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The Social Determinants of ‘Health’ of Embryos: Practices, Purposes, and Implications

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Chapter

9

Social determinants of 'health' of embryos

Roxanne Mykitiuk and Jeff Nisker

Introduction

An increasing focus on the biomedical determinants of the health of embryos and fetuses is resulting from new technical possibilities, clinical considerations and research purposes (Nisker and White, 2005), but also from social factors, and for a variety of reasons. An exploration of the determinants of health of embryos, just as an exploration of the determinants of child or adult health, must take into consideration traditional social determinants, including those related to the consequences of poverty, such as poor nutrition and toxic environments (World Health Organization, 1948; Wilkinson and Marmot, 2003; Raphael, 2004), but also laws, policies and institutions, which are also social determinants of health (Wilkinson and Marmot, 2003).

The increasing focus on determining the biomedical health of embryos or fetuses may have profound effects on the concept of health, not only as applied to these entities but as applied to existing children and adults. Conversely, concepts of both the biomedical and social health of children and adults may have profound effects on concepts of the biomedical and social health of embryos and the development of strategies to make such determinations. Accepting a purely biomedical concept of health empowers certain people and institutions with the ability to define health and manage healthcare, while simultaneously excluding others (Lippman, 1988).

We will use the term 'embryo health' in the understanding both that terms such as 'pre-embryo' (Handyside, Kontogianni, Hardy *et al.*, 1990; Nisker and Gore-Langton, 1995; Spallone, 1996), 'embryo' and 'fetus' represent a continuum of cell divisions and differentiations, and that attempts to construct distinctions based on time from fertilization are artificial and often derived for vested purposes and interests (Spallone, 1996; Fox, 2000; Post, 2003). However, we acknowledge that in some circumstances, an embryo and viable fetus should be viewed differently. Although not a person, the human embryo is a social entity (Duden, 1993; Franklin, 1997), and making determinations about the health of an embryo is always a socially informed process. Discussions about determinants of the health of the embryo must include both the *in vitro* and *in vivo* embryo, as well as the purposes for determining its health.

We explore the concept of embryo health by first examining the biomedical determinants of health under which embryos may be scrutinized and the purposes for which such biomedical determinations are made. We then examine the traditional social determinants of child and adult health and their relation to embryo health. Next we explore the effect of biomedical and social determinants of the health of embryos on constructing new

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ways to characterize the health of children and adults, including persons living with disabilities and those not yet born with disabilities. Following this discussion is an exploration of the differences between social determinants of embryo health that affect the biomedical health of children, and biomedical determinants of embryo health that are directed towards enhancing the perceived social health of children and their parents. Finally, we examine the implications of different concepts of health on determinations of the health of embryos, children and adults. Throughout this chapter, we locate considerations of the health of the embryo as social practices, existing in political, economic and social contexts, and we acknowledge that norms and values about child and adult health infuse determinations of embryo health and vice versa.

Biomedical determinants of the 'health' of embryos

In genetics laboratories, determinations of extra chromosomes or absent chromosomes, as well as deletions, additions and translocations of parts of chromosomes are made through viewing photomicrographs and other representations of chromosomes (Melotte, Debrock, D'Hooghe *et al.*, 2004), frequently enhanced by fluorescent *in situ* hybridization (FISH) (Delhanty, Griffin, Handyside *et al.*, 1993). Detection of markers for an increasing number of genetic conditions (Verlinsky, Rechitsky, Sharapova *et al.*, 2004; Marchini, Donnelly and Cardon, 2005) are made through determinations of specific DNA sequences after their amplification by polymerase chain reaction (PCR) (Mullis and Faloona, 1987). In 2004, PCR determinations of the health of embryos were reported for more than 300 genetic conditions (Verlinsky, Rechitsky, Sharapova *et al.*, 2004).

Preimplantation genetic diagnosis (PGD) allows biomedical determinations of embryo health to be made from a single cell from an *in vitro* fertilization (IVF) embryo (Handyside, Kontogianni, Hardy *et al.*, 1990), instead of through amniocentesis at 16 weeks gestational age (Serr, Sachs and Danon, 1955) or chorionic villus sampling (CVS) a few weeks earlier (Neilson and Alfirevic, 2006), obviating the need for consideration of abortion for genetic reasons (Nisker and Gore-Langton, 1995). However, PGD requires the woman to accept the risks of harm from IVF drugs (Abramov, Elchalal and Schenker, 1999), surgery (Alsalili, Yuzpe, Tummon *et al.*, 1995), and a decreased chance of becoming pregnant (Nisker and Gore-Langton, 1995; Mastenbroek, Twisk, Echten-Arends *et al.*, 2007). IVF clinics are increasingly employing 'routine screening' of IVF embryos or polar bodies for chromosomal anomalies to avoid both miscarriages (Verlinsky, Rechitsky, Sharapova *et al.*, 2004) and children 'affected' by irregular chromosome patterns.

In IVF laboratories prior to the advent of embryo cryopreservation (Trounson and Mohr, 1983), microscopic determinations of embryo health, including evidence of cell division, lack of fragmentation and blastomere symmetry and clarity, were undertaken in an attempt to determine the three (or more) 'best' or 'most suitable' embryos to transfer to the woman's uterus, with the remaining embryos discarded to avoid high-order multiple pregnancy (Lornage, Chorier, Bouliou *et al.*, 1995; Van Voorhis, Grinstead, Sparks *et al.*, 1999; Soderstrom-Anttila, Foudila, Ripatti *et al.*, 2001; Newton, McDermid, Tekpetey *et al.*, 2003; Nisker, White, Tekpetey *et al.*, 2006). For the past 15 years, embryos not transferred in the IVF treatment cycle have been cryopreserved for later transfer to the woman so that she may avoid the harms of additional IVF cycles (Alsalili, Yuzpe, Tummon *et al.*, 1995; Abramov, Elchalal, and Schenker, 1999).

The purpose of making a biomedical determination of the health of an embryo may alter perceptions of the health or suitability of embryos. For example, if the purpose of a

determination is to prevent having a child who would develop an X-linked recessive condition, the health of an embryo with a Y chromosome is viewed differently than if the purpose of the determination is to select the gender of a child for social reasons. Similarly, when identifying a DNA sequence associated with deafness (Levy, 2002) or dwarfism (Saito, Sekizawa, Morimoto *et al.*, 2000; Nunes, 2006), whether the purpose of the determination is to prevent giving birth to a child who is deaf or of short stature or to purposefully have a child with such a characteristic determines how the DNA sequence is viewed. Another example of how the same biomedical determinant of embryo health may be viewed differently because of its purpose is the testing an embryo for its suitability (after birth) to be a stem cell 'donor' for an ill child (Pennings, Schots and Liebaers, 2002; Verlinsky, Rechitsky, Sharapova *et al.*, 2004). For this purpose, embryos that would be seen as healthy and suitable for implantation based on biomedical determinations made for any other purpose, but are determined not to be histocompatibly suitable for stem cell 'donation' to the ill child, are discarded (please refer to Sheldon and Wilkinson, Chapter 17).

Research purposes may also alter perceptions of the biomedical health of embryos. For example, some stem cell researchers believe that 'fresh' embryos are preferable to cryopreserved embryos (donated after the woman no longer requires them for her reproductive purposes) for their purpose (Nisker and White, 2005). This preference has encouraged a recent revival of interest in microscopic determinants of the health of IVF embryos, and those embryos determined as likely to be unhealthy or unsuitable are 'donated' 'fresh' to stem cell research (Nisker and White, 2005; Nisker, White, Tekpetey *et al.*, 2006; McLeod and Baylis, 2007). No evidence exists that an embryo's potential to become a child can be completely ruled out until it stops dividing and degenerates (Newton, McDermid, Tekpetey *et al.*, 2003). In Australia, where until recently, all additional IVF embryos were viewed as having the capacity to be healthy, no 'fresh' embryos were donated to research (Nisker, White, Tekpetey *et al.*, 2006). However, in response to a desire of Australian stem cell researchers to use 'fresh' embryos for their research purposes, a recent National Health and Medical Research Council guideline (National Health and Medical Research Council [NHMRC], 2007) describes morphologic criteria by which embryos may be declared less healthy or less suitable and thus can be 'donated' 'fresh' to stem cell research.

Social determinants of the 'health' of embryos

The concept of social determinants of health emerges from the World Health Organization (WHO) definition of health (World Health Organization, 1948) and recognizes that economic and social conditions influence the health of individuals and communities (Raphael, 2004). These social determinants include factors such as ethnicity, community structure, economics and law (Frazee, Gilmour and Mykitiuk, 2002; Siegler and Epstein, 2003), as well as education, employment, working conditions, nutrition, healthcare services, transportation, housing, income and social inclusion (Hofrichter, 2003; Raphael, 2004). A social determinants approach reveals the ways in which health is dynamically produced within specific social environments and political contexts and by culturally informed perceptions of an individual's bodily experiences and functions (Krieger, 2005).

Many of the social determinants of health considered important for the biomedical health of children and adults may also be important determinants of the biomedical health of embryos. For example, poverty and its related social determinants of health, such as poor nutrition, toxic environment and infectious diseases can, when related to the health of women,

both prior to and during pregnancy, become social determinants of health of the embryo. Social determinants of health of embryos, such as malnutrition (Stanner, Bulmer, Andres *et al.*, 1997; Eriksson, Forsen, Tuomilehto *et al.*, 1999; Roseboom, Van Der Meulen, Osmond *et al.*, 2000; Montgomery and Ekblom, 2002; Plagemann, Rodekamp and Harder, 2004) including folic acid deficiency (Koren, 1993), and toxic environment (Peakall, Hallett, Bend *et al.*, 1982; Jarrell, Gocmen, Foster *et al.*, 1998) can result in biomedical impairments for the children they become. Poverty during pregnancy is associated with an increased incidence of smoking (Quinton, Cook and Peek, 2008), alcohol consumption (Koren, 1991), and drug addiction (King, 1997), all of which affect the embryo and could result respectively in fetal hypoxemia (Socol, Manning, Murata *et al.*, 1982; Ng and Zelikoff, 2007), fetal alcohol syndrome (Centers for Disease Control and Prevention [CDC], 2004; Chudley, Conry, Cook *et al.*, 2005), and crack cocaine syndrome (Singer, Minnes, Short *et al.*, 2004). Maternal poverty is also related to an increase in viral infections and other pathogens, which, when present during pregnancy, may affect the health of the embryo and eventually the health of the child that embryo may become (Goldenberg, Hauth and Andrews, 2000; Feigin, 2005).

These social determinants of embryo health can also have long-range effects on the biomedical health of the adults the embryos become (generally referred to as the 'Barker Hypothesis') (Barker, 1992). Research on a cohort of adults whose mothers were pregnant with them during the Dutch famine from 1944 to 1945 indicated that nutritional deprivation of pregnant women resulted in coronary artery disease in their offspring 50 years later (Roseboom, Van Der Meulen, Osmond *et al.*, 2000). Further, studies have shown an association, particularly in animals but also in humans, of nutritional deprivation and other factors, not only in coronary artery disease (Eriksson, Forsen, Tuomilehto *et al.*, 1999; Roseboom, Van Der Meulen, Osmond *et al.*, 2000), but in type II diabetes (Stanner, Bulmer, Andres *et al.*, 1997; Ravelli, Van Der Meulen, Michels *et al.*, 1998; Montgomery and Ekblom, 2002; Plagemann, Rodekamp and Harder, 2004).

Another social determinant of the biomedical health of the embryo is that women are delaying becoming pregnant (Nybo Andersen, Wohlfahrt, Christens *et al.*, 2000; Hammarberg, Clarke, Tough *et al.*, 2002), a factor that is conditioned by social and cultural contexts. Delaying pregnancy is increasingly common (most often in developed nations) for a variety of social reasons (Gosden and Rutherford, 1995; Hammarberg and Clarke, 2005; Nisker and Bergum, 2007), including pursuit of education, career and financial independence and being in a committed relationship. Because older women have an increased susceptibility to giving birth to children with chromosomal aneuploidy (Heffner, 2004; Society of Obstetricians and Gynaecologists of Canada [SOGC], 2007; Summers, Langlois, Wyatt *et al.*, 2007), they are more likely to undergo amniocentesis (American College of Obstetricians and Gynecologists [ACOG], 2001), chorionic villous sampling (Neilson and Alfirevic, 2006), or PGD (Berkowitz, Roberts and Minkoff, 2006), thus exposing their embryos and fetuses to biomedical determinations of genetic 'health.' Women who delay childbearing are also susceptible to infertility due to oocyte depletion (Pastor, Vanderhoof, Lim *et al.*, 2005), recurrent miscarriages (Benzies, 2008), endometriosis (Mishell, 2001), and fallopian tube damage (Mishell, 2001), and are thus more likely to undergo IVF, which exposes their embryos to a variety of biomedical determinants.

The association of advanced age and infertility has resulted in an increase in the use of fertility drugs, which can lead to an increase in multiple pregnancies and in children born prematurely (Drack, 1998; Barrett and Bocking, 2000; Elster, 2000; Adamson and Baker, 2004; Inder, Warfield, Wang *et al.*, 2005). These children have a preponderance of

long-term health problems (Drack, 1998; Barrett and Bocking, 2000; Elster, 2000; Adamson and Baker, 2004; Inder, Warfield, Wang *et al.*, 2005). If the social and economic factors leading to infertility were addressed so that women could be having children earlier and could be subject to fewer internal and external environmental 'causes' of infertility (Hull, Glazener, Kelly *et al.*, 1985; Thonneau, Marchand, Tallec *et al.*, 1991), the 'need' for IVF would be reduced along with the corresponding problems relating to embryo 'health'. One solution is to direct resources to infertility prevention strategies, such as reducing the incidence of sexually transmitted diseases, investing in changing the social conditions and correcting environmental conditions that contribute to infertility.

Although the fact of gestation focuses our attention on the relationship between maternal health and that of the embryo, paternal exposure to environmental and occupational toxins may, through genetic mutations in sperm, also affect the health of embryos, including those that become children (Singh, Muller and Berger, 2003; Thacker, 2004; Rubes, Selevan, Evenson *et al.*, 2005; Zini and Libman, 2006). A relationship has been observed between embryo health and paternal smoking, drug use and alcohol use (Rubes, Selevan, Evenson *et al.*, 2005; Zini and Libman, 2006). Further, men who are addicted to drugs or alcohol help to create a social environment that can harm maternal and embryo health. For example, male partners may encourage or pressure pregnant women to continue to use alcohol or drugs (Chavkin, Paone, Friedmann *et al.*, 1993). In addition, drug or alcohol addiction on the part of women, including those who are pregnant, is often a coping mechanism for dealing with the trauma of sexual and other forms of abuse (Silverman, Decker, Reed *et al.*, 2006). Pregnant women are more likely than non-pregnant women to be victims of domestic abuse (SOGC, 2005).

Economic factors are also social determinants of health (World Health Organization, 2005). Particular to embryo health, economic factors include allocation of resources to improve the social determinants of maternal and embryo health. Economic factors also facilitate access to the procedures that place embryos under DNA or microscopic lenses, as well as influencing the purpose for which they are placed under the lens. In some countries, economic factors allow some prospective parents to make determinations of embryo health, thus empowering some individuals, but not others, to make personal choices about genetic risk. In a social context that does not adequately support and accommodate people with impairments and their families, decisions about using PGD, amniocentesis or CVS to assess embryo health may be influenced by the perceived economic and social costs of having a genetically 'unhealthy' child.

The economic factor of low income predisposes some women in Canada and the United States to use fertility drugs without the safety of IVF and single embryo transfer, resulting in an even greater risk of multiple pregnancy and its consequences (Min, Claman and Hughes, 2006; Mykitiuk and Nisker, 2008). Equal access to IVF as exists in many European countries and Australia would decrease the impact of the social determinant of low income and its biomedical effects. However, IVF and fertility drugs may have long-term health effects on the child and adult that embryo may become, particularly in relation to Angelman syndrome (Cox, Burger, Lip *et al.*, 2002; Orstavik, Eiklid, van der Hagen *et al.*, 2003) and Beckwith-Wiedemann syndrome (DeBaun, Niemitz and Feinberg, 2003; Maher, Brueton, Bowdin *et al.*, 2003).

Further, any economic arguments must consider the financial costs of caring for premature neonates in the neonatal intensive care unit, as well as the care required to assist the children that survive with 'disabilities' (Barrett and Bocking, 2000; Gilbert, Nesbitt and

Danielsen, 2003; Phibbs and Schmitt, 2006; Nisker, 2008). The economic factors that influence who can access IVF, PGD, amniocentesis and CVS, and for what 'conditions' inform and are informed by prevailing conceptions about what health is, which in turn are products of social ideologies, institutions and decisions about the allocation of resources.

Regulation is also an important social determinant of health. The law establishes the role of the state in relation to improving health (Siegler and Epstein, 2003; Krieger, 2005), as well as creating and shaping the conditions within which health can be achieved (Frazee, Gilmour and Mykitiuk, 2002). Further, regulation plays an important role in shaping what we view as health, including the characterization of the health of embryos. Although a legal examination of what constitutes a healthy embryo is beyond the scope of this exploration, it should be noted that no jurisdiction has a comprehensive regulatory framework (such as a *Healthy Embryo Act*) that defines what a healthy embryo is and the conditions within which to achieve it. Rather, in Canada, the United Kingdom, Australia, New Zealand, France and Germany, an array of statutes, regulations, policy and case law form a corpus of jurisprudence about the embryo that examines a range of issues, including the legal status of the embryo; the legal consequences of harm to a fetus or embryo; judicial intervention into pregnancy; and the regulation of embryo research, creation, destruction, disposition and donation.

Although law exists pertaining to embryos and fetuses, we found scant reference to the health (and cognates) of an embryo or its ill health (and cognates). Moreover, in no legislative documents are any of these terms when used in relation to an embryo, ever defined. Thus, the legal conception or definition of health in relation to the embryo is most often a matter of judicial interpretation, often relating to the ultimate utility or purpose of the embryo. Indeed, even the legal definition of the terms 'embryo' and 'fetus' shift among jurisdictions and contexts (Fox, 2000).

A social determinants approach demonstrates that responsibility for embryo health rests not only on individual women but is shared with men, public institutions and social structures. For example, poor nutrition, toxic environments (including workplaces), drug and alcohol use, and poverty and violence, when mediated through the bodies of pregnant women, are all profoundly social determinants of embryo health. Inadequate social structures and social exclusion also have consequences, such as poverty, lack of education, poor employment, and poor healthcare, all of which can contribute to maternal or paternal behaviours and, through them, to poor embryo health (please refer to Karpin, Chapter 10).

A social determinants approach to embryo health requires us to attend to the social environments in which women, men and embryos exist, rather than locating health and illness exclusively within the individual body – be it an embryonic body or that of a person. This role of social environments is important to acknowledge, especially when biomedical assessments of embryo health are increasingly focused on embryos that have been created outside of women's bodies but are dependent on women's embodiment for gestation and birth. Optimizing the health of all embryos, not just those created by IVF, requires that we attend to the maternal and paternal 'environment' as a determinant of health of the embryo. Concern about the maternal environment itself requires us to care for and about the pregnant woman (i.e. ensuring adequate nutrition and prevention of exposures to toxins in the environment and workplace), because through her, embryo health is affected. In a social determinants approach, the health effects on the embryo are 'socialized' and not just 'individualized'.

Interwoven implications of determinants of the health of embryos, children and adults

Just as biomedical and social determinants of the health of an embryo are informed by ideas and evaluations of the characteristics of the child that embryo may become, as well as concepts of 'health', 'disease', 'illness', 'well-being' and 'disability' in children and adults, determinations of embryo health have implications for our perceptions of the social and biomedical health of children and adults. Biomedical and social determinants of embryo health share the assumption that the condition of health can not only be identified in embryos but that such a determination is important when considering the health of children and adults. Although the means and conditions through which health is determined and produced differ with biomedical and social approaches, health is construed by each as a goal worthy of pursuit and funding. Implicit in both biomedical and social determinants of health is the idea of an optimal, or at least preferred, normative concept of health and the possibility of making positive and negative evaluations of health. Therefore, we must attend to the criteria, both factual and normative, through which we assess the biomedical and social determinants of the health of embryos, and consider how such determinations are and ought to be made and the impact of such determinations of health on current and future children and adults.

Common to many understandings of health are the notions of absence of illness or disease and the normative functioning of biological systems (Wolbring, 2005). With these understandings, the aim of medicine is to prevent, diagnose and treat disease and illness. When an anomalous characteristic in morphological, functional or genetic make-up is detected, medicine aims to restore to 'species-typical functioning' the person who has lost her perceived biological health because of unfavourable biomedical or social determinants (Buchanan, Brock, Daniels *et al.*, 2000), which is achieved through treatment, rehabilitation or management of the impairment.

In the case of an embryo, to prevent the person born of a specific embryo from exhibiting disease, disability, impairment or sub-normative functioning, either discarding the embryo or performing an abortion is required (Buchanan, Brock, Daniels *et al.*, 2000), except in rare situations where strategies for correction can be employed during pregnancy or following birth, such as fetal surgery for open neural tube defect (Botto, Moore, Houry *et al.*, 1999) or cardiac anomaly (Harrison, 1996). Thus, rather than biomedical determinations of embryo health being strategies for preventing ill health (Steinbock, 2000; Shakespeare, 2006), they are generally techniques for selection (Asch, 2000; Parens and Asch, 2000; Asch, 2003; Asch and Wasserman, 2005). Alternatively, prevention of the impairment in the person whom that embryo may become can be achieved by improving social determinants of maternal health, such as better maternal diet, increasing the intake of folic acid, or reducing alcohol consumption (please refer to Karpin, Chapter 10).

The exponential increase in research funding in genomics will probably result in the identification of a genetic contribution to many human differences. How these differences are interpreted, placed into context, and acted upon could have social implications for current and future persons. In addition, genomics research will create new biomedical and social determinants of embryo health, which could in turn have implications on the perceived health of children and adults. For example, the differences in the DNA sequences in the genotypes of 'healthy'-appearing persons are called 'polymorphisms'. However, when a polymorphism is correlated with a particular 'phenotype' (observable expression of genotype), it becomes a

'mutation' (Gerald Kidder, personal communication, 2005). Once a DNA sequence is termed a 'mutation', embryos with this mutation may be viewed as unhealthy and then become the targets of the new clinical purpose of preventing individuals having these mutations through the use of PGD. Further, because the word 'mutation' could have a pejorative connotation, once the correlation between a genetic polymorphism and a particular phenotype is determined, children and adults with previously considered anomalous characteristics become children and adults with mutations, and could be viewed differently. However, the detection of a marker for a mutation does not alter the health of the potential child. Further, because the phenotypic expression of a gene may vary considerably (Morley, Molony, Weber *et al.*, 2004), and social determinants, such as education, family and government support, could greatly moderate the impact of the presence of an anomalous characteristic, whether or not a correlation with a mutation is known.

Social responses to the characterization of a trait as a mutation rather than a variance may have a profound impact on the social health of a child carrying a mutation. For example, the social perception and treatment of a child with 'attention deficit syndrome' may be dramatically altered if a mutation for this condition is discovered, thereby turning a learning difference into a genetic condition that could be 'prevented'. A child with a genetic mutation may be viewed differently from a child who may require specific social and educational services and accommodations. Children resulting from embryos with a mutation that could have been genetically tested and discarded may be looked upon as 'drains' on educational and social welfare systems, and their parents may be viewed as irresponsible for not preventing such drains (Rothman, 1986; Nisker and Bergum, 1999; Mykitiuk, 2002; Nisker and Bergum, 2007). Further, all children with learning-specific needs may eventually be looked upon as having a disease for which a gene mutation has not yet been found, rather than as individuals exhibiting characteristics within the wide and diverse range of human attributes.

As more biomedical determinants of embryo health become available to scrutinize indicators of the 'qualities' and characteristics of the prospective child, particularly those qualities that are socially valued and desired, social values and preferences about personal characteristics could become conflated with the health of the embryo. Giving social preferences a medical status, through their biomedical determinations in healthcare facilities and frequently through public funding, not only masks the fact that they are merely social preferences but simultaneously detracts attention and resources from the actual social determinants of health of embryos and children. For example, prospective parents who believe their child's social health and well-being are determined by factors related to enhanced cognitive capacity have, for more than 30 years, been creating embryos through the purchase of sperm from genius sperm banks (Flint, 2006). Similarly, prospective parents who believe their child's social health or well-being is determined by physical appearance can bid for the oocytes of 'Ron's Angels', 'models' whose photographs and other descriptors appear on the Internet (Nisker, 2001, 2002; Harris, 2003). Such attempts to enhance a child's social health and well-being may also inform uses of PGD to detect or select for qualities in the embryo, further calling into question the bases upon which determinations of embryonic and child health are made.

Determinations of embryo health are informed not only by concerns about the biomedical and social health of the child who may be born from that embryo, but considerations of the social health and well-being of third parties. For example, prospective parents may perceive their social health to be determined, or at least influenced, by having a 'healthy' child, or a child with specific characteristics, thereby justifying their use of technology to determine the biomedical health of the embryo. This perception could be shared

by potential parents who feel that they do not have the physical, emotional, social or financial resources to care for a child with a genetic 'condition', and potential parents who knowingly or unknowingly want to enhance how others view them by enhancing physical and cognitive characteristics of their children.

The use of PGD to select for genetic traits perceived by many to be associated with ill health or impairment, such as deafness (Levy, 2002; Savulescu, 2002), raises additional issues regarding the relationship between embryo health and that of children and adults. Just as lesbian members of the deaf community have used donor sperm (Levy, 2002; Savulescu, 2002) to increase their chances of having a child who is deaf, a couple seeking to use PGD to have a child who is deaf may be acting in an analogous manner to prospective parents who are legally allowed to access biomedical determinants to promote in their children the qualities they associate with social health. However, in New Zealand, the *Guidelines on Preimplantation Genetic Diagnosis 2005* prohibit the use of PGD for the selection of 'embryos with a genetic impairment seen in a parent'. In Australia, Victoria's Infertility Authority has also specifically prohibited 'the use of PGD to select in favour of genetic disease or abnormality' on the basis that it would be inconsistent with the first guiding principle of their Act: 'the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount'. In both countries, the legislation justifies the prohibitions according to the need to protect and ensure the best interests, well-being and health of children born as a result of PGD (neither piece of legislation, however, defines health) (Van Wagner, Mykitiuk and Nisker, 2008). However, it could be argued that such legislation regarding embryos may cause children and adults who are deaf to be seen as having a disease worth preventing (as well as not selecting for) (please refer to Sheldon and Wilkinson, Chapter 17).

The use of PGD to select embryos for the purpose of becoming a stem cell 'donor' (after birth) for an ill sibling serves as an example of third-party interest, as well as a model to further explore the concept of the health of an embryo and its relationship to the health of a child. In the situation of selecting an embryo to be a child who can be a stem cell donor (a 'saviour sibling'), embryos that are healthy according to biomedical determinants but lack the histocompatibility characteristics consistent with being a stem cell donor are discarded, as are embryos with markers for the ill child's genetic condition (Verlinsky, Rechitsky, Sharapova *et al.*, 2004).

In the United Kingdom, the use of PGD was permitted to select for an embryo to be a stem cell 'donor' (histocompatibility matched) for an ill sibling with an inherited condition (Human Fertilisation and Embryology Authority, 2001; Dyer, 2002), while in another case, the use of PGD for the purpose of selecting embryos for stem cell 'donation' was refused because the ill child did not have a genetic mutation for an inherited disease (Hall, 2002; Gavaghan, 2004; Sheldon and Wilkinson, 2004). In the former case, PGD was permitted to avoid having a child with a serious inherited disease of which the family was at risk, and thus performing PGD would constitute a health benefit to the child who developed from the embryo that had been screened, making it possible to prevent the birth of a child with a genetic condition. However, in the latter case 'the legal condition of allowing PGD to avoid serious disease was not applicable' (Bellamy, 2005) because the embryo was not at risk of having a gene for an inherited condition, and 'selection for an HLA [human leukocyte antigen] match alone would have no diagnostic and preventive function and would, therefore, set a new precedent of PGD being used solely for the purpose of creating offspring with specific desired traits' (Franklin and Roberts, 2006, p. 65) (please refer to Sheldon and Wilkinson, Chapter 17, for the current situation in the United Kingdom).

A similar logic animates the New Zealand *Guidelines on Preimplantation Genetic Diagnosis* (National Ethics Committee on Assisted Human Reproduction, 2005) that restricts PGD for HLA tissue typing to situations where there are 'therapeutic indications for the embryo to justify embryo biopsy' (Human Genome Research Project, 2006; Van Wagner, Mykitiuk and Nisker, 2008). This policy permits tissue typing where both the live child who would be the recipient of the transplant and the embryo are at risk of being affected by a 'familial single gene disorder or a familial sex-linked disorder' (National Ethics Committee on Assisted Human Reproduction, 2005, p. 6).

Restricting PGD to cases in which the 'embryo may benefit' (Gavaghan, 2004; Sheldon and Wilkinson, 2004) or have a 'therapeutic indication' (Human Genome Research Project, 2006) is problematic as an embryo cannot 'benefit' from the removal of a blastomere or blastocyst tissue (and its genetic testing), nor can a 'therapeutic intervention' occur for an embryo, although fetal surgery is sometimes a possibility for anomalies such as those related to the cardiovascular and neuroskeletal systems (Harrison, 1996; Botto, Moore, Houry *et al.*, 1999). Rather, the 'benefit' or 'therapeutic indication' implied in the United Kingdom and New Zealand examples is the destruction of the embryo: the antithesis of both a 'benefit' and a 'therapeutic indication' for that embryo. PGD does not provide a benefit to the embryo that is found not to have a genetic marker or the future child resulting from that embryo because the health of the future child is in no way improved by PGD. Rather, these embryos that are found not to carry a genetic marker have a slightly decreased chance of becoming a child because of the PGD process (Mastenbroek, Twisk, Echten-Arends *et al.*, 2007). The 'benefit' of PGD in these circumstances accrues not to the tested embryo but to third parties: the ill sibling who has a 'therapeutic indication' and her parents. Although the Human Fertilisation and Embryology Authority (HFEA) has recently overturned its decision regarding not permitting PGD unless the ill child has an inherited condition (Bellamy, 2005), the New Zealand guidelines remain in effect (please refer to Sheldon and Wilkinson, Chapter 17).

Determining the biomedical health of an embryo can have implications for the biomedical health of adults through testing embryos for genetic markers for adult-onset conditions such as Huntington's disease (Hayden, Bloch and Fahy, 1988), *BRCA*-gene breast cancer (Narod, Feunteun, Lynch *et al.*, 1991; Narod, Lynch, Conway *et al.*, 1993) and, most recently, Alzheimer's disease (Verlinsky, Rechitsky, Verlinsky *et al.*, 2002). Although an embryo carrying a gene marker for one of these conditions would result in a person that would likely live 40 years before the genetic condition expresses itself, because of the capacity to determine these gene markers, embryos that would have previously been considered healthy may now be considered unhealthy. In addition, although an embryo that is determined to have a genetic marker for Huntington's disease is almost certain to result in a person who will eventually develop the disease (Myers, 2004), a person born from an embryo with a marker for a *BRCA* gene mutation has a much lower chance of developing breast cancer (except for Ashkenazi Jewish women who have up to an 80% chance) (Narod, Madlensky, Bradley *et al.*, 1994), whereas a person born from an embryo that was determined to have a gene marker for Alzheimer's disease is even less certain to develop the disease.

The implications of different concepts of health on determinations of the health of embryos, children and adults

Interpretations of the concept of health have implications for biomedical and social determinations of the health of embryos, children and adults. Contrary to the common

biomedical concept of health, variation from 'species-typical functioning' (Buchanan, Brock, Daniels *et al.*, 2000) is not necessarily an indication of ill health because health is determined socially as much as it is biomedically (Davis, 1995; Taylor and Mykitiuk, 2001; Amundson, 2005; McMahan, 2005; Thomas, 2007). Biomedical differences or deviations from statistical 'norms' are often only indicators of poor health when declared so within a social context (Davis, 1995, 2002; Taylor and Mykitiuk, 2001).

Just as interpretations of the concept of health have implications for biomedical and social determinations of the health of embryos, children and adults, interpretations of the concept of health have implications for the meaning of 'disability' (Frazee, Gilmour and Mykitiuk, 2002; Wolbring, 2005; Thomas, 2007). Commonly 'disability refers to "limited activity" - not being able "to do things", and a "disabled person" is someone who has a medically certifiable "condition" that prevents him or her carrying out the full range of age-related activities considered normal' (Thomas, 2007, p. 12). This perspective 'assumes that an injury to the body - through illness, accident or "developmental abnormalities" in gestation - is the cause of disability' (Thomas, 2007, p. 12). Disabled people as a group are often regarded as patients who are unhealthy, where health is associated with a relationship to disease and illness and rarely with social health or well-being. Most often, biomedical determinants are examined for their contributions to the biological health of disabled people, whereas social determinants are rarely examined for their contributions to the biological and social well-being of disabled people (Wolbring, 2006). Treating disability is most often seen as a biomedical issue leading to its medicalization, in which the appropriate response becomes 'the development of health practices designed to reduce or eliminate the creation of people with such impairments' (Wasserman, Bickenbach and Wachbroit, 2005, p. 12).

However, what is disabling is the inflexibility and limitations of the social and physical environments and their failure to accommodate perceived individual variety and difference, coupled with discriminatory and oppressive attitudes towards and treatment of people with impairments (Taylor and Mykitiuk, 2001; Davis, 2002; Shakespeare, 2005; Wasserman, Bickenbach and Wachbroit, 2005; Shakespeare, 2006; Thomas, 2007). Having an impairment (or a biomedical condition) in a disabling environment does not mean that one is unhealthy, though it may be perceived that way. However, when biomedical differences in health arise, such outcomes are more often attributable to biological (and increasingly genetic) differences than to systemic disablism. But, even in cases where an individual does have a genetic difference or a biomedical anomaly, the material and social environment in which that individual lives may be more important in determining that person's health and well-being than the genetic difference or anomaly. This situation is due to the fact that people with impairments have less access both to health practitioners and to social determinants of health, such as education, employment, transportation and social support (Townsend, 1979). Rectifying social and physical challenges requires environmental and social justice responses and not individualized biomedical interventions.

The significance of environments, policies, values and services to determinations of disability and health is evidenced in the *International Classification of Functioning, Disability and Health* (ICF), the WHO's 2001 framework for describing and measuring disability and health (World Health Organization, 2001). Organized around the broad components of body functions (both physiological and psychological) and structure (anatomical parts), activities (execution of actions) and participation (involvement in a life situation), and environmental factors (World Health Organization, 2001), functioning and disability are viewed as the outcome of the complex interaction among the biological

structures and function of the individual's body and mind (often understood as impairments) and the contextual factors of the environment in which the person lives (e.g. legal and social structures, social attitudes, architectural structures) as well as personal factors (e.g. gender, age, education) (World Health Organization, 2001). According to the ICF scheme, body functions and structure are divided into a number of domains, while activities and participation are described in the domains of learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interaction and relationship; major life areas; and community, social and civic life. The term 'functioning' refers to all body functions, activities and participation, whereas 'disability' is an umbrella term for impairments, activity limitations and participation restrictions. Environmental and contextual factors interact with all of these components (World Health Organization, 2001) and include products and technology; the natural and human-made changes to the environment; support and relationships; attitudes and services; and systems and policies (World Health Organization, 2001).

The ICF classification treats all of these dimensions as interactive and dynamic and is neutral as to aetiology, placing the emphasis on function rather than condition or disease. What matters are the activity limitations and/or participation restrictions (if any) experienced by the person with the disease, condition or impairment, and the means by which such restrictions may be ameliorated. Activity limitations and participation restrictions can, in most cases, be remedied by assistive devices, anti-discrimination laws, and education, and, in some cases, by surgery and other forms of medical intervention.

Understanding health, disability, and functioning along the lines of the ICF renders problematic the use of morphological characteristics and genetic markers to assess embryo health, especially in contexts where they are intended to determine the health of the person that embryo may become. Indeed, biomedical determinants of embryo health reinforce a medicalized and diminished model of health and disability that runs counter to the understanding of health and disability that informs much law and social policy (*Eldridge v. British Columbia*, 1997; *Granovsky v. Canada*, 2000). This uncritical reliance on a single characteristic in the embryo 'dominates the judgment of its life prospects' and 'reproduces the stigmatization of people with disabilities at the level of reproductive choice' (Wasserman, Bickenbach and Wachbroit, 2005, p. 14).

Western Australia's Reproductive Technology Council (RTC), responsible for assessing applications for PGD, invokes the ICF criteria for the health of children and adults in its criteria for evaluating the 'risk and seriousness of the condition to be tested for' (Reproductive Technology Council, 2004), using some language that is identical to the ICF, including the family's 'experience with, and attitude to' the condition; the 'level of impairment to body functions and structures that is usually associated' with a condition; the difficulties expected in 'participating in activities such as learning and applying knowledge, communication, mobility, self care, employment, community, social and civic life'; the 'level of support' required and the 'capacity of the family' to provide it; and the 'prospects for new and longer term treatments and interventions for the condition' (Reproductive Technology Council, 2004). Although the RTC document refers to the 'embryo', determinations of 'a significant risk of a serious genetic abnormality or disease' in the embryo are contingent on views about the health of the child that embryo might become. However, a comprehensive evaluation of the social context in which the child will live part of any consideration for PGD, and even if such an evaluation is attempted as directed by the RTC, one cannot determine the level of health, disability and functioning of the potential child. Although PGD may be able to detect a marker for a genetic

condition, the manifestation of the condition in the child depends on varying genetic penetrance and the social environment in which the child will live.

The RTC guidelines are also problematic in that apart from an assessment of the 'capacity of the family' to provide support and an inquiry into longer term treatments and interventions, no other environmental factors, as set out in the ICF, are included. The social model of disability, upon which the ICF is modelled, requires looking beyond the support of families to the systemic support of institutions, services, systems, environments and policies to improve individual functioning, thereby increasing health and well-being and reducing the incidence of disability. Moreover, although considering the 'prospects for new and longer term treatments and interventions for the condition' as set out in the RTC guidelines could be considered to fall within the environmental factor of 'products and technology', arguably they promote an orientation that further locates the impairment or disability in the person. Indeed, although the RTC approach attempts to ground determinations of 'seriousness' within a social framework of health and disability, it fails to include those systemic elements that are essential to an enlightened social model. Rather, the assessment criteria re-inscribe a conception of disability that is located in the body of the disabled person. In our view, testing the embryo also operates as a form of 'synecdoche' (Parens and Asch, 2000; Asch and Wasserman, 2005) in which the part (the genetic mutation or characteristic) stands in for the whole (the qualities and characteristics of the person who always exists in a social context).

Because having an impairment is not necessarily incompatible with health or good quality of life (Amundson, 2005; Asch and Wasserman, 2005; McMahon, 2005), the regulations in New Zealand and Australia prohibiting the purposeful determination and implantation of an embryo with a gene for an impairment reflects a particular conception of health in these (and other) countries. Given that courts have recently adopted fundamental aspects of the social model of disability (*Eldridge v. British Columbia*, 1997; *Granovsky v. Canada*, 2000), a law premised on the idea that particular genetic traits associated with impairments are inherently incompatible with health or well-being is difficult to justify. Thus, prohibitions against selecting in favour of impairments stigmatize the impairment in question and, in many cases, associate functional limitations inconsistent with the actual lived experience of the condition. The presumption is that having the genetic mutation is incompatible with health without the possibility for assessment of actual functional limitation because the determination is being made in relation to an embryo. Ironically, the same societies that espouse the goals of including people with disabilities as fully equal and participating members (*Eldridge v. British Columbia*, 1997; *Granovsky v. Canada*, 2000) simultaneously promote the use of embryo selection 'to prevent the births of those who would live with disabilities' (Asch, 2003, p. 315).

Conclusion

Understanding the social determinants of health of embryos offers a counterbalance to the rapidly expanding technical capacities, clinical applications and research purposes of biomedical determinations of embryo 'health'. Both social and biomedical determinants of embryo health exist within social contexts and have normative and clinical implications. Conceptions of the biomedical and social health of children influence conceptions of embryo health, while biomedical and social determinants of embryo health construct new

characterizations of the health of children and adults. A distinction must be made between social determinants of embryo health that affect the biomedical health of children and biomedical determinants of embryo health that are perceived to enhance the social health of children and their parents. The health of embryos, like the health of children and adults, will always be an unstable concept reflecting the economic, social and political context within which its meaning is constructed.

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