

Understanding the need: donor conception and intermediary services

Thank you for asking me to speak today. Fertility nurses are really important people in the lives of couples and individuals who need help in founding a family, so I'm delighted to have the opportunity of talking with you about some of the consequences of donor conception and how what happens in the clinic can have a profound effect on how parents feel about using donor conception and their attitude towards 'telling'. I'm also going to talk about the range of skills and approaches, including formal 'intermediary services' that may be able to help with issues that arise during the long haul of parenting and for DC adults themselves.

Feelings of Parents

Just as donors' thoughts and feelings may be expected to change over the years, parents and children's experiences do not stop either. As the years pass the meanings that were attached to donor conception at the time of treatment change and with these changes can come different feelings that have an impact on relationships and behaviour. These changes are likely to be affected by a number of factors. Some will be to do with the increased confidence that many parents build up as their children grow older. However, many other parents remain doubtful, even slightly ashamed of having used donor conception to create their family, even though they love the children they created this way. There are many reasons why some parents feel comfortable and confident and others do not. One of them is whether or not they were offered adequate opportunities to think about the long-term impact that donor conception might have on their family and their child, before they actually had treatment. Another will be the messages, both upfront and subliminal, that they received from all levels of clinic staff about the meaning of using donor conception for family creation and the consistency of the attitude towards openness within the clinic. For instance, the receptionist may speak in

hushed tones about the donor even when no-one else is around, the counsellor may advocate ‘telling’, the consultant says, ‘well, it’s really up to you’ and different nurses say, ‘it’s the parenting you give them that really counts’ or ‘don’t worry, just go home and carry on as normal – things will sort themselves out later’. These mixed messages are not helpful for would-be parents at such an emotionally vulnerable time.

Non-telling families

For a family who were not encouraged and supported to be ‘open’ with their child about their conception, the passage of time may mean that they put the fact of their child’s origins so much to the back of their mind that they do ‘forget’ whilst the child is young. Alternatively, it may be that they become so uncomfortable with the secret that seems to sit like an unexploded bomb at the centre of their relationship with their son or daughter that they decide to ‘tell’ after all. If anyone else knows, and usually someone does, families run the risk of their child being told or finding out from someone else. Parents who continue to treat donor conception as a secret also have the increasing discomfort as their child grows older of lying or becoming evasive when the child asks questions about who they look like and there is talk about family habits and talents which they may not share.

Our experience at DC Network is that most of the really difficult problems that parents approach us about are the result of children not being ‘told’ from an early age, usually because parents have not come to an agreement about this before the child is born.

Needing support is normal

At any point during a child’s upbringing issues may arise that would benefit from being talked over with someone who has knowledge about and perhaps experience of parenting a donor conceived child. It is now generally accepted that all parents – not just those with DC children – are likely to need support and

guidance at some point in their children's lives. However, the issues around donor conception are still not well understood and parents with a very 'normal' need are often made to feel abnormal by services that treat donor conception as something too specialised for them to have anything to do with. That is, if parents feel they can approach mainstream services at all.

I'm going to go on to suggest some ways in which support and guidance can be offered at different levels in a moment, but first of all I want to consider the child, the person who has had no part in the decision making about their coming into being.

What about the children

None of us of course asks to be born. We are all the result of the hopes, desires, wishes and yes, accidents, our parents had. But I believe there is a special responsibility that comes with very deliberately creating a child using eggs, sperm or embryos that do not originate with the parenting couple or individual.

Donor conceived adults are quite clear that they have a right not to be deceived about their genetic background and ideally to be able to have the choice to have contact with the person or persons who provided the gametes necessary for their creation. My own daughter, now 21, is not looking for a father – she has a very good relationship with her dad – but she would dearly love to know the other half of her genetic inheritance. She has spoken of this as a feeling of 'holding her breath' until she knows, and this is exactly how an American DC teenager described meeting his donor to me. It was as if he could breathe more easily now.

Both my daughter and the US teenager had been told about their origins from when they were very little – they cannot remember not knowing, and they are very comfortable with the information and in their families. This does not, however, stop them from having a very normal and understandable interest in their donor's background. DC adults who were not told until they were older

tend to feel betrayed and angry...some for a short time and others for much longer. Many of these adults come from families where the divorce of their parents led to them being 'told' under the worst possible circumstances and some consider their donor to be their 'real father.'

Telling

Some parents hope that 'telling' will mean that their child will never have curiosity about their donor; will never challenge them as 'not being my real dad or mum', or go through a period of doubt about their place in the family. All these things do happen in some very normal, ordinary and happy donor conception families. What 'telling' under the best possible circumstances can mean is that parents have confidence in the decisions they have made, are able to share the information in a straightforward way with their child, expanding the detail as a child matures, asks questions and develops feelings and thoughts of their own. And if the child goes through a period of anxiety, anger or doubt, then parents are able to acknowledge their feelings and support them through the difficult time. Pain does not have to result in damage if it is responded to appropriately.

Impact of legal changes

The ending of anonymity for gamete donors in 2005 signalled the acknowledgement of the government that people created via donated gametes did have a right to know about their background and choose to have contact with their donor from age 18. The HFEA's latest Code of Practice states that, "Clinics should encourage and prepare patients to be open with their children from an early age about the circumstances of their conception." What has not yet been enshrined in any law or guidance is the imperative that parents MUST tell their children and this issue has been the subject of recent interest by the Joint Parliamentary Scrutiny Committee who have been looking at amendments to the HFE Act. They have asked the Government to look seriously at the

possibility of putting information about the fact of donor conception on children's birth certificates so that parents' hands are forced.

HFEA records open soon

In the meantime the first 18 year olds conceived following the enactment of the HFE Act in 1991, come of age in 2010. At this point any young person can approach the HFEA to ask if they were donor conceived. They can also get any non-identifying information that his or her parents have not passed on and discover the number, gender and year of birth of any other young people and children conceived from the same donor. If a donor has re-registered as 'willing to be known' this information can also be conveyed at this time. For both young people and their families any or all of this information could have a life-changing impact, particularly if the young person concerned has not been 'told' by his or her family. In anticipation of the register opening, the Department of Health asked the British Infertility Counselling Association to research the need for counselling services that might result from this and in 2002 they produced the report *Opening the Record*. This document recommended that intermediary services should be available not just for the young people themselves but for their wider family as well, recognising the ripples of disturbance that could spread to parents, siblings and grandparents. Although this report has been accepted in principle, funding for the services recommended have yet to be agreed.

Who might need services?

Apart from these 18 year olds, who else might need either formal intermediary services or informed guidance and support? Sperm donation has been practised in an organised way in the UK since the 1940s. The oldest DC adult known to me is 63 years old. It is impossible to know how many DC adults there are from the pre-1991 era, although when my husband and I first had treatment in

1982 there were several clinics, both NHS and private, offering DI in London, plus centres in Sheffield, Exeter, Manchester and elsewhere. By that time most clinics were operating a voluntary code on the numbers of children conceived from each donor but evidence from the papers of one donor from the 1950s shows that he was responsible for over 100 births. The only way that people conceived before August 1991 have a chance of making connections by mutual consent with their donor or half-siblings is via UK Donor Link, the voluntary register that is funded by the Department of Health.

The HFEA holds accurate records of all donor conception treatments and most live births from 1991 until now.

Just to quote some of the figures from the HFEA Register data published earlier this year –

27,267 live births between 1992 and 2004

1868 live births in first year – these children now 15

2431 live births in second year – now 14 year olds

How many know about their origins?

Increasing prevalence of unaccountable egg, embryo and some sperm donation abroad, means that these statistics will soon be an underestimate of the number of children born in this country via gamete donation. We do not yet know if conception abroad will raise significant issues for the children.

There are, therefore, potentially a very wide range of DC adults, children and their parents who may at some time during their lives require services from people who have some understanding of their particular issues and needs.

Who should provide services?

Who should be providing these services? At the moment some counsellors in clinics, mostly NHS ones, are able to see parents who have had gamete donation under their auspices many years before. If the counsellor is well qualified and experienced she or

he may be able to offer excellent support and guidance. But we know that many clinic counsellors do not have qualifications that enable them to go beyond the standard practice of implications counselling prior to treatment, and in any case most private clinics do not see their remit as extending to after-care many years beyond treatment. It is also true that many parents would not want to return to the scene of the emotional turmoil of their infertility and it would be inappropriate for donor conceived adults to receive counselling at an infertility clinic.

UK Donor Link has a network of trained counsellors all over the UK – mostly from adoption backgrounds – available to support and guide donor conceived adults, donors and extended families who register with them. It has been suggested that these people could provide a service for DC adults who approach the HFEA register, but the financial implications of this proposal have yet to be addressed in any real way.

At DC Network I talk on an almost daily basis with parents who have run into difficulties of one sort or another. Many can be supported and helped simply with good listening from someone who understands the issues. Others, such as the dad who rang to say that his wife was not bonding with their egg donation baby; the woman, pregnant with a DI child, wondering whether she should have an abortion as she felt she had made the wrong decision'; the mum whose ex-partner had taken out an injunction to stop her 'telling' their two DI children – all require a level of expertise, in psychology, family dynamics and the law, that is beyond our organisation.

I am a qualified counsellor and am lucky to have available to me the advice and support of a clinical psychologist, who is sometimes able to see families with serious problems, but there is no other service where the professionals concerned appear to have any knowledge about donor conception issues.

What is needed is to raise the profile of donor conception as one of the many ways of founding a family and alongside this an understanding of the ways that DC families – like any other family – may run into trouble at some point. It would probably be helpful to have a couple of centres of expertise and excellence in the country, but only those with the most serious problems might need direct help from them. These centres, however, could be responsible for informing and training a variety of professionals and para-professionals so that a wide range of people could help with problem solving and strategy building. The mix of skills that would then be available would give families choices about who they felt could best support them.

Change the culture to change the attitude

The only way to raise the profile of donor conception as simply one of the ways of creating a family is to change the culture of secrecy that has surrounded it for so long. Staff in clinics could play a major role here. Whilst donor conception, particularly sperm donation, is often treated as a final, desperate option for parenthood rather than simply not a first choice, then it is going to be difficult for would-be parents to think of it as anything other than second rate. Male doctors and embryologists have a particular problem with this one.

And whilst there is an ambivalent or inconsistent attitude to ‘telling’ would-be parents are going to be at best confused and at worst interpret such an attitude as colluding with their fears about what they are doing. A cheerful assumption that they are going to tell, backed up with some information about the literature that is available to support and guide them in carrying it through, could go a long way to helping would-be parents feel ‘normal’ and give them the confidence that ‘telling’ can be done without losing the love of their child or being laughed at by others.

To conclude, intermediary services at different levels according to need, would undoubtedly be of great value to DC families, but

what could help most in the long run is if clinics could shift their focus – at least where donor conception is concerned - from baby-making to understanding their role in creating families. The first is short-term (and of course vital for the family to come into existence at all), but the second is long-term and the consequences of donor-conception are life long.

May I ask you to go back to your clinics and initiate a discussion on how best you can put into practice the new HFEA Code of Practice guideline about supporting parents to tell at an early age. It could make all the difference.

Thank you.