

ABOUT US

PROGAR (<https://www.basw.co.uk/progar/>) has since the 1980s campaigned on matters concerning assisted reproduction, including surrogacy, in the UK and overseas. We have variously worked in partnership with donor-conceived adults, Barnardo's, Birth Registration Reform Group, Children's Society, Donor Conception Network, British Infertility Counselling Association (BICA), British Association for Adoption and Fostering (BAAF), Coram BAAF, National Association of Guardians ad Litem and Reporting Officers (NAGALRO), Children and Family Court Advisory and Support Service (Cafcass), Children and Families Across Borders (CFAB) and UK DonorLink.

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Brief Overview

PROGAR is pleased to make comment – albeit brief - on this current consultation and to make ourselves available for a more in-depth discussion, including about existing research and knowledge, should that be considered appropriate.

PROGAR'S core interest is in the long term implications of donor conception and surrogacy for the children and adults conceived through such routes, the families and networks in which they are raised and those that they may later establish as adults. We are also interested in such aspects for gamete donors, surrogates, their families and networks. As such we believe that it is critical that policies and practices from pre-conception onwards make paramount the interests and human rights of children. This approach is further supported by the British Association of Social Worker's Position Statement on Surrogacy, much of which also applies to donor conception (<https://www.basw.co.uk/resources/basw-position-statement-surrogacy-14th-december-2016>).

Recent years have seen significant changes in family forms and such diversity can be welcomed. However for those for whom their origins lie in third (or fourth) party assisted conception treatment services, such services and associated legal and policy frameworks can at times be too little informed by the longer term outcomes for those affected. At the same time family policy has not always kept sufficiently abreast of developments in assisted conception.

In summary, we invite you to consider the complex matters that can arise in the formation of families through the use of assisted conception, ones that we believe would benefit from putting the human rights and needs of the children to be conceived and those affected at the core.

FULL STATEMENT

PROGAR is pleased to make comment – albeit brief - on this current consultation and to make ourselves available for a more in-depth discussion, including about existing research and knowledge, should that be considered appropriate.

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Recent years have seen significant changes in family forms and such diversity can be welcomed. However for those for whom their origins lie in third (or fourth) party assisted conception treatment services, such services and associated legal and policy frameworks can at times be too little informed by the longer term outcomes for those affected. At the same time family policy has not always kept sufficiently abreast of developments in assisted conception. It is of note that the legal and policy frameworks for assisted conception fall under the Department of Health and Social Care and its regulator, the Human Fertilisation and Embryology Authority has no requirement to include a member on the Authority with expertise in children and families matters. At times, we believe this has led to medical and scientific considerations unhelpfully taking precedence over immediate and lifelong child and family-focussed considerations. One recent example is the *conceptualisation of surrogacy* adopted by the Law Commission of England and Wales and Scottish Law Commission in their 2019 consultation document on surrogacy law reform of surrogacy. They saw it as closer to natural conception and IVF than to adoption, despite the involvement of a woman carrying a pregnancy (whose conception sometimes involves the use of an egg donor), giving birth and relinquishing the baby to be raised by intended parents. The physical, psychological and social process itself is also not without risk for the surrogate herself as well as the offspring and we still know very little about the effect on the child of the foetal environment or the effect of separation at or soon after birth. PROGAR has instead argued that the different forms that family building take (i.e. including through non-traditional routes) should be seen as part of a continuum that requires different responses proportionate to the potential risks to, and needs of, the offspring, the human rights of those children affected and/or the State's responsibilities. At one end of that continuum come families formed through natural conception where there are no known risks to the health and safety of the children involved. At the other end can be found children born to parents known to pose a serious safeguarding risk (such as through substance abuse and so on) and adoptive families (where there are statutory responsibilities involved). Along the continuum should be placed families formed with the aid of donated gametes and/or surrogacy and further discussion is needed as to where that point should be and hence what requirements should differ in relation to scrutiny, legal processes and involvement of child welfare professionals in determining policy and practice.

We cover this and other aspects of surrogacy more fully in our detailed submission to the consultation (see our publications page at <https://www.basw.co.uk/progar/>). The Law Commissions are due to report in the autumn of this year and present a draft Surrogacy Reform Bill.

We would also like to note at this point that fertility treatments are increasingly provided by private businesses in the UK (currently at approximately two thirds of provision and growing) and overseas and there is now a global trade in gametes. This is also true of surrogacy arrangements in the international market; and while the UK itself is restricted to not-for-profit organisations, though the boundaries between not-for-profit and commercial bodies may warrant further scrutiny and surrogacy agencies are not

regulated. All of this also carries implications for the drivers of policy and practice decision-making.

Individuals conceived through assisted conception treatments using donated gametes and/or a surrogate can have three or more genetic, gestational and legal parents and, sometimes, large numbers of donor-related genetic relatives about whom they know little but may later find or be found by. These all carry the potential to be of significance to them, and the negotiation of their unfolding meaning and any relationships that are formed may be required throughout their lifetimes. We know very little, for example, of how DC and/or surrogate-born offspring manage the fact that the donor or surrogate may have been motivated by financial gain, especially given the discrepancies for some in their socio-economic situation when compared to intended parents. Existing children that are affected (such as the children of donors or surrogates or existing children of prospective parents) are rarely involved in the decision-making process about embarking on treatment and of course those to be conceived do not exist. The voices of donor-conceived and surrogate-born people are also notable for their absence from policy decision-making or regulatory bodies (such as the HFEA) and research with such groups remains limited and was historically dominated by studies of parents' reports of their children's progress and views. While the lobby for, and research with, donor-conceived people nationally and internationally has grown in recent years, there is still scope for it to be more influential and it will take many years yet for that for surrogate-born people to develop.

Understandably, service providers in this field are focussed on improving the chances of a successful pregnancy for those coming forward. As such, they are also keen, again understandably, to encourage the supply of people coming forward to donate their gametes or act as surrogates. As demand has risen in recent years, supply has not always kept pace and this has contributed (among other factors) to a growth in numbers travelling overseas for both donor conception treatments and surrogacy. This brings its own challenges, not least when destination countries have different legal frameworks to those in the UK with

regard, for example, to donor anonymity and/or legal parenthood and/or nationality; commercial provision, including payments to gamete donors, surrogates and 'brokers'; limits of numbers conceived per donor or surrogate; or medical standards. In addition, there have been recent sharp increases in the levels of imported gametes being used in UK licensed centres but the upper limit on the number of families being created in such centres (currently 10) does not apply to the use of these gametes in other countries even

though evidence is growing of the adverse implications of large numbers of donor-related siblings for both donor-conceived people and donors. It also means that any later contact between offspring and their genetic or gestational relatives may be complicated by not having a shared language or culture as well as there being a geographical distance. Given our focus on the well-being and human rights of children and their families, PROGAR is not concerned with 'supply and demand' aspects of donor conception or surrogacy: we neither promote nor condemn these practices. Instead we stress the importance of minimising the risk of the dominance of such drivers causing later harm and failing to pay sufficient attention to children's human rights whether domestically or in destination countries. There has been some work on this internationally through The Hague and also through International Social Services (ISS) but it is slow and there is much more to be done (<https://www.hcch.net/en/projects/legislative-projects/parentage-surrogacy>; <https://www.iss-ssi.org/index.php/en/news1/459-march-2021-iss-launches-the-verona-principles-for-the-protection-of-the-rights-of-the-child-born-through-surrogacy>).

We are aware of a growing lobby nationally and internationally with regard to surrogacy to enable the intended parents to register as legal parents from birth, thus replacing genetic and/or gestational

relationships with intended ones as the basis for conferring legal parenthood without independent post birth examination. This carries significant implications for the child over their lifetime and potentially in other areas of children's and family law. For example, following the use of surrogacy with or without the use of DC and indeed donor conception without surrogacy, there is currently no legal requirement on the parents raising the child to inform them of their origins (nor indeed on donors or surrogates informing any [other] children that they have). Research suggests this does not reliably happen and that openness about the use of donor conception is lagging behind openness about having used IVF itself or surrogacy without donated gametes. However later disclosure – which is usually accidental – is typically traumatic for the individual and those around them and, among other impacts, can at times cause permanent rifts in existing relationships. Secrecy has also been found to lead to DC people making life and health-related decisions, ignorant of their own genetic make up – for example about whether to have children when one 'parent' has a genetically transmissible condition – on the basis of assumed genetic connection to a parent that is later found out not to be the case. It has also led to parents withholding information from health professionals in order to maintain their secret. While DC offspring have the legal right from the age of 18 to receive identifying information about the donor from the HFEA, on request, they of course need to be aware of their origins in order to exercise that right. Those born through surrogacy arrangements currently have no right at all to request identifying information about their surrogate (though it is anticipated that this will be included in the draft Surrogacy Bill). The children of donors or surrogates have no route in the UK to register an interest in receiving or providing information and/or contact from their half siblings. The UN Convention on the Rights of Child clearly sets out the rights of all children to know their parents and it has been confirmed that this covers genetic and gestational parents as well as legal ones (<https://www.unicef.org/media/115331/file>). Although it is clearly important for legal certainty (and national identity) to be secured as soon as possible for a surrogate-born child, care needs to be taken not to cause difficulties in the longer term by rushing the process in the early days, as has been learnt from broader children's services work.

There continue to be some problems with the accurate completion of legal parenthood forms within UK licensed treatment centres for same sex couples. This despite the problem being known for several years and court cases having resulted.

All this contributes to our view that there is also a need to consider birth registration reform that would require the GRO to keep record of genetic, gestational and legal parents of all children registered that would then be made available to them. In itself, this would not of course remove all the barriers to DC and surrogate-born people becoming reliably aware of their origins but it will help. We are aware that the UK Birth Registration Reform Group is making a separate submission about this.

In keeping with this, we are aware of the growing lobby from the trans community to adopt gender-neutral language, with which we have some sympathy. A less well known aspect of trans matters, however, concerns a potential conflict with the rights of DC offspring to learn of the identity of the donor. Where a donor has subsequently transitioned, their previous identity will be protected under the Gender Recognition Act 2004, meaning that any donor offspring that they have will not be able to trace them unless they themselves notified the HFEA of their new identity. We believe the same will be true for adopted people whose birth parents have transitioned. This also needs addressing.

There are a number of other areas that PROGAR believes need to be considered, linked to the matters raised above and all of which we have raised with the HFEA and/or the Law Commissions; our list below is not exhaustive. (please note that the HFEA recently announced the establishment of a Legislative Reform Group to look at the workings of the Human Fertilisation and Embryology Acts):

Welfare of the child assessment – it is a requirement of the legislation that UK licensed centres must consider the welfare of the child to be conceived or those otherwise affected before deciding whether to allow anyone to proceed to treatment, to donate gametes or to act as a surrogate. Currently this is done in the majority of cases by the completion of a self-declaration form which we believe is inadequate – for example, it does not cover pending safeguarding investigations only completed ones nor any violence outside of the immediate family, and there is no involvement of child welfare professionals including in discussions as to whether to proceed to treatments. There are also barriers to seeking additional information from non-health agencies such as Probation and Children’s Services as the consent to disclosure/subject access form only covers approaches to health professionals. We are also aware of a range of approaches to handling such matters, i.e. different clinics are interpreting it in different ways and there is no national arena for agreeing on policy, making standardisation difficult to achieve.

Assuring the quality of donor information collected by UK clinics for later release to recipient parents and then to offspring from age 16 (non-identifying) and 18 (identifying) – there can be variability in the quality of information collected and parts of it are optional to complete. We consider that full completion should be a requirement and that donors should be routinely assisted in providing it. Given the current legal requirement that no information should be released that could lead to the identity of the donor being uncovered prior to a request by the DC offspring at age 18, any non-identifying information may need to be redacted. Anecdotally we are aware that this can at times lead to donors being discouraged from including identifying information in the first place, thus depriving 18+ DC offspring of information that they might find important. This also links to our next point. We are concerned that there is no requirement on surrogates to provide biographical information about themselves as they are not classed as donors (we anticipate this being addressed in the draft Surrogacy Bill).

Age at which identifying information can be released and extension of rights to children of donors and surrogates - Recent years have seen massive growth in the use of direct-to-consumer DNA testing (such as Ancestry.com, 23AndMe). This is affecting children and young people across a number of sectors, including adoption so warrants your consideration anyway. In the area of donor conception specifically, the identity of donors and donor relatives is being uncovered ahead of a DC person reaching the age of 18. Sometimes this is because the DC person themselves is undertaking tests and searching; sometimes searching is being done by recipient parents sending in their children’s DNA even from quite a young age. For some DC children and young people and their families, there is a growing understanding that facilitated information exchange and contact can be beneficial at a much earlier stage than is currently possible, an understanding that is also present in adoption. Donors too are searching. DC people are also being ‘found’ through this route, including those who are unaware of their origins and hence learning of them for the first time and again this may be while they are still young as well as when adult. This means the legal prohibitions on identity release are increasingly unsustainable. We also argue there is a duty of care to provide support and intermediary services in this area, including regarding information exchange and contact, as well as removing/reviewing the current age limits. In similar vein, we believe that the non-DC offspring of donors and surrogates should have rights of information exchange and possible contact extended to them as should those DC people not currently covered by the 2005 changes to prospectively lift donor-anonymity, i.e. those born between 1991 and 2005. Indeed we are increasingly discussing the possibility that the time will come when donors and surrogates will need to be identifiable from conception onwards.

Removing prohibitions of release of treatment-related information to other health professionals and exchange of genetic information by affected parties following DC and/or genetic surrogacy: PROGAR has urged changes to be made to current restrictions on who is informed about what. Currently clinic professionals can only notify other health professionals about what treatments have taken place with the consent of the patients (i.e. the recipient parents). This potentially leaves other health professionals in the dark. With regard to any later exchange of genetic information between the parties affected by donor conception or surrogacy, including other 'family' members and DC- and surrogacy born people themselves, this too is outdated and needs addressing. Much of this information only comes to light later but can be important to those who are genetically related. Concerns about the invasion of privacy in any later tracing are important to consider but not to stop the process getting underway, as now.

Making a requirement the assessment and preparation for parenthood and family life for those considering DC and/or surrogacy - it should be a requirement for those considering DC or surrogacy or those considering donating their gametes to take part in assessment and preparation. While it is currently a requirement for 'implications counselling' to be offered, treatment can go ahead without it and even where it is in place it is typically only for one session of around an hour.

Paying fuller attention to informed consent – although attention to this is good in relation to medical matters (though perhaps it could be made clearer that uncertainty remains about the lack of data regarding longer term outcomes on some aspects) we believe this could be improved in relation to understanding of non-medical outcomes. This includes the significance of openness. There are sparse long term data about psycho-social outcomes for DC or surrogate-born children, children of donors or surrogates and surrogates themselves. This exacerbates the danger whereby existing research findings from small-scale studies with a limited range of methodologies of no adverse effects can be used to make claims that about well-being or recommendations for change that are not sufficiently evidenced.

We also believe in the importance of what one might call 'active' consent. For example we believe that consents need to be revisited regularly – fertility treatments may be ongoing for months or even years so consents taken at the beginning need to be revisited. In surrogacy arrangements, we believe the consent of the surrogate to the intended [parents becoming the legal parents should always be actively sought post birth and not assumed. In keeping with this we fully support the UN Special Rapporteur on Child Selling's view that any pre-birth surrogacy agreements should be legally unenforceable.

In summary, we invite you to consider the complex matters that can arise in the formation of families through the use of assisted conception, ones that we believe would benefit from putting the human rights and needs of the children to be conceived and those affected at the core.