

Individual Response to the Review of the Human Reproductive Technology Act 1991 and the Surrogacy Act 2008

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Involvement in assisted reproduction matters: I have been involved in this field since the 1980s variously as a social work practitioner running a fertility counselling service for several years and as an academic. I have conducted research into donor conception, surrogacy, cancer-related fertility and adoption. I have been a Social and Ethical Inspector and External Adviser to the Human Fertilisation and Embryology Authority, most recently working with them on developing a pilot support and intermediary service for people approaching their Register for information release. A founder member of the British Infertility Counselling Association, I continue to edit their Practice Guide series. I am Chair of the multi-agency UK Project Group on Assisted Reproduction (PROGAR) which is administered by the British Association of Social Workers and draws on a number of national bodies concerned with child and family welfare (see Addendum). From 2003 to 2013, I was national adviser to UK DonorLink, the government funded DNA-based voluntary register for adults genetically related through donor conception. I am also actively involved with Donor Conception Network, the UK peer support organisation for families formed through donor conception and I contribute a seminar to their Preparation for Parenthood workshops. In 2010, I spent five weeks in Australia and New Zealand, funded by the Nuffield Foundation, to learn more about the ways in which your services and policies are run and developed; this included a visit to Western Australia. I am an Honorary Fellow (formerly Senior Lecturer) in the Department of Social Policy and Social Work, University of York.

PLEASE NOTE: I am not in a position to comment on the detailed application of the law in Western Australia; my comments come from my practice and research experience primarily here in the UK but also internationally, together with the guiding principles to which I adhere.

I wish to comment in particular on the following areas:

- Access to information by donor conceived people
- Surrogacy

I am firmly of the belief that the needs of those born as a result of ART, including surrogacy and regardless of whether the service is received in the domestic or international sphere, should be treated as paramount and these should be considered within a lifespan perspective rather than restricting their consideration to childhood alone. Of course the definition of 'needs' is a matter open to interpretation, especially when one considers the range of identified needs such as 'felt' 'absolute' or 'relative' and so on. I prefer to use the term 'human rights' which better enables consideration against universally accepted definitions in UN Conventions and elsewhere of what human beings should be afforded and hence gives access to commonly accepted standards. It also moves debate away from seeing the matter as a 'welfare' issue alone with a focus exclusively on

whether or not certain professional or parental practices are harmful. Of course the use of ‘human rights’ as a measure still leaves room for interpretation. Where there is considered to be a conflict of rights – such as donors’ rights to privacy versus donor conceived people’s right to information about their identity; or whether intended parents in surrogacy arrangements should be allowed to register the child at birth and hence remove any statutory record of the woman who gave birth – this allows the paramouncy of the rights of those born as a result of ART treatment to come into play¹.

A key reason for such paramouncy is that these individuals had no say (and hence could not exercise autonomy) in the decision to bring them into existence but they are the ones living their lives with the consequences (whatever they are – good, bad, neutral etc) throughout the whole of their lifetime.

Thus I argue that it is important in any review or policy making with regard to assisted reproduction that account is taken of the human rights of the offspring (and other offspring affected), the unique context of ART and its lifelong impact rather than focussing exclusively on medical and scientific matters. This should apply regardless of where the third party involvement takes place.

It seems clear to me that what follows from this are the following ‘rights’ for offspring:

- The right to regulated medical and scientific practices at the time of their conception that are well informed by current research together with longitudinal follow up studies on the bio-psycho-social development and wellbeing of offspring.
- The right to screening of prospective parents in such a way that meets the threshold of avoidance of potential ‘significant harm’ that is used in child protection services. Of course one cannot ensure that prospective parents will not harm their offspring and any checks need to be proportionate but it is not acceptable to do nothing, given the involvement of a third party, i.e. medical treatment services. In other words, a straight parallel with those conceiving without medical assistance cannot be drawn.
- The right to have parents who were provided with high quality preparation by the treating clinics for the additional parenting tasks that accompany family life where there has been third party involvement through the use of donated gametes and/or surrogacy arrangements. This includes close attention to helping them prepare to be fully open with their children about their origins from infancy, and to be alert to the implications of the growth in DNA testing (see more below)
- The right for their donors to have been similarly fully prepared. In keeping with this, in the UK we have recently been considering the impact of increasing numbers coming forward to store gametes in advance of transitioning to a different gender. While most are doing so for their own possible later use in assisted reproduction treatment, some are wishing to donate for the use of others. However under the UK Gender Recognition Act, a person’s original birth certificate is of restricted access post-transition, including to any offspring. It is my view and that of the PROGAR group that I chair that no person should be accepted as a donor if they are not prepared to keep the authorities up to date with any changes to their

¹ See, for example, the British Association of Social Workers Position Statement on Surrogacy - <https://www.basw.co.uk/resource/?id=5968>

identity, including their gender identity as this will otherwise conflict with the statutory rights of donor-conceived individuals to learn the identity of their donor from age 18.

- The right to full identifying and biographical information about their legal, genetic and social parent(s) and, in the case of gestational surrogacy, such information about the surrogate as well as the egg donor². This means that donors and surrogates should be required to provide such information about themselves and to do so to an agreed standard; and that there should be records statutorily held about the different parties holding a 'parent' role as defined in footnote 2. There is room for discussion as to the age at which identifying information should be made available though I am increasingly of the view that this should be from birth (and thus for their legal parents by proxy while they are a minor), not least because of the growing potential for identifying the parties involved through DNA testing (see below).
- The right to have access to a robust record-keeping system informed by their lifelong needs (and see more detail below).
- The right to a birth registration process that:
 - Provides clarity about their legal parenthood and nationality
 - Enables them to be aware of their origins and whether or not the parents raising them are also their genetic or gestational parents, including whether the woman who gave birth to them is also their genetic mother. This does not mean that those who are donor conceived or born through surrogacy arrangements should necessarily have a birth certificate that identifies this for all to see. It does mean, in my view, that birth certificates for all people should include a section that says that it is a certificate of legal parentage but not necessarily genetic parentage and directs people to those places where information about genetic parentage might be held³.
- And, importantly, the right not to have commercial gain as the motivator for the provision & advertising of services, including in surrogacy – see the recent report (2018) by the UN Special Rapporteur on what might constitute selling of children - http://www.un.org/en/ga/search/view_doc.asp?symbol=A/HRC/37/60.

The principles of record-keeping (including in government funded Registers) in this field are thus clear, in my view:

- There should be statutory requirements with regard to record keeping to ensure standardisation and transparency across services
- There should be long term research into the outcomes of ART (and hence access to Register data), including aspects specific to donor-assisted treatment and surrogacy. This should not focus exclusively on medical, scientific and developmental psychological matters but should instead include attention to impact on family and social processes, including whether children born through ART in general or donor-assisted ART or surrogacy in particular are

² As is made clear in the definition of who is considered a parent following assisted conception for the purposes of the UN Convention of the Rights of the Child – see Hodgkin, R. and Newell, P. (2007) *UNICEF Implementation Handbook for the Convention on the Rights of the Child* 3rd. ed.

³ See Marilyn Crawshaw, Eric Blyth and Julia Feast (2017) Can the UK's birth registration system better serve the interests of those born following collaborative assisted reproduction? *Reproductive Biomedicine & Society Online* 4 (2017) pp. 1-4 <http://dx.doi.org/10.1016/j.rbms.2016.12.004>

any more or less likely to come to the attention of child protection, mental health or court services than other groups; and whether their parents (if a couple) are any more or less likely to remain together. Given the low base of funding for such research when compared to that for medical/scientific/developmental psychology, there should be consideration given to state-funded research in this field.

- The relationship between the birth registration process and state/government funded Registers needs to be considered carefully for those conceived using donor(s) and/or surrogates, including the unique needs associated with gestational surrogacy where the birth mother appears on the original birth certificate and may therefore be erroneously assumed by the offspring to be their genetic mother.
- Record keeping requires close attention to confidentiality. However we have a situation in the UK whereby treatment centres cannot release information to family practitioners or other medical colleagues without the written permission of prospective parents. This requirement was instigated primarily to 'protect' prospective parents from stigma and is outdated insofar as it may paradoxically sustain stigma and could anyway adversely affect the right of people born through ART (whose rights should prevail).

There is now plenty of research as well as lay and practice evidence that those directly affected by donor conception want the *choice* about whether, when and how to access information relating to them, including identifying and biographical information about their donor(s), and, further, see this as their *right*.

There is also increasingly compelling evidence that the recent massive growth internationally in direct-to-consumer DNA testing is having a significant and growing impact on the numbers of people either using such services as a route to find people genetically related to them through donor conception or becoming aware for the first time that they themselves or their family members are directly affected by DC. In other words, donor anonymity is increasingly untenable. This is probably the biggest contemporary single influence on donor conception services and their aftermath that we have seen. Policies, treatment services, donor recruitment services and post conception psychosocial support services need to be alert to this – and all potential parents and donors advised of its implications⁴.

In keeping with all the above, I am also of the view that:

- Anyone considering surrogacy should be made aware of the additional potential complexity for the offspring where gestational surrogacy is used with an egg donor. The offspring will need to work out how to accommodate the meaning that each of these women hold for them over their lifespan. In addition, it may be more difficult for them to become aware of their origins depending on the availability of information being stored and released to them about both their genetic parent (the donor) and the woman who carried them through pregnancy and gave birth to them. There is some emerging evidence that prospective

⁴ See Debbie Kennett (2018) Personal genetic testing and the implications for the donor conception community IN http://www.bionews.org.uk/page_934804.asp; Marilyn Crawshaw (2017) Direct-to-consumer DNA testing – the fallout for individuals and their families unexpectedly learning of their donor conception origins, *Human Fertility* <https://doi.org/10.1080/14647273.2017.1339127>; Harper, J.C., Kennett, D. and Reisel, D. (2016) The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business *Human Reproduction*, DOI: 10.1093/humrep/dew065

parents are not always fully informed about these implications when ‘choosing’ which type of surrogacy arrangement to use, meaning that their ‘choice’ is not fully informed; indeed some parents report that they were not afforded such a choice. There is also some evidence that ‘intended parents’ may be more likely to tell their offspring about the involvement of a surrogate than about the involvement of an egg donor.

- Anyone considering donor-assisted treatment (including in surrogacy arrangements) should be provided with preparation for parenthood sessions that enable them to receive professional assistance to prepare for parenting and family life where there is genetic difference; this is in addition to being offered counselling if they wish it (the two are not the same).
- Parents of donor-conceived offspring should be provided with ongoing support, if they wish it, for talking with their children about their origins and associated matters.
- Donor-conceived offspring should be facilitated to have contact with their donor(s) if they wish, including through the support of well trained psycho-social professionals experienced in such work (in our experience in the UK, these are often social workers with a background in post adoption work).
- Those born as a result of donor-assisted treatment and non donor-conceived offspring of donors should be facilitated to have contact with each other if they wish (so-called ‘sibling’ contact), again with support as described in the previous bullet point. This should include children of the donor who are not donor conceived.
- There is an excellent model for intermediary services at VARTA.

If there is no age restriction on the release of information, then I suggest that there should be only one Register that records details of **all** donors, recipients and donor-conceived offspring and also allows non donor-conceived offspring of donors and other genetic relatives to register **if they wish**. Recipient parents should only be allowed access while their child is below the age of legal majority unless they have the written agreement of their child to access it later. Professional psycho-social support services should be available at all stages.

If there is an age restriction on the release of information, then I would support the continuing provision of a Voluntary Register (i.e. in addition to a statutory Register) that allows those who wish (donor-conceived offspring, donors, non donor-conceived offspring of donors, recipients and other genetic relatives) to register. All but recipients should be allowed to receive information and/or make contact if they wish at any stage/age; recipients should only be allowed access while their child is below the age of legal majority unless they have the written agreement of their child to access it later. Professional psycho-social support services should be available at all stages.

Finally I was encouraged to hear of the recent decision of the State of Victoria to allow retrospective release of information, with safeguards in place, and the provisional intention of South Australia to do so. Of course its operation is yet to be tested but I urge WA to adopt a similar progressive model.

I have only provided limited References in this submission but could provide a fuller list if this would be helpful. I am also attaching a Briefing Paper that has recently been produced by PROGAR, a UK multi agency group that I chair, in readiness for a forthcoming consultation by the Law Commission

for England and Wales on whether and how our UK surrogacy law needs to be reviewed; and invite you to read of the work on surrogacy of the Hague Conference on Private Law and that of International Social Services.

Thank you for the opportunity to comment on this important area.



Marilyn Crawshaw

15th March 2018

ADDENDUM

British Association of Social Workers (BASW) Project Group on Assisted Reproduction, PROGAR

BRIEFING PAPER

Children at the centre of surrogacy: human rights within a lifespan approach December 2017

WHO WE ARE

The British Association of Social Workers (BASW) Project Group on Assisted Reproduction, PROGAR (<https://www.basw.co.uk/progar/>) has since the 1980s campaigned in the UK and overseas on matters concerning assisted reproduction, including surrogacy. We have variously worked in partnership with donor-conceived adults, Barnardo's, Children's Society, Donor Conception Network, British Infertility Counselling Association (BICA), British Association for Adoption and Fostering (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.

OUR CORE VALUES

PROGAR has consistently argued the need for policy and practice to place children (and the adults they will become) centre-stage, use a lifespan perspective and consider what might be most likely to lead to healthy family and adult life where surrogacy arrangements and/or donor conception are the route to family life. Our contribution to the lifting of donor anonymity and the introduction of the Welfare Checklist into the Parental Orders process and our continuing lobby for birth registration reform are just three examples of this.

Our views are informed by a human rights stance. **Basic universal rights and freedoms protect every person simply because they are human and can** only be restricted in order to protect people and balance the rights of others. Human rights set down in law the rule book for governments on

how people should be treated and how power should be exercised. Our view is that children's human rights should be paramount in both surrogacy and any assisted reproduction contexts and this is set out in more detail in BASW's Position Statement on Surrogacy - <https://www.basw.co.uk/resource/?id=5968>.

LINKS TO HUMAN RIGHTS APPROACHES

Taking a children's human rights approach to surrogacy and drawing on the 1989 UN Convention of the Rights of the Child (to which the UK is a signatory), we have concerns in particular about the push for pre-authorised Parental Orders including changes to legal parentage at birth and the extension of eligibility for Parental Orders to those where neither partner has a genetic relationship to the child. Since restrictions were placed on international adoption, surrogacy is the only formal arena in the UK (and in most other jurisdictions) in which a child is carried through pregnancy by one person then raised by another without any *required* scrutiny or preparation of the adults involved. In addition, this field is hampered by the limited lobby for the thousands of offspring affected or yet to be born, the lack of pressure groups among adult surrogate-born children similar to those that have developed for donor-conceived individuals, and the pitiful absence of research into longer term outcomes for both domestic and cross border arrangements leading to an inappropriate reliance on what is available. Our concerns centre on the fact that calls for legislative change are largely silent on the following matters, which we consider essential to be in place if we are to secure children's human rights and which therefore should take priority:

- Given the complexity of surrogate-born children's 'parentage', PROGAR argues that their Article 7 (registration, name, nationality, care) human right to 'know' their parents and their Article 2 (non-discrimination) human right for them and their 'parents' to be free of any discrimination extends to *all* their 'parents'. While acknowledging the complexity and contested nature of terminology, we agree with the view expressed in the *Implementation Handbook for the Convention on the Rights of the Child* (Hodgkin & Newell 2007) that, for these purposes, 'parents' should include their 'genetic' and 'gestational'⁵ parents, their legal parents and the parents who are raising them (sometimes known as 'social' parents who may also be their legal and genetic parents and who are often referred to as 'intended/commissioning' parents). All are potentially significant to that child in the short and longer term making it important they can both 'know' of them *and* that they as well as their 'parents' are free from discrimination and treated with dignity and respect. Where the human rights of any of the adults conflict with those of the child, those of the child should be paramount.
- At present, children's human right to know all their 'parents' is not secured in many surrogacy arrangements:
 - Even if 'intended/commissioning parents' tell their children of their full origins (and there is nothing in law that *requires* them to do so), few jurisdictions, fertility treatment centres or gamete donor banks keep **registries** and provide services to enable surrogate-born offspring to have access, at any stage in their lifetime, to identifying biological/ gestational, genetic and biographical information about surrogates, donors or previous legal parents. Indeed some commissioning parents are *themselves* never aware of the identity of the surrogate let alone of the donor.

⁵ Surrogacy arrangements are of two main types: (i) where the surrogate uses her own eggs, known as genetic surrogacy and (ii) where the child is conceived with the use of eggs from either an egg donor or the intended mother, known as gestational surrogacy. In UK law, a woman who gives birth is automatically the legal parent of that child; there are only a small number of jurisdictions around the world where this is not the case in surrogacy arrangements.

- The situation is further complicated by **birth registration systems**. In the UK, both donor-conceived individuals conceived in a UK licensed clinic and surrogate-born individuals where there is a Parental Order in place have a statutory right to information held in state records. However information relating to donor conception is held by the HFEA and hence separate to that relating to Parental Orders (held by the Registrar General) and there is no requirement for the Registrar General to inform a surrogate-born offspring who was conceived with the use of a gamete donor approaching the Parental Order Register of the possibility of their donor-related information being held by the HFEA. In other words, gamete donors (or their use) are not recorded in the birth registration system⁶ leaving offspring dependent on learning elsewhere of their origins to realise they have a human right to exercise. For those born outside the UK, there are a myriad of approaches to birth registration. Although UK rules on access to information still apply to surrogate-born children on their entering the UK, this is dependant on 'intended/commissioning parents' applying for a Parental Order and one being granted.

- The decision about whether to use **genetic or gestational surrogacy** (where this is not for medical reasons such as where the intended mother has no womb but produces eggs) does not reliably take into account the child's right to know the identity of the surrogate (and egg donor if used) nor their potential need to make sense of the meaning of two or even three additional 'parents' (surrogate and donors) rather than only one ('surrogate') as their lives unfold. Gestational surrogacy decisions are typically more influenced by the intended/commissioning parents' desire (sometimes, perhaps often, influenced by clinic staff and surrogacy agencies) to reduce failure to relinquish the baby by the surrogate (though there is no robust evidence base of which we are aware to indicate genetic surrogates are less likely to relinquish the infant) or achieve ethnic similarity or 'distance' themselves from the fact of there being another genetic 'parent' to their intended child. Some fertility treatment centres and surrogacy agencies do not make clear that there are different options available and/or that there may be implications for the child in the long term to using a donor.

- Lack of access to identifying and non-identifying information about a child's surrogate or donor (where one is used) means that their potential need at some stage in their life-time (including from childhood) to **understand the epigenetic⁷, genetic, social and cultural context of the surrogate and donor** is compromised.

- Article 7 states that children have a human **right to have a nationality** but there can be a struggle to acquire nationality following international arrangements. Sometimes intended/commissioning parents go ahead with international arrangements in the knowledge that this may result in difficulties with nationality for the child or unrealistic hope that any difficulties may be readily overcome. Sometimes they do so because of incomplete information. In the case of couples, this can lead to one partner returning home pending the outcome of lengthy negotiations with the attendant risk to the emotional and general well-being of the child and risks to opportunities to bond and form attachments within the family unit. Even those returning to the UK easily, for example through declaring their intention to apply for a Parental Order, are not followed up so nationality and legal parentage may be left unresolved.

⁶ This would not necessarily mean naming them on birth certificates; there are other models available

⁷ The field of epigenetics remains little understood but evidence is growing that there are influences on the child to be born from the woman carrying the pregnancy regardless of whether or not she is genetically related

- Rather than seeing the ‘solution’ as the need for jurisdictions to recognise all cross-border arrangements and/or for legal parentage to be granted to the ‘intended/commissioning parents’ at or before birth, a children’s human rights approach would instead include **mandatory requirements for pre-conception scrutiny and preparation, minimum medical care standards and an official trail of [all] parentage and record keeping including through birth registration systems**. Any changes put in place to deal with nationality issues should not be at the expense of creating other longer term issues for the offspring.
- Children’s human rights include being **free from abuse or exploitation** (Articles 19 (protection from violence), 34 (sexual exploitation), 35 (abduction, sale and trafficking) and 36 (other forms of exploitation)). There are also concerns about the risk of exploitation for surrogates and intended/commissioning parents. We believe that the following should be in place in order to lower the risks of exploitation and abuse and heighten safeguards, especially of children:
 - Mandatory scrutiny and preparation procedures by professionals with child welfare expertise tailored to this context should be introduced prior to surrogacy arrangements being entered into and consideration given to how all parties that can best be supported through pregnancy and beyond birth.
 - Legal clarity about the status of surrogate-born children and of those raising them at each stage of the process: at birth, on discharge from hospital/place of birth (where applicable), on entry to the UK (where applicable), until a Parental Order is made, or in the event of no PO being applied for. Unlike any other child being cared for by someone who is not their legal parent there is currently no statutory oversight.
 - Where surrogacy-related requirements are in place - for example HFEA consent procedures as a requirement for conferring legal parenthood, requirements for bringing surrogate-born children into the UK - these should be followed up on. Given that the principle behind these policies is [presumably] based in the need to safeguard children, lack of follow up cannot be justified.
 - Strengthening and clarifying safeguards for children should not be at the expense of lowering children’s rights to access full information about their gestational, genetic/biological or legal parents
 - Commercial or other interests that encourage agencies and professionals to focus, knowingly or otherwise, on adults’ desires to be parents rather than the human rights of children should be banned.
 - There should be regulation of surrogacy agencies, brokers or fertility treatment services (both statutory and by relevant professional bodies) in order to ensure minimum standards and, among other matters, reduce the likelihood of children ending up disabled, suffering poor health or being abandoned; of surrogates receiving poor medical care; and of intended parents finding themselves held to ransom.
 - There is a need for improved international co-operation between countries’ jurisdictions, including through bilateral agreements. Given the global movements of surrogacy arrangements with new markets opening up all the time, monitoring is especially difficult.
 - Whether globally or domestically, the boundaries between surrogacy and child selling are arguably porous (even if such instances are small); the potential for child selling shrouded as surrogacy should be included on the radars of international and national child protection agencies.

IN CONCLUSION

PROGAR believes these are the core principles that should inform surrogacy arrangements when considered through a ‘children’s human rights’ lens and that should therefore inform where we put

our energies into improving the surrogacy world. While regulation (small 'r') of global and domestic arrangements is far from easy, that is not a reason to abdicate them to market forces. If we are determined to make paramount the human rights of children then we believe the priorities should be: mandatory assessment and preparation of all parties; rigorous keeping of detailed information about surrogates and donors and provision of good quality information release systems; introduction of legal measures to protect children ahead of Parental Orders being made; follow up of intended parents to ensure that Parental Order applications are made; stricter controls on exploitation of and discrimination against all parties, including through unchecked commercialism; radical review of birth registration systems; policing of minimum medical standards; and more extensive research.

Some key recent references:

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International Social Services: <http://www.iss-ssi.org/index.php/en/what-we-do-en/surrogacy>; http://www.iss-ssi.org/images/advocacy/Tab1-ISSAdvocacy/Fiches_Advocacy/Surrogacy_factsheet_ANG.pdf

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