# WHAT ABOUT ME? HOW FAR DO WE GO IN THE INTERESTS OF THE CHILD IN ASSISTED REPRODUCTIVE TECHNOLOGY

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The interests and welfare of children born with the assistance of ART are required to be addressed under State ART legislation and professional guidelines. However, these provide little guidance on what is meant by 'interests' or 'welfare'. By examining the legislation, guidelines and regulating authorities' own documents, together with recent court decisions at two frontiers relevant to ART, claims arising following negligent pre-implantation genetic diagnosis and posthumous reproduction, this article considers how far to go in interpreting the terms. It concludes that the courts have provided little guidance on the issue and therefore society must consider some difficult issues.

### I INTRODUCTION

The legislation regulating assisted reproductive technology (ART) in Victoria, South Australia (SA) and Western Australia (WA) all address the interests and welfare of children to be born with the assistance of ART. However, none of the relevant Acts describe what those interests are. Nor do they explain what is meant by welfare. In those States without specific ART legislation that instead rely on professional self-regulation, a similar problem arises. Further, while commentators often note that the interests and welfare of the child must be weighed in making decisions regarding ART, they rarely discuss what they mean by these terms. Even in the United Kingdom where the relevant authority, the Human Fertilisation and Embryology Authority, has recently reviewed how children's welfare is to be taken into account in decisions by ART clinics, there is little explanation of the term. The UK legislation is so vague in this

<sup>1</sup> Infertility Treatment Act 1995 (Vic); Reproductive Technology (Clinical Practices) Act 1988 (SA); Human Reproductive Technology Act 1991 (WA).

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For example, see L Fong, 'Balancing Rights and Interests in Access to Infertility Treatment' (2003) 9

\*Auckland University Law Review 1181; B Bennett, 'Posthumous Reproduction and the Meanings of Autonomy' (1999) 23 \*Melbourne University Law Review 286, 303.

<sup>&</sup>lt;sup>3</sup> Human Fertilisation and Embryology Authority, *The Code of Practice* 6<sup>th</sup> ed (2003) Part 3 < http://www.hfea.gov.uk/en/371.html> at 11 April 2007. See also *Human Fertilisation and Embryology Act* 1990 (UK), ss 13(1) and (5).

regard that commentators have observed that the welfare principle fails to specify 'what a child's welfare consists in'.<sup>4</sup>

Recently, there have been developments in Australia at a number of legal frontiers pertinent to the breadth of prospective children's 'interests' in ART. Two in particular, negligence in pre-implantation genetic diagnosis (PGD) recently addressed by the High Court, and posthumous reproduction recently reconsidered by the Victorian courts, bring the matter of prospective children's interests and welfare to the forefront. Whilst interests and welfare could consist of an extensive list of matters, the genetic inheritance and subsequent physical wellbeing of any prospective child will be closely determined by the manner in which ART is undertaken. These matters are the focus of this paper. Using the recent case law, legislation, professional guidelines and the regulating authorities' own documents, this article examines how 'interests' and 'welfare' has been and could be interpreted by the courts and other relevant bodies in the context of the physical wellbeing of children to be born with the assistance of ART.

### II ART REGULATION AND THE CHILD'S INTERESTS AND WELFARE

The Victorian ART legislation addresses the interests of prospective children in its guiding principles which are to inform the work of the statutory authority established under the Act, the Infertility Treatment Authority (ITA). The first and most important of these is that 'the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount'. Similarly, South Australian legislation provides that the welfare of any such child 'must be treated as of paramount importance'. In WA the objects of its ART legislation include ensuring that 'the prospective welfare of any child to be born consequent upon a procedure to which this Act relates is properly taken into consideration'. As noted in the Introduction above though, none of the legislation attempts to explain what is meant by interests or welfare in this context.

In those States without ART legislation, accreditation and self-regulation occurs under the National Health and Medical Research Council (NHMRC) Guidelines<sup>8</sup> and the Fertility Society of Australia's Reproductive Technology Accreditation Committee (RTAC) Code of Practice.<sup>9</sup> Once again whilst reference is made to the paramountcy of the welfare of people who may be born as a result of the use of ART, <sup>10</sup> there is no explanation of what is meant by welfare.

Regulation of ART clinical practice and research in Victoria, SA and WA is undertaken by statutory authorities established under their respective ART legislation, through a licensing system and imposition of conditions on such licences. The ITA is the most

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J A Laing and D S Oderberg, 'Artificial Reproduction, the "Welfare Principle", and the Common Good' (2005) 13 *Medical Law Review* 328, 330.

<sup>&</sup>lt;sup>5</sup> Infertility Treatment Act 1995 (Vic) s 5.

Reproductive Technology (Clinical Practices) Act 1988 (SA) s 10(2). See also Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995 (SA) r 13.

Human Reproductive Technology Act 1991 (WA) s 4(1)(d)(iv).

For example, Australian Government, NHMRC, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research (September 2004).

Reproductive Technology Accreditation Committee, Fertility Society of Australia, *Code of Practice for Assisted Reproductive Technology Units*, (4<sup>th</sup> revision, February 2005).

NHMRC Guidelines, above n 8, para 2.5. See also para 5.1.

directive of these authorities.<sup>11</sup> Pursuant to the Victorian authority's *Conditions for Licence*,<sup>12</sup> professional guidelines such as the NHMRC Guidelines and the RTAC Code of Practice also apply in Victoria.<sup>13</sup> They also apply in SA and WA.<sup>14</sup> However, if there is any inconsistency between the legislation and the guidelines, the legislation prevails.

The test for eligibility for ART in the various Acts provide little guidance on what matters are included in interests or welfare with respect to the prospective child although they do reflect an interest in health by referring to the prevention of transmission of disease. Eligibility is largely based on issues concerning the woman's fertility but treatment procedures are permitted where there is, in Victoria, a possibility that 'a genetic abnormality or a disease might be transmitted' to the prospective child or in SA, a 'risk that a genetic defect would be transmitted'. However, the legislation does not provide for what procedure can or must occur in such cases or what type of disease or defect is meant.

The WA legislation goes further than its' Victorian and SA counterparts. Whilst it provides that ART may be carried out where the child 'would otherwise be likely to be affected by a genetic abnormality or a disease', <sup>16</sup> it also provides that the licensee must give consideration to the welfare and interests of any prospective child. <sup>17</sup> ART may proceed provided that such consideration 'does not show any cause why the procedure should not be carried out'. <sup>18</sup> It is not clear how broadly this is to be interpreted. There are no eligibility requirements in the NHMRC Guidelines.

### III CHILDREN'S INTERESTS IN PGD

### A ART Regulation and Statutory Authorities' Practice

PGD combines IVF with genetic testing. A single cell is taken from *in vitro* embryos and genetically tested and their chromosomes analysed. Embryos for implantation are then selected on the basis of the results, allowing the avoidance of prospective children with unwanted attributes. <sup>19</sup> The Victorian and WA Acts allow PGD to occur in cases where a 'genetic abnormality or disease' may be transmitted to the prospective child. <sup>20</sup> Whilst such testing to avoid such diseases could be viewed as an interest of the child that would be included within the meaning of the word 'interests', the legislation gives no guidance on when PGD can be used other than providing that it can't be used for

Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995 (SA) r 2A; Directions under the Human Reproductive Technology Act 1991 (WA), WA Government Gazette, 30 November 2004, No 201, Special, para 1.1.

K Petersen et al, 'Assisted Reproductive Technologies: Professional and Legal Restrictions in Australian Clinics' (2005) 12 *Journal of Law and Medicine* 373, 376.

ITA, Conditions for Licence. Clinic, Hospitals and Day Procedure Centres, (7th ed, August 2006).

<sup>13</sup> Ibid s 1.2. RTAC above n 9 and NHMRC Guidelines, above n 8, s 1.3.

Infertility Treatment Act 1995 (Vic) s 8(3)(b); Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995 (SA) r 11(1)(b)(i)(B).

<sup>&</sup>lt;sup>16</sup> Human Reproductive Technology Act 1991 (WA) s 23(a)(ii).

Human Reproductive Technology Act 1991 (WA) s 23(e)(ii).

<sup>&</sup>lt;sup>18</sup> Human Reproductive Technology Act 1991 (WA) s 23(e).

<sup>19</sup> ITA, Genetic Testing and the Requirements of the Infertility Treatment Act 1995: Policy in Relation to the Use of Preimplantation Genetic Diagnosis (PGD) (April 2006) 1.

Infertility Treatment Act 1995 (Vic) s 8(3)(b); Human Reproductive Technology Act 1991 (WA) s 14(2b)(a)(ii).

social sex selection.<sup>21</sup> The Acts do not specify what is considered to be a '(serious in the case of WA) genetic abnormality or a disease'.<sup>22</sup>

The Victorian ITA's legal advice is that there is evidence that Parliament, in passing the legislation, 'intended the words receive a broad, purposive interpretation'. <sup>23</sup> But rather than Parliament specifying when PGD can be used, it is left to the doctor to decide whether the facts justify PGD. <sup>24</sup> The ITA has created a policy on PGD to assist clinicians and medical professionals in making those decisions. <sup>25</sup> The ITA's licensing power under the legislation is used to ensure the policy is followed.

Pursuant to the ITA's PGD policy, PGD may be offered by licensed clinics for genetic testing and most established uses do not require pre-approval from the ITA. However, in a small group of cases, notification to or pre-approval from the ITA is required. This includes where a particular use of PGD has not previously arisen. Importantly for this study, one of the criteria for assessment used by the ITA in such cases is that the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount. So, for example, PGD cannot be used to select for a disability, such as hereditary deafness. This is justified by the ITA as being because it would be contrary to the first guiding principle of the Act, namely the 'welfare and interests' of the child. But there is no indication of what those 'interests' include.

The WA legislation also creates a system for approval by the relevant statutory authority of diagnostic procedures on embryos although it has no specific list of preapproved conditions.<sup>30</sup> Each case requires approval from the Authority.<sup>31</sup> The Act requires satisfaction that the embryo is unlikely to be rendered unfit for implantation and that there be a serious risk of a serious genetic abnormality or disease in the embryo.<sup>32</sup> The WA Authority's own guidelines state approval will be based on a clinical geneticist's assessment. That assessment is to include consideration of the physical impairment caused by the disease and the resulting difficulties for the prospective child.<sup>33</sup> The NHMRC Guidelines provide that PGD must not be used for

That is, sex selection for non medical reasons. *Infertility Treatment Act 1995* (Vic) s 50; WA, Reproductive Technology Council, *Approval for Diagnostic Testing of Embryos. Advice to Clinics*, (Nov 2004) 5.

<sup>&</sup>lt;sup>22</sup> Infertility Treatment Act 1995 (Vic) s 8(3)(b); Human Reproductive Technology Act 1991 (WA) s 14(2b)(a)(ii). See also s 7.

<sup>&</sup>lt;sup>23</sup> PGD Policy, above n 19, 4.

<sup>24</sup> Ibid

<sup>25</sup> Ibid

<sup>&</sup>lt;sup>26</sup> See ibid 5 s 5.1 and ITA, Approved Genetic Testing. September 2006, List A and List B.

See PGD Policy, above n 19, 5 ss 5.2 and 5.3 and ITA, *Approved Genetic Testing. September 2006*, List C.

<sup>&</sup>lt;sup>28</sup> PGD Policy, above n 19, 6 s 6(a).

<sup>&</sup>lt;sup>29</sup> Ibid 2.

Directions under the Human Reproductive Technology Act 1991 (WA), WA Government Gazette, 30 November 2004, No 201, Special, paras 9.9-9.11.

WA, Reproductive Technology Council, Approval for Diagnostic Testing of Embryos. Advice to Clinics (Nov 2004) 4.

Human Reproductive Technology Act 1991 (WA) s 14(2b).

WA, RTC Advice, above n 31, 4-5. This is repeated on the application form.

'prevention of conditions that do not seriously harm the person to be born'. 34 They, like the Victorian and WA regimes, also prohibit social sex selection.<sup>35</sup>

Certainly then, both the Victorian and WA Authorities and NHMRC interpret the child's interests and welfare in the context of PGD as including an interest in avoiding serious harm or death due to genetic abnormality or disease (although what serious means is not explained) but not including an interest in being a sex chosen by their parents for social reasons. The SA legislation does not address PGD.

### В Wrongful Life Claims

The United Nations Convention on the Rights of the Child, 36 which Australia has ratified,<sup>37</sup> provides that in all actions concerning children by courts of law and authorities, amongst others, 'the best interests of the child shall be a primary consideration'. <sup>38</sup> Pursuant to Australian law, children, as legal persons, have the same rights and interests in having reasonable care taken with respect to them as anyone else. Further, provided the child is born alive, they can sue someone who caused them harm while in utero.<sup>39</sup> Even if the injury occurs while the child is still an embryo yet to be implanted or where the gametes are being collected for implantation, a duty of care can Again though, the child must be born alive because for the purposes of negligence law, until a child is born alive it is not a legal person.<sup>41</sup>

Two related legal claims are particularly relevant where a child is born with disabilities because of alleged negligence in prenatal testing, PGD or genetic counselling. The first, wrongful birth claims, are not particularly relevant here because they concern the rights of parents to bring an action against a professional where negligence leads to the birth of a child. Wrongful birth actions are generally considered to be a fairly straightforward extension of traditional negligence law and it is clear from the High Court's decision in Cattanach v Melchior that parents can be compensated. 42 Where, for example, there is evidence of inadequate testing or counselling, courts would have little difficulty in holding that the physician, scientist or counsellor involved has violated the duty of care owed to the parents and that this breach of duty was the cause of the birth of the child.<sup>43</sup>

Ibid Guidelines 11.1 and 12.2; WA RTC Advice, above n 31, 5.

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NHMRC Guidelines, above n 8, Guideline 12.2.

Opened for signature 20 November 1989, ATS 1991 no 4, arts 7, 8, (entered into force 2 September

As to the significance of the Convention in ascertaining the rights of children see J Tobin, The Convention on the Rights of the Child: The Rights and Best Interests of Children Conceived Through Assisted Reproduction (Victorian Law Reform Commission, 2004) 2. See also Minister for Immigration and Ethnic Affairs v Teoh (1995) 128 ALR 353, 365.

Convention on the Rights of the Child, opened for signature 20 November 1989, ATS 1991 no 4, art 3(1) (entered into force 2 September 1990).

Watt v Rama [1972] VR 353 (FC).

<sup>40</sup> X and Y (By Her Tutor X) v Pal (1991) 23 NSWLR 26, 30, 37.

K v T [1983] 1 Od R 396, aff'd on appeal in Attorney-General (ex rel Kerr) v T (1983) 1 Od R 404, 406-7; *In the Marriage of F* (1989) 13 Fam LR 189.

Cattanach v Melchior (2003) 215 CLR 1.

The parents must also show of course, that if there had been no negligence, the child would not have been born. It is not necessary that the child be disabled for this action to succeed.

The second claim more relevant to children's interests is the wrongful life claim. In this type of claim, the proceedings are taken by or on behalf of the child.<sup>44</sup> In these cases, the child alleges that but for the negligence of the professional they would not have experienced a life of suffering. The plaintiff infant, to sustain a cause of action for wrongful life and recover damages, must exhibit some defect, physical affliction or disability.

On 11 March 2002, wrongful life proceedings were commenced in Supreme Court of NSW on behalf of three severely disabled children. Two of these were ultimately appealled to the High Court and the decisions in them were the first High Court decisions on wrongful life in Australia. The first action, *Harriton v Stephens* (*'Harriton'*), involved disabilities to a child caused by maternal illness. These disabilities followed an alleged failure to diagnose rubella in the mother's first trimester of pregnancy. It was alleged that although the mother was displaying symptoms of rubella and expressly asked her doctor whether it was rubella, she was told that she didn't have rubella. The mother relied on the advice and continued the pregnancy. In 1980 the woman gave birth to a child, Alexia, with very severe rubella related disabilities including blindness, deafness, mental retardation, spasticity, inability to care for herself and the need for 24 hour care.

The second action, Waller v James; Waller v Hoolahan48 ('Waller'), concerned disabilities caused by the transmission of characteristics through genetic inheritance. It was alleged that if the parents had received adequate genetic counselling they would not have conceived a child. Instead a child, Keedon, was conceived and born in 2000 with the assistance of IVF. The father of the boy had a gene for a blood clotting disorder<sup>49</sup> which increases the propensity of blood to clot. The father was being treated by his GP for his condition and the couple's obstetrician was told this by both the GP and the father himself. The father's sperm was tested by Sydney IVF to determine if there was a genetic cause for his low sperm count and poor sperm motility; not to assess the genetic basis of the clotting disorder. The parents were recommended to have IVF, and the mother went on to become pregnant. During her pregnancy, the couple consulted a second obstetrician for prenatal care and prenatal tests for Down syndrome. One day after leaving hospital, Keedon suffered a cerebral thrombosis because of the clotting disorder he had inherited from his father, resulting in permanent brain damage, cerebral palsy and uncontrolled seizures. The parents were never told there could have been a genetic cause of the father's condition.

In both cases, the particular circumstances giving rise to the risk of the child being born with disabilities could not have been prevented by the professional. Both Alexia and

Note Kirby's J observations on the danger of labels like 'wrongful life'. *Harriton v Stephens* [2006] HCA 15 (9 May 2006) [8]–[13].

Edwards v Blomeley [2002] NSWSC 460 (Unreported, Studdert J, 12 June 2002); Harriton v Stephens [2002] NSWSC 461 (Unreported, Studdert J, 12 June 2002); Waller v James [2002] NSWSC 462 (Unreported, Studdert J, 12 June 2002). See further, M Ryan, 'Lives That Should Never Have Been?' (2002) 76 Law Institute Journal 44.

Harriton [2006] HCA 15 (Unreported, Gleeson CJ, Gummow, Kirby, Hayne, Callinan, Heydon and Crennan JJ, 9 May 2006); (2006) 226 ALR 391.

The proceedings were conducted on the basis of a set of agreed facts.

Waller [2006] HCA 16 (Unreported, Gleeson CJ, Gummow, Kirby, Hayne, Callinan, Heydon and Crennan JJ, 9 May 2006); (2006) 226 ALR 457.

Factor III deficiency, also known as anti-thrombin 3 or AT3 deficiency.

Keedon were always going to be the way they are if they were born. But in each case, it was alleged that the professionals involved failed to detect and advise the parents of the children of the existence of those circumstances. It was alleged that if the professionals had properly advised the parents, the parents would have taken steps to ensure, in the case of Alexia, the plaintiff would not have been born, or in the case of Keedon, not have been conceived.

A majority in both the NSW Court of Appeal (2:1, Mason P dissenting) and the High Court (6:1, Kirby J dissenting) dismissed the plaintiffs' appeals. Crennan J, with whom the majority of judges of the High Court agreed, concluded that '[l]ife with disabilities, like life, is not actionable'. Academics have split on whether or not this attitude is consistent with tort law principles. However, whilst there is considerable literature about wrongful life proceedings, little comment has been made on the ramifications of the courts' attitude to it for ART. Importantly for this study, in addition to settling that wrongful life claims are not possible in Australia, the decisions referred to above also comment on genetics and ART as well as 'interests' in the context of children born with the assistance of ART. It is in this context that the decisions of both the Court of Appeal and High Court will now be explored.

### 1 Starting point for considering such claims

The contrast in judges' attitudes towards the fast moving pace of genetics and PGD is particularly relevant to a study of the judiciary's attitude to the interests of prospective children in ART. Ipp JA of the NSW Court of Appeal was concerned that discoveries and potential discoveries in the field of genetics should make courts extremely cautious in extending the law of negligence to wrongful life claims, saying:

discoveries and potential discoveries in the field of genetics should make courts cautious in altering established principle so as to accommodate claims for wrongful life. At this stage of genetic science it is simply not possible to know what consequences would follow from the making of such changes. <sup>54</sup>

The cautious approach of the lower court can be contrasted with that of Kirby J in the High Court. Kirby J disagreed with Ipp JA's cautious attitude, saying:

Whether this Court likes it or not, genetic testing and other sophisticated technology is playing an increasingly significant role in reproductive decision-making ....

Tort law, by the threat of a liability to pay damages, can stimulate and require those who offer genetic services to take reasonable care in delivering those services. The prospects

For an analysis of the NSW Court of Appeal decision see G Kapterian, 'Harriton, Waller and Australian Negligence Law: Is There a Place for Wrongful Life?' (2006) 13 *Journal of Law and Medicine* 336; B Madden, 'Wrongful Life: "Born Disabled to a Catastrophic Degree" [2004] *Law Society Journal* 70.

In *Harriton*, Hayne and Callinan JJ deliver separate judgments and in *Waller*, Callinan J delivers a separate judgment.

<sup>&</sup>lt;sup>52</sup> Harriton [2006] HCA 15 (9 May 2006) [278].

For example, compare with D Stretton, 'The Birth Torts: Damages for Wrongful Birth and Wrongful Life' (2005) 10 *Deakin Law Review* 319; A Grey, 'Harriton v Stephens: Life, Logic and Legal Fictions' (2006) 28 *Sydney Law Review* 545; with S Todd, 'Wrongful Conception, Wrongful Birth and Wrongful Life' (2005) 27 *Sydney Law Review* 525.

Harriton (by her tutor) v Stephens; Waller (by his tutor) v James & Anor; Waller (by his tutor) v Hoolahan (2004) 59 NSWLR 694 [338] (Court of Appeal).

of discoveries in genetic science support, rather than detract from, the need for judicial elaboration of tort law in this area.<sup>55</sup>

Kirby J of the High Court was concerned that if the court failed to find that a duty was owed, the court would be giving doctors an exceptional immunity and would not be encouraging a proper standard of care in the future – one of the purposes of torts law. <sup>56</sup> It can be observed here that children, the same as adults, have an interest in proper care.

With respect to the claims before him, Kirby J goes on to say that unless there is some consideration justifying otherwise, these claims are like those cases establishing that a duty not to harm babies *in utero* is owed and there should be a duty of care here. The view of Kirby J though should be contrasted with the attitude of the majority of the High Court, represented by Crennan J, who said that Harriton's claim was a novel case. In novel cases, Crennan J said, the plaintiff's case needs to be one where the law can recognise a duty as a matter of principle and the plaintiff needs to be able to prove actual loss or damage has been suffered as a consequence of that duty. She went on to say that '[p]roving that actual loss or damage has been suffered requires proof of interference with a right or interest recognised as capable of protection by law' (emphasis added).<sup>57</sup>

### 2 Does the prospective child have a 'right' or 'interest'?

So, does the prospective child have such a right or interest? The plaintiff submitted in *Waller* that there should be such an interest, at least in cases of transmission of genetic disease as in Keedon's case. It was submitted that:

IVF is an important field of medical practice, that public policy and widespread community values (gleaned from legislation permitting IVF procedures) support parents who decide in particular cases that the transmission of genetic disease would not be in the best interests of a "potential child", and that IVF processes are specifically indicated to prevent the selection and implantation of embryos which would have such a disease.<sup>58</sup>

The majority of the High Court interprets the 'right or interest' that the plaintiff is asking for, as being a right or interest of a foetus to be aborted. In contrast to Kirby J's attitude, Crennan J, with whom the majority agreed, concludes that this is different to the right not to be physically injured by defendant while *in utero*. A particular concern for Crennan J in recognising the right or interest she defines is that it may create inconsistent duties for medical professionals, and a duty to take reasonable care for two different people where what is required of the professional by those people may conflict. That inconsistency would also, Crennan J thought, make it difficult for the court to determine what reasonable care required in the circumstances. In support of those concerns, Crennan J notes that the law doesn't require a foetus's best interests to be considered when making decisions as to the lawfulness of an abortion on basis of

<sup>&</sup>lt;sup>55</sup> Harriton [2006] HCA 15 (9 May 2006) [152].

Such an attitude is consistent with Kirby J's reasoning in *Cattanach v Melchior* where one reason for his finding medical professionals liable to parents was concern that the purposes of torts law be fulfilled. (2003) 215 CLR 1, [149], [161].

<sup>&</sup>lt;sup>57</sup> Harriton [2006] HCA 15 (9 May 2006) [225].

<sup>&</sup>lt;sup>58</sup> Waller [2006] HCA 16 (9 May 2006) [82].

<sup>&</sup>lt;sup>59</sup> Harriton [2006] HCA 15 (9 May 2006) [245].

<sup>60</sup> Ibid [249].

<sup>61</sup> Ibid.

the mother's physical and mental health<sup>62</sup> and nor can a doctor make a woman abort where pregnancy is risky to the mother's health or the foetus may be affected by rubella. As Crennan J expresses it, damage to Alexia is 'contingent on the free will, free choice and autonomy of the mother'.<sup>63</sup>

A number of responses can be made to these points.<sup>64</sup> First, as was the case in both these proceedings, if the mother does not have all the information that she reasonably could have (and is legally entitled to) how can the outcome be the result of her free will, free choice or autonomy? Secondly, it can be queried whether a duty to the child that requires medical professionals to provide information they were already under a duty to the mother to provide, really produces such a conflict for the professional, that the child's interests or rights should be denied? As noted by Kirby J, it is no answer that, in some States, the mother may have an action against the professional in respect of the negligence: she is not obliged to use the money for her child and may choose not to sue.<sup>65</sup> Finally, while the foetus's best interests are not paramount in decisions regarding abortion, they are considered. The starting point of laws regarding abortion in Victoria is that abortion is unlawful unless the risks to the mother justify otherwise.<sup>66</sup>

### 3 Causation

It is trite law that in any negligence proceedings, it must be shown that the defendant's breach of duty caused harm to the plaintiff. In the context of wrongful life proceedings Hayne J, a member of the majority in the High Court decision, points out that because these children could never have a life without disabilities, they could not show they had been damaged by the defendant's negligence. If the defendants were made to compensate them, they would be compensating the children for injuries they did not cause.

On the other hand, as Kirby J (in dissent) says, it is true the defendants did not cause Alexia's disabilities. But as Kirby J notes, doctors seldom do cause a patient's illness. For example, where they misdiagnose a lump in the breast losing the patient the chance for successful surgery the doctor did not cause the cancer. Nevertheless they can still be liable for the pain and cost of treating the illness that would have been prevented or cured by reasonable medical attention. Here Kirby J said, the only way to prevent Alexia's suffering would be to terminate the pregnancy and the defendant took away the chance to do that and so 'caused' the plaintiff's damage.

The attitude of Kirby J on this issue can also be seen in the dissenting judgment in the NSW Court of Appeal, of Mason P. Mason P perhaps reflects modern society's view in

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<sup>&</sup>lt;sup>62</sup> Ibid [247].

<sup>63</sup> Ibid [248].

<sup>64</sup> See also Grey, above n 53, 554-6.

<sup>65</sup> Ibid [147].

See Crimes Act 1958 (Vic) ss 65–6 and the 'Menhenitt rules' from R v Davidson [1969] VR 667, 672.

Harriton [2006] HCA 15 (9 May 2006) [270]. See also R Sharman, 'Wrongful Life Actions: The Legal and Ethical Hurdles' (2001) 9 Journal of Law and Medicine 233, 234.

<sup>&</sup>lt;sup>68</sup> Harriton [2006] HCA 15 (9 May 2006) [270].

<sup>69</sup> Harriton (2004) 59 NSWLR 694, 714 [110] (Mason P) cited by Kirby J Harriton [2006] HCA 15 (9 May 2006) [39].

<sup>&</sup>lt;sup>70</sup> Harriton [2006] HCA 15 (9 May 2006) [40].

his observation that '[i]n the realm of genetic diseases, we are no longer content to view as fate abnormalities preventable by widely-used screening techniques.'<sup>71</sup>

### 4 Amount of compensation payable

To show damage, the plaintiff must show that they are worse off as a result of the damage than if there had been no negligence. The Crennan J says that in wrongful life claims, the court would need to find that non-existence is better than life with disabilities and that it is impossible for the court to decide that. She says:

There is no practical possibility of a court (or jury) ever apprehending or evaluating, or receiving proof of, the actual loss or damage as claimed by the appellant. It cannot be determined in what sense Alexia Harriton's life with disabilities represents such a loss, deprivation or detriment compared with non-existence.<sup>73</sup>

Kirby J on the other hand says that the law already recognizes that in some cases non-existence is preferable to existence. For example, when life support is withdrawn from the terminally ill or severely disabled newborns, the separation of conjoined twins and the legalisation of suicide. Further, courts can value nebulous matters such as 'pain and suffering' and damages in wrongful birth cases, so why can't the courts assess damages here? As Mason P in dissent in the NSW court expresses it, the complaint is as to the children's present and future suffering and the needs it creates and the court is capable of assessing that. Finally, Kirby J says difficulties of quantification do not preclude relief if the plaintiff suffers actionable damage.

## 5 What level of disability is required?

As noted above, the majority of the High Court held that the children had no legal claim. But we know from the fact that PGD is permitted under the Victorian and WA regimes and NHMRC Guidelines that the respective State Parliaments and the authorities consider that children have some recognised 'interest' in PGD being done. But at what level of disability does that interest arise?<sup>77</sup>

In the NSW Court of Appeal, Mason P noted that wrongful life actions concern serious disabilities, not trivial issues like a child born with a squint. However, as both Crennan and Kirby JJ of the High Court note, if a particular level of injury is required before a duty can be owed in these cases, then these claims would be different to the rest of negligence where there is no common law level of property damage or personal injury that must be met before a duty is owed. In reality, these concerns are to some extent answered for negligence purposes by the fact that, as noted by Kirby J, in cases of minor defects, plaintiffs would be unable to show non-existence was preferable to life with a minor defect. Kirby J says:

<sup>72</sup> Ibid [251] (Crennan J).

<sup>&</sup>lt;sup>71</sup> Ibid [110].

<sup>&</sup>lt;sup>73</sup> Ibid [253]. See also *Harriton* (2004) 59 NSWLR 694 [232] (Ipp JA).

The courts in such cases are not giving a monetary figure to the issue but are still comparing existence with non-existence. *Harriton* [2006] HCA 15 (9 May 2006) [95].

<sup>&</sup>lt;sup>75</sup> *Harriton* (2004) 59 NSWLR 694 [155].

<sup>&</sup>lt;sup>76</sup> Harriton [2006] HCA 15 (9 May 2006) [84].

As to appropriateness of courts drawing a line in these circumstances, see Todd, above n 53, 540-2.

<sup>&</sup>lt;sup>78</sup> *Harriton* (2004) 59 NSWLR 694 [135].

<sup>&</sup>lt;sup>79</sup> *Harriton* [2006] HCA 15 (9 May 2006) [126].

Equally, proving breach of the duty of care would be problematic. For instance, in wrongful life actions arising out of failure to diagnose or a failure to warn, depending on the evidence, it may often be reasonable for the defendant to abstain from conducting tests for "minor defects" or from warning the prospective mother about such risks. 80

Nevertheless, in the context of understanding children's interests regarding ART (and PGD at least), society still must consider this issue because, as discussed above, the Victorian and WA Parliaments and Authorities and the NHMRC consider children's interests in PGD as at least including an interest in avoiding serious harm or death and PGD is taking place on that basis. Unfortunately, although some members of the NSW Court of Appeal explored this issue, only Kirby J pursued it in the High Court.

### In the NSW Court of Appeal, Ipp JA said:

the ethical and legal difficulties that will arise from this novel area of human endeavour are infinite and are as yet unfathomable. Some more obvious questions come to mind: will children be able to sue medical practitioners who fail to advise their parents that, for genetic reasons, they might become seriously disabled when, say, 35 years of age? Or that, for genetic reasons, they might be prone to serious depression? Or that they might be genetically programmed to commit acts of criminal violence? And what will be the duties of medical practitioners to carry out genetic testing? These difficult questions show the potentially far-reaching and incalculable reach of the changes to principle for which the appellants, in effect, contend.<sup>81</sup>

Spegilman CJ, the second member of the majority in the NSW decision, said:

the case raises an important issue of how public policy should respond to the practicability of eugenics.

The identification of what is to be regarded as "acceptable" physical characteristics of children is a field into which the law should not, at least at this stage of the development of knowledge, in my opinion, enter. Specifically, the law should be very slow to decide how much "disability" is to be regarded as acceptable. Is, for example, hereditary deafness enough? ... It is a short step to being asked to compensate for disappointed expectations about physical characteristics which parents wished their children to have. 82

Kirby J in *Harriton* responds to this by saying that courts are continually involved in line-drawing. <sup>83</sup> Unfortunately there were no further comments by the High Court. Given that this type of line drawing occurs whenever day to day decisions are made regarding PGD, it requires an answer, even if the courts refuse to assist children who suffer because of it.

IV CHILDREN'S INTERESTS IN POSTHUMOUS REPRODUCTION

A ART Regulation and Statutory Authorities' Practice

<sup>80</sup> Ibid.

<sup>81</sup> Harriton (2004) 59 NSWLR 694 [347].

<sup>82</sup> Ibid [30-1]

<sup>83</sup> *Harriton* [2006] HCA 15 (9 May 2006) [108].

Posthumous reproduction, that is, reproduction using gametes, usually sperm, from a person who is now deceased, <sup>84</sup> is permitted under the Victorian and SA legislation. Posthumous use of gametes is prohibited in WA. <sup>85</sup> Amendments to the Victorian Act in 2003 mean that it is no longer prohibited to use embryos formed prior to the death of the gamete provider. <sup>86</sup> The Victorian Supreme Court has recently confirmed that embryos can also be formed *in vitro* using gametes of a person known to be dead and then implanted into a woman. <sup>87</sup> As with PGD though, there is no provision clarifying what interests that a child may have concerning posthumous reproduction are to be included in 'interests' for the purposes of the guiding principle. The SA Act provides that stored embryos must be disposed of if one member of a couple has died unless the deceased consented to its use after their death. <sup>88</sup> Gametes and embryos can be used provided the person who produced the material consented to such use. <sup>89</sup> The NHMRC Guidelines allow for posthumous reproduction provided there is express consent from the now deceased to such use after their death. <sup>90</sup> Counselling of the prospective parents about the consequences of such use and a requirement that there be no adverse effect on the right of prospective children to know their biological parents is also required.

The Victorian ITA has produced a number of documents relevant to posthumous reproduction. These documents recognise only a limited range of interests of the child in regards to posthumous reproduction. The ITA's *Decision Making Guidelines for Services, Practitioners and Patients* regarding ART generally, provides a non-exhaustive list of matters it is recommended be discussed with ART patients. <sup>91</sup> In respect of the prospective child, this includes:

- 'Possible side effects and risks of the treatment to any resulting foetus or child'; 92
- 'Whether there are any consequences of a particular procedure which are not fully understood or foreseeable because of the current level of scientific and medical knowledge'; 93 and
- 'The risks of pregnancy loss, congenital anomalies'. 94

<sup>1980</sup> is the first reported occasion of posthumous sperm collection. S McLean, 'Post-mortem Human Reproduction: Legal and Other Regulatory Issues' (2002) 9 *Journal of Law and Medicine* 429, 435 citing S M Kerr et al, 'Postmortem Sperm Procurement' (1997) 157 *Journal of Urology* 2154.

Directions under the Human Reproductive Technology Act 1991 (WA), WA Government Gazette, 30 November 2004, No 201, Special, para 8.9.

<sup>&</sup>lt;sup>86</sup> Infertility Treatment Act 1995 (Vic) s 43.

AB v Attorney-General (Vic) [2005] VSC 180 (Unreported, Supreme Court of Victoria, Hargrave J, 27 May 2005). On this case see also B McSherry, 'Posthumous Reproduction' (2005) 13 Journal of Law and Medicine 15. On posthumous reproduction more generally, see K Bills, 'The Ethics and Legality of Posthumous Conception' (2005) 9 Southern Cross University Law Review 1; McLean, above n 84; Bennett, above n 2.

<sup>&</sup>lt;sup>88</sup> Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995 (SA) r 26(1), (2).

<sup>&</sup>lt;sup>89</sup> Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995 (SA) r 20.

NHMRC Guidelines, above n 8, 6.15. See also 6.16.

<sup>&</sup>lt;sup>91</sup> ITA Guidelines for Services, Practitioners and Patients. Decision Making Under the Infertility Treatment Act 1995 (Jan 2006) 13 s 4.

<sup>&</sup>lt;sup>92</sup> Ibid 13 s 4.1.3(d).

<sup>&</sup>lt;sup>93</sup> Ibid 14 s 4.1.3(h).

<sup>&</sup>lt;sup>94</sup> Ibid 14 s 4.1.3(i).

The ITA's *Guidelines on the Posthumous Use of Gametes and Embryos* require counselling to be provided to women wanting to undertake posthumous reproduction. Encouragingly, that counselling must 'take into account the potential consequences <u>for the child</u> should a live birth result' (emphasis added).<sup>95</sup>

However, in regard to what these 'consequences' may be, the only indication is the reference to:

the impact the death of the donor may have on the recipient's intention and ability to tell the child about their donor origin. 96

The ITA's Advance Directive for Posthumous Use of Stored Gametes by a Partner, to be signed by people storing gametes for use in ART, to address the situation where they may die with gametes still in storage, <sup>97</sup> provides for some considerations relevant to the welfare and interests of the child to be born in the context of posthumous reproduction. These are -

- 'The current lack of knowledge about the psychological impacts of posthumous conception on children so conceived;
- Ethical debates surrounding the intentional conception of a child who will never know one parent.'98

The Directive also strongly recommends 'that individuals or couples undertake counselling to assist them in considering these and <u>other highly sensitive issues</u> entailed in posthumous use' (emphasis added). <sup>99</sup>

It can be seen from the examination above that the ITA interprets child's 'interests' in the context of posthumous reproduction as meaning the –

- Psychological impact on the child of being created using gametes from someone who is now dead; and/or
- Effect on the child's ability to know their genetic origins/parent.

However, there is the possibility of a broader interpretation through phrases such as 'other highly sensitive issues' in the Directive and reference to unforeseeable consequences in the Decision Making Guidelines. The VLRC, which currently has a reference into ART in Victoria, has looked at posthumous reproduction. Its' recommendations regarding posthumous use of gametes are that this should be

<sup>95</sup> ITA, Guidelines on the Posthumous Use of Gametes and Embryos 3-7.

For example ibid 7.

There is no ITA form for people to provide advance consent to the extraction of gametes after their death and what is to be done with those gametes.

<sup>98</sup> ITA, Advance Directive for Posthumous Use of Stored Gametes by a Partner, Interim Form, 1.

<sup>99</sup> Ibid

The Terms of Reference were given in October 2002. More specifically its' task is to consider the desirability and feasibility of changes to the eligibility criteria in the *Infertility Treatment Act 1995* (Vic) and *Adoption Act 1984* (Vic) and the consequential changes that may lead to.

permitted but subject to the recipient being counselled about 'issues arising', including the possible effect on the child. What those 'issues' are, is not explained.

### B Courts' Interpretation

As noted above, the Victorian Supreme Court recently held that *in vitro* creation of an embryo using sperm from a woman's recently deceased husband is permitted under the *Infertility Treatment Act*, although on the particular facts it was not permitted because of lack of consent by the man. However, although the court addressed the issue of the donor's consent in depth, the interests of the prospective child were not considered at all. In a subsequent decision by the Victorian Civil and Administrative Tribunal, concerning the ITA's decision to refuse permission to the same woman to export her deceased husband's sperm interstate where it could be used, Morris J based his decision in favour of the woman on the Act's guiding principles and the broad discretion given to the ITA in the legislation. In looking at the first of the principles, that the welfare and interests of the child were paramount, Morris J said this required the court to examine whether any child born from a treatment procedure would be 'nourished, loved and supported'. He said this principle does not include in:

- 'welfare', how the child would view itself because it was created from posthumously collected sperm;
- 'interests', whether it is in the child's interests to know its genetic background and identity.

With respect, this 'definition' of interests seems unnecessarily narrow and not required in the context of the legislation. It is also at odds with the ITA's interpretation of 'interests' for the purposes of the legislation. More importantly, Parliament through legislation, allowing children born through ART using donor gametes or embryos access to information about their donor, has also indicated that it considers that the child's interests include knowledge of its genetic background and identity. This is in accord with the *Convention on the Rights of the Child*, which also stresses the importance of this interest by providing that children have the right, as far as possible, 'to know and be cared for by his or her parents'. Thus knowledge of one's genetic background could be included as an important part of 'interests' of the child in the context of ART regulation. But what about health? Just as with PGD, the question remains, how far do we go?

In Y v Austin Health and The Royal Women's Hospital, 106 a woman wanted a court order allowing her to have sperm extracted from her husband and stored for use after his death. The couple had been attempting to get pregnant for 18 months prior to the

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VLRC, Assisted Reproduction & Adoption. Position Paper Two: Parentage: Access to Information and Adoption (July 2005) [5.17].

<sup>&</sup>lt;sup>102</sup> YZ v Infertility Treatment Authority [2005] VCAT 2655.

Section 56(1)(b) prohibits the export of gametes from Victoria 'outside the body' but the ITA is given power to nevertheless approve export. *Infertility Treatment Act 1995* (Vic) s 56(2).

Infertility Treatment Act 1995 (Vic) s 56(2). Compare with the VLRC's recommendations that the export of gametes not be allowed to jurisdictions where use that would be illegal in Victoria, would be permitted. VLRC, Assisted Reproduction & Adoption. Position Paper Two: Parentage: Access to Information and Adoption (July 2005) [5.36], Interim Recommendation 31.

Convention on the Rights of the Child, opened for signature 20 November 1989, ATS 1991 no 4, art 7(1) (entered into force 2 September 1990).

<sup>&</sup>lt;sup>106</sup> [2005] VSC 427.

application. However, the husband had become very ill in late June 2004 and then suffered multi-organ failure. At the time of the application, he was in critical condition and died on the fourth day of the hearing. He was not informed of the proceedings prior to his death. The Victorian Supreme Court allowed the sperm to be extracted but it was later discovered that conception using the sperm was not possible. <sup>107</sup> As Connors asks, what if the problem was that the man 'had a genetic condition which could cause abnormality in a resulting embryo?' 108 In the context of this study, should the court take into account the interests of the prospective child in being born free of inherited disorders, including those that may cause death or serious harm, in making orders regarding extraction of sperm? Further, what if the widow was determined to proceed, for example, to obtain financial support from the deceased's estate?<sup>109</sup> As noted above, the Victorian Act certainly allows PGD on embryos to test for genetic abnormalities that lead to death or serious harm. But, as Connors notes, it does not expressly prohibit the use of gametes which it is known may transmit a genetic disease. 110 In that case, even if the court or ITA took into account the genetic fitness of the gametes, could the ART clinic concerned refuse to treat? The answer to that is yes given medical practitioners have the right to refuse to treat in non-life threatening situations. But does the as yet unconceived child have an interest in the court or ART clinic reviewing the deceased's medical records to ensure the deceased did not die from a genetic condition?<sup>111</sup>

It could be argued that the first guiding principle in the Victorian legislation requires both the ITA and the courts to consider the circumstances of the spouse's death and the transmission of genetic disease to uphold that principle, but it all depends on what is meant by 'interests'.

### V CONCLUSION

From the above examination it can be seen that whilst the State ART Acts, practice of the statutory Authorities and professional guidelines generally interpret the prospective child's 'interests' narrowly, the courts have been even less willing to widen the scope of 'interests' in this context. Nevertheless, society must consider what interests it thinks should be held as paramount when decisions regarding ART are made. It must consider whether, for example, such interests should include an interest in not having a disability caused either through negligence during PGD or the use of posthumously collected sperm that carries a significant risk of genetic disease. If 'interests' is to be interpreted more broadly than any of the Acts, the statutory Authorities, professional bodies or the courts currently seem to willing to do, five further issues must be addressed.

Firstly, why should posthumous conception have a screening process overseen by the court or an Authority when other fertilisation procedures don't?<sup>113</sup> There is not even a

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<sup>&</sup>lt;sup>107</sup> R Connors, 'Y v Austin Health and The Royal Women's Hospital' (2006) 13 *Journal of Law and Medicine* 292, 293.

<sup>&</sup>lt;sup>108</sup> Ibid.

<sup>&</sup>lt;sup>109</sup> Bills, above n 87, 5.

<sup>&</sup>lt;sup>110</sup> Connors, above n 107, 294.

<sup>111</sup> Ibid.

<sup>&</sup>lt;sup>112</sup> Ibid.

Except where donated gametes are used. The ITA's licensing conditions require centres to undertake appropriate donor screening as recommended by the RTAC Code of Practice, above n 9, s 9.9. *Conditions for Licence*, above n 12, ss 5.4, 5.5. See also *Health Act 1958* (Vic) s 133; *Health (Infectious Diseases) Regulations 2001* (Vic) reg 19, Sch 8; Petersen, above n 11. For SA, see *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995* (SA) r 12.

clear obligation under the legislation for patients to provide the information that they may have a genetic disease to their doctor. Only the Victorian Act provides that it is an offence to give false or misleading information or omit to give material information in an application, comment or request or when legislation requires information. 114 woman and her husband/de facto are required to give the prescribed information set out in the Regulations. 115 This includes 'details of any physical abnormality in either of them', but this would not clearly include a pre-symptomatic genetic condition that the person was aware of. Therefore if a screening process is to be included in the interests of the child, this aspect of the legislation would require amendment to ensure screening is effective.

Secondly, any children born using sperm from a now deceased man, will not only be fatherless in a practical sense but fatherless in a legal sense too. No man will be recognised as the legal father of a posthumously conceived child, 116 and that man's name would not even appear on the birth certificate. Therefore in settling the debate about the interests of children born to other than heterosexual couples to the recognition of their parents as legal parents, as the VLRC is currently addressing, this also needs to be addressed.

Thirdly, if children are to have an interest in having the genetic suitability of the gametes to be used in posthumous conception considered, are we also saying that parents need to have a certain level of genetic fitness to parent? Is that taking us towards eugenics as Ipp JA observed? Fourthly, but on a related issue, if such interests are recognised, society must address whether there should be a line below which a disability is not considered contrary to the child's interests and, if so, where such a line should be drawn. That is, what, if any, characteristics should be deemed unacceptable in the interests of the child?

Finally, if children are to have an interest in at least having the genetic fitness of gametes taken into account when courts, doctors or parents are making decisions regarding posthumous reproduction it needs to be recognised that the choice is really only whether the child is born or not because it is illegal to modify the embryo's DNA to correct the defect. 117 In that case, in light of the decision in *Harriton*, what is that interest worth given there can be no legal claim by a child born with a disability following a professional's negligence that caused the opportunity for the child not to be born to be lost?<sup>118</sup> Rather, as asserted by Grey, it can be suggested that 'tort law must play its established role of setting standards and redressing wrongs'. 119 If it does not, then the larger question for society is what 'is the responsibility owed to people with disability and those who care for them?' 120

It is up to society to decide how far is too far ...

Infertility Treatment Act 1995 (Vic) s 58.

Infertility Treatment Act 1995 (Vic) 10(2).

Unless the woman has repartnered and the new partner consented to the treatment procedure.

Prohibition of Human Cloning Act 2002 (Cth) s 18 and mirroring provision in Infertility Treatment Act 1995 (Vic) s 38J.

See further, D Hirsch, 'Revisiting "wrongful life" [2001] Plaintiff 30.

Grey, above n 53, 545.

W J Neville and B Lokuge, 'Wrongful life claims: dignity, disability and "a line in the sand" (2006) 185 MJA 558, 560.