HOW DO SINGLE MOTHERS BY CHOICE PROMOTE THE HEALTH AND WELLBEING OF THEIR DONOR-CONCEIVED CHILDREN AND WHAT ROLE SHOULD LAW PLAY?

ISSN: Online-2201-7275

DOI: 10.5204/qutlr.v18i2.758

FIONA KELLY*

There is increasing international consensus that the best interests of donor-conceived children should be the focal point of laws regulating assisted reproduction, with particular attention given to the promotion of children's health and wellbeing. To achieve this objective, the Australian regulatory system has adopted a position of openness, the presumption being that children's health is enhanced by access to information about their conception, their donors, and other donor relatives. This article explores the lived experience of 25 single mothers by choice (SMCs) who have attempted to promote the health and wellbeing of their donor-conceived children by exploring the possibility of seeking access to information about their child's donor and/or other donor relatives. It argues that, while aspects of Australia's regulatory framework facilitate the type of openness SMCs sought for their children, significant gaps remain. In particular, the absence of legislation in some states, and inconsistencies between and within state laws mean that the rights of donor-conceived children vary dramatically across the country.

I INTRODUCTION

Historically, the fertility industry has focused almost exclusively on the privacy and wellbeing of the adults involved, particularly the prospective parents. In the early days of donor conception, clinical practice sought to protect the traditional nuclear family by prioritising secrecy and requiring donor anonymity. Over time, however, a growing body of research has concluded that the health and wellbeing of donor-conceived children should be a focal point of any laws regulating the use of assisted reproduction. Increasingly, law prioritises the interests of the donor-conceived child, with particular attention given to the promotion of the child's health and wellbeing into

^{*} Professor at the La Trobe University Law School and Deputy Director of the Centre for Health Law & Society, , Melbourne, Australia. I would like to thank the women interviewed for this study who spoke so openly about their experiences and fears. I would also like to thank the anonymous referees for their thoughtful commentary on the article.

¹ Fiona Kelly and Deborah Dempsey, *The History of Donor Conception Records in Victoria: A Report Prepared for the Victorian Assisted Reproductive Treatment Authority* (2018).

² Sonia Allan, Donor Conception and the Search for Information: From Secrecy and Anonymity to Openness (Routledge, 2017).

³ Eric Blyth, Marilyn Crawshaw, Lucy Frith, and Caroline Jones, 'Donor-Conceived People's Views and Experiences of Their Genetic Origins: A Critical Analysis of the Research Evidence' (2012) 19 *Journal of Law and Medicine* 769 ['Donor-Conceived People's Views']; Eric Blyth and Lucy Frith, 'Donor Access to Genetic and Biographical History: An Analysis of Provisions in Different Jurisdictions Permitting Disclosure of Donor Identity" (2009) 23 *International Journal of Law, Policy and the Family* 174; Vasanti Jadva, Tabitha Freeman, Wendy Kramer, and Susan Golombok, 'The Experiences of Adolescents and Adults Conceived by Sperm Donation: Comparisons by Age of Disclosure and Family Type' (2009) 24 *Human Reproduction* 1909.; A J Turner and A Coyle, 'What Does it Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy' (2000) 15 *Human Reproduction* 2041.

adulthood. To achieve this objective, the Australian regulatory system has adopted a position of openness, the presumption being that children's overall health and wellbeing is enhanced by access to information about the nature of their conception, their donor(s), and other donor relatives. Parents are encouraged to tell their children they are donor-conceived and, in several Australian states, donor-conceived individuals have access, if they wish, to their donor's identity when they reach maturity, or earlier if the donor consents.⁴

This article explores both the law on the books and the lived experiences of SMCs who have sought to promote their child's health and wellbeing by exploring the possibility of accessing information about their child's genetic origins. SMCs are defined as un-partnered women who choose to conceive a child using assisted reproduction with the intention of being the child's sole parent from the outset. The focus on SMCs is for two reasons. First, they are the fastest growing user group of donor sperm in Australia and already make up the majority of users of donated gametes in some states. While SMCs may not be representative of all users of donated gametes, given their numbers, understanding how they view and promote their children's health needs is nonetheless key to understanding current and future trends within the field of third-party donor conception in Australia. Second, while seeking information about a child's donor relatives is increasingly popular among all users of donated gametes, SMCs are more likely than any other group to engage in donor linking, and to do so when their children are comparatively younger than the children of other families who participate in linking. Understanding their experiences with donor linking will provide important information about potential gaps in the existing regulatory framework that are likely to benefit all users of the system.

The article begins by providing some background to the development of Australia's donor conception laws, followed by an overview of the legal and regulatory framework. It then considers how the existing framework operates in practice, drawing on the experiences of 25 un-partnered women who have sought to promote their donor-conceived child's health and wellbeing, primarily by seeking access to information about the child's genetic origins. It is possible that donor-conceived children may have health and wellbeing interests that are distinct from those identified by their parent(s). However, the focus of this article is on the role of *parents* in health promotion.

⁴ National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproduction in Clinical Practice and Research* (2017) [5.6], [4.4.1] ('NHMRC Guidelines'); Louise Johnson, Kate Bourne and Karin Hammarbarg, 'Donor Conception Legislation in Victoria, Australia: The "Time to Tell" Campaign, Donor-Linking and Implications for Clinical Practice (2012) 19 *Journal of Law & Medicine* 803.

⁵ In Victoria in 2016–17, single women were the largest proportion of women treated with donor sperm (53 per cent), followed by women in same-sex relationships (34 per cent) and heterosexual relationships (13 per cent): Victorian Assisted Reproductive Treatment Authority, *Annual Report 2017* (2017) 30. Changes in technology have meant that far fewer heterosexual couples need to use donated gametes to conceive.

⁶ Jadva et al, above n 3; Fiona Kelly and Deborah Dempsey, 'Experiences and Motives of Australian Single Mothers by Choice Who Make Early Contact with Their Child's Donor Relatives' (2016) 24 *Medical Law Review* 571; Rosanna Hertz and Jane Mattes, 'Donor-shared Siblings or Genetic Strangers: New Families, Clans and the Internet' (2011) 32 *Journal of Family Issues* 1129; D Beeson, P K Jennings and W Kramer, 'Offspring Searching for their Sperm Donors: How Family Type Shapes the Process' (2011) 26 *Human Reproduction* 2415.

II BACKGROUND TO CURRENT DONOR CONCEPTION LAWS

Concerns about the short and long term health and wellbeing of donor-conceived children have been central to the shift towards openness in Australia's donor laws, with three key health-related arguments emerging. First, many donor-conceived Australians have argued before state and federal inquiries into donor conception practices, that having access to information about their genetic origins is integral to their process of identity formation. Donor-conceived adults have reported that when they are told, or inadvertently discover, that they are donor-conceived and that their donor is unknown, they feel that a piece of their identity is missing, and that the only way in which they can construct a complete sense of self is by knowing more about their donor. While not a universal experience, research has identified a strong desire on the part of many donor-conceived people to know and understand more about their donor, and by extension, themselves.

The second health-related argument frequently made in support of openness is that the physical health of donor-conceived people is compromised by their inability to access half their medical history. ¹¹ Even when health information is reported at the time of donation, it only provides a 'snapshot' in time, with no opportunity for the donor to update it as new information emerges. Lack of access to complete health information means donor-conceived people cannot provide an accurate family health history when receiving medical treatment. The absence of this information can have serious implications where a donor-conceived person is at elevated risk of developing a particular medical ailment or has inherited a significant genetic condition from their donor. ¹² The

⁷ The health and wellbeing of donor-conceived people have been central to all of the recent inquiries and parliamentary reviews of donor conception practices in Australia over the past decade. See, for eg, Committee on Law and Safety, Legislative Assembly, Parliament of New South Wales, *Managing Donor Conception Information*, No 2/55 (2013) ['Managing Donor Conception']; Senate Legal and Constitutional Affairs References Committee, Parliament of Australia, *Donor Conception Practices in Australia* (2011); Law Reform Committee, Parliament of Victoria, *Inquiry into Access by Donor Conceived People to Information about Donors* (2012); Standing Committee on Community Development, House of Assembly, Parliament of Tasmania, *Inquiry into Donor Conception Practices in Tasmania: Final Report* (2017); Sonia Allan, *Report on the Review of the Assisted Reproductive Treatment Act 1988 (SA)* (Department for Health and Ageing (SA), 2017).

⁸ See, for eg, submissions to Australian inquiries listed above n 7.

⁹ See Blyth et al, Donor-Conceived People's Views, above n 3, 769: in a recent systematic review of 13 empirical studies of donor-conceived children and adults regarding their experiences and perceptions of donor conception, the authors concluded that 'most donor-conceived people have an interest in securing information about their genetic and biographical heritage — more information than most of them have been able to obtain'; and noted that, 'Although a number of methodological limitations in the research base are identified, the authors conclude that the evidence is sufficiently robust to promote the implementation of policies and practices that promote transparency and openness in collaborative reproduction, thus reflecting the importance of maximizing future choices and opportunities for donor-conceived people'.

¹⁰ Rosanna Hertz, Margaret Nelson and Wendy Kramer, 'Donor Conceived Offspring Conceive of the Donor: The Relevance of Age, Awareness, and Family Form' (2013) *Social Science and Medicine* 52; V Jadva, T Freeman, W Kramer, and S Golombok, 'Experiences of Offspring Searching for and Contacting Their Donor Siblings and Donor' (2010) 20 *Reproductive Biomedicine Online* 523.

¹¹ Sonia Allan, 'Donor Conception, Secrecy and the Search for Information' (2012) 19 *Journal of Law and Medicine* 631.

¹² While the frequency of (reported) situations in which serious conditions arise appears relatively low, there have been a number of tragic cases. See, for eg, William Heisel, 'Code Unknown: Mother Discovers a Secret Donor History and Frightening Health Future', Center for Health Journalism, University of Southern California Annenberg, 31 October 2014 < https://www.centerforhealthjournalism.org/2014/10/30/code-unknown-mother-discovers-secret-

affected individual may miss the opportunity to participate in early screening, is at higher risk of misdiagnosis, or may receive delayed diagnosis or treatment when compared with a person who has full access to their parents' medical history.

Finally, being unable to identify one's donor and/or donor siblings may create a fear among donor-conceived people (and their parents) that they may unknowingly form a sexual relationship with a donor relative. ¹³ While such a possibility may seem unlikely, there are a number of reported cases of donor siblings coming in contact with each other inadvertently, ¹⁴ particularly when the children are being raised within small tight knit communities, such as those created by lesbian mothers and SMCs. ¹⁵ However, even if the likelihood of a consanguineous relationship is low, research suggests that the *perceived risk* of consanguinity takes a psychological toll on donor-conceived people. As Crawshaw has argued, 'policy makers and professionals need to be aware that the lived experience with regard to consanguinity does not necessarily reflect the statistical risk'. ¹⁶

III THE EXISTING LEGAL AND REGULATORY FRAMEWORK

The law and associated regulatory frameworks that govern assisted reproduction in Australia play a significant role in protecting and promoting the health and wellbeing of donor-conceived people, though it is far from comprehensive. The regulatory system is made up of a patchwork of state laws and national guidelines. There is no relevant federal law, though the Commonwealth *Family Law Act* intersects with state laws, particularly in relation to the establishment of legal parentage. Four Australian states — Victoria, New South Wales, Western Australia and South Australia — have legislation that regulates assisted reproduction, including the release of information to parties connected with donor conception. While the state laws vary in their scope and approach, the objects of each Act make reference to the importance of protecting the interests of children

donor-history-and-frightening-health-future>; 'Denmark Tightens Sperm Donor Law after NF1 Transmissions', *BBC News* (online), 25 September 2012, https://www.bbc.com/news/world-europe-19711565>; Jacqueline Mroz, 'In Choosing a Sperm Donor, a Roll of the Genetic Dice, *New York Times* (online), 14 May 2012 http://www.nytimes.com/2012/05/15/health/in-sperm-banks-a-matrix-of-untested-genetic-diseases.html>. See also the story of Australian woman, Narelle Grech: Farrah Tomazin, "Suddenly She's There": Daughter and Donor Dad United', *The Age* (online), 17 March 2013 http://www.theage.com.au/victoria/suddenly-shes-there-daughter-and-donor-dad-united-20130316-2g7mv.html>.

¹³ Parents frequently report concerns about accidental contact between half siblings, conceived using the same donor. See, for eg, Margaret Nelson, Rosanna Hertz and Wendy Kramer, 'Gamete Donor Anonymity and Limits on Numbers of Offspring: The Views of Three Stakeholders' (2015) 3 *Journal of Law and the Biosciences* 39, 41; Naomi Cahn, 'Accidental Incest: Drawing the Line — or the Curtain? — for Reproductive Technology (2009) 32 *Harvard Journal of Gender and the Law* 59; Jenni Millbank, 'Numerical Limits in Donor Conception Regimes: Genetic Links and 'Extended Family' in the Era of Identity Disclosure' (2014) 22 *Medical Law Review* 325.

¹⁴ Kelly and Dempsey, above n 6, 582, 588; Stu Marvel, *Tony Danza is My Sperm Donor? Queer Kinship and the Impact of Canadian Regulations Around Sperm Donation* (2013) 25 Canadian Journal of Women and the Law 221, 232.

¹⁵ Marvel, above n 14, 233.

¹⁶ Marilyn Crawshaw, Submission No 156 to Senate Legal and Constitutional Affairs Committee, Parliament of Australia, *Inquiry into Donor Conception Practices in Australia*, 2011, 7

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed_inquiries/2010-13/donorconception/submissions.

¹⁷ Family Law Act 1975 (Cth) s 60H.

¹⁸ Assisted Reproductive Treatment Act 1988 (Vic); Assisted Reproductive Treatment Act 1988 (SA); Human Reproductive Technology Act 1991 (WA); Assisted Reproductive Technology Act 2007 (NSW).

conceived using assisted reproduction. For example, in Victoria and South Australia, ¹⁹ the welfare and interests of persons born as a result of assisted reproduction are 'paramount', while in Western Australia their interests 'must be properly taken into consideration'. ²⁰

Promotion of the health and wellbeing of donor-conceived people is achieved via a number of measures in the state laws, most notably by providing individuals with access, if they wish, to their donor's identity. As noted earlier, knowledge of one's genetic origins is often considered integral to identity formation, ²¹ particularly in the context of Western society where we often privilege the importance of genetic heritage in our family building and society at large. Victoria, New South Wales and Western Australia each have a central register to which donor-conceived people can apply to access information about their donor, though access rights may vary depending on year of conception.²² In NSW and WA, donor-conceived people who were conceived after donor anonymity was abolished (2010 in NSW; 2004 in WA) may obtain their donor's identity when they turn 18 (NSW)²³ or 16 (WA).²⁴ Access to information is by right, as each donor consented to his or her identity being released when they donated. Individuals conceived prior to the abolition of anonymity in these two states can also obtain non-identifying information about their donor, where that information still exists.²⁵ In WA, those conceived prior to the abolition of anonymity, as well as donors, can also apply to the state's voluntary register, which enables 'matches' where all parties consent to information exchange. In NSW, people who were conceived prior to the abolition of anonymity, as well as donors, can voluntarily join the Central Register. ²⁶

The Victorian legislation also creates a system of registers, but is much broader in its application. Setting it apart from other jurisdictions, section 5(c) of the *Assisted Reproductive Treatment Act* 1988 (Vic) explicitly states that 'children born as the result of donated gametes *have a right* to information about their genetic parents'. This objective is achieved through retrospective application of the law, which came into effect in March 2017, and enables *all* donor-conceived people whenever they were conceived, to access their donor's identity once they turn 18. Victorian law also permits all donors to access the identities of their donor offspring provided the offspring consent. In addition, the Victorian legislation permits *parents* of donor-conceived children to apply for access to the identity of their child's donor before the child turns 18. This 'early contact' system requires the donor to consent to information release.

¹⁹ Assisted Reproductive Treatment Act 1988 (Vic) s 5(a); Assisted Reproductive Treatment Act 1988 (SA) s 4A.

²⁰ Human Reproductive Technology Act 1991 (WA) s 4(d)(iv).

²¹ Jadva et al, above n 3; Blyth et al, 'Donor-Conceived People's Views', above n 3.

²² Fertility clinics must record the details of participants in each donor conception procedure, including the resulting child, and provide it to the state central register.

²³ Assisted Reproductive Technology Act 2007 (NSW) s 37.

²⁴ Human Reproductive Technology Act 1991 (WA) ss 49(1a), 49(2d) and 49(2e).

²⁵ Human Reproductive Technology Act 1991 (WA) s 46(1); Assisted Reproductive Technology Act 2007 (NSW) s 41T.

²⁶ Assisted Reproductive Technology Act 2007 (NSW) ss 33B and 33C.

²⁷ Assisted Reproductive Treatment Act 1988 (Vic) s 5(c).

²⁸ While not all of Victoria's pre-1988 donor records have been located, a significant number of records still exist, enabling retrospective donor linking to occur: Kelly and Dempsey, above n 1.

²⁹ According to the Victorian Assisted Reproductive Treatment Authority ('VARTA'), in 2016–17 the category of applicant most likely to request identifying information from the Central Register was recipient parents. They were the second most likely type of applicant to apply to the Voluntary Register (after donors). Victorian Assisted Reproductive Treatment Authority, above n 5, 10, 12.

While South Australia has legislation regulating assisted reproduction, the state government has not acted on all the powers it provides. The *Assisted Reproductive Treatment Act 1988* (SA) gives donor-conceived people who were conceived after 2010 access to their donor's identity, provided the donor consents. The state government has the authority under the Act to create a central register, ³⁰ but has not yet done so. An application for access to donor information must therefore be made to the relevant fertility clinic. The *Assisted Reproductive Treatment Act* was reviewed in 2017 and the health of donor-conceived people was identified as a significant priority. ³¹ The review recommended that a donor conception register be established 'as a matter of priority', ³² and that it have retrospective application. It was also recommended that section 4A of the Act, which states that the welfare of the donor-conceived child is paramount, be amended so that it also refers to the *health* of the donor-conceived child. ³³ Finally, the review recommended that the legislation include an obligation to regularly update the donor's health information. The South Australian government committed to implementing most of the review's recommendations in 2018. ³⁴

In states and territories without legislation (Tasmania, ³⁵ Queensland, the Northern Territory and the ACT), fertility clinics are obliged to follow the National Health and Medical Research Council *Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice and Research* ('the NHMRC Guidelines'). ³⁶ The NHMRC Guidelines have, since 2005, recognised that people conceived using donated gametes are 'entitled to know the details of their genetic parents'. ³⁷ The Guidelines therefore require all Australian donors to agree to have their identity released to offspring. Clinics must also 'encourage and support early disclosure' by parents and support information release to those conceived after 2005. ³⁸ However, the NHMRC Guidelines are not legally enforceable, and may be subject to change.

The Reproductive Technology Accreditation Committee (RTAC) provides a final layer of regulation. Operating as a subcommittee of the Board of the Fertility Society of Australia, RTAC sets standards for the performance of assisted reproduction through an audited Code of Practice and the granting of licences to practise assisted reproduction within Australia. Accreditation from RTAC requires clinics to comply with state and federal laws, as well as the NHMRC Guidelines. While there are a growing numbers of means by which parents can promote the health and wellbeing of their donor-conceived children, navigating such a complex web of law and regulation can be challenging. The remainder of this article explores how SMCs understand the health needs

³⁰ Assisted Reproductive Treatment Act 1988 (SA) s 15(2).

³¹ Allan, above n 7.

³² Ibid 125, Recommendation 17.

³³ Ibid 100, Recommendation 16.

³⁴ South Australian Government, *Response to the Independent Review of the Assisted Reproductive Treatment Act* 1988, 19 November 2017 http://s3-ap-southeast-

^{2.} amazonaws.com/assets.yoursay.sa.gov.au/production/2017/11/30/01/31/43/7fc7ad82-e0dd-4c6f-94ae-d7f079469fc5/Govt% 20Response% 20to% 20the% 20Assisted% 20Reproductive% 20Treatment% 20Act% 20Review.pdf>.

³⁵ In 2017 Tasmania held an inquiry into the state's donor conception practices and is likely to enact legislation in the near future. See Standing Committee on Community Development, Parliament of Tasmania, above n 7.

³⁶ NHMRC Guidelines, above n 4.

³⁷ Ibid [5.6].

³⁸ Ibid [4.4.1], [5.6].

QUT Law Review – Contemporary Legal and Ethical Challenges in Children's Health: Reproduction, Technology, Capacity, Medicine and Violence

of their children and, where available, what legal and regulatory mechanisms they employ to promote those needs.

IV METHODOLOGY

To understand how SMCs promote the health and wellbeing of their donor-conceived children, 25 semi-structured qualitative interviews were conducted with SMCs from four Australian states.³⁹ The women were asked what health and wellbeing concerns they had for their donor-conceived children and how they had attempted to respond to them. They were also asked what legal and regulatory tools they had used, if any, to promote their child's health and wellbeing, and the extent to which the existing framework met their children's needs.

Women were eligible to participate in the study if they had conceived a child using donated sperm and were un-partnered at the time of conception. The 25 women who participated were recruited through an invitation posted on the Single Mothers by Choice and Donor Conception Australia Facebook groups, and the Solo Mothers by Choice Australia online forum. Interviews were semi-structured, conducted face-to-face or using Skype, and took between one to two hours. They were conducted between June and November of 2015. Each interview was recorded, transcribed, then thematically coded, and analysed. The interviews were de-identified prior to printing of transcripts, and pseudonyms have been given to all participants.

While the views expressed by SMCs about the health and wellbeing of their donor-conceived children are important to understanding the field, they may not be representative of all users of third party gametes. For example, SMCs may place greater weight on knowing the identity of their child's donor, and linking that information to their child's own developing sense of identity, because of social pressure to 'find a father' for their child. Single mothers continue to experience stigma in Australian society. Being able to provide a father or father-like figure for their child is likely to alleviate at least some of that stigma. SMCs may also feel more able than other parents to seek information about their child's donor because his presence in the life of the child does not threaten the significance of a second, genetically un-related parent, as it might for a lesbian or heterosexual couple. Without a second parent's feelings to consider, SMCs are able to draw a link between their child's wellbeing and knowing the donor's identity in a way that may be more challenging for coupled parents. Thus, care should be taken when applying the findings of this study to other user groups of donated gametes. However, as noted above, because SMCs are now the largest user group of donated gametes in Australia, their experiences are key to understanding current and future trends in the field.

In total, the 25 women interviewed had 36 donor-conceived children. The children ranged in age from four months to 18 years old, with an average age of five. Twenty-three of the women had conceived using donated sperm, five had also used donated eggs, and two conceived using embryos created with donated gametes, one in Australia and one overseas. Twenty-three of the women had conceived in Australia. An additional two conceived overseas using gametes from foreign donors in jurisdictions where anonymity is still permitted. The four states represented

³⁹ Ethics approval for this project was granted by La Trobe University (Application No 14-078).

⁴⁰ Abbie Goldberg and Joanna Scheib, 'Female-partnered and Single Women's Contact Motivations and Experiences with Donor-linked Families (2015) 30 *Human Reproduction* 1375; Hertz, Nelson and Kramer, above n 10.

within the sample (Victoria, Queensland, NSW and South Australia), provide a cross-section of jurisdictions with and without legislation that facilitates donor linking.

V OPENNESS: 'THERE'S NOT A TIME THAT THEY DIDN'T KNOW'

All of the women believed that openness and honesty were essential to the psychological health and wellbeing of their donor-conceived children. They spoke openly of their child's conception story, often rehearsing the telling of it while their child was still in the womb. As Lucy explained, 'it's about being open as early as possible so it's normalised and not a surprise; so there's not a time that they didn't know'. Three of the mothers drew on research that supported openness to explain their approach. For example, Janet had read extensively about the sometimes devastating impact of a donor-conceived adult discovering that their parents had conspired to keep their conception story secret, ⁴¹ and believed strongly that the current focus on openness was superior to the secrecy of the past. For Janet, the key to good health lay in telling her daughter as soon, and as often, as possible about her conception story. As she explained:

History has shown us that ... everyone copes a whole lot better when they have access to information. Then it's not hidden...This may be a gross generalisation, but a lot of people who come across as quite unhappy about [being donor-conceived] have been told later in life. You know, it hasn't been open and it hasn't been right from the start like it is with our kids.

As required by the NHMRC Guidelines, all of the women who conceived in Australia had been counselled by their fertility clinic to tell their children from an early age that they were donor-conceived. Almost all of the Victorian women had also attended the Victorian Assisted Reproductive Treatment Authority's (VARTA) annual 'Time to Tell' seminar, which provides information about when, how and why to tell. The existence of the donor registers in several states also helped create a culture of openness. The women knew their children were eventually entitled to their donor's identity, so it made sense to prepare them for it from the start.

VI FROM OPENNESS TO IDENTIFYING DONOR RELATIVES

For the majority of the mothers, it was a natural progression from telling their children that they were donor-conceived to considering how they could obtain more information about the donor and other donor relatives. In fact, 14 of the 25 women had successfully identified and/or made contact with their child's donor. An additional five women had attempted to identify the donor, but been unsuccessful. Thirteen of the women had some form of contact with their child's donor siblings, though 22 had attempted to make contact.

The women's primary motivation for identifying their child's donor was a belief that the child's psychological wellbeing depended on having access to their 'biological history'. Mirroring much

⁴¹ Jadva et al, above n 3.

⁴² Counselling must include a 'detailed discussion' of '(i) the potential long-term psychosocial implications for each individual and each family involved, *including the person who would be born*...(ii) the possibility that persons born may learn about their genetic origins from other sources (for example from family members or pathology testing) and may independently access information about their conception; and (iii) the possibility that persons born may attempt to make contact with the donor(s) in the future': NHMRC Guidelines, above n 4, [4.4.1].

⁴³ Johnson, Bourne and Hammarbarg above n 4.

of the psychological literature,⁴⁴ as well as the substantial media coverage of the issue,⁴⁵ the majority of the women expressed the belief that knowing one's genetic origins was integral to identity formation. As discussed above, state legislation and the NHMRC Guidelines provide for access to this information once the donor-conceived person reaches adulthood, though rights vary depending on the date of conception. However, the majority of the mothers were not content to wait until their child reached maturity. Almost all of those who had identified their child's donor did so before the child turned six.

For the women who sought early contact, the driving force was the opportunity for their child to *grow up* with a 'complete picture' of who they were. While the age and low numbers of donor-conceived children who have had early contact with their donors makes it difficult to determine whether it provides any health and wellbeing benefits, research on donor siblings who have met during childhood suggests that benefits may flow from contact. ⁴⁶ For Cynthia, the decision to seek early contact was made prior to conception. When choosing a donor she narrowed her choice to men who stated in their donor profiles that they were open to early contact. She described such contact as 'the single biggest gift you could give your [donor-conceived] child'. Cynthia began the process of obtaining the donor's identity when her son was 12 months old, applying via the Central Register in Victoria. After undergoing counselling, she submitted her application for early contact, hoping the donor would consent. Within weeks, she received a registered letter that included the donor's name and contact details. She then wrote him a letter to which he and his wife responded. Six months of emailing followed and then, when her son was 18 months old, they met the donor and his wife. A positive relationship has developed and they now meet several times a year. Cynthia explained what she saw as the benefits for her son:

I told the [donor] what I wanted which was for [my son] to know his genetic heritage. I didn't want it to be some fantasy that he grows up with, this idealised version of his father. I wanted him to just know ... to just grow up knowing him. And when [my son] is old enough he can make the decisions, so if he wants to see him more often ... that's up to him. My job is just to facilitate this knowledge of each other and make sure it's up to date and current and then [my son] can take over when he's old enough to.

Helen also saw the value of her daughter growing up knowing her donor, but because she had conceived in NSW, she did not have a legal pathway to early contact. However, like three other women in the sample, Helen was able to locate her donor via the internet, using information disclosed in his donor profile. Helen acknowledged that she could not predict whether her three year old daughter would definitely want information about her donor. However, she felt obliged

⁴⁴ Blyth et al, 'Donor-Conceived People's Views', above n 3.

⁴⁵ Three of the women stated that they had been heavily influenced by 'nightmare' stories in the media about donor-conceived adults who were angry that they grew up without access to information about their donor. See, for eg, Melissa Fyfe, 'When Sperm-donor Children Come Calling, *The Sydney Morning Herald: Good Weekend*, 2 September 2015; ABC Radio National, 'The Donor Detectives', *Background Briefing*, 6 December 2015 (Sarah Dingle); ABC Television, 'Searching for C11', *Australian Story*, 13 August 2014; Penelope Debelle, 'Conceived Via Sperm Donors, This is Their Emotional Quest to Find Their Mystery Dads', *The Advertiser* (Adelaide), 28 December 2014.

⁴⁶ Sherina Persaud et al, 'Adolescents Conceived through Donor Insemination in Mother-headed Families: A Qualitative Study of Motivations and Experiences of Contacting and Meeting Same-donor Offspring' (2017) 31 *Children & Society* 13.

to gather as much as possible so if her daughter had questions, Helen would be ready. As she explained:

[My daughter] might want a lot of information or she might want none, but I just wanted to make sure she had access to whatever information was available. So if there was information available sooner I would be jumping on that because I want her to have the information there. So I printed off the picture and everything else I could find.

Helen had decided not to contact the donor because she had not identified him via a 'legitimate' method (though there was none available to her). Instead, she chose to gather information and wait to gauge her daughter's level of interest. However, she had made inadvertent contact with a donor sibling through a social gathering for lesbian parents. The two women had both mentioned a distinctive feature of their donor to a mutual friend, who made the connection. The donor siblings have subsequently spent time together, but are too young to understand the nature of their relationship.

VII BARRIERS TO INFORMATION

While some of the women had been able to obtain their donor's identity when their children were still young, others faced significant barriers due to the absence of a legal pathway through which to pursue information. For Lara, whose daughter was 18, being able to identify the donor would have 'answered a lot of questions about [her] identity'. However, because her daughter was conceived in NSW prior to the abolition of anonymity, she had no statutory right to identifying information. Not knowing her donor's identity had sometimes been challenging for Lara's daughter. She had expressed an interest in finding her donor and had recently stated to Lara, 'I'd like to know who my father is'. Lara, however, had no obvious means of finding him. The information she had received at conception had amounted to 'less than 50 words', most of which related to his physical appearance. Lara felt the lack of information had created a void of sorts for her daughter.

Sometimes we have a go at a little guessing game where she goes, 'This part of me, do you think this is from your side or the other side?' So yeah, I think ... [knowing the donor's identity] would open up more of that kind of conversation. It might fill in a little bit of the picture. I think that for her, it would certainly fill in the missing part of a puzzle. I don't think she feels negatively about [being donor-conceived]. But I think that any [information] would help round out some of her sense of identity.

For Lara, who had one of the oldest children in the sample, the only way in which she could obtain information would be for NSW to introduce retrospective legislation akin to Victoria's. However, Lara was optimistic about the future, arguing that recent legal changes that put children's health and wellbeing at the centre of assisted reproduction meant that younger children would have better outcomes. As she noted:

We've got all this assisted technology, but now we've got a better sense of awareness of the rights of the child and about, you know, genes and all this other sort of stuff. So we do need to have regulated systems in place, and that just protects children, but also helps women who are in these difficult situations make better choices.

QUT Law Review – Contemporary Legal and Ethical Challenges in Children's Health: Reproduction, Technology, Capacity, Medicine and Violence

Lara's frustration with the inconsistent nature of Australia's assisted conception laws, and the impact the uneven access to information could have on the health and wellbeing of donor-conceived children, was echoed by a number of women. For those who had conceived in states without legislation, the only way in which they could obtain information about the donor or donor siblings was via their fertility clinic. However, most clinics were reticent to facilitate any information exchange between recipient parents and donors.

Eight women, mostly from Queensland and NSW, attempted to identify their child's donor via their fertility clinic. The women in this group did not necessarily request face-to-face contact with the donor. Rather, four of them simply wanted to be able to communicate with him. In these cases, the women requested that the clinic tell the donor he had received a 'thank you letter' from a recipient. However, most of the clinics refused to do so, with staff stating that contacting the donor in this way was contrary to clinic policy and in violation of the donor's privacy. Jasmine, for example, who conceived in Queensland, was told she could write a letter to the donor, but the clinic would not notify him of its existence. As she recounted:

I approached the clinic...and asked whether I can put a letter on file, like a letter of appreciation that they could send to him. They said yes [it could be put on the file], but they wouldn't disclose it until [my son] was 18. So wouldn't, you know, give it to the donor.

Lucy had a similar experience when she sent the donor a thank you letter via her Victorian fertility clinic when her first child was eight months old. When she followed up with the clinic several months later, staff refused to say whether they had forwarded the letter to the donor. Lucy was frustrated with the lack of transparency, but also believed the clinic was interfering with the donor's express intentions. He had stated on his profile that he was open to early contact and that had been one of the reasons Lucy had chosen him. When Lucy applied several years later to Victoria's Voluntary Register, she discovered her donor had also joined. He immediately consented to contact and has since built a positive relationship with her two children. It was Lucy's belief that the contact helped her children process their feelings around the donor and provided them with the concrete information they needed. Before they met the donor, the children had created a fantasy world around him.

I know it's just part of their process of being kids but they made up stories about him. [My four year old son's] story was that we had a Dad but then he got mutated and then he turned into a mutant — it's too much Ninja Turtles! — and [my daughter's] was, she just told strangers that he was over in England.

However, since meeting their donor, the stories have been replaced with reality. As Lucy noted, 'I wanted to have, to put another piece of the puzzle together for them. I didn't have hopes of, you know, constant contact with him or him having a big role, but now they know who is'. Lucy's donor was also able to confirm that he never received her letter.

Erica, who conceived in Queensland, was one of only two women who successfully accessed her donor's identifying information via her fertility clinic. Erica wanted to send a thank you letter to her donor when her daughter was one and the clinic obliged. As she recounted:

It must have been a year ago I sent him a thank you letter. I just sent it to [the clinic] thinking, you know, if they can pass it on they can. If they can't, that's okay by me. And behold...I got a letter back from him [via the clinic] which included a photo, which is double wow.

Erica, whose daughter is now three, continues to exchange regular emails with the donor, though they have chosen not to meet until the child expresses an interest. However, the photo of the donor sits on Erica's fridge and conversations with her daughter about who he is have begun. Knowing the donor's identity has put Erica's mind at rest. Her fear was that the donor would go overseas and the clinic would lose contact with him, or that he would die and they would not know until her daughter turned 18. She was also concerned that if her daughter became unwell, she would not have access to a complete medical history. While Erica had successfully managed to access the donor's identity, she felt strongly that it should not be a matter of 'luck'. As she noted, 'I'd like there to be an Australian registry. I don't understand how we as a country only have state regulations. It doesn't make sense to me. I think that anything that's dealing in human relationships needs a national system'.

VIII A CHILD-LED APPROACH

While the majority of the women believed that identifying the donor as early as possible would enhance their child's psychological wellbeing, three of the women felt that a 'child-centred approach' required them to be more cautious. The latter group were of the belief that the *child* should lead any exploration of the donor's identity. A search for the donor should therefore occur only when the child expressed such a desire. This was the approach taken by Tara, who did not have a personal interest in meeting her daughters' donor, but would take steps to identify him 'if [her daughters] felt differently'. Stephanie also favoured a child-led approach, stating that her 14 year old son, who was not currently interested in learning his donor's identity, should be in a position to 'author his own story'. She would support him in whatever he chose, but the decisions were his.

Some of the mothers were also conscious that by focusing too heavily on the importance of the donor to the child's wellbeing, they could be creating unrealistic expectations, which could not be met by the law. Tara, for example, spoke to her daughters, aged two and four, about their donor, but did not talk about them meeting or developing a relationship with him, as that was not what the Victorian law guaranteed. For Tara, it was important to align her children's expectations with the current legal reality.

I mean you're essentially kind of starting to create a relationship with a stranger. It's not even somebody who you meet and think, 'oh, we have a connection'. So I'm very conscious of not saying that when you turn 18 you can meet your donor and have a relationship with him. The information's available if they want to know anything, but I think assuming that there would be a relationship or even contact ... yeah, it's not something I'm putting out there.

Tara's focus was thus on balancing the need to be open with her children with the reality that even in an era of openness, the donor could be unwilling to develop a relationship with the children or even decline face-to-face contact. Tara hoped that by managing her children's expectations, she could minimise the psychological harm that could follow if the donor was uninterested in meeting them.

IX KNOWN DONORS

Given the significance the women placed on the importance to the child of knowing his or her biological origins, it is not surprising that over half of them expressed the view that having a *known* sperm donor, as opposed to a clinic donor, would better safeguard their child's health and wellbeing, as the child would grow up knowing the donor's identity and could potentially develop a relationship with him from birth. However, because of the uncertainty that surrounds the legal status of a known sperm donor who donates to an un-partnered woman, ⁴⁷ only two women felt comfortable pursuing this option. ⁴⁸

Isabel, for example, originally tried to conceive with a known donor whom she met through a friend. They discussed the process and future arrangements for about six months before she began to get cold feet. She had come across several media stories of women who had ended up in court with their known donor. As she explained:

It worried me in terms of, you think everything's going to be nice, but the legal stuff can get ugly really quickly. I became really worried about the legal ramifications. I was worried about what the law could do and it was still quite grey. I'd seen a few different things that have gone on where they've used a known donor and the known donor wants to be more involved in the child's life. It just got a bit scary.

Isabel reluctantly decided to switch to a clinic donor to protect herself against the legal uncertainty. However, when she got pregnant, she felt terrible guilt for having chosen a donor whose identity would be kept secret for 18 years. As she recounted:

[W]hen I was pregnant...I actually had to start seeing a counsellor because I was struggling with the donor issue. I'd really wanted to have a known donor so my child could know her biological origins. I really struggled with what I'd done.

Ultimately, women like Isabel are forced to choose between legal certainty and what they perceive to be best for their child's health and wellbeing. For Isabel, choosing a clinic donor provided her with the legal protection she needed. Yet, five years later, she clearly still struggled to reconcile the choice she had made.

The women were correct to be reticent about conceiving with a known donor. There is ongoing disagreement in the Family Court about whether a known donor to an un-partnered woman is a legal parent, in large part because the legislative provisions in the *Family Law Act* that sever the legal parentage of donors in cases of assisted conception do not reference un-partnered women.⁴⁹ While a recent Full Court of the Family Court decision overruled several trial decisions that granted legal parentage to known donors in circumstances where the donation was made to an un-

⁴⁷ For an overview of the law in this area as it pertains specifically to SMCs see: Fiona Kelly and Deborah Dempsey, 'The Family Law Implications of Early Contact Between Sperm Donors and Their Donor Offspring' (2016) 98 *Family Matters* 56.

⁴⁸ Neither of the women successfully carried a known donor pregnancy to term and both ultimately used a clinic donor to have their children.

⁴⁹ Family Law Act 1975 (Cth) s 60H(1).

partnered woman,⁵⁰ the decision has been appealed to the High Court. Thus, until there is legal clarity in this area, women are going to continue to be reluctant to choose known donors, despite a perception that having a known donor may provide psychological benefits to children.

X UPDATED HEALTH INFORMATION

The final concern the women expressed about the health of their donor-conceived children related to the lack of access to updated health information about the donor. As noted above, the absence of current paternal health information could create challenges for a child's medical treatment. In the most serious situations, it could result in misdiagnosis, delayed treatment, or a missed opportunity to participate in early screening. It was the view of all of the women that donors should be required to update their health status on a regular basis and that this information should be shared by clinics with recipient parents. Four women also suggested that there be a system by which to report significant health information about their children that could then be made available to other families who had used the same donor and the donor himself.

Stephanie, for example, who had decided to seek information about the donor only if her teenage son requested it, nonetheless felt there should be a 'mandatory process for collecting up-to-date health information from donors' and that the information should be provided to parents and donor-conceived adults. Stephanie argued that clinics should 'have a greater role' in gathering this information, as it was they who were profiting from the use of the sperm. Erica took a similar position, arguing that though she was in contact with her daughter's donor, there should be a formal mechanism by which to access health information that did not depend on donor contact. As she explained:

If [my daughter] became sick and if she needed some form of treatment, then this is where I'd like the law to be changed. So we can get his medical information. It's his medical background that we might need to know.

It was Erica's preference that there be an Australia-wide requirement that donor health information be gathered and frequently updated, arguing that such important issues should not be dealt with on a state-by-state basis.⁵¹

XI RECOMMENDATIONS FOR REFORM

While the women embraced the growing commitment to openness evident in the legal and regulatory reform of recent years, and often utilised the statutory options where available, a significant number remained dissatisfied with the status quo. Though Australia's laws and regulatory guidelines have as their premise the promotion of the health and wellbeing of donor-conceived children, their uneven application or lack of statutory force meant that the promise often went unfulfilled.

 $^{^{50}}$ Parsons and Anor & Masson [2018] FamCAFC 115; Groth v Banks [2013] FamCA 430; Masson & Parsons & Anor [2017] FamCA 789.

⁵¹ The division of constitutional power between the federal and state governments in the area of health makes it difficult to enact the types of laws Erica suggests. However, the states and territories could agree to implement consistent laws.

Most concerning to the women was the lack of consistency between and within state laws, with some donor-conceived children having access to information and services that were unavailable to children conceived in other states or in the same state but at an earlier date. The women felt strongly that it was a matter of equality that all donor-conceived children received identical treatment and that this was best achieved by having a national legislative framework or consistent state laws. Given the division of constitutional power between the federal and state governments in the area of health, and the impetus for change that is already present at the state level, pursuing consistent state laws is likely to be the most productive option. Since the interviews were conducted, South Australia and Tasmania have reviewed their donor conception practices, ⁵² while Western Australia commenced a review in 2018. ⁵³ In South Australia there now appears to be bipartisan support for laws similar to those found in Victoria. ⁵⁴ The outcome of the Tasmanian parliamentary review is not yet clear, but the committee recommended the introduction of donor registers and retrospective access to donor records. ⁵⁵ It is therefore likely that over the next few years the legal landscape will change considerably in a number of states, enabling more donor-conceived Australians to access their donor's identity if they wish.

The absence of access to updated health information could also be addressed through state legislation. The information could be gathered by fertility clinics or via the donor registers and made available to donor offspring and their parents. However, given that it is fertility clinics that recruit and screen donors, they are probably best placed to gather and disseminate this updated information. While this additional regulatory requirement would place a financial burden on clinics, they are arguably in the best position to absorb the cost.

The final concern raised by the women related to the lack of clarity around the legal status of known donors. As noted above, this is largely due to the omission of un-partnered women from the *Family Law Act* provision that defines legal parentage where assisted conception is used. ⁵⁶ It has been recommended on a number of occasions that Parliament address this legislative gap, ⁵⁷ and it is likely to be raised again during the Australian Law Reform Commission's review of the *Family Law Act* which commenced in September 2017. ⁵⁸ Clarifying the legal status of known donors to un-partnered women will enable women to make decisions about the type of donor they use that are driven by what they perceive to be in the best interests of their child, rather than fear.

XII CONCLUSION

The women interviewed for this study believed strongly that openness and access to information were key to the positive health and wellbeing of their donor-conceived children. Some came to

⁵² Standing Committee on Community Development, Parliament of Tasmania, above n 7; Allan, above n 7.

⁵³ See Department of Health (WA) *Review of the Human Reproductive Technology Act 1991 and the Surrogacy Act 2008* http://ww2.health.wa.gov.au/Review>.

⁵⁴ South Australian Government, Response to the Independent Review, above n 34.

⁵⁵ Standing Committee on Community Development, Parliament of Tasmania, above n 7, iv, xviii.

⁵⁶ Family Law Act 1975 (Cth) s 60H.

⁵⁷ Family Law Council of Australia, *Report on Parentage and the Family Law Act* (2013) 57; Kelly and Dempsey, above n 47.

Australian Law Reform Commission, *Review of the Family Law System* (2017) https://www.alrc.gov.au/inquiries/family-law-system.

this conclusion after reading research or media reports on the issue, while others relied on the advice of fertility counsellors and, in Victoria, VARTA. The women all embraced openness in their homes, speaking to their children from a young age about their conception story. Most of the women also sought information about their child(ren)'s donor, with many choosing to do so when their children were very young. There was an implicit belief among the women that the more information the child had, and the earlier it could be obtained, the better the child's health and wellbeing outcomes. This belief extended to identifying and having contact with the donor, with more than half of the women pursuing 'early contact'.

The existing legal and regulatory frameworks often supported the commitment of the women to openness and information seeking. However, some of the women identified gaps that they argued had the potential to compromise their children's health and wellbeing. In particular, the absence of state legislation, or inconsistencies between state laws, meant that the rights of donor-conceived children varied quite dramatically from state to state. There was overall agreement among the women that equality of access to information was needed. With a number of Australian states undergoing reform of their assisted reproduction laws, or contemplating the introduction of legislation for the first time, it will be important to continue to emphasise the importance of prioritising children's health and wellbeing.