Donor-Conceived Families

Relatedness and Regulation in the Digital Age

Fiona Kelly and Deborah Dempsey

Hundreds of thousands of people globally have been conceived through use of donated eggs, sperm or embryos (i.e. 'third-party assisted reproduction' or 'reproductive donation'), most at a time when donations were anonymous (Harper et al., 2016). In many countries that have reproductive donation programmes, anonymity for sperm, egg and embryo donors prevails, and research indicates that a significant number of parents continue not to tell their children that they are donor conceived (Readings, Blake, Casey, Jadva, & Golombok, 2011; Nordqvist & Smart, 2014). However, over the past two decades, there has been growing international debate about the potentially harmful effects of secrecy in donor-conception families. It is increasingly asserted that knowledge of one's genetic origins is constitutive of identity and emotionally important to people born of donated gametes (Turner, 2000; Blyth, 2012). In response to this cultural shift, a number of countries have ended donor anonymity by providing donor-conceived people with access to their donor's identity when they reach a certain age. Others have gone one step further and created mechanisms by which donor-conceived people and their donors can meet. This practice is known as 'donor linking'.

Donor-linking laws have emerged as a controversial policy response to the desire for information about 'donor relatives', that is, the term commonly used for the people to whom one has a biogenetic connection as a result of the use of donated eggs or sperm. Some jurisdictions, including Australia, Sweden, the Netherlands and the UK, have introduced laws mandating that identifying information about donors be registered and available to donor offspring, in the event that they want information about, or contact with, donors or, in some cases, donor siblings (offspring who share a donor). Each jurisdiction has taken a slightly different approach, with the key differences relating to who can access information, who can be the subject of a request for information, at what age a donor-conceived person might have access, and the nature and extent of support services available to donor-conceived people, recipient parents and donors who request information. For example, some jurisdictions such as Austria and Finland, limit information access to donor-conceived people who wish to know the identity of their donor, where conception occurred after the date the legislation commenced. In Finland this is possible at age 14, while Australia permits access at 18, unless there is a medical reason supporting earlier access. In other jurisdictions, such as the Netherlands, donor-conceived people can access information about their donors and their donor siblings. The latter is facilitated by a government-funded organisation. In 2015, the state of Victoria, Australia became the first jurisdiction in the world to provide retrospective access to donor records (but not donor-sibling records), which meant that the identities of previously anonymous donors can be released to donor-conceived people (Kelly & Dempsey, 2016). The delicate process of releasing this information and facilitating contact between the parties is undertaken by a statutory body and includes extensive counselling services. In this collection, a number of these systems are explored in detail.

Alongside legislative responses, non-statutory 'do-it-yourself' (DIY) linking options – where individuals use web-based donor registers, social media and direct-to-consumer genetic testing (DTCGT) to locate donor relatives – have become increasingly common globally, even in jurisdictions where statutory donor registers are available (Dempsey & Kelly, 2017; Crawshaw et al., 2015). DIY linking typically allows for connections between a much broader range of donor relatives than statutory systems, which tend to limit linking rights to donor-conceived people and their donor. In the DIY context, connections can be made between families who share the same sperm or egg donor, between the donor's children and his or her donor offspring, and donor siblings. Connections can also be made at any age, with a growing number of parents connecting with donor siblings and even their child's donor, while the child is still a minor. Many of these connections are enabled through new technologies that were not anticipated when anonymity laws were passed or even when more recent 'open' donor frameworks were introduced.

In this collection, we are particularly interested in the possibilities for donor linking in the digital age, defined here as the period during which Internet-facilitated online communications have enabled people to meet and connect, sometimes across vast geographic distances. We argue that these new technologies have created opportunities for relationships between donor relatives that were barely imaginable in the past. They also extend a new degree of agency to donor-conceived people, recipient parents and

Cambridge University Press & Assessment
978-1-009-00961-4 — Donor-Linked Families in the Digital Age
Edited by Fiona Kelly , Deborah Dempsey , Adrienne Byrt
Excerpt
More Information

donors, creating emotional complexities and ethical dilemmas that were previously unforeseen. The impact of the digital age is now felt at every stage of the donor conception journey. Web-based introduction sites such as UK-based Pride Angel and Sperm Donors Australia have normalised the relatively new phenomenon of ‘online sperm donation’, where potential donors and recipients meet each other online, just as dating sites such as Tinder have made it commonplace to find sex or love online. The emergence of these digital means by which to find a donor and/or maintain a connection after a child is conceived, has resulted in a democratisation of the process of donor conception and some relocation of power from fertility clinics to consumers. When prospective parents recruit their donors online, the boundaries around information sharing or contact between donors and their offspring are no longer dictated by fertility clinics or sperm banks. In the world of online sperm donation, the parties negotiate their own arrangements. While there have always been known donors, particularly within the lesbian and gay communities (McNair & Dempsey, 2002; Dempsey, 2010, 2012a, 2012b), the scale and geographic reach of online donation is new. In the past, known donor agreements were typically between friends or acquaintances. In the digital age, it is common for all interactions – with the exception of the insemination itself – to occur online.

Once children are conceived, various digital and medical technologies have enabled the formation of global online communities of donor-linked families (Hertz & Nelson, 2018), making it difficult for sperm banks and fertility clinics to control contact between families who used the same donor. Even in jurisdictions where anonymous donors are available, or where anonymity is imposed for the first 18 years of a child’s life, recipient parents and donor-conceived children and adults are unwilling to passively accept their fate. As communications and genetic technologies become more sophisticated, parents and offspring demonstrate ingenuity and creativity in subverting the law and clinical policies. Armed with donor numbers and non-identifying information such as hair and eye colour, parents and donor-conceived people can use the Internet to find donor siblings. Alternatively, direct-to-consumer DNA tests can be used to identify donor siblings, or even the donor or his relatives. While some sperm banks now counsel prospective donors about the possibility of their identity being revealed via DNA testing, others have doubled down on the promise of anonymity. For instance, a sperm bank in the United States recently took legal action against a mother who identified her daughter’s donor using a DNA test, in violation of the contract she signed which stated she would not attempt to locate or identify him.

Cambridge University Press & Assessment
978-1-009-00961-4 — Donor-Linked Families in the Digital Age
Edited by Fiona Kelly , Deborah Dempsey , Adrienne Byrt
Excerpt
More Information

The affordances of genetic and online technologies, coupled with the resourcefulness of those who use them, have changed the parameters of the long-standing debate about whether secrecy or openness is the best way for the state or the fertility industry to manage families created through third-party assisted reproduction. To a large degree the debate is moot, as the ability to maintain anonymity is no longer guaranteed. Some commentators have even proclaimed the 'end of anonymity' (e.g. Harper & Kennett, 2016) due to the relative ease with which a direct-to-consumer DNA kit, sometimes in tandem with online detective work, can reveal genetic relatives with a great degree of accuracy. While these assertions may be true in a practical sense, their relational and legal consequences demand further scrutiny (see Zadeh, 2016). For instance, does ending anonymity via digital means inevitably lead to openness, or at the very least, the end of secrecy? How is that openness experienced by those who choose it or have it forced upon them? Is there still a role for the law or the state in legislating for, and facilitating, openness in the digital age?

Overview of the Collection

Global in scope, this collection explores the practice, implications and challenges of donor linking. Through an exploration of the experiences of those who have engaged in donor linking across a variety of jurisdictions, it interrogates how cultural setting and family-type influence how openness and secrecy are understood and experienced.

The editorial position of the collection is that there is urgent need for a more nuanced approach to the somewhat polarised 'secrecy' versus 'openness' debate that has dominated public narratives and global policy discussions about donor-conception families, particularly in light of the technological advancements that have arguably led to a relocation of power over information from sperm banks and medical professionals to consumers and donor offspring themselves. It is often presumed that abolishing anonymity is an endpoint in the donor-conception debate. However, by exploring experiences of donor linking across a variety of jurisdictions, the collection provides new insights into what the 'end of anonymity' actually means for donor-conceived people, donors and parents and, perhaps most importantly, what happens after identities are revealed. At times, we question whether the 'secrecy versus openness' dichotomy is as straightforward as often presumed in the public narrative, particularly in light of research on the new Victorian legislation, which suggests that openness laws can create new secrets for some families

Cambridge University Press & Assessment
978-1-009-00961-4 — Donor-Linked Families in the Digital Age
Edited by Fiona Kelly , Deborah Dempsey , Adrienne Byrt
Excerpt
More Information

(Cosson, Dempsey & Kelly, 2022). In keeping with this approach, the collection interrogates the claim that we have in fact reached the 'end of anonymity' in third-party assisted conception, with reference to contemporary international evidence about how people conceive relatedness in donor conception and how they are using new technologies such as DNA testing and social media, as well as statutory systems for donor linking, to access information.

Part I: 'DIY' Donor Linking: Issues and Implications

Part I of the volume explores the increasing role of DIY technologies, sometimes used in tandem with legislative frameworks, to enable members of donor-linked families to discover and/or meet donor relatives, or to recruit donors that will be known to children from birth. This new dimension to donor linking demonstrates the ways in which decisions about secrecy and openness are no longer solely in the hands of fertility clinics and law makers. Rather, donor-conceived people, donors and parents have a new technology-enabled agency that allows them to connect with donor relatives outside of legal frameworks and according to their own timeline. The chapters in Part I highlight the vast array of DIY technologies available to the donor-conception community, from direct-to-consumer DNA testing, discussed in the Adams et al. chapter, to social media 'creeping' and other online sleuthing, discussed by Byrt and Dempsey, and also by Kelly. In their chapter about 'online sperm donors' – men who advertise their services via online platforms – Volks and Kelly highlight how new technologies are being used to bring prospective parents and donors together prior to conception, bypassing formal donation via a fertility clinic or sperm bank, and enabling contact between donor-conceived children and their online sperm donors from birth. All the chapters in Part I reveal the gap between what is permitted by law and what is happening online, raising the question of whether donor-linking laws continue to be relevant in the digital age.

Part I begins with the bold assertion by Adams et al. that 'donor anonymity is dead'. Through an exploration of the use by British donor-conceived people (DCPs) of both formal registers and DTCGT they argue that we have entered a new era where the prevalence of DTCGT has enabled the circumvention of existing policies and practices regarding donor conception, resulting in a dramatic expansion of opportunities to find genetic relatives. Consequently, control over information has moved from clinics, parents and legislators to DCPs themselves.

Cambridge University Press & Assessment
978-1-009-00961-4 — Donor-Linked Families in the Digital Age
Edited by Fiona Kelly , Deborah Dempsey , Adrienne Byrt
Excerpt
More Information

In her chapter on parents who use DIY methods to make contact with their child's donor siblings and/or donor while their child is still a minor, Kelly also argues that the widespread availability of new technologies, coupled with the ingenuity of those who use them, has resulted in the relocation of control over information from clinics and the government, to parents, DCPs and even donors. The parents in Kelly's sample, most of whom were single mothers by choice, believed that it was in the best interests of their children to have the opportunity to integrate their donor relatives into their lives from an early age. Their commitment to 'early contact' made them comfortable pursuing donor and donor-sibling connections via new technologies such as DTCGT and online sleuthing, even in circumstances where no legal right to information existed. Kelly speculates that this new trend, which is likely to increase with time as new technologies emerge, may undermine or even supplant the law, which currently puts relatively tight controls on contact between donor relatives. Perhaps surprisingly, however, Kelly found that while parents had fully embraced the opportunities provided by new technologies to engage in donor linking, the majority still favoured a formal system for early contact linking, regulated by law.

Byrt and Dempsey also explore the ways in which new technologies, particularly Facebook, are used to identify donor relatives. However, they do so through the prism of surveillance, exploring how DCPs, without the knowledge or consent of their donor relatives, engage in what has been referred to as 'creeping': an 'intense form of background checking that involves silently following an individual on one or more social media outlets without posting or commenting and doing expanded research on the person by following their social media friends and family members online' (Standlee, 2019). Byrt and Dempsey argue that the normalising of Internet 'creeping' raises questions about how the concept of contact should be understood in the digital age, and whether the law is capable of adequately responding to the non-consensual forms of contact enabled by new technologies.

The chapter by Volks and Kelly also explores the democratising power of the Internet, but through an analysis of the early contact experiences of 'online sperm donors', defined as men who donate their sperm via the growing number of online meeting groups for prospective parents and donors. For the men profiled by Volks and Kelly, one of the benefits of being an online sperm donor was the opportunity to negotiate ongoing contact with their donor offspring, an option that is not available when donating to a fertility clinic. While the nature and extent of contact sometimes

Cambridge University Press & Assessment
978-1-009-00961-4 — Donor-Linked Families in the Digital Age
Edited by Fiona Kelly , Deborah Dempsey , Adrienne Byrt
Excerpt
More Information

became a source of conflict between donors and their recipients, most were able to maintain a relationship with their donor offspring. These findings once again highlight the gap between what is permitted under the formal legal system and the opportunities afforded by new technologies.

In the final chapter in Part I, Zeghiche et al. draw on qualitative interviews with recipient parents and DCPs to explore the role DTCGT testing has played in revealing fertility fraud in Canada. In each case, genetic testing exposed the sperm substitution activities of fertility doctors that had occurred decades earlier. Zeghiche et al. argue that while sperm substitution has historically been treated as a marginal issue by both the public and the fertility industry, the availability of DNA testing means that this type of discovery could become more widespread, and that potential victims have the power to reveal the truth. As case numbers rise, it will be increasingly important to document the consequences for the affected families and the impact the information has on their understandings of family.

Part II: Children's and Adults' Lived Experiences in Diverse Donor-Linked Families

Part II of the collection explores the myriad experiences of DCPs, recipient parents and donors who attempt to connect with donor relatives, and the social and cultural significance given to these relationships. Each chapter addresses new forms of relatedness from the perspective of a particular group within the donor-conception community, highlighting the shifting nature of the role each plays in an era where anonymity is no longer the norm. As new types of kinship emerge, parties struggle with the limitations of language and existing familial categories, the shadow of anonymity that persists even when information is revealed and the challenges of integrating new members into established groups of donor relatives.

It begins with the exploration by Rosanna Hertz of the importance of donor-sibling networks to teens and young adults. Hertz draws on a qualitative study of donor-conceived young people who have connected through online registers and social media to explore how they situate their donor siblings within their existing kinship structures, and how they actively construct these new relationships. Traditional notions of kinship are challenged by these donor-sibling networks, which do not follow the usual rules of family. For many of the young people in these sibling networks, the genetic link created an expectation of emotional closeness between donor siblings, but actual closeness was the result of 'activating' the genetic relationship via practices of intimacy.

Similar themes emerged from the chapter by Indekeu and Maas, which explores the experiences of DCPs who make contact with 'same-donor offspring' via the Dutch organisation Fiom, which runs a voluntary DNA database (Fiom KID-DNA Database) for those conceived via gamete donation. Using the database, Fiom identifies 'same-donor offspring' groups and facilitates a group meeting for them. The chapter explores, from the perspective of the regulator, how to support same-donor offspring integrate these new relations into their lives, how to manage group dynamics, and the challenges of negotiating a continuously growing, often global network, of offspring, as new members join the register. While Hertz identifies largely positive experiences, Indekeu and Maas touch on the negative emotions experienced by some offspring, such as offspring of 'prolific donors' who struggled with the 'yuk factor' of being 'one of so many'.

The challenges posed by new forms of kinship are explored further by Gilman and Nordqvist, this time from the perspective of egg and sperm donors who have been located by their donor offspring or recipient parents. As anonymity is replaced with different forms of 'identity release', a growing number of donors are having to fashion new familial identities. While donors are cautioned to respect the parental boundaries of the families to which they have donated, they are also expected to be 'available' to their donor offspring. Unable to always reconcile the two, donors nonetheless commit to 'following the lead' of the families and donor-conceived people.

In Newton's chapter, which draws on the concept of 'familial haunting' to explore donor-conceived people's experiences of living with anonymity and absence, we witness the complex impact of anonymity on donor-conceived people. While many scholars in this field have asserted that anonymity is over, Newton explores the experiences of the many donor-conceived people for whom anonymity, and its effects, continue. Newton is particularly interested in the 'terrain of non-relationships and their links to (unbe)longing'. Her participants grapple with the ways in which unknown donor relatives are experienced as a 'ghostly presence', making themselves felt in the daily lives of DCPs, and often across generations.

Rhonda Shaw explores the cultural significance of kinship affinities among the Māori of Aotearoa and the implications for the social identity of people conceived using assisted reproduction. Shaw argues that the transfer of reproductive materials between known and unknown donors and recipients may have identity implications for Māori that may not be as significant for Pākehā. The chapter explores the experiences of

Cambridge University Press & Assessment
978-1-009-00961-4 — Donor-Linked Families in the Digital Age
Edited by Fiona Kelly , Deborah Dempsey , Adrienne Byrt
Excerpt
More Information

recipients of gametes, both Māori and non-Māori, and the ways in which they attempt to honour their children's whakapapa (their ancestral line), often through making arrangements that would give their children information about where they came from.

In the last contribution of Part II, Damien Riggs and colleagues consider how men, trans/masculine and non-binary people are bearing children through the use of known donor sperm and the relational complexities involved in explaining and navigating these relationships, both in the lead up to conception and throughout the children's lives. Riggs et al. argue there is a greater need to assist this diverse group of parents to navigate the complexities of disclosure and storytelling to children about donor conception, and to challenge prevailing cis-genderism in the way assumptions about the role of sperm donors may be made.

Part III: Institutionalised Resistance to Openness

The final part of the collection explores resistance to openness at the level of policy and law. In the digital age, institutionalised donor anonymity persists. Just as there are strong cultural impulses in play supporting legislative openness, there may be very strong cultural barriers to ending anonymity at the level of policy and law, as the case studies of the United States and Japan exemplify.

In the context of the United States, Naomi Cahn observes the extent to which the donor gamete industry is lightly regulated by both the federal government and individual states, linking this to the broader issue of why calls for legislative openness have been less successful in US jurisdictions. For Cahn, several factors are implicated in the reluctance to bolster regulation. These include concerns about the sperm supply, and the notion that ending anonymity would lead to a decrease in donor numbers, although this claim has been challenged in other jurisdictions. There is also the issue of reproductive politics in the United States more broadly, notably whether anti-abortion legislation could be deemed to apply to assisted reproductive technology.

Finally, Yukari Semba explores why donor anonymity prevails in Japan despite increasingly strong lobbying on the part of donor-conceived adults for information about their genetic origins. Semba traces the history of sperm donor anonymity in Japan, reviewing the position of various governmental committees since the late 1990s, which have reinstated anonymity for gamete donors despite increasing activism among donor-conceived individuals. She observes that donor conception remains a marginal issue for Japanese politicians because it is perceived to affect a very small proportion of the electorate. Sperm donor records, as medical records, are routinely destroyed after five years and there is a great deal of reluctance to challenge the status quo.

References

Blyth, E. (2012). Discovering the 'facts of life' following anonymous donor insemination. *International Journal of Law, Policy and the Family*, *26*(2), 143–161. https://doi.org/10.1093/lawfam/ebs006

Cosson, B., Dempsey, D., & Kelly, F. (2022). Secret shame – male infertility and donor conception in the wake of retrospective legislative change. *Men and Masculinities*, *25*(3), 497–515. https://doi.org/10.1177/1097184x211038329

Crawshaw, M., Daniels, K., Adams, D., Bourne, K., van Hooff, J. A. P., Kramer, W., … & Thorn, P. (2015). Emerging models for facilitating contact between people genetically related through donor conception: a preliminary analysis and discussion. *Reproductive Biomedicine & Society Online*, *1*(2), 71–80. https://doi.org/10.1016/j.rbms.2015.10.001

Dempsey, D. (2010). Conceiving and negotiating reproductive relationships: lesbians and gay men forming families with children. *Sociology*, *44*(6), 1145–1162. https://doi.org/10.1177%2F0038038510381607

Dempsey, D. (2012a). More like a donor or more like a father? Gay men's concepts of relatedness to children. *Sexualities*, *15*(2), 156–174. https://doi.org/10.1177%2F1363460711433735

Dempsey, D. (2012b). Gay male couples' paternal involvement in lesbian-parented families. *Journal of Family Studies*, *18*(2–3), 155–164. https://doi.org/10.5172/jfs.2012.18.2-3.155

Dempsey, D., & Kelly, F. (2017). Transnational third-party assisted conception: pursuing the desire for 'origins' information in the internet era. *Babies for Sale? Transnational Surrogacy, Human Rights and the Politics of Reproduction*, 204–217. https://doi.org/10.5040/9781350218567.ch-011

Harper, J. C., Kennett, D., & Reisel, D. (2016). The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business. *Human Reproduction*, *31*(6), 1135–1140. https://doi.org/10.1093/humrep/dew065

Hertz, R., & Nelson, M. K. (2018). *Random Families: Genetic Strangers, Sperm Donor Siblings, and the Creation of New Kin*. Oxford University Press.

Kelly, F. J., & Dempsey, D. J. (2016). Experiences and motives of Australian single mothers by choice who make early contact with their child's donor relatives. *Medical Law Review*, *24*(4), 571–590. https://doi.org/10.1093/medlaw/fww038

Kelly, F., & Dempsey, D. (2016). The family law implications of early contact between sperm donors and their donor offspring. *Family Matters*, (98), 56–63. https://doi.org/10.1093/lawfam/ebz011