Chapter 10

Taking care of the 'health' of preconceived human embryos or constructing legal harms

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Introduction

This chapter examines medical and legal claims around preconception health and preconception harm as they relate to future possible 'healthy embryos'. In the first part of the chapter, I give articulation to an imaginary entity – the 'preconceived embryo' – to bring to the fore the way that preconception healthcare directed to the health of future embryos (as distinct from preconception healthcare directed to the woman's own health) constructs a point of putative vulnerability fixed to material possibility – the embryo that might be conceived at some point in the future. This aspect of preconception healthcare relies on a spectral figure whose form is imprinted on the imagined material body of the future child. That future child's potential and purported abnormalities and disabilities, flaws and imperfections are in turn identified with the acts and omissions of the woman who – though she is yet to (and may not ever) become pregnant – has had her subjectivity displaced and reduced to maternal potential via the preconceived embryo.

In the second part of the chapter, the legal tort claim of preconception harm is examined. Preconception harm works in reverse to point to the moment in the past where harm was caused to an existing child's contemporary 'health' status. Here we see how harm is retrospectively discovered in the preconception acts of physicians, other healthcare practitioners, third parties and women themselves. In these cases we see how the legal system uses the attribution of existing personhood through live birth to create a duty to act in that person's interests even before that person was either thought of or biologically conceived, in other words, when that person 'existed' as the entity I refer to as a 'preconceived embryo'.

In the conclusion I explore how preconception healthcare initiatives that attribute responsibility for ensuring healthy embryos to women's (and to a lesser extent men's) management of their lifestyle and behaviours prior to conception are at odds with a legal system that, on the whole, exempts women from responsibility for preconception harm to their own children. Strong arguments are made for attribution of harm in the case of healthcare practitioner negligence, on the one hand, and protection of women from responsibility and its attendant scrutiny and surveillance on the other. However, especially in the case of prenatal and preimplantation testing, some developments challenge this distinction and suggest women and men be held responsible for harm to future children where a choice is made to continue a pregnancy or to bring about a pregnancy that will result in a 'disabled' child.

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This chapter is shaped by an overarching question: how does health have meaning when applied to the preconceived embryo? Because the preconceived embryo is a future possibility, it lacks a contemporary social context and a material being to support such claims to health status. Arguably, we cannot have a clear understanding of a being's health status where it is still only in the realm of the possible rather than the actual. If health is a construct the meaning of which is contingent on the social, economic and political context in which it is deployed, as Mykitiuk and Nisker argue (please refer to Chapter 9), then healthcare initiatives must focus on the current health status of the woman (or man) rather than the imagined health status of a putative preconceived embryo. Healthcare initiatives appropriately targeted at an existing individual's health enable the social conditions of that health status to be foregrounded. Thus, I caution against an activist approach to preconception healthcare that is motivated by the health of populations that do not yet exist and possibly never will. A better approach builds health initiatives around women (and men) for their own sake. If, alternatively, we perceive women's bodies as conduits for embryo health, we risk creating the conditions where women are found to be both morally and legally culpable for choices, acts, and omissions that are made in relation to their own bodies and that have a negative impact on the health status of a future-existing possible child. At the same time, however, it is necessary to ensure a legal system that can hold to account those individuals that deliberately or negligently harm future possible selves before they are conceived, once those individuals are born and gain legal personhood.[1] The question is how to distinguish preconception harms that ought to be legally remediable and harms that ought not. I argue, in this chapter, against creating a regime of legal responsibility for women and men who choose to conceive knowing that they risk an embryo with a disease or a disability due to their age, weight, their own health or carrier status, or for harm that is constituted through the ordinary everyday living of their lives.

I. Preconception health and the preconceived embryo

In recent years, a number of countries have developed preconception healthcare initiatives. Preconception healthcare, as it relates to producing healthy embryos, relies on the constitution of the healthy human person of the future by looking back into their past as it exists now in the contemporary moment of their possible conception. In this move, time is both compressed and dilated. Women's reproductive lifespans are both elongated and accelerated so that actions taken today are conflated with the child possibly conceived tomorrow. Consequently, women are counselled that what they eat, drink and do now affects directly the embryos they might produce in the future – their preconceived embryos.

The United States Centers for Disease Control and Prevention (CDC) released its *Recommendations to Improve Preconception Health and Health Care in the United States* in April 2006 (Department of Health and Human Services, Centers for Disease Control and Prevention [CDC], 2006). The recommendations are directed to all women who could possibly become pregnant, even those who have no immediate plans to do so (CDC, 2006, p. 9). Women who range in age from their mid-teens to their mid-forties are to be targeted in a campaign to provide risk assessment and counselling to reduce risks related to the outcomes of pregnancy. Ten recommendations are put forward by the CDC, including,

[1] In the jurisdictions examined in the chapter, live birth is almost always a precondition for legal personhood (Savell, 2006).

notably, Recommendation 4: 'Interventions for identified risks.' According to the CDC report, the recommendations are not prioritized (CDC, 2006, p. 9); however, a separate section highlights 14 primary risk interventions for preconception risks associated with adverse pregnancy outcomes (CDC, 2006, pp. 4–5). These interventions include chemical measures, such as the provision of folic acid supplementation and increasing the dosage of Levorhyroxine for hypothyroidism, and social and behavioural interventions, such as obesity control and eliminating alcohol and tobacco use (CDC, 2006, p. 5). According to the CDC, the aim of preconception healthcare interventions is to 'allow women to maintain optimal health for themselves, choose the number and spacing of their pregnancies and, when desired, prepare for a healthy baby' (CDC, 2006, p. 7).

When the recommendations were released, news media responses varied. In an article headlined 'Forever pregnant,' January Payne from the *Washington Post* described the recommendations as treating all women as 'pre-pregnant ... regardless of whether they plan to get pregnant anytime soon' (Payne, 2006). In a critical response to the recommendations and their overemphasis on women's personal responsibility for creating the conditions for the (re)production of healthy babies and future citizens, Payne argues:

> Among other things, this means all women between first menstrual period and menopause should take folic acid supplements, refrain from smoking, maintain a healthy weight and keep chronic conditions such as asthma and diabetes under control.
>
> (Payne, 2006)

In contrast, Clara Pirani (2007) of *The Australian* newspaper in an article carrying the headline 'Conception: never too early to be prepared' described the guidelines as a warning to women not to leave adopting a healthy lifestyle until it is too late. Pirani includes 'adult' men as an equal target of preconception care despite their marginal inclusion in the CDC recommendations, where they are referred to only by association. For instance, men are included as subjects of one of the four goals of the ten recommendations namely to 'Improve the knowledge and attitudes and behaviors of men and women related to preconception health' (CDC, 2006, p. 9). Pirani posits the following hypothetical to illustrate the way in which the CDC recommendations intrude on what might otherwise be considered individual freedoms:

> If you're a female aged between your mid-teens and mid-40s who is not planning to have children, would you be annoyed if your GP told you to drink less in case you became pregnant?
>
> As a male adult with no desire to become a father, would you be surprised if a doctor warned you that smoking could damage your sperm and threaten the health of your yet-to-be conceived baby?
>
> (Pirani, 2007)

She leaves both questions unanswered but gestures towards the potential equivalence of intergenerational responsibility between both men and women by juxtaposing the questions in this way. The CDC report describes the recommendations however, as a 'strategic plan for improving the health of women, their children and their families' (CDC, 2006, p. 9). The lack of emphasis on male responsibility is notable. Perhaps more important is the focus of the interventions on the health of those persons not yet conceived and those whose conception has not even been contemplated. The inclusion of all women from 'menarche to menopause' creates a holding place for the preconceived embryo in an imaginary family yet to be constructed (Karpin, 2006, p. 607) Furthermore, Pirani's reference to 'adult' men reflects the report's in attention to special interventions to educate or evaluate the preconception health of teenage boys. Why then has the CDC extended preconception care

initiatives to all women *capable* of becoming pregnant from 'menarche to menopause' and not solely to women *intending* to do so; and why is there no specific mention of the age and reproductive capacity of men who ought to be included? (CDC, 2006, p. 9).

The Health Council of the Netherlands, for instance, in its report on preconception care, *Preconception Care: A Good Beginning*, describes the period of preconception care more narrowly, as 'some months before conception to the first few weeks thereafter' (Health Council of the Netherlands, 2007, p. 19), which suggests that the target of preconception care initiatives is the woman (or couple) intending to become pregnant. On the other hand, the Public Health Agency of Canada has in the *Family-Centred Maternity and Newborn Care: National Guidelines* described the preconception period as 'incapable of neat definition' and states 'most women never really "know" when, or if, they will become pregnant' and 'clearly preconception care should be considered throughout one's life' (Government of Canada, 2000, p. 3.5).

While women sometimes become pregnant unexpectedly, it is arguable that potential harm to a future child would need to be significant, both in terms of the level of risk and the severity of the harm, before it is appropriate to counsel women to live in a constant state of risk preparedness. Asking women to maintain a healthy weight and give up alcohol is quite distinct, for instance, from ensuring all women are immunized against rubella and are offered appropriate treatment for existing chronic illnesses. The former demands an intrusion into the daily lives of women not for their own sake necessarily, but on behalf of an entity that may, or may not, be conceived. In the latter case, the intrusion is either momentary or has significant health benefits for the woman herself. Any preconception healthcare strategy, therefore, needs to separate and distinguish the different effects and goals of varying interventions to ensure that women are neither unfairly subject to disciplinary surveillance nor made unnecessarily apprehensive about potential harms to future conceived embryos.

If the central focus of preconception care is the 'preconceived embryo' – the imaginary entity I introduced at the beginning of this chapter – then it is easy to see why all women (and men) should subject themselves to what Elisabeth Ettorre describes in the comparable context of genetic testing, as a 'regime of reproductive ascetism and a discourse of shame' (Ettorre, 2000, p. 408). She argues that 'when pregnant bodies undergo ... invasive tests, this austere self-disciplining of reproductive ascetism can be viewed and experienced as necessary for the overall, external regulation of "fit" populations in consumer culture. In this regime, the female body emerges as a reproductive resource' (Ettorre, 2000, p. 408). Similarly, in the case of preconception care initiatives, if the woman is merely a conduit for the production of healthy embryos, then this kind of scrutiny and control will be viewed as appropriate and acceptable. However, I argue that the central focus should be on the woman and not on the non-existent – but pre-imagined and preconceived – 'healthy embryo'.

Indeed, the decision of the CDC to approach 'preconception care' as a public healthcare initiative that includes all women of child-bearing capacity sets it apart from preconception healthcare strategies in comparable countries and raises a number of difficult questions: Whose health is being targeted? Is it the health of women? Is it the health of what I call the 'preconceived' embryo? Or is it both? The Dutch report, for example, makes a clear distinction between the public health goals of the US approach and the approach of the Dutch Health Council, which is based on individual care:

> An important difference between the approach adopted by the CDC and that of the Committee that prepared the Dutch advisory report is that the CDC report has been written from a public

> health perspective, whereas the Health Council committee's report is primarily predicated on health benefits and the options available to individuals who wish to have a child.
>
> (Health Council of the Netherlands, 2007, p. 32)

The Dutch report's focus on the individual suggests an approach that foregrounds the woman as opposed to foregrounding potential future embryos. The language used by the CDC, on the other hand, is ambiguous. The goal of preconception care is described in the CDC recommendations in several different ways, including 'to promote the health of women of reproductive age before conception' (CDC, 2006, p.1); 'improvement of the health of women, their children and their families' (CDC, 2006, p. 9); to 'improve pregnancy-related outcomes' (CDC, 2006, p. 1); and 'to reduce risk factors that might affect future pregnancies' (CDC, 2006, p. 3). Given that one possible population that is being targeted – the preconceived embryo – does not yet exist, an approach based on this preferred population would be questionable. Elsewhere, strenuous efforts have been made to ensure that preconception care is not seen as the exclusive domain of women and that the implementation of behavioural and lifestyle changes is both voluntary and fully informed. The Canadian guidelines, for instance, note the following:

> Preparing for a healthy pregnancy is not the sole responsibility of either the mother or the family. Individual life patterns, social support networks, and social living conditions are all important factors in conceiving, giving birth to, and raising healthy children.
>
> (Government of Canada, 2000, p. 3.5)

This viewpoint also accords with the approach to healthy embryos laid out by Mykitiuk and Nisker (refer to Chapter 9). Significantly the CDC recommendations do recognize the importance of social determinants of health, noting that they 'also play a role in pregnancy outcomes' (CDC, 2006, p. 4), yet the first recommendation of this public health initiative is to encourage individual responsibility for good preconception health throughout a person's entire lifespan, including making men and women aware of biomedical, behavioural and social risks known to affect pregnancy outcomes (CDC, 2006, Recommendation 1:9).

Rather than highlighting individual responsibility, the Canadian approach highlights individual decision-making:

> Healthcare providers involved in preconception care enter into a collaborative partnership with a woman and her partner, enabling them to examine their own health and its influence on the health of their baby. The healthcare provider's role is to provide accurate information; translate and communicate this information in a clear and precise way; support the woman and/or couple's decision-making process; and offer and refer them to relevant services when appropriate. The information provided and techniques used to encourage effective discussion and communication will allow the woman and her partner to make an informed decision about having a baby. The decision, however, ultimately rests with the parents.
>
> (Government of Canada, 2000, p. 3.6)

The Dutch report too, describes preconception care as promoting 'the health of the mother-to-be and her child' (Health Council of the Netherlands, 2007, p. 12). The decision to take an individual approach, therefore, arguably ensures that the initiative focuses on existing persons who are contemplating having children, not on the preconceived embryo.

Thus far I have attempted to tease out the ways in which preconception care can be constructed either positively to benefit women or negatively to discipline them. I do not suggest that the goal of preconception care can simply be dismissed as directed towards a non-existent entity. On the contrary, many women and men may, in fact, want to be able to

engage in practices that will ensure the embryos they conceive are 'healthy' and will continue to engage in ascetic practices in the postconception period, namely during pregnancy and childbirth. Temporary restrictions on food and alcohol and relinquishment of other aspects of sociability, for example, are not unusual choices for women to make when pregnant or contemplating pregnancy. Nevertheless, it is important to unpack or deconstruct the rhetorical strategies that are operating in the context of directives such as the CDC recommendations because the focus on preconception care, and on women in particular, carries unstated assumptions about appropriate reproduction. As we shall see in the second part of this chapter, this focus also has the potential to generate an associated legal responsibility for certain kinds of behaviour, or inaction, on the part of the woman (now a mother) at what we are supposed to recognize as the preconception stage. Because the CDC guidelines do not distinguish between appropriate levels of risk management and behavioural modification for women intending to conceive compared with women who have no immediate intentions to do so, women may find themselves positioned as morally culpable for acts and behaviours they engage in prior to contemplating having children. Of course, it is another thing altogether for that moral culpability to be extended to legal culpability, yet it is easy to see how the line of causation can be expanded through these kinds of medical accounts of health effects. The cases described below suggest that although at this stage such an expansion is unlikely, it is not impossible.

Care needs to be taken, therefore, in the construction of preconception healthcare initiatives, to ensure that the emphasis is not on health outcomes for a putative child that may never be conceived but, instead, is directed to the care and health of the woman taking into account her specific reproductive intentions. To the contrary, according to Recommendation 1 of the CDC report, 'The target population for preconception health promotion is women from menarche to menopause, who are capable of having children, even if they do not intend to conceive' (CDC, 2006, p. 9). The inclusion of women who have no intention to conceive is based on the off-chance that, despite these intentions, they will in fact become pregnant. This position shifts the focus of care to a non-existent population of putative, yet-to-be conceived, future possible people. These possible people are positioned as needing protection against risks associated with the way that existing people – for the most part, women – live their ordinary lives. Such sweeping risk avoidance strategies are, I suggest, unwarranted. When concerns about women with diabetes, asthma and obesity, for example, are justified by emphasizing their potential harms to future embryos not to the existing health concerns of women, something very problematic is happening. Furthermore, when women are encouraged to live their lives to ensure 'healthy' embryos, rather than to ensure their own health and happiness, the implicit message is that the life not yet created has greater value than that of the woman herself.

Even in the context of intended conception, the idea of 'preconception care' relies on assumptions about what constitutes a 'risk' and what constitutes 'health' that needs to be further investigated. I turn to this task now.

What constitutes a 'healthy' embryo is not uncontroversial. The concept of a healthy embryo has become the subject of intense debate in recent times within both reproductive medicine and law (please refer to Mykitiuk and Nisker, Chapter 9). Considering the growing interest and investment of time and money in embryo-testing technologies, it is not surprising that pre-pregnancy or preconception healthcare to ensure the conception of 'healthy embryos' has also become a focus. For example, The *Australian Doctor* magazine describes an emphasis on 'preconception healthcare' as involving 'assessing the level of

risk of an adverse reproductive outcome in women or couples' (Cotterell, 2004, p. 35). However, what constitutes an adverse reproductive outcome needs to be more clearly articulated. Furthermore, the degree of risk that the outcome will occur also needs to be addressed. Instead, routinization and normalization of risk aversion relies on the assumption of a shared understanding of 'health' and a community in consensus about which outcomes must be avoided at all costs. This scenario is, however, far from the case. Disability critiques such as those offered by Asch and Wasserman (please refer to Chapter 14) and Gedge (please refer to Chapter 16) challenge assumptions made about desirable and undesirable health outcomes in the context of selecting and deselecting embryos. Furthermore, risk avoidance is not universally adhered to as a self-evident good. Many women choose to have children despite their own ill-health or without regard to constraining lifestyle advice. Some women decide to conceive knowing that they may pass on a hereditary condition, and many will continue a pregnancy in which a disability has been detected. Other women decide, in the in vitro fertilization (IVF) context, to implant an embryo that has tested positive for an anomaly via preimplantation genetic diagnosis (PGD) (Karpin, 2007). Unless we embark on a more nuanced and complex account of both risk and health, all of these women could be considered failed targets of preconception intervention, or worse, negligent and susceptible to legal claims for preconception torts.

'Preconception care', which, as we have seen, is in some measure directed at controlling the behaviour of women, has the potential therefore to diminish the legal and moral status of women as persons by prioritizing care for the non-existent preconceived embryo. But it is not all bad. Many of the initiatives set out in the CDC report can lead to better health outcomes for women generally, especially in the United States where healthcare provision is dependent on economic status. The CDC recommendations, for instance, discuss disparities in care, noting 'approximately 17 million women lack health insurance and are likely to postpone or forgo care' (CDC, 2006, p. 13). The report goes on to describe how lack of health insurance is more prominent among minority groups and those of lower socio-economic status (CDC, 2006, p. 5).

Although the CDC report has as its seventh recommendation the provision of health insurance coverage for women with low incomes, some argue the CDC approach to health is driven by a desire to create 'healthy babies' rather than healthy women. January Payne (2006, p. 2) reports Merry-K. Moos, a professor in the University of North Carolina's maternal fetal medicine division, who sat on the CDC advisory panel, as saying 'Healthier women have healthier pregnancies.' What seems to be going on here, then, is that women's bodies are identified as potential environments for the deployment of publicly desired health outcomes for a future population not yet conceived. Thus, women's health is tied to an expectation that they will make a sacrifice for the greater good.

Robin Mackenzie (2007, p. 307) describes a phenomenon whereby the deployment of what she calls 'sacralised images' 'permits the removal of salient decisions from their social context'. In the case of preconception health, the sacralized image is that of the healthy embryo as preconceived. This image justifies the provision of healthcare resources for women where otherwise no such resources would have been provided. In this way, and despite the CDC's attention to social determinants of health, concern for the health of the woman who might one day become pregnant is decontextualized from its likely social framework of poverty, lack of health insurance and lack of medical care more generally and is, instead, displaced onto the more morally value-laden and significantly less economically costly health of the embryo – even as it is yet to be conceived. It is worth recalling here that

recommendation one of the report is aimed at requiring 'individual responsibility across the lifespan' (CDC, 2006, p. 9), including being aware of both social risks and biomedical causes of ill health. To this end, the report notes the importance of a reproductive life plan for 'young women and couples' (CDC, 2006, p. 9). Notably, men are not singled out for a separate life plan.

The idea that women should begin preparation for a 'healthy' baby from the moment they pass through puberty suggests a world in which risk avoidance strategies are the guiding ethical principle. Mackenzie (2007, p. 308) cites the reduction of 'ethical discussions to calculations of risk, benefit and profit' as another example of the process of purification or decontextualization. In the context of preconception care, the strategy of shifting responsibility to the individual to avoid risk of harm to future possible people has a threefold effect. First, it displaces discussion away from individual well-being and health to possible harm to future individuals yet to be conceived – in other words, the focus becomes taking care of the health of the preconceived embryo. Second, it creates new obligations of risk avoidance that may involve radical lifestyle and behavioural changes; genetic tests where none would have been undertaken previously; decisions not to conceive where otherwise no such decision would have been made; and decisions to avoid a particular disorder or disease where its seriousness is either unproven or socially constructed. Third, it insists on a shared agreement about which 'risks' are to be guarded against and creates the potential for expectations that women will act in ways that prevent the conception of certain kinds of embryos designated 'unhealthy' without an adequate interrogation of that designation. In the context of genetics for instance, Nikolas Rose has argued that:

> In advanced liberal democracies ... genetics takes its salience within a political and ethical field in which individuals are increasingly obligated to formulate life strategies, to seek to maximize their life chances, to take actions or refrain from actions in order to increase the quality of their lives, and to act prudently in relation to themselves and to others.
>
> (Rose, 2006, p. 107)

The assumption is that in the non-genetic context, the obligation on women and parents to act 'prudently' would include decisions not to take certain reproductive risks. The human being who is 'genetically at risk' in Rose's account is the one already in existence (Rose, 2006). But, in the context of preconception healthcare, the at-risk human may be the putative child imagined as the preconceived embryo. What, then, does the responsibility to act prudently contain?

Abby Lippman describes 'the framing of natural experiences as causes of future diseases' as part of a new emphasis on risk management. She says 'the emphasis is on one's supposed risk of developing a problem, and in its most pernicious form, it makes being "at risk" itself a disease state' (Lippman, 2006, p. 18). Lippman goes on to explain a phenomenon she calls 'neomedicalization', which she describes as growing out of 'the current emphases (in North America) on "risk" and its management, and on individual "choice" and the offer of multiple "options" to women' (2006, p. 18). Of the 62 million women of child-bearing age in the United States who, the CDC guidelines suggest, will benefit from the 'multistrategic', 'action-oriented' initiatives, 17 million of these women are without health insurance (CDC, 2006, p. 13). Therefore, in more cynical moments, the remaining 45 million women could be viewed as offering an enormous opportunity for commercial growth. Lippman, for instance, argues that what she calls neomedicalization 'constructs health as a commodity, a resource needed for economic growth' (Lippman, 2006, pp. 18–19) and that 'by framing life

experiences as causes of disease, neomedicalization generates a whole "Selling Sickness" industry to create "pills for prevention"'. She says:

> Given that there are more healthy than diseased people in the world, offering a product that is claimed to help manage their risks can capture increasing numbers of those in need of some treatment. Finding the 'not-yet-sick' and the 'worried well', who could be offered some drug or device, is the goal.
>
> (Lippman, 2006, p. 19)

Although I am not suggesting that this is the motivation behind the CDC recommendations or other preconception care initiatives, it is important to consider the implications of conflating risk and disease and avoidance of risk and the production of health.

One way to throw this issue into a stark light is by looking back from the perspective of the individual who does exist in the world and who claims to have been subject to preconception harm. To do that, I want to turn to the complex arena of the so-called 'preconception' tort.

II. Preconception torts

In the second part of this chapter, I examine the idea of 'preconception harm' as a strategy for ensuring that negligent and harmful acts that cause damage to future conceived children are remediable. At the same time, I examine the line between the attribution of harm and the responsibility for care in the body of the woman who will eventually carry the embryo to term.

A preconception tort is a claim by a child born alive for damages from a negligent act that took place prior to that child's conception and resulted in harm to that child. This kind of claim has been recognized in case law in Australia and the United States and has been enacted into statute in the United Kingdom. The case law is patchy and, in some jurisdictions, confusion persists about the nature of this claim as compared with the less successful claim of wrongful life. A wrongful life claim is typically brought by a child claiming that he or she has been wrongfully given life. Although the claim is usually described as the wrong of being given life, John K. Mason (2007, p. 189) argues that a more accurate description would be the wrong of being 'alive and suffering as a result of another's negligence'. A preconception tort, however, is a more general claim for damage caused by acts that took place prior to conception and that have led to a disabled life. Although the issue of causation in a preconception tort will turn on the facts, the question of who owes a duty of care to a child prior to its conception raises more fundamental questions. Mason (2007, p. 196) asserts there is at least an arguable case 'that the physician attending a pregnant woman also owes a recognisable duty of care to her fetus', whereas it is harder to argue the same in relation to a yet-to-be-conceived entity:

> Thus, while a significant relationship between the fetus and its mother's physician may yet be regarded as uncertain, it will certainly be far more difficult to establish a proximate relationship giving rise to a duty of care between the healthcarer and a non-existent being.
>
> (Mason, 2007, p. 197)

However, in a number of cases, courts in Australia and the United States have found both causation and a duty of a care for preconception acts.

The cases

In Australia, the concept of preconception harm dates back to the 1982 case of *Kosky v. The Trustees of the Sisters of Charity* (1982). In this case, Tadgell J. of the Supreme Court of

Victoria held that a duty of care was owed by a hospital to a child with respect to a blood transfusion administered to his mother eight years before the child's conception. A further development of the claim occurred in the 1991 case of *X v. Pal and Others* (1991). In this case, the New South Wales Court of Appeal held that doctors owed a duty of care to a child born deformed and suffering from syphilis, when they failed to screen the child's mother for syphilis when she was pregnant with her previous child. Stewart and Stuhmcke describe this as a clear recognition in tort law of 'the rights of the unborn not to be injured' and as providing 'a remedy after birth, for harm occurring before birth caused by negligent acts before birth or even before conception' (Stewart and Stuhmcke, 2008, p. 59).

More recently, the High Court of Australia has considered and rejected a wrongful life claim brought by the parents of a child conceived via IVF (*Waller v. James; Waller v. Hoolahan* (2006)). In this case, the doctors were aware that the father had a condition known as anti-thrombin 3 (AT3) but failed to warn the parents prior to the use of IVF with cytoplasmic injection that the child had a 50% chance of inheriting the father's condition. The parents stated that, had they been informed of this risk, they would not have conceived the child in question, but instead would have either used donor sperm or waited for a test that could identify embryos without the condition. Although this situation seems to fall within the category of preconception negligence, the claim was nevertheless brought as a wrongful life claim and failed. The court has been consistently unwilling to entertain a claim for wrongful life because in the view of the majority of the court, 'being born' cannot constitute damage.[2]

The claims for preconception negligence that have been successful in Australia have to date only been claims against third-party healthcare providers. Based on earlier judicial commentary a claim for preconception negligence would not likely be successful against a mother. There is precedent in Australia recognizing maternal liability for harm suffered while in utero due to negligent driving (*Lynch v. Lynch*, 1991; *Bowditch v. McEwan*, 2002), however the court has made it clear that the duty owed by a mother to her child in utero is limited to negligent driving. Stewart and Stuhmcke describe the court in *Lynch v. Lynch*, for instance, as 'keen to confine the mother's duty to her unborn child to the situation of negligent driving so as not to make the mother liable to her child for other acts during pregnancy' (Stewart and Stuhmcke, 2008, p. 58). This view accords with the British approach, which specifically exempts mothers from liability for prenatal and preconception harms under the Congenital Disabilities (Civil Liability) Act 1976 (UK), apart from acts of negligent driving for which they can be held liable.

In the United States, a similar slippage has occurred between preconception claims and wrongful life claims, although the US courts have recognized preconception tort claims in a number of States going back as far as the 1970s (Bourne, 2001). In examining the claim for preconception harm as developed in the various States, Mason (2007, p. 197) argues that 'one cannot help feeling that the class of "potential child" should be regarded as too wide and too remote a basis on which to found such a legal duty on the individual physician'. He does, however, consider that it may not be too broad to expand the duty to 'the next affected child, or any other child' that the couple may have (Mason, 2007, p. 197).

The US case of *Hegyes v. Unjian Enterprises* (1991) directly addresses the scope and necessity of a duty. Insisting that a duty must be found, the court stated that to rely on

[2] This case was heard at the same time as another wrongful life claim, *Harriton v. Stephens* (2006), where the doctor failed to diagnose a rubella infection during pregnancy.

causation alone would allow for the possibility that the claim could 'go forward to eternity and back to the beginning of the world'. In this case, the question before the court was whether a motorist owed a duty to the not-yet-conceived child of a woman injured two years prior to the birth. Injuries sustained by the mother in the car accident as a result of the defendant's negligence were argued to have contributed to a premature labour and the birth of a child with significant disabilities.

The court held at [5]:

> In a preconception tort case, as in any negligence case, there is an overwhelming need to keep liability within reasonable bounds and to limit the areas of actionable causation by applying the concept of duty. In a nonmedical preconception negligence case where there is no alleged 'special relationship', it becomes more difficult to find a legal duty owed to the minor child and, hence, liability on the part of defendant. It cannot be said that, under the facts presented, defendant motorist owed a legal duty to plaintiff.

And later at [10]:

> A motorist cannot reasonably foresee that his or her negligent conduct might injure a child subsequently conceived by a woman several years after a car accident.

The court was at pains to draw a distinction between a motorist and a healthcare provider, who, it could be argued, has a special relationship with patients, such that a duty of care might exist for a subsequently conceived child. This situation prompts the question, what other special relationships might exist that give rise to such a duty? One such possible relationship is, of course, the relationship between parent and child. Although cases attributing a duty to a woman whose preconception acts harm her own subsequently conceived embryo do not exist in Australia and are rare in other jurisdictions, in fact, no clear legal ground prohibits such a claim.

Kirsten Smolensky (2008) argues, for instance, that 'parental tort liability is possible where parents intentionally engage in direct genetic interventions designed to create a child with a disabling trait' through manipulation or modification of the existing DNA of an embryo. However, she discounts their liability in relation to what she calls 'indirect pre-implantation genetic interventions, such as PGD' because simply choosing an existing embryo with a disability does not harm the identity (or person) that comes into being as they were already destined to have the disability.[3]

Alicia Ouellette, in responding to Smolensky's thesis, does not challenge the claim for parental liability but rather challenges her easy use of the language of harm as it relates to physical disability. She wants to complicate the claim that harm is self-evident where a physical disability is manifest. She states:

> A central tenet of disability studies is the rejection of the medical model of disability as a foundation for effective understanding of impairment or disability. The medical view of disability ... treats the individual as deficient and inherently inferior because she falls below an arbitrary physiological standard that delineates social acceptance and that can only be 'normalized' and incorporated into society through a medical cure.
>
> (Ouellette, 2008) (footnotes omitted)

Ouellette goes on to suggest that modifications that would not immediately be classed as disabilities may nevertheless be equally harmful:

[3] For critiques of her argument see Ouellette (2008) and King (2008).

> Consider, for example, a child born after her DNA was modified so that she would have white skin instead of the dark skin that would have manifested had she grown up with unaltered DNA. Consider another child whose genes were modified to turn him from gay to straight.
> (Ouellette, 2008)

Clearly, then, the idea of preconception negligence does presume some level of consensus about the nature of the damage that follows from the negligent act and to this extent controversy will emerge, particularly where a medical model of disability is adhered to rather than a social model. However, the question that I wish to focus on is whether, where parental action is involved, a different set of criteria for liability should be applied. The kinds of parental action I am thinking of include actively modifying an embryo's DNA (should it become permissible to do so) as suggested by Smolensky and Oullette; selecting in favour of rather than against an embryo with a disability; or engaging in risky preconception behaviour that results in harm to a later conceived child. I want to suggest that a strong argument supports treating parental action or inaction differently from harmful action or inaction by third parties. There may also be scope for a particular class of claims where the act or omission was done by a healthcare provider.

An example of such an approach is found in the UK Congenital Disabilities (Civil Liability) Act 1976. Under section 1(1) of the Act, a person other than the mother of the child will be liable for causing a child to be born disabled as a result of an act that occurred before its birth either by affecting the mother during her pregnancy or affecting either parent's capacity to have a 'normal, healthy child.' By virtue of subsection 4 however:

> In the case of an occurrence preceding the time of conception, the defendant is not answerable to the child if at that time either or both of the parents knew the risk of their child being born disabled (that is to say, the particular risk created by the occurrence); but should it be the child's father who is the defendant, this subsection does not apply if he knew of the risk and the mother did not.

New section 1(4A) includes in the definition of father in subsection (4) a woman who is a parent by virtue of sections 42 or 43 of the Human Fertilisation and Embryology Act 2008. These sections refer to situations where instead of a father, a second woman is a co-parent with the mother. Section 1A also extends the Act to cover infertility treatments where the disability is caused by 'an act or omission in the course of the selection, or the keeping or use outside the body, of the embryo carried by [the woman] or of the gametes used to bring about the creation of the embryo'. Liability therefore accrues unless the mother knew at the time of implantation or insemination of the risk of the child being born disabled. In the United Kingdom, then, the legislature has specifically excluded mothers from potential liability for such harms. The Act does not, however, exempt the mother from tort liability for prenatal negligence in the case of negligent driving (section 2).

The contemporary growth in assisted reproduction technologies would, one has to think, give rise to a whole new generation of claims including those made in relation to failed PGD and other forms of preimplantation technology and testing.[4] Apart from the kinds of harms described above, Goldberg (2007, p. 260) has identified a further group of potential claims under the rubric of what he calls preconception genetic torts. However, where the harm is to the chromosomal integrity of the mother or her gametes, a more complex calculation of causation, duty and harm arises. Goldberg (2007, p. 260) describes:

[4] A couple recently initiated a claim against an IVF clinic in Australia for failure to detect a cancer gene using PGD and IVF (Hudson, 2008).

a host of complicated questions that arise in the preconception genetic tort paradigm, including: (1) is chromosomal breakage a legally compensable injury in and of itself, or must an attendant syndrome or condition manifest to constitute a legally compensable injury? (2) Should the extent of the relief be limited to injuries resulting from developments prior to conception? (3) What relief should be granted where chromosomal breakage occurs during preconception, but where the genetic syndrome is multifactorial and only develops *in utero* (4) Is increased risk of cancer due to a preconception mutagen a legally compensable injury? (5) Who may sue? The Mother? The Child? The grandchildren of the mother? The great grandchildren? (6) Will it be impossible to prove that but for a defendant's negligence, a child would not have been born with chromosomal alteration or subsequent genetic disorders? (7) Should fears of multigenerational liability justify courts in denying preconception tort actions based on an analysis of proximate cause? (8) Should fears of the growing relevance of an individual's private genetic information to a personal injury action justify courts in denying the viability of preconception genetic torts?

The Canadian *Brave New World* report adds further complex issues to the mix. This report suggests that if claims for preconception torts become acceptable, a collateral right may emerge to be born free of genetic disabilities that may give rise to an obligation to provide preconception and PGD screening where 'there is a known risk of passing a genetic disease to a child' (Government of Canada, 2005, p. 3.33). Although there do appear to be limits to liabilities attaching to parents for their preconception behaviour, where the gametes are outside the bodies of the parents and the resulting embryo is in vitro, the Brave New World report asks whether this situation would give effect to a right not to be born with a genetic condition. This question is posited on the basis that because the gametes are outside the mother's body, there is no conflict with her rights (Government of Canada, 2005, p. 3.35). Even where the gametes are inside the body, however, whether women or men can be protected from claims for harm by putative children when born alive is unclear, unless a distinct line is drawn distinguishing parental preconception behaviour and harm from harm or injury caused by others. The *Brave New World* report, for instance, suggests that Article 24 (1) of the UN Convention on the Rights of the Child (CRC) that provides that State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health could be relied on 'to support an argument that children have a right to be born in the best possible state of health' (Government of Canada, 2005, p. 3.38). The report notes that although the 'duty would be to a future person, this approach accords with that already taken by the court in preconception tort claims, where the physician has a duty of care, when treating the woman, to any future children as well' (Government of Canada, 2005, p. 3.38).

Conclusion

In this chapter, I have traced the way in which the ideas of preconception health and preconception harm generate new medical and legal risks and responsibilities. In the case of preconception health, I have argued that initiatives that assign women responsibility for ensuring the production of future conceived healthy embryos by targeting their lifestyle and behaviours prior to conception even where they have no intention to conceive, overreach appropriate public health goals and result in a displacement of social goods away from women for their own sake and onto the entity I have termed the preconceived embryo. In the case of preconception harm, I have suggested that parents whose preconception acts cause harm to their future conceived embryos should not be considered negligent if those acts were in the ordinary course of their everyday lives.

Throughout the chapter, I have also traced a second, overarching line of inquiry that examines the question of what constitutes a risk and what constitutes health. Preconception

health as it relates to pregnancy outcomes aims to ensure that when conception occurs it occurs in a way that will optimize the health of the embryo conceived and, by extension, the future child. However, what constitutes a healthy embryo and a healthy child is by no means uncontroversial. In addition, there is a related assumption, that all women (and to a lesser extent men) should act, throughout their fertile lives, to avoid risks to the health of future progeny. This assumption has implications for women who choose to have disabled children or non-normative children defined by health providers and the courts as 'unhealthy.' Williams, Anderson and Farsides (2001, p. 226) argue 'the combination of technocratic emphasis on the baby-as-product and the development of technologies to assess fetal quality... has led to strong focus on the production of what has been termed the "perfect baby", with pregnant women being described as "genetic gatekeepers"'. A similar process occurs in the context of preconception healthcare initiatives, such as those put forward by the CDC. Women are targeted at earlier and earlier points in their reproductive life cycle to ensure that future pregnancy outcomes result in 'healthy babies'. In this sense, they are seen as gatekeepers of familial health even when they have yet to formulate an interest in forming a family of their own.

Risk avoidance strategies that are undertaken long before a baby has even been thought about, let alone conceived, and the willingness to attribute qualities of health to non-existent entities such as the 'preconceived embryo' through preconception healthcare must be questioned for their potential to implicate women in legal claims for negligent behaviour. In Australia, the courts have not been asked to adjudicate on the question of parental negligence preconception; however, there appears to be no legal impediment for such a claim. In the United States, the courts have been similarly unclear about whether such a legal claim would be actionable, whereas in the United Kingdom a clear preference has been legislated exempting mothers from claims for preconception and prenatal negligence, other than in the case of negligent driving. Notably fathers are not exempt under the UK legislation.

A regulatory system based on assessments of risk and benefit to future possible children at the preconception stage has the potential to lead to narrow and discriminatory assessments of health and to create burdens on those least able to meet them. As the CDC report notes, the women least likely to access healthcare are from low socioeconomic backgrounds (CDC, 2006, p. 4). Yet, a public health campaign to educate men and women about preconception health and risks to future progeny preconception that targets women from their first menstrual period to the onset of menopause creates responsibilities (moral and possibly legal) to an entity that is not yet (and maybe never will be) even conceived.

Throughout this chapter, my aim has been to show how the concept of preconception care and harm can too easily shift our focus away from healthcare concerns relating to existing people – men and women – in favour of initiatives to protect the health of non-existent future possible people. Although both women and men clearly need medical guidance and support in their reproductive decisions pre and post conception, I argue that such support should be framed around the needs and interests of the existing individuals and not based on future possible outcomes for future possible people.[5]

[5] I have argued similarly in relation to the regulation of ex utero technologically produced embryos that the embryo ought to be replaced as the central figure in legislation with the not-yet-pregnant pregnant woman. This figure is distinct from what January Payne (2006) has described as a coerced state of pre-pregnancy for all women of child-bearing capacity coming out of the CDC guidelines; whereas the CDC targets all women whether they want to become pregnant or not, my concept of the not-yet-pregnant pregnant woman relies on the woman's self-presentation as actively seeking pregnancy but who is not yet pregnant (Karpin, 2006).

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The 'Healthy' Embryo

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Edited by Jeff Nisker, François [illegible]
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Contents

Preface

Characterizations of both 'health' and of the human embryo, and how both should be created, vary considerably among and within investigative, clinical and social communities. Thus, when characterizations of 'health' and of the human embryo are taken together, the complex and controversial entity of a 'healthy' (or 'unhealthy') human embryo emerges. The increasing capabilities in genetic science and reproductive technology, and their potential clinical usages, have at the same time inspired hope for the new era of regenerative medicine and raised concern as to the strategies that are increasingly being developed to promote the perceived 'health' of a child not yet born or gestated (or even conceived). Exploring the concept of a 'healthy' embryo serves as a focal point from which disparate views emerge and are aired. Understanding what a 'healthy' embryo means to people with different perspectives opens discussion among researchers, scholars, clinicians and members of the general public. The results of these discussions may assist the regulators hurrying to catch up with the scientists by providing a framework that supports the benefits to the individual of genetic and reproductive science, while promoting the collective good.

To open this discussion, *The 'Healthy' Embryo: Social, Biomedical, Legal and Philosophical Perspectives*, brings together researchers and scholars from five countries and twelve disciplines to focus their methodologies, scholarship, and insights on the concept of a 'healthy' embryo, including how such a concept may shape and be shaped by conceptions of the health of children and adults. The authors bring their own perspectives on the 'healthy' embryo from the fields of philosophy, ethics, law, genetic and reproductive science, sociology, critical disabilities studies, women's studies, cultural studies, medicine, history, art history and health policy.

Section I focuses on the question of what is a human embryo, drawing on historical, social, and legal perspectives, and in light of twenty-first-century assisted reproduction and embryo research. Section II examines the recently developed entities that are 'humanesque embryos' and explores whether these entities should be considered human embryos. Section III investigates the reasons for and impacts of using 'healthy' as a characterizing term applied to human embryos. Section IV examines research using human (and 'humanesque') embryos, particularly the considerations that should precede but currently result from using 'healthy' human embryos for research purposes. Section V shifts the focus to reproductive purposes and explores the concept of 'healthy' (or 'unhealthy') embryos in regard to having a 'healthy' child. Authors in each section of the book enlist and contribute to insights in other sections.

This Preface presents the scope of the book, which is long in temporal consideration and broad in both subject area explored and perspectives of the investigators. It also describes how the book came into being, which in itself reflects how genetic and reproductive science and their clinical uses may precede ethics, social and legal research on the science being explored, as well as why genetic and reproductive scientists should participate step by step in research teams with investigators and scholars of several other disciplines. The Preface concludes with brief summaries of each chapter.

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Adrienne Asch PhD, MS is Director of the Center for Ethics at Yeshiva University, New York and the Edward and Robin Milstein Professor of Bioethics at Yeshiva University. She also holds an appointment in the Division of Bioethics of the Montefiore Medical Center and the Departments of Family and Social Medicine and Epidemiology and Population Health at Albert Einstein College of Medicine. She previously taught at Wellesley College, where she was the Henry R. Luce Professor in Biology, Ethics, and the Politics of Human Reproduction. Her work focuses on the ethical, political, psychological and social implications of human reproduction and the family. She has authored numerous articles and book chapters, and is the co-editor of *Prenatal Testing and Disability Rights* and *The Double-Edged Helix: Social Implications of Genetics in a Diverse Society*. She received her doctorate in social psychology from Columbia University, was a member of the board of the American Society for Bioethics and Humanities, the Clinton Task Force on Health Care Reform, and the Ethical, Legal, and Social Implications Policy Planning Group of the National Human Genome Research Institute. Dr. Asch is a newly elected board member of the American Civil Liberties Union and was recently appointed to the New York State Task Force on Life and the Law. Currently, she is a board member of the Society of Jewish Ethics and a fellow of the Hastings Center.

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Elisabeth Gedge PhD is an Associate Professor and the Chair of the Department of Philosophy at McMaster University in Hamilton, Ontario, Canada. Her primary areas of research interest and teaching are feminist bioethics, philosophy of law and philosophy of religion. Arriving at McMaster in 1991, Elisabeth has been active in the ethics community, having served for many years on the Hamilton Health Sciences Clinical Ethics Committee and the McMaster Research Ethics Board. She has been a member of several grants committees of the Canadian Institutes of Health Research, is a member of the editorial board of *Dialogue*, the journal of the Canadian Philosophical Association, and is a member of FAB, the Feminist Approaches to Bioethics Network. For over a decade Elisabeth's research has explored issues of equality and autonomy at the beginning and end of life, from an investigation of collaborative decision-making for persons with dementia to the impact of practices such as sex selection, contract pregnancy and prenatal testing on women's reproductive autonomy and status. Keenly interested in the overlap between legal and ethical concepts, she is currently investigating the 'turn to dignity' in contemporary jurisprudence and questioning the role this new discourse might play in women's liberatory understandings and strategies. Recent publications include: 'Symbolic harms and reproductive practices', in *Current Legal Issues 3: Law and Medicine*, eds. M. Freeman and A. Lewis. Oxford: Oxford University Press, 2000, pp. 327–340; 'Privacy, property and the family in the age of genetic testing: observations from transformative feminism', *Journal of Social Philosophy*, 33(3), Fall, 2001, 301–316; 'Collective moral imagination: making decisions for persons with dementia', *Journal of Medicine and Philosophy*, **29**(4), 2004, 435–450; 'Withholding and withdrawing life support in critical care settings: ethical issues concerning consent', Gedge E. (lead author), Giacomini M., Cook D., *Journal of Medical Ethics*, 33, 2007, 215–218.

Isabel Karpin BA/LLB LLM JSD is a Professor in the Faculty of Law at the University of Technology, Sydney. She teaches and researches in the areas of Health Law, Bioethics, Reproduction and the Law, Feminist Legal Theory, Law and Culture and Constitutional Law. Her particular focus has been laws that can broadly be described as regulating bodies. This includes laws governing reproductive technologies, biotechnology and genetic technologies and the challenges these pose to legal understandings of normality, disability, individuality, and family. She is currently involved in several major research projects in the areas of reproductive technology, disability and emergent genetic technologies including two Australian Research Council Grants: *The Legal Function of 'Serious Disability' in Prenatal and Neonatal HealthCare Settings* and *Enhancing Reproductive Opportunity in Australia: Reconsidering Consent, Altruism and the Legal Status of Embryos in ART Processes.* She is the author and co-author of a number of articles and book chapters including most recently 'The meaning of "serious disability" in the legal regulation of prenatal and neonatal decision-making', *Journal of Law and Medicine*, 16, 2008, 233–245 (with K. Savell); 'The uncanny embryos: legal limits to the human and reproduction without women', *Sydney Law Review*, 28 (4), 2006; and 'Genetics and the legal conception of self,' in *Ethics of the Body: Postconventional Challenges*, eds. Roxanne Mykitiuk and Margrit Shildrick. Cambridge, MA: MIT Press, 2005. Her book *Perfecting Pregnancy: Law, Disability and the Future of Reproduction* (with K. Savell) will be published soon by Cambridge University Press.

Jane Maienschein PhD is Regents' Professor, President's Professor and Parents, Association Professor at Arizona State University, where she is Director of the Center for Biology and Society. She specializes in the history and philosophy of biology and the way that biology, bioethics and biopolicy play out in society. Focusing on research in embryology, genetics and cell biology, Maienschein combines detailed analysis of the epistemological standards, theories, laboratory practices and experimental approaches with study of the people, institutions and the changing social, political and legal context in which science thrives. She is committed to teaching effectively and to public education about the life sciences and their human dimensions, and has won the History of Science Society's Joseph Hazen Education Award and all of Arizona State University's major teaching and other distinguished faculty awards. She served as co-editor of the *Journal of the History of Biology*, co-chair of the 2004 Gordon Conference on Science and Technology Policy, and has served as president of the History of Science Society and the International Society for History, Philosophy, and Social Studies of Biology. Her three books and 12 (co-)edited books include *Whose View of Life? Embryos, Cloning, and Stem Cells* (Harvard University Press, 2003 and 2005) and *From Embryology to Evo-Devo*, edited with Manfred Laubichler (MIT Press, 2007).

Carolyn McLeod PhD is Associate Professor and Graduate Chair in the Department of Philosophy at the University of Western Ontario. She also holds a cross appointment with Women's Studies and Feminist Research. Professor McLeod does research and teaches courses in reproductive ethics, moral psychology, feminist theory and the philosophy of race. The trajectory of her career is as follows. She did a BA (1992) and MA (1995) in philosophy at Queen's University, and a PhD (1999) at Dalhousie University under the supervision of Susan Sherwin. Her postdoctoral work (1999–2000) took place at the Bioethics Center, University of Minnesota and at Western, with funding from Minnesota and from the Social Sciences and Humanities Research Council of Canada (SSHRC). In 2001–2, she was Assistant Professor of Philosophy at the University of Tennessee, Knoxville. And from 2004 to 2006, she was a Lupina New Faculty Fellow in the Comparative Program on Health and Society at the Munk Centre for International Studies, University of Toronto. Professor's McLeod publications include her book, *Self-Trust and Reproductive Autonomy* (MIT Press, 2002) and numerous articles on the nature of different moral concepts (e.g., autonomy, integrity and objectification) or on practical issues in reproductive ethics (e.g., miscarriage, embryo and oocyte donation, contract pregnancy). The following are some of her recent publications: McLeod, C., ed., *Understanding and Protecting Reproductive Autonomy*, special issue of *Bioethics*, 32(1), 2009; McLeod, C., 'Referral in the wake of conscientious objection to abortion', *Hypatia: A Journal of Feminist Philosophy*, 23(4), 2008, 30–47; McLeod, C. and J. Ponesse, 'Infertility and moral luck: the politics of women blaming themselves for infertility', *International Journal of Feminist Approaches to Bioethics*, 1(1), 2008, 126–144; Baylis, F. and C. McLeod, 'The stem cell debate continues: the buying and selling of eggs for research', *Journal of Medical Ethics*, 33(12), 2007, 726–731.

Lianne McTavish PhD is Professor in the History of Art, Design, and Visual Culture at the University of Alberta, where she offers courses in early modern visual culture and critical museum theory. Lianne has received three SSHRC Standard Research Grants, as well as grants from the Hannah Institute for the History of Medicine and Canada Council for the Arts. Her interdisciplinary research, informed by her graduate degrees in Visual and Cultural

Studies, has centred on early modern French medical imagery, including articles in *Social History of Medicine* (2001), *Medical History* (2006), and a monograph, *Childbirth and the Display of Authority in Early Modern France* (2005). Her recent work in this area analyses representations of cure and convalescence in France, 1600–1800. Lianne has also published on the history and theory of museums: in *Cultural Studies* (1998), *Acadiensis* (2003), *New Museum Theory and Practice: An Introduction* (2005) and the *Canadian Historical Review* (2006), which was awarded the CHR prize for 2006. She is currently completing a book manuscript, *Between Museums: Exchanging Objects, Values and Identities, 1842–1950*. As an associate curator at the Beaverbrook Art Gallery from 2003 to 2007, Lianne has curated and written the catalogues for a number of exhibitions of contemporary art.

Roxanne Mykitiuk BA LLB LLM JSD is an Associate Professor of Law at Osgoode Hall Law School, York University, Toronto, where she teaches in the areas of Health Law and Bioethics, Children and the Law, Law and Disability and Family Law. She is the author or co-author of a number of articles and book chapters investigating legal, ethical and social implications of new reproductive technologies and the new genetics and the legal construction and regulation of embodiment and disability. She is also the co-editor with Martha Fineman of *The Public Nature of Private Violence* (Routledge, 1994), the co-editor with Margrit Shildrick of *Ethics of the Body: Rethinking the Conventions* (MIT Press, 2005) and the co-author with Trudo Lemmens and Mireille Lacroix of *Reading the Future: Legal and Ethical Challenges of New Predictive Genetic Testing* (Les Editions Themis, 2007). From 1990 to 1992 she was Senior Legal Researcher for the Royal Commission on New Reproductive Technologies. In 2002 she was appointed to the Ontario Advisory Committee on Genetics. Her most recent publications include: 'The Canadian Assisted Human Reproduction Act: protecting women's health while potentially allowing human SCNT into non-human oocytes', co-authored with Jeff Nisker and Robyn Bluhm, *American Journal of Bioethics*, 7(2), 2007; 'Sites of exclusion: disabled women's sexual and reproductive rights', co-authored with Ena Chadha, in Lee Ann Basser, Melinda Jones and Marcia Rioux (eds.), *Critical Perspectives on Human Rights and Disability Law*, Martinus Nijhoff, Brill Publishers (forthcoming); 'Regulating inheritable genetic modification or policing the fertile imagination: a feminist response', co-authored with Isabel Karpin, in John E. J. Rasko, Gabrielle O'Sullivan and Rachel Ankeny (eds.), *Exploring the Ethics of Germ-Line Gene Therapy*, Cambridge: Cambridge University Press, 2006; 'Prenatal diagnosis and pre-implantation genetic diagnosis: legal and ethical issues', co-authored with Stephanie Turnham and Mireille Lacroix, in Neil F. Sharpe and Ron Carter (eds.), *Genetic Testing: Care, Consent and Liability*, New York: JohnWiley, 2006; and 'Now you see her, now you don't: how law shapes disabled women's experience of exposure, surveillance and assessment in the clinical encounter', co-authored with Catherine Frazee and Joan Gilmour, in Dianne Pothier and Richard Devlin (eds.), *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law*, Vancouver: University of British Columbia Press, 2005. Professor Mykitiuk holds a number of current research grants funded by SSHRC, CIHR and Genome Canada.

Jeff Nisker MD PhD FRCSC FCAHS is a Professor of Obstetrics–Gynaecology and Oncology and Coordinator of Health Ethics and Humanities at the Schulich School of Medicine and Dentistry, University of Western Ontario. He holds Canadian Institutes of Health Research (CIHR) grants to investigate concepts such as 'health' and 'disease', particularly as they relate to preimplantation genetic diagnosis and prenatal genetic testing, and to study the use of theatre for citizen deliberation for health policy development, particularly regarding

ery, including articles in *Social* nonograph, *Childbirth and the* cent work in this area analyses)0. Lianne has also published on 1998), *Acadiensis* (2003), *New* he *Canadian Historical Review* ; currently completing a book *id Identities, 1842–1950.* As an) 2007, Lianne has curated and)orary art.

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reproductive and genetic technology. Jeff also holds a Genome Canada grant to explore meanings and understandings of terms used in genetic research. Jeff's national positions have included: Co-Chair of Health Canada's Advisory Committee on Reproductive and Genetic Technology; Scientific Officer of the CIHR Panel on Ethics, Law and Humanities; Editor-in-Chief of the *Journal of Obstetrics and Gynaecology Canada*; Chair of the Society of Obstetricians and Gynaecologists of Canada Ethics Committee; member of the CIHR Standing Committee on Ethics; Executive of the Canadian Bioethics Society; the National Council of Ethics in Human Research, Royal College of Physicians and Surgeons Ethics and Equity Committee and Health and Public Policy Committee. Jeff has written many scientific articles and book chapters as well as six plays. Recent publications related to this conference include: Nisker J. N., White A., Tekpetey F., Feyles V., 'Development and investigation of a free and informed choice process for embryo donation to stem cell research in Canada', *Journal of Obstetrics Gynaecology Canada*, **28** (10), 2006; Nisker J., White A. D., 'The CMA Code of Ethics and the donation of fresh embryos for stem cell research', Canadian Medical Association Journal, **173**(6), 2005; Mykitiuk R., Nisker J., Bluhm R., 'The Canadian AHR Act: protecting women's health while potentially allowing human SCNT into non-human oocytes', *American Journal of Bioethics*, 7(2), 2007; Nisker J., Martin D., Bluhm R., Daar A., 'Theatre as a public engagement tool for health-policy development', *Health Policy*, 78(2–3), 2006; Nisker J., Daar A. S., 'Moral presentation of genetics-based narratives', *Public Understanding of Science*, 15, 113–123, 2006. His plays exploring ethical issues in genetic testing and assisted reproduction have been performed throughout Canada, as well as in the United States, the United Kingdom, Australia and South Africa.

Rouven Porz DPhil is trained as a environmental biologist, with additional studies in philosophy and educational theory at the University of Saarbrücken, Germany. From 2002 to 2008 he worked as a PhD student, research associate and postdoctoral researcher at the Unit of Ethics in Biosciences, University of Basel. He held visiting scholarships at the University of Maastricht (The Netherlands), Geneva (Switzerland) and Newcastle-upon-Tyne (United Kingdom). Together with Jackie Leach Scully and Christoph Rehmann-Sutter he was involved in research projects focusing on bioethical issues in genetic testing, reproductive medicine, stem cell research and the methodology of empirical ethics. In the summer of 2008 he was appointed as the Head of the Unit of Ethics in the University Hospital of Bern, Switzerland. In addition, he is guest researcher at the Institute for Biomedical Ethics in Zürich, scientific representative of the Foundation Brocher in Geneva, board member of the Swiss Society for Biomedical Ethics and the editor of the EACME newsletter (European Association of Centres of Medical Ethics). His current research interest is in 'moral imagination and bioethics' (together with Dr. Kjetil Rommetveit, University of Bergen, Norway).

Radhika Rao AB JD is Professor of Law at the University of California, Hastings College of the Law in San Francisco, and served as Fulbright Distinguished Professor holding the Trento Chair in Law at the University of Trento, Italy, from March to July 2008. After receiving her AB in Physics and Chemistry from Harvard College and graduating *magna cum laude* from Harvard Law School, she clerked for Judge Richard Cudahy at the United States Court of Appeals for the Seventh Circuit and Justices Harry A. Blackmun and Thurgood Marshall at the United States Supreme Court. Professor Rao teaches and writes in the areas of biolaw, constitutional law, comparative constitutional law and property. She has been a visiting professor at Brooklyn Law School, the University of Michigan Law School

and the University of Trento, Italy. Professor Rao has written articles on abortion, assisted reproduction, cloning, stem cell research, genetics, gene patenting, and property versus privacy rights in the human body, some of which have been translated into Italian and Chinese. She was a member of the California Advisory Committee on Human Cloning and currently serves as a member of the California Human Embryonic Stem Cell Research Advisory Committee.

Christoph Rehmann-Sutter DPhil is Professor of Theory and Ethics of the Biosciences at the University of Lübeck in Germany. Born in 1959, he obtained a first training in molecular biology with a Diploma from the Biocenter at University of Basel, then a second training in philosophy and sociology at the Universities of Basel, Freiburg im Breisgau and the Technical University Darmstadt. In 1997–8 he joined the Department of Environmental Science, Policy and Management ESPM of the University of California at Berkeley as a Research Fellow. Together with Jackie Leach Scully, in 1996 he founded the Unit for Ethics in the Biosciences at the University of Basel. He has held Visiting Professorships at the London School of Economics and at Newcastle University. He was a board member and in 1999–2002 the President of the Swiss Society for Biomedical Ethics, and from 2001 to 2009 was Chair of the Swiss National Advisory Commission on Biomedical Ethics, elected by the Swiss Government. He has published widely and taught on biomedical ethics, research ethics, environmental ethics and philosophy of biology, especially genetics. Current research interests include the ethics and politics of stem cell research, reproductive medicine, genetics and end-of-life care.

Jason Scott Robert PhD is based in the School of Life Sciences at Arizona State University, where he is the Franca Oreffice Dean's Distinguished Professor, and Lincoln Associate Professor of Ethics in Biotechnology and Medicine. He is also Associate Professor of Basic Medical Sciences at the University of Arizona College of Medicine – Phoenix in partnership with Arizona State University. At ASU, he directs the Bioethics, Policy, and Law Program in the Center for Biology and Society, and is also affiliated with the Consortium for Science, Policy, and Outcomes. At the College of Medicine – Phoenix, he directs the Medicine and Society theme and is Director of Education for the Scholarly Project. Dr. Robert has published extensively in the philosophy of biology and bioethics, including a book on embryology, epigenesis and evolution with Cambridge University Press in 2004. His research currently focuses on how biologists and biomedical researchers can and should attempt to justify their research, especially where the research is deemed controversial or politically significant. Dr. Robert is a former member of the Stem Cell Network in Canada, and prior to moving to Arizona he held a Canadian Institutes of Health Research New Investigator Award in the Department of Philosophy at Dalhousie University.

Jackie Leach Scully PhD was born in Singapore and took a first degree in biochemistry from Oxford University. She received her PhD in molecular pathology from Cambridge and following that moved to Switzerland, where she worked first in retroviral and then in neurobiological research, specializing in the effects of steroids on neuronal degeneration. In 1998 she joined the newly founded Unit of Ethics in the Biosciences at the University of Basel as senior research associate. Her major research projects there concerned lay perceptions of somatic gene therapy and of genetic testing. From 2002 to 2004 she collaborated with the Policy, Ethics and Life Sciences Research Centre (PEALS) of Newcastle University on a project

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Sally Sheldon PhD studied at the Universities of Kent and Bordeaux, before obtaining her PhD from the European University Institute in Florence. Since 2006 she has been Co-Director of Research and Professor of Law at Kent Law School, UK, having previously taught for 12 years at Keele University. She teaches medical law and ethics at both undergraduate and postgraduate level. Her research interests are primarily in healthcare law and ethics, and the legal regulation of gender, especially with regard to the legal regulation of fatherhood. She has recently completed a book on fatherhood with Richard Collier of Newcastle Law School (*Fragmenting Fatherhood: A Socio-Legal Study*, Hart, 2008), with whom she also edited *Fathers' Rights Activism and Law Reform* (Hart, 2007). Her research on fatherhood was supported by a fellowship funded by the Economic and Social Research Council. Sally has worked on a range of topics within healthcare ethics, including the regulation of abortion services in the UK (resulting in her first book, *Beyond Control: Medical Power and Abortion Law*), FGM and cosmetic surgery, the creation of 'saviour siblings', and the regulation of reproductive technologies. A number of these papers have been co-authored with Professor Stephen Wilkinson of Keele's Centre for Professional Ethics.

Paul De Sousa PhD MSc trained as a developmental and reproductive biologist, with a specific interest in mechanisms controlling the creation of developmentally competent eggs and embryos and cell regeneration. This training included graduate and postdoctoral research at the Universities of Toronto and Western Ontario in Canada, and the University of Pennsylvania in the USA. In 1998 he joined the Roslin Institute in Scotland where he began applying his basic research interests to animal biotechnology, specifically the use of animal cloning by somatic cell nuclear transfer to create transgenic animals as models of disease and as organ donors for xenotransplantation. In 2002 his group began focusing on the derivation of new human embryo stem cells in accordance with emerging regulatory standards for therapeutic use. In 2005 he joined the University of Edinburgh as a Senior Research Fellow, establishing a laboratory focused on the use of human embryo stem cells in regenerative medicine and underpinning egg and embryo biotechnology. In concert with this he co-founded Roslin Cells Ltd, a not-for-profit company established in July 2006 as a tripartite collaboration between the Roslin Institute, the University of Edinburgh and the Scottish National Blood Transfusion Service for the derivation and marketing of research and therapeutic grade hESCs. He serves as Roslin Cells' Chief Scientific Officer and is the Person Responsible and Designated Individual for Roslin Cells' licences from the Human Fertilisation and Embryology Authority and the Human Tissue Authority, respectively.

Charis Thompson PhD received her undergraduate degree from Oxford University, UK, in Philosophy, Psychology and Physiology, and her PhD from the University of California, San Diego in Sociology (Science Studies). She was a National Science Foundation Postdoctoral Fellow in Science and Technology Studies at Cornell University, and held previous positions at the University of Illinois, Urbana–Champaign, and at Harvard University. She is currently Associate Professor in the Departments of Rhetoric and Gender and Women's Studies at the University of California, Berkeley. She is Director of the Berkeley Science, Technology, and Society Center, and the current director of the Designated Emphasis in Women, Gender, and Sexuality. She is also the Director of the Project on Stem Cells and Society at Berkeley's Stem Cell Center, where she serves as faculty mentor to the only two social science students supported by the California Institute for Regenerative Medicine's state-wide training grant. Thompson is the author of *Making Parents: The Ontological Choreography of Reproductive Technologies* (MIT Press, 2005), which won the 2007 Carson Prize from the Society for the Social Study of Science, and of numerous articles on reproductive and stem cell technologies. She serves on two Embryonic Stem Cell Research Oversight (ESCRO) committees.

Kai Wang PhD has worked since September 2006 as a research scholar the Cellular Reprogramming Laboratory led by Professor Jose Cibelli, at Michigan State University, East Lansing, MI. He received his PhD at the Stem Cell Research Center, Shanghai Second Medical University, China, in 2004. His first postdoctoral training was in Professor Keith Latham's laboratory at Temple University, Philadelphia, PA (2004–2006). His research focuses on understanding the molecular bases of cellular reprogramming and differentiation. He has published in *Biology of Reproduction*, *Cloning and Stem Cells*, *Cell Research*, *Reproduction*, *Zygote* and *Differentiation*.

David Wasserman JD is Director of Research at the Center for Ethics, Yeshiva University, New York and a former research scholar at the University of Maryland's Institute for Philosophy and Public Policy. He works on ethical and policy issues in reproduction, genetics, disability, and biomedical research. He has co-authored *Disability, Difference, Discrimination* with Anita Silvers and Mary Mahowald (1998) and co-edited *Quality of Life and Human Difference: Genetic Testing, Health-Care, and Disability*, with Robert Wachbroit and Jerome Bickenbach (2005).

Daniel M Weinstock PhD holds the Canada Research Chair in Ethics and Political Philosophy in the Philosophy Department of the Université de Montréal. He is the Founding Director of the Université de Montréal's Ethics Research Center. He has published extensively in a variety of areas in contemporary moral and political philosophy, particularly with respect to the just governance of multicultural societies. He is currently completing a study entitled *Families, Children, and the State*, which examines the normative issues involved in the social and political organization of childhood. Recent publications coming out of this research project have looked at the ethics of school funding, the justification for state involvement in the institution of marriage, and the limits on parental prerogatives to do with the transmission of patrimonial languages and cultures. Professor Weinstock has received a number of awards for his teaching and research. He was awarded the Université de Montréal's teaching prize in 1998. He was also awarded the Pierre-Elliott-Trudeau Prize in 2004, and the André-Laurendeau Prize in 2006. He has had extensive involvements in the field of public policy, having served on the Québec Commission tasked with looking into the issue of the place of

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religion in public schools (1997–9). He is at present the Chair of the Québec Public Health Ethics Committee, and a member of the advisory board of the Taylor/Bouchard Commission on Reasonable Accommodation. He was a member of an ad hoc committee formed at the request of Québec's Minister of Health to study normative issues in the management of risk in the context of pandemics, as well as of a committee investigating the ethical implications of new surveillance technologies.

Angela White is a PhD student at the University of Western Ontario. The goal of her doctoral research is to carry out a critical analysis of deliberative democratic theories, using John Rawls's theory of justice and H. L. A. Hart's legal theory to inform her critique. She completed her BA(Hons) in Philosophy at Dalhousie University, and her MA at Western. Her research interests include feminist theories of reproductive ethics, liberal theories of justice, and legal theory, particularly those of John Rawls and H. L. A. Hart, respectively.

Stephen Wilkinson DPhil became Professor of Bioethics at Keele University in 2006, having previously taught ethics and philosophy there since 1994. Professor Wilkinson has published on a wide range of topics in biomedical ethics including euthanasia, futility, methodology and separating conjoined twins. In addition, he has worked on the philosophy of mental health, with his 'Is "normal grief" a mental disorder?' winning the 1999 Philosophical Quarterly International Essay Prize. However his principal research areas are: (a) the 'commodification' or commercial exploitation of the human body in biomedical contexts, and (b) the ethics of 'assisted' human reproduction (and related legal and policy issues). His most significant published work on commodification is the book *Bodies for Sale: Ethics and Exploitation in the Human Body Trade* (Routledge, 2003). The writing of this was supported by a research award from the Arts and Humanities Research Board. Likewise, in reproductive ethics, his most substantial work is (or will be) a book entitled *Choosing Tomorrow's Children: The Ethics of Selective Reproduction*. This is scheduled for publication (by Oxford University Press) in 2009. The writing of this book was supported by a research award from the Arts and Humanities Research Council; it also builds on an earlier project on the concept of 'eugenics', which was funded by the Wellcome Trust's Biomedical Ethics Programme. He has produced a number of collaborative papers on medical ethics and law with Professor Sally Sheldon (Kent Law School). Their joint work has been cited by the Court of Appeal and the Parliamentary Joint Committee on the Human Tissue and Embryos (Draft) Bill (2007). He is a member of the Arts and Humanities Research Council's Peer Review College and was, until recently, a member of the Wellcome Trust's Biomedical Ethics Funding Panel. He is on the editorial and/or advisory boards of several journals, including *Bioethics, Clinical Ethics, Ethical Theory and Moral Practice* and *Res Publica*.