

## Response to Chapter 3

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# Reform of the Legal Framework for Origin Information in Assisted Reproduction

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KIRSTY HORSEY

### I. Introduction

Alan Brown and Katherine Wade contend that the UK's existing legal framework regarding origin information (including the collection, retention and disclosure of such information) for those conceived through reproductive technologies should be reformed. Their position is that the current provisions are inconsistent and incoherent, lacking 'principled, normative justifications, focusing upon protecting children's right to identity and respecting their developing autonomy'.

In accordance with their children's rights-based analysis,<sup>1</sup> Brown and Wade propose that a consistent approach should be adopted for the collection, retention and disclosure of origin information across different forms of assisted reproduction; that origin information be collected and held in a wider range of circumstances than is the case now; and mandatory disclosure of such information. They apply this to children conceived via gamete donation or surrogacy, as well as – more controversially – to those born following mitochondrial donation. This response considers and reflects on three things that may cause us to question aspects of Brown and Wade's proposal, as well as some other broader points. Specifically, it is arguable that the proposal raises potential issues related to privacy and practicalities, and risks (over-) geneticisation of familial relationships. First, some comment generally on state interference in families in the context of origin information.

<sup>1</sup>And presumably supported by others who favour an approach under the 1989 United Nations Convention on the Rights of the Child (UNCRC), with a particular interpretation of Art 7, which provides that '[e]very child has the right to be registered at birth ... and, as far as possible, to know and be cared for by their parents' and Art 8, which requires States Parties to 'respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference'. See also similar considerations regarding a child's interest in discovering the identity of their genetic parent under Art 8(1) of the European Convention on Human Rights (the right to respect for private and family life), as in *Mikulic v Croatia* App no 53176/99 [2002] FCR 720.

## II. State Interference in Families and Origin Information

It is broadly acceptable that the kinds of origin information that Brown and Wade discuss should be *available* to the people who want it. It is undeniable that some people might want/would be curious about it – or even place great importance on it – not only in a medical context, but also in terms of their self-identity. It is also a fact that there is no consistency about the type, amount and quality of origin information held about children born from the various assisted reproductive techniques we are concerned with here.<sup>2</sup>

In their 2019 consultation on surrogacy, the Law Commission of England and Wales and the Scottish Law Commission identified that it is somewhat anomalous that access to information about a surrogate who has used her own egg is not covered by the current rules on disclosure of donor information.<sup>3</sup> Neither is the law sufficiently clear about who can have access to exactly what information and in what situation in the context of different types of surrogacy arrangements. Consequently, there are certainly reforms that ought to occur. However, we must also note that the background reality is that many private or ‘do-it-yourself’ sperm donation and traditional<sup>4</sup> surrogacy arrangements occur, where no information is required to be collected and stored at all (other than the name of the birth parent required to register the birth).<sup>5</sup> Additionally, there will be overseas surrogacy arrangements or other procedures using donated gametes, where some origin information is unlikely to be available. Indeed, some people purposely travel to overseas destinations specifically to use anonymously donated gametes.

What is less clear than the idea of the *availability* of origin information (if obtained) is that the *disclosure* of such information as is collected and stored should be the mandate of the state. We must decide what value we place on identity/origin information (as compared with other information, such as medical histories), with full consideration of what identity ‘means’ (and whether it means different things to different people, depending on their circumstances). As the Law Commission of England and Wales explained when not taking forward a project on the reform of birth registration in its last programme of reform, if such a project *were* to be undertaken, a key consideration would be the ‘fundamental questions of for what reason and for whose benefit the record is kept’.<sup>6</sup>

<sup>2</sup> As identified by, eg, N Tohme et al, ‘A comparative study of sperm and egg donors’ personal descriptions and goodwill messages’ (2024) 48(1) *Reproductive Biomedicine Online* 1.

<sup>3</sup> *Building Families Through Surrogacy: A New Law* (Law Com No 244 and Scot Law Com No 167, 2019) para 10.60.

<sup>4</sup> In which the surrogate uses her own egg, usually involving home insemination.

<sup>5</sup> Births and Deaths Registrations Act 1953, s 10.

<sup>6</sup> Law Commission of England and Wales, *Thirteenth Programme of Law Reform* (Law Com Consultation Paper No 377) para 4.5.

Years ago, Carol Smart questioned the ‘assumption that [a child] has a need to know her origin’ and the ‘certainty that scientifically based knowledge/truth is best’, especially since ‘earlier generations were just as certain that a child’s welfare would be best protected if she was raised in ignorance.’<sup>7</sup> We must be mindful of proceeding on the basis of such changed assumptions, without first really and deeply investigating what it is that people want – or think that they want – and why they want it, or substituting views of adults for the supposed views of children.<sup>8</sup> There is a potential danger that the narrative underpinning such a proposal is driven by particular voices, with particular stories and (negative) experiences of finding out about their origins, often at an extreme and unusual end of the scale.<sup>9</sup> We also know that sometimes it can be in a child’s best interests *not to know* of their (genetic) origins. For example, various cases have found, with reference to the UNCRC, that all children have the ‘right to know the truth’, unless this is outweighed by any considerations for their welfare.<sup>10</sup>

We must take care that access to origin information is not posed as a utopian ideal, where everyone having children via assisted reproduction is (or should be) comfortable with it and ready for all that it brings, puts the correct information on the correct forms, etc. We know from the consent form issues that resulted in dozens of cases a few years ago, where consent was at issue and had affected the legal parenthood situation, that this is not always the case.<sup>11</sup> For one thing, access to all origin information is not the case in ‘normal’ reproduction. Furthermore, people, relationships and families are complicated – particularly in this area, where there may already be a lot of hurt and sensitivity (including cultural sensitivity) about how people have arrived at requiring help to have a child. People and families are also very *different*: if an interviewer asked people (even children) ‘Who is part of your family?’, or ‘Who do you feel a connection with?’, or even ‘Who would you like to know more about?’, it can be presumed that those questions would generate enormously varying answers.<sup>12</sup> As one example, Children’s Voices in Surrogacy Law shows that different children – even those with some

<sup>7</sup> C Smart, *Personal Life* (Cambridge, Polity Press, 2007) 125.

<sup>8</sup> As identified by Jane Fortin in ‘Children’s right to know their origins – too far, too fast?’ (2009) 21(3) *Child and Family Law Quarterly* 336, questioning her own previous position on knowledge of one’s (genetic) origins as stated in J Fortin, ‘Re F: “The Gooseberry Bush Approach”’ (1994) 57(2) *Modern Law Review* 296.

<sup>9</sup> eg, *Rose v Secretary of State for Health and Human Fertilisation and Embryology Authority* [2002] EWHC 1593 (Admin).

<sup>10</sup> Such as *Re H (Paternity: Blood Tests)* [2001] 2 FLR 65. See also *Re D (Paternity)* [2007] 2 FLR 26; and *Re J (Paternity: Welfare of Child)* [2007] 1 FLR 1064.

<sup>11</sup> See, eg, *In the matter of the Human Fertilisation and Embryology Act 2008 (Case K)* [2017] EWHC 50 (Fam), the twenty-fourth case of many to arise – appropriate consent forms in each of the cases had either been lost or were not the consent forms mandated for use by the Human Fertilisation and Embryology Authority under the 2008 Act.

<sup>12</sup> See, for a recent example of a situation generating very complicated familial relationships, *A v B & Ors* [2023] EWHC 1680 (Fam).

shared experiences – appear to attach different weights to genetic and origin information, and disclosure thereof.<sup>13</sup>

### III. Privacy

Privacy-based responses to contributions such as Brown and Wade’s are well-rehearsed. Therefore, much of what is here is about playing devil’s advocate and questioning some assumptions. Brown and Wade’s argument is based on children’s rights, as derived from the UNCRC (or interpretations of it) – and there is obviously something in this. We also know that adults have rights, including the right to respect for private and family life as guaranteed under Article 8 of the European Convention on Human Rights. Is it the case that children’s rights *necessarily* trump adults’ rights? It is not just information about the children’s origins that is being given, but also what is often very personal information about their parents.

Talking about privacy usually means engaging in some kind of balancing exercise. Children have the right to private and family life, too – is there not at least a question that providing information could disrupt what is otherwise a perfectly happy and stable family? And for what? Individual family circumstances can generate competing rights, not only between different parties but also as regards the interests of a single child.<sup>14</sup> On this basis, it is evidently arguable that there should be no mandatory origins information disclosure, or automatic disclosure by the state, even if there is agreement that all of the information that Brown and Wade propose should be recorded is available. Within this may be what could be called cultural arguments – for example, it is still the case that for some cultures or religions the use of donor gametes is sacrosanct, or that to have a child when unmarried has social consequences.<sup>15</sup>

## IV. Three Practicalities

### A. Telling

As is currently the case, unless automatic disclosure (either of the fact that information is held, or of the information itself) is mandated, the argument rests on parents telling their children about the way in which they were conceived. This

<sup>13</sup>See K Wade, K Horsey and Z Mahmoud, ‘Children’s Voices in Surrogacy Law: Phase One Preliminary Report’ (Leicester, University of Leicester, January 2023); and K Wade, K Horsey and Z Mahmoud, ‘Children’s Voices in Surrogacy Law: Phase Two Preliminary Report’ (Leicester, University of Leicester, April 2023).

<sup>14</sup>See discussion in Fortin (n 8) 345–46.

<sup>15</sup>R Lamont, *Family Law*, 2nd edn (Oxford, Oxford University Press, 2022) 329.

means – as now – that children born outside the heteronormative nuclear family form are at an advantage, as it will be self-evident that a third party (at least) will have been involved in their conception.

We probably all agree that telling the truth about how someone was born – and being open from a young age, as research in adoption, donor conception and surrogacy shows – is a good thing in most circumstances.<sup>16</sup> Research on surrogacy shows a slightly higher level of telling and intending to tell – and at a younger age – among those who had undertaken surrogacy domestically, compared to those who went overseas. There was also a difference (especially in the ‘intending to tell’ category where telling had not yet taken place) between married heterosexual couples (who were less likely to have told) and other parents.<sup>17</sup> The Law Commissions’ consultation on surrogacy highlighted research showing that even where there is telling about the surrogacy and/or the surrogate, children may still not be told if an egg donor is also used. What this, and broader research on disclosure more generally, evidences is the need for more work on telling and supporting people to tell, but not that mandatory disclosure – or even ‘nudge disclosure’ – would be a good idea.

## B. Private/ DIY Arrangements

As well as the issues raised by DIY arrangements noted in section II, children conceived in heterosexual relationships using donated sperm (including for surrogacy) *outside of a clinical context* are not captured by this proposal, and nor can they be. Therefore, this proposal results in a two-tier system (at least), with one group disadvantaged in informational terms compared to the other, almost a mirror image of the problem the proposal is trying to solve. What, if anything, can be done about this?

## C. Comparisons

By extension, what about ‘normal’ conception families where there has been, for example, an extramarital affair, deception or children born to a single mother who ‘just got pregnant’? Do we not risk a Jeremy Kyle-type situation where, if everyone *should* know their origins, then direct-to-consumer genetic testing (DTCGT) is

<sup>16</sup> Which is why these norms have found their way into policy and law: see Adoption and Children Act 2002, ss 56–65; Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations (SI 2004/1511), reg 2(2) and (3); Law Commission and Scottish Law Commission, *Building Families Through Surrogacy: A New Law*, vol II: *Full Report* (Law Com No 411, Scot Law Com No 262, 2023) ch 13.

<sup>17</sup> K Horsey et al, ‘Surrogacy in the UK: Myth busting and reform’, Report of the Surrogacy UK Working Group on Surrogacy Law Reform (Surrogacy UK, November 2015) at [kar.kent.ac.uk/59740/](http://kar.kent.ac.uk/59740/).

going to drive this (and is indeed already having an effect in the donor-conceived world)? This could potentially *harm* children and families (while making vast amounts of profit for testing companies).

## V. Over-Geneticising

The rise of DTCGT and ancestry tracing services arguably drove the understanding that genetic testing could/should be used to, for example, establish paternity where that is contested – including in the context of the Government’s earlier drive to make sure that men, especially unmarried fathers, paid child maintenance. The availability of these services marked a cultural shift in terms of potential knowledge about origins, which filtered into discussions about children conceived by assisted reproduction.<sup>18</sup> As Freeman and Richards noted, commonly held beliefs that ‘biological origins are a significant determinant of identity and kin relationships’ were given new credence by our ‘entrance into the new genetic era, marked by the Human Genome Project.’<sup>19</sup> This does not make it fact, and the idea that genetic relatedness is so important should be robustly questioned before such heightened assumptions drive us to change law and practice.<sup>20</sup> This is particularly the case in a context where the law has deliberately and rightly recognised the social aspects of parenthood in contexts such as gamete donation and, to an extent, surrogacy.<sup>21</sup>

Of course, well-established research indicates that it can be psychologically damaging for adopted children to learn late in life that they are adopted – and similarly in relation to donor conception.<sup>22</sup> It is perhaps inevitable that we reason by analogy that everyone should learn the ‘truth’ about who our parents are (or our genetic origins), whether or not we were adopted, donor conceived or born through surrogacy. However, questioning what this ‘truth’ means and its assumed importance significantly overlaps with the ‘telling’ issue. Where telling and knowledge of the manner of conception is the norm from a young age, such psychological issues are likely to be far less prevalent as the situation is normalised. This does not automatically translate to the right to know *who* (all) the people involved in one’s conception were. It does translate to educating and counselling fertility patients,

<sup>18</sup> Fortin (n 8) 342–43.

<sup>19</sup> T Freeman and M Richards, ‘DNA Testing and Kinship; Paternity, Genealogy and the Search for the “Truth” of our Genetic Origins’ in F Ebtehaj, B Lindley and M Richards (eds), *Kinship Matters* (Oxford, Hart Publishing, 2006) 67, 79.

<sup>20</sup> Though see F Darroch and I Smith, ‘Establishing Identity: How Direct-to-Consumer Genetic Testing Challenges the Assumption of Donor Anonymity’ (2021) 59(1) *Family Court Review* 103.

<sup>21</sup> With the potential for such relationships to be increasingly recognised in surrogacy, should the Law Commissions’ proposal for a new ‘pathway to parenthood’ ever become law. As Brown and Wade note, this would be accompanied by a new surrogacy register (akin to the current donation register) though, as noted, not all surrogacy arrangements will be (able to be) captured.

<sup>22</sup> Rose (n 9).

parents and even children at school, in the context of relationships and sex education, that telling and openness is best.<sup>23</sup>

In particular, over-geneticising origin information is relevant to mitochondrial donation. Even the terminology is somewhat controversial here – by including this technique with other reproductive technologies, Brown and Wade adopt a particular position. There is considerable irony in Brown and Wade’s argument about recording mitochondrial donors because of the over-geneticisation we already see as regards *nuclear* DNA. Others view mitochondrial donation (where there is no inheritance of nuclear DNA) more as a medical treatment that relies on IVF for its performance than a reproductive technology per se, and more like other tissue donation (including blood, bone marrow or even stem cells) or organ donation. That is, as the solution to a medical problem, geared not towards creating a child for someone who could not otherwise have one, but rather to allow for the birth of a *healthy* (or unaffected) child. Recording the mitochondrial donor, other than as a medical record, would double down on (over-) geneticisation<sup>24</sup> and play into the hands of the tabloid-style ‘three-parent children’ headlines prevalent during parliamentary debates.<sup>25</sup>

## VI. Conclusion

This response is not to dismiss Brown and Wade’s calls for better collection, retention and availability of origin information, or the need to encourage telling. Indeed, it may be that origin information is potentially important in developing a sense of narrative identity throughout a child’s life and as they develop into adulthood. However, there is much to be worked out first. The fact that – as the authors concede – this information is *potentially* important to some does not indicate mandatory or automatic disclosure to all, particularly as it may be *unimportant* to some and create conflicts of rights for, and with, others. Beyond privacy issues,

<sup>23</sup>This would also be the position of support organisations like the Donor Conception Network (dcnetwork.org/) and, as the authors identify, the Human Fertilisation and Embryology Authority. One interesting and perceptive observation from a young person involved in Children’s Voices in Surrogacy Law (n 13) was that ‘in an ideal situation [children] should be told as soon as possible, like, there shouldn’t be a kind of sit down “OK, here is how you came to be.” It just should, kind of, always be a known thing.’ Another put forward the idea of ‘drip feeding’ the information to ‘normalise’ it: see Phase 1 report, 23.

<sup>24</sup>This would be even more so in the context of future potential reproductive technologies, such as in vitro gametogenesis (IVG) and UTx (uterine transplant following donation), where what we are talking about is the donation of a body part or somatic cell.

<sup>25</sup>In its review of the techniques conducted prior to their being allowed in law, the Nuffield Council on Bioethics said ‘mitochondrial donation does not indicate, either biologically or legally, any notion of the child having either a “third parent”, or “second mother”’ and that a ‘donor of mitochondria should not have the same status in regulation as a reproductive egg or embryo donor in all aspects’. See Nuffield Council on Bioethics, *Novel Techniques for the Prevention of Mitochondrial DNA Disorders: An Ethical Review* (London, Nuffield Council on Bioethics, 2012) xvi.

there are practical problems raising issues of equity when the children discussed here are compared with others. Finally, over-geneticisation must be considered. In working through all this, I agree with the authors that a participatory approach to any new regulatory scheme would be best. We cannot assume what children's views on what information should be available to them will be – so we should ask them.

