

CENTRE FOR FAMILY RESEARCH

ANNUAL REPORT (Academic Year 2003 – 2004)

**Director of Centre
Professor Martin Richards**

**Deputy Director
Ms Helen Statham**

Members of the Centre

Research Staff and Post-Graduate Students*

Ms Shirlene Badger*
Dr Elizabeth Chapman
Dr Oonagh Corrigan
Dr Marc de Rosnay
Dr Claudia Downing
Ms Rosie Ensor (née Davie)*
Dr Gail Ewing
Dr Tabitha Freeman
Ms Leila Friese
Dr Joanna Hawthorne
Dr Claire Hughes

Dr Antonella Invernizzi
Dr Julie Jessop
Dr Lynne Jones
Ms Rachel Marfleet
Dr Shobita Parthasarathy
Mrs Maggie Ponder
Dr Ilina Singh
Ms Claire Snowdon
Dr Bryn Williams-Jones
Dr Anji Wilson

Associate Members

Dr Anna Bagnoli
Dr Andrew Bainham
Dr Shelley Day-Sclater
Dr Fatemeh Ebtehaj
Dr Margaret Ely
Dr Judith Ennew
Dr Nina Hallowell

Ms Bridget Lindley
Prof Juliet Mitchell
Mrs Frances Murton
Dr Thelma Quince
Dr Deborah Thom
Dr Jane Weaver

Support Staff

Administrative Secretary	Jill Brown
Data Manager/Librarian	Sally Roberts
Cleaner	Anne Burling

Current Management Committee

Professor Peter Lipton (Chair from October 2004) (Dept of History & Philosophy of Science)
 Dr Mary Griffin (Secretary) (from June 2004)
 Dr Mavis Maclean (Centre for Family Law and Policy, University of Oxford)
 Ms Maggie Ponder (co-opted June 2004)
 Professor Martin Richards (Director)
 Dr Jacqueline Scott (Social and Political Sciences Faculty)
 Ms Helen Statham (Deputy Director)
 Dr Darin Weinberg (Social and Political Sciences Faculty)

We owe a special vote of thanks to Professor Ian Goodyer who has stepped down as Chair of the Management Committee. He was our first Chair and he returned for a second stint. We also would like to thank Professor Bryan Turner and Ms Erica De'Ath for their service on the Committee.

Joiners and Leavers

Shirlene Badger joins us as a Wellcome Trust funded Ph.D student. She will be investigating the consequences of a genetic diagnosis of a group of severely obese children. These children are part of a research study headed by Dr Sadaf Faroqi in Professor Steve O'Rahilly's group in Clinical Biochemistry.

Dr Tabitha Freeman recently completed her Ph.D. at the University of Essex on a sociological analysis of fatherhood. She is developing a new study on the experience and social consequences of DNA paternity testing.

Dr Marc de Rosnay has a Research Fellowship at Churchill College and works on the emotional development of young children.

Dr Claire Hughes' Toddlers Up project has been growing almost as fast as the study children, and now includes a number of local and visiting researchers: Laila Freise (who has recently left the CFR), Keiko Fujisawa (from Tokyo); Dave Lambert (a former SPS student, now enrolled for a PhD) Jesse Leins (from Smith College, USA), Barbara March (from the University of Padua, Italy), Vanessa Murray (from Mexico), Yee-San Teoh (from Malaysia), Dr Anji Wilson and Dr Charlotte Wilson.

During the year we were pleased to welcome a larger than usual group of visitors from around the world. Indeed, we had visitors from every continent except Antarctica. In the visitor section below there are details of all those who worked in the Centre.

RESEARCH OF MEMBERS OF THE CENTRE

Professor Martin Richards – Director

Understanding inheritance and kinship connection (with Dr Anji Wilson). Funded by The Wellcome Trust. 2000 - 2004.

This qualitative study describes everyday concepts of inheritance and analyses possible connection between this and concepts of kinship and family obligation. Qualitative interviews with samples of young people and recent parents were carried out and the work is being prepared for publication.

Non-disclosure of genetic risk information (with Dr Angus Clarke, University of Cardiff and Lauren Kerzin-Storror, N.W. Regional Genetics Service and other collaborators). 2000 - 2004.

This multicentre audit study has collected data on the frequency and circumstances of non-disclosure to family members of significant genetic risk information following genetic counselling. It involves about 15 genetic centres in the UK and Australia. A paper has been submitted for publication.

Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability (with Nina Hallowell, Helen Statham and Lucy Raymond). Funded by The Wellcome Trust 2002-2006.

This ongoing study examining family members' perceptions and experiences of an X-linked severe learning problem before and after the associated gene mutation has been identified (or not) using a high throughput mutation detection technique (the Genetics of Learning Disability Study). See Helen Statham's entry for further details.

Informed consent and genetic data (Onora O'Neill, Patrick Bateson, Peter Lipton and Martin Richards). Funded by The Wellcome Trust 2002-2005.

This project began in July 2002 and is based in the King's College Research Centre.

The project tests the hypothesis that current informed consent procedures do not adequately address either the philosophical or practical difficulties of obtaining consent that can justify the collection, processing and disclosure of genetic data. The researcher appointed to the project is Dr Neil Manson.

Research based outside Cambridge

I am involved in the following collaborative projects:-

Legal Services Commission. FAINS action research. Professor Jan Walker, University of Newcastle and others.

The Basque Government and University of the Basque Country. Family interaction and psychological development of 5 year-old Basque children with Enrique Arranz. Euskal Herriko Unibertsitatea.

Swedish Council for Social Research. Conflict, negotiation and decision making post divorce with Helena Willén, Nordic School of Public Health, Gothenberg.

Canadian Institute of Health Research. Ethics of Health Research and Policy. Ph.D. and Post Doc Training Programme. Centre for Applied Ethics, University of British Columbia and Dept of Philosophy, Dalhousie University.

Genome Canada and Genome British Columbia. Genomics, Ethics, Environment, Economic, Law and Society (GE3LS) Dr. M. Burgess and others, Centre for Applied Ethics, University of British Columbia.

Work continues on the book being written with Laura Riley which has the working title of 'Biotech Babies'. The book is concerned with what is popularly referred to as 'designer babies' and will trace developments from the human selective breeding experiments of the 19th century through eugenic policies and practices and current practices of prenatal and pre-implantation screening and diagnosis and of reproductive technology to possible futures. Papers have been published on the nineteenth century Oneida selective breeding experiment.

I am a Director of the (Cambridge) Centre for Medical Genetics and Policy and on the Advisory Board for the Cambridge Genetic Knowledge Park.

I am a member of The Wellcome Trust Biomedical Ethics Panel.

I continue to serve on the Human Genetic Commission. I am the lead person on Biobank UK and Genetic data base research and I co-chair a working party on Reproductive Choice and Genetics and am a member of the working group on genetic identity and relationship testing.

I am a member of the Human Fertilization and Embryology Authority's Ethics and Law Committee and the HGC observer on the Authority.

Publications

Books

Blackwell Companion to the Sociology of Families (2003) (editor with J. Scott and J.K. Treas). Blackwell. ISBN 0-631-22158-1.

Children and their Families: Contact, Rights and Welfare (2003)(edited with A. Bainham, B. Lindley and L. Trinder). Richard Hart Publishers. ISBN 9.781841.132532

Hawthorne, J., Jessop, J., Pryor, J. and Richards, M. *Supporting Children Through Family Change: A Review of Interventions and Support Services for Children of Divorcing and Separating Parents*. (2003) YPS for the Joseph Rowntree Foundation, York. (ISBN 184263.073). Also available at www.jrf.org.uk

The New Human Genetics

Nuffield Council on Bioethics. Genetics and Human Behaviour: The ethical context (member of Working Party). London, Nuffield Council. ISBN. 190438403X. (2003).

Richards, M.P.M., Ponder, M., Pharoah, P., Everest, S. and Mackay, J. (2003), "Issues of consent and feedback in a genetic epidemiological study of women with breast cancer", *J. Medical Ethics*, 29, 93-96.

Richards, M.P.M. (2003), Lay understanding of heredity. *The Encyclopedia of the Human Genome*. Nature Publishing. ISBN 0-333-80386-8.

Richards, M.P.M. (2003), "Assisted reproduction, genetic technologies and family life", in J. Scott, J. Treas and M. Richards (eds), *Blackwell Companion to the Sociology of Families*, Blackwell, pp 478-498. ISBN 0-631-22158-1.

Richards, M.P.M. (2003), "Attitudes to genetic research and uses of genetic information: support, concerns and genetic discrimination", in B.M. Knoppers (ed), *Population and*

Genetics: Legal Socio-Ethical Perspectives, pp 567-578. Kluwer Legal International, ISBN 90-0413-878-9.

Richards, M.P.M. (2004), "Perfecting people: selective breeding at the Oneida Community 1869-1879 and the eugenic movement", *New Genetics and Society*, 23, 49-71.

Richards, M.P.M.(2004), "DNA families", *Biological Sciences Review*, 16, 8-11.

Richards, M.P.M. (2004), "A 19th century experiment in human selective breeding", *Nature Reviews: Genetics*, 5, 475-479.

Halliday, J.L., Collins, V.R., Aitken, M.A., Richards, M.P.M. and Olsson, C.A. (2004), "Genetics in public health - evolution or revolution?" *J. Epidemiol. & Community Health*, 58, 894-899.

Divorce, Family Change and Children

Wild, L.G. and Richards, M.P.M. (2003), "Exploring parent and child perceptions of interparental conflict", *Int. J. Law, Policy and Family*, 17, 366-384.

Richards, M.P.M. (2003), "Assisted reproduction and parental relationships", in A. Bainham, B. Lindley, M. Richards and L. Trinder (eds), *Children and their Families: Contact, Rights and Welfare*, Oxford: Hart, ISBN 1-84113-253-5.

Family Life

Olabarrieta, F., Martin, J.L., Arranz, E., Manzano, A., Azpiroz, A., Bellido, A., Oliva, A. and Richards, M.P.M. "Familiako giroaren kalitatea eta haurren garapen psikologikoa Euskal Autonomia Erkidegoan: azterketa deskriptiboa" [Family context and development in Basque children], *Uztaro*, 47, 81-95, 2003.

Ms Helen Statham

Senior Research Associate and Deputy Director

Current research

Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability, Genetics of Learning Disability (GOLD) Study – Grantholders are Martin Richards, Lucy Raymond and Nina Hallowell; Maggie Ponder is a co-worker on the study. The study began recruiting participants in April 2003 and will continue until February 2007.

The Wellcome Trust funded research - *Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability* – is a longitudinal study which follows families who have joined the Genetics of Learning Disability (GOLD) Study. The GOLD study aims to identify genes associated with learning disabilities in families currently without any specific diagnosis. The pattern of learning disability in the families suggests that it is likely that the condition is inherited in an X-linked way, ie the faulty gene is carried in females where it is not usually expressed, any son has a 50% chance of inheriting the faulty gene and in that situation, the boy will be affected. Although the psychosocial study is focussed on examining the beliefs, understandings, attitudes and behaviours of family members before and after genetic testing, we are also interested in other aspects of family life and the way in which these families are, or are not, supported by statutory services.

The study has been recruiting families to the study over the last year from all across the United Kingdom; we have interviewed members of 40 families, including mothers, fathers, sisters, brothers, grandparents and men who are themselves affected with a learning difficulty

or disability. At this stage of the study, none of the families has been given any genetic information. The data collected in interviews relate to aspects of family life when one or more family members has a learning disability; perceptions and explanations of the disorder in the absence of a genetic diagnosis; family relationships and communication; and experiences and expectations of participation in the GOLD study. We are working with the Cambridge Genetic Knowledge Park with a project that is aiming to draw up good-practice guidelines when genetic diagnosis is offered to parents of children with learning disabilities.

Preliminary analysis of interviews with family members where males are affected with a known genetic disorder causing learning disabilities (mostly) in males, Fragile-X, has been written up as a short report for the membership of the Fragile X Society; analysis of main study data is ongoing.

Previous research and other activities

Two recent previous research studies still generate considerable active interest. Two papers arising from the Nuffield Foundation funded study on decision-making around caesarean section (with Jane Weaver, now at Thames Valley University) are now ready for submission (see below). The findings of the studies funded by the NHS R&D and the Wellcome Trust, (carried out with Jo Green, University of Leeds and Wendy Solomou, now at Dept of Land Economy, Cambridge) which investigated psychological, social and service implications of prenatal diagnosis and parental decision making have been widely disseminated in the past year to policy makers with presentations and submissions to the Human Genetics Commission, The House of Commons Science and Technology Committee, subgroups of the National Screening Committee and Progress. Findings still form the basis of study days for health professionals working in the area of prenatal diagnosis and I have continued to work with the voluntary sector group Antenatal Results and Choices to translate research findings into practice. This year this has related to a handbook for professionals supporting parents in decision-making. Four papers from this study were accepted for presentation to the Edinburgh Congress of the International Society for Psychosomatic Obstetrics and Gynaecology (ISPOG).

I have continued to be a member of the Advisory Body of the ESRC-funded Innovative Health Technology Project: *Social implications of one-stop first trimester prenatal screening*; and I have just joined the Advisory Body of a new DoH initiative with DIPex (a web-based Directory of Patients' experiences co-ordinated from the Department of Primary Health Care, University of Oxford) on Ending a Pregnancy.

Dissemination and publications

Green, J.M., Kafetsios, K., Statham, H.E. and Snowdon, C.M. (2003), "Factor structure, validity and reliability of the Cambridge Worry Scale in a pregnant population", *Journal of Health Psychology* 8(6), 753-764.

Statham H. (2003), *Decision-making about prenatal diagnosis*. Presented to the Human Genetics Commission Working Group on Genetics and Reproductive Decision Making, September 2003 and published:

http://www.hgc.gov.uk/subgroups/reproduction_080903annexa.htm#hs

Statham, H and Ponder, M. (2004), *Families, Learning Disabilities & Genetics – a new research study* the Fragile-X Society Research Supplement Issue no 31: 17- 19.

Statham. H., Green, J.M. and Solomou, W. (2004), Published abstracts for ISPOG congress, in *Journal of Psychosomatic Obstetrics and Gynaecology* 25 (Supplement 1)

Feticide and late termination of pregnancy: perspectives of parents and health professionals page 107.

Emotional well being after a termination for abnormality: the impact of obstetric and social factors page 123.

When a baby is born with an abnormality: views of parents who did and did not have forewarning through prenatal diagnosis page 48.

Caring for bereaved parents – reviewing the evidence for benefit and harm page 108.

Weaver, J., Statham, H.E. and Richards, M.P.M. “Do women ask for unnecessary caesarean sections?” to be submitted to *British Medical Journal*.

Weaver, J. and Statham, H.E. “Caesarean section and psychological issues”, to be submitted to *British Journal of Midwifery*.

Invited lectures

Detection of fetal abnormality at different gestations: impact on parents and service implications Seminar, Department of Clinical Genetics, Addenbrookes Hospital, November 28th 2003.

‘We had a choice - and it was up to us to make that choice: how parents make decisions after prenatal diagnosis.’ Invited Speaker, Manchester, joint Life/Nowgen Disability and Reproductive choice workshop June 10th 2004.

Testing Times Invited contributor to public debate, Progress Trust, Cardiff June 16th 2004.

After prenatal diagnosis: the psychological consequences Invited speaker and workshop coordinator, Combined meeting of the All London Screening Committee and the Multiple Births Foundation, July 20th 2004.

Ms Shirlene Badger

Ph.D Student - funded by the Wellcome Trust Biomedical Ethics Programme

A genetic diagnosis for obesity: social and moral experiences of the body and responsibility in childhood

I joined the Centre for Family Research as a PhD student in October 2003. My Ph.D research is a qualitative investigation of the issues surrounding what happens when a group of children who are severely obese and their families receive a genetic diagnosis for obesity. Of particular interest is how children and families come to understand and experience a condition as genetic, the moral and social issues that arise with the genetic testing of obese children, and the impact on how individuals think about themselves, their bodies and family roles and relationships.

Other activities:

During the last academic year I have been involved in the organisation of the Cambridge Body Research Group. I presented a paper entitled ‘Methodological musings on the relationship between the research assistant and their work’ at the *Practical Ethics in Qualitative Family Research* Workshop, 15-16 March 2004. Cardiff University, Wales.

Badger, S. (2004), *Your health@DNAtailored.com*, in R. Hindmarsh and G. Lawrence (eds), *Recoding Nature: Critical Perspectives on Genetic Engineering*. Sydney: UNSW Press.

Kelly, B., Burnett, P., Pelusi, D., Badger, S., Varghese, F., Robertson, M. (2004), “Association between clinician factors and a patient’s wish to hasten death: terminally ill cancer patients and their doctors”, *Psychosomatics*, 45, 311-318.

Dr Elizabeth Chapman***Research Associate (part time) Centre for Family Research******Research Facilitator (part time) School of Humanities and Social Sciences (CSHSS)***Research Projects

1. Papworth NHS Trust

January 2004 – December 2004 (renewing annually)

Cystic fibrosis - palliative care, transplantation, family interactions, treatment adherence

Ventricular assist devices – quality of life, body image

2. Arthur Rank Hospice

January 2004 – December 2004 (renewing annually)

Working with the multidisciplinary pain group.

3. Addenbrookes NHS Trust

September 2003 – August 2006

Psychological input to the musculoskeletal pain service.

PublicationsChapman, E. and Bilton, D. (2004), "Patients' knowledge of cystic fibrosis: genetic determinism and implications for treatment", *Journal of Genetic Counseling*. (In press).Conference PresentationsThe 27th European Cystic Fibrosis Conference, June 2004, Birmingham.

The Continuum of Cystic Fibrosis: Home and Away

The Seventeenth Annual North American Cystic Fibrosis Conference, October 2003, Anaheim.

Palliative Care in Cystic Fibrosis: A Model of Good Practice

Associate Editor

Body Image: An International Journal of Research, Elsevier Science

Dr Oonagh Corrigan***Centre for Family Research and Cambridge Genetics Knowledge Park******The socio-cultural and ethical implications of innovative genetics-based drug development.******Sponsor: The Wellcome Trust.***

This project was completed in September 2003 and its findings highlighted some of the main social and ethical issues that arise in the research and development of pharmacogenetics. An end of grant report was produced. Several publications have also emanated from this study, in particular the book I co-edited on genetic databases, based on this study and other studies on DNA population collections has received a great deal of interest from policy makers and academics both in the UK and abroad.

ELSI Research and the Construction of "Legitimate" Expertise,***Sponsor: Social Sciences and Humanities Research Council of Canada Standard Grant.***

I am currently a collaborator on this Canadian study headed by Dr Jose Lopez from Ottawa and Professor Ann Robertson from the university of Toronto.

I have also begun work examining the socio-ethical issues related to embryonic stem cell research. I am currently working in an advisory capacity with other colleagues at the Cambridge Genetics Knowledge Park and will be developing further research this area during the coming year.

Publications

Tutton, R. and Corrigan, O.P. (eds), (2004), *Genetic Databases: Socio-Ethical Issues in the Collection and Use of DNA*, London: Routledge.

Corrigan, O.P. (2004), "Informed consent: the contradictory ethical safeguards in pharmacogenetics", in R. Tutton and O.P. Corrigan (eds), *Genetic Databases: Socio-Ethical Issues in the Collection and Use of DNA*, London: Routledge.

Tutton, R. and Corrigan, O.P. (2004), "Public participation in genetic databases", in R. Tutton and O.P. Corrigan (eds), *Genetic Databases: Socio-Ethical Issues in the Collection and Use of DNA*, London: Routledge.

Corrigan, O.P. (2003), "Empty ethics: the problem with informed consent", *Sociology of Health and Illness*, 25:7, 768-92.

Williams-Jones, B. and Corrigan, O.P. (2003), "Rhetoric and hype: where's the 'ethics' in pharmacogenomics?" *American Journal of Pharmacogenomics*, 3, 6, 375-383

Corrigan, O.P. (2003) "Ethical issues in patients' consent to pharmacogenomics trials", [Feature article] *Cambridge Genetics Knowledge Park Newsletter* Vol. 1. (http://www.cgkp.org.uk/resources/pdf/summer_2003-news.pdf)

Corrigan, O.P. and Williams-Jones, B. (2003), "Consent is not enough...Putting incompetent patients first in clinical trials" [Commentary], *The Lancet*, Vol. 361(9375), p. 2096-2097. (<http://genethics.ca/personal/Consent-Lancet.pdf>)

Presentations

Pharmacogenetic research: beyond the boundaries of consent', *Bioethics Across Borders: Joint Meeting of the American Society for Bioethics and Humanities and the Canadian Bioethics Society Conference*, Montréal, QC, Canada, Oct. 23-26, 2003.

'DNA banking: socio-ethical issues in pharmacogenetic databases', *Genetic Databases: Socio-ethical Issues in the Collection and Use of DNA. Workshop launch, Cambridge Genetics Knowledge Park*, Royal Society, London, June 8 2004.

'Obligations to consent, responsibilities to decide: passing the ethical buck?' *Oxford, Imperial and Cambridge ELSI Workshop*, Gonville and Caius, Cambridge, United Kingdom, Feb. 28, 2004.

'Drug development: clinical trials and PGx', *Translating Pharmacogenetics Research into Practice: Ethical and Policy Issues' Wellcome Trust Conference*, London, United Kingdom, Sept. 18, 2003.

Dr Marc de Rosnay

Centre for Family Research, Churchill College Junior Research Fellow

My area of research concerns children's emotional development, including their emotion understanding (i.e., the capacity to treat emotion as an object of knowledge) their emotional competence (i.e., the capacity to regulate and attenuate emotional experience), and the relationship between these factors. Following from my doctoral research, I am continuing to explore (i) children's capacity to link their understanding of the nature of mind with emotion (e.g., How do children come to integrate their understanding of false belief with an emotional outcome?), and (ii) the link between maternal discourse, attachment and children's emotion understanding. In order to develop this second project, I have recently applied, as a co-applicant, for a 3-year ESRC grant in conjunction with collaborators from the University of Durham. I am also collaborating with Profs. Cooper and Murray in Reading, where we are

looking at infants' sensitivity to maternal emotional responses in a social environment. This research is part of a large-scale longitudinal project on the intergenerational transmission of social anxiety.

Here in Cambridge, I have been actively involved in organising a workshop with Dr Hughes to be held on the 14th of October at CRASSH entitled, "Conversations and childhood: The impact of conversations on early social, emotional and cognitive development." The workshop, which will bring together internationally recognised scholars based in the United Kingdom and have a major teaching role for the incoming MPhil students, is funded by CRASSH and the Department of Social and Developmental Psychology, University of Cambridge. I am also preparing an application for a four year ESRC Career Development Fellowship, with Dr Hughes to act as my Mentor. The fellowship will draw on the workshop and, if successful, allow me to pursue a programme of research on the effects of linguistic interventions on children's social understanding and friendship interactions. I hope to submit this application at the end of the year.

Publications

Pons, F., Doudin, P.-A., Harris, P. and de Rosnay, M. (in press/2004), "Emotion understanding: Development, individual differences, causes and interventions", in F. Pons, D. Hancock, L. Lafortune and P.-A. Doudin (eds), *Emotions in Children and Pupils*, Aalborg: Aalborg University Press.

Pons, F., Harris, P. L. and de Rosnay, M. (2004), "Emotion comprehension between 3 and 11 years: Developmental periods and hierarchical organization", *European Journal of Developmental Psychology*, 1(2), 127-152.

de Rosnay, M., Pons, F., Harris, P. L. and Morrell, J. M. B. (2004), "A lag between understanding false belief and emotion attribution in young children: Relationships with linguistic ability and mothers' mental-state language", *British Journal of Developmental Psychology*, 22(2), 197-218.

Pons, F., Lawson, J., Harris, P. L., and de Rosnay, M. (2003), "Individual differences in children's emotion understanding: Effects of age and language", *Scandinavian Journal of Psychology*, 44(4), 347-353.

Dr Claudia Downing

Wellcome Trust Research Fellow in Biomedical Ethics (Jan 2002 – September 2005)

Research interests

Studying everyday ethical issues that arise for members of families facing late onset hereditary risk late onset genetic disorders with a view to developing a framework in which to explore these concerns in relation to a range of genetic disorders and risks which share some of these characteristics but which are not necessarily genetic. Developing a process model of personal decision-making that acknowledges the family context and processes in which decision making occurs and how decision-making shapes identity. Qualitative methods including the use of computerized qualitative data analysis packages, and developing innovative ways of presenting qualitative data.

Current research

Parenting in the space between health and illness: a comparative study of ethical dilemmas arising from the certain knowledge of a gene positive status for Huntington's disease and Myotonic Muscular Dystrophy.

Aims of the study

- to explore and document the ways in which ethical issues around parenting shape decision-making about predictive testing for late-onset genetic disorders,
- to clarify and compare the ethical dilemmas that arise when mothering or fathering in the certain knowledge that one parent is at-risk for or will be affected by a late-onset dominant genetic disorder in the future,
- to compare experiences of two late-onset dominant disorders, Myotonic Muscular Dystrophy and Huntington's disease,
- to consider how factors such as gender, certainty/uncertainty of genetic risk status, age of dependent children and relationships impact on how parenting is experienced at this time,
- to identify the nature of concerns that genetic information raises for parents in their interactions with professionals
- to disseminate information about the findings about mothering and fathering to families and professionals identified as having an interest in this information.

Publications

Downing, C. (2004), "Negotiating responsibility: case studies of reproductive decision-making and prenatal genetic testing in families facing Huntington disease", *Journal of Genetic Counseling*, (in press).

Conference and seminar presentations

Cambridge – Cardiff Genetics group, Conference Cardiff, March 2004 on Practical Ethics in Qualitative Family Research: *Participants' perspectives on taking part in qualitative research*.

4S-EASST Conference Paris, August 2004: *Concepts of time and accountability in families facing late-onset genetic disorders*.

Other activities

- I have resumed responsibility for organizing the CFR lunchtime seminars.
- Genetic Futures 50th Celebration of DNA organized in October and November 2003 by the Department of Health, the Royal Society, NESTA, BIO RAD, MRC, BBSRC and the Centre for Science Education at Sheffield Hallam University - I participated as an expert witness / facilitator for events held in Norwich and Belfast.
- I have continued to maintain links with the voluntary sector and spoke with families participating in the HD Awareness Week Events held at the Sue Ryder Home, Ely

Ms Rosie Ensor (née Davie)

Ph.D. student Toddlers 'At-Risk' of Developing Behaviour Problems: The Role of Interactions with Caregivers. Funded by the PPP Foundation (supervised by Dr. Claire Hughes) Commenced September 2002 – September 2005

Framed within a larger study of 140 toddlers, the overall aim of my PhD work is to examine how positive developmental outcomes are achieved in the context of social disadvantage, with a particular focus on mother-toddler positive interactions.

Teaching

During the last academic year I supervised second year student for a Experimental Psychology course (PSY2), and gave two two-hours lectures (INT1).

In press

Ensor, R. and Hughes, C. (2004), "More than talk: relations between emotion understanding and positive behaviour in toddlers", *British Journal of Developmental Psychology*.

Other activities

During the last academic year I supervised first year students taking Social Psychology, and second year students taking Experimental Psychology courses.

Dr Gail EwingResearch interests

Provision of primary care services; health visiting; palliative care. Qualitative methodologies; grounded theory. Early motherhood and infant weaning.

Research projects

Symptoms and Needs Assessment in the Provision of Palliative Care in the Community. A comparison between patients, carers and their primary health care teams.

Grant Holders: CJ Todd, G Ewing, SIG Barclay, J McCabe. Formerly Health Services Research Group, Institute of Public Health, Cambridge. Funded by the Dept of Health, Community Services Initiative, 1998-2002;

Further data analysis on this project (part time) January- June 2004

Presentations

Research Governance and Data Protection Legislation as Barriers to Recruitment

Gail Ewing, Chris Todd, Margaret Rogers, Stephen Barclay, Anna Martin and Janet McCabe. Palliative Care Congress, University of Warwick, 17 March 2004

Publications

Ewing, G., Todd, C., Rogers, M., Barclay, S., McCabe, J. and Martin, A. (2004), "Validation of a symptom measure suitable for use amongst palliative care patients in the community: CAMPAS-R", *Journal of Pain and Symptom Management*, 27, 287-299

Ewing, G., Rogers, M., Barclay, S., McCabe, J., Martin, A. and Todd, C. (2004), "Recruiting patients into a primary care based study of palliative care: Why is it so difficult?" *Palliative Medicine*, 18, 452-459

Dr Tabitha Freeman***Research Associate***

Since arriving at the Centre in January 2004, I have concentrated on completing my PhD and passed my viva in July. This research was supervised by Professor Leonore Davidoff (University of Essex) and funded by a Fuller Bequest Studentship and Postgraduate Research Studentship from the University of Essex. The thesis, entitled "Conceptualising fatherhood: gender, discourse and the paradoxes of patriarchy", assesses the representation of fatherhood across a range of cultural and theoretical domains, including psychoanalysis, social and political theory and the biological sciences. I am presently applying for project funding for research on the psycho-social and ethical implications of DNA paternity testing, with Professor Martin Richards and Dr. Bryn William-Jones.

Other activities:

Supervisions and seminar presentation on paternity testing for the biotechnologies and society paper (INT 4).

I co-organised a two-day symposium, Gender History, Women's History, Family History, sponsored by the journal, *Gender and History*, at the Institute of Community Studies, London, in May 2004.

Qualitative data analysis for Equal Opportunities projects at Cambridge University, including the Women's Forum.

Member of the BSA Human Reproduction Study Group.

Research Fellow, St. Edmund's College (from October 2004).

Conference presentations

Freeman, T. (2003), "Digging up the father: locating the paternal body in philosophical, psychoanalytic and popular discourse", Fathers Figures: Gender and Paternity in the Modern Age, Liverpool John Moores University, 30 June - 2 July 2003.

Publications

Freeman, T. (2003), "Loving fathers or deadbeat dads? The crisis of fatherhood in popular culture", in S. Earle and G. Letherby (eds), *Gender, Identity and Reproduction: Social Perspectives*, Basingstoke: Palgrave Macmillan.

Dr Joanna Hawthorne***Senior Research Associate***

March 2002-July 2004: Foretelling Futures: Dilemmas in Neonatal Neurology. Wellcome Trust Grant (No. 066458) with Professor Priscilla Alderson, Margaret Killen, Inga Warren and Dr. John Wyatt, London.

A social research project in four neonatal units interviewing parents and staff, about information sharing and uncertainty about the future development of the baby.

Publications

Hawthorne, J. (2003), "Understanding the language of babies", in J. Raphael-Leff (ed), *Parent-Infant Psychodynamics: Wild Things, Mirrors & Ghosts*, Whurr: London.

Hawthorne, J., Jessop, J., Pryor J., and Richards, M. (2003), "Supporting children through family change: A review of interventions and services for children of divorcing and separating parents." Joseph Rowntree Foundation.

In press

Hawthorne, J.T. (2004), "Psychological aspects of neonatal care", Chapter in Robertson's *Textbook of Neonatology, Fourth edition*. Edited by Janet M. Rennie, Churchill Livingstone: London.

Hawthorne, J. (2004), "The Brazelton Centre in Great Britain: Training health professionals in the Neonatal Behavioural Assessment Scale." Article for The Signal, Newsletter of the World Association for Infant Mental Health.

Hawthorne, J. (2004), "Understanding the psychological aspects of parenting and understanding baby behaviour", in "Working with Young Parents", Young parents and MIDIRS collaborative project.

In preparation

Hawthorne, J., Hutchon, B., Wolke, D. (2004), "The NBAS in community health settings: the UK, in T.B. Brazelton, B. Petruskas and J.K. Nugent (eds), *Looking Back, Looking Forward: What We Now Know About Newborn Infants and Their Families and What we Need to Do Next*, Johnson and Johnson Pediatric Institute: LLC.

Hawthorne, J. and Quince, T. (2004), "Ultrasound scanning in pregnancy and maternal anxiety." To be submitted.

Hawthorne, J, Alderson P, Killen M. (2004), "Belonging: parent-infant relationships around transfer and discharge from neonatal units". To be submitted.

Hawthorne, J. (2004), "Sharing information in neonatal units: Do practitioners present the worst case scenario?" To be submitted.

Hawthorne, J. (2004), "Developmental insights in neonatal units". To be submitted.

Leaflet

Hawthorne, J. (2003), Getting to Know your Baby: Using the Brazelton Neoantal Behavioural Assessment Scale (NBAS). Leaflet for the NICU, Addenbrookes NHS Trust, Cambridge

Posters and papers

Alderson, P., Hawthorne, J., Killen, M., Warren, I. (2003), "Foretelling Futures: Dilemmas in Neonatal Neurology: A social research project in four NICUs" Paper presented at the Infant Development in Neonatal Intensive Care Conference, London.

Hawthorne, J., Alderson, P., Killen, M., Warren, I. (2003), "Foretelling Futures: Dilemmas in Neonatal Neurology – Information sharing", Poster presented at the Society for Reproductive and Infant Psychology Conference, Dundee 2003. Abstract in Journal of Reproductive and Infant Psychology 21,3: 253-254.

Hawthorne, J., Alderson, P., Killen, M., Warren, I. (2003), "Who does this baby belong to? Foretelling Futures: Dilemmas in Neonatal Neurology". Poster at the World Association of Infant Mental Health 9th World Congress, Melbourne, Jan. 14-17, 2004.

Killen, M., Alderson, P., Hawthorne, J., Warren, I. (2003), "Researching interpretations of care in neonatal units. Foretelling futures: Dilemmas in Neonatal Neurology." Paper presented at Medical Sociology Conference, York.

Hawthorne J. Developmental insights in neonatal units. Poster to be submitted to Infant Development in Neonatal Units conference, London, March 2005

Other activities

Coordinator of the Brazelton Centre in Great Britain (registered charity number 1086814) which aims to promote an understanding of infant behaviour, and foster strong parent-infant relationships through research, and training for health professionals in the NBAS: I administrate, teach, train and organise study days and workshops. Training multi-disciplinary groups in Sure Start areas. Invited workshops.

Founder and organiser of the Infant Relationships Study Group – termly meetings on clinical and research topics concerning early relationships.

Brazelton trainer's meeting, Brazelton Institute, Boston, Mass., USA October 22nd-25th, 2002, Boston, USA : Presented activities of Brazelton Centre in Great Britain, and an intervention study using the NBAS. Developed plans for training trainers.

Committee Member of CAMPIP - Cambridge Parent-Infant Project, Parents First! and Developmental Care Group, NICU, Rosie Hospital

Honorary contract at the Rosie Hospital, Addenbrookes NHS Trust, Cambridge: Providing intervention for parents of babies in the NICU using the NBAS.

Sustaining member of the Board of Directors, Chicago Lying-In Hospital, Chicago.

Dr Claire Hughes

Predicting antisocial behaviour and peer problems.

Funding body: The Health Foundation (formerly known as the PPP Foundation)

Funding period: October 2002-2005 Funding value: £215K

Co-applicant Professor Judy Dunn, Institute of Psychiatry, London.

Claire Hughes is a Fellow of Newnham College, Cambridge, and a Lecturer in Developmental Psychology at the Faculty of Social & Political Sciences. She is an editor for the journal *Infant and Child Development* and *British Journal of Developmental Psychology* and her research interests include developmental psychopathology (including disruptive behaviour and autism) and individual differences in early social and cognitive development. Her current research includes a longitudinal study of social and cognitive development in toddlers from young mother, lone parent or low-income families (funded by the Health Foundation, and in collaboration with Professor Judy Dunn).

Research interests:

My current research focuses on the early origins of antisocial behaviour and peer problems. My research team are about to begin the third phase of this study, which will focus on the children in their schools and nurseries. This will involve classroom observations, filming each child with a best friend, and giving all the children (and their friends) a comprehensive set of cognitive tasks. Our goal is to examine both the real-life implications of individual differences in social understanding and self-control for young children's close relationships with family and friends, and the contribution of children's social relationships to their cognitive development.

The Toddlers Up project has been growing almost as fast as the study children, and now includes a number of local and visiting researchers: Laila Freise (who has recently left the CFR), Keiko Fujisawa (from Tokyo); Dave Lambert (a former SPS student, now enrolled for a PhD) Jesse Leins (from Smith College, USA), Barbara March (from the University of Padua, Italy), Vanessa Murray (from Mexico), Yee-San Teoh (from Malaysia), Dr Anji Wilson and Dr Charlotte Wilson.

Much of my sabbatical term was devoted to writing an application for a Career Establishment Award from the MRC; this application made it through to the final cut, but I have yet to hear whether it has been successful. If so, it will enable the current project to continue until the children are aged eight.

In Easter Term this year, I conducted a short study of the impact of exams on schoolchildren and their families, together with Jesse Leins, Dr Charlotte Wilson and Dr Brendan Burchell (funded by Hill & Knowlton). The findings on predictors of family stress from this study make an interesting comparison with the findings from my toddler study, and will form the basis for a new study on children's worry to be carried out with Dr Charlotte Wilson.

Currently I'm working with Dr Marc de Rosnay on a one-day meeting on 'Conversations and Childhood' –this workshop is co-funded by the new Department of Social and Developmental Psychology and by the Centre for Research in the Arts, Social Sciences and Humanities (CRASSH), and will form the basis for a *British Journal of Developmental*

Psychology special issue on the topic, as well as for an application by Dr de Rosnay for an ESRC Career Development Award.

Publications

Booth, R., Charlton, R., Hughes, C. and Happé, F. (2003), "Disentangling weak coherence and executive dysfunction: Planning drawing in Autism and ADHD", *Philos Trans R Soc Lond B Biol Sci*, 358, 387-92

Ensor, R., and Hughes, C. (2004), "More than talk: relations between theory of mind, emotion understanding and positive social behaviour in toddlers. *To appear in the British Journal of Developmental Psychology*.

Hughes, C. and Ensor, R. (2004), "Theory of mind and executive functions in two-year-olds: A family affair?" *To appear in a special issue of Developmental Neuropsychology*

Hughes, C. and Ensor, R. (2004) "Theory of mind, executive function and negative parenting as predictors of behavioural problems in two-year-olds", *Submitted to Journal of Child Psychology and Psychiatry*

Hughes, C., Jaffee, S., Happé, F., Taylor, A., Caspi, A. and Moffitt, T. (2004), "Origins of individual differences in theory of mind: from nature to nurture?" *To appear in Child Development*.

Kuntsi, J., Eley, T. C., Taylor, A., Hughes, C., Asherson, P., Caspi, A. and Moffitt, T. E. (2004), "The co-occurrence of ADHD and low IQ has genetic origins", *Neuropsychiatric Genetics, a section of the American Journal of Medical Genetics*, 124B, 41-47.

Ronald, A., Happé, F., Hughes, C. and Plomin, R (2004), "The nature and nurture of nice and nasty theory of mind", *Accepted by Social Development*.

Hughes, C. (in press), "Origins of individual differences in theory of mind and language: Twin study findings", in J.W.Astington, J. Baird, P. Zelazo and D. Olson, *Why Language Matters for Theory of Mind*, Oxford University Press: New York

Hughes, C. (in press), "Executive function and development", in B. Hopkins (ed), *Cambridge Encyclopedia of Child Development*: Cambridge University Press.

Hughes, C. (2003), "Making and breaking relationships", in A. Bainham, B. Lindley, M.P.M. Richards and E. Trinder (eds), *Parent Child Relationships and Contact: A Socio-Legal Analysis*, Hart: Oxford, UK. pp33-46.

Hughes, C., Graham, A. and Grayson, A. (in press), "Executive function in childhood: development and disorder in, J. Oates (ed), *Cognitive Development*: Open University Press.

Grants held

Grant holder for a study of the predictors of peer problems and antisocial behaviour (*funded by the Health Foundation, Award code: RG 34960; Oct 02-Oct 05, £215,255*)

Grant holder for a study of the impact of children's exam stress on families: (*funded by Hill and Knowlton, June-August 2004: £17,187*)

Dr Antonella Invernizzi

Children's Exploitation, Socialisation and Participation in Economy. A Comparative Analysis of Child Labour in Peru and Portugal. Grantholder. Funded by the Swiss National Science Foundation. October 2001-January 2004.

Publications

In collaboration with B.Milne, 'The role of the Street for European Children: Examples of problems and resources for children', in: Colozzi I./Giovannini G. (ed), *Young People in Europe. Risk, Autonomy and Responsibilities*, FrancoAngeli, 2003, pp. 35-53. Italian translation: 'Il ruolo della strada per i bambini europei: esempi di problemi e risorse', in: Colozzi I./Giovannini G. (Ed.) *Ragazzi in Europa tra tutela, autonomia e responsabilità*, Milano: FrancoAngeli, 2003, pp. 42-63 (ISBN: 9 788846 445445)

'Il lavoro minorile in Portogallo' in: *Bambini e adolescenti che lavorano. Un panorama dall'Italia all'Europa*. Ed. By M.T. Tagliaventi Questioni e Documenti. Quaderno N. 30, Centro nazionale di documentazione e analisi per l'infanzia e l'adolescenza/Istituto degli Innocenti, May 2004, pp. 145-159 (available on the website: www.minori.it)

In press

"Children's work in Portugal. An exploration of children's motivations, family organisation and views on socialisation", 2003.

"What will doctors eat if we all go to university?" Views on children's work in the Algarve (Portugal) and their implication for social policy, 2004, in publication.

Unpublished:

Children's exploitation, socialisation and participation in economy. A comparative analysis of child labour in Peru and Portugal. Scientific Report for the Swiss National Science Foundation, Cambridge, March 2004, 102 pp.

When does work allow children a greater participation? Decision-making related to children's working activities in Portugal and Peru. Paper presented at International Symposium "What does Work mean to Children? Theoretical Approaches and International Empirical Reports", Berlin, 12. – 17. April 2004.

Dr Julie Jessop**Senior Research Associate**

From October 2003 to September 2004 I worked as part of a three year Wellcome Trust funded bio-ethics project looking at issues surrounding human tissue collection in the UK. The project was based at Kings College Cambridge, with the principal investigator being Dr. Bronwyn Parry.

Other interests/activities:

I am a member of the Cambridge Socio-Legal Group and wrote a chapter on the development of sexuality for their latest book which was published in June (see publications).

I acted as co-ordinator for the Qualitative Women's Workshop on Family and Household Research. This is a research group which meets bi-monthly to discuss theoretical and analytical advances in feminist research and which has published a series of books on various research issues.

In October 2004 I shall be leaving the Centre and sailing (in a 105ft tug) to Vancouver, with the aim being to conduct aid work along the way. Those who may be interested will be able to check our progress at www.flyingbuzzard.com (presently under construction).

Recent publications:

Ribbens-McCarthy, J. with Jessop, J.A. (forthcoming 2005), "Disrupted Transitions? Bereavement and Young People", Buckingham: Open University Press.

Jessop, J.A. (2004), "The development of sexuality", in A. Bainham, B. Brooks-Gordon and L. Gelsthorpe (eds), *Sexuality Repositioned: Diversity and the Law*. Oxford: Hart Publishing.

Simpson, R., Jessop J.A. and McCarthy, P. (2003), "Fathers after Divorce", in A. Bainham, B. Lindley, M. Richards and L. Trinder (eds), *Children and Their Families: Contact, Rights and Welfare*. Oxford: Hart Publishing.

Dr Lynne Jones***Senior Research Associate***

Research activities include completing a book on children's understanding of war in Bosnia, *Then They Started Shooting. Growing Up in Wartime Bosnia*, to be published next year by Harvard University Press.

Currently working in West Africa.

In press

Jones, L., Rrustemi, A., Shahini, M. and Uka, A. (2003), "Mental health services for war affected children: report of a survey in Kosovo", *British Journal of Psychiatry*.

Ms Rachel Marfleet***Research Assistant***

I worked with Dr Claire Hughes and Rosie Davie on a research project looking into the early origins of antisocial behaviour in 140 toddlers. I participated in recruitment, home visits, lab visits and other background tasks but left the project in March 2004.

Dr Shobita Parthasarathy***Wellcome Post-Doctoral Fellow***Research interests/activities

I am interested in the comparative and international politics of genetics and biotechnology, particularly medical biotechnology. Specific topics of interest include: globalization and biotechnology; how national political cultures influence the development of biomedicine; the role of patient advocacy groups in the conduct of biomedicine; the assignment and use of intellectual property in the area of biotechnology; and the role and influence of the biotechnology industry. More broadly, I do work in the fields of science and technology studies, medical sociology, political sociology, and bioethics.

Research Fellowship, "Global Technologies for the Global Consumer: An Exploration of the Transnational Politics of the Genomic Age", Biomedical Ethics Programme, The Wellcome Trust, UK. (Summer 2003-2006)

Short description of project

My current project uses the European politics over patenting human biotechnology as a case study to investigate the dynamics of globalization in the field of genomic medicine. Scholars and popular writers alike argue that the world is increasingly interdependent, with

transnational advocacy groups, multinational corporations, and international laws operating across national boundaries. Attempts to configure European intellectual property law in the area of biotechnology to resemble its American counterpart, however, have not been simple or straightforward. While biotechnology companies and industry lobby associations argue that a strong European intellectual property regime will facilitate transnational research and development and international technology transfer, many European governments and advocacy groups respond that participation in a global patenting regime conflicts with deeply held national identities, interests in promoting innovation for the public good, and commitments to equal access to health care. In these debates, alliances have formed not only within countries, but also transnationally among groups with similar ideological commitments. How do the processes of globalization work? How are national regulatory frameworks, laws, norms, and values reconciled in the international arena, and what roles do transnational advocacy groups play? How do these politics influence the development and governance of science and technology, and what are the implications for the users of genomic medicine? What are the implications of these international politics for national approaches to public health? By investigating how these politics unfold and are resolved, this systematic and empirically in-depth analysis explores the challenges of globalization, its influence on the development of science and technology, and the consequences it has for the global citizen.

Other activities, lectures or presentations given

Understanding the Strategies of Patient Advocacy Groups in the United States.? Kellogg School of Management, Northwestern University, March 2004.

A Patent Battleground: Building Europe through the Politics of Patenting Biotechnology.? Presentation to *Society for the Social Studies of Science/EASST*, Paris, August 2004.

The Patent is Political: Intellectual Property, Biotechnology, and the Implications for European Health Care. Presentation to the *American Sociological Association*, San Francisco, CA, August 2004.

National Forms of Biomedicine: Governing Genetic Testing for Breast and Ovarian Cancer in the US and Britain. Presentation to the *Society for the Study of Symbolic Interaction*, San Francisco, CA, August 2004.

Publications

“Regulating risk: defining genetic privacy in the US and Britain?” *Science, Technology, and Human Values*, (Vol. 9, No. 3, Summer 2004).

“Building genetic medicine: a comparative study of genetic testing for breast cancer in the United States and Britain”, *Social Studies of Science*, (to be published December 2004).

“Reconceptualizing technology transfer: the challenge of building an international system of genetic testing for breast cancer” in D.H. Guston and D. Sarewitz (eds), *Shaping Science and Technology Policy: The Next Generation of Research*, University of Wisconsin Press (in press).

“The patent is political: the consequences of patenting the BRCA genes in Britain?” *Community Genetics Supplement* (in press).

“Cloning expertise: understanding the National Bioethics Advisory Commission through the birth of Dolly the sheep? *Social Studies of Science* (paper accepted)

Ms Maggie Ponder***Research Associate - part time***Research activity

Co-worker with Helen Statham on the study - *Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability*. We aim to follow families who have been recruited to the Genetics of Learning Disability (GOLD) Study. The GOLD study aims to identify genes associated with learning disabilities in families currently without any specific diagnosis but where the pattern of inheritance suggests X-linked inheritance. The psychosocial study will examine the beliefs, understandings, attitudes and behaviours of family members before and after genetic testing.

Other activities

- Trustee of the Neurofibromatosis Association.
- Chairman of the Genetic Interest Group.
- Member of the executive board of the Cambridge Genetic Knowledge Park.
- Consumer representative on the Genetic Commissioning Advisory Group (GenCAG).
- Member of the Cambridge Local Research Ethics Committee.

The Neurofibromatosis Association is a national charity set up to provide help and support to families affected by neurofibromatosis and raise money to support research.

The Genetic Interest Group is a national alliance of charities and groups representing people affected by all types of genetic disorders. The main purposes are to provide information for families and others, educate the medical professions about genetic disorders and influence policy for the benefit of people living with genetic disorders. The trustees have responsibility for overseeing the work and of strategic planning. I represent GIG at official meetings both in the UK and Europe.

Dr Ilina SinghResearch activities

1. Ongoing interviews with children taking psychostimulant medication for ADHD and their parents to understand the implications of drug treatment for children's sense of self and personal agency.
2. Senior Researcher, GENDEP project, London School of Economics

Funded by the EU 6th framework program, we are investigating the social, ethical and legal implications of using pharmacogenomic technologies in drug treatments for depression. This project is a collaboration between the Institute of Psychiatry, the London School of Economics and clinical sites in several European countries.

Teaching

Gender and the Family (SPS); Bioethics (HPS and the Medical School); History and Culture of Psychopharmacology (HPS); Qualitative Research Methods (London School of Economics)

Clinical activities

Member of ADHD Clinic Team at Brookside Family Consultation Centre, part of the Cambridge University Dept. of Developmental Psychiatry

Other intellectual activities

1. *Managing Editor*, BioSocieties: An international journal for social studies of the life sciences, genomics and neuroscience. *Published by Cambridge University Press, to be launched in January 2006.*

2. *Organizer*, ESRC Neuroscience Seminar Series. *This seminar series is a joint venture between the University of Nottingham and the London School of Economics*

Talks

“Moral Dilemmas and Ritalin Riddles,” Medical Sociology Conference, York, UK

“Mothers and Sons: Stimulant Drug Advertising 1960 – present,” Wellcome Trust History of Psychology Seminar

“Social Anxiety – an up and coming psychiatric disease category?” ESRC Neuroscience Seminar

“Mothers and Sons: Stimulant Drug Advertising 1960 – present,” Gender Studies Group, University of Cambridge

“Authenticity and Ritalin Dosing,” Oxford University, Ethics Centre

Publications

Singh, I. (2003), “Boys will be boys: Fathers’ perspectives on ADHD symptoms, diagnosis and drug treatment”, *Harvard Review of Psychiatry*, 11 (6), 308-316.

Singh, I. (2004), “Doing their jobs: mothering with Ritalin in a culture of mother-blame”, *Social Science and Medicine*, 59, 1193-1205.

Singh, I. (2004), Entry on ADHD, Sage Encyclopedia of Mental Illness

In press

Singh, I. (2005), “Troubling facts: review of ADHD: the facts”, *Infant and Child Development*.

Singh, I. (2005), “Mothers and sons: stimulant drug advertising, 1960 – present”, to appear in an edited volume on the history of psychiatric drugs, edited by Edward Shorter and Andrea Toon.

Under review:

Singh, I. “Moral Dilemmas and Ritalin Riddles”, *American Journal of Bioethics*

Ms Claire Snowdon***Research Fellow******Views of participants in neonatal randomized controlled trials***

In recent years three related studies have been carried out, focusing on the views of participants in trials.

The first study was funded by the Department of Health and Wellcome through the National Perinatal Epidemiology Unit and involved qualitative analysis of interviews with around 80 parents of critically ill newborn babies enrolled in a clinical trial (The ECMO Trial). The research focused on parents’ perceptions of the trial, the doctor-patient relationship, results of the trial and management of informed consent.

This work was developed further as a research fellow at the London School of Hygiene and Tropical Medicine, funded by The Nuffield Foundation. It examines the same issues with two neonatal trials (The INNOVO Trial, the CANADA Trial) and two antenatal trials (the TEAMS

Trial and ORACLE). It involves 145 interviews with staff and parents linked to these trials. Analysis of the data is continuing. Papers have been written on professional and parental attitudes to post mortems for clinical trials, doctors attitudes to the ethical foundations of trials (equipoise) and the inclusion of bereaved parents in sensitive research. A paper which seeks to explain the fast decisions that parents often made about trial participation is in preparation.

Data were collected for a third related study during 2002. The study was funded by Heartlink and involved taping informed consent procedures with follow up interviews with staff and parents whose babies were included in a pre-trial study of the safety and feasibility of hypothermia and ECMO. Funds are being sought to analyse and write up these data.

Investigation into factors and interventions associated with good and poor recruitment to multicentre trials. Funded by MRC and the NHS HTA Programme. March 2002 -July 2004.

With colleagues at the London School of Hygiene and Tropical Medicine and the Health Services Research Unit, University of Aberdeen, the study examines factors affecting recruitment to trials from three perspectives. It involves an epidemiological review of trial data, a qualitative interview study involving trial principal and local investigators, trial managers and local recruiters, and a study of the feasibility of applying business theory to the management of clinical trials. I was responsible for the qualitative study.

Publications

Green, J.M., Kafetsios, K., Statham, H.E. and Snowdon, C.M. (2003), "Factor structure, validity and reliability of the Cambridge Worry Scale in a pregnant population", *Journal of Health Psychology* 8(6).

In press

Snowdon, C., Elbourne, D., Garcia, J. (2004), "Perinatal pathology in the context of a clinical trial: a review of the literature", *Archives of Diseases in Childhood*.

Snowdon, C., Elbourne, D., Garcia, J. (2004), "Perinatal pathology in the context of a clinical trial: attitudes of neonatologists and pathologists", *Archives of Diseases in Childhood*.

Snowdon, C., Elbourne, D., Garcia, J. (2004), "Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents", *Archives of Diseases in Childhood*.

Dr Bryn Williams-Jones

Post-Doctoral Fellowship, Research Council of Canada

Current research

I have been involved with a number of different projects this year:

- In May 2004 I was out in Halifax, Canada for a workshop with business representatives, part of a Canadian funded project on which I am collaborator, *Biotech Ethics: Corporate Decisions as Key to Better Health and Better Health Policy*. This project has recently received full funding and I will continue to collaborate, go out for workshops, and co-author some articles on biotech and business ethics.
- With Oonagh Corrigan, I am collaborator on another Canadian funded study, *ELSI Research and the Construction of "Legitimate" Expertise*, headed by former UK colleague Jose Lopez – we still have hopes of getting some form of parallel research going in the UK, even if just through getting other researchers interested!

- With Tabitha Freeman and Martin Richards, I am Co-Applicant on a grant being submitted to the Nuffield Foundation, *Regulating Fatherhood: An Investigation into the Psycho-Social and Ethical Implications of DNA Paternity Testing*. If funded, this will form much of my research for the New Year.

I am still interested in university-industry relations and have plans to do some interviewing in the Fall. In the meantime, all my focus is on working up a monograph that present a sophisticated synthesis of the social, ethical and policy issues arising with the broad range of genetic tests offered in the public and private spheres.

Publications

Williams-Jones, B. and Burgess, M. (2004), "Social contract theory and just decision-making: lessons from genetic testing for the BRCA mutations", *Kennedy Institute of Ethics Journal*, 14(2), p. 115-142. (<http://www.genethics.ca/personal/SCT.pdf>)

Williams-Jones, B. (2004), "Book review: who owns life?" *Theoretical Medicine and Bioethics*, Vol. 25(2), p. 165-169.

Williams-Jones, B. and Graham, J. (2003), "Actor-network theory: a tool to support ethical analysis of commercial genetic testing", *New Genetics and Society*, 22(3), p. 271-296.

Williams-Jones, B. and Corrigan, O.P. (2003), "Rhetoric and hype: where's the 'ethics' in pharmacogenomics?" *American Journal of Pharmacogenomics*, 3(6), p. 375-383.

Williams-Jones, B. (2003), "Where there's a Web, there's a way: commercial genetic testing and the Internet", *Community Genetics*, 6(1), p. 46-57.

Corrigan, O.P. and Williams-Jones, B. (2003), "Consent is not enough...putting incompetent patients first in clinical trials", [Commentary] *The Lancet*, 361(9375), p. 2096-2097.

In press

Corrigan, O.P. and Williams-Jones, B. (2005), "Pharmacogenetics: the bioethical problem of DNA investment banking", *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*.

Williams-Jones, B. (2004), "A spoonful of trust helps the Nanotech go down", *Health Law Review*.

Williams-Jones, B. (2004), "Ethics and social responsibility in the life sciences", *Canadian Chemical News/L'Actualité chimique canadienne (ACCN)*.

Presentations

Social Contract Theory and Just Decision-Making: Lessons from Genetic Testing for the BRCA Mutations (Invited) Oncogenetics: Achievements and Challenges, Montreal, QC, Canada, Oct. 7-8, 2004.

Expanding My Bioethical Toolbox: Innovatively Interdisciplinary or a Dangerous Liaison? in session 'Ethics Wars': Exploring the Socio-Ethics of Genetics Research, EASST/4S conference, Public Proofs - Science, Technology and Democracy, Paris, France, Aug. 25-28, 2004.

Is This My Child? Where Am I From?: Direct-to-Consumer Genetic Testing for Paternity and Genealogy Genomics and Society: First Lancaster-Cardiff CESAGen International Conference, The Royal Society, London, United Kingdom, Mar. 2-3, 2004.

Charting the Genesis and Expansion of ELSI Programs in Canada and the United Kingdom, Bioethics Across Borders: Joint Meeting of the American Society for Bioethics and Humanities and the Canadian Bioethics Society Conference, Montréal, QC, Canada, Oct. 23-26, 2003.

In addition to conference presentations, I gave numerous guest lectures and seminars on various aspects of my research, at research centres around the UK.

Teaching

From Jan. to July 2004, I was a visiting lecturer at City University's Dept. of Sociology, where I taught the *Ethical Issues in Health Research* course, as part of the Core Module for M.Sc. in Research Methods Allied to Health.

I continued providing supervisions for undergraduate students in the *Biomedical Technologies and Society; Medicine, Ethics and the Law; and Biological Sciences (Bioethics)* papers, and also supervised a Master's in BioScience Enterprise dissertation (Ms. Susana Velez-Castrillon, *The Impact of Ethical Investment on the Future of Life Science Businesses in the UK*).

Co-organizer (with Dr. O. Corrigan), Genetics Group Seminars, Centre for Family Research, Faculty of Social & Political Sciences, University of Cambridge.

Dr Anji Wilson

Research Associate

Understanding Inheritance: Kinship Connections and Genetics (with Martin Richards). Funded by The Wellcome Trust 2000-2003

Current research

I have been working on a qualitative study investigating concepts of inheritance, genetics, family and kinship in a non-clinical sample of students and parents of young children. The study has involved over sixty pilot and full study interviews, which have been transcribed and are being analysed. Papers on lay concepts of inheritance and family obligations are currently in preparation. Further funding to study these concepts in samples from different ethnic backgrounds and younger individuals will be sought.

I have also been working with another Wellcome Trust funded project, 'From the Corporeal to the Informational', with colleagues from the Bioethics Project on Human Sample Collections, based at King's College Research Centre. We have been interviewing a sample of approximately one hundred people, aged 65 plus and from five locations, about their attitudes to tissue donations for research. The findings from these interviews will be presented in the form of a report to the Wellcome Trust.

Other activities

April 2004-June 2004: As part of the final dissemination of the Joseph Rowntree Foundation funded 'Family Change Series' I have presented the findings of our study on school support (see below in references) at JRF funded seminars in Manchester and London. I also facilitated workshops at these meetings. I also attended final round table discussions about policy implications of the JRF research.

June 2004: Renewed links with local mediation centre and drafted questionnaire for use in pilot evaluation of parental support services at the mediation centre.

Publications

Wilson, A., Edwards, J., Allen, S. and Dasgupta, C. (2003), "Schools and family change: school-based support for children experiencing divorce and separation", (Family Change Series), York: YPS/Joseph Rowntree Foundation.

Cooper, P.J., Murray, L., Wilson, A. and Romaniuk, H. (2003), "Controlled trial of the short- and long-term effect of psychological treatment of post-partum depression: 1. Impact on maternal mood", *British Journal of Psychiatry*, 182, 412-419.

Murray, L., Cooper, P.J., Wilson, A. and Romaniuk, H. (2003), "Controlled trial of the short- and long-term effect of psychological treatment of post-partum depression: 2. Impact on the mother-child relationship", *British Journal of Psychiatry*, 182, 420-427.

ASSOCIATE MEMBERS

Dr Andrew Bainham

Faculty of Law, University of Cambridge, Fellow of Christ's College

I am the Chair of the Cambridge Socio-Legal Group and I continue to be Editor of the *International Survey of Family Law*. I have continued to be involved with the reform of Romania's child protection system and new adoption laws. During the period in question I have visited Romania several times and have been involved in the training of key personnel in the child protection authorities on the international conventions affecting children and families as well as with the new child protection and adoption laws. I have taken part in conferences in different parts of Romania including Gura Homurului (Northern Moldavia), Braila (Southern Moldavia), Râmnicu Valcea (Valcea) and Targu Mures (Transylvania).

I am co-editor of two Socio Legal Group volumes published this year, *Children and Their Families: Contact, Rights and Welfare* (A. Bainham, B. Lindley, M. Richards and L. Trinder, eds, published in 2003) and *Sexuality Repositioned: Diversity and the Law*, (A. Bainham, B. Brooks-Gordon, L. Gelsthorpe and M. Johnson, eds, published in 2004).

Publications

Bainham, A., Lindley, B., Richards, M. and Trinder, L. (eds), (2003), *Children and Their Families: Contact, Rights and Welfare*, Oxford: Hart.

Bainham, A. (2003), "Contact as a right and obligation", in A. Bainham, B. Lindley, M. Richards and L. Trinder (eds), *Children and Their Families: Contact, Rights and Welfare*, pp. 61-88, Oxford: Hart.

Bainham, A. (2003), "International adoption from Romania : Why the moratorium should not be ended", *Child and Family Law Quarterly* 15, 223-236.

Bainham, A. (2003), 3 *Romanian Journal of Society and Politics* (published in English) at pp. 54-60.

Bainham, A., Brooks-Gordon, B., Gelsthorpe, L. and Johnson, M. (eds), (2004), *Sexuality Repositioned: Diversity and the Law*, Oxford: Hart.

Bainham, A. and Brooks-Gordon, B. (2004), "Reforming the law on sexual offences", in A. Bainham, B. Brooks-Gordon, L. Gelsthorpe and M. Johnson (eds), *Sexuality Repositioned: Diversity and the Law*, Oxford: Hart.

Dr Shelley Day Sclater

Reader in Psychosocial Studies, Centre for Narrative Research, University of East London

Dr Shelley Day Sclater works part time at the Centre for Narrative Research, University of East London, and part time as a freelance writer and researcher. Shelley was co-founder, with Martin Richards and Andrew Bainham, of the Cambridge Socio-Legal Group.

Her research interests broadly include:

- qualitative and narrative methodologies
- psychological and socio-legal studies of families, parents and relationships
- applications of psychoanalysis in social research
- theoretical work on subjectivities

She is currently working on 2 books: The first is a 'popular' book on Sexual Attraction. The other involves working with students from a range of cultural backgrounds to produce personal narratives of their diverse experiences of 'family'.

Recent publications include a co-edited interdisciplinary book on surrogacy, a co-edited special issue of the journal *Qualitative Inquiry* on 'Narrative and Art', several book chapters and refereed papers, as well as articles in popular magazines.

Cook, R., Day Sclater, S. and Kaganas, F. (eds), (2003), *Surrogacy: International Perspectives*, Oxford: Hart.

Saarnivaara, M. and Bochner, A. (eds), (2003), *Arts and Narrative Inquiries*, Special Issue of the Journal *Qualitative Inquiry* 9 (4) (S Day Sclater, Deputy Editor)

Day Sclater, S. (2003), "Epilogue: art as inquiry", in M. Saarnivaara and A. Bochner (eds), *Arts and Narrative Inquiries*, special issue of *Qualitative Research* 9(4), 621-624

Day Sclater, S. (2003), "What is the subject?" *Narrative Inquiry* 13(2), 317-330

Cook, R., Day Sclater, S. and Kaganas, F. (2003), "Introduction", in R Cook, S Day Sclater and F. Kaganas (eds), (2003), *Surrogacy: International Perspectives*, Oxford: Hart.

Day Sclater, S. and Kaganas, F. (2003), "Contact: mothers, welfare and rights", in A. Bainham, B. Lindley, M. Richards and L. Trinder (eds), *Parents and Children: Contact, Rights and Welfare*, Oxford: Hart.

Day Sclater, S. (2003), Families Reunited: Following Bob Geldof's impassioned plea for a change in the legal system to suit single fathers, parenting expert Dr Shelley Day Sclater suggests that it is not necessarily the law that needs changing. *FQ*, Winter 2003, 56-59.

Day Sclater, S. (2003), "The Wild Cattle of Chillingham Castle", *The Northumbrian*, October 2004.

Andrews, M., Day Sclater, S., Squire, C. and Treacher, A. (eds), (2004), *The Uses of Narrative: Explorations in Sociology, Psychology and Cultural Studies*, Piscataway, NJ, Transaction Publishers, Rutgers, The State University of New Jersey.

Kaganas, F. and Day Sclater, S. (2004), "Contact disputes: narrative constructions of good parents", *Feminist Legal Studies*, 12, 1-27.

Andrews, M., Day Sclater, S., Squire, C. and Tamboukou, M. (2004), "Stories of Narrative Research", in C. Seale, D. Silverman, J. Gubrium and G. Gobo (eds), *Qualitative Research Practice*, London: Sage.

Day Sclater, S. (2004), Review of *Divorcing Responsibly*, by Helen Reece, Hart, 264pp, ISBN: 1-84113-015-X, published September 2003, THES 13 February 2004

Day Sclater, S. (2004), Review of *Therapeutic Dimensions of Autobiography in Creative Writing*, by Celia Hunt, 208pp, ISBN 1-85302-747-2, Jessica Kingsley, *Auto/biography* (in press)

Day Sclater, S. (2004), Review of *Therapy Culture* by Frank Furedi, 245pp, ISBN 0-415-32159-X, Routledge, *The Psychologist*, 17(6):343

Day Sclater, S. (2004), Review of *Therapy Culture* by Frank Furedi, 245pp, ISBN 0-415-32159-X, Routledge, *Auto/biography* (in press)

Dr. Fatemeh EbtehajCurrent research interests :

My thesis work was conducted on Iranian exile women at midlife. I am currently drawing on this research to publish articles in journals concerned with women's issues, narrative and discursive psychology, exile and migration. I am also extending the scope of this study to include women of other generations. As part of a separate project, I am examining the impact of migration and exile on family relationships, highlighting issues related to care for the elderly.

Dr Margaret Ely

Margaret Ely was awarded the Ph.D. degree in June, 2004. Her thesis was entitled "Dealing with missing data on alcohol consumption using diet diaries in a birth cohort study".

Publications

Ely, M., Hardy, R., Longford, N., Wadsworth M.E.J. "The relationship of mid-life affective disorder and alcohol consumption with responses to the CAGE: the role of adolescent psychological and behavioural characteristics" Submitted to *Psychological Medicine*.

Jarrett, P M, Ritchie I K, Albadran L, Glen S K, Bridges A B and Ely M., "Do thigh tourniquets contribute to the formation of intra-operative venous emboli? a randomised prospective trial", Submitted to the *Journal of Bone and Joint Surgery*.

Ely, M., Melzer, D., Brayne, C. and Opit, L. (2003) *The Cognitively Disability Planning Model: estimating characteristics and continuing care needs of people with cognitive disability, including dementia, in local populations. Computer Program and Documentation. Eastern Region Public Health Observatory website.* <http://www.erpho.org.uk/methods.asp>.

Dr Judith EnnewTeaching/research

- a) Technical Advisor and trainer, Save the Children Southeast, East Asia and the Pacific Regional Office, on the United Nations Secretary General's Global Study on Violence Against Children.
- b) Technical Advisor and trainer for Save the Children UK Philippines, Monitoring Children's Rights.
- c) Research technical advisor and designer, evaluation of Participation of Children and Young People in Southeast, East Asia and Pacific in Events and Forums Leading to and Following Up on the United Nations General Assembly Special Session for Children, 2002.
- d) Research evaluation of capacity building programme in child participation 2000-2004, Save the Children Sweden, Regional Office for Southeast Asia and the Pacific, Hanoi, Vietnam.

Editorial and other

Editorial Board: *Children's Geographies*.

International Editorial Board: *Childhood*.

Independent expert, Steering Committee for the East Asia and Pacific Regional Consultation on the United Nations Secretary General's Global Study on Violence Against Children.

Visiting Scholar, National University of Singapore, Asian MetaCentre, October 2004

Scientific Committee Organiser, Asia-Pacific Childhoods: An Ethnography of Childhood Workshop, July 2006, National University of Singapore.

Invited lectures/papers

Vagrant and street children: The right to be properly researched and the 'right policies', International Conference on Vagrant Children, Hebei, China, October 2003.

The right to be properly researched: Ethics, participation and triangulation in research with working children, Die Bedeutung von Arbeit aus der Sicht der Kinder – theoretische Ansätze und empirische Forschungsergebnisse aus internationaler Perspektive 12.-17. April 2004 Berlin, Max-Planck-Gesellschaft

Publications

'Setting directions: Towards a regional strategy to address the corporal punishment of children' in *Towards a strategy to address the corporal punishment of children in Southeast, East Asia and Pacific: Proceedings of the International Save the Children Alliance Regional Workshop on Corporal Punishment of Children, 6-9 October, 2003, Bangkok, Thailand*, Bangkok, International Save the Children Alliance.

Working with street children: Exploring ways for ADB assistance, Manila, Asian Development Bank.

Entries for Jean La Fontaine and Audrey Richards in Vered Amit (ed) *Biographical dictionary of social and cultural anthropology*, Routledge.

With Paul Stephenson *Questioning the basis of our work: Christianity, children's rights and development*, Bangkok, Tearfund and Black on White Publications.

With Yuli Hastadewi, *Seen and Heard: Participation of Children and Young People in Southeast, East Asia and Pacific in Events and Forums Leading to and Following Up on the United Nations General Assembly Special Session for Children, 2002*, Bangkok, International Save the Children Alliance Regional Office for Southeast, East Asia and the Pacific.

With Dominique Pierre Plateau, *Resource Handbook: How to research the physical and emotional punishment of children*, Bangkok, Save the Children Southeast, East Asia and the Pacific Regional Office.

Reprint of Chapter 5 of *The Sexual Exploitation of Children*, Polity Press and 'Outside Childhood: Street Children's Rights', from Franklin B., (ed.) *Children's Rights: A Handbook of Comparative Policies and Practice*, Routledge in Nick Frost (ed.), *Child welfare: Major themes in health and social welfare*, London, Routledge.

Dr Nina Hallowell

Lecturer in Social Sciences and Public Health, Public Health Sciences, The Medical School, University of Edinburgh

Research interests

Whilst the main focus of my research is the social and ethical implications of the new genetic technologies, my research interests also include: the sociology of risk, the sociology of the body and research ethics. Main themes:

- *Cancer genetics: ethical and social issues*
- *The relationship between bioethics and empirical research*
- *The use of human sample collections (particularly DNA) as a research resource*
- *Lay understanding of health risks and risk management*

- *Lay-Professional interaction*

Selected publications

Hallowell, N., Mackay, J., Richards, M.P.M., Gore, M. and Jacobs, I. (2004), "High-risk premenopausal women's experiences of undergoing prophylactic oophorectomy: a descriptive study", *Genetic Testing* (In press).

Hallowell, N., Ardern-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C. and Watson, M. (2004), "Men's decision-making about predictive BRCA1/2 testing: the role of family". *Journal of Genetic Counseling* (In press).

Hallowell, N., Lawton, J., Gregory, S. (2004), *Reflections on Research: The Realities of doing Research in the Social Sciences*, Open University Press (In press).

Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A. and Watson, M. (2004), "Accommodating risk: women's responses to BRCA1/2 genetic testing following a cancer diagnosis", *Social Science & Medicine* 59, 553-565.

Hallowell, N. (2003), "Ethics and evidence", in D.N. Cooper (ed.), *The Encyclopedia of the Human Genome*, London: Nature Publishing Group.

Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A., Murday, V., and Watson, M. (2003), "Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information", *Journal of Medical Ethics* 29, 74-79.

Hallowell N (2003) A response to Angus Clarke "Family obligations and the limits to 'autonomy'", *Journal of Medical Ethics*, 29, 79.

Ms Bridget Lindley

I am actively involved in the Socio-Legal Group as described below. I am also developing plans with Martin to apply for further funding to develop further practice tools on support for parents involved in child protection procedures.

My work at the Centre has included the following:

Research: Qualitative study on advice and advocacy for families in child protection cases

From 1997-2001, I worked part time at the Centre with Martin Richards on a qualitative study, which explored the process of advocacy for parents in child protection cases, in which the local authority was making enquiries under s.47 Children Act 1989.

The study found that despite some resistance amongst professionals to the advocate's involvement, there was nevertheless a strong consensus that advocacy is helpful or very helpful provided the advocate has specialist knowledge and experience of the child protection process and issues, conducts him/herself in a professional, non-adversarial manner and becomes involved early on in the process. However, it also showed that there was an urgent need for a national advocacy protocol to be drawn up, giving guidance about professional, ethical and practice issues.

Protocol for practitioners:

In order to address this latter need the Department of Health commissioned Martin Richards and myself to develop a protocol on advice and advocacy for parents in such cases. The protocol draws upon the research evidence, and was also developed in consultation with a wide range of childcare and advocacy organisations, the Department of Health, the ADSS, the Law Society, and members of the judiciary. Broadly, it outlines the practice issues which need to be addressed by both advocates, social workers and other child care professionals

when advocates become involved, and also explored the ethical considerations for advocates working in this context, in which the avoidance of collusion with both the parent and the local authority is crucial. It is the first time such a protocol has been developed at a national level. This document is available on www.sps.cam.ac.uk/CFR/advocacyprotocol.

Current advocacy project:

Family Rights Group, London has developed a 3 year advocacy project for families who are involved in child protection processes in London, using the Protocol as the framework for its service provision. I am the legal adviser on that project, part-time. The project has completed its first year and has attracted interest at a national policy level. Further information about the project can be found on FRG website: www.frg.org.uk.

Publications

Lindley, B. (2003), "Spare a thought for the parents", *Community Care*, August, p 34-35.

Socio-Legal Group

I am vice chair of the Social-Legal Group, and have been an editor of our recent publication: Bainham, A., Lindley, B., Richards, M.P.M. and Trinder, L. (eds) (2003), *Children and their Families: Contact, Rights and Welfare*, Oxford, Hart. In addition to editing the book with my colleagues, introducing Bob Geldof as a contributor and co-ordinating the project, I also organised the launch party for the book which was held at the Nuffield Foundation on 11th September 2003. This event was very successful and was attended by senior members of the legislature and Parliament, and also had some press coverage (see page 2).

I am currently involved in early discussions with Martin Richards and Fatima Ezbehaj to develop another seminar series for the group on *Kinship: Rights, Obligations and Law in a Changing Society*. This is likely to result in the publication of an edited book in 2006.

Professor Juliet Mitchell

Faculty of Social and Political Sciences and Fellow of Jesus College

Research interests

My research has been directed to relating siblings to group processes. With this in view I have qualified in a one-year training in Group Analysis (Cambridge Group Analysis) which was both academic and experiential.

Publications:

Mitchell, J. (2004), "Gender, family and mental illness", *Research Review Suppl.* 15, 101-107.

Mitchell, J. (2004), "Review of P. Coles, The Importance of Sibling Relationships in Psychoanalysis", *International Journal of Psychoanalysis*, 85(2), 557-561.

Mitchell, J. (2004), "Natasha and Hélène in Tolstoy's *War and Peace*: gender conventions and creativity", selected from F. Moretti (ed), *le Romano* vol. III, for English edition, in press.

Mitchell, J. (2004), "Procreative mothers (sexual difference) and child-free sisters (gender): feminism and fertility", *European Journal of Women's Studies*, 11(4).

Young, L. and Mitchell, J. (2004), "The study of the experiences of child evacuation during World War Two with special reference to sibling relationships", *Critical Psychology*, in press.

Mitchell, J. (2003), *Siblings: Sex and Violence*, Cambridge: Polity Press.

New translations: *Mad Men and Medusas* – Italian, and in press Estonian, Slovenian, Spanish. *Psychoanalysis and Feminism* – Estonian. *Who's Afraid of Feminism* – Estonian.

Public and Keynote Lectures: Institute of Filosofia, Naples; Panteion University, Athens; Bilgri University, Istanbul; Institute of Filosofia, Bologna; Courthauld Institute, London; European Philosophy, British Library, London; 2004 Annual London Consortium Lecture, Tate Britain; Yorkshire Psychotherapy Groups, Playhouse Theatre, Leeds; University of Seoul, S. Korea; Institute of Social Science, Amsterdam; Future of the Humanities Conference, Prato.

Radio: *In Our Time*. Melvyn Bragg.

Dr Deborah Thom

College Lecturer, Director of Studies in History and Tutor, Robinson College Cambridge

Taught on papers on bio-engineering and the family in SPS IIB; on the history of British psychology in HPS and on a new course for the History Tripos part 1 Themes and Sources on The Body in History as well as on the history of the politics of gender in part II.

Publications

Thom, D. (2004), "Politics and the people: Brian Simon and the campaign against intelligence testing", *History of Education*, Autumn.

Thom, D. (2004), Entries for Lady Hester Adrian, Lilian Barker, Mrs Cecil Chesterton, Barbara Drake, Dr Emanuel Miller in the new *Dictionary of National Biography*, Oxford.

Thom, D. (2003), "Making War spectacular", in G. Braybon (ed), *Evidence, History and the Great War*, Berghahn Books.

Lectures and conferences

Thom, D. (2003), Plenary lecture 'Brian Simon and the campaign against intelligence testing'. Conference of the History of Education Society, Homerton College, Cambridge, December 2003.

Thom, D. (2004) "Of course the women do not actually ... dig the graves", women and war photographs', Social History Society conference, University of Rouen, France, January 2004.

Thom, D. (2004) "'Of course the women do not actually ... blow the glass', women and the work photograph', Annual conference on Work, Centre for Contemporary British History, Institute for Historical Research, London, July 2004.

VISITORS

Ms Serena Lecce

Serena Lecce is a PhD Student from the University of Pavia. Her research interests are in developmental psychology and more specifically, in children's representations of their close relationships (friendships and sibling relationships). She spent 6 months at the Centre as a visiting researcher, working with Dr Claire Hughes on a project on "hard to manage" children's relationships with their friend and sibling. The main goal of the study was to investigate how "at risk" children use their cognitive and emotional abilities in real life. This year she hopes to write a paper with Dr Claire Hughes outlining differences in children's talk about inner states in their conversations with siblings and friends.

Dr Kerry Petersen

Dr Kerry Petersen teaches medical law and torts at La Trobe University and the major focus her research has been on human reproduction law. She is co-editing "Disputes and Dilemmas in Health Law" (Federation Press) with Dr Ian Freckelton and while at the CFR conducted comparative research into the regulation of human reproduction for her chapter "Reproductive Health Law: Emerging Dilemmas" in the book. She also attended hearings at the House of Commons held by the Select Committee which has been appointed to review the regulation of the assisted reproductive technologies in the UK.

Recent publications

"Assisted reproductive technologies: professional and legal restrictions in Australian clinics", *Journal of Law and Medicine*, (forthcoming) (co-authors: G Baker, M Pitts & R Thorpe).

"The rights of donor-conceived children to know the identity of their donor: the problem of the known unknowns and the unknown unknowns" in B. Bennett and G. Tomossy (eds), *Globalisation and Health*, (Kluwer, 2004)(forthcoming).

"Abortion laws: comparative and feminist perspectives in Australia, England and the United States" in B. Bennett, *Abortion*, Ashgate: UK, 2004. (forthcoming) [Reprint].

"The sexual zone between childhood and the age of majority: claims to sexual freedoms versus protectionist policies" in B.M. Brooks-Gordon, L.R. Gelsthorpe, M.H. Johnson and A. Bainham. *Sexuality Repositioned: Diversity and the Law*, Hart Publishing: Oxford, 2004, 351-372.

Dr Helena Willén

Dr Helen Willén from the Nordic School of Public Health visited several times during the year in connection with the collaborative study of couple's decision-making related to divorce.

Dr Jan Pryor

Dr Jan Pryor visited us from New Zealand. She is the Director of the newly formed Roy McKenzie's Centre for the Study of Families at Wellington. We send our best wishes to this sister centre in the southern hemisphere.

Professor Ann Robertson

*Associate Professor, Department of Public Health Sciences, University of Toronto
Visiting Scholar, Centre for Family Research, October 2002 – June 2003*

Research

2002- 2003, Canadian Institutes of Health Research (Institute of Genetics) Career Transition Award - to study policy issues at the intersection of human genetics, bioethics and public health, under the mentorship of Dr. Martin Richards.

Grants held

2003-2005, Principal Investigator, "It's all in our genes": A Critical Analysis of Media Representations of Genetic Risk for Breast Cancer". Funded by Social Sciences and Humanities Research Council (SSHRC) of Canada, \$48,500.

2000-2005, Co-Investigator, "International and Comparative Perspectives on the Regulation of Genomic Research and Health Systems and Insurance" (Dr. Trudo Lemmons, PI). Project of Canadian Program on Genomics and Global Health (Dr. Peter Singer, Director) Funded by Genome Canada/Genome Ontario. \$1,000,000.

2000-03, Principal Investigator, "Towards a Phenomenology of Risk: The Case of Genetic Testing for Breast Cancer." Funded by Social Sciences and Humanities Research Council (SSHRC) of Canada. \$40,000.

Publications

Denny, K., Coburn, D., Mykhalovskiy, E., McDonough, P., Robertson, A. and Love, R. (2003), "Population health: a brief critique", *American Journal of Public Health*, 93 (3), 392-396.

Buckeridge, D., Mason, R., Robertson, A., Frank, L., Glazier, R. and Purdon, L. with C. G. Amrhein, N. Chaudhuri, E. Fuller-Thompson, P. Gozdyra, D. Hulchanski, G. Moldofsky, M. Thompson and Wright, R. (2002), "Health data maps: a case study of a community/ university research collaboration", *Social Science and Medicine*, 55 (7), 1189-1206.

Dr Silvana Santos

Silvana Santos is a post-doctoral visiting researcher from the University of São Paulo, Brazil. Her interests are both in education and genetics. She has studied everyday ideas of inherited disorders in Brazilian families. She is at the Centre for Family Research for five months working with Professor Martin Richards. She hopes to organize a collaboration to study the evolution of ideas to genetic disorders in a rural community of Brazil. How would the ideas inside a rural community change with introduction of new genetics information and genetic testing?

Grant held

Research Fellowship of the FAPESP (Fundação de Amparo a Pesquisa do Estado de São Paulo) (Funded period – September 2005 – January – 2005).

Publications

Kok, F., Santos, S., Amorin, S., Macedo-Souza, L.I., Starling, A., Zatz, M. (submitted), "Spastic paraplegia, optic atrophy and neuropathy: SOAP syndrome", *Annals of Neurology*.

Santos, S., Infante-Malachias, M.E., Amabis, J.M. (2004), "Estratégias meta cognitivas de aprendizaje en la planificación de una secuencia didáctica sobre digestión", *Journal of Science Education*, 5 (1), 24-27.

Santos, S. and Bizzo. (in press), "From new genetics to everyday knowledge: ideas about how genetic diseases are transmitted in two large Brazilian families", *Science Education*.

Koga, D., Santos, S., Infante-Malachias, M.E., Amabis, J.M. (in press), La influencia de dos secuencias didácticas sobre la construcción de narraciones de los estudiantes de enseñanza básica: un ejemplo sobre el tema electricidad, *Journal of Science Education*.

INTEREST GROUPS AND WORKSHOPS

Cambridge Genetics Group

The Group has had a regular series of seminars through the 3 terms of the academic year organised by Drs Oonagh Corrigan and Bryn Williams-Jones. Seminar speakers have come from Cambridge and more widely and we have been able to take advantage of the presence of a number of overseas visitors in Cambridge to invite them to give seminars. Members of the Group are drawn from a wide variety of institutions in Cambridge including the Centre for

Family Research, History and Philosophy of Science, Social Anthropology, Law, Public Health, Medical Genetics and Public Health Genetics.

For the next academic year the Group's activities will receive financial support from the Cambridge Genetic Knowledge Park.

The Group is open to anyone interested in social science and ELSI research related to genetics and genomics. Anyone wishing to be on our email mailing list should contact one of the organisers (Oonagh Corrigan, opc22@cam.ac.uk, Bryn Williams-Jones, bw244@cam.ac.uk, and Martin Richards, mpmr@cam.ac.uk).

Martin Richards

Cambridge Body Research Group

The Cambridge Body Research Group began in 1999 as an interdisciplinary group drawing heavily from recent interest in the sociology and anthropology of the body. After a brief period of inactivity the group is again organising a full programme of seminars during term time coordinated by Professor Bryan Turner, Dr Darin Weinberg and Shirlene Badger. During the past academic year seminar topics have included explorations of dance and the body, sleep, reproductive medicine and ageing and bodily appearance. An updated website has been launched and includes further information about the group and full details about its activities (<http://www.sps.cam.ac.uk/body/index.htm>).

Shirlene Badger

The Brazelton Centre

Activities of the Brazelton Centre in Great Britain 2003-2004

Work at the Brazelton Centre focuses on promoting healthy parent-infant relationships. Through conferences and workshops aimed at health professionals, information about infant behaviour and development and assessment, and parent-infant relationships are presented. The Centre was opened in 1997 and so far has trained 41 health professionals in the Neonatal Behavioural Assessment Scale (NBAS), and has 70 people in the process of training. The Centre is a charity with three trustees and 6 co-founders. The NBAS has been used in research and as a supportive intervention in 700 studies worldwide. Johnson and Johnson funded the Centre in 1997-1998 and a conference in Cambridge in 1997. The Johnson and Johnson Pediatric Institute funded a conference in London in 2004 with Dr. T. Berry Brazelton and Dr. Kevin Nugent as keynote speakers. Almost 400 people attended. A video called "More than Words can Say" about infant behaviour was also funded. Future plans include invited presentations to the Polish Neonatal Society, the Mother and Child Institute, Warsaw and the International Association of Infant Massage. Workshops, training and conferences are advertised, and the next one-day workshop will be in Spring, 2005.

For information: www.brazelton.co.uk

Tel. 01223-245791

Infant Relationships Study Group

This group meets termly for seminars, discussion and presentations on parent-infant relationships and infant mental health issues. It aims to include academics, health professionals and volunteers who work with infants. Several members of this group are also involved in the founding of CAMPIP, the Cambridge Parent-Infant Project, an infant mental health service in Cambridge. Joint presentations are organised.

Joanna Hawthorne

Cambridge Socio-Legal Group

The Group's current and recent seminars

The Contact Project

Bainham, A., Lindley, B., Richards, M. and Trinder, L. (eds), (2002), *Children and Their Families: Contact, Rights and Welfare*. Oxford: Hart.

The Sexuality Project

In April 2003 the Group held a residential seminar at Pembroke College Cambridge on the subject of Sexuality. This resulted in publication of the book, *Sexuality Repositioned : Diversity and the Law* in June 2004. The book was edited by Belinda Brooks-Gordon, Loraine Gelsthorpe, Martin Johnson and Andrew Bainham and again published by Hart. The launch at the House of Lords on June 17th was generously hosted by Lord Faulkner of Worcester and attended by Baroness Hale of Richmond and Mr. Justice Wood. The speakers were Martin Johnson, Loraine Gelsthorpe, Andrew Bainham and Belinda-Brooks-Gordon who also chaired the event.

The book takes a radical look at sexual diversity and how our sexualities are being refashioned and repositioned. It contains a diverse collection of inter-disciplinary contributions. These range over, inter alia, the recent reform of the law governing sexual offences, same-sex partnerships, treatment of sex offenders, sexuality in the work place, sexual abuse of children, prostitution, pornography, the sexuality of the young, biomedical and legal approaches to sexual orientation and intersexuality, sexual activism, historical and futuristic perspectives on sexuality. Those contributing chapters to the book were Loraine Gelsthorpe; Jeffrey Weeks; Ken Plummer; Lynne Segal; Linda McDowell; Craig Lind; Zoe-Jane Playdon; Martin Johnson; Pak-Lee Chau and Jonathan Herring; Julie Jessop; Roger Ingham; Andrew Bainham and Belinda Brooks-Gordon; Andrew Webber; Michael Freeman; David Pearl; Kerry Petersen; Joanna Phoenix; Belinda Brooks-Gordon, Charlotte Bilby and Tracey Kenworthy.

Bainham, A., Brooks-Gordon, B., Gelsthorpe, L. and Johnson, M. (eds), (2004), *Sexuality Repositioned : Diversity and the Law*, Oxford: Hart.

Forthcoming Projects

The Group plans to take forward two further projects on the subjects of 'Kinship and Care' and 'Death' respectively. It is expected that the seminars for these projects will take place in 2005.

LUNCHTIME SEMINARS 2003/2004
held at the Centre for Family Research

Michaelmas 2003

- 4th November Professor Leonore Davidoff
 (Department of Sociology, University of Essex)
The Legacy of the Nineteenth Century Bourgeois Family and the Wool Merchant's Son
- 11th November Joe Murray
 (Institute of Criminology, University of Cambridge)
Children of Imprisoned Fathers
- 25th November Dr Jan Pryor
 (School of Psychology and Roy McKenzie Centre for the Study of Families, Victoria University of Wellington, New Zealand)
The Silent Treatment: Parental Estrangement and Adolescents' Well-being
- 2nd December Dr Joanna Hawthorne
 (Centre for Family Research and Brazelton Centre, Addenbrookes, Cambridge)
The Brazelton Centre: Supporting Early Parent-Infant Relationships

Lent 2004

- 27th January Svetla Baloutzova
 (Department of History, University of Cambridge)
Measuring illegitimacy in socialist Bulgaria: 'wanton wenches' and minority issues
- 4th February (Joint meeting with SPS Media Research Group)
 Sonia Livingstone
 (Department of Media and Communications, LSE, London)
Mediating the public/private boundary: emerging practices of domestic interne tuse among children
- 10th February Linda McKie
 (Centre for Research on Families and Relationships, Glasgow Caledonian University)
Theories, violence, and families: the 'myths' of sociological analysis
- 9th March Marc de Rosnay
 (Centre for Family Research, University of Cambridge)
 Title to be announced

Easter 2004

- 11th May Louise Bryant
(Academic Unit of Psychiatry and Behavioural Sciences,
University of Leeds)
*Prenatal screening for Down's syndrome; the relationship between
attitudes towards the condition and testing intentions*
- 25th May Dr Virginia Morrow
(Child Focused Research Centre, Brunel University)
*The implications of gender differences for supporting children:
a critical review paper*
- 8th June Dr Elizabeth Chapman
(Adult Cystic Fibrosis Centre, Papworth Hospital)
The Continuum of Maturation with Cystic Fibrosis: Home and Away

The Margaret Lowenfeld Library

The library of the Institute of Child Psychology is housed in our premises. This came to us through the Lowenfeld Trustees. The book collection has been added to the main University Library Newton catalogue. We also have been given some archival material relating to Dr Lowenfeld and the Institute of Child Psychology, and recent additions include research papers from the late Terence Moore, and the Lydia Jackson correspondence from the Leeds Russian Archive. The library also includes books given by Professor Harry Highkin following the death of his wife Elspeth, who was a research student in the Centre at the time of her death.

In March 2005 the Lowenfeld archive will be transferred to the Wellcome Trust History of Medicine Archive with the test materials (mosaics, World etc) going to the Science Museum which already has some Lowenfeld materials on long term loan from the Lowenfeld Trustees.

Professor Martin Richards

Research interests

Psychosocial aspects of genetic and reproductive technologies. Children and family life.

Research grants

Understanding inheritance and kinship connection (with Dr Anji Wilson). Funded by The Wellcome Trust. 2000 - 2004.

Non-disclosure of genetic risk information (with Dr Angus Clarke, University of Cardiff and Lauren Kerzin-Storarr, N.W. Regional Genetics Service and other collaborators). 2000 - 2004.

Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability (with Nina Hallowell, Helen Statham and Lucy Raymond). Funded by The Wellcome Trust 2002-2006.

Informed consent and genetic data (Onora O'Neill, Patrick Bateson, Peter Lipton and Martin Richards). Funded by The Wellcome Trust 2002-2005.

Research based outside Cambridge

I am involved in the following collaborative projects:-

Legal Services Commission. FAINS action research. Professor Jan Walker, University of Newcastle and others.

The Basque Government and University of the Basque Country. Family interaction and psychological development of 5 year-old Basque children with Enrique Arranz. Euskal Herriko Unibertsitatea.

Swedish Council for Social Research. Conflict, negotiation and decision making post divorce with Helena Willén, Nordic School of Public Health, Gothenberg.

Canadian Institute of Health Research. Ethics of Health Research and Policy. Ph.D. and Post Doc Training Programme. Centre for Applied Ethics, University of British Columbia and Dept of Philosophy, Dalhousie University.

Genome Canada and Genome British Columbia. Genomics, Ethics, Environment, Economic, Law and Society (GE3LS) Dr. M. Burgess and others, Centre for Applied Ethics, University of British Columbia.

I am a Director of the (Cambridge) Centre for Medical Genetics and Policy and am on the Advisory Board for the Cambridge Genetic Knowledge Park.

I serve on The Wellcome Trust Biomedical Ethics Panel and Human Genetics Commission.

I am a member of the Human Fertilization and Embryology Authority's Ethics and Law Committee and the HGC observer on the Authority.

Publications

Books

Blackwell Companion to the Sociology of Families (2003) (editor with J. Scott and J.K. Treas). Blackwell. ISBN 0-631-22158-1.

The New Human Genetics

Nuffield Council on Bioethics. Genetics and Human Behaviour: The ethical context (member of Working Party). London, Nuffield Council. ISBN. 190438403X. (2003).

Richards, M.P.M. (2003), "Assisted reproduction, genetic technologies and family life", in J. Scott, J. Treas and M. Richards (eds), *Blackwell Companion to the Sociology of Families*, Blackwell, pp 478-498. ISBN 0-631-22158-1.

Richards, M.P.M. (2003), "Attitudes to genetic research and uses of genetic information: support, concerns and genetic discrimination", in B.M. Knoppers (ed), *Population and Genetics: Legal Socio-Ethical Perspectives*, pp 567-578. Kluwer Legal International, ISBN 90-0413-878-9.

Richards, M.P.M. (2004), "Perfecting people: selective breeding at the Oneida Community 1869-1879 and the eugenic movement", *New Genetics and Society*, 23, 49-71.

Richards, M.P.M.(2004), "DNA families", *Biological Sciences Review*, 16, 8-11.

Richards, M.P.M. (2004), "A 19th century experiment in human selective breeding", *Nature Reviews: Genetics*, 5, 475-479.

Halliday, J.L., Collins, V.R., Aitken, M.A., Richards, M.P.M. and Olsson, C.A. (2004), "Genetics in public health - evolution or revolution?" *J. Epidemiol. & Community Health*, 58, 894-899.

Families and Children

Wild, L.G. and Richards, M.P.M. (2003), "Exploring parent and child perceptions of interparental conflict", *Int. J. Law, Policy and Family*, 17, 366-384.

Olabarrieta, F., Martin, J.L., Arranz, E., Manzano, A., Azpiroz, A., Bellido, A., Oliva, A. and Richards, M.P.M. "Familiako giroaren kalitatea eta haurren garapen psikologikoa Euskal Autonomia Erkidegoan: azterketa deskriptiboa" [Family context and development in Basque children], *Uztaro*, 47, 81-95, 2003.

