

## The *Children and Family Relationships Act 2015* and Disclosure of Genetic Origins Information to Children: Donor-Conceived Perspectives

Donna Lyons\* and Donal Lyons\*\*

This article considers the “right to identity” provisions in the *Children and Family Relationships Act 2015* and their adequacy in guaranteeing to the donor-conceived child the right to access identifying donor information in this jurisdiction. The article presents the findings of a study which investigates the perspectives of donor-conceived individuals on the importance or otherwise of access to identifying information prior to what is at present the legal age of maturity in Ireland. The principal research method used in this article is empirical in nature, with doctrinal research being drawn upon as a complement to the empirical research.

### I – Introduction

The Irish Government has recognised the donor-conceived person’s “right to identity” through the *Children and Family Relationships Act 2015* (*2015 Act*), which will prohibit the practice of anonymous donation in Ireland. The *2015 Act* thus provides that the donor-conceived person may access identifying information about their donor where certain conditions are met.<sup>1</sup> One condition is that the age of 18 must have been obtained before they will be entitled to access information which identifies the donor, that is, “date of birth and contact details of the relevant donor, as recorded in the Register”.<sup>2</sup> Non-identifying donor information will be accessible by the donor-conceived person upon reaching 18, or by the parent or guardian of the donor-conceived child who is under the age of 18.<sup>3</sup> The donor-conceived person who has attained the age of 18 will also be entitled to obtain identifying and/or non-identifying information about donor siblings under certain conditions.<sup>4</sup>

---

\* LL.B. (Dub.), LL.M. (N.Y.U.), Ph.D. (Dub.), Attorney-at-Law (N.Y.).

\*\* B.Sc. (Dub.), M.Sc. (Dub.), M.Phil. in Literary Translation (Dub.). The authors would like to thank Eric Blyth and Neville Cox for helpful comments on an earlier draft of this article. Sincere gratitude is also due to those donor-conceived individuals who participated in the present study, thereby sharing deeply personal experiences of, and attitudes towards, donor conception policies.

<sup>1</sup> Section 33 of the *2015 Act* provides for the establishment of a “National Donor-Conceived Person Register” which will be responsible for the storage and release of relevant information about donors, donor-conceived people and intending parents.

<sup>2</sup> *Ibid.*, s. 35(1).

<sup>3</sup> *Ibid.*, s. 34(1)(a).

<sup>4</sup> A system of voluntary registration will be established under ss. 36-38 of the *2015 Act*. It should be noted further that s. 39 of the *2015 Act* will provide for “annotations” to be attached to births certificates of donor-conceived people, which will be accessible by the donor-conceived person upon attaining the age of 18.

The goal of the survey study, which is the primary focus of this article, was to establish whether donor-conceived people experienced curiosity about genetic relatives prior to attaining adulthood. It was also hoped that the study would establish what the perspectives of those individuals were on the questions of the appropriate age at which they should be entitled to access identifying information, whether parental consent should be a requirement for access to this information, and what effect access to such information might have, if any, on patterns of parental disclosure regarding the fact of donor conception. A particular focus of the survey was to establish whether donor-conceived people believed that the age requirement was appropriately chosen, bearing in mind that the *2015 Act* stipulates that access to identifying information will be made available to donor-conceived individuals at the age of 18, and further that at least half of those jurisdictions prohibiting anonymity lay down the same stipulation.<sup>5</sup>

A long-standing tradition exists whereby policy-makers consult with those most affected by proposed legal measures when creating legislation, so that the law might maximise the well-being of its citizens.<sup>6</sup> Such consultations will often include reliance on empirical data documenting the views of those affected.<sup>7</sup> This article thus presents the findings of a study which investigates, for the first time, the perspectives of donor-conceived individuals on the importance, or otherwise, of access to identifying information prior to what is at present the legal age of maturity in Ireland. Before examining the relevant elements of this study, the following section will review the empirical data published to date, where this relates specifically to the donor-conceived person's need for information about their genetic heritage.

---

<sup>5</sup> These States comprise of Finland, New South Wales, New Zealand, Norway, Switzerland, and the United Kingdom. Some of these jurisdictions allow for limited exceptions to be made to the general rule.

<sup>6</sup> For example, the Law Reform Commission of Ireland engages in wide consultation with individual citizens, civil society organisations, and relevant stakeholders prior to developing reform proposals: available <<http://www.lawreform.ie/your-views-.455.html>> (date accessed: 11 January 2017). The Government will also consult widely prior to passing legislation. In the context of the *2015 Act*, a Joint Committee was established to conduct this consultation: available <<http://www.oireachtas.ie/parliament/mediazone/pressreleases/name-22435-en.html>> (date accessed: 11 January 2017).

<sup>7</sup> For example, the Irish Government considered empirical data relating to donor-conceived people, as summarised by the Commission on Assisted Human Reproduction (Commission on Assisted Human Reproduction, *Report of the Commission on Assisted Human Reproduction* (Government Publications Office, 2005)), in developing proposals on the right to identity in the *2015 Act*. The legal literature will also frequently rely on empirical data when considering the right to identity. See, for example, D. Madden, *Medicine, Ethics and the Law*, 2<sup>nd</sup> ed. (Dublin: Bloomsbury Professional, 2011) at 172-175.

## II – Literature Review

A significant amount of research has been produced in the social sciences concerning the importance of both disclosure of donor conception, as well as the importance of access to donor and donor sibling information by the donor-conceived person. Much of the research published to date points to the conclusion that donor-conceived children who are aware of the donor conception are not negatively affected by the possession of this information as such. This conclusion has been arrived at through longitudinal studies of donor conception families,<sup>8</sup> as well as studies comparing families in which disclosure takes place with those in which disclosure does not take place.<sup>9</sup> Indeed, where disclosure has taken place, the relationship between parents and donor-conceived children has been found to be more positive in certain respects than in families in which the method of conception remains a secret.<sup>10</sup> Disclosure of the fact of donor conception may, on this basis, be considered to be a positive act for both the donor-conceived individual and for the recipient family as a whole.

Children who have been informed of their donor conception at an early age have been more likely to respond positively to this revelation, whereas those who have obtained this information in adulthood have been more likely to react negatively and to suggest that parental secrecy regarding the fact of donor conception has caused them psychological harm.<sup>11</sup> Those who have been informed later in life have reported experiencing shock, genetic

---

<sup>8</sup> S. Golombok, "Families Created by Reproductive Donation" [2013] 7(1) *Child Development Perspectives* 61 [hereinafter Golombok 2013]; Nuffield Council on Bioethics, *Donor Conception: Ethical Aspects of Information Sharing* (London: Nuffield Council on Bioethics, 2013); S. Golombok, A. Brewaeys, M.T. Giavazzi, D. Guerra, F. MacCallum & J. Rust, "The European Study of Assisted Reproduction Families: The Transition to Adolescence" [2002] 17 *Human Reproduction* 830; S. Golombok, A. Brewaeys, R. Cook, M.T. Giavazzi & D. Guerra, "Parenting Infants Conceived by Gamete Donation" [2004] 18 *Journal of Family Psychology* 443; S. Golombok C. Murray, V. Jadva, E. Lycett, F. MacCallum & J. Rust, "Non-Genetic and Non-Gestational Parenthood: Consequences for Parent-Child Relationships and the Psychological Well-Being of Mothers, Fathers and Children at Age 3" [2006] 29 *Human Reproduction* 1918 [hereinafter Golombok 2006].

<sup>9</sup> R. Nachtigall, J.M. Tschann, S. Szkupinski-Quiroga, L. Pitcher & G. Becker, "Stigma, Disclosure, and Family Functioning among Parents of Children Conceived Through Donor Insemination" [1997] 68 *Fertility and Sterility* 83; R.D. Nachtigall, L. Pitcher, J.M. Tschann, G. Becker & S. Szkupinski Quiroga, "The Disclosure Decision: Concerns and Issues of Parents and Children Conceived through Donor Insemination" [1998] 178 *American Journal of Obstetrics and Gynecology* 1165; E. Lycett, K. Daniels, R. Curson & S. Golombok, "Offspring Created as a Result of Donor Insemination: A Study of Family Relationships, Child Adjustment, and Disclosure" [2004] 82 *Fertility and Sterility* 172; E. Lycett, K. Daniels, R. Curson & S. Golombok, "School Aged Children of Donor Insemination: A Study of Parents' Disclosure Patterns" [2005] 20 *Human Reproduction* 810.

<sup>10</sup> S. Golombok, J. Readings, L. Blake, P. Casey, L. Mellish, A. Marks & V. Jadva, "Children Conceived by Gamete Donation: The Impact of Openness about Donor Conception on Psychological Adjustment and Parent-Child Relationships at Age 7" [2011] 25(2) *Journal of Family Psychology* 230 [hereinafter Golombok 2011].

<sup>11</sup> A. Turner & A. Coyle, "What Does It Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Practice" (2000) 15(9) *Human Reproduction* 2041 [hereinafter Turner & Coyle]; V. Jadva, T. Freeman, W. Kramer & S. Golombok, "The Experiences of Adolescents and Adults Conceived by Sperm Donation: Comparisons by Age of Disclosure and Family Type" [2009] 24(8) *Human Reproduction* 1909 [hereinafter Jadva 2009].

discontinuity, anger towards their parents and feelings of mistrust.<sup>12</sup> Early disclosure has also been linked to effects on the parent-child relationship which range from neutral to positive.<sup>13</sup> Overall, therefore, the findings to date suggest that not only is the act of disclosure a positive step for both the donor-conceived individual and for the family as a whole, but that early disclosure is particularly beneficial for all concerned.

This begs the question as to whether legal regulation should encourage, or indeed, require recipient parents to disclose the fact of donor conception to any children born to them following donation. While some evidence suggests that requiring identity-release in donor conception gives rise to increased rates of disclosure, and that counselling and education programmes designed to encourage parents to reveal this information may also assist,<sup>14</sup> there is also a small amount of evidence to suggest that a prohibition on anonymity alone may in fact deter some parents from telling their children about the donor conception.<sup>15</sup> Therefore, the literature to date has not presented a flawless practical solution to the problem of parental secrecy in donor conception and it is hoped that workable and effective solutions are advanced through research and policy measures in the coming years.

Much emphasis has been placed upon the importance of the genetic connection between donor and donor-conceived person. As a result, it has been suggested that the latter has a right to information about their biological relatives.<sup>16</sup> The vast majority of studies in this area report a desire on the part of at least some donor-conceived people to obtain identifying information about the donor.<sup>17</sup> A variety of motivations underpin the desire for information, but basic curiosity is a common sentiment reported by participants.<sup>18</sup> Interest

---

<sup>12</sup> Turner & Coyle, *ibid.*; see also D. Beeson, P. Jennings & W. Kramer, "Offspring Searching for Their Sperm Donors: How Family Type Shapes the Process" [2011] *Human Reproduction* 26(9) 2415.

<sup>13</sup> J. Scheib, M. Riordan & S. Rubin, "Adolescents with Open-Identity Sperm Donors: Reports from 12-17 Year Olds" [2005] 20 *Human Reproduction* 239 [hereinafter Scheib, Riordan & Rubin].

<sup>14</sup> See, for example, L. Johnson, K. Bourne & K. Hammarberg, "Donor Conception in Victoria, Australia: The 'Time to Tell' Campaign, Donor-Linking and Implications for Clinical Practice" [2012] 19 *Journal of Law and Medicine* 803 [hereinafter Johnson *et al.*].

<sup>15</sup> J. Appleby, L. Blake & T. Freeman, "Is Disclosure in the Best Interests of Children Conceived by Donation?" in M. Richards, G. Pennings & J. Appleby, eds., *Reproductive Donation: Practices, Policies and Bioethics* (Cambridge: Cambridge University Press, 2012).

<sup>16</sup> E. Blyth, M. Crawshaw, L. Frith & C. Jones, "Donor-Conceived People's Views and Experiences of Their Genetic Origins: A Critical Analysis of the Research Evidence" [2012] 19(4) *Journal of Law and Medicine* 769 [hereinafter Blyth].

<sup>17</sup> Scheib, Riordan & Rubin, *supra* note 13; M. Kirkman, "Genetic Connection and Relationships in Narratives of Donor Assisted Conception" [2004] 2 *Australian Journal of Emerging Technologies and Society* 1 [hereinafter Kirkman].

<sup>18</sup> Scheib, Riordan & Rubin, *ibid.*

has also been expressed about the donor-conceived person's donor siblings.<sup>19</sup> Understandably, then, it is extremely common for donor-conceived individuals to experience curiosity regarding their genetic heritage and in this light, to express a wish to have access to information about their donors and donor siblings.

There have been relatively few reports regarding the outcomes of meetings between donor-conceived people and their donors and/or donor siblings. In those few studies which have been published on this matter, a great majority of parents, donor-conceived people and donors have reported positive outcomes.<sup>20</sup> However, there is also some evidence that outcomes have been variable and not always positive.<sup>21</sup> While this is an important consideration, it does not indicate that donor-conceived people ever experience regret at having obtained identifying information to begin with. Furthermore, it does not negate the importance of taking into account the views of those most affected by legislative provisions when developing law reform and consequently, permitting donor-conceived individuals to determine what is ultimately in their own best interests.<sup>22</sup> Indeed, access to identifying donor information need not necessarily lead to communication with the donor, the latter naturally depending upon the wishes of all parties as well as possible practical obstacles, such as undocumented changes in the donor's contact information.

The donor-conceived person's desire to know more about their genetic origins may be greater or lesser at different periods in their life. Some donor-conceived people will develop an enhanced interest, for example, upon becoming parents themselves.<sup>23</sup> However, it is not just adults who are expressing curiosity; donor-conceived children and adolescents have also

---

<sup>19</sup> P. Mahlstedt, K. LaBounty & W. Kennedy, "The Views of Adult Offspring of Sperm Donation: Essential Feedback for the Development of Ethical Guidelines Within the Practice of Assisted Reproductive Technology in the United States" [2010] 93 *Fertility and Sterility* 2236; I. Rodino, P. Burton & K. Sanders, "Donor Information Considered Important to Donors, Recipients and Offspring: An Australian Perspective" [2011] 22 *Reproductive BioMedicine Online* 303.

<sup>20</sup> V. Jadvá, T. Freeman, W. Kramer & S. Golombok, "Experiences of Offspring Searching for and Contacting Their Donor Siblings and Donor" [2010] 20 *Reproductive BioMedicine Online* 523 [hereinafter Jadvá 2010]; R. Hertz, M. Nelson & W. Kramer, "Sperm Donors Describe the Experience of Contact with Their Donor-Conceived Offspring" [2015] 7(2) *Facts, Views and Vision in ObGyn* 91; O. van den Akker, M.A. Crawshaw, E.D. Blyth & L.J. Frith, "Expectations and Experiences of Gamete Donors and Donor-Conceived Adults Searching for Genetic Relatives using DNA Linking through a Voluntary Register" [2015] 30(1) *Human Reproduction* 111.

<sup>21</sup> Jadvá 2010, *ibid.*; A. Cushing, "I Just Want More Information about Who I Am: The Search Experience of Sperm Donor Offspring, Searching for Information Searching for Their Donors and Genetic Heritage" [2010] 15(2) *Information Research* 428.

<sup>22</sup> This issue is referred to in Section I, above.

<sup>23</sup> T. Freeman, K. Bourne, V. Jadvá & V. Smith, "Making Connections: Contact between Sperm Donor Relations" in T. Freeman, S. Graham & M. Richards, eds., *Relatedness in Assisted Reproduction: Families, Origins and Identities* (Cambridge: Cambridge University Press, 2014) 270 at 276–284 [hereinafter Freeman *et al.*].

been found to have an interest in their genetic origins. Many donor-conceived people who were informed about the donor conception during childhood or adolescence have expressed curiosity about the donor following this disclosure.<sup>24</sup> Adolescents in lesbian-parent families will be less likely to seek identifying donor information than those in heterosexual-parent families, but even in the former situations, a significant minority would like to have information about the donor's identity.<sup>25</sup>

It has also been found that donor-conceived children develop a greater understanding of the significance of donor conception during the adolescent period, "a developmental phase in which identity issues and conflict within the parent-child relationships may also become more prevalent".<sup>26</sup> Adolescents have expressed interest, in particular, in relation to potential similarities between the donor's physical and character traits and their own.<sup>27</sup> In a 2005 study involving 29 youths between the ages of 12 and 17 (most of whom had "always known" about the donor conception, and all of whom would be entitled to learn the identity of the donor at the age of 18), it is notable that 25 (86.2%) of the youths reported feeling curiosity about their donor.<sup>28</sup> Moreover, all but one participant was likely to seek information relating to the donor's identity, with 16 (55.2%) reporting that they intended to obtain the information as soon as they were legally entitled to.<sup>29</sup> The youths were not asked whether they would obtain the information at a younger age if the opportunity were available to them, or whether they believed that youths under the age of 18 should, in general, be entitled to access genetic information. Notwithstanding, it is clear from the above study, as well as those preceding and following it, that the desire for genetic information is of very real concern amongst donor-conceived individuals below the age of 18.

---

<sup>24</sup> L. Blake, S. Zadeh, H. Statham, T. Freeman, "Families Created by Assisted Reproduction: Children's Perspectives" in T. Freeman, S. Graham, F. Ebtehaj, M. Richards, eds., *Relatedness in Assisted Reproduction: Families, Origins and Identities* (Cambridge: Cambridge University Press, 2014) [hereinafter Blake]; T. Freeman & S. Golombok, "Donor Insemination Families: A Follow-Up Study of Disclosure Decisions, Family Relationships and Child Adjustment at Adolescence" [2012] 25 *Reproductive BioMedicine Online* 193 [hereinafter Freeman & Golombok].

<sup>25</sup> K. Vanfraussen, I. Ponjaert-Kristoffersen, A. Brewaeyts, "An Attempt to Reconstruct Children's Donor Concept: A Comparison between Children's and Lesbian Parents' Attitudes towards Donor Anonymity" [2001] 16(9) *Human Reproduction* 2019.

<sup>26</sup> T. Freeman, "Gamete Donation, Information Sharing and the Best Interests of the Child: An Overview of the Psychosocial Evidence" [2015] 33(1) *Monash Bioethics Review* 45.

<sup>27</sup> E. Ilioi & S. Golombok, "Psychological Adjustment in Adolescents Conceived by Assisted Reproduction Techniques: A Systematic Review" [2015] 21(1) *Human Reproduction Update* 84 [hereinafter Ilioi & Golombok].

<sup>28</sup> Scheib, Riordan & Rubin, *supra* note 13.

<sup>29</sup> While 24.1% were not sure when they would come forward, 13.8% planned to obtain the information at age 18 or later, and 3.4% thought that they would obtain the information after college. Scheib, Riordan & Rubin, *supra* note 13.

Interestingly, no studies have been published to date dealing solely with the question of whether donor-conceived people under the age of 18 wish to have access to identifying donor and/or donor sibling information before attaining adulthood. The remainder of this article will therefore document empirical research which has been conducted specifically to investigate this important question.

### **III – Materials and Methods**

Donor conception support networks around the globe were contacted and were asked to forward a questionnaire to their donor-conceived members which described the research and posed several questions. Those organisations which agreed to circulate the questionnaire consisted of: the U.K. Donor Conception Network (D.C. Network or D.C.N.); the Donor Conceived Register (formerly U.K. DonorLink); the US Donor Sibling Registry (D.S.R.); the Australian Donor Conception Support Group (D.C.S.G.); the Australian Donor Conceived People Network (A.D.C.P.N.); the German donor conception network, Spenderkinder (which circulated the questionnaire among its German, Austrian and Swiss members); the Scandinavian organisation, Seed Siblings (which circulated the questionnaire among its Swedish, Norwegian and Danish members); the Dutch organisation, Stichting Donorkind (which circulated the questionnaire among its Dutch members and also forwarded it to its sister organisation in Belgium); the European donor conception group, Donor Offspring Europe; and finally, the international group, Donor Conceived Perspectives: Voices from the Offspring.

The questionnaire consisted of eight questions, the majority of which were open-ended.<sup>30</sup> Participants were first asked about their gender and age. The substantive questions then focused on the curiosity experienced by donor-conceived individuals about their donor and/or donor siblings, the right of donor-conceived individuals to access identifying information about the donor and/or donor siblings and, finally, on the age at which this information should be made available by the State both to the donor-conceived individual and to their parents. Information about recent legislative developments in Ireland in the form of the *2015 Act* was provided in this context. The questionnaire also focused on the effect that

---

<sup>30</sup> The following was considered when constructing the questionnaire: F. Fowler, *Survey Research Methods* (Boston: SAGE Publications, 2002); B. Gillham, *Developing A Questionnaire*, 2<sup>nd</sup> ed. (London: Bloomsbury Academic, 2008); N. Bradburn, S. Sudman & B. Wansink, *Asking Questions: The Definitive Guide to Questionnaire Design – For Market Research, Political Polls, and Social and Health Questionnaires* (San Francisco: Jossey-Bass, 2004).

enhanced rights of access to such information might have on disclosure by parents of donor-conceived individuals. The questionnaire concluded by allowing respondents to add information that they felt might be of further interest or relevance.

E-mail was chosen as a primary mode of communication, due to the ease with which it may be utilised and the potential for swift responses. The use of e-mail as a method for gathering data via a questionnaire was also found to be appropriate in that respondents appeared to feel comfortable writing extensively about deeply personal issues, which was reflected in the richness of data provided.

Interpretative Phenomenological Analysis (I.P.A.) was employed to identify the themes which emerged from the questionnaire responses.<sup>31</sup> It was felt that an I.P.A. analysis was most appropriate due to its potential to uncover insights into the subjective experiences of donor-conceived people and their attitudes regarding how the law should operate in practice. I.P.A. has traditionally been used in the context of studies with a psychological component, and the method focuses on personal meaning and sense-making in a particular context, for those who share a certain experience.<sup>32</sup> This approach was particularly suitable to the investigation into the attitudes of donor-conceived people regarding the need or desire to know their biological relatives during childhood and adolescence.

## **IV – Findings**

### **A. Biographical Information**

In total, there were 39 respondents. Of these, 31 (79.5%) were female and eight (20.5%) were male. Their mean age was 30 (age range: 8–72) which included three respondents under the age of 16.<sup>33</sup> Of the 39 replies, 17 came from the United States (43.6%), six from the Netherlands (15.4%), four from the United Kingdom (10.3%), three from Australia (7.7%),

---

<sup>31</sup> J. P. Williams, “Emergent Themes” in Lisa Given, ed., *The Sage Encyclopaedia of Qualitative Research Methods*, (Thousand Oaks, California: SAGE Publications, 2008); J. Smith, P. Flowers & P. Larkin, *Interpretative Phenomenological Analysis: Theory, Method and Research* (London: SAGE Publications 2009) [hereinafter Smith, Flowers & Larkin].

<sup>32</sup> Smith, Flowers & Larkin, *ibid.* at 45.

<sup>33</sup> These were a girl of 8 and another of 11, whose mothers provided consent, translated some of the more complex questions into age-appropriate language, and transcribed their daughters’ responses, and a girl of 15 whose mother gave consent but who provided her own written responses without assistance.



three from Germany (7.7%), two from France (5.1%) and one each from Austria, Belgium, Ireland and Switzerland (each just under 2.6%).<sup>34</sup>

With respect to donor conception organisations, 17 (43.6%) participants responded from the D.S.R.; six (15.4%) from Donorkind; three (7.7%) from the A.D.C.P.N.; three (7.7%) from Spenderkinder; three (7.7%) from Donor Offspring Europe; two (5.1%) from the D.C. Network; two (5.1%) from the Donor Conceived Register; and one (2.6%) from each of Donor Conceived Perspectives: Voices from the Offspring and Scandinavian Seed Siblings. In addition, there was one participant who had been forwarded the questionnaire by a member of the D.S.R., but who was not herself a member. Table 1 below displays the gender and age of each sequentially-coded respondent.

**Table 1: Gender and Age of Respondents**

Code	Gender	Age	Code	Gender	Age	Code	Gender	Age
US01	Male	25	IE01	Female	19	AU03	Female	38
US02	Female	32	US13	Male	17	CH01	Female	38
US03	Female	35	US14	Female	46	NL05	Female	36
US04	Female	31	US15	Female	21	NL06	Female	33
US05	Female	49	US16	Female	46	FR01	Male	36
US06	Female	8	AU01	Male	41	GB01	Female	22
NL01	Female	34	AU02	Male	37	FR02	Male	21
US07	Female	20	AT01	Female	26	GB02	Female	24
US08	Female	33	US17	Female	72	DE02	Female	11
US09	Female	42	NL02	Female	41	DE03	Female	35
US10	Female	34	NL03	Female	23	BE01	Male	23
US11	Female	66	DE01	Female	41	GB03	Female	25
US12	Female	28	NL04	Male	26	GB04	Female	15

<sup>34</sup> The respondents were primarily coded using the International Organization for Standardization standard country coding system: I.S.O. 3166-1 alpha-2. Within this, the respondents were coded sequentially in order of receipt of their initial response to the questionnaire. The resulting 39 codes were thus: US01 to US17, NL01 to NL06, GB01 to GB04, AU01 to AU03, DE01 to DE03, FR01 to FR02, AT01, BE01, CH01 and IE01.

## **B. Emergent Theme 1: Lack of Parental Disclosure and Secrecy within Families Considered Wrong**

All participants to the study believed very strongly that the practice of secrecy in donor conception families, that is, the choice made by parents not to disclose the fact of donor conception to their children, is wrong and harmful to the donor-conceived individual. The following extracts from questionnaires illustrate this point clearly:

Family secrets have a harmful effect on the family climate and relationships. (CH01)

Parents and children deserve real, human, supportive, loving relationships with each other. Such relationships are not really possible when children are lied to about their origins. (US14)

It is selfish and cruel to keep this a secret. (US15)

Eleven participants (28.2%) volunteered that not only should familial secrecy be avoided, but that it is in the child's best interests for parents to disclose the fact of donor conception at a young age, on the grounds that the child will process the information in a more natural way and will not feel betrayed by parental lies at a later stage:

If you ask me, the sooner you tell a child, the better it will cope and the more natural the situation will be. (AT01)

I have been aware of my donor conception for as long as I can remember, and I believe this is a good way for parents to go about it. (GB04)

It should be told by parents as early as possible! (NL05)

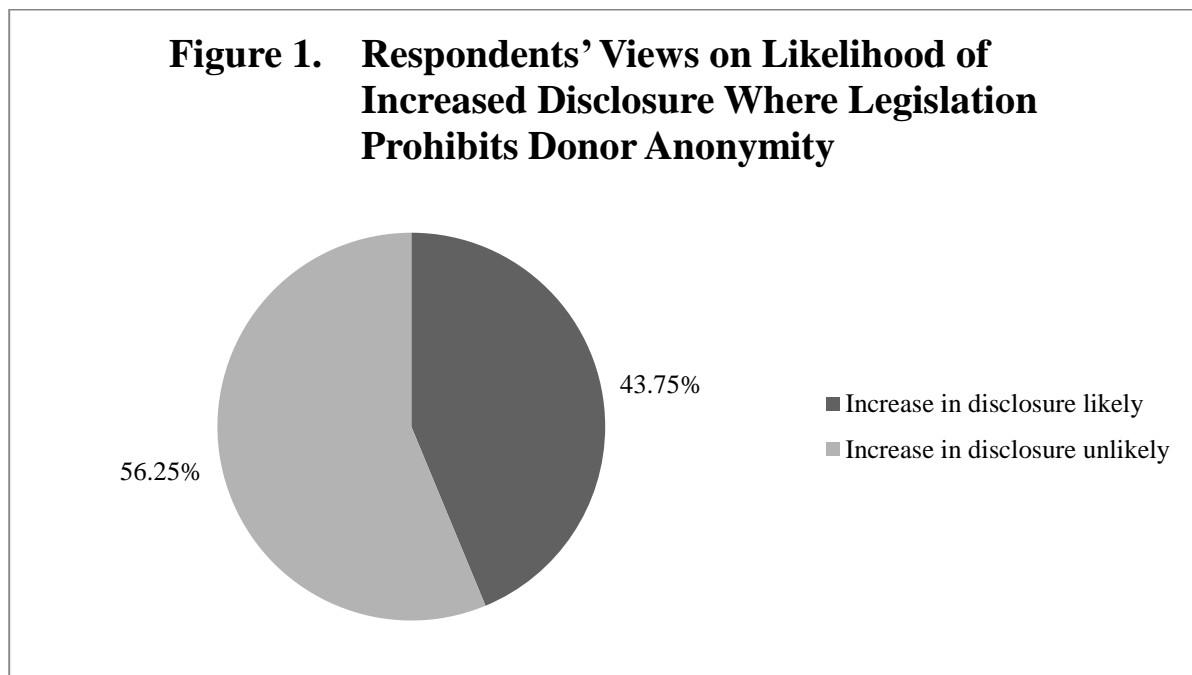
I think a lot of parents choose to tell their children later, just like I was told I came from a donor when I was 21, but I think it would be better to just tell it as soon as possible and never keep it silent, because a child's whole youth will seem like a lie. (NL03)

The questionnaire asked whether respondents felt that parents would be more likely to disclose if donor-conceived children were legally entitled to identifying information under the age of 18. Of the 32 individuals who responded to this question,<sup>35</sup> 14 (43.75%) expressed a belief that parents would be more likely to tell their children about the donor conception in the first place and 18 participants (56.25%) expressed their belief that such a legal

---

<sup>35</sup> Seven individuals stated that they did not have an answer to this question.

development would not give rise to increased parental disclosure overall. The differing attitudes regarding this question are illustrated in Figure 1.



Four respondents (10.3%) volunteered that accurate birth information should be recorded on the child's original birth certificate in order to circumvent any attempts by parents to maintain the secret:

[T]he donor-conceived status should be truthfully stated on their birth certificate so their genetic heritage is accurately recorded. It's healthier for them and in fact healthier for their legal parents to confront the truth and properly deal with their infertility rather than hide and lie and push everything under the rug. (US12)

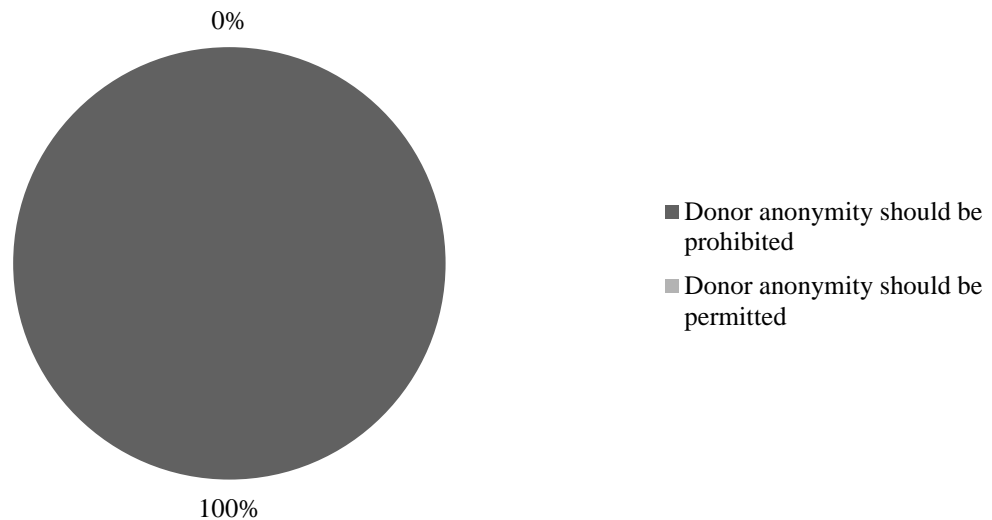
I think any secrecy is wrong and that the biological father of a child should be noted on their birth certificate ... or mother for egg donation ... . I think it should be open knowledge on the birth certificate from the beginning ... . (US17)

Six (15.4%) participants also emphasised the importance of providing counselling for prospective parents and societal education around this issue in order to encourage greater incidence of parental disclosure.

### C. Emergent Theme 2: The "Right to Know" and Anonymity as Unacceptable

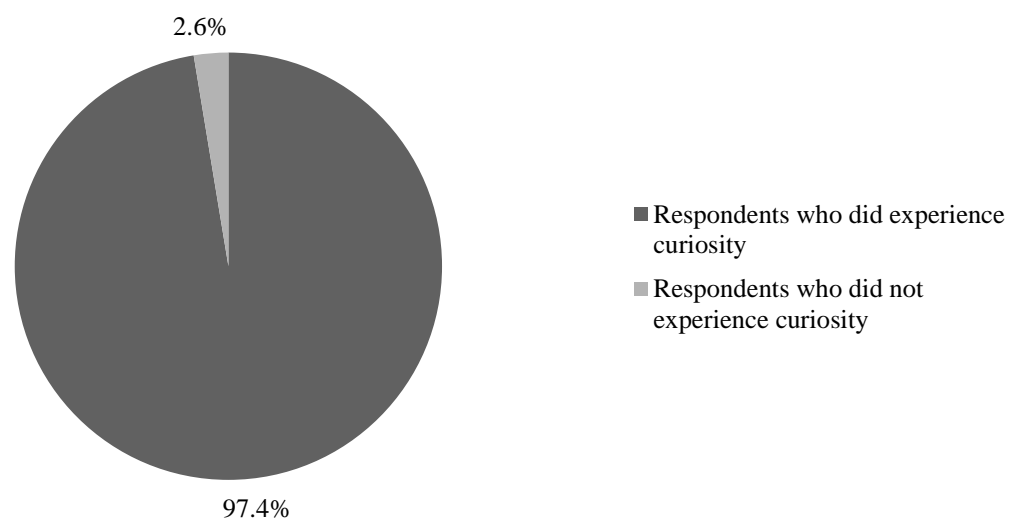
All respondents expressed their belief that protecting the donor's anonymity is unacceptable and should be prohibited as a practice. This is illustrated in Figure 2.

**Figure 2. Respondents' Views on Policies Relating to Donor Anonymity**



Related to this, was the fact that the vast majority of respondents (38 out of 39, or 97.4%) reported experiencing curiosity about their donor and/or donor siblings, as illustrated in Figure 3.

**Figure 3. Percentage of Respondents Experiencing Curiosity about the Donor**



The aforementioned respondents emphasised the importance of knowing the donor's identity, and the longing and frustration which accompanies not possessing this information. The following are a selection of extracts from the participants' questionnaires to this effect:

I would really want to know more about my biological father. Not necessarily because I want him to be a part of my life, but just to know if I look like him and which characteristics I inherited from him. (NL03)

It's ... an intense longing and pain to know my biological relatives and ancestry, and helplessness, because I was born with no right to know. (US15)

[I]t was a devastatingly confusing, painful, re-evaluation of who I am – thought I was. It was a deep spiritual, primal need. (US05)

It took me 68 years to find out who my biological father was and find my half-brother. But I would never have stopped looking. (US17)

Fourteen participants (35.9%) reflected on the suffering they, and other donor-conceived people known to them, had experienced as a result of the policy of anonymity.

From experience, I can say that the lack of information about a biological parent can be very detrimental to a person's mental health. (NL04)

The truth is I would have rather never been born. But I'm here and I want to help as much as I can so more children don't suffer. ... I constantly run into walls. ... This is not fair... . (US15)

My greatest wound since finding out has been that rootless feeling. (FR01)

Being a sperm donor baby is amazing but it also comes with a lot of trouble. I struggled with depression for many years because I felt I wasn't good enough for a father. (GB01)

I think more research needs to be done on those (now adult) DC offspring on their psychological wellbeing because, at least anecdotally, I think we suffer more from depression and other detrimental effects from our insecurity concerning our origins. (AU02)

Eight respondents (20.5%) stated that donor information belongs to the donor-conceived person, rather than to the treatment clinic or the State.

If a kid wants the information and actively seeks it out, it should be given since it belongs to them. (US07)

I believe donor-conceived children should have full awareness of their donor conception, and therefore should have the information made readily available to them

... . I think this information should have been made readily available to me and my (donor-conceived) siblings as it is part of our life and part of us. (GB04)

I do not believe that donor agencies should offer the option for donors to withhold their identities from their potential children. ... These policies are outdated in a progressive world and should be reformed to accommodate children regardless of whether or not they want to know. (US13)

Four participants (10.3%) welcomed the recent passage of legislation in Ireland prohibiting donor anonymity (information regarding this was included in the questionnaires' supporting material). This further emphasised their strong views in favour of identity disclosure:

I am heartened to hear that Ireland has outlawed donor anonymity. (US04)

I learned from a genetic test ... that I may have 20% Irish blood: hail to my cousins for this law! (FR01)

Congratulations to the members of parliament who created and passed this law. (FR02)

I'm glad Irish law decides to respect the wish to know the donor. Hopefully this will stimulate changes in other countries, like Belgium. ... I say we go for the complete abolishment of donor anonymity. Everyone should have the chance to know his biological origin. (BE01)

Seven participants (17.9%) argued that donor-conceived people should be consulted in the decision as to whether or not they are entitled to access identifying information about their genetic relatives. Such beliefs stemmed from a general consensus that the donor conception community would inevitably be opposed to a policy of donor anonymity.

We do not get to choose our life being created but we should have a choice in knowing who we are and who our siblings may be. (US10)

Any legal decisions made should be based on the experiences of those most affected. In this case, it's the donor-conceived children who must live out the ramifications of their parents' and donors' decisions without having consented to the method of their creation. (US03)

It was common for respondents to report, however, that despite its desirability, consultation between policy-makers and the donor conception community does not occur regularly in practice and that donor anonymity policies do not operate in favour of the donor-conceived child as a result.

It's rare in the DC community to actually be asked your opinion about any factors which affect your situation. (AU02)

It is inherently unfair for a child to be forcibly born into the world lacking a parent without having any say in the matter. Children have no outlets to voice their opinion about a system that is run by adults who did not go through what they did ... . It is easy to feel like a single drop of water in an ocean with no real say in what is going on ... . (US13)

#### **D. Emergent Theme 3: The Curiosity of the Donor-Conceived Child during Childhood and Adolescence**

The questionnaire asked whether respondents had experienced curiosity about their donor and/or donor siblings, and if so, at what age they first experienced this curiosity. Of the 39 respondents, 14 “always knew” about the donor conception and 25 were informed at various points throughout their lives. Twenty-four respondents stated that they experienced curiosity about their donors and potential donor siblings as soon as they were informed about, or discovered<sup>36</sup> their donor-conceived status. Of these 24 respondents, five were informed before they attained 18 years, and 19 were informed between the ages of 18 and 47. One participant (GB02) was informed about the donor conception at age 16, but only began to experience curiosity at the age of 19, noting that “in hindsight, I think I was in denial”. Of those respondents who always knew about the circumstances surrounding their birth (14 in total), all but one began to experience curiosity before reaching 18, 11 below the age of ten, and two between the ages of ten and 17. One participant (GB01) noted that she had curiosity about her donor for as long as she could remember but only began to experience curiosity about potential donor siblings at the age of 16, when she was informed of the possibility of connecting with them. Only one participant (NL01), who always knew, stated that she had never experienced curiosity about her donor or donor siblings (and had no interest in meeting them).<sup>37</sup>

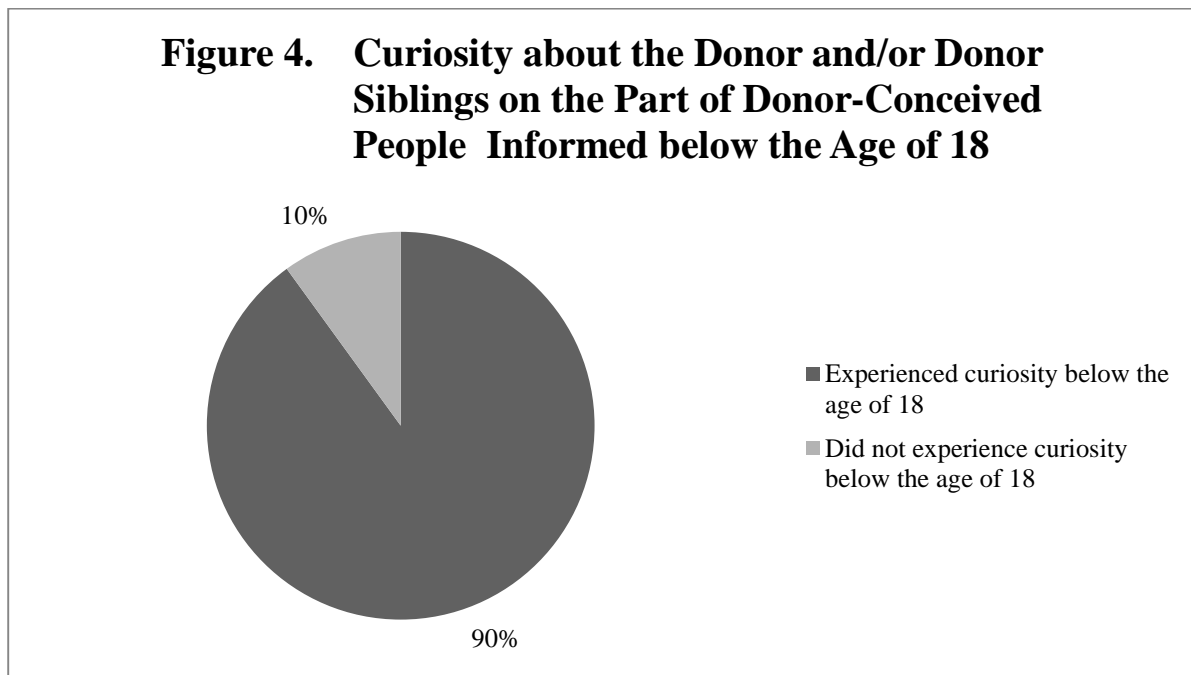
Therefore, of those participants who were made aware of their donor conception status below the age of 18 (in total, 20 individuals), 18 (90%) experienced curiosity before adulthood, and two (10%) did not. Figure 4, below, illustrates this information. Of those individuals who were made aware of their donor conception status during adulthood, all 19 (100%)

---

<sup>36</sup> In two cases, respondents reported having discovered their lack of genetic connection to their social fathers themselves. One participant (US17), who reported having brown eyes and whose parents “had very, very blue eyes”, worked it out during a biology lesson in high school. Another (AU03) “accidentally found out” by reading her medical file at the age of 21.

<sup>37</sup> NL01 still advocated for access to information for under-18s, proposing the age of 16 as the most appropriate option.

experienced curiosity as soon as they were provided with this information. The strongest theme which emerged from this study was that curiosity about the donor and/or donor siblings arises in donor-conceived people long before adulthood. It is hypothesised that this finding will be confirmed by future studies. This is certainly suggested by the statement of one respondent (US04), to the effect that “my curiosity would have begun immediately at whatever age I became aware of being donor-conceived, no matter how young I was”. Awareness of donor conception status is therefore inherently linked to curiosity in the present sample, irrespective of the individual’s age.



Several respondents commented on the nature of the curiosity that they had experienced regarding their donor and/or donor siblings. For one, the curiosity was frequent but tolerable, even positive:

I have been curious about my donor since the beginning. My parents have always told me about my conception and where I came from so I grew up knowing that there was someone else out there who was 50% of me. I have thought about him and what he’s doing right now pretty much every day of my life. Not in like, a frustrated longing way – I think that being a donor kid is really cool and thinking about it has become second nature. (US07)

Another respondent, who found out about her donor conception at the age of ten, described the relief and excitement which accompanied her curiosity upon finding out about her donor conception status:



I immediately wanted to know who this man was, what he likes, what makes him laugh, whether he has other children – a family of his ‘own’, whether he knows that I exist, *etc.* Unfortunately I could not communicate this with my parents. I found the message very exciting; I was not ‘shocked’ that I was unrelated to my social father. Rather, it was a relief to me, because I do not really have very much in common with my social father and always thought that it should have been different. I could better understand why my father had become so withdrawn into his work ... . I had always wanted siblings ... . I found the idea of at least having half-siblings very nice. (DE01)

In that instance, the respondent was provided with an explanation of why her relationship with her father seemed “different” and why he had become so “withdrawn into his work”. In this instance, the prospect of having donor siblings, or half-siblings as a result of the donor’s beginning his own family, was a comforting thought. Moreover, having the truth disclosed was in itself a positive experience. The curiosity which arose from this does not appear to have disturbed the respondent by reason of its intensity. For others, however, the curiosity was indeed described as more of a sense of intense and painful longing, as noted above.<sup>38</sup>

#### **E. Emergent Theme 4: Parental Access to Identifying Information on Behalf of Donor-Conceived Child**

The questionnaire asked whether the parents of donor-conceived people should be permitted to such information on behalf of their children below the age of 18, noting that the *2015 Act* permits donor-conceived people to access identifying donor information at the age of 18. The arbitrariness of solely providing information to individuals over the age of 18 was frequently alluded to in responses:

I believe that meaningful relationships can be forged with a donor when a donor-conceived person is still a child. I do not see why the child has to wait until he or she is 18 to find out who his or her donor is. (US02)

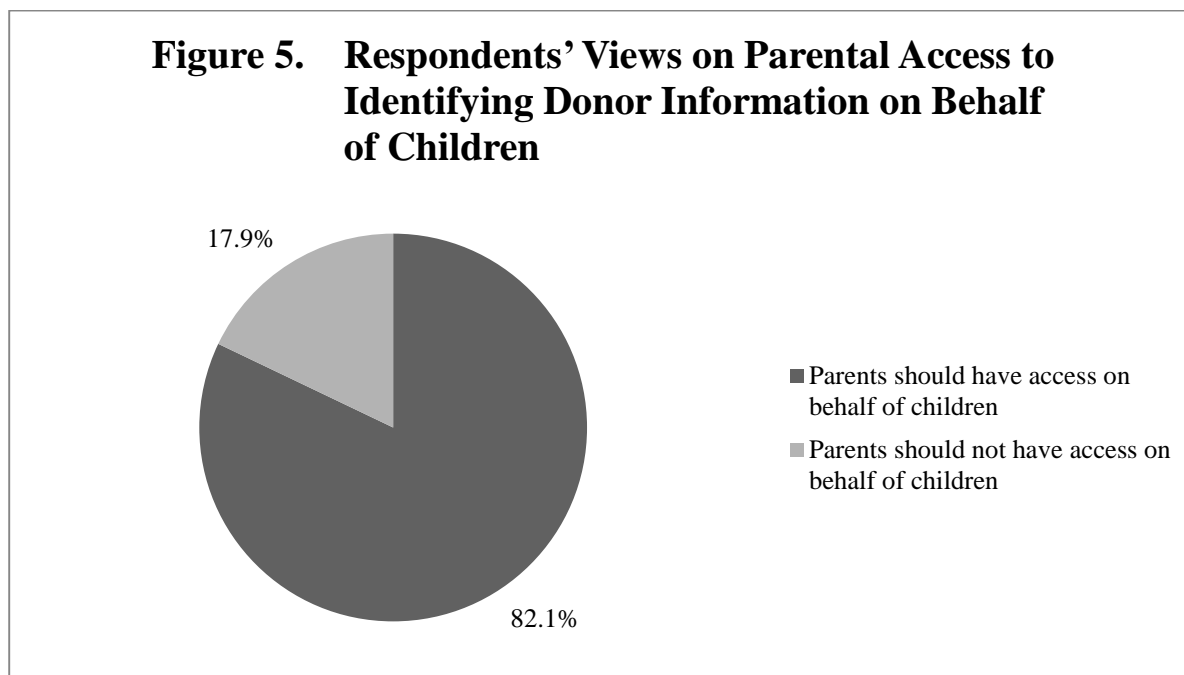
I believe it is important for donor-conceived children to be fully aware of the situation from a younger age than that of 18. I think donor-conceived children should be able to access any information they need about their donor from a younger age and therefore the parents should be able to access this information for them. (GB04)

Among the respondents, 32 (82.1%) were of the opinion that parents should have access to identifying information about the donor/donor siblings on behalf of their children,

---

<sup>38</sup> Quotations from responses to this effect were provided in Emergent Theme 2, above.

where their children were under the age of 18, and therefore not entitled to access that information themselves. This information is illustrated in Figure 5.



The reasons provided for permitting parents to access this information on behalf of young people were varied. Fourteen (35.9%) stated that donor-conceived people should have access to identifying information as soon as they request it and that parental access on behalf of children would facilitate this:

I believe the parents should have access to that information so that they can provide it to their children who are too young to obtain it themselves (*e.g.* before they can read and write). (US08)

I think parents should have access to the donor data in the interests of the child. Why should the 'child' have to wait until the age of 18 to have the right to access the identity of the donor? I think children are in a position much earlier to develop a desire to know their ancestry. (CH01)

Children should receive this information as soon as they ask for it. (DE02)

Two respondents (5.1%) volunteered that parents are in an ideal position to share this information with their children and to guide them through the challenges that it might pose to the young person's emotional development:

It's great to know our genetic info but it's a lot to process emotionally. (US09)

[Parents] are in a unique position to be able to act as a mediator for the benefit of the reconciliation of their children's familial, environmental and biological identities. I think that in most cases parents would act in the interests of their children. (AU02)

Thirteen respondents (33.3%) referred to identifying information as an essential factor in facilitating healthy identity formation in children, leading to the conclusion that the age of 18 is too late to receive what they considered to be crucial information:

Children begin to form their identities well in advance of age 18, and knowing where half of their genetics came from plays a large role in identity formation. (US03)

People develop their sense of identity and place in/sense of the world throughout their developmental years. They should be allowed to know and be known (develop a relationship with) their full family – both biological and social – from day one. The random age of 18 is much too late. In my opinion I think it is psychologically damaging to make those conceived of these practices wait so long. (US05)

Our identity is developing and taking shape strongly in our teen years and it's better to organically and slowly incorporate our biological parent into that equation, rather than be hit with it like a brick bat at the vulnerable age of 18. (US12)

I think that most parents will be aware that delaying the revelation of this information, especially during adolescence, will be detrimental to their child. (AU02)

Where children can find out about their biological heritage from a young age, their personal story will be more solidified, and a stronger identity and sense of confidence result. (US03)

[I]t should be allowed to happen before the start of adolescence, when the main window of identity construction occurs ... so that they can grow up knowing who they are. (AU01)

It's important that you can know your donor before puberty, which is a difficult time from an identity point of view. (BE01)

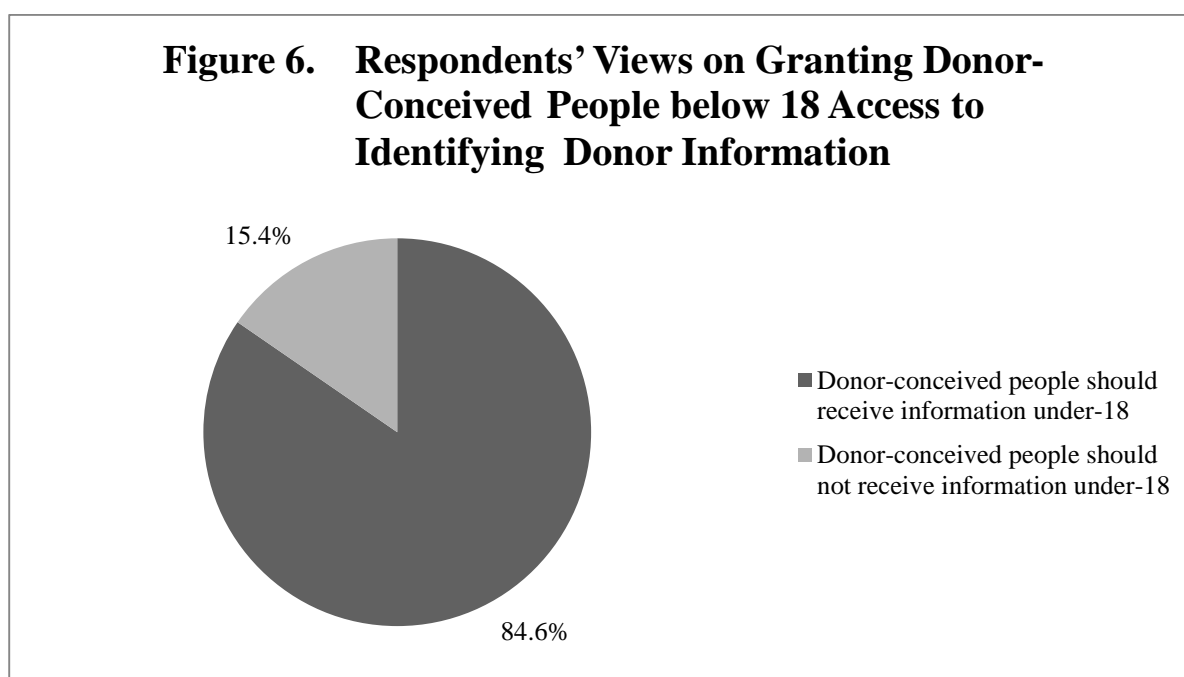
Two participants (5.1%) stressed the possibility that if the donor-conceived individual is required to wait until they have reached adulthood to access identifying information, then the donor may have passed away in the intervening years:

What if the donor dies and the child never gets an opportunity to meet their father/mother? (US12)

[I]f the decision by the child is made to search for relatives it should be followed through as soon as possible (in case of death *etc.*) ... . (GB02)

### F. Emergent Theme 5: Young People Accessing Donor Information without Parental Consent

The questionnaire also asked participants whether donor-conceived people under the age of 18 should be entitled to access identifying information about the donor without the consent of their parents, and if so, at what age they should be permitted to access such information. Of the participants, 33 (84.6%) suggested that donor-conceived people should be entitled to access the relevant information below the age of 18, and six (15.4%) were of the opinion that 18 is an appropriate age for information release. This information is illustrated in Figure 6.



Six participants (15.4%) were of the view that donor-conceived people should only have access to identifying information about their donor and donor siblings at the age of 18, the majority of whom reported that emotional maturity is more likely to have been attained upon reaching adulthood.

Thirty-three participants (84.6%) stated that donor-conceived people under the age of 18 should be permitted to access this information without first obtaining the consent of their parents. The justifications provided for these responses varied. Of these, three (10%) noted the potential for continuing to involve parents in the process, even where their consent has not strictly been obtained. One participant (US05) suggested that the State should “perhaps require a counsellor to notify the parents of the child’s request in order to prepare them for

what is to come". Another (GB02) suggested that "parents should be informed but not give consent".

The importance of genetic relationships was again emphasised by those participants who firmly believed that young people should have access to identifying information: "[i]t is outrageous to deny a child a relationship with their biological parent(s), siblings and grandparents" (US04):

I have always known that it wasn't fair for that information to be withheld from me. How is it fair that when father's day rolls around, 7-year old me has to watch my fellow classmates make cards while I can't even ask who mine is. (US13)

Again, several participants (eight or 20.5%) volunteered that since identity formation takes place during childhood and adolescence, parents should not be entitled to circumvent the child's access to identifying information about the donor and/or donor siblings in cases where the child wishes to obtain it:

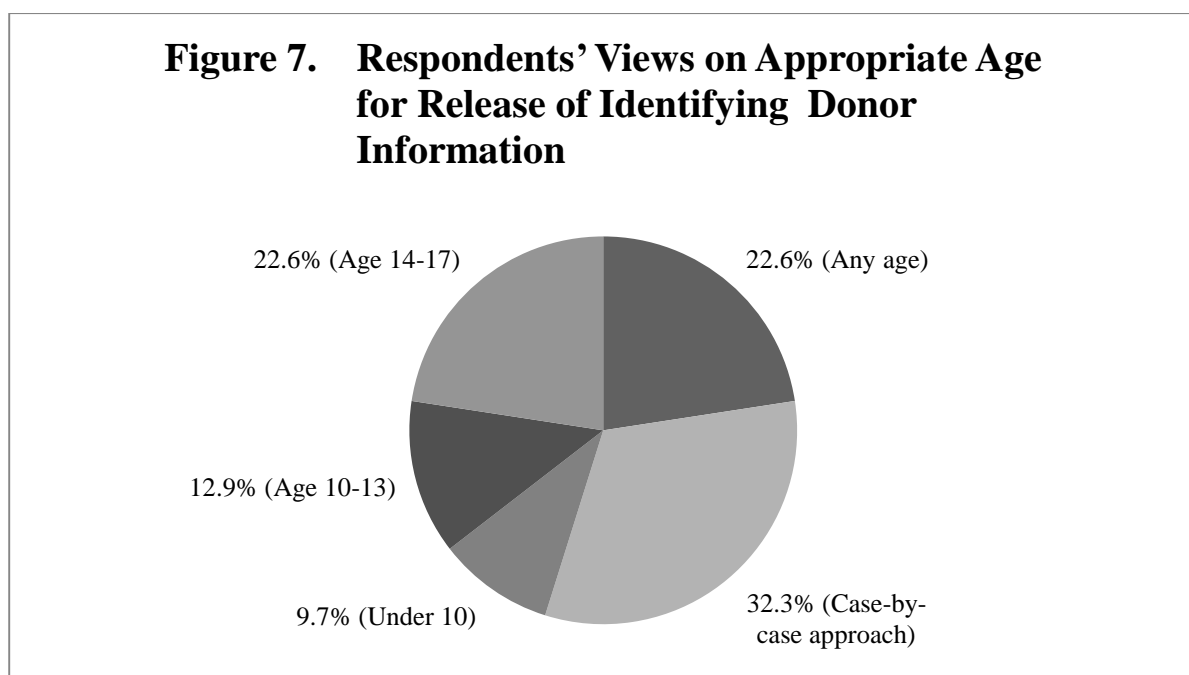
Children should not be denied essential information about themselves at any stage, and parents shouldn't be allowed to make that decision for them since the results of denying such information can be psychologically damaging. (US03)

Indeed, one participant (DE03) stated that she would not want her parents to be involved in the process, "as they would always carry a certain form of ambiguity about my interest in my genetic father and siblings".

Responses regarding the appropriate age at which children should be entitled to receive this information varied. Three respondents (7.7%) highlighted the importance of placing the best interests of the child front and centre when choosing an appropriate age at which to disclose donor information:

The decision to restrict the age of access to identifying information in some countries around the world to after the age of 18 is purely based on the age of legal maturity and not based on any psychological or sociological evidence or research. It is vital information for the person conceived this way ... . Practice and policy should be predicated on the best interests of the child and not what the parents, clinicians, or donors want. If the child's best interests are better served by knowing this when they are young... then the age of 18 should be removed as a stipulation. (AU01)

Among the 39 participants, 31 (79.5%) answered the survey's question regarding the appropriate age at which donor-conceived children should be granted access to identifying donor information. Seven (22.6%) of these suggested that such information should be available to the donor-conceived child at "any age." A further ten (32.3%) suggested that information should be released on a case-by-case basis, depending on the maturity of the donor-conceived child. Three (9.7%) were of the opinion that information should be available to donor-conceived children under the age of ten, while four (12.9%) suggested that it should be available between the ages of ten and 13, and seven (22.6%) available between the ages of 14 and 17. This information is illustrated in Figure 7.



One participant made it clear that the "right to know" dictates that the child should have this information as soon as they request it due to the harm that is avoided in knowing, rather than the potential harm which might be caused through finding out:

I think what these questions are getting at is whether someone under 18 can handle the details of their conception. I believe that regardless of age you have the right to know where you came from and the earlier the better. Because I knew of my donor conception from a young age, I grew up with it being normal and now have a healthy understanding of family and a parent's love regardless of biological relation. Of course, not everyone is in this situation, and it may be harder for, say, a 13-year-old to suddenly find out they're not related to their dad. But what does waiting until they're 18 accomplish? Maturity? Maybe, but I don't think you will find many donor kids

saying 'I'm glad I waited to find out who I was'... . If a kid wants the information and actively seeks it out, it should be given since it belongs to them. (US07)

It is also interesting to note the emphasis placed by this particular participant on the value of receiving the information at an early age, a point which was also made by participants in the context of informing donor-conceived children about the fact of their donor conception. Several respondents (nine or 23.1%) echoed this view:

I honestly feel that they should know as soon as possible. Being donor conceived is harder to process as an adult. My feelings come from first-hand experience with my half-siblings learning above the age of 30. (US10)

I don't think you can put an age on when someone is ready for this information. I was given my donor's file when I was maybe 8, and although I couldn't contact him because he's anonymous, that info meant so much to me. I think there's a misconception that at a certain age you're still 'not ready' to handle the details of your own identity. I think that's absurd and an opinion only held by those with no personal donor/donor sibling experience. (US07)

Indeed, one respondent pointed to the youth of the child as an advantage in cases where the donor is not receptive to a potential communication:

If the donor doesn't respond positively, a young child can bounce back easily. He or she will not have spent years of hoping only to be let down, if the answer is already known early on. (US03)

As noted above, ten respondents (32.3%) suggested that the information should be available to children on a case-by-case basis as soon as they are "sufficiently mature". Elaborating on this, one participant (US03) stated that the child should be permitted to access the information at "any age the child is capable of understanding what is going on, and this will vary based on intelligence and developmental rate". Another participant (CH01) suggested that a child will be ready to receive the information once they can "formulate and justify their desire for knowledge of their ancestry". The arbitrariness of generally applicable age requirements was commonly alluded to, and it was therefore accepted that this would require a case-by-case analysis:

I think younger individuals are capable of making such a decision ... . [Deciding] on a case-by-case basis would be good, as some children might be more mature sooner and waiting until you turn a certain age to receive the information is not ideal. (NL03)

I think there should be a possibility for an exception for children under 18, to be judged on a case-by-case basis. The age of 18 is a random number and doesn't correspond to the same level of maturity in each child. (NL06)

It depends on the child, some children would be happy with the information, and others would be frightened. (DE02)

Case-by-case ... as long as a responsible adult has judged the situation and the individual to be stable enough for the decision. (GB02)

One of the respondents who was in favour of a case-by-case analysis nonetheless cautioned against permitting disclosure at too late an age:

I think a case-by-case approach is most suitable due to the fact that children can be so different at a given age, but in general I think from the age of 12 it might be appropriate. (NL02)

One participant (AU03) suggested that “mandatory counselling and information sessions” are an important component of the case-by-case approach as they would better prepare the donor-conceived individual, particularly if they are a child, for the process of receiving information and potentially making contact with their donor and/or donor siblings. Two further responses echoed this view:

It would be desirable if children and young people were accompanied and supported by psychologists. (CH01)

To prevent psychological shock it might be done with the help of a doctor or a psychologist ... . (FR01)

## **V – Discussion**

The belief expressed by all participants in this study to the effect that the practice of secrecy in donor conception families is wrong and harmful to the donor-conceived individual, is consistent with previous studies, particularly those conducted by Golombok and others at the Centre for Family Research at the University of Cambridge, which report that parental secrecy in the donor conception context may cause the donor-conceived child, and the recipient family as a whole, psychological and inter-personal harm.<sup>39</sup> The suggestion by participants to this study that not only should familial secrecy be avoided, but that it is in the child's best interests for parents to disclose the fact of donor conception at a young age, also

---

<sup>39</sup> Golombok 2011, *supra* note 10; Golombok 2006, *supra* note 8; Golombok 2013, *supra* note 8.



tallies with research previously published, in particular, by Jadvá and others, as well as Turner and Coyle, on this issue.<sup>40</sup>

Respondents were divided on whether parents would be more likely to tell their children about the donor conception should a law come into effect providing access to identifying information for under-18s (44% stating that disclosure would be more likely, 56% stating that it would not). Instead, participants recommended methods such as birth registration, mandatory disclosure, and education and counselling as a means of addressing parental secrecy. This would support previous studies, in particular, that of Johnson, Bourne and Hammarberg, concluding that measures such as prohibiting anonymity, introducing annotated birth registration, and implementing education and counselling programmes, taken together, are likely to increase rates of disclosure.<sup>41</sup> The finding would not support the contention that prohibiting anonymity alone, even if children below the age of 18 were permitted to access genetic information, would increase rates of disclosure. A more thorough understanding of this point may be obtained through future studies examining the views of recipient parents regarding disclosure.

The belief expressed by all participants that the policy of anonymity should be prohibited, accords with previous studies reporting the desire on the part of donor-conceived people to obtain identifying information about the donor.<sup>42</sup> In this study, curiosity was noted as a recurring motivation for such information, which conforms to previous studies, including Scheib, Riordan and Rubin, as well as Kirkman, reporting on the motivations of donor-conceived people to access genetic information.<sup>43</sup> The vast majority of participants who discovered their donor conception in childhood or adolescence reported that curiosity about genetic relatives arose long before adulthood. In general, awareness of the donor conception status was inherently linked to curiosity irrespective of the individual's age. Such a finding is consistent with studies to date which have touched upon this theme, in particular, those published by Blake and others, Freeman and Golombok, Ilioi and Golombok, and Scheib, Riordan and Rubin.<sup>44</sup>

---

<sup>40</sup> Jadvá 2009, *supra* note 11; Turner and Coyle, *supra* note 11.

<sup>41</sup> Johnson *et al*, *supra* note 14.

<sup>42</sup> Blyth, *supra* note 16.

<sup>43</sup> Scheib, Riordan & Rubin, *supra* note 13; Kirkman, *supra* note 17.

<sup>44</sup> Blake, *supra* note 24; Freeman and Golombok, *supra* note 24; Ilioi & Golombok, *supra* note 27; Scheib, Riordan & Rubin, *supra* note 13.

Some participants stated that the curiosity was not just vague or positive, but rather an intense longing, and considering all responses together, it would appear that the curiosity became greater with the passage of time. This may suggest that providing donor-conceived people with information relating to genetic heritage at a young age would prevent the curiosity from escalating into a painful longing.

This study also presents findings on issues which have not previously been documented in the social science literature. The study reported that many donor-conceived individuals wished to be involved in the decision as to whether or not they are entitled to access identifying information. Furthermore, a large majority (82.1%) of participants were strongly of the view that parents should have access to identifying information about the donor/donor siblings on behalf of their children. Participants emphasised the arbitrariness of the legal age of maturity and highlighted the importance of prioritising the best interests of the child when developing policy in this area. For many, this meant that children should have access to the information at any age they choose and several respondents suggested that parents are in an ideal position to share this information with their children and to guide them through the challenges that it might pose to the young person's emotional development. It is interesting to note, that even in a sample of participants, many of whom expressed some amount of distrust towards their social parents, over 80% would have liked their social parents to have been granted access to donor information on their behalf. It could consequentially be hypothesised that arguments which are occasionally made regarding the importance of limiting the parental right to information on the grounds of the child's right to privacy may be overstated.

It was also interesting to note how common it was for respondents to refer to identifying information as an essential factor in facilitating healthy identity formation in childhood and adolescence. In this sample, at least, identity and genetics were inherently linked. Moreover, a large majority felt that donor-conceived individuals under the age of 18 would be ready to receive and responsibly use identifying information without the need for parental consent or guidance. Responses varied widely regarding the appropriate age at which children should be entitled to receive this information, with a significant proportion believing that the child should be able to obtain the information at "any age", and many others expressing the view that the information should be available to children as soon as they are "sufficiently mature". Since 35 of the 39 respondents were adults, and thus could be said to be able to reflect on the maturity and capacity of their younger selves with some (albeit limited)

degree of objectivity, it was significant that such a large majority deemed donor-conceived youths (of varying ages, but all under the age of 18) to be sufficiently mature to process and benefit from donor information.

It should be noted that this study is not without its limitations. For example, cultural and legal differences between respondents may have affected the results. As discussed above, participants hailed from the United States, Australia (Victoria and South Australia), the United Kingdom, Germany, France, the Netherlands, Austria, Belgium, Switzerland and Ireland. All participants therefore originated from “first world” countries with western, capitalist leanings and with relatively common political interests. This commonality in perspective may have affected the results of the study, and studies conducted in systems with vastly differing historical, economic, religious, legal and cultural experiences and perspectives may have yielded different findings.

Notwithstanding, the results are informative, in particular for those countries which continue to adhere to a “western” perspective, including that of Ireland. In the legal context, no formal prohibition on donor anonymity is in place in the United States, South Australia, France or Belgium and such a prohibition has yet to be commenced in Ireland. However, donor anonymity *is* prohibited in Victoria (Australia), the United Kingdom, Germany, the Netherlands, Austria and Switzerland.<sup>45</sup> Participants in countries without a prohibition on anonymity were no less likely to denounce parental secrecy, policies of anonymity or to endorse access below the age of 18 than those in countries where a prohibition on anonymity is in place, and vice versa. Nor was there any pattern regarding participant responses from common law as opposed to civil law jurisdictions. However, regarding the specific age at which donor-conceived children should be entitled to access identifying information without parental consent, respondents in countries where access was already available below the age of 18 were slightly more likely to favour the age requirement in place in their own jurisdiction. This may reflect the sentiment which emerged through the surveys that choosing an age for information-release is necessarily an arbitrary act, and may indicate that where access to information is available prior to adulthood, donor-conceived people will generally express contentment with the age(s) selected by the government in their particular jurisdiction.

---

<sup>45</sup> The age requirements in place in these latter jurisdictions is discussed below, and for a detailed comparative analysis of donor anonymity policies, see D. Lyons, “Extending the ‘Right to Identity’ to Donor-Conceived Children in Ireland: A Jurisdictional Case Study” (2017) 7(1) I.J.L.S. 1 [hereinafter Lyons].

It is also noteworthy that participants were self-selecting. It is possible that those who volunteered their participation through the donor conception networks had a particular desire or need to resolve difficult feelings regarding their conception, and that non-participating donor-conceived people may have had different perspectives on the matters discussed. Moreover, due to the relatively small nature of the donor conception community, it is possible that certain concepts or attitudes have been shared across donor conception networks, thereby influencing the responses provided. There were no obvious patterns as regards responses provided by male or female participants (31 female versus eight male), so it is not clear whether the overrepresentation of female participants is significant, but this possibility cannot be ruled out.

Despite the limitations of the sample, the findings do provide valuable insights into how some donor-conceived people feel about the importance of accessing the identity of genetic relatives before attaining adulthood. It is common practice in the social science literature to study small and, as a consequence, unrepresentative samples to derive findings regarding attitudes, perspectives and behaviours of donor-conceived people and recipient families within these samples.<sup>46</sup> This is particularly common in the context of donor conception because the secrecy and stigma which continues to shroud the practice has resulted in a situation in which only a percentage of those conceived using donor gametes or embryos are in fact aware of their donor conception status, and indeed only a percentage of those who are aware of their birth origins are willing to speak openly about their experiences. Qualitative research findings are generally not considered in isolation, but in tandem with other related studies and while it is very important to pay heed to individual qualitative research findings, it is just as important to bear in mind that each study comprises part of a greater body of research, which, examined as a whole, may be used to inform policy. Therefore, future research studying similar matters but with different samples will also be of significant value.

In the context of the *2015 Act* and its potential extension, it would be particularly useful to inquire into the views of donor-conceived people in Ireland<sup>47</sup> in order to ascertain whether a similarly high proportion of donor-conceived people in this jurisdiction wish to obtain identifying information before attaining the age of 18.

---

<sup>46</sup> This can be seen throughout the social science literature examined in Section II, above.

<sup>47</sup> It will be remembered that only one Irish participant took part in the study.

## **VI – Potential Implications for Irish Law**

While the literature documenting the psychosocial implications of anonymous donation is proliferating and is not yet conclusive, the *2015 Act* can be welcomed on the basis that it takes into account the views expressed by donor-conceived people to date regarding their need for genetic origins information. The *2015 Act* might, on the same basis, reasonably be extended to donor-conceived people under the age of 18. The study presented above provides valuable information regarding the views of donor-conceived people on this matter, which might be taken into account by the government, in tandem with other considerations such as competing interests, practical issues arising, and any potential future studies on this specific issue, in determining whether the “right to identity” of donor-conceived *children* in Ireland should be recognised and vindicated. Based on the findings, it could be hypothesised that the issue of parental secrecy regarding the fact of donor conception (as opposed to the policy anonymity and consequent lack of access to donor information) cannot adequately be addressed through a principled extension of the right to information relating to genetic heritage under the *2015 Act*, but instead that a series of pragmatic measures implementing the right to identity in practice will be required to address the problem. The pragmatic options available to the Irish government are outlined below.

As one of the co-authors has argued elsewhere, an analysis of comparative jurisdictions offering rights of access to genetic origins information to donor-conceived children under the age of 18 illustrates the fact that the right manifests itself in various ways and that there is by no means one single universally accepted best practice approach in this area.<sup>48</sup> To date, excluding Ireland, there are 12 jurisdictions worldwide which have deemed anonymous donation to be contrary to domestic law. These jurisdictions hail from both civil and common law traditions and comprise of Austria, Finland, Germany, the Netherlands, New South Wales, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, Victoria, and Western Australia. Norway and Finland are the only jurisdictions which permit access to donor information by the donor-conceived person upon attaining the age of 18, with no exceptions being made for access at an earlier age. All other jurisdictions provide for some access, even if very limited, under the age of 18. Of particular note are Austria, providing access at age 14, the Netherlands and Western Australia, providing access at age 16, Victoria

---

<sup>48</sup> Lyons, *supra* note 45.

and Sweden, providing access at “sufficient maturity”, and finally, Germany, providing access in principle at “any age”.

The options available to the Irish government therefore include: introducing a generally applicable age requirement, such as that of 14 or 16; introducing an approach to information release based on the “sufficient maturity” or “best interests” of the child; annotating the child’s birth certificate with donor information and providing access to the annotated birth certificate before the child attains the age of 18; providing identifying genetic information to recipient parents on behalf of their donor-conceived children; or any combination of the above. Other measures which have proven to be effective in comparative jurisdictions include: the drafting of specific legislation on release of donor records; the establishment of a central registry for the storage and release of such information; the provision of mandatory counselling; and the roll-out of education and outreach programmes to encourage increased parental disclosure and to reduce the stigma surrounding the practice of donor conception.

Those jurisdictions which have experienced the greatest efficacy in the protection of the donor-conceived child’s right to identity in practice have not simply laid down a bald judicial statement or legislative provision regarding the age at which access will be permitted, but have ensured the guarantee of access in practice through the establishment of central registers, the annotation of birth certificates to incentivise parental disclosure, and the creation of support and information systems for those parties subject to the donor conception arrangement.<sup>49</sup>

Those comparative jurisdictions which have been least efficacious in securing the rights of the donor-conceived child have been circumvented by parental secrecy, the lack of a central register, the lack of legislation regulating donor conception, and the absence of recruitment of domestic donors. The Irish government has pre-emptively avoided some of the above hurdles through the drafting of legislation, the creation of a National Donor Conceived Person Register, the annotation of birth certificates incentivising parental disclosure (which may be accessed by the donor-conceived individual at age 18), and the laying down of structures which will encourage the domestic recruitment of donors.<sup>50</sup>

---

<sup>49</sup> *Ibid.*

<sup>50</sup> *Ibid.*

Should the Irish government wish to extend the right to identity to donor-conceived children in this jurisdiction, it might consider the introduction of a generally applicable age requirement for access under the age of 18; the introduction of an exception to the general age requirement where the child is considered to be “sufficiently mature”, the release of genetic information to recipient parents on behalf of their donor-conceived children, the introduction of mandatory counselling prior to access,<sup>51</sup> and the roll-out of education and outreach programmes for the benefit of all parties to the donor conception arrangement, and in particular, for the benefit of the donor-conceived child.<sup>52</sup>

---

<sup>51</sup> While individuals seeking to record information on the central register in Ireland on a *voluntary* basis will be required to undergo counselling prior to recording information (*2015 Act*, s. 38(2)), the same requirement does not apply where information is mandatorily recorded by the State, that is, in the case of release of donor information for those party to a standard donor conception arrangement governed by the *2015 Act*.

<sup>52</sup> Lyons, *supra* note 45.