



**ESRC GENOMICS NETWORK: GENOMICS AND IDENTITY POLITICS
WORKSHOP SERIES 2009-03-02**

**We Are Family? The Genetics and Identity Politics of Parenthood and
Family**

19th – 20th February 2009, ESRC Genomics Forum, Edinburgh.

Workshop Report

Maren Kotz

Background to Workshop:

This was the fourth workshop held as part of a stream of five workshops investigating the phenomenon of genetics and genetic knowledge within the sphere of identity politics. Previous workshops have focussed on issues such as the categorisation of ethnicity (E-genis); health activism (Cesagen); the forensic use of DNA and genetic databases (EGN Forum). The final event will bring some of the major themes discussed throughout the series together and is planned for later in 2009. This is a report of the fourth workshop that raised questions about how family and parent-child relationships are constructed, resisted or affirmed, and the role of genetics in that process. The discussions were based around three inter-linked themes: 1) Reproducing the family: *Children of your “own” or “your own” children?* 2) Children’s “need” for a father and mother: *Who’s the Daddy?* 3) What and who is family?

Issues for discussion included:

- What implications does the recent recommendation by the HFEA to remove reference to the “need for a father” have for lesbian and gay couples wishing to have a child?
- How has the need for couples to have their “own” children interacted with technological and medical advances?
- Should children born from donated eggs or sperm be able to source this information from their birth certificates?
- What is family in the context of genetic risk information?
- In the absence of a biological connection to a parent, does a social connection suffice? In what ways is genetic inheritance important?
- How do we recognise and maintain family relationships? For example, what is the role of character traits and physical resemblances in maintaining relations?

The event was organised by Gill Haddow at INNOGEN with help and support from Katie Featherstone, Janet Carsten and Jennifer Speirs. Thanks go to Angela McEwan at INNOGEN and Margaret Rennex at the EGN Forum for essential administrative support.

The workshop brought together academics from the fields of science studies, anthropology and counselling to discuss the role of genetics with regards to changing constructions of the family and kin relationships in different legal and social arenas. Reproductive technologies and the ways in which they raise questions about the importance of “genetic information” proved to be one of the main anchor points of discussion. The workshop finished with an experimental exploration of family concepts and narratives by using fiction writing.

Speakers: Katie Featherstone (Senior Lecturer, Nursing Health and Social Care Research Centre, Cardiff University)

Martin Richards (Emeritus Professor of Family Research, University of Cambridge).

Jennifer Speirs (Research Fellow, Innogen, University of Edinburgh)

Carol Smart (Professor of Sociology, Morgan Centre of the Study of Relationships and Personal Live, University of Manchester).

Commentators: Janet Carsten (Professor of Anthropology, University of Edinburgh)

Caroline Jones (Lecturer at the School of Law, University of Southampton)

Susan Kelly (Senior Research Fellow, Egenis, University of Exeter)

Session 1: Family Secrets:

The first workshop session “Family Secrets” had Katie Featherstone from the Nursing Health and Social Care Research Centre of Cardiff University present on “Risk and Relations: kinship and genetic risk”. The second speaker in the session was Carol Smart from Manchester University. She spoke about “Family Secrets: Law and Understandings of Openness in Everyday Relationships”. While Smart focused on “reproductive secrets” within everyday family life, using data from the Mass Observation Archive, Featherstone focused on the specific clinical setting of genetic risk information procedures and how this information was then dealt with by families and individuals outside of the clinic. She argued that new reproductive technologies have the capacity to destabilise classic kinship categories, while genetic technologies within risk research seem rather to reinforce traditional concepts of kinship, which attribute great social importance to genetic ties. Drawing on her own ethnographic work and on collaborations with other Cardiff researchers, Featherstone described how clinicians mainly assume unobstructed and straight forward channels of communication about genetic risks “running in the family”– while more complex communication strategies were adopted by the concerned families. Featherstone then went on to describe different “risk management strategies” within everyday family life. For instance, how genetic risks were talked about in these non-clinical settings ranged from employing rhetorical devices, such as humour or detachment, to very often deferring the disclosure of the risk information to the rest of the family, while firmly stating to be willing to disclose in the future. She argued that some of these strategies, e.g. the search for “the right time to tell”, could be interpreted as “performing responsibility” in conjunction with the clinical discourse on taking responsibility for one’s genetic risks.

Moving away from the clinical setting altogether and focusing on “family secrets” as a more general theme to family life, Carol Smart then went on to explore conflicting moralities and concepts of truth in family information “politics”. From her research on covert issues in family life as reported to the Mass Observation Archive, she presented narratives on family secrecy as a source of joy and mystery – and deliberation on changing concepts of family and morality. She also explored the concepts of “genetic truth” and “kinship certainty” as they have sprung up in recent precedent cases on parental responsibility. Arguing from a Foucauldian perspective, Smart argued that attention should be paid to the power relations embedded in, for instance, the presented court debates on genetic, legal and local familial truths. Diagnosing a growing legal tendency to prefer “genetic truths” instead of more complex relational approaches, Smart contested the one-dimensionality of claims about the harmfulness of family secrets and the harmlessness of truth telling.

Janet Carsten commented on both papers by pointing out their commonalities in focusing on the pressures to be open and to reveal “personal truths” in very personal relationships. Nevertheless, the papers approached these issues from highly divergent starting points: while Smart took the everyday normality and even pleasures of interacting and interpreting family secrets as a starting point for her discussion, Featherstone focused more on the risk discourse around family. Carsten also warned against becoming too narrowly focused on concepts of truth and information in relationships, thereby losing sight of the processuality and relationality of these ties. In the ensuing open discussion the concept of child welfare as informing legal discussions around “genetic truth” in a family context came under closer scrutiny as presupposing a forever passive child that never grows up. It was also argued that “DNA based truths” lack the temporality of more local familial truths and are therefore potentially more compatible with similar legal concepts.

Session 2: Who are Family?

The second workshop session “Who are family?” examined concepts of parentage and “the making of” families within the complexities of what Martin Richards called “collaborative reproduction”. As the first speaker in the session he gave a paper entitled “Who are father and family in the realms of assisted reproduction and DNA testing”. Richards started off by exploring the concept of collaborative reproduction with regards to donor insemination (DI), pointing to various actors involved in the process: not only social parents, clinicians and donors, but also regulators and judges. Richards pointed to the differences between what he perceived as a growing genetic essentialism within legal disputes on paternity and the prevailing tendency of parents opting for DI to maintain secrecy on the treatment, thereby creating “as if” families. He also pointed out that only lesbian couples and single women seem to be actually forming new collaborative reproductive families by integrating the “extended donor family” into their kinship networks. Richards argued that one unexpected outcome of research into these networking processes at the Cambridge Centre for Family Research was the prevalence of searches for half-siblings through donor registry websites, these searches outnumbering the searches for actual donors.

Innogen researcher Jennifer Speirs’ paper “Family Matters?” also focused on social and regulatory issues with regards to donor insemination. Speirs took as an exploratory starting point for her paper describing her anthropological research into a Gaelic speaking community where she described identity, kinship and genetic inheritance as existing as closely intertwined concepts. She then went on to discuss the findings of her research into DI and possible contacts between DI children and donors, pointing out that even though often reported otherwise, the former donors she interviewed were actually interested in finding out about their donor offspring. She argued that it

was mainly the lack of a “cultural script” for managing contact, and exclusive ideas of fatherhood (where the genetic was threatening to override the social), that produced some anxieties with donors and their families and which informed the views of health professionals and policy makers on the subject.

Caroline Jones from the University of Southampton in her commentary related the two papers to discussions around identity in the first session and pointed to the prevalence of critiques of the concept of genetic identity throughout the workshop. Jones also argued that some of the problems regarding the legal regulation of kinship ties, especially with regards to relatively new reproductive technologies, stemmed from the implication of inherently different social arenas, one being the arena of regulation with its “in-built” need for clarity and one being everyday life with its intrinsic ambivalences. The following open discussion focused on the prevalence of exclusive concepts of parenthood as a likely historical outcome of a mix of the practical politics of material inheritance and religious ideology.

Session 3: Family Matters

Friday’s sessions were more exploratory, consisting of a roundtable discussion led by Susan Kelly (Egenis, Exeter) on “Family Matters?” and writing workshop led by the Genomics Forum writer in residence Pippa Goldschmidt. Kelly chose two themes for further discussion within the roundtable framework. Firstly, she asked how eugenic ideas – or the prevention of eugenics – were related to the regulation of DI. Secondly, she queried how one could actually unpack the “incest-taboos” with regards to DI for further analysis. She pointed out that the discourse around incest in a US-American context was characterised by eugenic connotations and also by discussions around social pathologies, and noted that she could also see eugenic ideas implicitly resonating with the official selection processes of donors. In the ensuing discussion unwitting incest was identified as a prevailing “folk” concern with regards to DI, which could potentially gain more prevalence in settings with very few donors and close networking between DI children (e.g. through new internet based networks). However, it was also stressed that the concept of incest is so inherently culturally and symbolically laden in other social contexts that its applicability could be questioned with regards to DI offspring. Even though it was dismissed in the discussion that there is a strong connection between eugenics and DI as an actually applied method for assisted reproduction, it was pointed out that there is a history within the historical eugenic movement of reflecting on sperm donation as a eugenic project – influencing such projects as the now defunct Noble Prize winner sperm bank in the USA.

Drawing the workshop to a close, the writing workshop invited participants to explore concepts of the family and kinship narratives by the means of fiction writing. Participants first discussed several extracts from fiction writing which dealt with family relationships. Passages

chosen for discussion were, among others, “Oranges are Not the Only Fruit” by Jeanette Winterson and “The Adoption Papers” by Jackie Kay. The following more general discussion concentrated on the central role of story-telling as a means of constructing identities, with family narratives playing a vital part in this process. It was also discussed how fiction writing could actually provide an experimental context for social science researchers to explore cultural and personal meanings of family. The workshop closed with the participants writing and discussing short literary episodes, so called “flash fictions” on family secrets.

The evaluation report showed that the vast majority of attendees were very satisfied with the structure of the workshop, presentations, opportunities for networking, location, dinner etc. The presentations were visually recorded and made available on the EGN web-site (www.genomicsnetwork.ac.uk).

Synopsis prepared by Maren Klotz

Speakers and Attendee Biographies:

Janet Carsten:

Janet Carsten has conducted fieldwork in Malaysia and Britain. After completing her PhD at the London School of Economics, she was a Research Fellow at the University of Cambridge, and Lecturer at the University of Manchester. She has given guest lectures and keynote addresses at Johns Hopkins University, the National University of Taiwan, UCLA, the University of Copenhagen, and University of Michigan. Janet Carsten has recently published an edited volume on kinship and memory, and has been awarded a three year Leverhulme Major Research Fellowship from September 2007 to conduct new research on articulations between popular and medical ideas about blood in Britain and Malaysia.

Emma Clavering:

I have worked for several years exploring various aspects of family social worlds including issues around health, diversity, and marginalisation. My current research is an ethnographic study of changing notions of self and kinship for families involved with paediatric genetic services (PI: Janice McLaughlin). This 3 year project started in Nov 2008, and we are planning to begin the fieldwork in Spring 2009.

Sarah Cunningham-Burley:

Sarah is Co-Director of the Centre for Research on Families and Relationships at Edinburgh University and her research interests span medical and family sociology and include the social aspects of genetics and stem cell research, as well as research on families, health and illness across the lifecourse.

Katie Featherstone:

Featherstone's expertise is in the sociology of biomedical knowledge, with particular emphasis on the social consequences of new genetic technologies and the technologies of clinical evaluation and translation. The recurrent theme of this work is the production and translation of biomedical knowledge and the interaction between the laboratory, the clinic, and patient populations. Her methodological expertise is in qualitative and ethnographic research methods. Featherstone has produced a body of ethnographic and qualitative work that includes a number of studies examining social aspects of genomics. Specifically: kinship and disclosure in the context of genetic risk information (the monograph 'Risky Relations' funded by The Wellcome Trust); the social consequences and clinical utilisation of new genetic technologies, specifically within dysmorphology and the classification of genetic syndromes (ESRC); and the molecular, clinical, and family construction of Rett syndrome (The Healthcare Trust). In addition, she has a body of work using qualitative and ethnographic methods to examine the technologies of health service

evaluation and clinical translation, examining the randomised controlled trial (MRC), clinical guidelines, and appropriateness ratings (NHS). Featherstone leads the 'Genomics' research theme and is Director of Postgraduate Studies (Research) within the School of Nursing and Midwifery Studies. She is also part of the Cesagen 'Biomedicine, Identity and Behaviour' theme and is leading their collaboration (with the Department of Psychological Medicine, Cardiff) to examine the development and translation of genetic technologies for complex (polygenic) conditions within the field of psychiatry.

Pippa Goldschmidt:

Pippa Goldschmidt is currently a writer in residence at the Forum. She has just received an MLitt in creative writing from Glasgow University and has had several short stories published. Much of her writing is inspired by science. She used to be an astronomer, and has also worked in Government in a variety of policy areas, including the regulation of outer space.

Gill Haddow:

I am senior research fellow at the ESRC Innogen Centre and my interests are mainly in the area of the sociology of genetics and the body. I joined in 2004 to work on the public consultation of Generation Scotland. This research is completed although I will be building upon it in order to look closer at the effects public consultation has on the governance of large-scale DNA databases. Other research interests include organ donation and transplantation, the democratic mandate of genetic interest groups and the regulation of cytoplasmic embryos and xenotransplantation.

Erica Haimes:

Erica is Professor of Sociology in the School of Geography, Politics and Sociology, University of Newcastle and is also Executive Director of PEALS (Policy, Ethics and Life Sciences) Research Centre, a collaboration between the universities of Newcastle and Durham and the International Centre for Life, Newcastle.

Katrina Hargreaves:

Katrina is a researcher with an interest in genetics and identity in the context of assisted conception using donor gametes. For her PhD she carried out a qualitative study of New Zealand families with children conceived by donor insemination. She currently holds a position as a Research Fellow at the Social Science Research Unit, Institute of Education, University of London.

Christine Hauskeller:

I am Senior Research Fellow in Egenis and lead and conduct research on Genetic Knowledge and Human Identity and on Biomedical Life Science. My training was in Germany and included an MA in Philosophy, Sociology and Psychoanalysis and a PhD in Philosophy on Theories of the Subject and the Body. My presently personal research interest is on the interaction between epistemologies and ontologies shaping the different disciplinary forms of knowledge and certainty that contribute to the sciences of life and humanity. For more information see the Egenis staff web pages.

Caroline Jones:

Caroline is a Lecturer at the School of Law, University of Southampton. Her research interests lie in assisted conception and the regulation of reproductive technologies; constructions of kinship and family; and in the fields of family, tort and health care law generally. She is a founder member and coordinator for the Health, Ethics and Law (HEAL) network at the University of Southampton, and the author of *Why Donor Insemination Requires Developments in Family Law* (Edwin Mellen, 2007)."

Susan Kelly:

My principle areas of interest are a sociology of the science of fetal/maternal cell and other natural and produced forms of micro/chimerism, with a particular interest in the 'disruptive' potential of various forms of genetic multiplicity; the phenomenology of impairment specifically within the context of genetic and other biomedical intervention into childhood genetic disorders; and the production (e.g., through genome wide association studies), impacts and clinical implications of genetic discoveries for common and complex disorders. As a Senior Research Fellow at Egenis, I am developing or continuing projects in these areas.

Maren Klotz:

Maren is employed as a research fellow and PHD student at the Collaboratory for Anthropology and the Life Sciences (CSL) at the Department for European Ethnology of the Humboldt University Berlin / Germany. She is also a PHD student at the EGENIS Centre in Exeter. Her PHD is supervised under a cotutelle agreement by Christine Hauskeller at Egenis and Stefan Beck at CSL. The working title of her ongoing bi-national PHD project is: "Managing Kinship-Knowledge: Familial and regulatory 'information-management' during assisted conception". Maren holds an MSc from the Egenis Centre and an undergraduate degree in Social Anthropology / European Ethnology from the Humboldt University Berlin. She is particularly interested in regulatory and familial practices regarding anonymity, secrecy and everyday practices of data-management regarding both reproductive technologies and adoption.

Ali Maleki:

PhD Student in Science and Technology Studies; Fields of interests: Policy in high tech industries, Innovation Policy in Life science industry, Innovation in developing countries Science, Technology and Development, Transformation from natural resources to knowledge economies.

Petra Nordqvist:

Petra is in the third and final year of her PhD studies into lesbian couples' experiences and understandings of donor conception. She takes a particular interest in notions and constructions of biology, genes, likeness and togetherness in relation to ideas of connectedness, family, kin, race and sexuality in donor conception.

Hilary Osborne:

Hilary began work at the Genomics Forum in June 2008 to establish a network for public engagement with healthcare genetics – Gengage. Hilary has a background in health service management and has previously worked at a hospital in Kent and for a national network dedicated to service improvement and sharing good practice.

Martin Richards:

Until my retirement I was Director of the Centre for Family Research and Professor of Family Research at the Centre for Family Research, University of Cambridge where I carried out research on parent-child relationships and aspects of family life. For the past decade my work has focussed on social aspects of genetic and reproductive technologies. I am Vice-Chair of the UK Biobank Ethics and Governance Council and a member of the HFEA Ethics and Law Group

Gillian Scott:

Gillian Scott is the Development Officer for the Genetic Interest Group in Scotland. She is involved in patient engagement and representation to inform the political and professional discussions about the services and resources needed to provide high quality medical genetic services for the future. Her background is as a Genetic Counsellor. She is on the UK & Eire Genetic Counsellor Registration Board and on the Scottish Genetic Education (ScotGEN) Steering Committee.

Roona Simpson:

Roona is a Research Fellow at the Centre for Research in Families and Relationships. Her teaching and research interests include changing conceptions of the family, and intimate citizenship.

Carol Smart:

Carol Smart is Professor of Sociology at the University of Manchester where she is also Co-Director of the Morgan Centre for the Study of Relationships and Personal Life. She has carried out research on families and relationships for many years and her latest book, *Personal Life*, was published by Polity in 2007.

Jennifer Smith:

Jen's research in this area has focussed on the construction of identity in relation to public and policy debates around access to reproductive technologies. A specific focus has been on the constructed relationship between the 'potential mother' identities constructed through the debates and the putative identity of the frequently evoked imagined 'unborn child' identity. Her phd thesis (UNiversity of Queensland, Australia, 2005) used parliamentary debate, newspaper texts and women's personal narratives to investigate the construction of women's identities as mothers in the Australian debate around single and lesbian women accessing reproductive technologies. Smith, J.L. 2006 'Mothergovern: public policy debates on access to reproductive technologies' *Reframing Social Policy: A Governmental Approach* C. McDonald and G. Marston (eds), London, Edward Elgar. Smith, J. L. 2003, 'Suitable Mothers': Lesbian and single women and the 'unborn' in Australian parliamentary discourse' *Critical Social Policy* 23(1):63-88.

Jennifer Speirs:

Jennifer Speirs obtained her PhD in 2008 for a thesis entitled 'Secretly connected? Anonymous semen donation, genetics and meanings of kinship'. She qualified originally as a medical social worker and has extensive experience in the statutory and voluntary social work sectors in the UK especially in the areas of community social work, child care, adoption and fostering, origins counselling and infertility counselling. She was a lay inspector for the Human Fertilisation and Embryology Authority from 1991 to 2007. She is a sessional counsellor for UK Donorlink and represents the British Association of Social Work on the advisory council of the National Gamete Donation Trust.

Steve Sturdy:

Steve is Deputy Director of the ESRC Genomics Policy and Research Forum and Senior Lecturer in Science Studies at the University of Edinburgh. He has researched extensively in the social history of medicine and medical science, and he is currently writing a book chapter on identity politics and forensic uses of DNA technologies.

Richard Tutton:

Richard works at the intersections of the social studies of science and medical sociology, with interests in the social and political aspects of biomedicine and genomics, and more specifically

in the banking of human tissue and the implications of contemporary life sciences for identity and citizenship.

Dita Wickins-Drazilova:

Dita is currently employed at the Department of Philosophy, Lancaster University, as a research assistant working on IDEFICS project assessing the problem of raising prevalence of obesity in children: <http://www.lancs.ac.uk/fass/philosophy/activities/226/>. She also works at the Sheffield Institute of Biotechnological Law and Ethics (SIBLE), University of Sheffield on the PRIVILEGED project that deals with ethical and legal issues of the use of genetic databases and biobanks for research: <http://www.privilegedproject.eu/>. Her research interests include biomedical ethics, public-health, ethics and biomedical ethics concerning childhood, animal bioethics, use of animals in research, and governance of biobanks and genetic databases.

Sarah Wilson:

Sarah is currently a Lecturer in Sociology at the University of Stirling where she teaches an option on the Sociology of Childhood. Her LLM thesis explored the question whether biographical information concerning the sperm donor should be disclosed to children conceived through donor insemination with reference to legal developments in Sweden, Australia, England and Scotland. It criticised arguments for disclosure based solely on the importance of genetic ties. These arguments were analysed in terms of a 'fixed' notion of identity. However, I argued for disclosure based on a notion of 'narrative identity'. This notion underlined the importance of social parenthood as compared with genetic ties. However, it could also provide an explanation for the disclosure of biographical information to children in this and analogous positions with reference to the difficulties caused by their uncertainty as to their past. This thesis formed the basis for an article: Wilson, S. (1997) 'Identity, Genealogy and the Social Family: the Case of Donor Insemination' *International Journal of Law, Policy and the Family*, 11, 270-279. Recent research work has focused on family life and relations in the context of parental drug and alcohol problems.

Steve Yearley:

Steve is Director of the ESRC Genomics Policy and Research Forum at the University of Edinburgh; he is also Professor of the Sociology of Scientific Knowledge. Starting out in the natural sciences (chemistry and geology), Steve migrated through the philosophy of science to the empirical study of "science in society". Steve is interested in technical and scientific controversies that spill out beyond scientific domains, and is concerned with the way such topics are regulated.

Zxyyann Lu

My research program has been gender and medicine focused on medical technology and body in recent years. I have researched on risk knowledge construction of HRT by Taiwanese women. Instead of biomedical interpretations of HRT risks by physicians, I found women tended to interpret and manage their HRT risks based on their body constitution such as genetics, lifestyle, or social relation such as marital or colleagues. My current research on the policy of risk management for alternative therapies for the middle aged population with osteoarthritis has indicated that the controversies on policy regulation over a drug have reframed the preventive discourse of osteoarthritis and drug efficacy. In addition, my research project at University of Edinburgh will focus on the comparative study of policies between UK and Taiwan. The attempt is to examine how mass surveillance technology perpetuates the knowledge of a diseased menopausal body, affected by osteoporosis. In addition, voluntary practices of self-surveillance may represent the governmental strategy of disciplinary power by which menopausal women are monitored in the framework of neo-liberalism emphasizing individual choice and freedom.