




GENETICS AND THE TRANSFORMATION OF THE PERSONAL

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The shared nature of genetic information presents new challenges for legal understandings of the self. Within traditional legal discourses the individual is conceptualised as separate and autonomous. In contrast, the genetic individual is understood as inherently relational. This paper analyses the transformation of our understandings of the personal. The transformative processes are assessed through discussion of the changing meanings of privacy in the context of genetic information within families; changing views over access to information about biological parentage by children conceived through assisted reproductive technology; preimplantation genetic diagnosis and the changing context of reproductive decision-making.

I GENETICS AND THE TRANSFORMATION OF THE PERSONAL



The mapping of the human genome has opened a range of new possibilities for genetic research and new treatments for disease and genetic conditions. These possibilities have also been accompanied by ethical and legal challenges. Many of these challenges have involved resolving questions about the boundaries between the rights of individuals and others to genetic information. Increasingly, we must face the legal and ethical challenges associated with the shared nature of genetic information and the meaning of genetic privacy, particularly in the context of disclosure of genetic information to family members. Genetics is also creating a new impetus for information about biological parentage by individuals who were conceived using donated gametes, highlighting the role of genetics in contemporary understandings of personal identity. Finally, genetics is transforming the realm of reproductive decision-making by providing prospective parents with an increasing amount of information about their embryos, and, when combined with reproductive technologies, new possibilities for choosing between embryos on the basis of their characteristics.

Within each of these areas the meaning of ‘personal information’ is a key issue. Within all of these areas of debate, the common theme is one of the balance between the individual and the community, between private and public interests and questions of who has the right to regulate both access to and the use of that

* Professor of Health and Medical Law, Faculty of Law, University of Sydney. An earlier version of this paper was presented at the 18th Annual Medico-legal Congress, Sydney, 26–27 February 2009. This paper was supported by a University of Sydney Bridging Support Grant. I would like to thank Isabel Karpin and the anonymous reviewer for their insightful comments on an earlier version of this paper.



information. What is apparent in the debates over genetic information is that our understandings of what is personal and private are being transformed by the shared nature of genetic information, by the needs of individuals for access to information, and by our own desires to know more about ourselves and our families. In each of these areas, the realm of the personal, and of the self, is being reworked by a dialogue between the personal and the genetic. Increasingly, the genetic self emerges as an inherently relational individual who exists in contrast to idealised and individualised legal subjects.

II GENETIC PRIVACY

In the late 1990s and early 2000s much of the debate about law and genetics centred on issues of genetic privacy. To a large degree these debates were influenced by the recognition of the potential for genetics to provide significant information about an individual's current or future health and for this information to be of potential relevance to an individual's employment or insurance. The issue of genetic privacy was therefore closely linked with concerns about genetic discrimination. In one sense, the use of medical information for employment or insurance purposes was not new. Doctors and insurers have long used family medical histories to identify patients at risk of developing particular conditions.¹ However, genetic information promised to be more detailed and less uncertain than family medical histories. It also brought with it the potential to identify individuals at risk before they became unwell. Concern began to be expressed about the 'presymptomatically ill'² being labelled as unwell or at risk when they may never in fact develop the condition in question. Indeed, while genetic science seems to offer certainty, in fact, the information it provides is far more nuanced, for the meaning of a particular gene or genetic mutation for an individual's health will depend upon the penetrance³ of that gene.

Genetic information is very appealing. It is scientific, somewhat mysterious to those of us who do not have scientific backgrounds, and it appears to offer a certainty for the conclusions we may draw from it. However, as the reminder about gene penetrance shows, genetic information is often more probabilistic than predictive. The current fascination with all things genetic and the apparent certainty offered by genetic information can lead towards what has been termed 'genetic essentialism' and the assumption that people really are simply a product of their genes.⁴ If we assume that genetic information is predictive and attribute more certainty to it than we should, there is a risk that individuals who will never develop the condition will be discriminated against. Certainly, concerns have been expressed about the potential for individuals to be disadvantaged in the

1 Australian Law Reform Commission ('ALRC'), *Essentially Yours: The Protection of Human Genetic Information in Australia*, Report No 96 (2003) [3.3].

2 Rochelle Dreyfuss and Dorothy Nelkin, 'The Jurisprudence of Genetics' (1992) 45 *Vanderbilt Law Review* 313, 318.

3 ALRC, above n 1, [2.24]–[2.27].

4 Dreyfuss and Nelkin, above n 2, 320–1.

context of employment and in the context of applications for insurance,⁵ with one recent article reporting verified cases of genetic discrimination.⁶

Given the sensitivity of genetic information, individuals clearly have an interest in ensuring that the privacy of their genetic information is maintained. However, the meaning of this interest and of any rights that might pertain to it is far less certain. Information about health, disease and risk that once seemed to be personal information, relating only to the individual in question, is no longer regarded as purely personal. Two trends are evident here. First is the way in which the individual, in being geneticised, becomes an object of scrutiny. The corporeal bounds of the body dissolve in the face of medical monitoring and observation. Evident in this process is the emergence of a new way of living in which, as Nikolas Rose explains:

once diagnosed with susceptibilities the responsible asymptomatic individual is enrolled for a life sentence in the world of medicine – of tests, of drugs, of self-examination and self-definition as a ‘prepatient’ suffering from a protosickness. And, in the near future, perhaps, they will subject themselves to new forms of monitoring that engender a new ethical relation to the self.⁷

The second transformation of the personal occurs in the boundaries between the individual and the familial. Increasingly, genetic information is regarded as intrinsically familial. This is because genetic information about an individual also reveals information about the individual’s family members. Thus the move from (broad) medical information to (specific) genetic information has been associated with a move from the private/individual to the (more) public/familial. These families are bound together through a common link of genetic alterations, forming what Dolgin refers to as the ‘medicalized family’.⁸

This understanding of the genetic as no longer intrinsically individual and private does represent a clear shift in the ways we conceptualise medical information. Obligations of confidentiality for health professionals embodied in codes of ethics and legal obligations of confidentiality through either statute or common law have traditionally reinforced the individual and non-public nature of medical

5 Kristine Barlow-Stewart and David Keays, ‘Genetic Discrimination in Australia’ (2001) 8 *Journal of Law and Medicine* 250; Margaret Otlowski, ‘Avoiding Genetic Discrimination in Insurance: An Exploration of the Legality and Ethics of Precautionary Measures in Anticipation of Unfavourable Test Outcomes’ (2001) 20 *Monash Bioethics Review* 24; Susan Wolf, ‘Beyond “Genetic Discrimination”: Toward the Broader Harm of Geneticism’ (1995) 23 *Journal of Law, Medicine and Ethics* 345; Sandra Taylor et al, ‘Investigating Genetic Discrimination in Australia: Perceptions and Experiences of Clinical Genetic Service Clients Regarding Coercion to Test, Insurance and Employment’ (2007) 5 *Australian Journal of Emerging Technologies and Society* 63.

6 Kristine Barlow-Stewart et al, ‘Verification of Consumers’ Experiences and Perceptions of Genetic Discrimination and Its Impact on Utilization of Genetic Testing’ (2009) 11 *Genetics in Medicine* 193.

7 Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-first Century* (2007) 94.

8 Janet Dolgin, ‘Biological Evaluations: Blood, Genes and Family’ (2008) 41 *Akron Law Review* 347, 389.

information.⁹ In recent decades the growing use of computers, databases and the internet has raised awareness of the importance of privacy protections and increasingly privacy laws and guidelines have sought to protect individuals from intrusions on their privacy and disclosure of personal information. Indeed, it is this broader context for privacy that provides some of the impetus to the genetic privacy debates.

The inclusion of genetics within privacy laws is far from straightforward. First of all, there is the question of whether genetic privacy should be protected through the enactment of specific genetic privacy laws, or whether it should be protected by amending existing privacy laws. Special genetic privacy laws have been criticised as ‘genetic exceptionalism’ – an approach that sees genetics, and the issues raised by genetics, as somehow different from the privacy issues raised in other areas.¹⁰ This is always a challenge when deciding how the law should respond to new technologies.¹¹ There is much to be said for adapting existing laws so that they include and cover new technologies generally rather than continually crafting new, specific laws for each new technology that emerges – a response which risks what Derek Morgan calls ‘the Red Queen defence: forever rushing to stay in one place’.¹² However, even the task of amending existing laws is often a challenging one.

Privacy law is concerned with our control over the ways that our personal information is used. Existing laws are generally written for records, either written or electronic. How does genetic information fit within this framework?¹³ In Australia the *Privacy Act 1988* (Cth) (*‘Privacy Act’*) now includes genetic information in the definition of health information for the purposes of the Act.¹⁴ In New South Wales the *Health Records and Information Privacy Act 2002* (NSW) defines ‘personal information’ to include ‘such things as an individual’s fingerprints, retina prints, body samples or genetic characteristics’¹⁵ and also includes genetic characteristics within the definition of ‘health information’.¹⁶ The *Health Records Act 2001* (Vic) also includes ‘other personal information that is genetic information about an individual in a form which is or could be predictive of the health (at any time) of the individual or any of his or her descendants’

9 For discussion of obligations of confidentiality in the context of health care see Janine McIlwraith and Bill Madden, *Health Care & the Law* (4th ed, 2006) ch 7; Loane Skene, *Law and Medical Practice: Rights, Duties, Claims and Defences* (3rd ed, 2008) ch 9.

10 For discussion see ALRC, above n 1, [3.41]–[3.55].

11 See Belinda Bennett, *Health Law’s Kaleidoscope: Health Law Rights in a Global Age* (2008) ch 1; Roger Brownsword, *Rights, Regulation, and the Technological Revolution* (2008).

12 Derek Morgan, *Issues in Medical Law and Ethics* (2001) 37.

13 For discussion see ALRC, above n 1, [8.4] – [8.13].

14 *Privacy Act 1988* (Cth) s 6: The definition of ‘health information’ includes ‘genetic information about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual’.

15 *Health Records and Information Privacy Act 2002* (NSW) s 5(2).

16 *Health Records and Information Privacy Act 2002* (NSW) s 6: The definition of ‘health information’ includes ‘other personal information that is genetic information about an individual arising from a health service provided to the individual in a form that is or could be predictive of the health (at any time) of the individual or of any sibling, relative or descendant of the individual’.

within the definition of 'health information'.¹⁷ In contrast, the Australian Capital Territory's *Health Records (Privacy and Access) Act 1997* (ACT) does not expressly include genetic information within the definition of a 'record'.

The traditional boundaries of privacy around the individual have been blurred somewhat by our understandings of the shared nature of genetic information, and the rights or interests of family members to know the results of genetic testing that may be of relevance to them.¹⁸ This raises a series of complex matters about the meaning of privacy in a context where medical information is understood to 'belong' to more than one person: about how best to protect privacy in these circumstances and about how best to provide information based on genetic test results to biological relatives.¹⁹ Information about an individual can be provided to a family member with the individual's consent. However, if an individual does not agree to a family member being provided with genetic information, as can sometimes happen,²⁰ can a doctor or other health professional provide that information?²¹ It is important to note that non-disclosure of genetic information within families is not necessarily due to poor family connections or a lack of care about the implications of the results for relatives. On the contrary, individuals may be reluctant or unsure about disclosing genetic information to relatives out of concern for the distress or harm that the information may bring.²²

In Australia, disclosure of personal information is regulated at the federal level by the *Privacy Act*. Many States and Territories also have privacy legislation, some specifically relating to health information and records.²³ The *Privacy Act* contains a number of Information Privacy Principles ('IPPs') and National Privacy Principles ('NPPs') which govern the collection, use, storage and disclosure of personal information. These provisions essentially impose strict limitations on disclosure of personal information without consent. The circumstances in which disclosure of information is permitted without consent are limited²⁴ but include a provision permitting disclosure if it is necessary to lessen or prevent 'a serious

¹⁷ *Health Records Act 2001* (Vic) s 3.

¹⁸ ALRC, above n 1, [3.25].

¹⁹ For debate on these issues see Dean Bell and Belinda Bennett, 'Genetic Secrets and the Family' (2001) 9 *Medical Law Review* 130; Loane Skene, 'Genetic Secrets and the Family: A Response to Bell and Bennett' (2001) 9 *Medical Law Review* 162; Roy Gilbar, 'Medical Confidentiality within the Family: The Doctor's Duty Reconsidered' (2004) 18 *International Journal of Law, Policy and the Family* 195; Agata Bober, 'Passing It On: Should Health Care Professionals Be Permitted to Disclose Patients' Genetic Information to Their Reproductive Partners?' (2006) 14 *Journal of Law and Medicine* 262.

²⁰ Angus Clarke et al, 'Genetic Professionals' Reports of Nondisclosure of Genetic Risk Information within Families' (2005) 13 *European Journal of Human Genetics* 556, 560: Clarke et al found that less than one percent of genetic clinic consultations were associated with non-disclosure and that, based on second-hand evidence from professionals, the most common reason for non-disclosure was the desire to protect relatives from anxiety.

²¹ Bell and Bennett, above n 19; Skene, 'Genetic Secrets and the Family: A Response to Bell and Bennett', above n 19; Gilbar, above n 19; Béatrice Godard et al, 'Guidelines for Disclosing Genetic Information to Family Members: From Development to Use' (2006) 5 *Familial Cancer* 103.

²² Clarke et al, above n 20; Nina Hallowell et al, 'Balancing Autonomy and Responsibility: The Ethics of Generating and Disclosing Genetic Information' (2003) 29 *Journal of Medical Ethics* 74.

²³ See, eg, *Health Records and Information Privacy Act 2002* (NSW); *Health Records Act 2001* (Vic); *Health Records (Privacy and Access) Act 1997* (ACT).

²⁴ *Privacy Act 1988* (Cth) sch 3 s 2.1.

and imminent threat to an individual's life, health or safety'.²⁵ Most genetic conditions would be unlikely to satisfy the test of being a 'serious and imminent threat' since most would take time to become apparent.²⁶

In response to the recommendations of the Australian Law Reform Commission in its *Essentially Yours* Report,²⁷ the Australian government passed amendments to the *Privacy Act*. The amendments include a new provision in the NPPs: sch 3 s 2.1(ea), permitting disclosure by an organisation that has obtained the genetic information in the course of providing a health service to an individual where:

the organisation reasonably believes that the use or disclosure is necessary to lessen or prevent a serious threat to the life, health or safety (whether or not the threat is imminent) of an individual who is a genetic relative of the individual to whom the genetic information relates.²⁸

The disclosure must also be in accordance with guidelines to be issued by the National Health and Medical Research Council ('NHMRC') and approved by the Privacy Commissioner under a new s 95AA of the *Privacy Act* and, in the case of a disclosure, the recipient of the information must be the individual's genetic relative.²⁹ While these amendments only affect potential liability for breach of the provisions of the *Privacy Act* and do not provide immunity from common law actions for breach of confidentiality,³⁰ the amendments are indicative of a move towards a redefining of genetic information from the personal to the familial. As Margaret Otlowski has commented:

this process of legislative change, and the inevitable discussion that it will generate, are likely to raise awareness regarding these issues and ultimately promote an environment in which disclosure is brought within the mainstream of accepted, even expected, clinical practice.³¹

In February 2008 the NHMRC issued a *Consultation Draft* of guidelines for health practitioners on disclosure of genetic information to a patient's genetic relatives under s 95AA of the *Privacy Act*.³² Importantly, the *Consultation Draft* guidelines require that:

- 'Reasonable steps should be taken to obtain the patient's consent to disclose genetic information to at-risk genetic relatives';³³

25 *Privacy Act 1988* (Cth) sch 3 s 2.1(e)(i).

26 ALRC, above n 1, [21.66].

27 ALRC, above n 1.

28 *Privacy Act 1988* (Cth) sch 3 s 2.1(ea)(i).

29 *Privacy Act 1988* (Cth) sch 3 s 2.1(ea), amended by *Privacy Legislation Amendment Act 2006* (Cth) sch 2 s 4.

30 Margaret Otlowski, 'Disclosure of Genetic Information to At-risk Relatives: Recent Amendments to the *Privacy Act 1988* (Cth)' (2007) 187 *Medical Journal of Australia* 398, 399.

31 *Ibid.*

32 National Health and Medical Research Council ('NHMRC'), *Disclosure of Genetic Information to a Patient's Genetic Relatives under Section 95AA of the Privacy Act 1988 (Cth): Guidelines for Health Practitioners in the Private Sector*, Consultation Draft (2008) ('*Consultation Draft*').

33 *Ibid.* 25.

- '[d]isclosure of genetic information without consent may proceed only if a *serious* threat to the life, health or safety of genetic relatives exists';³⁴ and
- disclosure is 'necessary to *lessen or prevent* a serious threat to the life, health or safety of genetic relative'.³⁵

The guidelines in the *Consultation Draft* would not require health professionals to disclose genetic information to a patient's genetic relatives but set out a framework to be followed if they do decide to make a disclosure. Indeed, if a practitioner seeks to rely on the provisions of the *Privacy Act* in making the disclosure, then it would be necessary to follow the guidelines.³⁶ As the 2008 guidelines are only a consultation draft, when the final guidelines are released we will have some useful guidance for health professionals in this area.

While the issue of disclosure of genetic information to relatives raises questions about the rights of relatives to genetic knowledge, it also paradoxically raises the issue of whether there is a right not to know. The centrality of autonomy discourses to bioethics and health law in the West would tend to support the concept of a right not to know genetic information. UNESCO's *Universal Declaration on the Human Genome and Human Rights*³⁷ supports this right, stating in article 5c: 'The right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected'. But how important is the right not to know?³⁸ Does being told familial genetic information undermine one's right to be free of such knowledge? Can genetic information potentially limit the horizons of one's future? Much will depend on the individual and on the genetic condition in question. One may, for example, prefer not to have information about one's genetic status, if the condition in question is serious and incurable, but prefer to be given genetic information, if the condition is one that could be treated.

The real difficulty with the right not to know is that the moment the issue of genetic information is raised with the person, they are made aware that genetic results exist and one can no longer say that the individual does not know. On the other hand, if the person is told nothing, then their ability to make a choice is also compromised. Of course, a person may have already made their wishes known to their doctor or family members, particularly in the case of inherited conditions where there may have been some discussion in the family. Graeme Laurie has also suggested that a number of other factors may be relevant to the decision of whether to disclose information. These include:

- the availability of treatment or cure for the condition;
- the severity of the condition and likelihood of its onset;

34 Ibid 31.

35 Ibid 33.

36 Ibid 7.

37 United Nations Educational, Scientific and Cultural Organization ('UNESCO'), *Universal Declaration on the Human Genome and Human Rights*, 29th plen mtg, Res 31 (1997).

38 Jane Wilson, 'To Know or Not to Know? Genetic Ignorance, Autonomy and Paternalism' (2005) 19 *Bioethics* 492.

- the nature of genetic testing the individual might need to undergo;
- the nature of the information to be disclosed, eg how certain is it;
- the nature of the request; and
- the views and likely reaction of the person that the information will be disclosed to.³⁹

The concept of the right not to know shows just how challenging it is to identify and articulate our genetic privacy interests in advance.

III GENETICS AND THE DEFINITION OF FAMILY

While modern genetics has impacted on our understandings of illness and led to broader understandings of privacy which move beyond the individual to include the family, genetics has also fed into our desires for information about who we are related to. This trend is most evident in the move, apparent in recent years, to allow individuals who were conceived using donated gametes to gain access to information about their biological parentage. This point should not be overstated. After all, when we think about the historical links between paternity and inheritance,⁴⁰ it is clear that there is nothing new about concerns over biological parentage while the popularity of genealogical research shows that we have an enduring interest in knowing who we are related to.

The combination of genetics and reproductive technologies has added a new angle to these issues. The use of donated sperm, eggs and embryos allows social and biological parentage to be separated. For children who were conceived using donated reproductive material (typically, donated sperm), their wish to obtain information about their biological parent echoes calls by adopted children for information about their birth parents. While there are these similarities with adoption, there are also obvious differences. The most obvious difference is that children conceived through artificial fertilisation techniques are generally related to one of their birth parents. However, like many adopted children, children conceived through artificial fertilisation may not be told the truth about their biological parentage.

Traditionally, donor insemination was characterised by secrecy and the statutory schemes regulating this area did not provide rights to information about biological parentage for children conceived using donated gametes, nor were rights to information about biological offspring given to those who donated gametes for use in artificial fertilisation programs. Over time in Australia and overseas, we

39 Graeme Laurie, *Genetic Privacy: A Challenge to Medico-legal Norms* (2002) 261–4. For further discussion on the right not to know see Rosalind McDougall, 'Rethinking the "Right Not to Know"' (2004) 23 *Monash Bioethics Review* 22.

40 Carol Smart, "'There Is of Course the Distinction Dictated by Nature": Law and the Problem of Paternity' in Michelle Stanworth (ed), *Reproductive Technologies: Gender, Motherhood and Medicine* (1987) 98, 99.

have seen a dramatic change in the laws and policies in this area. In part, change in this area has echoed changes in openness in the area of adoption.⁴¹ In part too, it is in line with greater recognition of children's rights⁴² and with the increasing social acceptance of assisted reproductive technology ('ART') which has lessened the pressures for secrecy. Despite this growing trend, the international literature continues to show that many parents do not tell their children the truth about their biological parentage.⁴³ Within this debate about openness, there are also concerns that donors may be unwilling to donate if they are unable to do so anonymously.

The regulation of reproductive technology in Australia is an example of the effects of federalism on the provision and regulation of health care in Australia. Under the *Constitution* there are very few powers relating to health that are given to the Commonwealth. Most powers relating to health therefore fall to the States. There has been some federal harmonisation of laws relevant to ART but this has been largely limited to the laws relating to stem cell research and cloning technologies, where there is a comprehensive framework of legislation at the Commonwealth and State level.⁴⁴ Only four States have legislation regulating the provision of ART: (1) Victoria, which first introduced legislation in the early 1980s,⁴⁵ then in 1995,⁴⁶ and last year passed new legislation, the *Assisted Reproductive Treatment Act 2008* (Vic) ('*Victorian Act*'); (2) South Australia;⁴⁷ (3) Western Australia;⁴⁸ and, most recently, (4) New South Wales.⁴⁹ For those States without such legislation, the NHMRC's *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research*⁵⁰ ('*NHMRC Guidelines*') provide ethical guidance. Furthermore, although the *NHMRC*

41 Erica Haimes, "'Secrecy': What Can Artificial Reproduction Learn from Adoption?" (1988) 2 *International Journal of Law and the Family* 46. For further discussion of legal and social trends towards openness and access to information about biological parentage see Bennett, above n 11, ch 2.

42 Kerry Petersen, 'The Rights of Donor-conceived Children to Know the Identity of Their Donor: The Problem of the Known Unknowns and the Unknown Unknowns' in Belinda Bennett and George Tomossy (eds), *Globalization and Health: Challenges for Health Law and Bioethics* (2006) 155–7; John Tobin, *The Convention on the Rights of the Child: The Rights and Best Interests of Children Conceived through Assisted Reproduction* (2004).

43 Infertility Treatment Authority, *Donor Conception: Parents Disclosing Donor Conception to Their Children: What Does the Literature Tell Us?* (2006).

44 *Research Involving Human Embryos Act 2002* (Cth); *Prohibition of Human Cloning for Reproduction Act 2002* (Cth); *Human Cloning for Reproduction and Other Prohibited Practices Act 2003* (NSW); *Research Involving Human Embryos (New South Wales) Act 2003* (NSW); *Infertility Treatment Act 1995* (Vic); *Research Involving Human Embryos and Prohibition of Human Cloning Act 2003* (Qld); *Prohibition of Human Cloning Act 2003* (SA); *Research Involving Human Embryos Act 2003* (SA); *Human Cloning for Reproduction and Other Prohibited Practices Act 2003* (Tas); *Human Embryonic Research Regulation Act 2003* (Tas); *Human Reproductive Technology Act 1991* (WA); *Human Cloning and Embryo Research Act 2004* (ACT).

45 *Infertility (Medical Procedures) Act 1984* (Vic).

46 *Infertility Treatment Act 1995* (Vic).

47 *Reproductive Technology (Clinical Practices) Act 1988* (SA).

48 *Human Reproductive Technology Act 1991* (WA).

49 *Assisted Reproductive Technology Act 2007* (NSW). See also Malcolm Smith, 'Reviewing Regulation of Assisted Reproductive Technology in New South Wales: The *Assisted Reproductive Technology Act 2007* (NSW)' (2008) 16 *Journal of Law and Medicine* 120.

50 NHMRC, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007).

Guidelines are only guidelines, their force is strengthened by the fact that the Reproductive Technology Accreditation Committee ('RTAC') of the Fertility Society of Australia requires adherence to the *NHMRC Guidelines* as a condition of accreditation,⁵¹ while some States also expressly require compliance with the *NHMRC Guidelines* within their legislative frameworks.⁵²

Although the regulation of ART in Australia has been, and continues to be, a patchwork of legislation and guidelines,⁵³ there has been a considerable degree of uniformity in terms of addressing the legal status of children conceived using donated eggs and sperm. In all Australian States and Territories, there is legislation on the status of children conceived through artificial fertilisation procedures.⁵⁴ There are some variations between the provisions; however, the basic effect of them is to create parentage presumptions such that the sperm donor is not regarded as the legal father of a child conceived using donated sperm. Instead, the husband of the woman who underwent the fertilisation procedure with his consent is regarded as the child's legal father. If a donated egg is used, then the egg donor is not regarded as the child's legal mother. Instead, it is the birth mother who is regarded as the child's legal mother. The effect of these provisions is to support the position of the child's social parents and has traditionally been seen as being in the best interests of the family. As the Warnock Committee in the UK noted in its 1984 Report, the presumption of paternity for the 'social' father was 'consistent with the husband's assuming all parental rights and duties with regard to the child'.⁵⁵ These provisions gave the family the appearance of normality and the anonymity of the donor ensured that the family's 'non-conformity cannot be manifested in the form of a real, living person'.⁵⁶ However, although these presumptions remain, there is a growing trend towards openness, both in Australia and overseas. This openness includes greater recognition of the rights of

51 Reproductive Technology Accreditation Committee, Fertility Society of Australia, *Code of Practice for Assisted Reproductive Technology Units* (2008) critical criteria 1. See also Don Chalmers, 'Professional Self-regulation and Guidelines in Assisted Reproduction' (2002) 9 *Journal of Law and Medicine* 414; Douglas Saunders, 'The Australian Experience of Self-Accreditation' in Jennifer Gunning and Helen Szoke (eds), *The Regulation of Assisted Reproductive Technology* (2003); Kerry Petersen et al., 'Assisted Reproductive Technologies: Professional and Legal Restrictions in Australian Clinics' (2005) 12 *Journal of Law and Medicine* 373.

52 Infertility Treatment Authority ('ITA'), *Conditions for Licence* (8th ed, 2008) [1.3]. The ITA is established pursuant to the *Infertility Treatment Act 1995* (Vic) pt 9; *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995* (SA) sch cl 2A.

53 Helen Szoke, 'Australia – A Federated Structure of Statutory Regulation of ART' in Jennifer Gunning and Helen Szoke (eds), *The Regulation of Assisted Reproductive Technology* (2003) 75.

54 *Status of Children Act 1996* (NSW) s 14; *Status of Children Act 1974* (Vic) s 10D; *Family Relationships Act 1975* (SA) ss 10D, 10E; *Status of Children Act 1974* (Tas) s 10C; *Status of Children Act 1978* (Qld) s 16; *Artificial Conception Act 1985* (WA) s 6; *Parentage Act 2004* (ACT) s 11; *Status of Children Act 1978* (NT) s 5D; *Family Law Act 1975* (Cth) s 60H.

55 Dame Mary Warnock, *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, Cmnd 9314 (1984) [4.25].

56 Erica Haimes, 'Recreating the Family? Policy Consideration Relating to the "New" Reproductive Technologies' in Maureen McNeil, Ian Varcoe and Steven Yearley (eds), *The New Reproductive Technologies* (1990) 160.

same-sex couples and legislative changes to parentage laws permitting a woman's same-sex partner to be listed as the second parent on a child's birth certificate.⁵⁷

The *NHMRC Guidelines* provide clear support for openness and honesty within the family about biological origins. Paragraph 6.1 states:

Persons conceived using ART procedures are entitled to know their genetic parents. Clinics must not use donated gametes in reproductive procedures unless the donor has consented to the release of identifying information about himself or herself to the persons conceived using his or her gametes. Clinics must not mix gametes in a way that confuses the genetic parentage of the persons who are born.⁵⁸

In addition, paragraph 6.1.2 lends further support to this, stating:

Clinics should help prospective recipients to understand the significant biological connection that their children have with the gamete donor. Recipients should be advised that their children are entitled to knowledge of their genetic parents and siblings; they should therefore be encouraged to tell their children about their origins.⁵⁹

Each of the States with legislation regulating assisted conception has provisions addressing the issue of access to information when donated gametes have been used. In each State, the gamete donor and an adult donor offspring are entitled to apply for access to information about each other.⁶⁰ Yet, this move to openness has been a gradual one. The transformation in social attitudes towards openness about gamete donation is evident in the legislative changes in Victoria, which has had legislation governing ART for the longest period of any Australian jurisdiction. Identifying information is released if the gametes were donated after 31 December 1997; or if they were donated between 1 July 1988 and 31 December 1997 and the donor has consented to the disclosure.⁶¹ Between July 1988 and December 1997, donors were able to indicate, at the time of donation, whether they consented to identifying information about them being released to their offspring in the future. Since then, all donors have been made aware, at the time of donation, that identifying information about them might be released in the future.⁶² Prior to 1988 donations were anonymous so the Register does not hold identifying information about donors. The *Victorian Act* will also facilitate access to information for donors and children of donor conception. Importantly, one of the five guiding principles in the new Act is that 'children born as a result

57 *Artificial Conception Act 1985* (WA) s 6A; *Status of Children Act* (NT) s 5DA; *Parentage Act 2004* (ACT) s 11(4); *Status of Children Act 1974* (Vic) ss 11-13.

58 NHMRC, above n 50, [6.1].

59 *Ibid* [6.1.2].

60 *Assisted Reproductive Treatment Act 2008* (Vic) s 59(a)(ii); *Reproductive Technology (Clinical Practices) Act 1988* (SA) s 18(1); *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995* (SA) cl 36; *Human Reproductive Technology Act 1991* (WA) s 49(2); *Assisted Reproductive Technology Act 2007* (NSW) s 37(1). For discussion of the New South Wales legislation, see Julie Hamblin, 'Anonymity of IVF Donors in NSW' (2008) 88 *Precedent* 36.

61 *Assisted Reproductive Treatment Act 2008* (Vic) s 59(b).

62 Explanatory Memorandum, *Assisted Reproductive Treatment Bill 2008* (Vic) cl 59.

of the use of donated gametes have a right to information about their genetic parents.’⁶³

In Victoria, the first in-vitro fertilization (‘IVF’) donor-conceived children began to turn 18 in 2006 and were then eligible to apply for information without their parents’ consent. If the Infertility Treatment Authority (‘ITA’) contacted one of these young adults after receiving a request from a donor, there was a risk that that could be the first time the young adult found out that they were conceived through a donor program. In order to address this dilemma, the ITA has been running a public awareness campaign, called ‘Time to Tell’, to raise awareness of the rights of individuals involved in donor conception and to provide support for individuals involved in donor programs.⁶⁴

Evident within the move to openness about gamete donation is recognition that the interests of others sometimes outweigh the interests of the individual. As discussed above, this is already evident in the conceptualisation of genetic information as familial rather than individual in contrast to other forms of medical information. With gamete donation, we can see that the interests of the gamete donor to anonymity and of the infertile couple to privacy which characterised gamete donation in the early stages of IVF have been replaced with a new set of priorities which focus on the rights of the child conceived as a result of the use of donated gametes. The establishment of registers of information about the various parties and the gradual extension of rights of access to that information clearly illustrates this point.

However, the move towards openness is not absolute. Despite clear evidence of the trend away from secrecy and anonymity and towards openness, consent requirements can be seen as a limiting factor. In Victoria, for example, the new *Victorian Act* will allow a donor-conceived person to consent (or withhold their consent) to the release of their identifying information to the donor.⁶⁵ A similar provision exists in the new *Assisted Reproductive Technology Act 2007* (NSW) (‘*NSW Act*’).⁶⁶ The legislation in South Australia and Western Australia also requires consent from an individual before identifying information about them can be released.⁶⁷ The consent requirements can be seen as part of a balancing of the interests of the various parties and a reflection of the transitional nature of changes in this area. Despite the limitations imposed by consent requirements, there is a clear recognition of the importance of biological information for parties involved in assisted reproduction, particularly in the context of information about biological parentage for knowledge of inherited conditions or at least predisposition to inherited conditions. Genetics is at the heart of this trend towards openness. For example, in the *NSW Act*, the health interests of the child

63 *Assisted Reproductive Treatment Act 2008* (Vic) s 5(c).

64 For discussion see Louise Johnson and Helen Kane, ‘Regulation of Donor Conception and the “Time to Tell” Campaign’ (2007) 15 *Journal of Law and Medicine* 117.

65 *Assisted Reproductive Treatment Act 2008* (Vic) s 58.

66 *Assisted Reproductive Technology Act 2007* (NSW) s 39(2).

67 *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995* (SA) cl 36; *Human Reproductive Technology Act 1991* (WA) s 49(2).

become the primary consideration with the legislation providing that a parent will be able to apply for access to identifying information about the donor

if the disclosure of that information is reasonably necessary to save the life of the child or to prevent serious damage to the child's physical or psychological health and the information cannot reasonably be obtained by the parent in any other way.⁶⁸

If the disclosure is to prevent serious harm to the child's psychological health, the Director-General must not authorise the disclosure 'unless a registered medical practitioner with expertise in mental health or a registered psychologist has certified in writing that the damage is likely to occur unless the disclosure takes place'.⁶⁹

There is also recognition of the importance of information about biological parentage to the identity of children conceived using donated gametes. Interestingly, in some jurisdictions, the interest in having knowledge about biological relatives is recognised as being broader than simply that of parent and child. According to the *Victorian Act*, a person descended from a donor-conceived person is able to apply for information held in the Register,⁷⁰ while the *NSW Act* will allow adult donor offspring to apply for information about their donor offspring siblings.⁷¹ These new provisions, which recognise that familial interests extend beyond the circle of the infertile couple, donor and donor offspring, provide a more complete understanding of the complex ties and relationships that make up our understandings of kinship in contemporary society.

As Janet Dolgin has argued, genetics plays a central role in contemporary understandings of the family.⁷² In choosing to undergo ART procedures in an attempt to have a child who is genetically related to at least one member of the couple, and perhaps to both of them, prospective parents 'seem to envision genes as a fit foundation on which to construct familial *relationships*'.⁷³ The genetic link between parent and child is seen as helping to create a family⁷⁴ that is traditional in all respects except for its means of creation. For donor offspring searching for their biological (donor) parent, the concept of 'family' is 'constructed around suppositions about DNA and little else'.⁷⁵ There is, as Dolgin points out, no shared family history to cement the familial ties.⁷⁶ Instead, DNA is seen as the binding link to donor parents and siblings, although this is hardly surprising given the societal value attached to such information.

68 *Assisted Reproductive Technology Act 2007* (NSW) s 38(1)(c).

69 *Assisted Reproductive Technology Act 2007* (NSW) s 38(3).

70 *Assisted Reproductive Treatment Act 2008* (Vic) s 60.

71 *Assisted Reproductive Technology Act 2007* (NSW) s 37.

72 Dolgin, above n 8.

73 *Ibid* 370.

74 *Ibid*.

75 *Ibid* 386.

76 *Ibid*.

Through the development of registers and statutory provisions for access to information we are seeing a clear transition from secrecy to openness in the context of access to information about biological parentage in ART programs. As with disclosure of genetic information within the family where we have seen a transition from medical information as personal to one that recognises broader rights, so too with donor conception we are seeing a move away from a focus on the rights of parents and donors to privacy and towards openness and recognition of the interests of donor offspring to information about their biological parentage.

IV SAVIOUR SIBLINGS

One of the other ways in which genetics and reproductive technologies are reshaping our understandings of personal relationships is in the area of using these technologies to exercise choice over the characteristics of our offspring.⁷⁷ Preimplantation genetic diagnosis ('PGD') is the genetic testing of IVF embryos by removing one or more cells of the embryo and testing them in order to determine whether the embryo is suitable for transfer to the woman. Only those embryos that do not have the genetic disorder or condition will be transferred to the woman. It is used primarily to identify the sex of the embryo in relation to sex-linked inherited conditions such as muscular dystrophy or haemophilia; single gene disorders such as fragile X syndrome, cystic fibrosis and Huntington's disease; and to detect chromosomal imbalances in cases of recurrent implantation failure or recurrent miscarriage.⁷⁸ PGD has also been used to select against the genetic mutation associated with early-onset Alzheimer's disease,⁷⁹ and in the UK the Human Fertilisation and Embryology Authority ('HFEA') has decided to permit, in principle, PGD to be used to test for inherited breast, bowel and ovarian cancers.⁸⁰

The use of PGD means that couples who already have a family history of inherited disease are spared the emotional difficulties associated with having to decide whether to terminate affected pregnancies. Without the use of PGD, these couples would be faced with difficult choices if they wished to avoid having a child affected by the genetic condition. They could, for example, decide to avoid pregnancy; perhaps, to adopt children; to use donated gametes (sperm or eggs) instead of the gametes of the affected partner; or to become pregnant and to use prenatal

77 Isabel Karpin and Belinda Bennett, 'Genetic Technologies and the Regulation of Reproductive Decision-making in Australia' (2006) 14 *Journal of Law and Medicine* 127.

78 ITA, *Approved Genetic Testing* (2009) [List B] PGD Schedule – September 2009 <<http://www.ita.org.au/www/257/1001127/search.asp?frombox=true&searchstring=schedule+of+Approved+Genetic+Testing&selecttype=1>> at 3 October 2009. See also *Infertility Treatment Act 1995* (Vic) s 8(3)(b).

79 Yury Verlinsky et al, 'Preimplantation Diagnosis for Early-onset Alzheimer Disease Caused by V717L Mutation' (2002) 287 *Journal of the American Medical Association* 1018.

80 Human Fertilisation and Embryology Authority ('HFEA'), *Authority Decision on the Use of PGD for Lower Penetrance, Later Onset Inherited Conditions* (2006) HFEA, <http://www.hfea.gov.uk/docs/The_Authority_decision_Choices_and_boundaries.pdf> at 3 October 2009. See also David Cram and Adrienne Pope, 'Preimplantation Genetic Diagnosis: Current and Future Perspectives' (2007) 15 *Journal of Law and Medicine* 36, 40.

diagnosis and then decide whether to terminate affected pregnancies. Despite its advantages, PGD raises concerns about its potential eugenic effects and about the rights of parents to choose the characteristics of their children,⁸¹ the seriousness of the genetic conditions to be tested for, and the scope of laws permitting PGD.⁸² Given the choice inherent in PGD, there is debate as to whether parents, when choosing between embryos, have a duty to choose those which would have the best possible life – a duty that Savulescu calls ‘procreative beneficence’⁸³ – and whether parents should be allowed to use PGD for ‘negative enhancement’.⁸⁴ The core issue here is the scope of parental decision-making power to utilise genetic and reproductive technologies in relation to the characteristics of their (future) children.

The ability of parents to select characteristics of their offspring through the use of PGD resonates with the value contemporary society places on individual autonomy and choice, particularly, consumer choice.⁸⁵ In this context, genetics is seen not so much as the basis for familial connections, but rather as the foundation for an individual’s characteristics.⁸⁶ Here genetics may serve to destabilise traditional understandings of the role of the family in childrearing:

A serious instability can be found at the center of families defined through one generation’s autonomous (self-conscious) choices about another generation’s DNA. Perhaps most troubling, the locus of familial responsibility may shift away from parents as guides and role models towards DNA as the presumed arbiter of social behaviour.⁸⁷

PGD can also be combined with Human Leukocyte Antigen (‘HLA’) matching to conceive a child who would be both unaffected and a matched tissue donor for an existing affected child. For example, it was used for a couple who had a six-year-old child with Fanconi anaemia: the parents wanted to conceive an unaffected child who would, once born, be a matched cord blood donor for their sick child.⁸⁸

81 Bennett, above n 11, ch 4; Isabel Karpin and Belinda Bennett, ‘Freedom to Choose? Embryo Selection, Reproductive Decision-making and the Role of the State’ (2008) 88 *Precedent* 4; Michael Sandel, *The Case against Perfection: Ethics in the Age of Genetic Engineering* (2007).

82 Rosamund Scott, ‘Choosing between Possible Lives: Legal and Ethical Issues in Preimplantation Genetic Diagnosis’ (2006) 26 *Oxford Journal of Legal Studies* 153; Rosamund Scott et al, ‘The Appropriate Extent of Preimplantation Genetic Diagnosis: Health Professionals’ and Scientists’ Views on the Requirements for a “Significant Risk of a Serious Genetic Condition”’ (2007) 15 *Medical Law Review* 320; Estair Van Wagner, Roxanne Mykitiuk and Jeff Nisker, ‘The “Affected” Post-preimplantation Genetic Diagnosis Embryo’ in Belinda Bennett, Terry Carney and Isabel Karpin (eds), *The Brave New World of Health* (2008) 37.

83 Julian Savulescu, ‘Procreative Beneficence: Why We Should Select the Best Children’ (2001) 15 *Bioethics* 413. Cf Michael Parker, ‘The Best Possible Child’ (2007) 33 *Journal of Medical Ethics* 279; Robert Sparrow, ‘Procreative Beneficence, Obligation and Eugenics’ (2007) 3 *Genomics, Society and Policy* 43. See also Julian Savulescu, ‘In Defence of Procreative Beneficence’ (2007) 33 *Journal of Medical Ethics* 284.

84 Isabel Karpin, ‘Choosing Disability: Preimplantation Genetic Diagnosis and Negative Enhancement’ (2007) 15 *Journal of Law and Medicine* 89.

85 Dolgin above n 8, 378.

86 Ibid 371.

87 Ibid 379.

88 Yury Verlinky et al, ‘Preimplantation Genetic Diagnosis for Fanconi Anemia Combined with HLA Matching’ (2001) 285 *Journal of the American Medical Association* 3130.

It is also possible to use HLA testing to select HLA-matched offspring without PGD of a causative gene when an existing child has a bone marrow failure requiring compatible stem cell transplantation.⁸⁹ The idea of conceiving a child who is destined to be a tissue donor for an affected sibling is controversial and raises some interesting questions for legal regulation.⁹⁰ Should parents be allowed to choose the characteristics of their children in this way? If a child is conceived to be a compatible donor for a sibling, does this somehow limit the future for that child? Is this the wrong reason to have a child? And, importantly for lawyers, does the state have a role in regulating decisions in this area?

Evident within the statutory provisions and guidelines in this area are three key considerations: (1) the interests of the child to be born are paramount; (2) PGD with HLA matching should only be used for serious, life-threatening conditions; and (3) the use of PGD with HLA matching should be limited to situations where the child to be born will be a sibling for the affected child. That is, that these technologies should not be used to benefit family members other than siblings, thus avoiding the potential for intergenerational conflicts of interest that might arise if, for example, a child were created for the benefit of an affected parent. These considerations are reflected in the *NHMRC Guidelines*, which currently require that clinics

12.3 Seek advice before using PGD to select an embryo with compatible tissue for a sibling

Except in the case of siblings, PGD must not be used to select a child to be born with compatible tissue for use by another person.

When requested to select an embryo with tissues compatible with a sibling of a child to be born, clinics must seek advice from a clinical ethics committee (or relevant state or territory regulatory agency).

12.3.1 The ethics committee or relevant agency should ascertain that:

- the use of PGD will not adversely affect the welfare and interests of the child who may be born;
- the medical condition of the sibling to be treated is life-threatening;
- other means to manage the condition are not available; and
- the wish of the parents to have another child as an addition to their family and not merely as a source of tissue.⁹¹

89 Yury Verlinky et al, 'Preimplantation HLA Testing' (2004) 291 *Journal of the American Medical Association* 2079. See Cram and Pope, above n 80, 41.

90 Belinda Bennett, 'Symbiotic Relationships: Saviour Siblings, Family Rights and Biomedicine' (2005) 19 *Australian Journal of Family Law* 195; Sally Sheldon and Stephen Wilkinson, 'Should Select Saviour Siblings Be Banned?' (2004) 30 *Journal of Medical Ethics* 533; Katrien Devolder, 'Preimplantation HLA Typing: Having Children to Save Our Loved Ones' (2005) 31 *Journal of Medical Ethics* 582; Susan Wolf, Jeffrey Kahn and John Wagner, 'Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits' (2003) 31 *Journal of Law, Medicine and Ethics* 327.

91 NHMRC, above n 50, [12.3.1].

In Victoria, South Australia and Western Australia the effect of the legislation is to prevent the use of PGD and tissue typing solely to create a tissue-matched child for an affected sibling. In other words, PGD and HLA could be used to ensure that the embryo selected is free of the genetic disease in question, and the tissue typing will ensure that the child, once born, will be a matched donor.⁹² However, PGD could not be used in the absence of concern over transmission of a genetic condition. The *NSW Act* does not address the use of PGD, leaving the *NHMRC Guidelines* to govern this area. The new *NSW Act* also does not address eligibility criteria for ART treatment and unlike Victoria, South Australia and Western Australia does not require individuals to be infertile or at risk of passing on a genetic condition in order to be able to access ART. Accordingly, the *NSW Act* leaves open the possibility that couples could seek to use PGD purely for tissue typing purposes⁹³ and so allowing the creation of a tissue-matched child who is sick with a non-genetic condition.

The issues surrounding 'saviour siblings' once again highlight the transformative potential of genetic and other technologies, with a child's genetic and biological makeup seen as a potential resource for another family member. In contrast to the sharing of genetic information within families and access to information about biological parentage discussed above, with 'saviour siblings' we see a clear shift from information to physical biology as the focus of attention. In other words, it is not just genetic information that is a benefit to others, but rather the individual's physical makeup itself that becomes the resource for others.

In one sense, there is nothing particularly new about intra-familial tissue donations. Human tissue legislation in Australian jurisdictions permits donation of regenerative tissue to a parent or sibling,⁹⁴ or to a family member or relative,⁹⁵ while donations to others generally are not permitted.⁹⁶ This system thus recognises that medical interests are shared between close family members and

92 Infertility Treatment Authority, *Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis* (2004); *Reproductive Technology (Clinical Practices) Act 1995* (SA) s 13(3)(b)(ii); *Human Reproductive Technology Act 1991* (WA) ss 7, 14(2)(b); Western Australia Reproductive Technology Council, *Policy on Approval of Diagnostic Procedures Involving Embryos* (2008). See Michelle Taylor-Sands, 'Selecting "Saviour Siblings": Reconsidering the Regulation in Australia of Pre-implantation Genetic Diagnosis in Conjunction with Tissue Typing' (2007) 14 *Journal of Law and Medicine* 551, 558-9.

93 Taylor-Sands, above n 92, 560; Smith, above n 49, 129.

94 *Human Tissue Act 1983* (NSW) s 10; *Human Tissue Act 1982* (Vic) s 15; *Transplantation and Anatomy Act 1979* (Qld) s 12B.

95 *Human Tissue and Transplantation Act 1982* (WA) s 13; *Human Tissue Act 1985* (Tas) s 12; *Transplantation and Anatomy Act 1978* (ACT) s 13. In these jurisdictions the legislation permits transplantation to 'the body of another member of the family or to the body of a relative of the child'. In the Northern Territory the *Human Tissue Transplant Act* (NT) does not contain any provisions relating to donation of tissue by children, suggesting that donations by children are not permitted in the Northern Territory.

96 As indicated above, most Australian States and Territories limit transplantations of regenerative tissue removed from children to use for the benefit of a sibling, immediate family member or relative of the child. In South Australia the *Transplantation and Anatomy Act 1983* (SA) s 13 permits donations of regenerative tissue by a child and does not limit such donations to immediate family members, instead allowing 'transplantation of the tissue to the body of another living person referred to in the consent': s 13(1). However, the consent to the removal of the tissue must be approved by a Ministerial Committee: s 13(3).

that the chance of donor compatibility is much higher for close relatives than it is for the general population.⁹⁷ What is special about the ‘saviour sibling’ situation is that an individual is *created* for the benefit of another family member and that the individual self-ownership that we regard as an integral part of the self is, from the outset, reconfigured as familial.

Through the development and use of PGD we are seeing the transformation of reproduction through genetic technologies. Although PGD is only utilised in relation to IVF embryos and its social impact is arguably limited, the combination of genetic and reproductive technologies does alter the reproductive landscape in new ways so as to give parents unprecedented power over their prospective children in ways that do transform our understandings of the self.

V TRANSFORMING THE PERSONAL

Each of the above examples – of genetic privacy, of access to information about biological parentage in the context of gamete donation, and of the use of PGD to select the characteristics of future offspring – reveals the ways in which genetic information is impacting upon contemporary understandings of the personal and the boundaries between us and others. Discussion of genetics often focuses on the individual and the specifics of genetic difference. Genetic information is, therefore, that which marks us as individual, unique and different. Yet, as the above discussion shows, genetic information also tells a different story; one that is communal, linked and similar. It is through our genetics that we are linked to others – through our genes that are not ours alone, but also form part of our familial story, past and present, forming the biological bonds that join us to others, structuring the family and defining – at least in part – who we are and who our children will be. Through all of these ways, genetics configures us as inherently relational. As Nikolas Rose observes:

Genetic identity is thus revealed and established within a web of genetic connectedness overlaid upon a web of family bonds and family memories, with the burden of mutual obligations and caring commitments, and with all the ethical dilemmas they entail.⁹⁸

This connectedness has implications for the law. As discussed above, the relational aspects of genetic information present new challenges for legal understandings of the self. Through its inherent relatedness, genetic information presents a fundamental shift in the conceptualisation of the realm of the personal and of the self. This shift is apparent because the realm of the personal in liberal legalism is precisely that – personal. The singularity of the autonomous legal person is at the heart of the Western legal tradition and its understanding of rights and

97 A sibling has a 1:4 chance of being a compatible bone marrow donor for a sick sibling: Children’s Cancer Centre, ‘Types of Bone Marrow Transplants’ (2009) Royal Children’s Hospital Melbourne <www.rch.org.au/cc/treatments.cfm?doc_id=11595> at 3 October 2009.

98 Rose, above n 7, 111–12.

entitlements. Genetic information represents the shifting sands undermining this tradition. As Karpin notes:

biogenetic discourses, which emphasize shared identity and participation in the common genetic pool, reveal the monstrousness in all of us. This is challenging to law because such discourses expose the impossibility of the autonomous, self-sufficient individual of liberal legalism.⁹⁹

In this sense, then, genetic information has a transformative potential. It provides opportunities for new understandings of the placing of the individual in relation to others and, in so doing, stamps us not as the isolated, autonomous individuals of liberal legalism but rather as connected, linked and tied to others in ways that can be complex, messy and challenging. Genetic information positions the individual at the heart of liberal legalism as relational rather than separate and thus demands a rethinking of the core premises upon which the dominant discourses of legal theory are built. It could be argued that family law also recognises individuals in relational ways and that there is nothing inherently new about genetics. Certainly, laws relating to marriage, divorce and custody of children are directly concerned with the relationships between individuals. The argument in this paper is that genetic information moves beyond the relationships *between* individuals and configures the individuals *themselves* as relational, at a genetic level, in ways that challenge the construction of the autonomous self within Western legal thought.

Developments in both modern genetics and reproductive technologies have presented, and are continuing to present, a range of new ethical and legal challenges in terms of the way we manage personal information and personal choices. Information about genetic health, biological parentage, and reproductive decision-making touches people's lives in deeply personal ways. The laws and policies governing these areas are complex, and scientific advances are often well ahead of legal reforms. There is a continuing role for lawyers in ensuring that our laws are well-crafted, that they are in keeping with national and international developments, and that the rights and interests of those touched by them are fully taken into account. As the above discussion shows, genetics is reshaping our understandings of the personal in some fundamental ways that present important challenges for law and ethics. The question of whose rights and interests are to be taken into account (and how that should be done) remains one of the enduring challenges for contemporary health law and policy.

⁹⁹ Isabel Karpin, 'Genetics and the Legal Conception of Self' in Margrit Shildrick and Roxanne Mykitiuk (eds), *Ethics of the Body: Postconventional Challenges* (2005) 195, 196.