

Chapter 5

Ethical considerations

Chapter 5 – Ethical considerations

Chapter 5: overview

- Ethical consideration of the principles that should govern information sharing in donor conception should start from a focus on people, and relationships, rather than from abstract principles.

Interests and rights

- Important interests arise for each of the parties involved in donor conception: the significance placed by many on knowledge of, and contact with, those with whom they have close biological links; the value placed on having children and the autonomy of the family unit; the need for boundaries beyond which public/state interference is not acceptable; the privacy associated with personal information; the significance placed on the keeping of promises and honouring of contracts. These are often expressed in the language of 'rights'.
- Using the language of 'interests', rather than 'rights', however, enables us first to 'unpack' what we know about the nature of those interests, and then go on to consider at a second stage the extent to which others might be held to bear responsibilities in connection with those interests.
- It is not the role of this Working Party to make any judgment as to the appropriate degree of importance to be attached by any individual to any interest. However, the extent to which these interests are widely expressed and shared is relevant to the degree of moral responsibility that this creates in others. In turn, this is relevant in determining what action may be demanded on the part of public bodies.

Values

- Many interests arise specifically in the context of relationships, and widely-valued characteristics of those relationships include *trust* and *honesty*. '*Openness*' is also valued by many. Openness, however, is not necessarily synonymous with '*honesty*': in particular, choosing not to disclose private information is not usually considered to be dishonest. Difficulties arise in the context of '*openness*' in donor conception because information about donor conception may be simultaneously private information about the parents or donor, and information about the donor-conceived person. Openness in this context should not be regarded as intrinsically valuable, but rather as important in so far as it contributes to the quality of relationships within the family, and to the well-being both of parents and of donor-conceived people.

Weighing interests

- Where interests potentially conflict, the interests of one party to a relationship should not, as a matter of principle, automatically take precedence over any others. Accordingly, the interests of different parties always have to be weighed. In practice, it will fall to the parents of donor-conceived children to weigh the interests in any particular decision regarding disclosure, unless the risk of harm to others is sufficient to justify external intrusion into family life by third parties. Such power must be exercised responsibly.

Responsibilities

- The parents of donor-conceived children have a responsibility to avoid, where reasonably possible, any harmful consequences that may follow for their children from the fact that they were donor-conceived. Such responsibilities include a willingness both to take account of the evidence available regarding disclosure, and to engage as necessary with professional support, when determining what is likely to be best for their donor-conceived child in their particular circumstances.
- Responsibilities also arise for donors and for donor-conceived people. In choosing to donate, donors have a responsibility to think carefully about the consequences: for themselves and their own families; for the recipients of the donated gametes; and for the resulting person. In turn, donor-conceived people have a responsibility, commensurate with their age and understanding, to do their best to understand the reasons why their parents chose to create a family through treatment with donated gametes, and why they made the decisions they did about disclosure. Where the prospect of contact arises, donor-conceived people and donors each have a responsibility to be sensitive to the needs of the other, including the potential for impact on the other's own family.
- Third parties, including both professionals and the state in its regulatory role, also have responsibilities. It is acceptable for third parties to take account of the welfare of any future child in providing reproductive treatment services, even though in such cases there is no possible '*alternative life*' for the prospective child. However, interventions to prohibit treatment can only be justified where there is a risk of significant harm or neglect to future children. A failure to disclose to children that they are donor-conceived should not be regarded as constituting such a risk. Given the evidence of the importance attached by some donor-conceived people to information about their donor, both professionals and the state have a responsibility with respect to the collection and retention of such information.

The stewardship role of the state

- The state has a '*stewardship*' role in providing conditions, whether physical or social, that help and enable people in making their choices. Having enabled and endorsed donor conception as a means of creating a family, the state should also be concerned to take action that is likely to promote the welfare of people affected by donor conception, where this can be achieved without unreasonably interfering with the interests of others. This should include encouraging a social environment where the creation of families through donor conception is seen as unremarkable: as one way among a number of others of building a family.

Introduction: people and relationships

- 5.1 As the evidence reviewed in Chapter 4 reminds us, donor conception is first and foremost about *people*: the people who are conceived through donor gametes or surrogacy; the people who seek treatment with donor gametes in order to realise their wish to become parents; the people who donate eggs, sperm or embryos, or act as surrogates, in order to enable others to create families; and people who are close to those directly affected by donor conception. The Working Party takes the view that any debate about the ethical considerations that should inform public policy on donor conception should start not with the analysis of abstract principles, but with the people concerned, and the reality of their lives. ‘People’, in turn, do not exist in isolation but within a web of relationships with one another: such webs extend out beyond the ‘family’ (see paragraph 1.11) into the wider communities in which people live, work, play, go to school, socialise, worship and so forth. Within those relationships, individuals may have multiple roles: the Working Party heard from parents of donor-conceived offspring who are themselves donors, from an adopted person who became a donor, and of a donor-conceived person who himself became a donor, to name only a few such examples. More broadly, of course, roles and relationships evolve and change over time in all families and communities, as children grow up, take on adult roles in their communities, and themselves become parents.

Box 5.1: People and relationships – quotes from donor-conceived people, parents, and donors

“No amount of ‘information’ about gamete providers can ever replace the role of the displaced and marginalised ‘third party’, biological parent. It is perfectly normal and understandable for a child to want to know simple and seemingly inconsequential things, such as if their father or mother owned a pet dog and what was it called, or at what age their parents learned to swim, or if they ever fell out of a tree and broke their arm. Such questions about a gamete provider cannot be answered from the data on a fertility clinic tick-box questionnaire. Parents represent family and family is about relationships, not about information.” [Donor-conceived adult]

“I’d always known something wasn’t quite right that there was something different about me but I just didn’t know what, it was such a relief when I was finally told that I was donor-conceived. This meant all the feelings and suspicions I’d had were real. It didn’t change the way I felt about my dad at all but I still want to know more. I’d love to know about my genetic family, to trace my family tree as well as draw a connection to my half siblings.” [Donor-conceived adult]

“When people ask, ‘who’s your real father?’, I pedantically stop them and say, ‘My real father is the man who raised me.’ That’s *real* to me... There’s a sperm donor and a parenting father and these roles both exist.” [Donor-conceived adult]

“I carried him, felt him kick, gave him life. I am the mother and will love him so much that he will never question. I would have never had him if I had to tell.” [Mother of child conceived through egg donation]... “I’m worried he’s going to find out one day and turn against both of us because of our deceit. If I had 100% certainty [that he would never find out] it would never be an issue, it would be ok; but we don’t and it’s hanging over me, over us, like a big cloud.” [Father of same child]

“Coming from a family background of secrets and lies, I was determined that no child of mine would ever be brought up like that. We had decided before even starting treatment that any child we had would be told the truth from an early age. It was easy to tell and I loved spending time making books to show and explain; as our son got older, we told him more details and answered all questions honestly. It feels really good to know that he knows about his genetic background. It has never been a problem or an issue!” [Mother of child conceived through egg donation]

“[Disclosure] is a decision that only the parents can take. It is no one else’s business. No one undertakes the treatment needed to secure a donor-conceived baby lightly.” [Prospective parent of donor-conceived child]

“My wife and I share a relationship with our children borne of bandages for scuffed knees, bedtime stories, and piggyback rides in the park. I treasure this. But someday they may want to meet you. Maybe someday you’ll want to meet these wonderful people you helped to create.” [Father of child conceived through sperm donation in ‘Letters to my donor’]

“The donor contributes an incredible gift to make this mission possible, at little or no benefit to themselves, and since anonymity ceased they live with the knowledge that at some point in the future, they may be contacted by a person who is their genetic offspring and half sibling to their own children and this is a massive responsibility to live with and not one I feel donors take lightly.” [Egg donor]

“I have always treasured the knowledge that out there, somewhere, are my offspring. In my head I have kept a little calendar, ticking off your years... In a perfect world my donor-conceived children have no need of me, feel no gap, no distress, and no desire to find me. But for those that do, then I wish to be there for them, and willingly.” [Sperm donor]

Rights, interests, values and responsibilities

- 5.2 Much of the contemporary ethical and legal debate on information disclosure in donor conception has been phrased in the language of *rights*: the right of a donor-conceived person to know the truth about their origins and have information about, or contact with, their donor; the right of individuals or couples to become parents; the right of parents to decide for themselves how to bring up their children; the rights of individuals to their privacy (variously defined); the right of donors to have the original terms under which they donated honoured.³⁹⁷ These rights claims seek to protect important *interests* for each of the parties involved: the significance placed by many on knowledge of, and contact with, those with whom they have close biological links; the value placed on having children and the autonomy of the family unit; the need for boundaries beyond which public/state interference is not acceptable; and the significance placed on the keeping of promises and honouring of contracts.³⁹⁸ In turn, these interests are strongly associated with *values* or *goods*, such as love, trust, and openness within relationships.³⁹⁹
- 5.3 Starting from the language of rights, however, is effectively to start with *conclusions*: the conclusion that particular interests are of sufficient importance to impose duties on others to ensure that the right-holder is able to enjoy the interest in question.⁴⁰⁰ Using the language of interests, on the other hand, enables us first to ‘unpack’ what we know about the nature of those interests, and then go on to consider at a second stage the extent to which others might be held to bear responsibilities in connection with the promotion or protection of those interests.
- 5.4 We note also that the language of rights is often perceived as one of conflict: of asserting the claims of one individual against another, with the intention that the rights of one will be held to ‘trump’ or extinguish the rights of the other.⁴⁰¹ It is also a language that encourages a focus on the individual: of one person’s rights being isolated and pitted against another’s. And yet, as we postulated above, a fundamental feature of all families (whether created through donor conception or otherwise) is that of complex, interweaving relationships, where action taken by one person, or impacting on one person, will have inevitable effects both on others and on the relationships between them. The language of ‘interests’, by contrast, offers a less adversarial tool for exploring what is at stake for the many different parties to donor conception and in the relationships that exist between them, and for identifying where interests coincide, as well as where they conflict. The language of interests is flexible: while the language of rights may suggest immutability and the need for enforcement, people’s perceptions both of their own interests and those of others may change over time, allowing for mutual resolution.

³⁹⁷ For a summary of ‘rights’-based claims, see: Jones C (2010) The identification of ‘parents’ and ‘siblings’: new possibilities under the reformed Human Fertilisation and Embryology Act, in *Rights, gender and family law*, Wallbank J, Choudhry S, and Herring J (Editors) (Abingdon: Routledge).

³⁹⁸ By way of contrast, we note here the prominence of Hart’s ‘choice theory’ of rights, which he developed in response to the Benthamite or ‘interest theory’: Hart HLA (1984) Are there any natural rights?, in *Theories of rights*, Waldron J (Editor) (Oxford: Oxford University Press), 77-90, at page 81. However, we have found an approach to rights that hinges, in part at least, on the notion of interests to be more appropriate to the subject matter here. In any event, Hart himself acknowledged that the choice theory cannot adequately explain either all legal rights or, more particularly, those which are part of social and political morality: Hart HLA (1973) Bentham on legal rights, in *Oxford essays in jurisprudence (second series)*, Simpson AWB (Editor) (Oxford: The Clarendon Press), as noted by Waldron J (1984) *Theories of rights* (Oxford: Oxford University Press), at page 9.

³⁹⁹ Such values may understood to be intrinsic (ends in themselves) or as instrumental (contributing to another intrinsic good) - see paragraphs 5.22 to 5.33.

⁴⁰⁰ See, for example, the discussion of ‘interest theories’ of rights in Waldron J (1984) *Theories of rights* (Oxford: Oxford University Press).

⁴⁰¹ We note that this is in the context of the language of rights being deployed rhetorically, or in the sense of rights as ‘trumps’. International human rights law, by contrast, distinguishes between ‘absolute rights’ and ‘qualified rights’: interference with a person’s qualified rights can be justified by reference to the rights and interests of others. We return to this point at the end of this chapter (see paragraph 5.72); our critique here relates to the rhetorical use of rights where no ‘balancing’ of competing rights claims is envisaged. For a discussion of the language of rights and the different ways in which it may be deployed, see: Tobin J (2012) Donor-conceived individuals and access to information about their genetic origins: the relevance and role of rights *Journal of Law & Medicine* 19: 742-57.

5.5 This chapter will therefore consider the issues at stake first in terms of the *interests* of all the people concerned and the *values* associated with these interests, and then of the *roles and responsibilities* of those (both people and organisations) to whom one might potentially look for the protection, or promotion, of those interests. In some cases, an interest could be thought sufficiently strong to ground a moral right, with a corresponding moral duty on another to ensure that right is protected. Moreover, depending on the strength of the interest, it may then be considered appropriate to seek to protect that right in law, thus supplementing a moral duty with a legal one. We will therefore go on to consider, in Chapter 6, the implications of these interests and responsibilities for regulation within the UK, and in particular whether the nature and weight of any of those interests points to the need for regulatory change to provide for legally enforceable rights and duties in particular areas.

Interests

5.6 We alluded above to the many parties involved in donor conception. We set out below a number of these parties, and the interests they may have in connection with the disclosure of information about donor conception, drawing on the research evidence currently available and the evidence presented to the Working Party, as summarised in Chapter 4. We note here that, depending on the individual, the strength of these interests ranges from the expression of a mild preference to the identification of essential conditions for the person in question. Some go further and claim that what is at stake is not limited to something they themselves feel strongly about, but something to be regarded as a universal or objective interest for any human being: an essential condition for ‘human flourishing’. We take the view that it is not the role of this Working Party to make any judgment as to the appropriate degree of importance to be attached by any individual to any interest: as we noted in Chapter 1, there is tremendous plurality of opinion within the UK alone as to the meaning to be ascribed to gametes and the biological connections they create (see paragraphs 1.20 and 1.21), and we have demonstrated in Chapter 4 a similar range of feeling among donor-conceived people as to what it means to be donor-conceived (see paragraphs 4.13 to 4.20). However, the extent to which these interests are widely expressed and shared *is* relevant to the degree of moral responsibility that this creates in others and, in turn, to the required policy response. In this connection, the claim to objectiveness or universality can be understood as an assertion that the interest in question is one that deserves, or even demands, special consideration by others.

Donor-conceived people

5.7 As we have seen in Chapter 4, some donor-conceived people have expressed very strongly the view that knowledge of their biological origins, in the sense both of the truth about the circumstances of their conception and of knowledge of their donor, is essential to both their sense of self and to their social identity: their understanding of ‘who they are’, and of where they fit in the world.⁴⁰² For some, this knowledge is so important that seeking it has become a major focus of their adult lives, and ‘information’ alone is not enough: what is really desired is contact, with the subsequent possibility of forming meaningful relationships with their donor. Indeed, it has been argued in the literature on donor conception that a child’s knowledge of, and relationship with, their biological progenitors is “a basic good on which most people rely in their pursuit of self-knowledge and identity formation”.⁴⁰³ For others, what might be described as ‘biographical’ information about their donor, information that would help contribute towards a ‘back story’ or ‘narrative’ for their life and give them an idea of the kind of person who provided half their biological material, is valuable and significant, without necessarily being regarded as

⁴⁰² Haslanger helpfully distinguishes between a sense of ‘self’, concerning “the cluster of basic traits that allow an individual to function as an agent, some of which are measured by the notion of ‘personal identity’... and ‘social identity’ to refer to a person’s reference group orientation”: how one navigates one’s relationship with one’s reference group. See: Haslanger S (2009) Family, ancestry and self: what is the moral significance of biological ties? *Adoption & Culture* 2(1).

⁴⁰³ Velleman JD (2005) Family history *Philosophical Papers* 34(3): 357-78, at 365.

vital to their well-being. Others again express very little interest at all in information about their donor (see paragraph 4.22). However, a much clearer message emerges with respect to being told in the first place that they are donor-conceived: in a survey of members of the Donor Sibling Registry (DSR), only one per cent of donor-conceived adolescents and adults said that they wished they had never been told, indicating a very strong preference for having this information even where the initial experience of finding out may be negative (see paragraphs 4.14 to 4.20).

- 5.8 It is clearly not possible to say that *all* or *most* donor-conceived people, if aware of the fact that donor gametes were used in their conception, regard information about their donor, or the possibility of subsequent contact, as being of overwhelming importance in their lives and crucial for their ability to flourish as an individual. The wide spectrum of opinion even among the relatively small number of donor-conceived people who spoke in person to the Working Party (a spectrum reflected also in surveys of donor-conceived people belonging to the DSR - see paragraph 4.14) suggests that it is hard to substantiate the claim that information about one's biological connections is a 'basic good' in the sense of something that is *essential* for human flourishing, for having any kind of 'good life'. It does, moreover, seem likely that the environment in which a person grows up, and in particular the value placed both by the person's family and their wider community on the importance of biological connection and the influence of genetic inheritance on life choices, will affect how donor-conceived individuals conceptualise information about their donor (see paragraphs 1.27 to 1.29 and 4.19). Nevertheless, it is certainly the case that *some* donor-conceived people do view such information, and contact, as absolutely core to their sense of self and their social identity, and have suffered harm as a result of not knowing until later in life that they were donor-conceived, or in not having access to the information that they have sought. The possibility of contact with, and possibly a lifelong relationship with others conceived through the same donor ('donor-conceived siblings') is clearly also found by some to play an important part in their life (see paragraph 4.25).
- 5.9 It is, of course, impossible to know how donor-conceived people who do *not* know how they were conceived would judge their own interests. While we know from the longitudinal studies of non-disclosing families that these function well, at least into early adolescence (see paragraph 4.30), we cannot know how the donor-conceived people concerned would value the opportunity to know about their means of conception or about their donor, and we cannot judge how 'never knowing' may affect a person's flourishing as an individual. All that can be noted on this point is that very few donor-conceived people (albeit of a sample of those joining a contact register) wish that they had not been told; and that those who are told very young appear to have positive experiences of absorbing the fact of being donor-conceived into their life narrative, without being exposed to the risk of shock from inadvertent disclosure or discovery. The possibility that donor-conceived people may feel some sense of "genetic disconnection" and hence begin to have doubts about their biological connection with their parents is also raised in some qualitative studies.⁴⁰⁴
- 5.10 More generally, donor-conceived people, like all people, have a strong interest in a happy, well-functioning family life during childhood and beyond, and in family relationships that will help them develop into well-adjusted adults. Both during childhood and later, they also have an interest in knowing that they are not at significant risk of developing serious genetic conditions from their donor, and in not providing misleading 'family history' (i.e. that belonging to their non-biologically-connected parents) to their doctors; they also have an interest in receiving other medical information about their donor if this would have an impact on the health care they receive (see paragraphs 3.24 and 3.26).

⁴⁰⁴ See, for example, Daniels KR, Grace VM, and Gillett WR (2011) Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception *Human Reproduction* **26(10)**: 2783-90. Similar points were made to us by Rachel Pepa and Christine Whipp (factfinding meetings on 24 April 2012 and 16 July 2012). However, adolescents in natural conception families may also experience doubts as to whether they 'belong' with their families. See, for example, the views expressed at Experience Project (2013) *I feel like I don't belong*, available at: <http://www.experienceproject.com/groups/Feel-Like-I-Dont-Belong/33530>.

Prospective parents

- 5.11 The desire to have children, to create a family ‘of one’s own’, is widely recognised as a very powerful human drive. While a minority of people do not feel any such desire and actively choose not to have children, the lengths to which some individuals and couples will go in order to have a child provides some indication of the strength of feeling engendered, and the role played by the creation of a family in a lifetime narrative. Infertility has been described as a rupture in the life trajectory that people have imagined for themselves. All societies structure the life course around phases with attendant expectations. Partnership or marriage and having children are a significant part of the imagined trajectory of social life, which is not to say that all members of a society subscribe to, or desire, that ‘phase’ (which for some confers adulthood) but that it is widely disseminated as an ideal. Infertility disrupts life plans: it breaks a perceived continuity into the future.⁴⁰⁵ The expectations of an older generation to have grandchildren, and the desire of peers to share similar experiences, adds additional social pressure. The distress of involuntary childlessness may be acute, and those who do not go down the route of bypassing infertility, through assisted reproduction or adoption, have to reconfigure their life stories and their senses of self in ways that project them into a different future from the one they had previously imagined.
- 5.12 Before the development (and general availability) of treatment services involving donor gametes, the only other option open to those who wanted a family, but who were unable to conceive with their own gametes, was adoption. However, as noted earlier (see paragraphs 1.23 and 1.24), comparisons between adoption and donor conception are not straightforward. In particular, it has never been appropriate to regard adoption as a simple ‘solution’ to infertility, in that adoption services are essentially services for *children*, not for prospective parents. The placing of children for adoption may indeed enable couples and individuals who have been unable to have a biologically-related child to have the family life they strongly desire. However, this is not the primary purpose of adoption services, which is rather to make the best possible arrangements for the particular child for whom those services have responsibility, rather than to meet the needs and desires of prospective adoptive parents. Those who wish to adopt will not necessarily always be able to do so.
- 5.13 Treatment with donor gametes, by contrast, leads to the birth of a child, who would not otherwise have existed, directly into that child’s social and legal family. Thus the wider availability of treatment services involving donor gametes, combined also with changing social attitudes to parenting by same-sex couples and single women, has opened up the possibility of a new kind of parenthood for many couples and individuals who, in the past, would have been obliged to accept the impossibility of creating their own family. This form of parenthood differs from adoptive parenthood further through the existence, for the most part, of a genetic link with one of the child’s parents,⁴⁰⁶ as well as through the experience of pregnancy, birth and early nurture. Any proposed action that might limit access to such services (whether through any form of screening of those eligible to access services, or through reduced availability of donor gametes) would therefore have the potential to affect, or indeed to prevent altogether, the realisation of the reproductive interests of those for whom these services provide their only route to parenthood.

⁴⁰⁵ Becker G (1999) *Disrupted lives: how people create meaning in a chaotic world* (Berkeley: University of California Press).

⁴⁰⁶ In embryo donation, or ‘double donation’ of egg and sperm, no such genetic link will, however, exist; it is also possible for there to be no genetic link between children born as a result of a surrogacy arrangement and their social family, although in the UK such a link is required for a parental order to be made. Equally, it is possible for there to be full genetic links between the legal parents and the child, where a surrogate mother carries a child conceived from the gametes of both intended parents.

Parents (and their wider families)

- 5.14 While the interests of prospective parents are firmly focused around the establishment of a pregnancy, once a child is born the 'prospective' parents become parents, who share the same interests as parents in any other family. Such general 'parental' interests include respect for the privacy and autonomy of family life, reflecting the importance placed on being able to bring up one's children in accordance with one's own values, perhaps with support on request from professionals or state services but without such support being forced on them against their will. While the nature of this 'respect' for parental control of family life will vary significantly in different societies, and over time (we note, in particular, greatly varying cultural attitudes to the role of extended family members in the bringing up of children), we suggest that respect for the autonomy of family life, however defined, may be considered to be essential for the well-being both of the parents and of their offspring, and that hence this interest demands special attention (see paragraph 5.6).⁴⁰⁷ Parents of donor-conceived children may also have a strong interest in being seen as the 'only' or 'real' parents of their child (see paragraph 2.1), and in being able to leave behind them the often difficult and stressful period of fertility treatment. For some, the possibility of their child later identifying the donor, resulting in potential contact with both the donor and the donor's wider family, may be perceived as an unwelcome intrusion into their own family space.
- 5.15 Parents of donor-conceived children may, on the other hand, have interests in accessing information about the gamete donor who enabled them to become parents. However, as was the case in relation to the views of donor-conceived adults, responses to the Working Party's consultative activities demonstrated a very wide range of views by parents as to the nature of this interest: from those who felt that parents needed to know little or nothing about the donor (because they were looking for "just a bit of genetic material that matched [partner]"⁴⁰⁸), to those who felt that detailed biographical information was crucial in order for them to help their children absorb the fact of their being donor-conceived into their understanding of themselves.⁴⁰⁹ All parents, however, have an interest in being reassured that their child's donor has been appropriately screened for significant genetic conditions and hence the risk of the transmission of serious conditions is very low; they also have an interest in receiving medical information about the donor if such information has implications for the health care of their child, and hence for their ability to parent (see paragraphs 3.24 and 3.26).
- 5.16 A few respondents went beyond emphasising the importance of biographical information about their child's donor to suggest that ongoing contact with the donor, donor-conceived siblings, or both, would be in the interests of both parents and offspring during the donor-conceived person's childhood, particularly where children were being brought up in single parent households.⁴¹⁰ The number of parents of donor-conceived offspring signing up to contact registers such as the DSR while their child is still young illustrates that such contact is regarded positively by a significant number of donor-conceived families, particularly those headed by solo mothers or same-sex couples (see paragraph 4.28). Such a focus on 'family to family' contact emphasises how the wider family or kinship network may also potentially have interests arising out of the sharing of information about donor conception. The Working Party was told of ongoing research with the grandparent generation in donor-conceived families, which highlighted the possibility of generational differences with respect to privacy and openness about donor conception leading to family conflict: some grandparents, for example, "frankly could not

⁴⁰⁷ See, for example, how experimental social models such as kibbutzim have shifted back from fully communal arrangements to a greater focus on the family: http://www.jewishvirtuallibrary.org/jsource/Society_&_Culture/kibbutz.html ('raising children'). See also the discussion of the 'goods' found in familial relationships in: Brighouse H, and Swift A (2009) Legitimate parental partiality *Philosophy & Public Affairs* 37(1): 43-80.

⁴⁰⁸ Factfinding meeting with people directly affected by donor conception, 27 April 2012.

⁴⁰⁹ Factfinding meeting with people directly affected by donor conception, 27 April 2012.

⁴¹⁰ Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: <http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering>.

understand the need to talk about it in the first place”.⁴¹¹ In contrast, some grandparents reported finding it a burden being required to maintain the secret about treatment with donor gametes: for example where women undergoing treatment confided in their mothers for emotional support but asked them to tell no one else.⁴¹²

Donors (and their wider families)

- 5.17 Two very different sets of interests might be identified for donors: those that arise in connection with the original terms under which they donated gametes; and those that arise in connection with the possibility of a relationship with their donor-conceived offspring (and potentially also the donor-conceived person’s family). People who donated gametes before the change in the law in the UK in 2005 donated on the understanding that their identity would never be made known to any resulting offspring, and may feel strongly that such understandings (whether or not they legally constituted a contract) should be honoured. Such an interest may be defined narrowly, in terms of ‘fair dealing’ with donors, or more broadly in terms of the importance of maintaining trust in health care systems (whether private or NHS). Whether or not the relationship between donors and clinics may be strictly defined as a ‘patient’/professional relationship, it is clear that donation takes place in a clinical relationship involving expectations of confidentiality and trust, and that both the donors involved, and the wider health care system, have interests in the trust in that system being maintained.⁴¹³
- 5.18 The way in which donors view their interests with respect to their donor-conceived offspring is likely to be strongly affected by the environment in which they donated (see paragraph 5.34). Those who donated at a time when the culture of donation was based on anonymity and non-disclosure may feel that they have few, if any, interests in knowing about the future welfare of any offspring (see paragraph 4.59). Those, on the other hand, who donated on the basis that their donor-conceived offspring would be able to obtain identifying information about them on reaching the age of 18, are more likely to have thought carefully about the future person or persons who might be created as a result of their donation, and to feel that they have an interest in being reassured about their future well-being (see paragraph 4.59). Such donors also have an interest in being able to prepare for the possibility of future contact, both psychologically and practically, for example through telling their own family about the existence of donor-conceived offspring. In the context of such potential contact, donors further have an interest that any people conceived as a result of their donation have been able to integrate the knowledge of their conception well into their lives, and do not have expectations of the donor (for example of a ‘parental’ relationship) that the donor is unable to meet.
- 5.19 Some donors would go further, and claim an interest in actively ensuring the welfare of their donor-conceived offspring during their childhood: for example by specifying the kind of home in which the child may be brought up, or through direct and ongoing contact during their offspring’s childhood.⁴¹⁴ In some cases of known donation, these interests are explicitly recognised in the terms of the agreement between the donor and recipient parent(s) (see paragraph 2.4). The

⁴¹¹ Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester, responding to the Working Party’s call for evidence. The end of their research project, which is entitled ‘Relative strangers’, was marked by a conference on ‘Genetic identities, personal lives and assisted donor conception’, which took place on 22 March 2013. See: <http://www.socialsciences.manchester.ac.uk/morgancentre/events/2012-13/relative-strangers-manchester/index.html>. See also: Morgan Centre for the Study of Relationships and Personal Life, University of Manchester (2013) *Relative strangers*, available at: <http://www.socialsciences.manchester.ac.uk/morgancentre/research/relative-strangers/index.html>.

⁴¹² Nordqvist P, and Smart C (2013) Relational lives, relational selves: assisted reproduction and the impact on grandparents, in *We are family? Perceptions of relatedness in assisted conception families*, Freeman T, Ebtehaj F, Graham S, and Richards M (Editors) (Cambridge: Cambridge University Press).

⁴¹³ See: Rees A (2012) Keeping mum about dad: ‘contracts’ to protect gamete donor anonymity *Journal of Law & Medicine* **19(4)**: 758-68 for a more extended discussion of the legal basis on which understandings about anonymity might rest, and the extent to which there might be public policy reasons for respecting them.

⁴¹⁴ Factfinding session with people with personal experience of donor conception, 27 April 2012. The desire on the part of some donors to control the environment in which a child, born as a result of their donation, will grow up is also found in the restrictions placed by some donors on the use of their donated gametes, for example in specifying particular family forms.

current regulated system of ‘unknown’ donation, on the other hand, excludes the legal recognition of any such interest: the underpinning premise of the provisions in the Human Fertilisation and Embryology Act and associated regulations is that those donating gametes or embryos to strangers have no claim in respect of, or responsibility for, any resulting offspring. In legislating in 2004 to ensure that future donor-conceived offspring would be able to contact their donor at the age of 18, the Government recognised the potential for donor-conceived adults to have an interest in contacting, and possibly developing a relationship with, their donor. However, it did not acknowledge any corresponding interests on the part of donors, other than a statutory entitlement from 2008 to know the number, sex and year of birth of any offspring born as a result of their donation.

- 5.20 Donors’ own families – in particular their partners and children – also potentially have interests arising out of the sharing of information about donor conception and potential contact between donor-conceived people and donors. While the extent to which donors’ partners are involved in the decision to donate, or are told of an earlier donation varies considerably, all partners have an interest in ensuring that contact with donor-conceived offspring does not have a negative impact on their own family unit (see paragraphs 4.53 to 4.55). The strength of feeling that donation may potentially engender in some donors’ partners is demonstrated by recent representations put to the Human Fertilisation and Embryology Authority (HFEA) that donation should not be permitted without the consent of the donor’s partner.⁴¹⁵ Similarly, donors’ own children may or may not welcome the idea of contact with their parent’s donor-conceived offspring (see paragraph 4.56); those who do desire contact cannot initiate it, but must wait for the donor-conceived person to do so if they wish. Donors’ parents may feel a sense of loss that they have grandchildren whom they cannot see grow up, and/or actively embrace a grandparental role where the sharing of identifying information makes contact possible (see paragraphs 4.53 and 4.56).
- 5.21 Finally, donors and their families also have an interest in being informed in the exceptional case where a donor-conceived person has been found to have a serious genetic condition (see paragraph 3.26). Information about such a diagnosis (which does not of itself need to involve any identifying information about the donor-conceived person) could have medical implications both for donors themselves, and for any other genetic offspring, whether their ‘own’ or donor-conceived.⁴¹⁶

Values in relationships

- 5.22 We have identified above some of the interests that may be at stake in connection with information disclosure about donor conception for each party affected: for donor-conceived people (both as children and as adults); for prospective parents; for parents; for donors; and for the wider families of all the above. However, many of these interests arise specifically in the context of the relationships (actual and potential) that may exist between these different parties. As we saw in Chapter 4, when people speak about the interests at stake in donor conception, they often refer to *values* that they regard as essential in shaping those relationships, and we now turn to a consideration of these values.⁴¹⁷
- 5.23 Both *trust* and *honesty* are often identified as being aspects of relationships that are highly valued as playing a central part in promoting well-being within families. We saw earlier how

⁴¹⁵ Daily Mail (26 August 2012) *Wife whose husband became secret sperm donor calls for change in the law to require partners’ consent*, available at: <http://www.dailymail.co.uk/news/article-2193780/Sperm-donation-Wife-man-secretly-donated-sperm-calls-spouses-consent-mandatory.html>.

⁴¹⁶ See also: Raes I, Ravelingien A and Pennings G (2 July 2012) *Abstract book of the 28th EHSRE annual meeting: ethics of donation and surrogacy (session 21) - the right of the gamete donor to know his/her genetic offspring (O-085)*, available at: http://humrep.oxfordjournals.org/content/27/suppl_2/ii32.full for a more extended discussion of the interests of donors and their families.

⁴¹⁷ We note here that, while the ‘values’ we identify may also be considered to be virtues, in the sense of character traits of people (the extent to which individuals are trustworthy, honest, etc.), our focus here is on the characteristics of *relationships*, and what it is that is valued in them by those who have a stake in donor conception.

concerns about trustworthiness and truth-telling within parent-child relationships may influence parents' decisions to disclose or not disclose the use of donor gametes in conception, and in the reactions of some donor-conceived people when they found out late or inadvertently about the circumstances of their conception (see paragraphs 4.16 and 4.17). Similarly, references to trust and honesty arose in the evidence given to the Working Party when respondents explained the reasons underpinning their own decisions to disclose or not. The value placed by many on kinship relationships founded on trust and honesty may be explained by the nature of those relationships: predicated on intimacy, the shared vulnerability of an interconnected life, and the inherent dependency of children, when young, on those who care for them (a dependency which over time may invert, as parents age and children grow up and take on adult roles).⁴¹⁸

- 5.24 A further value that is often put forward in the context of relationships is that of *openness* or *transparency*. While these terms may at times be used synonymously with 'honesty' or 'truthfulness', we suggest this need not be the case: a person who chooses not to share information is choosing not to be 'open' but is not necessarily being dishonest. We explore this distinction further below.
- 5.25 Some of those who shared their experiences with the Working Party saw openness within relationships (contrasted explicitly with 'secrecy' or 'deception') as inherently good: for example it was argued that an absence of such openness creates a 'secret system' of those who decide to keep information secret, those who become secret-holders, and those who are unaware and hence excluded from the secret.⁴¹⁹ Often it is people directly affected by the information who belong in this excluded 'unaware' group: as one donor-conceived adult commented forcefully: "You can't make a decision about whether or not to tell somebody something you don't know yourself".⁴²⁰ Some of the parents to whom the Working Party spoke emphasised that they saw information about their child's conception as information that they as parents 'held in trust' for that child, with a duty to pass it on appropriately during childhood, until the child was mature enough to take on ownership of it for themselves.⁴²¹ On such a view, openness about donor conception is seen as something automatically owed by the parent to the child because of the nature of the information at stake. Sharing information is thus seen as the good or right thing to do in and of itself, regardless of broader consequences, whether good or bad.
- 5.26 The views on openness expressed by some of the parents and practitioners who came to meet the Working Party also appear in the literature on donor conception: it has been argued that "deception of this nature" (that is, failure to disclose to children that they were conceived through donated gametes) "constitutes a wrong in that it violates the respect owed to that child", regardless of any consequential harmful outcome.⁴²² Such a categorical wrong may be understood as an 'existential lie' (a 'Lebenslüge'); a fundamental deception on the part of parents about the nature of their children's being, that cannot in any case be justified and is inherently disrespectful.
- 5.27 Others, however, question whether there is a simple physical 'truth' that should automatically take precedence over other kinds of 'truth' (such as those arising from gestation or from active caring and love), noting that openness and secrecy within families are not simply matters of personal integrity but also of social, legal and cultural context.⁴²³ It is argued that 'family

⁴¹⁸ We note here, however, that such an understanding of kinship relationships cannot be claimed to be universal: in some cultures, much greater weight may be placed on, for example, authority, devotion or obedience. See: Montgomery H (2009) *An introduction to childhood: anthropological perspectives on children's lives* (Chichester: Wiley-Blackwell).

⁴¹⁹ Factfinding meeting with practitioners, 30 May 2012.

⁴²⁰ Rachel Pepa, responding to the Working Party's call for evidence.

⁴²¹ Factfinding meeting with people directly affected by donor conception, 27 April 2012. Similar views were expressed in the meeting with practitioners on 30 May 2012.

⁴²² See, for example, Cowden M (2012) 'No harm, no foul': a child's right to know their genetic parents *International Journal of Law, Policy and the Family* 26(1): 102-26.

⁴²³ Smart C (2009) Family secrets: law and understandings of openness in everyday relationships *Journal of Social Policy* 38(4): 551-67; Smart C (2011) Families, secrets and memories *Sociology* 45(4): 539-53. See also: Bowby R (2013) *A child*

secrets', while not necessarily good things, may be felt to be necessary for the preservation of relationships; and that physical or genetic truth may be less important than stabilising fictions. The perceived need for secrecy about particular things at particular times may be understood as a response to social vulnerability, and it is suggested that "an emergent insistence on genetic truth and transparency may simply create other forms of vulnerability, especially if cultural mores and familial norms have not changed greatly".⁴²⁴ Some respondents to the Working Party's call for evidence similarly challenged the notion that openness or transparency should automatically be seen as a positive value in itself, noting that while concealment allows for the option of future disclosure, openness does not allow for an option of future concealment.⁴²⁵ The concern about the irrevocability of disclosure underlies the hesitancy experienced by a number of parents about disclosing to their donor-conceived offspring when they are very young: the fear that young children cannot be expected to keep this information to themselves – and yet that when they are older they themselves may wish that they had been more reticent.⁴²⁶ As one prospective parent put it to us: "Once information is 'out', there is no way of putting it back 'in' again: a child who discloses to others when they are young cannot recreate their own privacy."⁴²⁷

- 5.28 The difficulty, if not impossibility, of making a limited disclosure only to the donor-conceived person himself or herself brings into consideration a further value often cited in the context of relationships, that of *privacy*: openness with a young child inevitably entails openness within a much wider family and community circle. Thus, in addition to concerns that parents may have as to their children's own future wishes about sharing information about donor conception, privacy concerns also arise more directly at the time of disclosure, in terms of the impact on the parents, on the child, and on other close family members. Openness between parents and child is highly likely to lead to information that parents may regard as deeply private being publicly discussed – for example by other parents at the child's nursery or school. At worst, this wider disclosure may lead to stigmatisation and even exclusion from the parents' broader family or social or religious community. The way in which the sharing of information within the family cannot be separated out from disclosure to the wider community was emphasised to us in a response to our call for evidence based on an ongoing research project looking at the experiences of parents and grandparents of donor-conceived people: it was commented that "our research suggests that parents want to be 'honest' but that total openness and complete loss of control over information was usually far too worrying".⁴²⁸
- 5.29 The terms 'truth', 'honesty', 'openness', 'transparency', 'privacy', 'secrecy', 'deception' and 'lies' arise repeatedly in research with people affected by donor conception when describing attitudes to disclosure and non-disclosure. Each of these terms carries with it particular moral connotations associated with the perceived desirability of disclosure or acceptability of non-disclosure. In particular, the term 'privacy' (with its connotations of justifiable constraints on information sharing) and the term 'secrecy' (with its implications of cover-up and intent to deceive) may be used by different people to justify or criticise the same decision not to disclose; and it may be very difficult to distinguish between what is legitimately private and what is inappropriately secret. It was suggested to the Working Party that one way of making this distinction was to define secrecy as "withholding information that is vital to a child's identity formation or well-being, hence causing detriment to the child".⁴²⁹ Such a definition, however, again takes as its starting point the vital importance of information about donor conception to donor-conceived people in all cases, which, as we have already noted, is a claim that is not

of one's own: parental stories (Oxford: Oxford University Press), in particular chapter 12, *Parental secrets in Thomas Hardy's The Mayor of Casterbridge*.

⁴²⁴ Smart C (2009) Family secrets: law and understandings of openness in everyday relationships *Journal of Social Policy* **38(4)**: 551-67, at 564.

⁴²⁵ Professor Marilyn Strathern, responding to the Working Party's call for evidence.

⁴²⁶ Factfinding meeting with researchers, 30 May 2010.

⁴²⁷ Factfinding meeting with prospective parent, 17 July 2012.

⁴²⁸ Professor Carol Smart and Dr Petra Nordqvist, The University of Manchester, responding to the Working Party's call for evidence.

⁴²⁹ Factfinding meeting with practitioners, 30 May 2012.

substantiated (see paragraph 5.8). A very different argument might also be made: that if a parent believes that there is ‘nothing to tell’ (see paragraph 4.9), then there is no ‘secrecy’ or ‘deception’ involved in not disclosing. However, this argument, too, cannot stand alone: just because the parent regards the information as ‘nothing’, this does not mean that their children would regard its value in the same way, if ever put in a position to make such a judgment.

- 5.30 The difficulties encountered in disentangling what (in the context of information about donor conception) may be rightly regarded as private, and what constitutes a secret from which the donor-conceived person is dishonestly or disrespectfully excluded, brings us back again to the central significance of relationships in donor conception. Information that a person is donor-conceived is indisputably information *about* that person; it is also, however, information *about* their legal parents, and potentially also *about* the donor if the information serves to identify them.⁴³⁰ Where treatment with donor gametes was sought because of infertility on the part of one or both of the legal parents, that information may be regarded as particularly sensitive personal information. Just as it would be wrong to dismiss the anger and distress of many donor-conceived people about the way information has been withheld from them just because not every donor-conceived person shares these views, it would also be wrong to downplay the extent to which, for some parents, personal information about the circumstances in which their children were conceived is deeply private.
- 5.31 Similarly, while UK donors are now recruited with a very clear understanding that identifying information about them will be shared, on request, with any resulting offspring at the age of 18 (and non-identifying information shared with the prospective parents even before treatment), donors recruited before 2005 donated on the clear understanding that identifying information would *not* be given out to anyone. Many of these may feel strongly that this personal information is private to them (see paragraph 4.57). As the different examples cited above demonstrate, the way in which information about donor conception may be regarded by a number of different parties as ‘their’ (personal) information relates both to the fact of donor conception (and in many cases the associated infertility) and to identifying information about the donor. *Non-identifying* information about the donor, on the other hand, may fall into a different class of information, in that it could potentially be shared with both parents and offspring without risk of the donor’s privacy being breached, although the increasingly fine line between ‘identifying’ and ‘non-identifying’ information should be noted (see paragraph 2.14).
- 5.32 Thus, information relating to donor conception may both be said to be personal (in many cases also regarded as private) information relating to each of the parties involved, and ‘interpersonal’ information, in that more than one person has a stake in it. Moreover the very nature of that information is that it is about relationships, or potential relationships: relationships created in the absence of biological connection, and the possibility of future relationships created in adulthood on the basis of that biological connection. Non-disclosure of information about oneself (by a parent, or by a donor) could be characterised as an action based on concern for privacy, while non-disclosure of information about the other (by a parent about their donor-conceived child) could equally well be characterised as secrecy or dishonesty. Neither can provide a decisive ethical guide to action, because the information is at one and the same time information about all of these people.
- 5.33 Rather than starting from the point that ‘openness’ in donor conception is intrinsically valuable, it is helpful to seek to identify more precisely what it is that an emphasis on openness seeks to promote. **The Working Party takes the view that openness to children about their means of conception is important in so far as it contributes to the quality of relationships within the family, and to the well-being both of parents and of donor-conceived people.** Thus, openness may or may not be beneficial, depending on the context. In many cases, openness

⁴³⁰ The way in which information may be both ‘personal’ and ‘shared’ is also recognised in data protection law: see Taylor M (2012) *Genetic data and the law* (Cambridge: Cambridge University Press).

within the family will undoubtedly contribute significantly to the well-being of family members and to the relationships between them. In some cases, however, openness about donor conception may potentially have the opposite effect, particularly where families created through donor conception come from communities where donor conception itself is not widely accepted, or where 'openness' more generally is not necessarily given the same value as it currently has in Euro-American societies.

The role of the environment

- 5.34 As we noted earlier (see, for example, paragraphs 1.27 to 1.29), the wider social and legal environment in which parents bring up their children exercises a substantial influence both on what is seen as acceptable, and what is, or should be, valued in family relationships. Research with donor-conceived families brings to light the concerns expressed in the early days of donor conception that the use of donor gametes, or indeed of any reproductive technology such as IVF, would be immoral or 'unnatural';⁴³¹ and such attitudes seem highly likely to have influenced both past professional advice to parents not to tell anyone about their treatment, and parents' own levels of comfort with the way in which they created their family. The extent to which the use of donor gametes is regarded as an acceptable way of creating a family (a key factor influencing the extent to which it will, in practice, be feasible for families to be open if they wish) continues to vary considerably between and within communities (see paragraphs 4.33 and 4.40). Stigma is still widely associated with infertility, especially male infertility.
- 5.35 As the significant shift in professional and legal attitudes to questions of openness and information sharing in donor conception has demonstrated, this wider social 'environment' in which parental decisions are made can, and does, change. Technological developments enabling the easier sharing of information, and also potentially contributing to inadvertent discovery of genetic discontinuity between parent and child, also have the capacity to change the basis on which parents make decisions about withholding or sharing information (see paragraph 2.14). While, as we noted earlier, the influences behind the shift in attitudes over the past 20 years in the UK are multiple and complex (see paragraph 2.20), we highlight here the potential role that the state may play in this area. While it is not, in the view of the Working Party, the role of the state actively to challenge the views of individuals or faith communities with respect to the acceptability of donor conception, the state does have a potential role in promoting an environment in which negative views about particular family forms *can* be challenged, and where an acceptance of diversity is encouraged. We return to this point in paragraphs 5.66 to 5.71 below.

Weighing interests

- 5.36 Earlier in this chapter, we identified many of the interests that those concerned with donor conception have in connection with information disclosure – whether information about the use of donor gametes in conception, non-identifying information about the donor, or identifying information that would make it possible for a donor-conceived person to make contact, and potentially form a relationship, with their donor. We have based this analysis on what people with personal experience of donor conception have told us about what matters to them, and on the research evidence reviewed in Chapter 4. It is clear that these interests overlap and may, in specific cases, either coincide or conflict. This is unsurprising, given that the use of donor gametes creates a complex and interwoven network or web of actual and potential relationships.
- 5.37 We have already highlighted the wide variety of experiences and attitudes to the significance of information about biological connections. A further point to note is that the summary of interests above does not (and indeed, could not) include the views of those who are donor-conceived but

⁴³¹ See, for example, Golombok S, Brewaeys A, Cook R *et al.* (1996) The European study of assisted reproduction families: family functioning and child development *Human Reproduction* **11**(10): 2324-31.

do not know. From what the Working Party learned from people who found out that they were donor-conceived later in life or in adverse circumstances, it is clear that such inadvertent disclosure or discovery may have harmful long-term consequences. However, whether it is better to know or not know (and never find out) is a different question that cannot be answered on the basis of these testimonies (see paragraph 5.9). The Working Party was struck by the fact that at one meeting with a group of people with personal experience of donor conception, the donor-conceived people present did not feel it was harmful *never* to find out one's origins (emphasising, rather, the harm of inadvertent disclosure or discovery); these attitudes contrasted with those of many of the recipient parents in the same meeting, who felt strongly that non-disclosure itself constituted a wrong.⁴³² They were not, however, shared by other donor-conceived people who contributed to the Working Party's deliberations, who took the view that non-disclosure was inherently harmful.⁴³³

- 5.38 When the interests in question coincide, it is possible, in principle, to handle issues relating to information disclosure in a way that satisfies the interests of all those concerned. For instance, when parents of donor-conceived children regard openness about donor conception as an important basis for a trusting relationship with their children, difficult questions may still arise with regard to the practicalities as to when and how to tell, but a clear basis exists for resolving these issues in a way that serves the interests of all members of the family. Similarly, if donors and the people born from their donated gametes have the same wishes with regard to possible contact, this may still be a sensitive matter and a potential ground for both illusions and disillusion, but in such cases there is, at least, a basis for having the interests of both parties satisfied. However, it is clear that in other cases the interests in question may conflict. If, for example, the donor does not want to engage in the kind of contact the donor-conceived person very much desires, the interests of the latter will be frustrated. Where interests conflict, it will not be possible to satisfy both.
- 5.39 Here we come to the heart of the problem: how to handle questions relating to information sharing, and in particular relating to disclosure of the use of donor gametes, if there is no way in which this can be done without frustrating the interests of one of the parties. This problem is exacerbated by the fact that the competing interests differ in kind: interests at stake including what might be described as 'identity' interests, privacy interests and (in the exceptional cases where medical information will significantly affect health care) medical interests. One view that was put to the Working Party was that the only way of dealing with these conflicts is always to prioritise the interests of donor-conceived individuals, regarding these as 'paramount', in the same way that courts regard the welfare of children as 'paramount' when called upon to make decisions about their upbringing or future.⁴³⁴ Arguments for this position include the fact that, without ever being asked for their own views, donor-conceived people find themselves facing the potentially far-reaching implications of their parents' decisions; and the belief that donor-conceived people are the ones most affected.⁴³⁵ An alternative view recommends that it should be the interests of prospective and then actual parents that should be prioritised, as without their (successful) use of donor gametes, subsequent individuals would not exist in the first place.⁴³⁶

⁴³² Factfinding meetings with people with personal experience of donation, 27 April 2012.

⁴³³ Factfinding meeting with Rachel Pepa, 24 April 2012; factfinding meeting with Christine Whipp, 16 July 2012.

⁴³⁴ See, for example, the response to the Working Party's evidence call from PROGAR (Project Group on Assisted Reproduction, British Association of Social Workers). See also the use of this principle of 'paramountcy' in the Australian state of Victoria: Parliament of Victoria Law Reform Committee (2012) *Inquiry into access by donor-conceived people to information about donors: final report*, available at: http://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/DCP_Final_Report.pdf.

⁴³⁵ Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: <http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering>.

⁴³⁶ Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing - summary of call for evidence*, available at: <http://www.nuffieldbioethics.org/donor-conception/donor-conception-evidence-gathering>.

- 5.40 We return here to the fact that a key feature of reproduction in general, and the use of donor conception in particular, is the creation of connections and relationships between people. Against this backdrop, the Working Party takes the view that there is no one right place to start when analysing these conflicts of interest; and in particular that the interests of one party to a relationship should not, as a matter of principle, automatically take precedence over any others.⁴³⁷ Accordingly, the interests of different parties always have to be weighed. The question then arises as to *how* such a process of weighing interests may be undertaken and, very importantly from a policy perspective, *who* could or should be responsible for undertaking it. We have suggested above that some degree of autonomy in family life, of being free to make decisions about what is right for one's own family, is objectively important for the well-being of both parents and their offspring (see paragraph 5.14). In the case of decisions relating to disclosure of the use of donor gametes, such 'family' autonomy must be understood as 'parental' autonomy, given that, by definition at this point, parents are in control of what their children know. The notion of 'weighing' interests may imply a neutral third party making a judgment, and parents clearly are not 'neutral', in that their own interests, as well as those of their children, are at stake. Yet the idea of a third party, such as a health or social care professional (whether acting in accordance with a professionally-agreed code of practice, or mandated via state regulation) being responsible for determining whose interests should prevail in a particular case, suggests a degree of external intrusion into family life that is regarded as unacceptable in almost all other circumstances.
- 5.41 The way in which we respond to this conundrum depends on how we conceptualise the roles and responsibilities of those concerned. Below, we consider first the responsibilities that arise, on a personal level, within the various relationships created through the use of donor gametes in conception, noting how these are inherently reciprocal by nature of the fact that they arise in relationships. We then go on to consider the responsibilities of third parties connected with donor conception: the professional responsibilities of the professionals who help create donor-conceived families; and the responsibilities of the state both in its role as regulator of assisted reproduction and in its wider functions.

Reciprocal responsibilities within relationships

Responsibilities of parents to their donor-conceived child

Responsibilities to future children

- 5.42 It is generally agreed that parents have a moral responsibility to promote the well-being of their children. Having that responsibility is part of what it means to be in a parental role. At the outset, since at one point in time there are only prospective parents and prospective children, the strength of parents' obligations to tell children about their means of conception needs to be considered in relation to the ethical debate about responsible reproduction. Are there any circumstances where prospective parents who know at the time they are considering treatment that they will be unable or unlikely to disclose the use of donor gametes to any resulting child ought, ethically, to refrain from seeking treatment altogether?
- 5.43 The key issue at stake here is the nature and extent of the harm that might result from having children in these circumstances.⁴³⁸ There is considerable ethical and legal discussion as to what

⁴³⁷ We note here, that while 'paramountcy' has a role in the Children Act when judicial decisions affecting a child's welfare are required, on an ethical (and even legal) level there can be no expectation that parents should completely sacrifice their interests when these compete with their children's. Indeed, any such requirement to treat one child's interests always as paramount would be impossible for parents with more than one child. We also note that such a principle is not helpful in determining the competing interests of adults: see Chisholm R (2012) Information rights and donor conception: lessons from adoption? *Journal of Law & Medicine* **19**(4): 722-41.

⁴³⁸ Some would argue that a preliminary question is whether for children born to parents not committed to openness, a different life (one with disclosing parents) would have been possible at all. If not, then it could be argued that creating any life, other than a 'life not worth living at all' is a morally acceptable outcome of fertility treatment, an argument we consider further in paragraph 5.58. Where a 'different life' *would* be possible (i.e. where the parents could, in fact, choose to

degree of harm to prospective children might be considered to be sufficiently serious to trigger action by third parties, and we consider this later as we discuss the possible role of professionals or the state in controlling or restricting access to treatment services in such cases (see paragraphs 5.56 to 5.62). However, we return here to the evidence that we have reviewed in Chapter 4, where we saw that families in which parents choose not to disclose to their offspring that they are donor-conceived have been found to function well into early adolescence although much less is known about families with older offspring (see paragraphs 4.29 to 4.32). Harms may potentially arise if donor-conceived people find out late, or inadvertently, although from the limited survey data available it would appear that in many cases initial negative reactions will fade over time (see paragraph 4.14); moreover, we have no way of knowing how often in practice such inadvertent disclosure or discovery arises. We do not underestimate the distress experienced by some donor-conceived offspring whose parents have chosen not to be open with them about their use of donor gametes, and who later feel betrayed. However, based on the evidence, it does not appear that the level of this risk, or the extent of the potential harm, is so great that prospective parents could be held to be acting wrongly if they seek treatment with donor gametes without being sure that they can commit in advance to openness. While we recognise that the evidence in this area (particularly with respect to families with older donor-conceived children) is still limited, and that the risks of inadvertent disclosure or discovery may potentially increase as a result of technological and social developments (see paragraphs 1.27 to 1.30), nevertheless we suggest that much clearer proof of likely harm would be required to justify the claim that parents act intrinsically wrongly in creating a family without being able to commit in advance to openness about the means used to conceive.

- 5.44 We need now to move beyond discussion of the circumstances in which prospective parents might be held to be acting wrongly or irresponsibly in having children in the first place, and consider the separate question of how those children are cared for after birth. That is, in the light of the above discussion, our primary concern in relation to parents' responsibilities towards their donor-conceived children relates to how extensive these responsibilities may be to an actual, rather than prospective, child. Such responsibilities arise primarily after birth, in their care of the child; however, as we note below, responsibilities may also arise in the way that parents prepare for parenthood, once they have made the decision to create a family with donor gametes.

Responsibilities to children

- 5.45 After a child has been born, we suggest that parents have obligations to do their best to promote the welfare and personal development of their children in a way that will enable them, so far as parents can reasonably achieve this, to grow into autonomous, considerate and responsible adults with a high degree of well-being. In doing so, parents are also entitled to take account of their own interests, and those of others for whom they have responsibility such as dependent relatives. We consider that most people would broadly agree with this approach.
- 5.46 In the course of parenting, particular obligations may arise in particular circumstances. The Working Party takes the view that, in the light of the evidence reviewed in Chapter 4, the parents of donor-conceived children have a moral responsibility to avoid, where reasonably possible, any harmful consequences that may follow for their children from the fact that they were donor-conceived. We argued above that the possibility of harm arising from inadvertent disclosure or discovery is not sufficient to justify the conclusion that parents act wrongly if they use donor gametes without committing to openness in advance. However, there *is* sufficient

disclose), then the possibility of this 'alternative life' becomes relevant: the responsibilities of parents once a child has been born and questions of disclosure become 'real' are discussed in paragraphs 5.45 to 5.49. The Working Party encountered one example where parents actively delayed treatment with donor gametes until the change in the law with respect to anonymity, thus ensuring a 'different life' (one with access to information about the donor) would be possible for their child: Factfinding meetings with people with person experience of donor conception, 27 April 2012.

evidence to point to the conclusion that, **other things being equal, it will usually be better for children to be told, by their parents and at any early age, that they are donor-conceived** (see paragraph 4.61). In not telling their children early on, parents not only run the risk of harm arising from later disclosure in adverse circumstances; they also lose the opportunity of using disclosure as a positive means of affirming their decision to create a family using donor conception and helping their child absorb their origins into their personal narrative. Moreover, many of the reasons parents give for not disclosing, in particular concerns about negative impacts both on their child and on family relationships, have been demonstrated to be unfounded (see paragraphs 4.31, 4.32, 4.42 and 4.43). We noted above that, in practice, it will almost inevitably be parents who undertake the 'weighing of interests' involved in making decisions about disclosure, despite the fact that they cannot be a neutral party in this decision, and are in a position of power in relation to their offspring with respect to the information they hold. Such power has to be exercised responsibly.

- 5.47 **The Working Party takes the view that the parents of donor-conceived children thus have a responsibility to give careful consideration to the question as to whether or not they should be open with their children about how they were conceived. In particular, we suggest that this responsibility includes a willingness both to take account of the evidence available, and to engage as necessary with professional support, when determining what is best in their particular circumstances.** In suggesting such a responsibility (moral not legal) on the part of parents, we note that this must be matched by parallel responsibilities on the part of the state and professionals as to the level of support available and the manner in which that support is provided (see paragraphs 5.64 and 5.70).
- 5.48 However, it does not necessarily follow from the above discussion that it is never justifiable to withhold knowledge from children about the use of donor gametes. In some cases, parents may have strong reasons for not telling that may override the initial presumptions that such openness is likely to promote their child's welfare. For instance, the Working Party heard anxieties from some religious and cultural perspectives as to the potential for very negative reactions to the use of donor gametes in reproduction (see paragraphs 4.34 to 4.40). In such circumstances, openness may lead to stigmatisation within the parents' community, so that parents may feel that the hazards – both for themselves *and* for their children – of disclosure may be much greater than those of non-disclosure. In such cases, there may well be a *coincidence of interest* in not disclosing early, in that the parents' concerns are to avoid harm to their family unit as a whole. It is, however, important to acknowledge that concerns about the stigmatisation of infertility or the fear of social disapproval of the use of donor gametes, may arise or not in a variety of circumstances, and that social pressures or expectations are not homogenous within particular communities. Parents, regardless of their social or cultural background, will need to consider their own specific situation in making their decisions about disclosure.
- 5.49 Some parents may thus find that they have strong reasons for not telling their children that they were conceived using donor gametes. For instance, they may be concerned about the impact of such disclosure both on their children's welfare, and on the welfare of the family unit as a whole. In other cases, parents who have had a long and painful struggle with fertility issues may feel that their fertility problems are a private matter, and that they have a justifiable interest in protecting these from the scrutiny of others. Where these privacy concerns on the part of the parents, as opposed to concerns about the welfare of the child or the family unit as a whole, constitute the main reason for non-disclosure, the interests of the parents and offspring may no longer coincide, and the challenge of weighing competing (and potentially incommensurable), interests arises.
- 5.50 Since, as we have argued, disclosure is in most cases likely to be the best option for the child, parents have a responsibility to consider whether any reasons they may have for not telling are significant enough, in their circumstances, to justify non-disclosure. Some of those who decide not to disclose do so from a fear of consequences that may turn out to be unfounded: indeed, the available evidence suggests that almost all who eventually decide to disclose are glad that they did so (see paragraph 4.42). This suggests that there is a potential role for professionals in helping and supporting parents to overcome any fears that may stand in the way of choosing

what in many cases may be the best option for themselves and their child. Ultimately, however, making such decisions is an inherent part of the parental role, and indeed only parents will usually know enough about their own family situation to judge what they, in their particular circumstances, should do with respect to disclosure. Only in very exceptional cases, where there is reason to fear the child might suffer significant harm, may third party intervention be justified in such decision-making. We return in Chapter 6 to consider the exceptional circumstances in which such harm might arise (see paragraphs 6.24 and 6.50). We also consider below the role of the state in promoting and encouraging an environment where parents who want to disclose feel able to do so without fears of negative consequences either for themselves or for their children (see paragraphs 5.70 and 5.71).

Responsibilities that arise as a recipient to a donor

- 5.51 Donation of gametes is frequently described as a gift, with donors ultimately giving the ‘gift of life’. It is not surprising, given what is known about the compulsion to reciprocate a gift, that people should consider ‘repayment’ in some way. However it is also the case in the UK that there has been a general reluctance to commodify body parts: it is often argued that human biological materials such as blood and organs should be kept out of the market, and that in the context of bodily material altruistic gifts, without expectation of remuneration, are preferable. The Council’s earlier report on *Human bodies* highlighted a more mixed response to donated bodily material with some people arguing that payment in these circumstances was also ethically appropriate. Nonetheless, as in the findings of that report, the gift is a powerful image in the discussion of donated gametes and surrogacy. In donated gametes the gift can also signify a complete handover of bodily material with no further claim or expectation of reciprocity, or it can signify an ongoing relationship whereby return is expected, albeit not necessarily directly. As one donor wrote: “A huge thank you to the wonderful lady who has donated her eggs to help us start a family. I’ll never know you but your generosity is something I can only aim to match in the future. You have given us a true gift.”⁴³⁹ In this case, the recipient aims to ‘match’ the donor’s generosity in some way in the future.
- 5.52 Another less predictable way of reciprocating the gift of donation was presented to the Working Party in terms of the *responsibilities* a recipient may owe to their donor. It was noted that the way in which the recipient told their offspring of the facts of their conception, or the way in which they talked about the donor, would impact on how the donor-conceived person perceived the facts of their conception, which would in turn impact on how they perceived the donor. This might have implications for how the donor-conceived person related to the donor in the event of later contact. This was described to us in two ways: first, that failure to disclose was not fair to donors given the possibility of inadvertent disclosure and later contact; second, that if the donor-conceived person were told badly, then they might be angry with, or resentful of, the donor – which again would be unfair to the donor. The Working Party agrees that, in accepting eggs or sperm from a donor, whether known or unknown, recipients thereby incur a responsibility towards that donor to ensure that their gift does not later rebound on them. Such a responsibility would require, in particular, that recipient parents include the donor’s interests as one of the factors to be taken into account in their considerations about disclosure, and that they act to minimise the risk of any possible future harm arising for the donor as a result of their donation.

Responsibilities that arise as a donor (to donor-conceived offspring, recipients and the donor’s own family)

- 5.53 In donating gametes in the knowledge that such donation may lead to the creation of a future person, donors have a responsibility to think carefully about the consequences: for themselves and their own families; for the recipients of the donated gametes; and for the resulting person.

⁴³⁹ Metro (22 May 2012) *Good deed feed*, available at: <http://e-edition.metro.co.uk/2012/05/22/15.html>.

While some of donors' responsibilities to recipients and future offspring might be held to be discharged through the practice of donating through a licensed clinic, with the associated protections, we suggest that donors themselves, in choosing to donate, nevertheless incur a number of responsibilities that cannot be discharged by others: for example the responsibility of participating frankly and honestly in the medical screening procedure; of giving serious consideration to the way they provide information about themselves and their motivations for both recipients and future resulting people to read; and of giving due consideration to the possibility of future contact. We discuss further in Chapter 6 the extent of these responsibilities, including the possibility of providing additional information at a later stage in the rare cases where serious medical information of relevance to the donor-conceived person emerges after donation (see paragraphs 6.63 to 6.66). In recognising these responsibilities, however, we reiterate that the fundamental premise of donor conception is that the recipients of donated gametes will become the true and only parents of the resulting child, and that the only circumstances in which donors should be considered to have ongoing responsibilities during the childhood of the person resulting from the donation (with the exception of the rare medical cases cited above) is where such responsibility forms part of the agreement with the recipients. In some such cases, indeed, it may be more appropriate to refer to a 'co-parent' rather than a 'donor' (see paragraph 2.4).⁴⁴⁰

- 5.54 In choosing to donate, donors also have a responsibility towards their own families, in particular (where applicable) their partner and their children. We have noted earlier the potential impact, both positive and negative, that identity-release donation may have on the donor's own family, whether contact is made with the donor-conceived person and their family during childhood, or not until adulthood (see paragraphs 4.53 to 4.58). Just as prospective parents have a responsibility to give careful consideration to the question of whether or not they should tell their children they are donor-conceived (see paragraph 5.47), potential donors have a responsibility to take account of the potential impact of donation on their own close family members, including the possibility that any future contact may affect a future partner and as-yet unborn children.

Responsibilities as donor-conceived person: to parents and donor

- 5.55 Donor-conceived people, unlike both their parents and their donor, did not have any choice at all in connection with decisions about the use of donor gametes in conception. Nevertheless, it could be argued that they, like all offspring, have responsibilities towards their parents, and just as particular parental obligations arise in particular circumstances, so may particular obligations arise for donor-conceived people. We recognise that those who find out late, or inadvertently, that they were donor-conceived may feel distressed and angry that their parents have not been open with them (see paragraph 4.14), and that, in such circumstances, the use of donor gametes may cause strong feelings within families. Nevertheless, we suggest that donor-conceived people have a responsibility, commensurate with their age and understanding, to do their best to understand the reasons why their parents chose to create a family through treatment with donated gametes, and why they made the decisions they did about disclosure: in short to be aware that parents, too, may be vulnerable. Just as we suggest that parents' responsibilities to take account of their disclosure decisions on the well-being of their children are matched by responsibilities on the part of professionals and the state to ensure that support is available, support should also be available, where necessary, to help donor-conceived people understand the facts of their donor conception from the perspective of the other actors involved (see paragraph 6.34). Similarly, we suggest that, if seeking contact with their donor, donor-conceived adults have a responsibility to consider the impact on others and to be sensitive in their approach; and that, in turn, they should be able to turn to external sources of support to help them in what may be a difficult and emotional process (see paragraph 6.38).

⁴⁴⁰ For a contrary view on the responsibilities of donors, see: Benatar D (1999) The unbearable lightness of bringing into being *Journal of Applied Philosophy* **16**(2): 173-80.

Responsibilities of third parties

The role of professionals and fertility clinics

- 5.56 We have discussed above the moral responsibilities that may arise for each of the parties directly involved in donor conception. A separate question then arises as to the possible role of third parties in ‘intervening’ in connection with these responsibilities, with the aim of preventing or limiting harm to those who are potentially vulnerable, particularly children. Before discussing the role of the state (whose role in intervening to protect the welfare of children is well-established), we point to the special role that clinics and professionals have in this context. We note, however that these two roles may in practice be interrelated: that depending on the regulatory framework established in any particular country, the responsibilities of professionals may be guided entirely by professional codes of practice and ethics or may, additionally, be subject to specific requirements set down by law. Thus, in the UK, professionals working in the fertility field are bound to act in accordance with statutory requirements and, in particular, with the statutory *Code of practice* published by the HFEA.⁴⁴¹ Hence their actions are guided by dual (if in practice generally overlapping) requirements: to act in accordance with their professional responsibilities, and additionally to act, where necessary, to ensure that the requirements specified by the state are met.⁴⁴²
- 5.57 Clinics and professionals who provide fertility treatment services involving the use of donor gametes, embryos or surrogacy are not only providing ‘medical treatment’ to the ‘patient’ in front of them: they are causally and intentionally involved in creating a child. It is widely accepted that it is therefore part of their professional responsibility to take into account the welfare of the child who would not exist but for their help (see paragraph 5.61). This means that there may come a point where professionals should not provide the reproductive assistance requested. However, there is less consensus about *when* this should be the case.⁴⁴³ For our discussion, the question is whether professionals should refuse treatment to patients who are not fully committed in advance to openness.
- 5.58 According to one relatively mainstream ethical view, professionals should refuse fertility treatment only in the very rare cases where the resulting child would have a life that was so miserable that any reasonable person would rather not have existed at all. This is sometimes called the ‘wrongful life standard’.⁴⁴⁴ It is based on the argument that, excluding the rare cases of a truly miserable life, a child cannot be harmed by being brought into the only existence he or she could possibly have.⁴⁴⁵ We note that some donor-conceived individuals have indeed asserted that it would be better for prospective parents not to have children at all, than to use

⁴⁴¹ The HFEA includes lay as well as professional membership, and the statutory requirements set out in the HFE Acts derive from parliamentary consideration of wider public concerns regarding assisted reproduction/use of donor gametes, and hence again are not limited to, although clearly overlap with, considerations of professional responsibility.

⁴⁴² Practice may vary considerably between clinics and professionals, despite the fact that they are operating under the same regulatory regime and guidance. See, for example, in a related context, how professionals draw on their own social and ethical perspectives when following professional guidelines in order to classify embryos as ‘spare’: Ehrlich K, Williams C, and Farsides B (2010) Fresh or frozen? Classifying ‘spare’ embryos for donation to human embryonic stem cell research *Social Science & Medicine* 71(12): 2204-11. However, the HFEA *Code of practice* acts to constrain some aspects of professionals’ discretion in making judgments based on their own values, for example by specifying that “staff at the centre must not unlawfully discriminate against patients or donors by allowing their personal views to affect adversely the professional relationship with them, or the treatment they provide or arrange”: Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 29.7.

⁴⁴³ Pennings G (1999) Measuring the welfare of the child: in search of the appropriate evaluation principle *Human Reproduction* 14(5): 1146-50.

⁴⁴⁴ See, for example, Buchanan A, Brock D, Daniels N, and Wikler D (2000) *From chance to choice: genetics and justice* (Cambridge: Cambridge University Press), at page 235.

⁴⁴⁵ With regard to our discussion, this argument is primarily relevant only to cases where prospective parents really have no option at all of disclosing to their child the means of his or her conception. Where the parental decision not to tell is susceptible to change, the alternative to ‘life with non-disclosing parents’ is not non-existence but rather life with ‘disclosing’ parents.

donated gametes to conceive.⁴⁴⁶ Based on the evidence, however, it is fair to say that this is not a typical perspective on the impact of being donor-conceived. Indeed, the kinds of circumstances that are thought to give rise to a serious risk of a life that an individual would think not worth living are very rare, and typically associated, for example, with the most rare, painful and disabling forms of disease. So we may conclude that in cases where the reasoning behind the wrongful life standard applies, this standard does not lead to the conclusion that professionals should refrain from offering fertility treatment with donor gametes to prospective parents who do not intend to tell.

5.59 The ‘wrongful life’ standard has been criticised as expressing a too minimal understanding of both parental and professional responsibility.⁴⁴⁷ In its guidance for professionals, the European Society of Human Reproduction and Embryology (ESHRE) has proposed instead the “reasonable welfare” standard, according to which the criterion for ethically acceptable (assisted) reproduction is the absence of “a high risk of serious harm”, where “serious harm” is taken to refer to a seriously diminished quality of life, regardless of whether for this particular child a better life would have been possible.⁴⁴⁸ In the UK, the HFEA similarly interprets the legal requirement that clinics should take account of the welfare of any resulting child by requiring them to “consider factors that are likely to cause a risk of significant harm or neglect” to a future child.⁴⁴⁹ Again we do not consider that the evidence reviewed in Chapter 4 demonstrates that there is a ‘high’ risk of ‘serious’ or ‘significant’ harm to offspring whose parents choose not to be open about their use of donated gametes in their conception. So we may conclude that on the standards followed by ESHRE and the HFEA, there are also no grounds for saying that professionals should not provide fertility treatment involving the use of donor gametes to those not committed to disclosure.

5.60 In the debate about assisted reproduction, some seem to adhere to a third standard, according to which reproduction is only acceptable if it can be expected that the child will have an optimal life.⁴⁵⁰ This ‘maximum welfare’ standard entails using the same criteria that are also used in the context of adoption, where the only consideration is the need to find the best possible home for a particular child who has already been born. However, it is hard to justify third party intervention to prevent prospective parents from choosing to reproduce where their children cannot grow up in the best possible circumstances. Such a claim would imply, for instance, that parents should be prevented from having children when they are poor, or when one of the parents is ill or disabled, or when an existing child is ill or disabled (so that the parents may have to put extra time into caring for another child). As it is generally not considered morally irresponsible for parents in these circumstances to have children, it would be discriminatory to use this standard to refuse fertility treatment to those who cannot reproduce naturally.⁴⁵¹

⁴⁴⁶ See, for example, TangledWebsUK (2013) *Why we believe donor conception is harmful*, available at: <http://www.tangledwebs.org.uk/tw/WhyWrong/>.

⁴⁴⁷ See, for example, Steinbock B, and McClamrock R (1994) When is birth unfair to the child? *Hastings Center Report* **24(6)**: 15-21, where a principle of “parental responsibility” is suggested, under which it is not morally acceptable to have a child unless it can be given “a decent chance of a happy life” (pp17-8), since “bringing children into existence under very adverse conditions is unfair to the children themselves” (at page 19).

⁴⁴⁸ Pennings G, De Wert G, Shenfield F *et al.* (2007) ESHRE Task Force on Ethics and Law 13: the welfare of the child in medically assisted reproduction *Human Reproduction* **22(10)**: 2585-8.

⁴⁴⁹ Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, at paragraph 8.10.

⁴⁵⁰ See Pennings G (1999) Measuring the welfare of the child: in search of the appropriate evaluation principle *Human Reproduction* **14(5)**: 1146-50 for a discussion of all three standards. Recent analysis compatible with the idea of a “maximum welfare standard” can also be found in Savulescu J (2001) Procreative beneficence: why we should select the best children *Bioethics* **15(5-6)**: 413-26. As our analysis demonstrates, we reject an argument to the effect that parents have a duty, when making reproductive decisions, to ‘maximise’ the interests of their future children, or to select ‘the best possible child’, as put forward in Savulescu. For criticism of Savulescu’s approach see, for example, Glover J (2006) *Choosing children: genes, disability and design* (Oxford: Oxford University Press) at page 54, and Scott R (2007) Why parents have no duty to select ‘the best’ children *Clinical Ethics* **2(3)**: 149-54.

⁴⁵¹ We note that refusal by professionals to provide treatment differs in some respects from active ‘third party intervention’ in family life, as found, for example, in child protection measures. However, given that such treatment is licensed and made available to the public as a whole through state regulation, prospective parents are highly likely to perceive any such refusal of treatment as ‘intervention’ in their desire to create a family.

- 5.61 Indeed, the argument has been made that the whole idea that third parties (whether acting in accordance with professional norms or in order to implement statutory requirements) should be able to intervene in the reproductive choices of others is inherently discriminatory: how can such intervention be justified in the case of those needing assistance to conceive, when it would be seen as unacceptably intrusive to intervene with the reproductive choices of those able to conceive without assistance?⁴⁵² In response to arguments such as these, the HFEA has tightened its interpretation of the ‘welfare’ clause in order to make it clear that clinics may only refuse treatment in the most serious of circumstances: the examples of “risk of significant harm or neglect” being cited in the latest *Code of practice* include such circumstances as previous convictions involving children, child protection measures taken regarding existing children, or a history of family violence, along with circumstances (such as serious ill-health or addiction) that are likely to lead to the parent being unable to care for the child throughout childhood.⁴⁵³ The rationale for including *some* form of ‘welfare’ provision within the Human Fertilisation and Embryology Act, however, is defended on the grounds that, where third party involvement is required in reproduction, there is a duty on those providing that assistance to consider the longer-term implications.⁴⁵⁴
- 5.62 The Working Party takes the view that it *is* acceptable for third parties (in this case both the professionals involved in assisted reproduction and the regulator, under whose guidelines professionals must operate) to take account of the welfare of any future child in providing treatment services, whether or not donor gametes are also used in treatment. However, the standard used in making such welfare judgments is clearly crucial and will have a direct bearing on how rarely, or otherwise, the welfare of the future child will be of legitimate concern to third parties. **We believe that the HFEA has taken the right approach in focusing on factors that are “likely to cause a risk of significant harm or neglect” to future children, a standard of harm that is likely only rarely to be fulfilled, and reiterate that we do not believe that a failure to disclose to offspring that they are donor-conceived should be regarded as constituting such a risk.** A policy decision to deny treatment to prospective parents on these grounds could only be justified by evidence that children born in such circumstances are indeed likely to suffer serious harm. As we have discussed in Chapter 4, the evidence does not bear out this claim, notwithstanding the distress and difficulties that some individuals have undoubtedly experienced.
- 5.63 As we stressed above, clinics and professionals who provide treatment services involving the use of donor gametes, embryos or surrogacy are not simply providing ‘medical treatment’ to the ‘patient’ in front of them: they are causally and intentionally involved in creating a child. In addition to what has been said above about the responsibility to take account of the welfare of the child before providing treatment, it is therefore part of their professional responsibility to take into account the prospective parents’ need for information and support not only in connection with the clinical procedures involved, but also in connection with the bigger picture of what is being undertaken. Such a professional responsibility is particularly important given the asymmetry of knowledge that inevitably exists between clinics and patients, particularly when patients are first contemplating treatment; and in the light of the potentially conflicting interests (financial interests, reputational interests and so forth) that clinics may have in the way they run services, recruit donors, and provide options to patients.

⁴⁵² Jackson E (2002) Conception and the irrelevance of the welfare principle *The Modern Law Review* **65(2)**: 176-203.

⁴⁵³ Human Fertilisation and Embryology Authority (2011) *Code of practice 8th edition*, available at: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf, guidance note 8. Compare with guidance in earlier versions of the *Code of practice*: for example in the sixth edition, factors to be taken into account included “the commitment to raise children” and “the ability to provide a stable and supportive environment for a child/children”. See: Human Fertilisation and Embryology Authority (2003) *Code of practice 6th edition*, available at: http://www.hfea.gov.uk/docs/Code_of_Practice_Sixth_Edition.pdf, at paragraph 3.12.

⁴⁵⁴ See, for example, the views of professionals expressed in Lee E, Macvarish J and Sheldon S (2012) *Assessing child welfare under the Human Fertilisation and Embryology Act: the new law* (Canterbury: University of Kent), available at: http://blogs.kent.ac.uk/parentingculturestudies/files/2012/06/Summary_Assessing-Child-Welfare-final.pdf.

- 5.64 One way in which clinics currently meet this professional obligation is through the provision (or offer) of pre-treatment counselling sessions to enable prospective parents to consider the implications of their treatment options. As part of this, prospective parents should have the opportunity to express their thoughts and concerns about disclosure, find out about the research evidence available on disclosure (demonstrating that many of the anxieties of parents about disclosure have been shown to be unfounded), and explore the risk of inadvertent disclosure or discovery and the related potential for harm. They should be aware that it may not be possible to ensure that their child will never find out about their means of conception, and that a decision not to disclose necessarily entails both the risk of possible later harm from inadvertent discovery, and also the lost opportunity to use early disclosure as a positive way of affirming their decision to create a family using donor conception and helping their child absorb their origins into their personal narrative (see paragraph 5.46). However, it should also be acknowledged that parents may have other reasons that, for them, are more weighty, such as (but not limited to) the impact of a stigmatising environment. The proper outcome of such pre-treatment counselling is that prospective parents should be supported in making a decision that is truly their own, in the light of the best evidence available, and after taking the opportunity to explore their own situation and concerns with a person who is both well-informed and non-judgmental.
- 5.65 Clinics also have a responsibility both to recipients (and indirectly through them to future donor-conceived people) and to donors, in their role of 'information collector/information provider'. As we discussed earlier in the particular context of medical information, the only information about the donor potentially available to recipients and donor-conceived people under the age of 18 is that provided on the donor information form (see paragraph 3.21). The approach that clinic staff take to the importance of the information thus provided is likely to influence how donors regard this task, and how much trouble is taken in fulfilling it. We return to the question of the role of clinics in supporting donors, both in thinking through their intention to donate and in providing information about themselves, in Chapter 6 (see paragraphs 6.63 and 6.64).

The role of the state: the stewardship model

- 5.66 We have discussed above the role of third parties in intervening in the reproductive decisions of others: in practice these third parties are the health professionals working in fertility clinics. Depending on the regulatory system in place, the actions of such professionals may be guided entirely by their own professional standards and codes of conduct, or they may also be subject to additional regulatory guidance mandated by the state. Thus, in the UK, this area is governed by the Human Fertilisation and Embryology Act 1990 (as amended by the Human Fertilisation and Embryology Act 2008), and the HFEA is tasked with key regulatory functions (see paragraph 1.7).
- 5.67 However, whether or not the *regulatory* role with respect to the governance of assisted reproduction services is exercised by professional organisations or by bodies established for the purpose by the state, states also potentially have a wider role with respect to donor conception and the support of families created through donor conception. The nature and extent of this role depends on rather wider considerations of the proper role of the state. The Nuffield Council, in its earlier report *Public health: ethical issues*, presented what it described as a 'stewardship model' of the state, distinguishing such a model both from a *laissez-faire* libertarian approach to state responsibilities, and from an overly-intrusive 'nanny state':

"The concept of stewardship means that liberal states have responsibilities to look after important needs of people both individually and collectively. Therefore, they are stewards both to individual people, taking account of different needs arising from factors such as age, gender, ethnic background or socio-economic status, and to the population as a whole... In our view, the notion of stewardship gives

expression to the obligation on states to seek to provide conditions that allow people to be healthy, especially in relation to reducing health inequalities.”⁴⁵⁵

A key aspect of the role of the ‘stewardship’ state is thus to *facilitate* what are seen as beneficial behaviours: to ‘provide conditions’, whether physical or social, that help and enable people in making their choices, while avoiding active intrusion in those choices unless there is very strong evidence to justify such intrusion for the benefit of others.

- 5.68 The Council advocated this stewardship model of the state initially in the context of the state’s public health duties, and, in a modified form, in the context of promoting the donation of bodily materials to benefit others.⁴⁵⁶ We suggest here that this concept of the state, which explicitly recognises the ‘important needs’ of both individuals and people collectively with respect to their health, and emphasises the role of the state in ‘providing conditions’ that promote healthy behaviour, may also provide a helpful guide in considering what role the state ought to play with respect to the regulation of donor conception services and the associated questions of information collection, retention and disclosure. While we have concluded above that neither the state (in its regulatory role), nor professionals, are justified in preventing assisted conception, other than in circumstances of potentially significant harm, this leaves open the degree to which the state might take action to promote the interests of those affected by donor conception, where this can be done without placing an undue burden on others. In considering what burdens might be ‘undue’, both the interests of others also concerned in donor conception, and also the interests of wider society in terms of the allocation of scarce resources, need to be considered.
- 5.69 In the UK context, we note that the state has chosen to regulate, in both NHS and private clinics, how treatment services are provided, the circumstances in which gamete and embryo donation is permitted, and the information that must be retained about donors. As a result of statutory regulation, only those donors who can contemplate becoming identifiable when their donor-conceived offspring reach the age of 18, may now donate. The publicly-funded NHS provides some (limited) access to treatment services using donor gametes. We therefore suggest that, in enabling (through legal provisions regarding parenthood, for instance) *and* endorsing in this way donor conception as a means of creating a family, **the state should also be concerned to take action that is likely to promote the welfare of people affected by donor conception, where this can be achieved without unreasonably interfering with the interests of others.**
- 5.70 In particular, the state, through its regulator the HFEA, has the opportunity both to *influence* the way prospective parents view the prospect of raising donor-conceived children and to *support* them in this process. Such action may promote the welfare of donor-conceived individuals by ensuring that their parents are well-placed to make a decision based on full consideration both of the evidence of the impacts of disclosure and their own personal family circumstances, without unjustifiably intruding into the reproductive decisions of prospective parents. In the light of the evidence that inadvertent or late disclosure may be harmful for donor-conceived individuals, we therefore consider that **the state is justified in taking steps to try to ensure that parents are informed about the best available evidence about disclosure, and to support them in considering this evidence both before conception and, where applicable, in their later preparations for disclosure as their child grows up.** We consider further in Chapter 6 how these responsibilities might be implemented in practice.

⁴⁵⁵ Nuffield Council on Bioethics (2007) *Public health: ethical issues*, available at: <http://nuffieldbioethics.org/public-health>, at paragraph 2.41.

⁴⁵⁶ Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*, available at: <http://nuffieldbioethics.org/donation>.

- 5.71 We further suggest that the state could take on a ‘facilitative’ role in promoting the well-being of people affected by donor conception by **encouraging a social environment where the creation of families through donor conception is seen as unremarkable**: as one way among a number of others of building a family.⁴⁵⁷ Such a role should not be understood as promoting ‘special arrangements’ for particular family forms, but rather as one of inclusivity: encouraging the acceptance of diversity both in the way people become parents, and in the plethora of ways in which they create ‘kin’. We return in Chapter 6 to consider in more detail how our suggestion of a stewardship state might help determine a policy response to the various proposals put forward, both to the Working Party and elsewhere, to the current regulation of donor conception.
- 5.72 Finally, we note in this chapter that the state, under its international human rights obligations (codified in UK law through the Human Rights Act 1998), is required to ensure that the human rights of all those within its jurisdiction, as set out in the European Convention on Human Rights, are properly protected. We have argued throughout this report for an analysis of the competing concerns of those personally affected by donor conception in terms of ‘interests’ and ‘responsibilities’ rather than of ‘rights’. We conclude by highlighting how the interpretation of human rights law, despite the terminology of ‘rights’, similarly has at its heart both the weighing of potentially conflicting interests, and the consideration of the proportionality of any interference on the part of the state with those interests. Our conclusions coincide closely with current interpretations of the human rights obligations established by the European Convention on Human Rights (see paragraphs 2.28 and 2.29).

⁴⁵⁷ See, for example, Haslanger S (2009) Family, ancestry and self: what is the moral significance of biological ties? *Adoption & Culture* **2(1)**. Haslanger highlights the importance of cultural ‘schemas’ in providing social bases for healthy identity formation, and argues that rather than reify particular schemas, such as the traditional nuclear family, the dominance of these schemas should be challenged and alternatives constructed. See also: Archard D (2012) The future of the family *Ethics and Social Welfare* **6(2)**: 132-42.