

## Who Do You Think You Are?

### *Identity and Childhood in Australian Healthcare Ethics*

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Those of our readers familiar with a certain popular, globally syndicated television program that traces the genealogical narratives of prominent individuals will recognize that I have borrowed my title. The long-running social history documentary series *Who Do You Think You Are?*<sup>1</sup> regularly uncovers the issue at the heart of this essay on contemporary debates in healthcare ethics in Australia: that is, identity as heritage, both social and genetic. All of the participants in the series begin by returning to their own childhoods and familial connections to search out the grounding for their sense of self. By the closing credits, each subject's sense of identity has been challenged, shifted, and in some instances radically reshaped.

This notion of a search for identity in combination with the status of children shares common threads with the two case studies explored here. The first relates to children diagnosed with gender identity disorder (GID) (or gender dysphoria [GD]); the second relates to the rights of the adult children of anonymous sperm donors. In each, what is at stake is the capacity of individuals to determine their identity and the medical-ethical dilemmas that affect their actual ability to do so. For children diagnosed with GID who are seeking hormone

therapy in anticipation of puberty, they and their guardians assert they have the rational capacities to make life- and body-altering decisions. These children feel trapped in a body whose genetic sex does not match their gender identity. By contrast, the rational capacities of adult children born of anonymous sperm donation who seek access to records about their biological fathers are not in question. They are searching for the unknown half of their genetic identity, which has been denied them since conception. Many of them are concerned about the potential health risks to which they may be prone or the possibility of unwittingly entering into incestuous relationships. In both of these examples, decisions about how (or whether) these individuals may proceed are a matter in which healthcare professionals are intimately involved. They are also issues in which socially, historically, and politically contingent ideas of childhood, and what it is to be a child, prevail.

In 1989, as part of the near-unanimous signing and ratifying of the United Nations Convention on the Rights of the Child (CROC),<sup>2</sup> mainstream Australia agreed to adhere to a conception of children and a definition of childhood as embodied in that document, and to uphold the rights of children accordingly. In requiring nation-states to act in "the best interests of the child," the UN explicitly and implicitly promotes an idea of childhood as a time of innocence and vulnerability, and children

I would like to thank Dr. John Waugh of the University of Melbourne for clarifying the legal issues around *Re: Jamie*.

as not yet rationally competent. Nevertheless, the understanding of childhood promoted by the UN is a historically and culturally contingent construction<sup>3</sup> that is based on normative expectations of children of the developed world (e.g., children don't work, they play). Such a narrow conception of children and childhood is not necessarily appropriate or helpful in situations in which people under the age of 18 can be shown to be agents in control of their lives. However, in amendments, the UN and the International Labour Organization (ILO) have shown some understanding of the ability (and need) of children in developing contexts to combine forms of employment with attainment of education. Nevertheless, children's rational capacities are generally treated as subordinate to those of adults.

In Australia, 18 is the age at which one is generally considered an adult. At 18 one may vote and, if found guilty of criminal offences, may be sent to an adult prison.<sup>4</sup> In relation to medical treatment, a child is considered incapable of giving fully informed consent, and adults—parents, guardians, doctors, and judges—remain the primary decisionmakers for and about children. In Australia it has been recognized that a person over the age of 16, although still a minor, has the capacity to give informed consent to medical treatment and to have an independent relationship with his or her medical practitioner. Similarly, a "mature minor" (a child intellectually capable of understanding the nature and consequences of the relevant treatment, at perhaps 14 or 15 years of age) may be considered able to make decisions about consenting to medical treatment.

### **Children and Gender Identity Disorder**

Our first example, the treatment of children with GID, is a more socially complex

and challenging phenomenon than most. The condition is defined by a psychiatric diagnosis and subject to psychotherapeutic intervention, but the medical treatments used to realize the individual child's desired gender identity are hormonal. Surgery is not performed until adulthood, that is, at the minimum age of 18. Furthermore, in Australia the progression to medical treatment—in addition to psychotherapeutic techniques—through the use of puberty-suppressing or hormonal drugs is considered a "special medical procedure" (or, more properly, "treatment") and as such cannot be consented to by the child, the child's parents, or his or her guardians alone. Such treatment requires consent from a judge of the Family Court of Australia, a federal court that has jurisdiction over family law matters in general and this area of law in particular.

The Family Court's powers over special medical procedures originated in a court decision in 1992, which aimed to protect the rights and well-being of children by shielding them from medical interventions that were considered outside the ordinary scope of parents' or guardians' powers. Among the features that define such procedures are the following: an incorrect decision would lead to grave consequences, an incorrect decision would result in a significant risk to the child's best interests, or the treatment may not in itself "be grave and irreversible but may be of significant risk, ethically sensitive or disputed."<sup>5</sup> Furthermore, in approving such a procedure, a judge must be satisfied that treatment is a "step of last resort."<sup>6</sup> We can hear in these parameters the CROC requirement that the best interests of the child be upheld at all times.

Initially, this overriding of the powers of a parent or guardian was the outcome of Marion's Case, in which the parents of "Marion," a pubescent female child who

had a significant intellectual disability in addition to other medical problems, wished to sterilize their daughter to remove the distress she experienced during menstruation.<sup>7</sup> The eventual outcome of the case was that the sterilization was judged to be a special case and that decisions related to such procedures should be made by a judge of the Family Court. Since the initial judgment, the parameters of what is considered a special medical procedure have been broadened specifically to encompass gender reassignment in minors and otherwise uncontroversial medical treatments for which parental consent has been refused. The result has been that a person under 18 in Australia who wishes to undergo hormone treatment in anticipation of gender reassignment must seek consent through the Family Court.

Hence, in instances in which the treatment teams, the parents, and the child concerned all wish to proceed with medical treatment to avoid the onset of puberty of the repudiated sex and instead hormonally induce the physical characteristics of the sex with which the child identifies, a judge of the Family Court has the final say. With all parties in agreement, such treatment is likely to be approved once the child has reached 15 or 16—that is, if the family has the financial resources to cover the expenses involved in seeking the required consent through the court, which was recently estimated at costing between AUD 20,000 and AUD 35,000.<sup>8</sup>

The recent case of *Re Jamie* [2011] FamCA 248 is more challenging, as Jamie, born genetically male but socially female since she was a toddler, will not turn 13 until May 2013.<sup>9</sup> In the first stage of this case, in line with the precedent that treatment for GID is a special medical procedure, Dessau J and the parents assumed that the pro-

posed treatment was within the definition of such procedures and required a determination by the court.<sup>10</sup> The judge supported puberty-suppressing treatment but rejected a request to begin estrogen therapy, leaving that decision until Jamie reached the age of 15 or 16, the accepted age for beginning such treatment. As Cameron Stewart notes,<sup>11</sup> an important aspect of this case is that the parents have subsequently appealed the status of the treatment as a special medical procedure. Should they be successful and obtain an outcome that supports their capacity—rather than that of a judge of the Family Court—to give informed consent and therefore make the decision whether to treat GID, decisions about whether, when, and how to proceed with hormone therapies for children with GID will revert to the families and the doctors of the young person concerned.

In public reporting of this and other similar cases both in Australia and elsewhere there have been dissenting viewpoints on proceeding with such treatments, aside from contestations regarding the legal restrictions on who may consent to treatment. It is known that there are long-term health risks, such as osteoporosis, implicit in the relevant hormone treatments and irreversible effects, such as diminished fertility, which may adversely affect the individual should there be a reversal in identity later in adolescence or adulthood. Weighted against these potential risks is the real anguish that a child with GID feels, which may lead to suicidal or self-injuring behavior. At a social level, gender theorists question whether GID itself is at least in part a response to the power and rigidity of gender norms. What remains is the fact that decisions about personal identity are being made on behalf of the child by adults.

### **Children of Anonymous Sperm Donors**

This fact leads directly into the discussion of our second example, in which the intersection of identity, children, and medicine is imbricated in the complex history of social and medical responses to infertility in Australia. Until the development of IVF and its flow-on technologies, which did not become viable alternatives until the mid-1980s, the only recourse for infertile couples who wanted to be parents was to foster, to adopt, or, if the cause was male infertility, sperm donation. Until 1988, sperm donors remained anonymous, and any details recorded about them were subject to medical confidentiality. The children of anonymous sperm donors were, and indeed still are, subject to life-shaping decisions about consent made for them. The ethical arguments and implications surrounding the current calls for the opening of these records repeat the debates held in the early 1980s over unsealing closed adoption records, and for that reason it is worth giving a brief background of adoption practices in Australia.<sup>12</sup>

Like other developed countries that experienced the wave of social change that flowed through the 1960s, Australia took part in the sexual revolution largely made possible by the wider availability of the contraceptive pill. Prior to the pill making it possible to have sex without a high likelihood of bearing a child as a consequence, the overwhelming social stigma attached to unmarried pregnant women ensured that only women with the strongest personalities, or those whose families were prepared to weather the stigma to support them, kept their children. With the introduction of the single mothers' pension in 1972, unmarried women were afforded a financial avenue that allowed them to keep their babies, and the statistics incontrovertibly prove that they chose to do so. The

numbers of babies available for adoption dropped from nearly 10,000 in 1971–1972 to fewer than 700 by 1995–1996.<sup>13</sup> This number has continued to fall, and according to the most recent data, for 2010–2011, there were 384 finalized adoptions in Australia.<sup>14</sup>

Although sperm donation had been available prior to this dramatic drop in the availability of babies for adoption, its importance rose as an option of last resort for male infertility and an essential adjunct to IVF experimentation. In Australia, sale of human gametes is prohibited, but donors are (and were) compensated for their time and expenses in providing their donation. In the late 1970s, when a boyfriend of mine considered donating, the payment was AUD 20. Today, due to more stringent requirements on donations, the payment is more likely to be closer to AUD 350.<sup>15</sup> As noted previously, prior to 1988 sperm donors were guaranteed anonymity. Since 1998, nonidentifying details and the medical history of the donor are provided to the recipients prior to fertilization, and any sperm donor enters into the process on the understanding that he will potentially be sought out by his genetic offspring. Those offspring born between 1988 and the end of 1997 may seek information if the donor consents to making the information available.<sup>16</sup>

Offspring of anonymous donation, that is, adults who are now at least 25, have no access to the records of their genetic fathers. The issue of contention for contemporary Australian healthcare professionals is that there is significant lobbying and pressure being put on governments—each state has its own regulations—to make available the identities of donor fathers, whether or not they desire it. One of the most prominent advocates for opening the records on sperm donors prior to 1988 is a 30-year-old Melbourne woman, Narelle Grech, who has aggressive bowel cancer that

has a possible genetic link. She wants not only to meet her biological parent and to warn her eight half-siblings of their potential risk of developing the disease,<sup>17</sup> but also to ensure that full medical histories are available not only to those who have been conceived and born since 1998 but to all donor offspring for whom such records exist. As an advocate, her personal case is compelling, but, when faced with a cross-parliamentary law-reform committee recommendation made in March 2012 that the rights of the children should prevail, the Victorian government recently deferred a decision for six months to conduct further stakeholder consultations.<sup>18</sup>

Where health professionals have publicly demurred is on the basis of the original assurance of confidentiality and the possibility that trust in the profession will be undermined if that assurance is reneged upon. This is certainly an issue, but it is also precisely the same set of arguments raised in the 1970s and 1980s when adoption lobbyists fought to revoke the anonymity of the files of adopted children, many of whom were in their sixties and had happy relationships with their adoptive parents, yet remained deeply concerned with uncovering their identity.<sup>19</sup> Those laws were changed, and the attitude toward adoption itself has radically altered. This has led to repeated formal apologies being made (or in preparation) for decades of past adoption practices by federal and state governments, state and federal authorities, hospitals, and religious institutions.<sup>20</sup>

The practices of secrecy, the inability to access identifying files, and the obstinacy on the part of bureaucracies are being replayed in relation to calls to rescind the anonymity of sperm donors (as well as in relation to international adoptions).<sup>21</sup> It is not clear that the opening of adoption files did undermine trust in the institutions that fought that openness.

It was equally possible that the reluctance of those institutions to be open and their resistance to change had a far greater effect in undermining them and fostering negative perceptions of their actions. What has drawn wider approval is the ability of the parties to realize that an earlier practice was unjustifiable, was open to harming those involved because it was not sufficiently thought through, and was manifestly not in the best interests of the child.

With regard to anonymous sperm donation, in the middle are the children, who could not be asked if they wanted to be conceived, who may live to develop medical problems of which they have been denied forewarning, and/or who as a result of secrecy lack the capacity to take precautions to avoid developing conditions of which they are at risk. The best interests of the child—now an adult—who would result from a sperm donation were considered in a manner subordinate to the wishes of adults. The adult children of sperm donors, like adult children of closed adoptions, were conceived in an act in which the participants failed to foresee or fully appreciate the consequences for the child once he or she is an adult. Like children with GID, the interests of children of sperm donors remain subordinated because of decisions made by adults on their behalf, “in the best interests of the child.”

## Notes

1. *Who Do You Think You Are?* Wall to Wall and BBC 1, 2004–2012.
2. United Nations. *UN Convention on the Rights of the Child 1989*; available at <http://www2.ohchr.org/english/law/crc.htm> (last accessed 29 Nov 2012). Australia became signatory in 1989 and ratified it in 1990, and it came into force for Australia in 1991. Only three member states of the UN are not party to the CROC: Somalia and South Sudan have neither signed nor ratified the Convention,

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- and the United States has signed but not ratified.
3. Ariès, P. *Centuries of Childhood: A Social History of Family Life*. Baldick R, trans. New York: Alfred A. Knopf; 1962.
  4. Laws on the age for consensual sexual activity vary from state to state and range from 16, to 17, and to 18, although the last only applies in Queensland, and specifically for anal sex. Defenses may also be made for consensual sex at younger ages for a range of reasons. See <http://www.aifs.gov.au/cfca/pubs/factsheets/a142090/index.html> (last accessed 1 Dec 2012).
  5. Family Court of Australia. *A Question of Right Treatment: The Family Court and Special Medical Procedures for Children, an Introductory Guide for Use in Victoria*, with a foreword by Chief Justice Alastair Nicholson. Melbourne: Family Court of Australia Publications Unit; 1998, at vii.
  6. See note 5, Family Court of Australia 1998, at vi.
  7. See note 5, Family Court of Australia 1998, at 2.
  8. Robotham J. Child sex-change ruling fails to solve the confusion. *The Age* 2012 Feb 11.
  9. See note 8, Robotham 2012.
  10. Stewart C, Cockburn T, Madden B, Callaghan S, Ryan CJ. Leave to intervene in cases of gender identity disorder; normative causation; financial harms and involuntary treatment; and the right to be protected from suicide. *Journal of Bioethical Inquiry* 2012;9:235.
  11. See note 10, Stewart et al. 2012.
  12. For more general information and a list of publications arising from the ARC-funded History of Adoption Project, see <http://www.arts.monash.edu.au/historyofadoption/index.php>. (last accessed 1 Dec 2012).
  13. Broadbent A, Bentley R. *Adoptions Australia 1995–96*. Child Welfare Series no. 19. Cat. no. CWS 3. Canberra: AIHW; 1997.
  14. AIHW. *Adoptions Australia 2010–11*. Child Welfare Series no. 52. Cat. no. CWS 40. Canberra: AIHW; 2011.
  15. A raft of tests is required to identify and exclude donations infected with transmissible diseases and some genetic conditions. The figure of AUD 350 is based on one clinic's pricing schedule: <http://www.spermdonorsaustralia.com.au/how-start> (last accessed 29 Nov 2012).
  16. Hagan K. More time needed for egg, sperm donor decision. *The Age* 2012 Oct 12.
  17. See note 16, Hagan 2012.
  18. See note 16, Hagan 2012.
  19. Again, the dates of legislation vary from state to state, but formal adoption was not possible until the late 1920s. My own father's adoption in Victoria was not formalized until 1930, when he was 10, under the Adoptions of Children Act 1928, although he had been with the people he believed to be his parents from the age of 3. See also the History of Adoption Project, <http://www.arts.monash.edu.au/historyofadoption/index.php> (last accessed 29 Nov 2012).
  20. See Pollard A. From secrecy to openness: The Victorian adoption reform movement, [doctoral dissertation]. Monash University, under examination; Cuthbert D, Quartly M. Forced adoption in the national story of apology and regret. *Australian Journal of Politics and History* 2012;58(1):82–96.
  21. See Cuthbert D, Cregan K. *Global Childhoods: Issues and Debates*. London: Sage; Forthcoming, for deeper discussions of the issue of children as objects of national and global concern.