

# New Families and Genetic Identities: Developments in law, policy & research.

Conference held at the LSE, 20-21<sup>st</sup> June 2013

This conference report was written by Antony Blackburn-Starza, PhD Candidate at Kent Law School and class teacher on the medical law course at the LSE.

It is often said that reproductive technologies (RTs) challenge traditional family models, but what has received less attention to date is how these 'new families' navigate the complex thicket of social, legal and policy norms involved in coming to terms with - or understanding of - their involvement in RT.

A two-day conference organised by Professor Carol Smart and Dr Petra Nordqvist of the University of Manchester's Morgan Centre and Dr Julie McCandless of the Department of Law at the London School of Economics (LSE) explored the importance of resemblance, relatedness and genetic connection in families who have used RT – particularly donor conception - and the meaning attached to genes. Below is an overview of some key themes that emerged from a very thought provoking and illuminating two days.

## **Families**

The presentations provided insight into how families experience RT and the meanings attached to biological origin and genetic identity. People are, on the whole, very interested in their own genetics and their ancestry. Dr Nick Barrett, genealogist for the BBC's 'Who Do You Think You Are?', opened the second day of the conference by emphasising how finding about one's genealogy is not simply a pastime for the retired, but carries a great deal of meaning for those wanting to track down and personalise genealogical information.

Personal identification with the past helps people build their own identity, Barrett said. Historical placing and narratives were some of the core concepts that emerged from the presentations, but how are these played out within family units?

Professor Carol Smart and Dr Petra Nordqvist from the University of Manchester presented research into the experiences of living with donor conception in heterosexual and lesbian families, highlighting the relative importance of resemblance in each family and the feeling of

belonging. These safe or common assurances can be challenged when a child born using donated gametes, or from non-traditional conception, is introduced into the family.

This research emphasised that the wider family is important to how a child feels as belonging to that family and highlighted the multilayered relational bonds that make up the family unit. For these families, genes clearly matter. Our place is important to our ontological security and positioning space, Professor Smart said, but this importance is not necessarily played out in the most logical or rational way.

As much as a child's origins count, the way different family members interpret this varies enormously and is constructed within a complex system of everyday relationships. Perhaps, then, an understanding of kinship rather than lineage can help one to appreciate the meanings of genes in families, suggested Professor Smart. Professor Jennifer Mason, University of Manchester, said her research showed that resemblance is frequently discussed in families in a combination of potent and trivial forms. It is a force to be reckoned with, not reducible to genes or kinship, she said.

These are 'affinities and alterities' - changing, dynamic and unsettled. They are negotiated, contested, and jostling, said Professor Mason. As such, it appears that the meaning attached to genetics is necessarily unique to each family arrangement, and any attempt to generalise across the board may lose this crucial aspect.

Families also build their own narratives around identity, explained Dr Janice McLaughlin and Dr Emma Clavering, University of Newcastle. The act of changing a name or surname to avoid a negatively viewed past, for example, can silence undesirable social factors. It seems, therefore, that the ability to fashion one's identity by past, present and future is not limited to each individual member of a family, but can be orchestrated by a family as a unit.

Just to add to the mix, the interaction between the 'family' and genetics is not only reactive and reflexive, but also recasts pre-existing belief-sets. New scientific discoveries do not write themselves onto blank slates unimpressed by existing cultural framework, explained Professor Smart - there is a great deal of tussle that goes on here. But RT also presents very real challenges.

A family's experience of adapting from a 'traditional model' and introducing a child conceived by RT can involve an array of emotions as well. Families struggle with disconnection where everyday differences are spotted, picking up on preferences that are not matched in the family. These can serve as everyday reminders, for the family, that the child may not be genetically related, and the lack of a genetic connection can give rise to a feeling of loss. From a counselling perspective, Tracey Sainsbury of the London Women's Clinic said that parents and families are seeking certainty and are anxious, with revolving feelings around the donation process. However, in a supportive environment, through bargaining and dialogue, people can deal with issues much better.

What was remarkable about this theme was just how naturally fluid feelings within families were. This 'ability to get on with things' was later highlighted by the University of Kent's Professor Sally Sheldon, who pointed out that although people may hold cultural preconceptions, families have an ability to get on with things and can do so in a flexible and sophisticated way. What emerged from the presentations was a very interesting balance

between the unease and vulnerability expressed by some, with a countervailing robustness and resolution to accommodate any potentially threatening differences, either explicit or implicit, into the family 'unit'.

## **The Law**

Another central theme that emerged from the two days was the relative inadequacy of the law's response in ensuring proper recognition of new forms of familial relationships - 'relative', in that the law remains always slow to catch up with fast-paced social change. How can the law, charged with ensuring certainty and clarity, possibly respond to such changes? Messiness can be a significant problem for lawyers, Professor Sheldon pointed out. The issue also raises important jurisprudential questions about law's positioning in its response to families using RT.

There are few people more experienced to provide an overview of the law on parenthood and its application to new families than Baroness Hale, deputy president of the Supreme Court, presenting the first session. The law on parenthood considers the birth mother as the legal mother. For legal fathers, the situation can be remarkably complicated, but the need for determining cases in the best interests of the child requires consideration of parenting roles. However, the rules, designed to ensure a child has two legal parents, interfere with genetic parenthood without consideration of the welfare of the child. The potential gap between how the law operates and how families operate was a key theme that emerged from the conference.

For example, there is a difference between a legal parent and what it means to a child to have a parent, Lady Hale said, remarking also that family networks are an important feature in a child's life. Furthermore, gestational parenthood is not the same as social or psychological parenthood. In response, Natalie Gamble, of the law firm Natalie Gamble Associates, acknowledged that welfare could not be placed any more centrally but the way it is applied in practice can be problematic. The language we have to explain family dynamics is immature, she said.

The conflict between the law's certainty and the fluidity of new family arrangements was neatly summed up in the discussion over birth certificates. The LSE's Dr Julie McCandless highlighted how birth certificates have been characterised as a 'true genetic' record of a child's origins, but there is no straightforward view on parenthood or genetic identity. Registration is not just about recording information, she said, but can be seen as something that facilitates the parents' relationship with the child. Perhaps the law needs to catch up with this way of thinking.

However, it is one thing to charge the law with the need to keep pace with society, and another to appreciate that the law itself is politically charged. The rules around birth registration have historically evolved from political realities. Professor Eddy Higgs, University of Essex, explained how civil and church registration originally underpinned property rights and inheritance, but as the state came to regulate birth certificates it became less about lineage and more about eligibility for state services. Birth registration is not about the biological family, he explained, but the legal family – about rights and obligations. Perhaps, then, the law's separation for people's expectations and understandings is not surprising.

But should the law be so receptive to social use of genetic concepts, new families and the meaning conferred by things like birth registration? Professor Carol Sanger, Columbia University, spoke of legislative measures in the USA to introduce so called 'Missing Angel Acts' (permitting the recording of a still birth through a 'birth' as opposed to a 'death' certificate) and highlighted some concerns with the 'therapeutic use of the law'. Although such practices demonstrate how mundane legal rules can be translated into meaningful symbolic gestures, is the use of such 'legal fictions' ethical? Or are we being too fastidious, she asked?

Professor Titti Mattsson, University of Lund, provided a comparative view from Sweden and said that genetic bonding has become an explicit concern for the legislature. A shift away from genetic relations to parenting was also observed, she said. Providing another perspective from Denmark, which has maintained donor anonymity, Professor Janne Rothmar Herrmann, University of Copenhagen, explained how many saw no need for special regulation as fertility procedures are offered by the medical professionals. Guidelines focus on safety and quality control. Lessons from these jurisdictions highlight the many different ways of doing things.

## **Policy**

Developing policy in light of such complexity must be quite terrifying. Dr Rhona Knight, chair of the Nuffield Council on Bioethics' working party on donor conception, placed emphasis on values in relationships, saying that openness – telling the child about their biological origin – contributes to the quality of the relationship. The state, in a stewardship role, should support decision making and not remove choice.

The policy of supporting families in reaching their own decisions was an important theme of the conference. Venessa Smith of the London Women's Clinic spoke about her obligations as coordinator of a sperm bank to give the right advice, especially when some people return years later to ask questions about the donor. When patients decide on a donor, the most obvious thing to think about is a physical match, as well as family relatives or parties, she explained. But that has become less important for some lesbian couples who want to match donors to the non-genetic partner, or for single women who want to match according to the partner they want to meet. Interestingly, patients create stories with that donor, she said, and want to continue using them. The bigger picture becomes important – how much information we need to make the right choices.

On disclosure, the University of Cambridge's Professor Susan Golombok presented new data on how donor conceived children understand biological heritage around the age of seven. For those who were told by the age of four or five, no negative reactions were reported. Children do not appear to be distressed by donor conception or surrogacy – they seem to integrate information about the donor conception or surrogacy into their family narratives. This again, seemed to affirm the family's ability to assimilate complex information in an open and supportive environment.

The conference was interesting in the way it addressed key debates around parenthood, genetic identity and donor anonymity. Debates around Rt and collaborative reproduction can at times appear to rest on individualised notions of rights and responsibilities, but, for me, this conference demonstrated that such considerations leave out the influential role played by

other family members, and how understanding is partly orchestrated by familial arrangements.

Considering the regulatory challenge in this area, if there is one, the final presentation of the conference sent out a clear message that we should not resist change without logical and defensible reasons. Professor John Harris, University of Manchester, closed the conference with an argument against the ban on human reproductive cloning. He challenged some long held assumptions against permitting the technique and reconsidered the evidence for a cloning ban that, in his view, could not justify the prohibition of a potentially life saving technique.

Cloning, he said, was a case study for our attitudes about genetic identity and similarity. The sort of knee jerk reaction in response to human cloning might be a lesson for those troubled by the idea of new genetic families. If we remain clear headed about the way we think about new forms of family models created by RT, perhaps our conception of the right mode of regulation will remain evidence based. Prohibition – or perhaps even intervention – must be justified. Further still, perhaps we should embrace change, as Harris urges. If we leave behind romantic associations with genes and genetics, and all that we build around this, then policy making and the laws that accompany could take a rather different form. Whether families themselves will do this, however, is rather questionable.