'm just starting to go: 'Oh, right, I need to think about ... what am I going to do about embryos'?... because they do hover—a cloud that hovers over me—just it's there and I need to make a decision.... I have five minute conversations with my husband... there's always some other drama happening, someone needs a wee wee or someone's fallen off a chair or whatever... I'm going, 'The embryos are our children'; he's going, 'No, they're just embryos—hang on, the phone's ringing'. And so we never ever had that conversation about what we're going to do about them. He's laughing at me; I'm going, 'This is breaking my heart, these embryos'. (Ruby)

Institutionalized 'regard' for human embryos has taken different forms in law around the world, leading to a range of adverse impacts upon the women who generated them. Laws and policies motivated by a belief in the innate sanctity or value of human embryos have tried to prevent embryo destruction through a range of measures, such as limiting the numbers generated, mandating immediate implantation, prohibiting storage or donation for research, or prohibiting destruction more broadly.<sup>1</sup> These laws, in turn, intrude upon (or completely override) women's decision making, and/or drive them into unsafe or less safe reproductive practices, such as increased numbers of stimulated *in vitro* fertilization (IVF) cycles, higher numbers of embryos being implanted (leading to higher multiple birth rates), coercive donation practices, or evasive travel to other regimes for treatment.

Australia, like the UK, could be characterized as broadly liberal and secular in its approach to the regulation of IVF. Both countries provide fairly liberal access to a wide range of state-subsidized treatment practices, and neither country has attempted to attribute personhood<sup>2</sup> or specific legal protections to the human embryo. Yet both have also crafted rules and ethical guidance that refer to the 'special status' of the human embryo<sup>3</sup> and prescribe 'respect' and 'regard' for it—at times in preference to the desires of the woman who generated it. Storage limits provide a paradoxical example of this. Mandated statutory limits in the UK<sup>4</sup> and some Australian states were based originally upon fears about the viability of embryos after long-term freezing and about

<sup>1</sup> This includes past and present laws in countries such as Italy, Spain, Germany, and Switzerland; for example, see Françoise Shenfield et al., *Cross Border Reproductive Care in Six European Countries*, 25 HUM. REPROD. 1361 (2010); John Robertson, *Protecting Embryos and Burdening Woman: Assisted Reproduction in Italy*, 19 HUM. REPROD. 1693 (2004); Paolo Emanuele L. Setti et al., *Italian Constitutional Court Modifications of a Restrictive Assisted Reproduction Technology Law Significantly Improve Pregnancy Rate*, HUM. REPROD. 376 (2011). This is not to suggest that such laws necessarily reflect the views of medical practitioners, patients, or the public: see Tanja Krones et al., *What is the Preimplantation Embryo?*, 63 SOC. SCI. MED. 20 (2006).

<sup>2</sup> For a thoughtful and grounded critique of 'life debates' in the USA and the role of political and cultural context in generating constructions of the embryo, see Elizabeth Roberts, *Abandonment and Accumulation: Embryonic Futures in the United States and Ecuador*, 25 MED. ANTHROPOL. Q. 232 (2011).

<sup>3</sup> See UK Department of Health and Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, Cmnd. 9314 (1984) (hereinafter 'The Warnock Report'), para. 11.17; Human Fertilisation and Embryology Authority (HFEA), *Code of Practice* (2015), para. 15.13. For discussion, see David Gomez, *The Special Status of the Human Embryo in the Regulation of Assisted Conception and Research in the United Kingdom*, 17 MLJI 6 (2011).

<sup>4</sup> Human Fertilisation and Embryology Act 1990 (UK), s. 14.

extending the 'conventional reproductive competence' of the mother-to-be,<sup>5</sup> but have since focused more on concern to limit the responsibility of storage providers.<sup>6</sup> The wishes of the woman—whether to utilize the embryo herself in a pregnancy attempt, to donate it for the reproductive use of another woman, to store it either for a further period until she is reconciled to its destruction or for an indefinite period if she is not, or to remove and discard the embryo in circumstances of her own making—are not prioritized within such a framework.<sup>7</sup> The perverse effect of law in this situation is that the embryo's welfare may require its destruction—a destruction that is both mandated and *respectful*. (Although Baroness Warnock herself said, at a later point, 'You cannot respectfully pour something down the sink ... I think that what we meant by the rather foolish expression 'respect' was that the early embryo should never be used frivolously ...'.<sup>8</sup>)

When a major review of Australian laws on embryo research was held in 2005, the terms of reference set down in legislation required the committee to take into account 'community standards'. An entire chapter of the report was devoted to the question of what exactly such standards were.<sup>9</sup> Ultimately, the committee sidestepped any definitive answer by acknowledging that there is no 'single set of values and interests (or "standards") held by a single "community"'.<sup>10</sup> However, the report went on to utilize a device common in many such policy documents before and since—identifying a pluralistic moral framework but simultaneously asserting universal regard:

Although a range of views was expressed about the precise moral status of preimplantation embryos in particular, there was an overall acceptance that human embryos created by the fertilisation of a human egg by a human sperm are entities of some social and ethical significance because of their association with the start of human life.<sup>11</sup>

I take issue with this premise for two reasons: one is the idea that embryos are of abstract significance to society at large rather than of specific significance to the woman undertaking treatment, and the other is that this significance is due to the potential for life rather than its representation of the myriad potentialities and desires (both

<sup>5</sup> See discussion in Anita Stuhmcke & Eloise Chandler, *Storage Limits of Gametes and Embryos: Regulation in Search of Policy Justification*, 22 J. L. MED. 121, 123–125 (2014); The Warnock Report, *supra* note 3, para. 10.10.

<sup>6</sup> See e.g., National Health and Medical Research Council (NHMRC), *Draft Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*; Public Consultation 2015, section 7 [https://consultations.nhmrc.gov.au/public\\_consultations/assisted-reproductive-tech](https://consultations.nhmrc.gov.au/public_consultations/assisted-reproductive-tech) (accessed Sept. 15, 2016). In the USA and Canada where there are no external storage limits, this concern is more pressing; see Alana Cattapan & Francoise Baylis, *Frozen in Perpetuity: 'Abandoned Embryos' in Canada*, REPROD. BIOMED. SOC. (2016) DOI 10.1016/j.rbms.2016.04.002.

<sup>7</sup> See Jenni Millbank et al., *Enhancing Reproductive Opportunity: A Study of Decision-Making Concerning Stored Embryos: Report* (2013) [http://allabouttheembryo.net/embryo\\_wp/?page\\_id=43](http://allabouttheembryo.net/embryo_wp/?page_id=43) (accessed Sept. 15, 2016).

<sup>8</sup> HL Deb, Dec. 5, 2002, Col. 1327, quoted in House of Commons Science and Technology Committee, *Human Reproductive Technologies and the Law* (2005), FIFTH REPORT OF SESSION 2004–2005, vol. 1, ch. 4, para. 61. And see Emily Jackson, *Fraudulent Stem Cell Research and Respect for the Embryo*, 1 BIOSOCIETIES 349 (2006).

<sup>9</sup> Legislation Review Committee, *Legislation Review: Prohibition of Human Cloning Act 2002 and Research Involving Human Embryos Act 2002: Reports* (2005) (hereinafter 'Lockhart Review'), ch. 7. In contrast, the next review in 2011 spent a mere page on the issue: Legislation Review Committee, *Legislation Review: Prohibition of Human Cloning Act 2002 and Research Involving Embryos Act 2002* (2011) ('Heerey Review'), para. 4.3.

<sup>10</sup> Lockhart Review, *supra* note 9, at 69, para. 7.1.

<sup>11</sup> Lockhart Review, *supra* note 9, at xv.

imagined and real) to the woman herself. It is *she* who makes these meanings and to whom regard should be accorded. As Isabel Karpin has argued:

The embryo is only connected with its potential for personhood by female embodiment. Those who wish to make the argument that all embryos have equivalent value do so only by rendering the female body irrelevant. In order to do this, a complex process of disappearing has to take place.<sup>12</sup>

To illustrate this issue, legislation in the Australian states of Victoria and Western Australia continues to maintain strict 10-year limits on embryo storage, although both now allow requests to the regulator for extensions if there are 'reasonable' or 'special' grounds. The Western Australian regulator, in a policy document aimed at patients, notes that while 'some participants understandably consider that they are entitled to determine how their embryos are dealt with' (a position 'respected and understood' by the Council), it is 'not considered appropriate by the legislature or by Council' to store embryos indefinitely. In outlining the considerations which govern the policy on extensions, the Council includes 'equity, welfare and general standards prevailing in the community'. In a section entitled 'when approval will not be considered', it identifies reasons such as a 'wish to keep an embryo in storage indefinitely, or [a] wish to be buried with the embryo'.<sup>13</sup> In the context of a general policy document, the latter wish is very particular and must almost certainly have arisen as the result of a specific, and previously denied, request. If one accepts that an embryo is an entity of significance to the woman from whom and for whom it was created, why should her wish to be buried with it not be given serious moral consideration and deferred to unless there is some compelling imperative to do otherwise? How are the views of the community, or regard for the embryo, determinative of such a wish?

The purpose of this paper is to explore the underlying contest in values over the subject/object of regard in ethical rules and laws governing IVF practices and stem cell research—the woman or the embryo—in order to make space for a more profound rethinking in the future. First, by examining in some detail one Australian policy document from the 1980s, I explore in a concrete way how the centrality of the embryo in the ethical and regulatory terrain was established very early on, and how women disappeared in this process. Section II then examines how a consistent centering of the embryo continued at the highest levels, by tracing through various iterations of national ethical guidelines on assisted reproductive treatment. I go on to suggest that the institutional structure of this key ethics body in Australia, absent a guarantee of female participation or perspective, continues to predetermine and reproduce this framework through its mandatory mix of clinical and religious membership.

In Section III of the paper, I turn to ask what could a woman-centered regard look like? To do so, I relay detailed narratives from five women discussing the disposition of their stored embryos. These participants were drawn from a larger empirical study of the impact of law and policy on IVF users in Australia with a particular focus on decision

<sup>12</sup> Isabel Karpin, *The Uncanny Embryos: Legal Limits to the Human and Reproduction Without Women*, 28 SYDNEY. L. REV. 600, 603 (2006).

<sup>13</sup> Reproductive Technology Council of WA, *Policy on Embryo Storage and Applications to Extend Beyond 10 Years* (2010) [http://www.rtc.org.au/clinics/docs/embryo\\_storage\\_policy.pdf](http://www.rtc.org.au/clinics/docs/embryo_storage_policy.pdf) (accessed Sept. 15, 2016)

making concerning stored embryos.<sup>14</sup> The study comprised 48 interviews with a total of 54 interviewees augmented by a survey.<sup>15</sup> In semistructured interviews, participants were asked for their views about use of embryos, including scenarios of relationship separation or death of a partner, as well as their views about donation and wishes regarding disposal. For those who had actually been through donation or disposal follow-up questions were asked about these experiences. Thus, interviewee's sense of relationality with the embryo arose through a more targeted and instrumentalist discussion about use and disposal. Many of these interviewees expressed intense distress and dismay when faced with the operation of legal rules or clinical policies that they experienced as intruding upon their decision making. As one interviewee, Clarice, noted even the process of categorization of embryos is arguably not 'sophisticated enough to capture what those embryos are to the people who created them':

Spare to whom? ... They are spare in the sense, for some of them, that they haven't been used yet and, obviously for some of them, they'll never be used. Well, for a start, those are two very different categories. In what sense is your future child, for those who might still be going to use them in the future, spare? Why is that child any more spare or floating or for some broad Government consensus to decide what happens to it [than] a future child you might have through the normal channels, as it were? ... I do think the law should acknowledge that surplus has a connotation of additional and, therefore ... less valuable than what you already have. I don't think that that is really the case with embryos. (Clarice)

My focus in this paper is exclusively on the perspective of the woman undertaking treatment. Although the woman's partner may also have a considerable emotional investment in the process, and I do not discount this attachment, this work rests on the premise, demonstrated through much previous empirical work, that women experience a greater sense of connectedness to, and investment in, stored IVF embryos, in part due

<sup>14</sup> The study utilized a multimethod recruitment process, using both clinical avenues and broader advertising to the public and drew responses from patients who had undertaken IVF treatment in all Australian jurisdictions except the Northern Territory. Volunteers were invited to participate through either engaging in face-to-face or phone interviews or by filling out a survey either online or by hand. Recruitment covered the period July 2010 to July 2012. The sole inclusion criterion of the broader study was that participants currently or previously had stored embryos created through IVF. A survey was utilized to gauge broad trends with in-depth semi-structured interviews to explore participant views and reasoning. Valid surveys were completed by 349 participants. Quantitative data collected through the surveys were statistically analysed with the aid of SPSS. Qualitative data both in surveys and interviews were subject to thematic analysis. Each member of the research team undertook multiple readings of interview transcripts and survey open responses both throughout the data collection period and afterwards, coding emergent themes. Identified themes were then subject to comparative analysis among the entire research team to ensure uniformity of interpretation. Ethics approval to conduct this research was obtained through the University of Technology Sydney Human Research Ethics Committee UTS HREC Reference Number: 2009-262A and 2015000094.

<sup>15</sup> Interviews were semistructured. All interviewees are represented by a pseudonym. Interview duration varied between 30 minutes and 90 minutes, with most lasting around one hour. In common with most empirical research on fertility, participants in the study were overwhelmingly female. Participants tended to be in married or de facto relationships and were generally between 31 and 40 years of age, had typically commenced treatment in the last 2 to 10 years, conceived children through IVF, and most still had embryos in storage at the time of their participation. Nearly half of those with embryos in storage indicated that they had completed their IVF treatment. While the majority of participants had used their own gametes in their IVF treatment, around one-third were recipients of donated gametes or embryos. For more detail on the methods and findings of the study, see Jenni Millbank et al., *Enhancing Reproductive Opportunity: A Study Of Decision-Making Concerning Stored Embryos: Report*, [http://allabouttheembryo.net/embryo.wp/?page\\_id=43](http://allabouttheembryo.net/embryo.wp/?page_id=43) (2013), accessed Oct. 5, 2016.

to their far greater physical involvement in the process of creating them.<sup>16</sup> Embryos were created from, and of, the woman, and intended for return to her: at the time of generation these were steps in the process of a pregnancy-to-be, but return was interrupted, prolonged or foreclosed by later events (such as the birth of children, or separation of a relationship). This sense of disembodiment was experienced as deeply jarring by interviewees:

knowing that they're just sitting there, sitting there, sitting there and I can't use them, it creates a whole way of thinking around them that is different, I think, than it would otherwise be. (Danielle)

Women referred to their stored embryos as 'hovering' (Ruby, Rose), 'floating' (Clarice), 'suspended' (Laurie), and 'remote' (Sam). Through exploring some of these narratives, I try to tease out an approach which attends to the individual, even idiosyncratic nature of each woman's relational matrix, in which her extra-utero embryo (or embryos) plays some role of significance to her and within her sense of kinship. I draw upon, and build on the relational autonomy work of feminist theorists such as Nedelsky, Baylis, and Downie among others,<sup>17</sup> to argue for a framework of decision making that has regard to the woman as a connected entity exercising reproductive choice among a range of outcomes and processes, rather than simply having the option of consenting to, or refusing, those that are presented to her.<sup>18</sup>

### THE EMBRYO AS ETHICAL SUBJECT

The status of the human embryo in Australian law and ethical guidance literature appears through a patchwork of injunctions, absences, and prohibitions. These regulations address who may generate and deal with out-of-body embryos through criminal prohibitions and licensing provisions, dictate how decisions must be made about embryos in IVF processes (including pregnancy attempts, testing, storage, donation, and destruction), and by whom and to what uses such embryos may be put when unwanted or deemed unsuitable for reproductive use.<sup>19</sup> These documents are numerous and, moreover, have undergone many incarnations since IVF became an accepted and increasingly widespread medical procedure. The significance and unique value of the human embryo is a unifying premise across the board. Thus, for example, Australian national ethics guidelines at different times have instructed that limits to research are

<sup>16</sup> See e.g., Emily Jackson, *Degendering Reproduction?* 16 MED. L. REV. 346 (2008); Tara Cousineau & Alice Domar, *Psychological Impact of Infertility*, 21 BEST PRAC. & RES. CLIN. OBSTET. & GYNAECOL. 293 (2007); Sheryl de Lacey, *Parent Identity and 'Virtual' Children: Why Patients Discard Rather Than Donate Unused Embryos*, 20 HUM. REPROD. 1661 (2005); Jenni Millbank et al., *Towards Facilitative Regulation of Assisted Reproductive Treatment in Australia*, 20 J. L. MED. 701 (2013).

<sup>17</sup> JENNIFER NEDELSKY, *LAW'S RELATIONS: A RELATIONAL THEORY OF SELF, AUTONOMY, AND LAW* (2011); Françoise Bayliss, *The Self in Situ: A Relational Account of Personal Identity*, in *BEING RELATIONAL: REFLECTIONS ON RELATIONAL THEORY AND HEALTH LAW* (Jocelyn Downie & Jennifer Llewellyn eds, 2012).

<sup>18</sup> See e.g., Angela Campbell's feminist case for 'choice' rather than consent, within a framework of critical legal pluralism: *SISTER WIVES, SURROGATES AND SEX WORKERS: OUTLAWS BY CHOICE?* (2013).

<sup>19</sup> See e.g., *supra* note 16, Jenni Millbank et al., *Towards Facilitative Regulation of Assisted Reproductive Treatment in Australia*, 20 J. L. MED. 701 (2013).

required to 'reflect the human nature of the embryo' (1996),<sup>20</sup> that embryos are 'not to be treated as mere tissue' (2004),<sup>21</sup> that they 'warrant serious moral consideration' (2007, 2015)<sup>22</sup> or are 'widely regarded as objects of serious moral consideration' (2004), and that they command 'respect' (2004).<sup>23</sup> Yet the basis of this significance is often unstated—assumed or simply asserted as a universal truth—with little articulation of *why* these entities matter and to *whom*.<sup>24</sup> How did it come to pass that 'we' all agreed on the special status of the human embryo, even though no one is recorded as having agreed on what that status was, exactly?

The 1980s saw a plethora of inquiries and policy documents generated as governments struggled to keep pace with the rapid development of reproductive technologies.<sup>25</sup> In the Australian federation, parliamentary inquiries, independent law reform agencies, specialist appointed inquiry bodies, and pre-existing ethical bodies vied with each other, and often repeated each other, in a flurry of investigation which—at least in the short term—produced a comparably small amount of legislation regulating the sphere, but which set an overarching template for the scope and terms of much ethical guidance, policy and practice in the decades which followed. I have selected for discussion here a federal parliamentary inquiry that commenced in 1985 and reported in 1986.

**The Question Accepted By All: What Is The Respect Due To The Human Embryo?**  
In 1985, Senator Brian Harradine, a devout Catholic and lifelong anti-abortion advocate, introduced a bill into the Australian Senate to ban 'non-therapeutic' experimentation on human embryos. The bill was referred to a parliamentary committee with broad terms of reference which included whether it is necessary, or desirable, to freeze, conduct research on, or destroy embryos, and what prohibitions, sanctions, and regulatory bodies should be established as a consequence of its findings.<sup>26</sup> The committee, led by Senator Tate, ultimately recommended against allowing any form of experimentation on human embryos.

The Tate Report has often been overlooked in favor of other more robustly reasoned or directly influential reports (in particular, the Waller inquiry laid out the template for Victorian law, which was both the first and most comprehensive IVF regulation in

<sup>20</sup> National Health and Medical Research Council (NHMRC), *Ethical Guidelines on Assisted Reproductive Technology* (1996) at 1.

<sup>21</sup> NHMRC, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2004) at 13 para. 5.2, 45 para. 15.2.

<sup>22</sup> NHMRC, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007) at 10 (para. 2.6); NHMRC, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (Draft) (2015), *supra* note 6, para. 3.1.

<sup>23</sup> NHMRC (2004), *supra* note 21, at 28 para. 8.9, 49 para. 17.4.

<sup>24</sup> Australia has kept very detailed records of IVF treatment and outcomes since the early 1990s. Yet the number of women undertaking treatment, rather than the number of treatment cycles, pregnancies, and births, has only recently been counted. In 2013, almost 40,000 women undertook one or more cycles of IVF treatment. See Alan Macalldowie et al., *Assisted Reproductive Technology in Australia and New Zealand 2013* (2015) at vi.

<sup>25</sup> For an overview of these developments, see Dianne Nicol et al., *Regulating Biomedical Advances: Embryonic Stem Cell Research*, 2 MACQUARIE L. J. 31 (2002); Don Chalmers, *Professional Self-Regulation and Guidelines in Assisted Reproduction*, 9 J. L. MED. 414 (2002).

<sup>26</sup> Senate Select Committee on the Human Embryo Experimentation Bill 1985, *Human Embryo Experimentation in Australia* (1986) (hereinafter 'Tate Report') at v.

Australia).<sup>27</sup> While the Tate Report discussed here did not feed immediately into law, it does appear to have had significant influence on the terms of the nationally applicable *Ethical Guidelines on Assisted Reproductive Technology* (ART) issued by the National Health and Medical Research Council (NHMRC) in 1996, 2004, and 2007. It also pre-saged aspects of the 2002 prohibition on human cloning laws. The report is of note for the starkness of the contest of ideas visible in its pages, where the majority characterizes the embryo as a human subject demanding guardianship, while a vigorous dissent by two female senators argued for the centrality of women's reproductive freedom and decision-making capacity. Looking back 30 years to their arguments gives a dramatic sense of how different the legislative and ethical frameworks governing IVF in Australia would have been had the minority carried the day.

The majority report characterized the embryo as an ethical subject or child-like entity, declaring that 'the embryo of the human species should be regarded as if it were a human subject for the purposes of biomedical ethics'.<sup>28</sup> The majority report pursued this characterization most strikingly through two rhetorical manoeuvres: asserting that the Helsinki Declaration on human experimentation<sup>29</sup> was applicable to any research on human embryos and adopting a 'guardianship' model toward decision making concerning human embryos. These steps went beyond most other Australian public inquiries in overtly characterizing the embryo as a child-becoming. Yet the majority report also introduced a discursive practice replicated in many later reports and ethical guidelines, namely, the assertion of a pluralistic framework of diverse or divergent views on the embryo *simultaneously* with the assertion of universal regard for the human embryo as a distinct and valued entity to whom something is *owed*.<sup>30</sup>

In a diverting side step, the majority claimed a 'well-accepted' ethical framework when introducing the very features that were most contentious<sup>31</sup> in its reasoning, saying at the outset:

The Committee recognises that in putting forward its view in a pluralist society it cannot claim to reflect a unanimous view of the community. Nevertheless it considers that ... its resolution of the issues is based on other well accepted features of our social and legal arrangements, particularly guardianship and biomedical ethics ... It is in this framework that the Committee answers the question accepted by all as the correct query: *what is the respect due to the human embryo?*<sup>32</sup>

Over 30 years have passed and, in my view, we are all still caught in a framework that perpetually asks and answers this wrong question—as if it were the obvious and,

<sup>27</sup> Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilisation, 1982–1984, *Consolidated Reports* (1990) ('Waller Reports'). On the history of this legislation in comparison with the UK approach, see Kerry Petersen, *The Regulation of Assisted Reproductive Technology: A Comparative Study of Permissive and Prescriptive Laws and Policies*, 9 J. L. MED. 483 (2009).

<sup>28</sup> Tate Report, *supra* note 26, at 3.18.

<sup>29</sup> World Medical Association, *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects* (1964) (amended 2013). The declaration was reproduced in full in Appendix VII to the Tate Report.

<sup>30</sup> See e.g., Lockhart Review, *supra* note 9, at 87.

<sup>31</sup> For a contemporaneous critique, see Pascal Kasimba & Stephen Buckle, *Embryos and Children: Problems Raised by the Majority Report of the Tate Report on Human Embryo Experimentation*, 2 AJFL 228 (1988).

<sup>32</sup> Tate Report, *supra* note 26, at xiii (emphasis added). Elsewhere, the majority rests its conclusions on the 'ethical behaviour owed to that entity resulting from the fertilisation': *Id.*, para. 2.15.

indeed, only question.<sup>33</sup> I suggest that we still do not ask, as we ought to, 'What is the respect due to the woman undertaking treatment?'

The majority Tate Report laid down a blueprint of the *subject* embryo, a uniquely human entity oriented toward future development that must be respected and protected.

If, as is the view of the Committee, the embryo may be properly described as genetically new human life organised as a distinct entity oriented towards further development, then the stance and behaviour proper to adopt towards it would include not frustrating a process which commands respect because its thrust is towards the further development of a biologically individuated member of the human species.<sup>34</sup>

It is worth highlighting the disappearance of women in this framework through the simple reversal of replacing the embryo with a woman in the text, which might then look something like this:

*As the woman undertaking treatment is existing human life oriented towards further reproduction; the stance and behaviour proper to adopt towards her ... includes not frustrating her process, which commands respect because it is hers.*

Interestingly, Senators Crowley and Zakharov in the minority appear to have found it rhetorically easier to replace the embryo with a rock than with a woman when they argued in their dissenting report:

Any object or thing has an infinite number of possible future courses. For a non-sentient or inanimate thing, e.g., a rock, the particular future outcome that actually happens is determined by forces outside of itself. An embryo is like a rock in this respect—it cannot make decisions for itself. Its future is decided by others. It has potential only in virtue of decisions by others about it.<sup>35</sup>

The minority report concurred with the majority that, unlike a rock, the embryo's developmental potential is something of 'great significance', but argued that 'without a uterus, there is no development' and, thus, the focus should be on the decision-making capacity of the woman.<sup>36</sup> With rather unnerving prescience, they noted that unless it is the woman who makes decisions, 'society will determine the developmental potential of the embryo'.<sup>37</sup>

Crowley and Zakharov critiqued the inherent contradictions in the 'guardianship' and subject/patient models of embryonic status promoted by the report, noting, for example, that the freezing of embryos for possible later use *cannot* be characterized as a therapeutic intervention on behalf of the embryo (not least of all because of the very low success rates with thawing at the time). Rather, embryonic freezing is a medical decision

<sup>33</sup> The Warnock Report asked, in a slightly less loaded fashion, 'how is it right to treat the human embryo?' (*supra* note 3, para. 11.09). In 2002, the UK House of Commons Science and Technology Committee stated, 'At the heart of any review of assisted reproduction legislation is the fundamental question of the status to be accorded to the human embryo' (*supra* note 8, vol. 1, ch. 3, para. 24).

<sup>34</sup> Tate Report, *supra* note 26, at xiv (conclusions para. 6).

<sup>35</sup> *Id.* at [D.20], 70.

<sup>36</sup> *Id.* at [D.23], [D.28].

<sup>37</sup> *Id.* at [D.24].

made by, and for the health benefit of the intended mother.<sup>38</sup> Likewise, the minority senators noted that the majority report did not support implantation against the wishes of the woman, and therefore countenanced the willful destruction of embryos as an inevitable consequence of women's participation in IVF treatment programs.<sup>39</sup>

The minority argued it was a 'consequential logical step' that the woman making decisions about implantation should 'have the same unfettered responsibility for decisions prior to implantation'.<sup>40</sup> They concluded that the woman 'into whose uterus the embryo is placed' or the couple,

should determine all such other decisions as to, for example, how many embryos are produced, how many are placed in the uterus at any one time, whether and how many of their embryos are frozen, and if and when such surplus embryos are allowed to succumb. In all these decisions the couple will have regard to the advice, information and counsel given them by their doctor ....

....

Women have had to fight for their rights to their children in times past. We see the same arguments as to their rights apply here. The woman and/or the couple are the appropriate and proper decision makers.<sup>41</sup>

It bears reflecting that many of these decisions continue to be severely constrained, or even removed, by law and policy, rather than being in the hands of the woman undergoing treatment.

### THE EMBRYO AS SUBJECT OF REGARD IN NATIONAL ETHICAL GUIDELINES

ART ethical guidelines, alert from the outset to the movement of embryos from the realm of reproductive treatment to research, have addressed both practices.<sup>42</sup> These guidelines perform a significant role in national regulation of ART in Australia, although their influence has changed over time.<sup>43</sup> Since 2002, national law has provided that embryos can only be used or developed in the course of a woman's reproductive treatment by ART units that have been accredited by the Fertility Society of Australia's

<sup>38</sup> Put simply, the reduced likelihood of successful thawing and implantation per embryo is subsumed by the benefit to the woman of fewer stimulated IVF cycles (and her ability to control the timing and spacing of her children through enhanced ability to attain a pregnancy at a later age with 'younger' embryos).

<sup>39</sup> This point remains germane, as the creation of extra embryos for storage is routine IVF practice (a cycle creating around 10–15 embryos is regarded as 'ideal', with a strict Australian standard of transferring only one or, in certain circumstances, a maximum of two embryos at a time). See Sesh Sunkara et al., *Association Between the Number of Eggs and Live Births in IVF Treatment*, 26 HUM. REPROD. 1768 (2011).

<sup>40</sup> Tate Report, *supra* note 26, at [D.48].

<sup>41</sup> *Id.* at [D.50], [D.52].

<sup>42</sup> Sarah Franklin, *Embryonic Economies: The Double Reproductive Value of Stem Cells*, 1 BIOSOCIETIES 71 (2006).

<sup>43</sup> When first established, the NHMRC Guidelines were the only form of external governance of ART practice in Australia, pre-dating any State-based legislation, and influential through a peer-norm-based inspection and voluntary compliance process: NHMRC, *In Vitro Fertilisation Centres in Australia: Their Observance of the National Health and Medical Research Council Guidelines* (1987). After Victoria introduced legislation regulating ART in 1984 (operative from 1988) as did South Australia in 1988 and Western Australia in 1991, the NHMRC guidelines were subordinate to law in those states, but continued to operate in all other states and territories.

Reproductive Technology Accreditation Committee (RTAC), which in turn requires evidence of compliance with the NHMRC Ethical Guidelines.<sup>44</sup> In addition, three of the four Australian states that currently legislate on the provision of ART in their jurisdictions also explicitly require compliance with the NHMRC Ethical Guidelines.<sup>45</sup> Thus, the current NHMRC guidelines, although expressed in the flexible and normative mode of 'guidelines' rather than law, are actually enshrined by law as the most significant governance instrument in ART practice across Australia.

The first guidance from the NHMRC came in the 1982 *In Vitro Fertilisation and Embryo Transfer: Supplementary Note 4* to the NHMRC Statement on Human Experimentation, which predated the findings of the Warnock Report. At a page and a half, the document is astonishingly brief to the modern eye. It covers nine points in total, addressing the requirement of an institutional ethics committee and record keeping, the treatment of infertility within 'an accepted family relationship', requirements of consent for patients and donors, the claim that surrogacy is 'not yet capable of ethical resolution' because of the uncertainty of maternal status, the unacceptability of cloning, and the ability for conscientious objection by clinic staff. While point 7 states that the 'wishes of donors' (gamete providers) should be taken into account in setting a storage limit for embryos, the document undoes this rather by going on to recommend 'a set upper limit which would be of the order of ten years'—a limit that is then carried through several iterations of the guidelines over the following three decades. Stuhmcke and Chandler note that at the time this limit was first proposed the freezing of embryos was still a highly experimental procedure; yet the limit has persisted and 'regulators have continued to cast the need for storage limits as being self-evident'.<sup>46</sup>

The 1996 Guidelines are considerably more detailed and reflect the influence of the 1986 Tate Report. For example, the Introduction to the 1996 Guidelines includes the 'ethical and social values' engaged by ART, recognizing that:

[A]ny experimentation and research involved in these technologies should be limited in ways which *reflect the human nature of the embryo*, acknowledging that there is a diversity of views on what constitutes the moral status of a human embryo, particularly in the early stages of development.<sup>47</sup>

In a brief, one-page section on research, the 1996 Guidelines direct that 'non-therapeutic research' which 'does not harm the embryo' may be approved by an ethics

<sup>44</sup> Research Involving Human Embryos Act 2002 (Cth), s. 11. RTAC, *Code of Practice for Assisted Reproductive Technology Units* (revised Aug. 2015) ('RTAC Code of Practice'), <http://www.fertilitysociety.com.au/wp-content/uploads/RTAC-COP-2015.pdf> (accessed June 1, 2016).

<sup>45</sup> See Assisted Reproductive Treatment Regulations 2010 (SA), reg. 8(2)(a); Victorian Assisted Reproductive Treatment Authority (VARTA), *Information for Registered ART Providers* (Jan. 2014) notes that compliance with the NHMRC Ethical Guidelines is a condition of registration; see Assisted Reproductive Treatment Act 2008 (Vic), pt. 8; Human Reproductive Technology Act 1991 (WA), ss 33(2)(ea), 29(5)(aa). NSW does not expressly require this, but there are few areas of inconsistency: Assisted Reproductive Technology Act 2007 (NSW).

<sup>46</sup> Stuhmcke & Chandler, *supra* note 5, at 132. Notably in 290 survey responses in the current study to a question about desired storage limits only 55 respondents nominated a limit under 10 years, with the majority preferring no limit or a limit framed in terms of the recipient's reproductive lifetime: see Isabel Karpin et al., *Analysing IVF Participant Understanding of, Involvement in, and Control over Embryo Storage and Destruction in Australia*, 20 J. L. MED. 811 (2013).

<sup>47</sup> NHMRC (1996), *supra* note 20, at 1 (emphasis added).

committee, but procedures that involve destruction should only be approved in exceptional circumstances.<sup>48</sup> In a discursive frame that arguably anthropomorphizes the embryo, the guidelines provide that 'embryo experimentation should normally be limited to therapeutic procedures which leave the embryo, or embryos, *with an expectation of implantation and development*'.<sup>49</sup> The embryo is framed not as an object of concern with a future potentiality that should be protected, but rather as a *subject* with its *own expectations* of futurity in a manner very reminiscent of the 1986 Tate Report. This statement appears to belie the pluralism of the opening introduction in the 1996 ethical guidance on the diversity of views on the 'moral status' of the embryo as it is implicitly accorded a version of personhood or sentience. The other effect, relatedly, is to erase the woman (and her partner) who created, and presumably consented to any research activity on their embryo. It is her body in which the hope of implantation rests and surely it is she who holds an expectation that the embryo will be implanted, rather than the other way around. Yet her wishes and concerns vanish.

The 2003 Draft Guidelines for Public Consultation (which preceded the 2004 Guidelines) state that the working group was guided by 'a respect for human life at all stages of development'.<sup>50</sup> This provision was notably dropped from the final version.<sup>51</sup> A number of other changes between the drafts and final versions of the guidelines alert us to the contested values concerning embryos, and those who generate them, within the committee. For instance, the 2003 Draft Guidelines provided, 'People who wish to make use of reproductive procedures should be encouraged to do so in ways that are respectful of human life and the dignity of all human beings'.<sup>52</sup> In the 2004 final version, however, 'human life' has been removed and replaced with 'all involved', and the injunction no longer applies to the patients who use ART but rather to the clinicians who provide it.<sup>53</sup> The 2004 Guidelines also added for the first time a stand-alone provision headed, 'Respect human embryos', which states that 'While there are different views held in our community about the moral status of a human embryo, one view that is very widely shared is that embryos are not to be treated as mere tissue'.<sup>54</sup> So while we can't agree upon what embryos are, we are all taken to agree on what they are *not*. The placing of this statement is also revealing as it is immediately followed by a subprovision requiring clinicians to limit the number of embryos created. Thus, the overarching object of the provision is to ward off the prospect of the future destruction of unused embryos.

More strikingly, the language of life, and death, has fluctuated across iterations. For example, the language of death and dying that appeared in relation to embryo destruction in the 2003 draft was replaced in the 2004 final version by the terminology

<sup>48</sup> *Id.* at 10, paras 6.3, 6.4.

<sup>49</sup> *Id.*, para. 6.2 (emphasis added).

<sup>50</sup> NHMRC, *Ethical Guidelines on the Use of Reproductive Technology in Clinical Practice and Research: Draft for Public Consultation* (Feb. 2003) at 2.

<sup>51</sup> The final version instead states that 'the welfare of people who may be born as a result of the use of ART is paramount' and then includes, for the first time, 'the autonomy' of individuals utilizing ART: NHMRC (2004), *supra* note 21, at 5, paras 2.5, 2.6.

<sup>52</sup> NHMRC (2003), *supra* note 50, para 5.1.

<sup>53</sup> NHMRC (2004), *supra* note 21, at 13, para. 5.1.

<sup>54</sup> *Id.* (para. 5.2). Repeated in the section on research, *Id.* at 45, para. 15.2.

of 'disposal'.<sup>55</sup> Conversely, the 2007 amendments, repeated in the 2015 draft, introduced the language of 'life' with the inclusion of a non-statutory<sup>56</sup> and, arguably, surplus definition of the 'embryo' as 'a living entity in the earliest stages of development' (at the same time that such language was dropped from federal legislation).

While many incarnations of the guidelines include some reference to 'regard' for the 'long-term welfare' of the women and men who utilize ART with various provisions concerning requirements for informed consent, patients are arguably rendered passive objects insofar as they are governed by rules that delimit what they may and may not consent to, rather than active subjects who should be consulted, or deferred to, in generating or determining options or actions. There is one striking exception in the 1996 Guidelines concerning disposal: 'Embryos may be allowed to succumb by withdrawal of support. Each clinic is to have protocols in place for this purpose. If indicated in their consent, the *preferences of a couple who generated an embryo are to be respected in this matter*'.<sup>57</sup> This carries through to the 2004/2007 Guidelines which continue to include provision for 'respect' for 'the wishes of the persons for whom the embryos are stored', specifically in relation to the decision to discard, and the method of disposal.<sup>58</sup> It is interesting that in the 2015 Draft Guidelines the comparable provisions on storage and disposal drop the language of respect for the embryo (or the wishes of its progenitors) and instead speak of 'managing' storage and disposal of embryos, offering 'options' and 'reasonable time' for the 'individual or couple' to consent or take action.<sup>59</sup> The language of regard, respect, and wishes falls away in the 2015 draft. The overall message from these changes is ambiguous: the presence of patients is more prominent, with references throughout to 'individuals and couples' undertaking treatment, yet these references are continually ungendered. Apart from an introductory provision requiring respect for 'women and intended parents', the woman seeking pregnancy is never explicitly mentioned.

In fact women, as such, hardly appear at all in any iteration of the guidelines. There is only one instance in the research provisions of the 2004 version (amended 2007) of the guidelines in which the woman patient's well-being is *linked* to concern for the embryo within a frame of maternity. Under the heading, 'Respect the embryo and all persons involved', the provision reads: 'Respect for the dignity and wellbeing of the mother and the embryo must take precedence over any expected benefits of knowledge.

<sup>55</sup> Compare NHMRC (2003), *supra* note 50, paras. 9.7, 9.13 with NHMRC (2004), *supra* note 21, at 27, 28, paras 8.5, 8.7.2 ('die' in the 2003 draft was replaced in the final 2004 version with 'disposal'. This was likewise reflected in the provisions on research, the 2003 draft refers to information being given to embryo providers that the 'embryo is allowed to die', which was replaced in the 2004 version with information on 'what will happen to each embryo').

<sup>56</sup> The 2004 Guidelines contained a definition of 'human embryo' that reflected the terms of 2002 federal legislation ('a live embryo'). A revised 2006 legislative definition of 'human embryo' ('a discrete entity') was reflected in the definition of 'human embryo' in the 2007 revision of the ethical guidelines, and then carried through into the 2015 draft guidelines: Prohibition on Human Cloning Act 2002 (Cth), s. 8; Research Involving Human Embryos Act 2002 (Cth), s. 7. The added definition of 'embryo' therefore sits alongside the definition of 'human embryo'.

<sup>57</sup> NHMRC (1996), *supra* note 20, at 11, para. 7.4 (emphasis added).

<sup>58</sup> NHMRC (2004), *supra* note 21, at 27–28, paras 8.7, 8.9.1.

<sup>59</sup> NHMRC (2015), *supra* note 6, paras 7.2, 7.3, 7.6.

There must be no foreseeable harm to the embryo that would make it unfit for transfer to the woman'.<sup>60</sup>

While the heading centers the embryo, the text of the provision appears to reverse this by beginning with 'the mother'. This language is particularly striking because she is not—yet—a mother. She is someone who intends to be a mother. Elsewhere, she is 'the woman' or a 'person for whom the embryo was created', a 'person responsible for the embryo' or a 'gamete provider'. Here the woman and her embryo's interests and well-being are aligned for the only time as her maternity is envisaged—even though the embryo is still at this point disembodied. Transfer is imagined as the (shared) goal, and they are 'the mother and the embryo'. In another sense, one could argue that the provision implies that she is the mother that the embryo has *an expectation of being implanted within*. Respect and dignity are language choices that occur elsewhere in the guidelines in relation to the entity of the embryo suggesting that it is human-ish; they are discordant choices for a woman's intentions and desires for achieving pregnancy, again suggesting a reorienting of value toward the embryo even when the woman herself makes a rare appearance.

Isabel Karpin has argued that,

Failure, excess, loss, repetition, and waiting as well as successes are all part of the IVF experience. They are part of the woman's embodied experience of the process and often lead to the development of a powerful feeling of connectedness with the frozen embryo that didn't exist at the beginning of the process.

....  
[A] legal response that treats all embryos as the same, requiring an abstract form of disengaged respect at the same time as a pragmatic recognition of their disposability, fails to account for the complex and embedded integration of these embryos in the selfhood of the women who care about them.<sup>61</sup>

I suggest that the institutional structure behind the Australian ethical guidelines is, at least in part, responsible for creating this space for the embryo as a contested but constantly centered ethical subject, not-quite-life but not-mere-cells.

### Knowledge and Expertise

The National Health and Medical Research Act of 1992 set up a legislative structure for the organization and in the process abolished the first set of 1982 ART guidelines. Each set of guidelines has been since been produced by a two-stage consultation process mandated by the legislation, in which a public consultation is followed by a draft document that then forms the basis of further consultation before final guidelines are produced.<sup>62</sup> While this is an admirably transparent process in guaranteeing input from professionals, researchers, and the public, the transition to this model involved,

<sup>60</sup> NHMRC (2004), *supra* note 21, at 49, para. 17.4; NHMRC (2007), *supra* note 22, at 71, para. 17.7. The 2007 revision separates out research on embryos that will be used to attempt pregnancy and those that will not. In contrast to the Tate Report, then, the approach to therapeutic intervention in the guidelines also addresses the interest of the woman in having access to a viable embryo.

<sup>61</sup> Isabel Karpin, *The Legal and Relational Identity of the Non-Yet Generation*, 4 L. INNOVATION & TECHNOL. 122, 140, 141 (2012).

<sup>62</sup> National Health and Medical Research Council Act 1992 (Cth), s. 13.

regrettably, abandoning an earlier commitment to the input of 'women and men', including 'at least one laywoman and one layman'.<sup>63</sup>

Since 1992 the statutory composition of the Australian Health Ethics Committee, the body responsible for issuing the guidelines, mandated by s 36 requires a Chair and those with *knowledge/expertise* in:

- ethics of medical research;
- regulation of the medical profession;
- law;
- philosophy;
- religion;

and *experience* in:

- medical research;
- public health research;
- social science research;
- clinical medical practice;
- nursing or allied health practices;

and *understanding* of:

- health consumer issues;
- concerns of people with a disability (along with no more than two 'other persons' with relevant expertise).

There appears to be an implicit hierarchy of knowledge, expertise, experience, and understanding as epistemological forms relevant to the Committee's work. There is no requirement of gender equity, nor of lay or consumer membership as such. Thus far, the person with expertise in religion has always been a minister of religion and/or a theologian—always a Christian, always a man, and usually a Catholic. At no stage has there ever been equal representation of women on the working groups responsible for the ART ethical guidelines. If anything gender parity has declined with the passage of time.<sup>64</sup> Perhaps of greater significance is that only one member is selected to represent 'knowledge of issues that concern people who access reproductive technology'. This notably does not specify a woman who has herself undertaken IVF, and generally appears

<sup>63</sup> NHMRC, *Supplementary Note 1 Institutional Ethics Committees* (IEC) (1992).

<sup>64</sup> The membership of the group which devised the 1982 Supplementary Note is not public. However, the 1986 review of implementation of the guidelines was undertaken by a nine-person Medical Research Ethics Committee, in which there were three women: two laywomen and one scientist. The 1996 Guidelines were put together by a working group established in 1994, which had seven people on it, of whom three were women: NHMRC (1996), *supra* note 20, at unnumbered page. The 2004 version comprised two separate working groups over the period of development, the first with three female members out of a panel of nine, and the second with three out of 10: NHMRC (2004), *supra* note 21, at 55, 56 (Appendix A). The 2015 version was devised by a group of 11, of whom 4 were women: Assisted Reproductive Technology (ART) Working Committee, *Disclosure of Interests* (2015) [https://www.nhmrc.gov.au/\\_files\\_nhmrc/file/health\\_ethics/ethcial\\_issues/disclosure\\_of\\_interests\\_july\\_2015.pdf](https://www.nhmrc.gov.au/_files_nhmrc/file/health_ethics/ethcial_issues/disclosure_of_interests_july_2015.pdf) (accessed June 1, 2016).

to be someone with current or past experience as an infertility or genetics counselor or nurse.

I suggest that this institutional model, excluding women patients and requiring religious input, locks us into an ethical framework that, through every incarnation of tinkering, continues to center the abstract entity of the disembodied human embryo at the expense of the embodied woman patient. Although I am more concerned with the understandings and views of women patients than the community at large, it is noteworthy that one of the few Australian studies of community attitudes to the human embryo found that:

[I]mportant gender differences were identified... Women were more likely to indicate that the right way to use an embryo was to transfer it to another woman or use it in research help another infertile woman. ... Women were also more likely to reject the involvement of external decision makers such as ethics committees or Government bodies, or even the man whose spermatozoon was used to make the embryo in decisions about embryo disposition.

...

As far as is known, the difference in views between women and men pertaining to embryo status, acceptable uses and responsibility for disposition decisions is one that has not been previously identified or investigated in community consultation. The present findings suggest that it is important to address gender difference in consultation processes and to have balanced gender representation in policy-making processes.<sup>65</sup>

This leads me to the embodied woman patient, and the question of what she might regard as important or relevant in decision making about stored IVF embryos

#### WHAT WOULD WOMAN-CENTERED REGARD LOOK LIKE?

Feminist relational autonomy accounts of personhood 'repudiate the notion of a disembodied rational calculator' and instead attend to the agency of 'embodied, socially engaged beings'.<sup>66</sup> In 2006, Karpin suggested that a feminist regulatory response to ART 'begin by challenging the primacy of the disembodied embryo', including challenging 'both its physical detachment from the female body and its social detachment from the parental relation' by foregrounding the figure of the '*not yet pregnant pregnant woman*'.<sup>67</sup> In recent joint work, we have proposed, building upon the work of feminist theorists such as Nedelsky, Baylis, and Downie among others, a relational sense of the embryo that centers the woman and values the 'intensely personal and infinitely variable' meaning of the embryo *to her*.<sup>68</sup> This frame allows us to regard a woman's decision making concerning her stored embryos as part of a broader political and social context

<sup>65</sup> Sheryl de Lacey et al, *Perceptions of Embryo Status and Embryo Use in an Australian Community*, 24 REPROD. BIOMED. ONLINE 727, 742, 743 (2012).

<sup>66</sup> Anne Donchin, *Towards a Gender-Sensitive Assisted Reproduction Policy*, 23 BIOETHICS 28, 34 (2009).

<sup>67</sup> Karpin, *supra* note 12, at 621.

<sup>68</sup> Jenni Millbank et al., *Towards Facilitative Regulation of Assisted Reproductive Treatment in Australia*, 20 J. L. MED. 701 (2013), *supra* note 16, at 704. Cf. Martin Johnson, *Escaping the Tyranny of the Embryo? A New Approach to ART Regulation Based on UK and Australian Experiences*, 21 HUM. REPROD. 2756 (2006) (arguing for a distinction between the embryo intended to be a child and the embryo not so intended); see also Lockhart Review, *supra* note 9 (featuring a number of supporters of this distinction based on intended use in ch. 7, 'Community Standards on Status and Use of Embryos').

but also accepts that this experience incorporates an individualized, fluid and variable sense of kinship and belonging, in which the embryo *may* (but not must) be regarded as part. As with feminist work on pregnancy loss, it is a difficult but important task to craft a space in public discourse that can acknowledge women's experience of relationality in reproduction without having fetal/embryonic personhood claims imposed upon it.<sup>69</sup> This is particularly difficult in political contexts where anti-abortion discourse is prevalent (such as in the USA where it has extended to claims of personhood for embryos, including for example the imposition of 'adoption' models onto practices such as embryo donation).<sup>70</sup>

In this section of the paper, I explore the 'matrix of relations' through the narratives of a series of women patients from our study, each of whom was speaking about the prospect of destruction of her stored embryos, although for some that prospect was more imminent than for others (and one had actually kept physical possession of the vials in which her embryos had previously perished). There is a rich body of published research addressing patient decision making about stored embryos, which I do not attempt to address here.<sup>71</sup> Rather I focus on a small number of women in detail, in order to illustrate the unique relational nature of each woman's understanding of her embryos and how they fit for her with her own sense of herself as a mother and patient, and with her partner, children, and other kin. I stress that very few participants in our study, and none of the women quoted here, understood their own embryos to be 'life' or attributed personhood or almost babyhood to them. Likewise very few participants were opposed to destruction of embryos *per se*. They also notably did not speak of embryos as something special, requiring regard in an abstract sense, or about the value that should be accorded to other people's embryos; rather they spoke about the value and meaning of their own embryos in a very specific, conditional, and, I suggest, embodied relation.

### Regard as a relation, and as the product of labor: Rose

At the time of interview, Rose was the single mother of a six-month-old child. Rose had eight embryos in storage which she had not yet decided whether she would utilize in further pregnancy attempts. Considering the possibility of future destruction, Rose said:

[B]ecause of the very personal process I had to go through to get them and the fact that one of them is my daughter asleep in the bedroom [I feel] that they deserve better than just sort of being defrosted on a bench and flushed down the sink or whatever is going to happen to them. I would like the chance to be able to do something with them.

Like many other participants, Rose expressed the view that her stored embryos were closely connected to her *through* their connection with her existing child or children.

<sup>69</sup> See e.g., Helen Keane, *Foetal Personhood and Representations of the Absent Child in Pregnancy Loss Memorialization*, 10 FEMINIST THEORY 153 (2009); Catherine Kevin, 'I Did Not Lose My Baby... My Baby Just Died' *Twenty-First Century Discourses on Miscarriage in Political and Historical Context*, 110 SOUTH ATL. Q. 849 (2011).

<sup>70</sup> See e.g., Bernard Dickens, *The Use and Disposal of Stored Embryos*, 134 INTERNATIONAL JOURNAL OF GYNAECOLOGY AND OBSTETRICS 114 (2016); Glenn Cohen, 'Religion and Reproductive Technology' in LAW, RELIGION AND HEALTH IN THE UNITED STATES (Lynch H., Cohen G. & Sepper E. eds, forthcoming 2017).

<sup>71</sup> For a concise summary, see Sheryl de Lacey, *Decision Making about Frozen Supernumerary Human Embryos*, 16 HUM. FERTIL. 31 (2013).

This sense of sibling connection was expressed by participants in our study, as by those in many other studies,<sup>72</sup> particularly in relation to reluctance to donate embryos for the reproductive use of another woman.<sup>73</sup> Yet it also went far beyond this.

For many of our participants, this sense of connection with embryos was particularly acute when, as with Rose, their child had come from the same treatment cycle: that is, when one embryo had been transferred and became an existing child while others from the same 'batch' were stored for later use. In such instances, a number of women expressed a sense of their embryos as spectral twins of their existing child—'Is there going to be another little girl with red hair like my daughter has, or a little boy, is he going to look exactly the same as him, because they've come from the same batch?' (Phoebe)—or as interchangeable with them—I look at my Claudia and I go, "My god they're all potential Claudia's" (Ruby) — 'It was just the embryologist's choice which meant we have the babies ... we do now and not one or both of those in storage' (Survey 241).<sup>74</sup>

Many women said that they did not want their embryos to be wasted, or treated as waste (Juliet, Joanne, Sarah, Sam) and expressed distress at the prospect of them being 'flushed' or 'shoved' down the sink or toilet (Nikki, Ruby, Sam, Kate), or 'chucked' in a bin (Veronica, Danielle). Here Rose articulates her embryos as 'deserving' of 'something better' than an imagined and abject ending—a waste product left on a bench and 'flushed down the sink'. In this sense she is reflecting the idea in national ethics guidance that embryos are not mere cells and even could be seen as putting a subject position requiring regard: in that it is *they* that deserve a particular end or process. Yet wrapped around this is a series of other relationships and demands for regard. The embryos deserve this because of what Rose herself *had to go through* to get them. It is her embodied effort, pain, and sacrifice in IVF processes that call for regard to be given to them, as well as their interchangeability with her sleeping child. Thus, Rose articulates her embryos simultaneously as both 'work object' and 'love object'.<sup>75</sup> However, she does so not to assert their inherent value, but rather her own desire to have some control over the outcome and 'do something with them' when they are discarded. Her choice would be to bury them in her garden.

### Connection to the body: Apple

At the time of interview, Apple had a one-year-old child and was mid-cycle in a further pregnancy attempt, which she described as having 'two [embryos] *with me* at the moment, and one on ice'. Like Rose, Apple did not actually know what occurred when embryos are discarded and so imagined it as a process of abandonment or clinical disregard:

<sup>72</sup> See e.g., Bangsbo et al., *Patients' Attitudes Towards Donation of Surplus Cryopreserved Embryos for Treatment and Research*, 19 HUM. REPROD 2415 (2004); Giuliana Fuscaldo et al., *How to Facilitate Decisions about Surplus Embryos: Patients' Views*, 22 HUM. REPROD. 3129 (2007).

<sup>73</sup> See e.g., Sheryl de Lacey, *supra* note 16; *Parent Identity and 'Virtual' Children: Why Patients Discard Rather than Donate Unused Embryos*, 20 HUM. REPROD. 1661 (2005).

<sup>74</sup> For a more detailed discussion, see Jenni Millbank et al., *Embryo Donation for Reproductive Use in Australia*, 20 J. L. MED. 789 (2013).

<sup>75</sup> See Kathryn Ehrlich et al., *The Embryo as Moral Work Object: PGD/IVF Staff Views and Experiences*, 30 SOCIOLOGICAL HEALTH ILLN. 772 (2008) (discussing these issues in the context of ART staff, rather than women patients); see also Karpin, *supra* note 61, at 142 (describing the embryo as a 'nascent love object').

[L]eaving them to die in a Petri dish seems wrong. Just sort of letting them defrost and never make it kind of seems wrong. So in an ideal world, and I don't know if it's a possibility but what I'd like to do is have them put back in at a time where I know they're not going to make it so at least they're in the right environment when they don't make it.

Apple expresses a wish for what has been termed 'compassionate transfer' in the literature,<sup>76</sup> a process not publicly offered in Australia, and only available when requested by the patient at certain clinics, in which the embryos are transferred at a time in the woman's cycle or in such a way (for example to the vagina rather than the uterus) that they are very unlikely to result in pregnancy.

Although Apple begins by saying 'die' and 'defrost' when referring to the imagined end in the Petri dish, she then re-characterizes this end as 'not making it' and wants this process to be completed within her body which is 'the right environment'. Many women we interviewed expressed a sense of discomfort or wrongness at the ongoing and unanticipated out-of-bodyness of their stored embryos. This was reflected in their language around disposal, which invoked images of being tossed in rubbish bins or flushed down sinks or toilets. Apple's renaturalization of the disposal process is expressed as something mitigating an implicit sense of loss ('at least they're in the right place') that follows a logical order of the cycle in which, regardless of pregnancy, the embryos are returned to the body whence they came. Accordingly, her claim of relation is about the embryos' relation to her body as well as about her relation to the IVF process, which is perhaps more acute because she is in the process as she speaks.

#### An end that is not yet final: Phoebe

Phoebe had two children from IVF and seven embryos from the same treatment cycle that she had stored for 10 years. At the time of interview she had been compelled to dispose of these embryos when the storage limit was reached in her jurisdiction and her clinic withdrew the option to donate embryos to research (which had been her preference). She had approached her clinic and been permitted to take her embryos home. Phoebe said that she 'wasn't silly' and was well aware that the embryos were no longer viable within a short time of taking possession of them, repeatedly noting that they weren't 'really there' anymore. Nonetheless, she had placed the vials in the butter compartment of her fridge, where they had remained for the past nine months. Phoebe explained this process:

[T]hey're still sitting in my fridge because I now don't know where—I know I sound like a fruit loop but I'm not. I don't know where to put them. We'd decided that we would either plant a tree or something like that; we would incorporate them, pot them in with the tree and that would be our memory sort of thing. But probably the fact that we've got a puppy ... and she's a total nut case, I think she'd dig the tree up. So I think that's probably—no, I don't want that just to happen just yet.

I could always probably plant a tree where she can't get to it but anyway it's just something that we haven't done. Plus we would also have to choose a time and a place that ... the children weren't around that I didn't then have to go in and explain to them. They know they're IVF babies but I wouldn't want to go any further with that ....

<sup>76</sup> See David Ellison & Isabel Karpin, *Death Without Life: Grievability and IVF*, 110 SOUTH ATL. Q. 765 (2011).

I can always basically look at that particular tree or plant and think, well, I've got that memory of everything that I've gone through over the past 15 years basically, and that's the last memory I suppose. That's the end of the line and this is where they are and I can look at that and then think, well, that's a living object. I know the plant could die or whatever but you know what I mean?

It's just there as like a memory for me, probably more me. My husband, I don't know men sort of tend to think a bit—oh what's the word—they're just very cut and dried, where I think women, especially going through process of IVF it's all the what ifs and you think a bit more about everything that you're going through, you're navigating through.

... It's a clear tube with a yellow lid and it's in the specimen bag tucked away behind the butter ... [because] it's up high and the children can't reach that far yet. I think I would hate for them to one day open that butter or that area and go, 'Mum, what's this?' So yeah, I know I'm making light of it but I know I've probably got a limited time. I do need to find that plant and I do need to sort that out because there will come—

So basically there'll be a day when I think, right, I see a plant and I'll think, well, that's the plant I want, and I'll just do it, minus the dog and the kids.

There is a complex and intersecting web of relationships at work for Phoebe. The embryos are intimately connected to her, much more so than to her husband or existing children from the same 'batch'. Elsewhere, she says she is 'probably a bit more emotionally attached to them than the next woman', having just relayed the 'bit of a rough trot' she had with IVF including her near death experience from an earlier ectopic pregnancy. In this sense the tree she imagines is a record of her own arduous process and she implicitly characterizes it as a memory of her, for her. But the ceremony is also for the embryos as the end of a line, an end of her process, and an end of themselves. The children and puppy are imagined as incursions on this private space, opening the butter compartment, digging up the tree.

The choice of the fridge for storage, even in the express knowledge that this was unrelated to viability, uncomfortably and ambivalently mirrors the cold storage of the clinic. Phoebe chose not the freezer, but the butter compartment, in fact the warmest part of the fridge, gesturing perhaps toward the warmth and containment of the bodily environment that the embryos would *not* be returned to in order to offset the coldness of mechanized storage? In all of these things appears the shadow of the other, none exists in a separate or distinct state. Even the living tree which marks and transforms a death of sorts (the end of the line) into a different kind of life is imagined to be vulnerable to the too lively puppy, and immediately acknowledged as something that could itself die.

In re-reading Phoebe's interview transcript, it is striking that she characterizes the embryos as both there and not there in a process that is over but not yet *complete*:

I'm not silly, like I know this is the next step, we'll get it done. I realise I'm going to be sad with the next step, then that will be final. Even though I know it is now, that it's all done and dusted now sort of thing, and it's now just the next step of having the symbol, I suppose. I've just got to then do that and then it will be—

The word 'over' remains unspoken, the sentence unfinished.

**Something useful to someone, that I would have felt really good about: Scarlet**

Scarlet had a one- and a two-year-old child through IVF with two embryos left in storage. Scarlet strongly wished to donate her embryos for the reproductive use of others and, having been denied access to her clinic's donation program because of a genetic condition, she had then self-recruited recipients and begun a known-donation process with a couple who were aware of and understood the condition. Scarlet described the condition:

My family have a—not a disease, that's the wrong word—an illness that's passed from mother to child and so all those embryos have this illness and both of my children do. It's a 100 per cent transmission to the child but then the child inherits it in varying disease. So they can have like a five per cent disability, which you wouldn't even notice right up to 100 per cent.

Scarlet volunteered that she had been taken aback when the clinic counselor proposed that she and her partner should both let their own parents know about the donation:

By the time the child was say 18 or 20 there's absolutely no guarantee our parents will even be around, so I just didn't think that that—I thought that was probably going a step too far. It's one thing to explain to our children that they may have siblings out there that they're biologically related to. I think it's probably more than my mum for instance could cope with.

In imagining future kin, Scarlet saw the embryos as connected to her children, but not to her parents, and she actively resisted the clinic's emphasis on genetic link.

However, the clinic's ethics committee refused to allow the donation to go ahead on the basis that it would not be in the potential child's best interests.<sup>77</sup> Scarlet's response to this rejection reads back from the embryos as children-to-be, or rather as children-who-will-never-be, to her own children's disability, to her sense of herself as a mother to those children and of herself as a person with a disability:

I find it a really difficult argument to accept, because I have produced two children from exactly the same set of embryos and in essence they're saying that that was not in the best interests of my children. Now that's quite a confronting statement because I think my children are immensely loved and showered with everything they need and they're well built up, well cared for and it's hard to say that it was not in their best interests to even exist.

... I have the exact same disability as these embryos and I guess that's also saying that it would be in my best interests not to exist. A lot of people with disabilities and a lot of parents of children with disabilities would find that an extremely confronting point of view.

I've read things of parents with children with serious disabilities like cystic fibrosis and those kind of illnesses, where the child is wheelchair bound—I live a very normal life—and those parents say they would not be without those children. They love them so much.

<sup>77</sup> On the assessment of potential offspring interests in ART practice in Australia, see Rachel Thorpe et al., *In the Best Interests of the Child? Regulating Assisted Reproductive Technologies and the Well-being of Offspring in Three Australian States*, 26 INT. J. L. POL'Y FAM. 259 (2012); de Lacey et al., *Child Interests in Assisted Reproductive Technology: How is the Welfare Principle Applied in Practice?* 30 HUM. REPROD. 616 (2015).

I guess a committee has decided I think in an extremely stretched sense of what is the best interests of the child.

Physical selves and loved selves are merged as 'well' in Scarlet's effort to articulate best interests within a web of kin and social relations. At the end of the interview, Scarlet said that she felt it was a terrible waste and unfair that the couple had been denied the chance to receive her embryos, noting that the clinic had a two-year waiting list for donation and was currently closed to new recipients.<sup>78</sup> She added that she too had been denied the chance to do something she would have 'felt really good about'.

Scarlet was very committed to the idea of her embryos as something of worth: 'There was never any doubt in both mine and my husband's mind that if they could be used for something, they should be. It's a really hard process to get to have embryos'. As a result, she then tried to donate them for research into the specific genetic condition she experienced, but was told that this 'wasn't worth it' for two embryos, so she then pursued donation to broader research.

### The part of me that kind of still makes me a mother: Chloe

Chloe was the only interviewee in the study who had completed her treatment without actually having a child or sustained a pregnancy. Because of her age and the fact that she had experienced multiple miscarriages, she was not planning any further pregnancy attempts. She had stopped treatment when she still had one embryo in storage and had kept it for almost six years by the time of the interview. She said:

The only way I can articulate it is this is the only physical thing I have that's the closest to being a child. This is all I have left... it's an embryo. It's viable... this is for me personally emotionally — it is a potential child that you and your husband have created. You have nothing else left. This is it, the last hope. ...I can't get rid of it. Maybe I need to keep this forever. I just can't do it....

That's the dilemma that we go through constantly. I keep looking at it, every six months it comes and I go I've got to do something, I've got to do something and I just stuff the paperwork away in the desk and go, no, something inside me still feels okay that I've got this living little thing there. That's mine.

... [I]t's the only living thing that I've created. Everyone else is — but it kind of still makes me a mother.

As with Rose, implicit claims to personhood are specific and contingent: this embryo is viable *for me*, potentially a child, a living thing that is *mine*.

<sup>78</sup> Note that this ethical issue is distinct from selecting embryos in favor of disability, as these were the only available embryos, and indeed had been utilized in her own treatment with no ethical objection. For discussion of the issue of use of affected embryos for reproductive donation, see Sheryl de Lacey & Rob Norman, *What Should We do with Donated Embryos that may be Genetically Affected?* 19 HUM. REPROD. 1065 (2004). It is noteworthy that the 2015 draft NHMRC guidelines for the first time state that donation of affected embryos should not be 'arbitrarily prohibited' but should instead allow for a careful assessment of risks and impact with the recipient, including genetic counseling: National Health and Medical Research Council (NHMRC), *Draft Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research; Public Consultation 2015*, *supra* note 6, at [6.3], [https://consultations.nhmrc.gov.au/public\\_consultations/assisted-reproductive-tech](https://consultations.nhmrc.gov.au/public_consultations/assisted-reproductive-tech) (accessed Sept. 15, 2016).

'Hope' and potentiality are very particular and embodied in the IVF context, in which women repeatedly, often over a number of years, have embryos transferred into their bodies and then wait for a week to two weeks to see if they 'take' a process of not-quite or temporary pregnancy. The relation of this embryo is to hope and to Chloe's deeply internal sense of herself as a mother, although in any real sense the hoped for future is lost and she is a mother-never-to-be. In this sense, building on Karpin, Chloe is a never-to-be-pregnant pregnant woman.

This quote from Chloe is the only interview quote that, when I have presented at conferences, workshops, and professional fora, has always caused at least one person listening to visibly cry. In my view, this reaction from listeners speaks to an ability of the community, if properly informed, to have regard for women first and foremost in policy and practice that has, to date, been dominated by regard for the disembodied embryo. It is worth restating that Chloe's wishes are not honored in law, and her embryo will almost certainly have been compulsorily destroyed by the time of writing as a result of the 10-year storage limit in her jurisdiction.

### CONCLUSION

Many laws and ethical documents in Australia, as elsewhere, instruct us that disembodied embryos created through IVF processes are not mere tissue; they are 'widely regarded' as unique objects of serious moral consideration with a 'special status' that commands 'respect'. This paper has engaged in an historical analysis of Australian ethical governance to document how this characterization came to pass. These ethical and policy documents characterize the embryo as an object of ideological compromise: not mere cells and not life, but a poorly bounded and endlessly contested something-in-between. I argue that the woman whose desire for a child or children created this embryo, and who inhabits the body to whom it may one day be returned, is an omission or at best an afterthought in such frameworks.

The paper engages with the narratives of women patients about their sense of connectedness to their stored or discarded embryos, drawn from a larger study on decision making concerning patient's experience of decision making about IVF embryos. I draw on a selection of these narratives in some detail to illustrate their complex and contingent experiences of regard, kinship and connection with their embryos and to ask how we could reorient law and policy toward the concerns, needs, and desires of such women. Decisions about storage and destruction are critical conflict points that have triggered expressions of dismay by IVF participants when their feelings of connectedness with their embryos are disregarded.<sup>79</sup> These are not the only areas in which ART law and policy prioritize a universalized and disembodied respect for the embryo over and above the feelings and wishes of those who created them, but they are the most acute and, particularly in the case of destruction, the most painfully paradoxical.

Changing legal regulation and ethics governance to include the perspective of women patients on their IVF embryos is a slow endeavor. It is notable that the 2015 draft the NHMRC guidelines, for the first time in their 30 year history, drop the requirement of an embryo storage limit of 10 years. Yet they do so in a way that continues to sideline the woman undertaking treatment. First, the draft takes as a starting point

<sup>79</sup> Anita Stuhmcke, *Tick Tock Goes the Clock: Rethinking Policy and Embryo Storage Limits*, 22 FEMINIST LEGAL STUD. 285 (2014).

the administrative priorities of the clinic in disposing of unclaimed embryos; and second, it prioritizes the scientific expertise of the clinic in determining viability. Only then does it go on to note that the duration of storage *may* also depend upon the 'personal preferences' of the couple.<sup>80</sup>

Isabel Karpin has argued that in developing ideas of relational selfhood, we are *not* obliged to treat woman and embryo as equal or to situate the embryo 'as a rights bearing entity that requires protection'. We *are* obliged to 'respond to female agency and embodiment formed through this complex (and sometimes uneasy) negotiation with a matrix of relations and familial possibilities'<sup>81</sup>—and, I would add, with imagined future possibilities and relations, including foreclosed and no longer possible futures, losses, and potentialities hitherto unimagined. An ethical framework premised on respect for the woman undertaking treatment must ask first what these relations mean to the woman and then seek to accommodate this meaning. I suggest that an embedded institutional structure, such as that in place in Australia for the past 25 years through the NHMRC, which legislatively mandates religious representation, and which does not require the embodied perspective of a woman patient, will continue to center abstract notions of regard for embryos at the expense of the needs of women who undertake IVF treatment.

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<sup>80</sup> National Health and Medical Research Council (NHMRC), *Draft Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*; Public Consultation 2015, *supra* note 6, [https://consultations.nhmrc.gov.au/public\\_consultations/assisted-reproductive-tech](https://consultations.nhmrc.gov.au/public_consultations/assisted-reproductive-tech) (accessed Sept. 15, 2016).

<sup>81</sup> Karpin, *supra* note 61, at 143.