


# Disciplined parents and autonomous children: information sharing as governing device in Swedish identity-release gamete donation

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## ABSTRACT

This article analyses shifts and continuities in Swedish regulation of information sharing in identity-release donor conception. At a time when families include both solo and same-sex parenting, I draw on a practice-oriented method to compare legal and pre-legislative documents from the early 1980s with those of the late 2010s as developed in a Swedish national context. Following the turn to openness in donor conception, I discuss the practical implications of framing access to information from the hospitals' so-called 'special medical record' as a children's right, when information is in fact only available after 'maturity' is reached. Furthermore, I show how a significant change in the understanding of child-parent relationships in donor-conceived families is articulated in the 2019 legislation. If early policy documents portrayed donor-conceived children as potentially problematic for not 'knowing their origin', I argue that now it is parents in donor-conceived families who are constructed as potentially problematic. Drawing on critical kinship theory, I conclude that Swedish policy-making on information sharing in donor conception relies on a symbolic rather than material understanding of genetic relatedness that fails to acknowledge how different family forms might have different needs. Based on these findings, I suggest that policymakers take into account the implications a changing view on family life and genetics have for children and parents following donor conception.

**KEYWORDS:** Donor conception, Gamete and embryo donation, Family law, Public policy, Document analysis, Critical kinship studies, Solo mothers, Same-sex parents

## I. INTRODUCTION

Donated gametes, including eggs, sperm and embryos, are increasingly part of reproductive methods in fertility medicine. In the last decades, national laws on donor conception have commonly been altered to enable identity-release donations rather than anonymous

ones.<sup>1</sup> Known as the turn to openness,<sup>2</sup> this means that donor-conceived offspring can access information about donor(s) from a clinic or registry when reaching maturity. Acknowledging findings that some donor-conceived individuals are never told about the donation by their parents<sup>3</sup> and the historical formation of donor conception as one based on secrecy and a mandate of non-disclosure,<sup>4</sup> scholars have examined the complex social and cultural notions that influence parent's disclosure practices with donor-conceived offspring.<sup>5</sup>

At a time when affordable DNA tests combined with online media technologies have drastically re-shaped gamete and embryo donation practices globally,<sup>6</sup> many have argued that anonymity in donor conception simply no longer exists.<sup>7</sup> Furthermore, medical practices have been re-modelled through increased use of genetic testing, diagnostics, and heritability.<sup>8</sup> Another aspect of how genetics are changing meaning is in new types of family-making where 'women-headed families', such as solo mothers and lesbian couples, might be more inclined to search for the donors on behalf of their children or otherwise show more interest in connecting with donor-sibling families as compared with heterosexual couples.<sup>9</sup> While some have suggested that new types of family forms might alter information sharing needs after donation, this has seldom been analysed in relation to existing policy frameworks.

With Sweden as my case, this article aims to discuss how the regulation of information sharing in donor-assisted conception is connected to an overall state governing in the field of fertility medicine. This includes not only national legislation concerning who has access to medically assisted conception but also public policy on how parenthood and family life ought to be conducted. Using a practice-oriented document analysis, I demonstrate how the invention of the 'special medical record' as a documentation device enabled a reframing of information sharing and secrecy in donor conception in Sweden.

Sweden presents an interesting case for policy-making on donor conception, as it was the first country to outlaw anonymous gamete donation in 1985.<sup>10</sup> In recent years, Swedish policy-making has been referred to as a role model, not only for its early adaptation,<sup>11</sup> but

<sup>1</sup> E. Blyth and L. Frith, 'Donor-Conceived People's Access to Genetic and Biographical History: An Analysis of Provisions in Different Jurisdictions Permitting Disclosure of Donor Identity' (2009) 23 (2) *International Journal of Law, Policy, and the Family* 174–91; S. Allan, *Donor Conception and the Search for Information: From Secrecy and Anonymity to Openness* (New York: Routledge, 2017).

<sup>2</sup> P. Nordqvist, 'The Drive for Openness in Donor Conception: Disclosure and The Trouble with Real Life' (2014) 28 (3) *International Journal of Law, Policy and the Family* 321–38.

<sup>3</sup> S. Isaksson and others, 'Two Decades after Legislation on Identifiable Donors in Sweden: Are Recipient Couples Ready to be Open About Using Gamete Donation?' (2011) 26 (4) *Human Reproduction* 853–60; L.D. Applegarth and others, 'Parental Disclosure to Offspring Created with Oocyte Donation: Intentions versus Reality' (2016) 31 (8) *Human Reproduction* 1809–15.

<sup>4</sup> C. Smart, 'Law and the Regulation of Family Secrets' (2010) 24 (3) *International Journal of Law, Policy and the Family* 397–413; G. Newton and others, 'Truth, Proof, Sleuth: Trust in Direct-to-Consumer DNA Testing and Other Sources of Identity Information among Australian Donor-Conceived People' (2022) 57 (1) *Sociology* 36–53.

<sup>5</sup> A. Indekeu and others, 'Factors Contributing to Parental Decision-Making in Disclosing Donor Conception: A Systematic Review' (2013) 19 (6) *Human Reproduction Update* 714–33; Nordqvist (n 2); S. Zadeh, 'Disclosure of Donor Conception in the Era of Non-Anonymity: Safeguarding and Promoting the Interests of Donor-Conceived Individuals?' (2016) 31 (11) *Human Reproduction* 2416–20.

<sup>6</sup> C. Krolokke and others, *Critical Kinship Studies* (London: Rowman and Littlefield International, 2015); R. Andreassen, *Mediated Kinship: Gender, Race and Sexuality in Donor Families* (London: Routledge, 2018).

<sup>7</sup> J.C. Harper, D. Kennett and D. Reisel, 'The End of Donor Anonymity: How Genetic Testing Is Likely to Drive Anonymous Gamete Donation out of Business' (2016) 31 (6) *Human Reproduction (Oxford)* 1135–40.

<sup>8</sup> A.E. Clarke and others, 'Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine' (2003) 68 (2) *American Sociological Review* 161–94.

<sup>9</sup> Andreassen (n 6).

<sup>10</sup> J. Stoll, *Swedish Donor Offspring and Their Legal Right to Information* (Uppsala: Juridiska institutionen, Uppsala universitet, 2008); J. Lind, 'The Rights of Intended Children: The Best Interests of the Child Argument in Assisted Reproduction Policy' (2019) 26 (3) *Childhood* 352–68.

<sup>11</sup> L. Eriksson, 'Finland as a late regulator of assisted reproduction: a permissive policy under debate' in M. Lie and N. Lykke (eds.), *Assisted Reproduction across Borders: Feminist Perspectives on Normalizations, Disruptions and Transmissions* (London: Routledge, 2016) pp. 124–35.

also for applying the notion of ‘maturity’ rather than ‘adult age’ regarding when donor-conceived individuals can access donor-specific information.<sup>12</sup> This means donor records can be accessed earlier than strictly at the age of 18 years.

Moreover, the Swedish regulation of parents’ information sharing with their offspring was recently sharpened. Since 2019, parents using donor gametes from a fertility clinic are obligated, rather than recommended, to share information about the conception with their offspring.<sup>13</sup> However, in the Swedish model it is only the child and not the recipient parents that have the right to donor-specific information from the hospital’s special medical record. As I will argue, this means that children’s right to information about donors relies on a de-linking of children and their parents, and implies that children must reach a certain autonomy before having access to donor-specific information.

In the next section, I present my analytical method and describe the legal material chosen for analysis. I then go on to discuss the historical and legal context of Swedish policy-making on donor conception in relation to the article’s focus on the special medical record. The analysis is divided into three analytical sections (numbered IV–VII), followed by a concluding discussion. Drawing on sociological findings<sup>14</sup> and feminist anthropological theory,<sup>15</sup> I highlight shifts in societal understandings of two concepts, namely ‘family’ and ‘the best interest of the child’ and go on to discuss my findings in relation to scholarship on family law. Based on these findings, I suggest that policymakers take into account the implications a changing view on family life and genetics have for children and parents following donor conception.

## II. DOING DOCUMENT ANALYSIS OF GOVERNMENT POLICY: MATERIAL AND METHOD

As part of a larger ethnographic study on decision-making in donor conception, my analytical approach is inspired by a practice-oriented method of reading pre-legislative and legal documents. Instead of viewing policy texts as mere representations of a problem or external discourse, I approach policy documents as integral to the practices studied.<sup>16</sup> This enables me to empirically investigate the relation between regulatory documents and the ‘issues’ or ‘objects’ they are about.

This approach is particularly well suited for a study of Swedish policy-making, as major social policy changes all come about through the so-called ‘governmental commissions’ that are intimately linked to social science.<sup>17</sup> Often described as unique in an international context,<sup>18</sup> the purpose of these commissions is to facilitate long-term planning of societal change in a structured and transparent manner.<sup>19</sup> Typically, governmental commissions are appointed early in a policy process and provided with written directives regarding which issues to address (and similarly, what not to examine). The results are published as official reports which are distributed to selected stakeholders, who are then invited to comment in an open referral process. The collected statements are subsequently sorted into categories and incorporated into a government bill.

<sup>12</sup> Blyth and Frith (n 1).

<sup>13</sup> Prop 2017/18:155 *Regeringens Proposition: Modernare Regler om assisterad befruktning och föräldraskap* [Government Bill on embryo and double donation] p. 36.

<sup>14</sup> Nordqvist (n 2); Newton and others (n 4), P. Nordqvist, ‘Genetic Thinking and Everyday Living: On Family Practices and Family Imaginaries’ (2017) 65 (4) *The Sociological Review* 865–81.

<sup>15</sup> Smart (n 4); J. Edwards, ‘Undoing kinship’ in F. Ebtehaj et al. (eds.) *Relatedness in Assisted Reproduction: Families, Origins and Identities* (Cambridge: Cambridge University Press, 2014) pp. 44–60.

<sup>16</sup> K. Asdal and H. Reinertsen, *Doing Document Analysis: A Practice-Oriented Method* (Los Angeles: SAGE, 2022).

<sup>17</sup> Å. Lundqvist and C. Roman, ‘Construction(s) of Swedish Family Policy 1930-2000’ (2008) 33 (2) *Journal of Family History* 216–36.

<sup>18</sup> C. Jonsson Malm, *Att plantera ett barn: internationella adoptioner och assisterad befruktning i svensk reproduktionspolitik* (Lund: Historiska institutionen, Lunds universitet, 2011).

<sup>19</sup> S. Edenheim, *Begärets lagar: moderna statliga utredningar och heteronormativitetens genealogi* (Eslöv: Symposion, 2005) pp. 17–18.

Approaching documents as inherent to social practices entails viewing them as ‘tools’ or ‘sites’ that enable the ‘governing of things’.<sup>20</sup> Thus, I analyse documents not only as textual entities aligning with certain discourses but rather as tools that enable a certain mode of governance. Furthermore, I examine how the creation of documents with a certain official status is used to enable some practices while disabling others. Additionally, I explore how certain dilemmas involved in ethically charged or value-laden reproductive debates are ‘solved’ through the establishment and ordering of documents. Viewing documents as ‘sites’ also enables the document analysis to function as a form of ethnographic fieldwork. In my analysis, I am therefore looking for different kinds of activities – what is going on and what is done, in and through the documents.<sup>21</sup> By focusing on two different points in time and analysing how policymakers respond to comments made by various referral bodies, I am able to trace different actions taking place in and through the creation of public documents.

From the earlier period (1981–1985) when donor conception was first regulated in law, I examined all the main documents relating to the Insemination Act that came into effect in March 1985.<sup>22</sup> From the later period (2016–2019), I utilised the official legislative and pre-legislative documents that were part of the 2019 revision of the Law on genetic integrity (2006: 351).<sup>23</sup>

This article’s focus on two points in time, as specified above, means that other commission documents on donor conception before and after these years are not accounted for in the analysis. Additionally, issues unrelated to a governing of information sharing and disclosure are not discussed. Before proceeding to the analysis, I provide background information on laws regarding assisted reproduction in Sweden and on how policy-making in medical and family law has served as a means to regulate families, children, and clinics.

### III. BACKGROUND: THE SPECIAL MEDICAL RECORD AND THE SWEDISH POLICY CONTEXT

Swedish legislation of the 1980s and 1990s is commonly described as highly regulatory and not very permissive with regard to assisted reproductive technologies.<sup>24</sup> However, both the types of treatments permitted and the groups eligible for treatment have continuously expanded since the early 2000s.<sup>25</sup> Today, lesbian couples and single women are eligible for the same tax-funded reproductive health care as heterosexual couples with fertility problems.<sup>26</sup>

<sup>20</sup> Asdal and Reinertsen (n 16) 43–44.

<sup>21</sup> Compare *Ibid.*

<sup>22</sup> These include: SOU 1983: 42 *Barn genom insemination, Huvudbetänkande av inseminationsutredningen* [Swedish Governmental Official Report “Children conceived by artificial insemination, Main report of the Insemination Investigation”]; Prop 1984/85:2 *Regeringens proposition om artificiella inseminationer* [Government Bill on artificial insemination]; LU 1984/85:10 *Lagutskottets betänkande om artificiella inseminationer* [Parliamentary Standing Committee on Civil-Law Legislation “The law committee’s report on artificial insemination”]; SFS 1984:1140 *Lag om insemination* [Swedish Statute Book 1984:1140 “Law on artificial insemination”].

<sup>23</sup> These include: SOU 2016:11 *Olika vägar till föräldraskap, Huvudbetänkande* [Swedish Governmental Official Report “Different paths to parenthood, Main report of the Path to parenthood investigation”]; Prop 2017/18:155 (n 13); SFS 2018:1283 *Lag om ändring i lagen (2006:351) om genetisk integritet m.m.* [“Revision of Act 2006:351 on Law on Genetic Integrity”].

<sup>24</sup> Nordic Council of Ministers, *Assisted Reproduction in the Nordic Countries: A Comparative Study of Policies and Regulation* (Nordic Council of Ministers: TemaNord 2006:505, Copenhagen 2006); I. Engeli and C. Rothmayr Allison, ‘Governing New Reproductive Technologies Across Western Europe: The Gender Dimension’ in M. Lie and N. Lykke (eds.) *Assisted Reproduction across Borders: Feminist Perspectives on Normalizations, Disruptions and Transmissions* (London: Routledge, 2016).

<sup>25</sup> H. Tinnerholm Ljungberg, *Omöjliga familjen: ideologi och fantasi i svensk reproduktionspolitik* (Stockholm: Statsvetenskapliga institutionen, Stockholms universitet, 2015); A. Skoog Svanberg, G. Sydsjö and C. Lampic, ‘Psychosocial Aspects of Identity-Release Gamete Donation – Perspectives of Donors, Recipients, and Offspring’ (2020) 125 (2) *Uppsala Journal of Medical Sciences* 175–82.

<sup>26</sup> E. Elenis and others, ‘Access to Infertility Evaluation and Treatment in Two Public Fertility Clinics and the Reasons for Withholding It: A Prospective Survey Cohort Study of Healthcare Professionals’ (2020) 10 (12) *BMJ Open* 1–7; U. Dahl and R. Andreassen, ‘Donors We Choose: Race, Nation and the Biopolitics of (Queer) Assisted Reproduction in Scandinavia’ (2023) 18 *BioSocieties* 79–101.

In 2020, nearly 2000 inseminations with donated sperm and more than 2600 IVF treatments with either donated eggs or sperm were conducted at Swedish public and private clinics, resulting in 950 children being born.<sup>27</sup> While insemination with donor sperm was initially a technology for different-sex couples with male factor infertility, as of the last few years, lesbian couples and single women are the majority of patients reproducing with donated sperm in Sweden, with single women accounting for about 45 per cent of the treatments.<sup>28</sup>

Double donation and embryo donation were made legally permitted in Sweden in 2019.<sup>29</sup> Simultaneously, the formulation in Law on genetic integrity that intended parents of donor offspring *should* ('bör' in Swedish) tell their children about being donor conceived was replaced by the wording that parents *shall* ('ska' in Swedish) inform their children about the use of a donor/donors.<sup>30</sup> It has thereby become a legal requirement for parents to inform their children that they are donor conceived (a similar law is in place for adoption). These legal changes as of 2019 meant firstly that previous arguments about the importance of at least one genetic link between parent(s) and children in donor-conceived families were abandoned.<sup>31</sup> Secondly, the conditions for how and when information ought to be shared in donor-conceived families were reinforced.

While both double and embryo donations imply that the child will have not one but two donors, embryo donations have been understood as complicated in Swedish policy-making as it might commonly lead to full genetic 'siblings' in other families. As a result, the new law of 2019 also made it possible for donor-conceived children to add their own names to the special medical record, and thus become known to other children with the same donors.<sup>32</sup> Interestingly, this is the first time a horizontal genetic link is handled as potentially important for donor-conceived families in Swedish public policy.

As part of the 1985 regulation of donor conception,<sup>33</sup> *special medical records* were implemented in public health clinics. The issue of whether children do in practice receive this information has been revisited in subsequent pre-legislative policymaking.<sup>34</sup> The re-wording of the Parents and Children's Act in 2019 can be understood as one outcome of the concern that a significant number of (heterosexual) parents do not tell their children about the use of a donor.<sup>35</sup> The 2017 proposition<sup>36</sup> preceding the new law,<sup>37</sup> also makes explicit that it is the child conceived, and not the child's parents, that should make decisions about whether or not to use the possibility of obtaining more information about the donor, thus emphasizing the agency of the individual with a genetic link to the donor/donors.

The recent shift to openness in many countries, and the idea that it is the donor-conceived person who should (independently) access this information, is however more complex in 'real life'.<sup>38</sup> As discussed throughout this article, disclosure of donor conception, although regarded as information belonging to the child, does in fact also influence other

<sup>27</sup> National Registry of Assisted Reproduction. Q-IVF 2022. <<http://www.ucr.uu.se/qivf/>> (23 December 2023, date last accessed).

<sup>28</sup> Ibid.

<sup>29</sup> SFS 2018:1283 (n 23).

<sup>30</sup> SFS 2006:351 *Lag om genetisk integritet m.m.* [Swedish Statute Book "Law on genetic integrity"].

<sup>31</sup> See Tinnerholm Ljungberg (n 25).

<sup>32</sup> Prop 2017/18:155 (n 13).

<sup>33</sup> SFS 1984:1140 (n 22).

<sup>34</sup> See for instance SOU 2007:3 *Föräldraskap vid assisterad befruktning*. [Swedish Governmental Official Report "Parenthood with assisted reproduction"].

<sup>35</sup> Board of Health and Welfare (SoS 2000:6) *Får barnen veta? Barn som fötts efter givarinsemination* ["Can the children find out? Children born following donor insemination"]. Socialstyrelsen: Stockholm; C. Lampic and others, 'National Survey of Donor-Conceived Individuals Who Requested Information about Their Sperm Donor – Experiences from 17 Years of Identity Releases in Sweden' (2022) 37 (3) *Human Reproduction (Oxford)* 510–21.

<sup>36</sup> Prop 2017/18:155 (n 13).

<sup>37</sup> SFS 2018:1283 (n 23).

<sup>38</sup> Nordqvist (n 2).

parties and family members. Sociological findings suggest that parental disclosure can be understood as ‘embedded in relationships formed over time’.<sup>39</sup> From such a relational perspective, a singular focus on the child as ‘autonomous’ risks separating the child from its wider family network, not taking into account the relational nature of both family life and decision-making. In the next section, I turn to the analysis and begin by discussing information sharing in relation to *the best interest of the child*.

#### IV. REGULATING DISCLOSURE WHILE PROTECTING FAMILIES, CHILDREN, AND DONORS

‘The best interest of the child’ has been a key consideration in Swedish family law throughout the 1900s.<sup>40</sup> However, how to best implement this concept in practice has remained a contested issue.<sup>41</sup> Law makers in the Nordic countries have often interpreted ‘the best interest of the child’ in relation to existing conditions in reproduction and family making. This approach has largely resulted in action-directed and normative regulations rather than enforceable ones, with less attention given to already existing children, and how their best interests might be accommodated.<sup>42</sup> The official regulation of disclosure in 1985 and 2019 are similar examples of normative rather than enforceable legislation. However, while the imperative to disclose is a normative one, the special medical record – implemented from 1 March 1985 – is a material document and documentation practice that can be traced over time.

In the following, I analyse *how children’s right to information about their origin* was made into an issue in need of legislation in the early 1980s. Following Asdal and Reinertsen’s<sup>43</sup> focus on issue-making in public policy, I ask in what way the regulation of disclosure was framed as a *children’s right’s issue* in public documents, and what kind of family or kinship model it presupposes. I trace what kind of modifying work is taking place in and through documents, and how that enables a certain type of governing of families, parenthood, and clinical practices. In short, I demonstrate how the documentation device *special medical record* is presented as the solution that is able to preserve *donor secrecy, family integrity, and children’s right to know*. Then, I proceed to discuss some of the limitations and inherent paradoxes of the special medical record in relation to national identity and a changing socio-medical landscape.

In LU 1984/85:10, issued by the Parliamentary Standing Committee on Civil-Law Legislation, children’s right to have knowledge of their origin is presented as a (contested) issue in donor conception; a dilemma that would if realized lead to the removal of anonymity for sperm donors<sup>44</sup>:

The issue that has called for most attention, not only during this committee’s work and its referral process, but also in the public debate, concerns *the child’s right to have knowledge of its origin*, an issue that clashes with anonymity protection for sperm donors. (emphasis in original)<sup>45</sup>

<sup>39</sup> Ibid 333.

<sup>40</sup> Stoll (n 10); A. Singer, ‘Den moderna reproduktionstekniken – en utmaning för familjerätten’ (2008) 6 (2) *Tidsskrift for familierett, arverett og barnevernrettslige spørgsmål* 94–105.

<sup>41</sup> J. Lind, ‘The Rights of Intended Children: The Best Interests of the Child Argument in Assisted Reproduction Policy’ (2019) 26 (3) *Childhood* 352–68.

<sup>42</sup> Singer (n 40).

<sup>43</sup> Asdal and Reinertsen (n 16) 101–23.

<sup>44</sup> All translations from Swedish to English done by the author.

<sup>45</sup> LU 1984/85:10: (n 22) 55.

Two things are noteworthy in this context. First, the assumed interests of donor-conceived individuals are positioned *against* the interests of sperm donors – an interest, assumedly, to remain anonymous. Placing these two in opposition to one another implies that ‘the child’s right to have knowledge of its origin’ refers to something else than access to medical records or simply being informed that one is donor conceived. Indeed, the emphasis is placed on receiving identifiable information about the donor’s *identity*. As I will go on to discuss, this information is preserved only through the special medical record, a paper-based journal to be kept in safe storage at the facilitating clinic.

A second point concerns the framing of donor-conceived offspring as *children* with rights. It should here be noted that the term *child* can have two parallel meanings. ‘Child’ can refer to a person being under 18 years old, what we might think of as ‘a minor’. It can also describe a kinship relation that does not depend on age, such as being a child of one’s parent (s). While the latter is a relational position, they are both juridical terms. Thus the argument creates an inherent paradox, as it is not clear if donor-conceived individuals should have access to information from the special medical journal already as minors; eg, during their actual childhood.

A short background to how the right to information came to be framed as a children’s rights issue in the pre-legislative documents of the Law on artificial insemination<sup>46</sup> is here needed. The governmental directives given for the Insemination Act<sup>47</sup> do not include a children’s rights approach. Instead, donor-conceived individuals’ potential right to information is joined together with issues of privacy protection for sperm donors under the headline ‘privacy issues’.<sup>48</sup> Apart from general statements of ensuring children ‘good living conditions’, the main topics to investigate involves legal paternity for children and safeguarding donors from later legal or financial claims. This follows a tradition of trying to prevent situations of ‘unknown’ fatherhood that has characterized Swedish family law during the 1900s.<sup>49</sup>

However, in the commission of 1983,<sup>50</sup> ‘the child’s right to have knowledge of its origin and other privacy issues’ is made into a separate section. Here donor-conceived individual’s right to information is transformed into an issue separable from those concerning legal parenthood. Moreover, the Commission’s special examiner Tore Sverne, and his previous role as Chairman of the Commission on Children’s Rights in 1979, is assumed to have played a significant role in steering the Commission towards issues of children’s legal protection.<sup>51</sup> Next, I go through how the special medical record is invented as the device that can safeguard children’s rights without jeopardizing the family unit.

## V. SUFFICIENT MATURITY AND TIMING OF DISCLOSURE – TWO ISSUES OF THE 1980S

From the 1985 regulation, the right to information from the special medical journal can be exercised first when the child has reached ‘tillräcklig mognad’, eg, *sufficient maturity*.<sup>52</sup> In the Government Bill on artificial insemination,<sup>53</sup> the investigator refers to this as early adulthood or later teenage years. It is therefore not any child at any time that can be granted

<sup>46</sup> SFS 1984:1140 (n 22).

<sup>47</sup> Governmental Directives, Dir 1981:72, reprinted in SOU 1983:42 (n 13).

<sup>48</sup> SOU 1983:42 (n 22) 27.

<sup>49</sup> Singer (n 40).

<sup>50</sup> SOU 1983:42 (n 22).

<sup>51</sup> Nordic Council of Ministers (n 24).

<sup>52</sup> SFS 1984:1140 (n 22).

<sup>53</sup> Prop 1984/85:2 (n 22).

information about their gamete donor. Rather, it is stressed that children ought not to be given information that might be harmful to them.

I argue that in the early 1980s documents, the issue of disclosure and children's right to information is presented as a double-edged sword. On the one hand, access to information is framed as a children's rights issue. On the other hand, information about a donor's identity is understood as potentially harmful to either children and/or families. In particular, secrecy concerning family relations is described as harmful to donor-conceived children. However, it is regarded as protective of donors.<sup>54</sup> Thus, in the 1980s insemination debate, not only donor anonymity, but family lies and secrets are explicitly discussed. The possibility that donor-conceived children might find out about the donation by mistake, or at a less suitable time in life, is perceived as a threat to the emotional well-being and integrity of the family unit. In LU 1984/85:10, one response is quoted, highlighting the inability of parents to control the disclosure and thus protect the integrity of their family unit:

How is the parental situation affected, if both parents know, that a for them unknown person, the sperm donor, will enter their lives when the child reaches a certain age? What kind of effect will this have, for instance for the legal father's whole-hearted engagement with the child? The risk for negative effects on the parental role is obvious, which is not beneficial to the child.<sup>55</sup>

In this quote, a father's enactment of family and paternity through what we might call social care ('whole-hearted engagement') is naturalized as a consequence of him being perceived as the 'real' and only father in a certain type of family constellation. Here the assumption seems to be that *genetic paternity* automatically results in a caring relationship to the child, while uncertainty of the relationship might prevent a caring engagement. Thus, the well-being of the child is positioned as dependent on the father being certain of his biological kin relation to the child. In consequence, children's best interest is configured as dependent not only on legal certainty but on the effects that (un-)certainty will, or might, have for social care and commitment.

We might note that this line of argument not only addresses the supposed vulnerability of the social and legal father, but also the child's well-being, and thus the interest of the child is dependent on the interest of the parent(s), here the father. The threat posed by the unknown third-party – here, the sperm donor – is thus a threat to the parental role(s) and only indirectly a threat to the donor-conceived child when not viewed as 'assured biological kin'. Later on in the same paragraph, the sperm donor is referred to as 'the biological father' with an envisioned (future) family of his own, who might in turn be negatively affected by being sought out by donor offspring, as might his own (envisioned) family unit. Disclosure of donation, rather than the donation itself, is here positioned as something that might rearrange kinship and thus as an aspect to be thoroughly controlled and contained. The management of disclosure hence has the potential to protect both family units and above all, children within both families.

Carol Smart<sup>56</sup> has shown that there is a heterosexual logic underpinning what is regarded as 'family secrets'. Through analysing in what contexts secrets within family relations are constructed as harmful and to whom, Smart argues that part of becoming kin might also entail learning 'what not to know'.<sup>57</sup> Clearly, the examples I have discussed so far assume a heterosexual nuclear family unit where kin relations are assured and the kinship tree is 'in

<sup>54</sup> LU 1984/85:10 (n 22) 55.

<sup>55</sup> LU 1984/85:10 (n. 22) 34.

<sup>56</sup> Smart (n 4).

<sup>57</sup> Ibid 409.



order'. It is precisely in this social constellation that donor conception can be created as a secret that you seemingly can choose to be 'open' about or not. Implicit in the arguments of knowing/not knowing is not only the heterosexual, monogamous family unit, but the idea of likeness and of shared racial and ethnic features. As shown by Becker, a central feature of anchoring children as belonging to their family is enacted through 'resemblance talk' which in some family formations can create challenges with regards to disclosure decisions.<sup>58</sup>

The trouble with how donor conception is articulated in LU 1984/85, I argue, is ultimately a dilemma of unruly or uncertain kinship relations, expressed both as a concern for the child and perhaps more importantly, for the integrity of the family unit. Not only does the legal and social father lack a genetic kinship tie with the children. Added to the mix is the possibility that a donor years after the donation might regret this non-relation to the child/children. As envisioned by the legislators, this might in turn disturb not only one but two family units. In the examples provided, genetic kinship relations are thus understood as connections that can be activated or de-activated by the social organization of information and relations.<sup>59</sup> Furthermore, *knowledge* about genetic relatedness, rather than relatedness in itself, is understood as constitutive of the social dimensions of the parent-child relationship, for instance in influencing or hindering a caring engagement.

The idea that donor-conceived families and children should for all time be protected from knowledge about their genetic origin is however not the final conclusion of the document. While both emotional disturbance and shock are to be anticipated in the donor-conceived child, such risks are mitigated with reference to 'the right timing of disclosure' and that the child should be 'mature enough'. Overall, the document leaves room for quite some ambiguity with regard to individual cases:

When [as in exact time] the child will be informed about [the donation] is not possible to specify. But it is of importance that the child is mature enough to be able to receive a message that initially can be perceived as difficult and shocking to the child and result in emotional disturbances. It can [as argued by the Board of Health and Social Welfare] not be ruled out that there might be cases where it would not be in the child's best interest to be informed about the insemination.<sup>60</sup>

Policy-makers and politicians during the 1980s based many of their arguments regarding donor conception on a comparison with adoption policies and practices. Jonsson Malm argues that the governmental commission in the public report 'Parenthood after assisted reproduction' SOU 1984:1140 pathologies donor-conceived children for 'not knowing their origin'.<sup>61</sup> Jonsson Malm further contends that when donor-conceived children are constructed as rootless (or unsettled), they are indirectly positioned as problematic. Not knowing one's origin (here synonymous with genetic/biological origin) is equated with mental ill-health and social as well as psychological problems. Interestingly, while experiences of adopted children are used to argue for the right to have knowledge of one's origin if donor conceived, this is a right that adopted children themselves did not have at the time. As Jonsson Malm shows, this can be understood as not only contradictory but as a form of selective/ideological use of history.<sup>62</sup>

<sup>58</sup> G. Becker, A. Butler and R. D. Nachtigall, 'Resemblance Talk: A Challenge for Parents Whose Children Were Conceived with Donor Gametes in the US' (2005) 61 (6) *Social Science & Medicine* 1300–09; Compare A. Indeku, 'Parent's Expectations and Experiences of Resemblance through Donor Conception' (2015) 34 (4) *New Genetics and Society* 398–416.

<sup>59</sup> Compare Edwards (n 15).

<sup>60</sup> LU 1984/85:10 (n 22) 22.

<sup>61</sup> Jonsson Malm (n 18) 167. Compare SOU 1984:1140 (n 22).

<sup>62</sup> *Ibid* 166–67.

The documents created in the 1980s to resolve the issues of disclosure and information sharing show that policymakers and politicians largely equated donor-conceived children's position with the situation of adopted children.<sup>63</sup> While secrecy was originally the norm in adoption practices in Sweden, the 1960s saw an increase of transnational adoptions from low-income countries. In Sweden, at the time being perceived as a racially homogenous and white nation, the non-resemblance between parents and children in international adoption practices seems to have reinforced a new ideal of openness. In the words of the 1983 governmental commission: 'due to the divergent appearance of the children it was no longer possible to maintain an aspiration to keep the child's origin secret'.<sup>64</sup> While 'appearance' in this context is clearly a code for skin colour and other racial features, no such discussions are brought up with regard to donor conception.

While children's right to information from the special medical record was repeatedly emphasized and the timing of disclosure was discussed in several paragraphs throughout the pre-legislative documents,<sup>65</sup> a few things stand out in how the issue was finally handled. On the one hand, it is recognized that children cannot make use of the right to information without their parents informing them about the donor conception. On the other hand, no clear steps are suggested to make it probable that children would actually receive this information:

The issue of whether the child should be informed at all about being conceived through donor insemination is not regulated by the proposition, but will rather be handed over to the parents. However, the department head believes that the parents should inform the child about this at an appropriate time.<sup>66</sup>

What we end up with at the end of LU 1984/85:10 (and as suggested by Prop 1984/85:2) is a sort of non-regulation, and yet, a kind of recommendation that children should be told about their conception and origin. If initially donor-conceived children are constructed as 'orphans' and problematic, it is, I argue, in later policy documents parents that risk being constructed as difficult if unable to perform the right kind of openness or timing of information sharing. In conclusion, while the policy documents of the 1980s stress that it is only the child's parents who can decide whether and when to inform the child of how it was conceived, the obligation is foregrounded that 'the parents should inform the child'.<sup>67</sup> As we will see, this obligation was both strengthened and challenged in later policy adjustments.

## VI. OUTSIDE MARKETS AND NATIONAL COHERENCE – ISSUES OF THE 2010S

In the decades between 1985 and 2019, Swedish legislation on donor conception changed a number of times, gradually including both new kinds of treatment options and patient groups.<sup>68</sup> Next, I discuss two issues from the 2016–2019 pre-legislative documents. Here, a new legislation to enable double and embryo donation is prepared along with a requirement that parents inform children about being donor conceived.

<sup>63</sup> SOU 1983:42 (n 22) 16-17.

<sup>64</sup> *Ibid* 110.

<sup>65</sup> *Ibid*; LU 1984/85:10 (n 22); Prop. 1984/85:2 (n 22).

<sup>66</sup> LU 1984/85:10 (n 22) 55.

<sup>67</sup> *Ibid*.

<sup>68</sup> Tinnerholm Ljungberg (n 25); National Registry of Assisted Reproduction (n 27).

In 2016, the new Committee *Different paths to parenthood* still refers to the first governmental proposition on insemination when arguing for a revised legislation.<sup>69</sup> As donors can now be multiple, so can the hospital's special medical records:

A person who was conceived following a fertilization outside the body with donated gametes or with a donated fertilized egg, and who has reached sufficient maturity, has the right to access the information recorded in the hospital's special record or records.<sup>70</sup> (original emphasis not included)

The requirement of sufficient maturity should normally not be considered fulfilled until the person has reached the upper teenage years. The right to information about the donor only applies to the child. His or her guardian, or former guardian, therefore has no such right (prop. 1984/85:2 16 and 27).<sup>71</sup> (Reference in original)

As we can see above, the 2016 Committee makes a clear reference to the special medical journal first proposed by the 1984 insemination bill.<sup>72</sup> In the later proposition of 2017,<sup>73</sup> donor-conceived people's right to information about their genetic origin is again traced back to the early 1980s commission:

Since the law (1984:1140) on insemination was approved in Sweden in 1985, those conceived after assisted reproduction with donated gametes have had a right to obtain information about their genetic origin.<sup>74</sup>

The document here places the right to information about one's genetic origin as a persistent feature of Swedish fertility medicine from the early 1980s to the late 2010s. Citing the very first law on donor insemination in Sweden, the new proposal presented in 2017 is thus framed as following a continuity within national legislation. Thus, as I will go on to show, a legal document from 1984 continues to be a central part of regulating donor-conception practices, both at fertility clinics and in the Children and Parents Code.

In this section, I examine the 2017/18:155 proposition that later became law. Here, the government proposes to parliament not only to enable embryo and double donations but also to change the wording of the Children and Parents Code. If the focus of the 1984 proposition was on preserving stable family units and avoiding uncertainty in (paternal) kin relations, the 2017 proposition emphasizes a (privatized/individual) right to information about genetic origin as the preferable foundation for the regulation of parenthood:

A starting point for parenthood regulation should, as far as possible, be that it is designed to strengthen children's right to information about their genetic origin, ie give the child the right to receive information about a donor's identity. This means that the rules should be designed in such a way as to encourage involuntary childless people to carry out assisted reproduction where the child has such a right.<sup>75</sup>

In the decades that have passed since 1984, both medical and genetic knowledge and practices have gone through substantial changes. With regards to public policy, an awareness of

<sup>69</sup> SOU 2016:11 (n 23).

<sup>70</sup> Ibid 87.

<sup>71</sup> Ibid 110.

<sup>72</sup> Prop 1984/85:2 (n 22).

<sup>73</sup> Prop 2017/18:155 (n 13).

<sup>74</sup> Ibid 52–53.

<sup>75</sup> Ibid 52.

the global fertility market and cross-border fertility travel is now accounted for in terms of the right to donor information.<sup>76</sup> In addition, the former reference to biological origin and the emphasis on paternal kinship lines are replaced by a focus on genetic origin. The reference to donors in third-party reproduction is no longer presented as a threat to donor-conceived families. Rather, information about donors is viewed as a (positive) future possibility for the child at mature age. Being informed that one is donor-conceived is no longer assumed to have further consequences for the child as a minor.

Previously, policymakers have consistently argued that it is important for children to have at least one genetic link to one of its parents.<sup>77</sup> In the proposition from 2017 this view is abandoned in order to enable double and embryo donations, which allows for both one- and two-parent family constellations where both eggs and sperm have been donated – either separately, in the form of double donation, or in making use of an already fertilized embryo. A considerable reframing of the issue is thus called for in Prop 2017/18:155. Firstly, the argument that at least one genetic link should be maintained in donor-conceived families is no longer valid. Secondly, it is necessary to continue to show how the suggested changes are in the best interest of children. After listing the proposals, the document concludes as follows:

The proposals might have positive consequences for children.<sup>78</sup>

The proposals mean, among other things, that more children are given a statutory right to obtain information about their genetic origin, and that the ability to collect such information is improved.<sup>79</sup>

My reading of these two statements is that a significant re-framing of the issue is taking place. Instead of highlighting that double and embryo donation results in more children growing up without their genetic relatives, policymakers here rephrase this ‘issue’ in terms of ‘the right to obtain information’ about genetic origin. What is meant by positive consequences for children, however, remains vague. As I have previously discussed, it is not necessarily *as children* that donor-conceived individuals can access any of the collected and stored information about a donor/donors. And, unlike in several other countries, it is only donor-conceived individuals themselves, and not their parents, that can access information from the special medical record.

These statements also reinforce a national logic, where treatment in Sweden is conducted differently from those performed in other countries. A clearly stated aim of the 2017 proposition is to discourage intended parents from seeking treatment in countries where they might make use of anonymous donor gametes or embryos:

In other countries, a donor may be anonymous. However, a child conceived with donated eggs or sperm through Swedish healthcare is, when he or she has reached sufficient maturity, entitled to receive information about the donor as recorded in a special medical record.<sup>80</sup>

The trade-off here seems obvious: in making double- and embryo donations legal, those currently making use of reproductive cross-border travel should be encouraged to get the treatment at a clinic (in Sweden) that only allows for open-release donations. The reference to the special medical record is here used as a guarantee for a regulated reproduction that

<sup>76</sup> M. Lie and N. Lykke, *Assisted Reproduction Across Borders: Feminist Perspectives on Normalizations, Disruptions and Transmissions*, Routledge Advances in Feminist Studies and Intersectionality (New York: Routledge, 2017).

<sup>77</sup> Tinnerholm Ljungberg (n 25).

<sup>78</sup> 2017/18:155 (n 13) 63.

<sup>79</sup> *Ibid* 65.

<sup>80</sup> *Ibid* 25–26.

follows particular norms associated with the borders of the Swedish nation. In line with Jasanoff's<sup>81</sup> argument that regulations in life science areas have become integrated aspects of nation-building, the Swedish model leaves little room for learning from other countries or criticizing parts of current legal frameworks. Thus, the practice of double and embryo donation gets linked to a particular kind of national futurity that fits well with the highly sought-after image of Swedish public policy as being particularly responsible and child-friendly. The possibility that (some) other countries might provide donor-conceived families with other resources such as biographical information or medical records already during the child's upbringing, is not considered. Thus, the borders of the nation, and upholding a controlled biopolitics remain central to Swedish public reproductive policy.

From a practice-oriented perspective, the importance of donor gametes being regulated is expressed in SOU 2016:11 and Prop 2017/18:155 through a particular idea of how the right to information ought to be organized. While new groups of intended parents, such as lesbian couples and single women, can both be granted access to tax-funded donor conception in the Swedish welfare state, new models for information sharing and disclosure are not easily accommodated. In particular, while being deprived of information is no longer acceptable, having access to information too early is also viewed as a possible threat to the child's right to make independent decisions. For instance, one referral response to SOU 2016:11 suggests that donor-conceived children should be able to receive information about other children born through the same donor in order to establish contact during the children's upbringing. While this could be regarded as respecting the child's genetic connections, the suggestion is quickly dismissed by the policymakers on the grounds that it would make it necessary for parents to have access to donor data meant solely for the (mature) child:

It is the child born after (donor) treatment, and not the child's parent(s), that have the right to information about the child's genetic origin. Although the parents have an obligation to inform the child about his or her conception, it is for the child to decide if he or she wants to find out the identity of the donor or of genetic siblings. It is therefore not appropriate [as suggested by the referral body 'Femmis'] to give the child's legal guardian(s) access to information about donors and genetic siblings in order for the child to be in contact with during its upbringing.<sup>82</sup>

As demonstrated by the above response to the solo motherhood network Femmis<sup>83</sup>, 'new' types of families ought not to produce new practices. Rather, they are expected to imitate the needs associated with the 'old' family type. Consequently, we are seeing a rather interesting paradox here. What does it mean, concretely, to be talking about children's rights while not including the children's parents and/or family as important for the child as a minor? Framing a certain practice as in the interest of children regardless of family type or situation, policymakers seem to view the possibility that donor-conceived individuals could be granted access to donor-specific information during their upbringing as an imposition of a parental wish. While the stress on the donor-conceived children to be able to make their own decisions could be read as well-intended, in practice it results in a refusal to allow earlier access to information. It also relies on the separation of the child from its parents, thus failing to understand the situation from a relational perspective.<sup>84</sup>

<sup>81</sup> S. Jasanoff, *Designs on Nature: Science and Democracy in Europe and the United States* (Princeton, NJ: Princeton University Press, 2005).

<sup>82</sup> Prop 2017/18:155 (n 13) 38.

<sup>83</sup> Femmis is a network for solo mothers by donation, founded in 2005 in Sweden. See website: <https://www.femmis.se> (23 December 2023, date last accessed).

<sup>84</sup> Nordqvist (n 2).

Thus far, I have analysed how Swedish policy documents from two different time periods relate to each other and to societal changes and argued that the state regulates donor-conception families and parenthood through regulating access to information. How this is done in practice, takes place through the special medical record. To consolidate the analytical pieces presented above, I now turn to a closer discussion of the implications of my findings.

## VII. DISCUSSION

The findings presented in this article underscore the importance of reading policy documents in relation to the particular family and kinship practices they both enable and disable. Through a practice-oriented analysis of Swedish national legislation and pre-legislative documents of the early 1980s and the late 2010s, I have shown how the ‘special medical record’ was made into a governing device for Swedish gamete donation practices. I argue, not that information about one’s origin is unnecessary or negative following donor conception. Instead, I have pointed to how the emphasis on a children’s rights perspective in Swedish law-making on donor conception rests on a paradox, ultimately stemming from the double meaning of the child as both a relational and age-specific position. The significance of this analysis lies not in linguistic aspects, but in its real-life implications for donor-conceived children. As discussed, access to information from the hospital’s special medical record can occur first during late teenage years.

In the analysis, I have traced how the regulation of disclosure in Swedish law-making came to be framed as an issue of children’s rights. Here, the comparison of two different time periods has been especially helpful. As demonstrated by my reading, the notion of ‘the best interest of the child’ has undergone a significant shift – from a focus on the heteronormative family unit and parental (in particular, paternal) security in 1985, to a focus on donor-conceived individuals’ privatized right to be informed about their conception and genetic heritage in 2019.

A practice-oriented reading of pre-legislative documents has allowed me to highlight the impact of significant societal changes throughout the time periods. I have shown that while Swedish assisted reproduction has witnessed significant changes in recognized family structures since 1985, now encompassing options for both same-sex and solo parenting, the framework for information sharing in donor conception has remained based on a traditional, nuclear family model. At the same time, a change that does appear with the 2019 legislation is a new position on parental decision-making. If the 1980s documents depict the donor-conceived child as potentially problematic due to its ‘orphan’ status,<sup>85</sup> in the 2010s, it is the parents of donor-conceived children who face the risk of being perceived as problematic. I have interpreted this as yet another societal shift in the understanding of families and child/parent relationships.

Following these conclusions, I argue that a significant change between the public policy of the early 1980s and the late 2010s lies in the construction of the relationship between parents and children in donor-conceived families. While parents in the 1980s are positioned as capable of using their own judgement in considering the best interest of their (particular) child(ren), in contrast, the public policies of the late 2010s demonstrate an increased emphasis on the need for the state to regulate the responsibility of parental information sharing. From the perspective of parents in donor-conceived families, this implies a reinforcement of the requirement that they provide the child with information that is, in purely informational

<sup>85</sup> See Jonsson Malm (n 18).

terms, 'negative'. While parents are obligated to provide certain information to their child, they are themselves, according to Swedish legislation, not entitled to either medical, biographical or identifying information about the donor/donors.<sup>86</sup> In essence, the information about genetic identity that is foregrounded as critical for children's well-being that parents can provide remains this: that the child be informed about the non-genetic link between themselves and their socio-legal parent(s).

Drawing on Melhuus,<sup>87</sup> I argue that laws are significant in that they tend to reflect dominant social concerns while simultaneously seeking to regulate or enhance certain ideals and practices. A prominent example is the case of state regulation of parental disclosure decisions. The language used in Swedish policy, stipulating that parents *must* inform their children, can on the one hand be viewed as a reflection of a societal ideal that emphasizes genetic origin as constitutive of identity and belonging. On the other hand, it can also be read as an attempt to discipline behaviour (of parents and perhaps also clinicians) in order to regulate practices of information sharing.

On a general policy level, the analysis suggests that the Swedish government's oversight of donor conception has taken place in part through the measures aimed at controlling access to information and disclosure. Consequently, the regulation of donor conception has occurred not only through delimiting who is eligible for medically assisted reproduction,<sup>88</sup> but also through the regulation of information sharing. Here, I have pointed to the importance of the special medical record as a regulatory mechanism, facilitating future access to donor records while maintaining the temporary de-linking that underlies identity-release donation.

Theoretically, my analysis builds on both sociological findings and critical kinship studies, and the understanding that genetic kinship ties are not inherently meaningful but instead require activation or deactivation within their social context.<sup>89</sup> The model of identity-release gamete donation can be understood as a temporary deactivating of the relation to the donor.<sup>90</sup> In relation to genetic kinship ties, I have argued that the pre-legislative documents, and in particular the special medical record, tend to establish genetic links as primarily of symbolic rather than material importance. For instance, although a children's rights perspective is continuously stressed, the possibility for donor-conceived children to have access to medical health records of the donor during their upbringing, if needed, is not facilitated by the hospital's recordkeeping. During both time periods, the right to information about one's origin is deemed important for psychological or 'identity-related' reasons, which in turn motivates that it is not provided too early. More pragmatic reasons, such as wanting to know the donor's traits, ethnicity, or medical history are not accounted for.

Building on the above analysis, I propose that matching practices in donor conception reveal the mere symbolic value ascribed to genes and genetic relatedness. While looking 'a-like' in donor-conceived families is frequently noted as beneficial for the child, clinical matching based on physical characteristics also serves the purpose of ensuring the child 'blends in', thus avoiding explicit questioning of the child's belonging to the family.<sup>91</sup> If, as Swedish policy assumes, having accurate information about one's genetic inheritance is essential for children, then resemblance within the family would likely make it less obvious for others to recognize the use of a donor. Thus, the strong emphasis on family resemblance also risks placing yet another paradox at the heart of the openness paradigm: while it is

<sup>86</sup> Compare R. Łukasiewicz and A. Sonia, "Donor-matching' in Third-party Reproduction: a Comparative Analysis of Law and Practice in Europe" (2022) 36 (1) *International Journal of Law, Policy, and the Family* 1–21.

<sup>87</sup> M. Melhuus, *Problems of Conception Issues of Law, Biotechnology, and Kinship* (New York: Berghahn Books, 2012).

<sup>88</sup> Jonsson Malm (n 18); Tinnerholm Ljungberg (n 22).

<sup>89</sup> Edwards (n 15).

<sup>90</sup> Compare Nordqvist (n 2).

<sup>91</sup> Becker (n 58); Dahl and Andreassen (n 26).

important to inform children about how they were conceived, somehow it is still (equally) important that the use of a donor should not be obvious to those unaware. Consequently, this places donor-conceived families (heterosexual and homosexual couples as well as solo parent families) in a position where they are expected to mimic the always already valued genetic link, which in these cases is actually missing. This, I argue, suggests yet another layer of symbolism in the regulation of donor-conceived families.

To conclude, the Swedish regulation of donor conception appears carefully drafted so as to not disrupt the current kinship and family model, but rather, to strengthen it. What is lost, I argue, is a practice-based understanding of what it means that neither the parents nor children in donor-conceived families can have access to medical or biographical information about the donor should there be such a need during the child's upbringing. Building upon the paradoxes outlined in this article, further policy developments should earnestly consider the diverse experiences of donor-conceived families. Additionally, the shifting perspective on family life and genetics, particularly in relation to genetically bound conditions, requires thorough consideration for both individuals and families.

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