CENTRE FOR FAMILY RESEARCH

ANNUAL REPORT

(Academic Year 2001 – 2002)

Director of Centre Professor Martin Richards

Deputy Director Ms Helen Statham

Members of the Centre

Research Staff and Post-Graduate Students*

Dr Anna Bagnoli Dr Julie Jessop Dr Elizabeth Chapman Dr Lynne Jones Dr Claudia Downing **Bridget Lindley** Dr Fatemeh Ebtehai Dr. Chris Mann Dr Judith Ennew Maggie Ponder Georgina Haarhoff* Laura Riley Marji Halati* Dr Ilina Singh Dr Joanna Hawthorne Claire Snowdon Dr Claire Hughes Dr. Jane Weaver Dr Antonella Invernizzi Dr Anji Wilson

Associate Members

Lucy Allcock*Eva LloydDr Andrew BainhamProf Juliet MitchellDr Shelley Day SclaterFrances MurtonMargaret ElyDr Thelma QuinceDr Gail EwingDr Eileen RichardsonDr Nina HallowellDr Deborah Thom

New Members of the Centre 2002-2003

Dr Oonagh Corrigan Dr Ann Robertson Dr Shobita Parthasarathy Dr Bryn Williams-Jones Ms Rosie Davie

Assistant Staff

Administrative Secretary

Jill Brown

Data Manager/Librarian

Sally Roberts

Cleaner

Anne Burling

Management Committee

Professor Ian Goodyer (Chair until May 2002, Division of Developmental Psychiatry, University of Cambridge)

Professor Tony Manstead (Acting Chair from June 2002, Faculty of Social and Political Sciences)

Ms Erica de'Ath (National Council for Voluntary Child Care Organisations, London)

Dr Mavis Maclean (Centre for Family Law and Policy, University of Oxford)

Professor Martin Richards

Dr Jacqueline Scott (Social and Political Sciences Faculty)

Ms Helen Statham

Professor Bryan Turner (Social and Political Sciences Faculty)

Ms Kate Stacey (Secretary)

Dr Darren Weinberg (Social and Political Sciences Faculty)

Joiners and Leavers

We welcome Dr Oonagh Corrigan who has been appointed to one of the Cambridge Genetic Knowledge Park lecturerships. Oonagh holds a Wellcome Trust Fellowship and has been in the Department of Sociology at Goldsmiths working on social aspects of pharmacogenetics.

Dr Bryn Williams-Jones joins us from the Applied Ethics Centre at the University of British Columbia. He is a post-doctoral fellow who is working on industrial-academic relationships in biotechnology. He also holds a fellowship at Homerton College.

Dr Shobita Parthasarathy recently completed a PhD on a comparison of genetic testing for BRCA1/2 in the Sociology of Science and Technology Program at Yale University. She has been awarded a Wellcome Trust Fellowship for work at the Centre.

Dr Ann Robertson from the University of Toronto is visiting the Centre for 8 months. She holds a Career Transition Award from Canadian Institute of Health Research, Institute of Genetics to study human genetics and ethics. Her research interest is in the meanings and uses of the notion of 'genetic risk' in policies and practices related to genetic testing for late onset disease.

Dr Elizabeth Chapman who has completed her Wellcome Trust Fellowship has been appointed as Research Facilitator for the Council for the School of Social Sciences and Humanities. This is a half time post and she will work in the Centre for the remainder of her time. From the new year she will be working part time at the Arthur

Rank Hospice investigating a number of research questions connected with pain in terminally ill patients with cancer, and will also be involved in research part time at Papworth Hospital working with patients with end-stage cystic fibrosis and who are considering and undergoing transplantation.

Ms Rosie Davie graduated in July 2002 and commenced her doctoral research in October 2002. The topic for her Ph.D. is interaction between parents and toddlers 'at risk' of developing behaviour problems.

Dr Chris Mann has moved to the Cambridge Institute of Education where she will continue her work on gender differences in educational attainment.

Ms Laura Riley has returned to a post as researcher for BBC TV.

Research Workshops

During the year the Centre has hosted, and in most cases organised, the following Research Workshops. The name in brackets is the contact person in each case.

- The Sociology of the Body Group (Liz Chapman)
- The Psycho-Social Aspects of Genetics Group. Regular meetings with colleagues from the Institute of Medical Genetics at Cardiff have continued during the year (Martin Richards)
- The Infant Relationships Study Group (Joanna Hawthorne)
- The Cambridge Biomedical Ethics Forum (Jointly organised by Tim Lewens (HPS), Bronwyn Parry (King's College) and Martin Richards)
- The Child Research Working Group (Julie Jessop)
- The Cambridge Socio-Legal Group. Seminars were held on contact and family relationships. The volume resulting from these will be published by Hart in Spring 2003. 'Body Lore and Laws', edited by Andrew Bainham, Shelley Day-Sclater and Martin Richards was published in 2002. A new project on socio-legal aspects of sexualities is being planned (Andrew Bainham).

RESEARCH OF MEMBERS OF THE CENTRE

Martin Richards - Director

Professor of Family Research, Faculty of Social and Political Sciences

A review of interventions and support services for children experiencing parental divorce and other major family change (with Dr Jan Pryor, Division of Psychology, Victoria University of Wellington, New Zealand, Dr Joanna Hawthorne and Dr Julie Jessop). Funded by the Joseph Rowntree Foundation. 2000 - 2002.

This project provides a review of services directed at children. The work has been completed and the report delivered to the Joseph Rowntree Foundation and this will be published in January 2003.

Understanding inheritance and kinship connection (with Dr Anji Wilson). Funded by The Wellcome Trust. 2000 - 2003.

This qualitative study explores connections between knowledge of inheritance and concepts of kinship and family obligation. Qualitative interviews are being conducted with samples of young people and recent parents.

Non-disclosure of genetic risk information (with Dr Angus Clarke, University of Cardiff and Lauren Kerzin-Storrar, N.W. Regional Genetics Service and other collaborators). 2000 - 2003.

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.

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 study will examine family members' perceptions and experiences of an X-linked severe learning problem before and after the associated gene mutation has been identified using a high throughput mutation detection technique (the Genetics of Learning Disability study). Work on this new project will begin in December.

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 will be based in the King's College Research Centre. In the future it will be transferred to the newly created Medical Genetics and Policy Centre which will be based in the Strangeways Laboratories.

The project will test 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.

The follow-up study of participants in an epidemiological study of breast cancer (with Maggie Ponder, Paul Pharoah, Sarah Everest and James Mackay) was completed during the year and the resulting paper will be published in the Journal of Medical Ethics.

Cambridge has received a major grant under the Department of Health/Department of Trade and Industry Genetic Knowledge Park Initiative. This will support posts in the social sciences, philosophy, law, general practice and health economics. In addition there is development of the work of the Genetics and Policy Unit.

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.

I have served on the Nuffield Council on Bioethics working party on genes and Behaviour. The report 'Genes and Behaviour: The ethical context' was published in October 2002.

The final stages of editorial work (with Jackie Scott and Judy Treas) for the Blackwell Companion on Sociology of the Family are being completed. The book will be published in 2003.

During the year the new SPS Part IIB Course Biomedical Technologies and Society which I had designed was taught for the first time.

I am on the steering group of the Marriage, Divorce and Family Workshop. This holds an annual residential conference and more frequent daylong seminars which bring together researchers and policy makers and is supported by a grant from the Lord Chancellor's Department.

The Wellcome Trust has revised its arrangements for the funding of work on biomedical ethics and communication and public perception of science. The Medicine in Society Panel on which I serve will hold its final meeting in November 2002. I have been appointed to the newly formed Biomedical Ethics Panel.

I am a member of the external Faculty of the CIHR Training Programme in Research Ethics and Health Policy and the Democracy, Ethics and Genomics Project at the Centre for Applied Ethics at the University of British Columbia..

In July and August I made a research and lecture trip to Australia and New Zealand. I gave a number of University lectures and took part in a series of seminars for the New Zealand Family Court.

I am external examiner for the M.Sc. in Genetic Counselling at the University of Manchester.

My membership of the Human Genetic Commission continues. During the year the major report 'Inside Information: Balancing interests in the use of personal genetic data' was published.

Publications

Bainham, A., Day-Sclater, S. and Richards, M.P.M. (eds.) 2002. *Body Lore and Laws*. Oxford: Hart.



Richards, M.P.M. 2002. 'Future Bodies: Some History and Future Prospects of Human Genetic Selection'. In A. Bainham, S. Day-Sclater and M.P.M. Richards (eds.), *Body Lore and Laws*. Oxford: Hart.

Hallowell, N., Jacob, I., Richards, M., Mackay, J. and Gore, M. 2001. 'Surveillance or surgery? A description of the factors that influence high-risk pre-menopausal women's decision about prophylactic surgery'. *Journal of Medical Genetics* 38: 683-691.

Richards, M., Ponder, M., Pharoah, P., Everest, S. and Mackay, J. 2002. 'Issues of consent and feedback in a genetic epidemiological study of women with breast cancer'. *Journal of Medical Ethics (in press)*.

Richards, M.P.M. 2003. 'Assisted reproduction and genetic technologies and family life'. In J. Scott, J. Treas and M. Richards (eds.). Blackwell Companion on the Sociology of the Family. Blackwell (in press).

Hawthorne, J., Jessop, J., Pryor, J. and Richards, M. 2002. 'Separation, Divorce and Family Change: A review of interventions and support services for children'. Report to the Joseph Rowntree Foundation.

Richards, M.P.M. 2002. 'Changing Family Life: social demographic, and cultural changes affecting family life'. Keynote address; Seminars for the New Zealand Family Court 'At Least Two Parents', Auckland, Christchurch and Wellington. To appear in proceedings.

Richards, M.P.M. 2002. 'Attitudes to Genetic Research and Uses of genetic Information: support, concerns and genetic discrimination'. Keynote address, 3rd International DNA Sampling Conference, Montreal. To appear in proceedings.

Nuffield Council on Bioethics. 2002. 'Genes and Behaviour: The Ethical Context'. London.

Richards, M.P.M. 'Reproductive technologies and parenthood'. In A. Bainham, B. Lindley, M.P.M. Richards and E. Trinder (eds) *Parent-child Relationship and Contact: A Socio-Legal Analysis*. Oxford: Hart. In press.

Helen Statham - Deputy Director

Senior Research Associate

During this year three studies have come to an end and detailed reports concerning these are now available. The two studies relating to prenatal diagnosis and termination or continuing pregnancies and decision making after prenatal diagnosis have been widely disseminated either via the reports or in a range of study days and conferences. The findings are particularly timely and are being utilised by the UK National Screening Committee (Antenatal Subgroup) and by the voluntary sector group ARC (Antenatal Results and Choices) that works with the public and health professionals in this area. The study of decision making around caesarean section has finished and the final report will be completed shortly. Again this is a study in a topical area with a high media and professional profile.

Recent Dissemination Activities

Published

Statham, H., Solomou, W. and Green, J.M. 2001. "When a baby has an abnormality: a study of parents' experiences." Volume 1 of the report of a study funded by a grant from the NHS (R&D) Mother and Child Health Initiative (MCH 4-12) 'Detection of fetal abnormality at different gestations: impact on parents and service implications'. Cambridge: Centre for Family Research, University of Cambridge.

Statham, H., Solomou, W. and Green, J.M. 2002. "When a baby has an abnormality: a study of health professionals' experiences." Volume 2 of the report of a study funded by a grant from the NHS (R&D) Mother and Child Health Initiative (MCH 4-12) 'Detection of fetal abnormality at different gestations: impact on parents and service implications'. Cambridge: Centre for Family Research, University of Cambridge.

Statham,H. and Solomou, W. 2002. "Prenatal diagnosis of abnormality: how parents make decisions when faced with real ethical dilemmas". Report of a study funded by the Wellcome Trust, submitted to the Trust and available from the Centre for Family Research later in 2002.

Statham, H., Solomou, W. and Green, J.M. 2002. "Feticide and late termination of pregnancy: impact on parents and health professionals." *European Journal of Human Genetics* 10 (Supplement 1): 315

Statham, H., Solomou, W. and Green, J.M. 2002. "Emotional well being after a termination for abnormality: the impact of obstetric and social factors". *European Journal of Human Genetics* 10 (Supplement 1): 323-324

In press

Statham, H. 2002. "Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences". *Fetal and Maternal Medicine Review*.

Statham, H. "The parents' reactions to termination of pregnancy for fetal abnormality: from a mother's point of view" AND

Statham, H., Solomou, W. and Green, J.M. Continuing a pregnancy after the diagnosis of an anomaly: parents' experiences. In press *Prenatal Diagnosis: the human side* (2nd Edition 2003) Eds: Lenore Abramsky and Jean Chapple

Statham, H., Solomou, W. and Green, J.M. 2003. "Communication of prenatal screening and diagnosis results to community health professionals" *Public Health*.

Green, J., Kafetsios, K., Statham, H. and Snowdon, C. "What do pregnant women worry about? Factor structure, Validity, and Reliability of the Cambridge Worries Scale." *Journal of Health Psychology*.

Conference and study day presentations

Statham, H. "Late termination of pregnancy and feticide: law and policy, practice and ethics." Invited speaker, North West Thames Annual Perinatal Mortality Meeting, London May 2002.

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Statham, H. "Decision making after prenatal diagnosis and continuing with affected pregnancies." Invited speaker, Annual Course on Prenatal Screening, Cardiff May 2002.

Statham, H., Solomou, W. and Green, J.M. "Feticide and late termination of pregnancy: impact on parents and health professionals." European Meeting on Psychosocial Aspects of Genetics, Strasbourg May 2002.

Statham, H., Solomou, W. and Green, J.M. "Emotional well being after a termination for abnormality: the impact of obstetric and social factors". European Meeting on Psychosocial Aspects of Genetics, Strasbourg May 2002.

Statham, H. "Detection of fetal abnormality at different gestation; impact on parents and service implications." Invited Speaker, Department of Obstetrics and Gynaecology Seminars, QE2 Hospital Welwyn July 2002.

Dr Anna Bagnoli

ESRC Postdoctoral Fellowship

Centre for Family Research, University of Cambridge, July 2002 - June 2003

Awards

Ramon y Cajal Scholarship

European Parliament, Directorate General for Research, DG IV, STOA, (Scientific and Technological Options Assessment), Brussels, Belgium, October 2001- January 2002

Training Activities

'Migrant Identities', Annarita Buttafuoco Summer School on Women's History and Cultures, (University of Siena, University of Rome, Italian Society of Women Historians), Siena, Certosa di Pontignano, Italy, 18 – 24 August.

Publications

Bagnoli, A. 2001. Narratives of Identity and Migration: An Autobiographical Study on Young People in England and Italy. PhD Thesis, University of Cambridge

Bagnoli, A. (forthcoming, 2002). The Identities of Young People in Europe. A Research on the Process of Identity Construction Among European Young People: Suggestions for Policies, and the EC 'White Paper on Youth'. STOA Briefing Note n. 513/2002 EN, PE n. 311.198, to be published also on the European Parliament website.

Bagnoli, A. (submitted 2002). 'Imagining the lost other: the experience of loss and the process of identity construction in young people'.

Dr Elizabeth Chapman

My Wellcome Trust Post-Doctoral study "A comparison of two genetic conditions (Huntington's disease and cystic fibros the implications of differences or similar decisions" ended on 30th April 2002. I resulted in the following publications: (Huntington's disease and cystic fibrosis): their conceptualisation in the body and the implications of differences or similarities for education, counselling and ethical decisions" ended on 30th April 2002. That study and continuation of other interests

Research interests

Psychosocial aspects of the new genetics, medicine, health and illness particularly focusing on bio-ethical issues, embodiment, and lay understanding of genetic processes. Past and present illness conditions studied included HIV/AIDS, cystic fibrosis, and Huntington's disease. I have a developing interest in embodiment, identity, family processes, and ethical decision-making in transplantation.

I started a new job in the University in May 2002 as Research Facilitator for the School Humanities and Social Sciences (half time) and continue my research work in the other half of my time as an Associate Member of the Centre.

Publications

Chapman, E. and Smith, J.A. 2002. 'Interpretative phenomenological analysis and the new genetics'. *Journal of Health Psychology* 7: 125-130.

Chapman, E. 2002. 'The social and ethical implications of changing genetic technologies'. *Journal of Health Psychology* 7: 195-206.

Chapman, E. 2002. 'Ethical dilemmas in testing for late onset conditions: reactions to testing and perceived impact on other family members'. *Journal of Genetic Counseling* 11:351-367.

Chapman, E. 2002. 'Body image and the complications of HIV treatment'. FOCUS: A Guide to AIDS Research and Counseling 17: 1-5.

Chapman, E. 2002. 'Patient impact of negative representations of HIV'. AIDS Patient Care and STDs 16: 271-275.

Chapman, E. 2002. 'Perceptions of the body and genetic risk'. In A. Bainham, S. Day-Sclater and M. Richards (eds.), *Body Lore and Laws*. Oxford: Hart.

Chapman E. 2002. 'Body image issues in individuals with HIV and AIDS'. In T.F. Cash and T. Pruzinsky (eds), *Body Image. A Handbook of Theory, Research, and Clinical Practice.* New York: Guilford Publications.

Chapman, E. 2002. 'Prenatal Testing and Disability Rights – Book Review'. Sociology of Health and Illness 24: 493-495.

Chapman, E. 2002. 'Difficult decisions: the social and ethical implications of advances in medical technology'. *Community Genetics*. In press

Chapman, E. 2002. 'The Misunderstood Gene – Book Review. New Genetics and Society, in press.

Chapman, E. 2002. 'Three Books on the Body'. Review, Sociology of Health and Illness, in press.

Conferences

BSA Medical Sociology Group, September 2001, York "Criteria used in decisions following prenatal testing: how do these relate to the experiences of people with genetic conditions?"

European Health Psychology Society and British Psychological Society Division of Health Psychology, September 2001, St Andrews, "Patients' Knowledge of CF: Implications for Treatment".

Dr Claudia Downing

Following my PhD I was awarded a Wellcome Trust Research Fellow in Biomedical Ethics (Jan 2002 – December 2004)

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.

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. Qualitative methods including the use of computerized qualitative data analysis packages.

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

Book review of Haker, H. & Beyleveld, D. (eds) The Ethics of Genetics in Human Procreation, in *New Genetics and Society*, 21(2), 254-255.

Conference presentations

European Association for the Study of Science and Technology (EASST) conference in York, 31st July - 3rd August 2002, where I presented a paper entitled: The model of responsibility: social accountability in the age of the new genetics.

Other Activities

I was invited to Sweden for two weeks in April to teach on the qualitative methods module which forms part of the masters programme at the Nordic School of Public Health in Gothenberg. I also presented the findings from my PhD research to local groups of the Huntington's Disease Association.

Dr Fatemeh Ebtehaj

Research interests: Gender related issues; psychological development, especially issues related to exile and/or emigration; narrative and cultural psychology; discourse analysis.

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<u>Current research:</u> My PhD thesis work (completed in 2002) was conducted on Iranian exile women at midlife. I am currently drawing on it to write and hopefully publish some articles in journals concerned with women's issues, narrative and discursive psychology, exile and emigration. I am also extending my research to women of other generations by interviewing women both younger and older women.

Dr Judith Ennew Contact Person for Childwatch International

Publications

- J. Ennew, 2002, Future generations and global standards: Children's rights at the end of the millennium, in MacClancy, J.V., (ed.) *Exotic no more: Anthropology on the front lines*, University of Chicago Press, pp 338-350.
- J. Ennew, 2002, 'Outside Childhood: Street Children's Rights', in Franklin B., (ed.) The new handbook of children's Rights: Comparative Policies and Practice, Routledge pp388-403

Editor (with Virginia Morrow) of Childhood Vol. 9 No. 1 February 2002, Special issue children and the politics of modernity: a tribute to Sharon Stephens

(with Virginia Morrow) 'Releasing the energy: celebrating the inspiration of Sharon Stephens' in *Childhood* Vol. 9 No. 1 February 2002, *Special issue children and the politics of modernity: a tribute to Sharon Stephens* pp 5-18.

Research and writing

Technical advisor/trainer:

- (a) UNICEF Bosnia and Herzegovina, Capacity-building research on children in institutions;
- (b) UNICEF Indonesia, Capacity-building research on child labour and child commercial sex workers.

Lead evaluator of UNICEF 'Global Programme on education as a strategy to prevent child labour'.

Advisory Committees etc

University Faculty of Education and Language Studies on course U212 'Childhood 0-18'

Through Mahidol University (Thailand) and Australian National University technical advisor to the Philippines Local Government Services on street children and children's rights.

Georgina Haarhoff

The experience of cancer in those with a genetic versus a sporadic form of colorectal cancer. Funded by ESRC. 1999 – 2002. Supervised by Prof. Bryan Turner. Academic Adviser, Prof. Martin Richards

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Joffe, H. and Haarhoff, G. (2002). 'Representations of far-flung illnesses: the case of Ebola in Britain' *Social Science and Medicine*, 54(6), 955-969

Haarhoff, G. (2000). Book Review: Carson, R.A. and Rothstein, M.A. (1999, Eds). Behavioral Genetics: the clash of culture and biology. Baltimore: John Hopkins Press. *New Genetics and Society*, 19(3), 392-393

Haarhoff, G. (2002). Book Review: Hancock, P., Hughes, B., Jagger, E., Paterson, K., Russell, R., Tulle-Winton, E. and Tyler, M. (2000). The Body, Culture and Society. An Introduction. Buckingham: Open University Press. *Sociology of Health and Illness*, 24 (2)

Dr Joanna Hawthorne

Senior Research Associate (part-time)

Foretelling Futures: Dilemmas in Neonatal Neurology. Wellcome Trust grant with: Professor Priscilla Alderson, Inga Warren and Dr. John Wyatt, London. March 2002-March 2004

A social research project in four neonatal units using interviews with parents and staff to examine the information doctors give and parents receive when the baby has a neurological problem, the concerns parents have about the future, and baby's neurobehavioural responses to neonatal care.

Publications and reports

Separation, Divorce and Family Change: A review of interventions and support services for children. With Julie Jessop, Jan Pryor and Martin Richards. Report to the Joseph Rowntree Foundation, June 2002.

Anxiety in the Antenatal Clinic: The risks and benefits of screening for renal abnormalities and choroid plexus cysts. With T.A. Quince. Abstract of paper in the *Journal of Reproductive and Infant Psychology*, 2000.

Using Brazelton concepts with sick newborns. Poster abstract in Journal of Reproductive and Infant Psychology, 2001

Follow-up of babies from a neonatal unit using the Brazelton Neonatal Behavioural Assessment Scale. Poster abstract in *Journal of Reproductive and Infant Psychology*, 2002 (in print)

Follow-up of babies from the neonatal unit using the Brazelton Neonatal Behavioural Assessment Scale. Report to the Rosie Hospital, Cambridge, March 2002

Understanding your baby. In Bounty Book from Royal College of Midwives, with Sue Brough in Transition to Parenting – an open learning resource for midwives (1999)

Understanding the language of babies. Chapter in Where the Wild Things Are, Whurr, London. 2002 (in press).

Psychological Aspects of Neonatal Care. Chapter in *Roberton's Textbook of Neonatology*, Fourth edition. Edited by Janet M. Rennie. In preparation, 2002

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Other activities

Coordinator of the Brazelton Centre in Great Britain (charity): administration, teaching, training and organisation of study days.

The Brazelton Centre's goals are to promote an understanding in infant behaviour and to foster strong infant-parent relationships through training for health professionals and research. egistered charity number 1086814

Organised the Infant Relationships Study Group - termly meetings

Steering Committee Member of CAMPIP - Cambridge Parent-Infant Project, an infant mental health project.

Member of Developmental Care Group, Rosie Hospital. Organising study day.

Honorary contract at the Rosie hospital: Providing intervention for parents of babies in the NICU using the NBAS.

Dr Claire Hughes

Research interests:

problems. With funding from the PPP Foundation, and in collaboration with Professor Judy Dunn at the Institute of Psychiatry in London I am about to begin a new study of 'at risk' toddlers (Rosie Davie and Julie Jessop will also be working on this project). This study is a 3-year investigation involving multiple observations (at home, in the lab and later on at school) of the children with various social partners (mother, sibling, unfamiliar peer, friend) and a communication of the children with various social partners cognition (fledgling '') cognition (fledgling 'theory of mind' skills and emotion understanding) and executive function (inhibitory control, working memory, planning). Our goal is to examine both the real-life implications of individual differences in these domains for young children's close relationships with family and friends, and the contribution of children's social relationships to their cognitive development.

> More broadly, my research interests are in developmental psychopathology, including disruptive behaviour and autism. This year I hope to submit a programme grant to the MRC to enable me to bring together my interests in autism, disruptive behaviour and peer relationships.

Publications

Booth, R., Charlton, R., Hughes, C. and Happé, F. 2002. Disentangling weak coherence and executive dysfunction: Planning drawing in Autism and ADHD. Philosophical Transactions in Cognitive Psychology (Special issue on Autism) in press

Brophy, M., Taylor, E., & Hughes, C. 2002. "To go or not to go: inhibitory control in 'hard to manage' children." Infant and Child Development, Special Issue on Executive Functions and Development 11: 125-140.

Dunn, J. & Hughes, C. (2001). ""I've got some swords and you're dead!" Violent fantasy, antisocial behaviour, friendship, and moral sensibility in young children." Child Development 72: 491-505.

Fisher, N., Dunn, J. & Hughes, C. 2002. "Advanced tests of theory of mind: Are appearances deceptive? Findings from a study of 8-year-olds." *Journal of Cognition and Development (in review)*.

Hughes, C. (2001a). Executive Dysfunction in Autism: Its nature and implications for the everyday problems experienced by individuals with autism. In J. Burack & T. Charman & N. Yirmiya & P. Zelazo (Eds.), *The Development of Autism* (pp. 255-274). Mahwah, NJ: Lawrence Erbaum Associates.

Hughes, C. (2001b). From infancy to inferences: Current perspectives on intentionality. *Journal of Cognitive Development* 2: 221-240.

Hughes, C. (2002a). Executive functions and development: Emerging themes. *Infant and Child Development, Special Issue on Executive Functions and Development* 11: 201-210.

Hughes, C. (2002b). Executive functions and development: Why the interest? *Infant and Child Development, Special Issue on Executive Functions and Development* 11: 69-72.

Hughes, C. (in press). Executive Function and Development. In B. Hopkins (Ed.), Cambridge Encyclopedia of Child Development: Cambridge University Press

Hughes, C. (in progress). Making and Breaking Relationships. In A. Bainham, B. Lindley, M.P.M. Richards, E. Trinder (eds.) *Parent Child Relationships and Contact: A socio-legal analysis*. Hart: Oxford, UK.

Hughes, C., Cutting, A., & Dunn, J. (2001). "Acting nasty in the face of failure: Longitudinal observations of 'hard to manage' children playing a rigged competitive game with friend." *Journal of Abnormal Child Psychology* 29: 403-416.

Hughes, C., & Dunn, J. (in press). ""When I say a naughty word." Children's accounts of anger and sadness in self, mother and friend: Longitudinal findings from ages four to seven." *British Journal of Developmental Psychology*.

Hughes, C., & Graham, A. 2002. Measuring executive functions in childhood: Problems & solutions? *Child and Adolescent Mental Health* 131-142.

Hughes, C., & Graham, A. (in press). Executive Function in Childhood: Development and disorder. In J. Oates (Ed.), *Cognitive Development*. Buckinghak: Open University Press.

Hughes, C. & Leekam, S. 2002. What are the links between theory of mind and social relations? Review, reflections and new directions for studies of typical and atypical development. *Social Development in press*.

Kuntsi, J., Eley, T., Taylor, A., Hughes, C., Asherson, P., Caspi, A. & Moffitt, T.E. 2002 The co-occurrence of ADHD and low IQ has genetic origins. *Submitted to Psychiatric Genetics*

Dr Antonella Invernizzi

Research interests

Children rights, children's work, socialisation, exploitation, participation, family, survival strategies.

Publications

fieldward

Invernizzi A. 2001. La Vie Quotidienne des Enfants Travailleurs. Stratégies de Survie et Socialisation Dans les Rues de Lima, L'Harmattan: Paris.

Invernizzi, A. 2001. 'Street Working Children in Lima: the Child's Surcharge Between Survival Strategies and Socialisation'. *International Journal of Anthropology*. Vol. 16: 127-142.

Invernizzi, A. (In collaboration with B. Milne). 2002. 'The Role of the Street for European Children: Examples of Problems and Resources for Children'. In I. Colozzi, G. Giovannini (eds.), *Unprotected Time of Young People in the EU*. Alma Mater /Homeless Book: Faenza.

Invernizzi, A. (In collaboration with B. Milne) 2001. Protected and Unprotected Time and Space: A Theoretical and Research Overview. Report for the Alma Mater Foundation and for the Scientific Committee of the Project "Unprotected Time in Europe", University of Bologna. (available on the CD-Rom "Unprotected Time of young people in the EU: Research Material", Alma Mater Foundation).

I was awarded a Swiss National Science Foundation grant for a two year research on child labour in Peru and Portugal, starting October 2001. Since Spring 2002 I have been carrying out fieldwork in Portugal.

I gave a paper at the Swiss Congress of Sociology, SOCIO-01 (« Représentations de l'enfance et actions en faveurs des enfants travailleurs dans les pays du Sud. »). With B. Milne I gave a paper at the Conference "Unprotected time of young people in Europe". University of Bologna, 25-27 October 2001 ("The role of the street for European Children: examples of their problems and resources"). I joined the IUAES Commission on Anthropology of Children, Youth and Childhood and am co-editor of its Newsletter.

Dr Julie Jessop

Research Associate

I was awarded my Ph.D., "Psychosocial Dynamics of Post-Divorce Parenting: Pleasures, Pitfalls and New Partners", in December, 2001. Since then I have worked on a research project based at the Centre looking at the interventions and support services for children experiencing divorce and family change. This project was funded by the Joseph Rowntree Foundation and was conducted in conjunction with Prof. Martin Richards, Dr. Jan Pryor (New Zealand), and Dr. Joanna Hawthorne. The final report for the project was submitted in June and is due to be published in January, 2003.

From October, 2002 I shall be working on Dr. Claire Hughes' project into anti-social behaviour disorders in young children.

Other activities/interests

I help co-ordinate the Child Research Working Group, based at the Centre, which is an inter-disciplinary group concerned with all aspects of research being carried out for and with children.

Survey Shirts

Other.

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I am a member of Cambridge Socio-Legal Group and have been involved with their latest book on contact.

I am also the co-ordinator of the Qualitative Women's Workshop on Family and Household Research. This is a research group, presently based at South Bank University, which meets bi-monthly to discuss theoretical and analytic advances in feminist research. I have recently completed co-editing a book produced by the Workshop on ethics in qualitative research.

Publications

Simpson, R., Jessop, J.A. and McCarthy, P. (forthcoming, 2003) "Fathers After Divorce." In A. Bainham., B. Lindley, B., M. Richards, and L. Trinder (eds) *Parent-Child Relationships and Contact*, Oxford: Hart Publishing.

Duncombe, J. and Jessop, J.A. (2002) "Rapport and the ethics of 'faking friendship'." In M. Mauthner, M. Birch, J.A. Jessop, and T. Miller (eds) *Ethics in Qualitative Research*. London: Sage Publications.

Dr Lynne Jones OBE, MA Oxon, MB ChB, MRCPscych. PhD.

Research Interests

Children and war, refugee mental health, psychosocial programmes in the humanitarian field, the relationship between politics and mental health: questions of impunity, political neutrality, genocide, implications for humanitarian aid; Impact of war on moral development, role of empathy

An Ethnographic study of Children's Understanding of Political Violence 1997-present. Funded by William T. Grant Foundation (U.S.), Sole investigator

This project compares young teenagers from both sides of the conflict in Bosnia - Hercegovina and looks at the relationship between their mental health and political and social understanding. One of the major goals is to examine of the stereotypes about the impact of war on young people's mental health and the appropriateness of some of the assessment and treatment practises in postconflict psychiatry. I have completed three papers, working jointly with a co-author and former CFR associate, Kostas Kafetsios These are all in press (see below) and I am working on the final part of a book due for publication in the US next year.

Teaching in mental health and humanitarian negotiation

I am currently a tutor for the Centre for International Health and Cooperation, Fordham University, New York. I teach mental health on the International Diploma in Humanitarian Assistance; and Negotiation Training on the Humanitarian Negotiator's Course. Both these courses are attended by humanitarian workers at the senior management level for international organisations, NGO's and the military.

Publications:

I write regularly for The London Review of Books (under the pen name Lynne Mastnak). I have written for The New Statesman, The Guardian, and other journals on the Balkans, and on peace and human rights issues.

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States of Change: A Central European Diary, Autumn 1989. London: Merlin Press, 1990.

Keeping the Peace: A Woman's Peace Handbook. Editor, London: The Women's Press, 1983.

Notes For Thinking About Attachment Grief And Loss In Societies Subject To Political Violence. (2002) In International Child Health Care: A practical manual of hospital care for children worldwide, (eds.) D. Southall, B. Coulta, C. Ronald, S. Parke, London: British Medical Association.

What Is The PsychoSocial Domain And The Role Of The Mental Health Professional In Post Conflict Societies? In Psychosocial And Trauma Response In War Torn Societies: The Case Of Kosovo, Psychosocial Notebook, 1 November 2000, International Organisation For Migration, Geneva

Nationalism Can Be Beneficial. In Nationalism and Ethnic Conflict, (ed.) Charles P. Cozic, San Diego: Greenhaven Press, 1994.

Perceptions of "Peace Women" at Greenham Common 1981-85: A Participants View. In Images of Women in Peace and War: Cross Cultural and Historical Perspectives, (eds.) S. Macdonald, P. Holden and S. Ardener, London: Macmillan, 1987

Chapters contributed to Greenham Common: Women at the Wire, (eds.) Barbara Harford and Sarah Hopkins, London: The Women's Press, 1984.

Assessing Adolescent Mental Health in War-Affected Societies: The Significance of Symptoms, with K. Kafetsios, Child Abuse and Neglect: The International Journal (forthcoming)

Adolescent Understandings of Political Violence and Psychological Well being. A Oualitative Study From Bosnia Hercegovina. Social Science and Medicine (forthcoming).

Bridget Lindley

Qualitative study on advice and advocacy for families in child protection cases. Funded by the Nuffield Foundation and latterly the Department of Health.

Commenced 1997-Ends 2002

I was working part time (50%) at the Centre with Martin Richards on a qualitative study, which explored the process of advocacy for parents in ability. 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. These enquiries are conducted within an administrative rather than judicial framework. The rationale for the study was that partnership between parents and the local authority is regarded as the fundamental principle underpinning the successful protection of children. Yet it may not always be achievable in every case because where there is a divergence of views between the social worker and the parents about the risk to the child, the social worker's duty to protect the child takes precedence over their role as advocate for the family as a whole, often leaving the parents unsupported. When this occurs, parents may need to be supported by an independent advocate in order to be able to participate effectively in the process from an informed position.

Such advocacy is promoted in government guidance (Working Together, DoH,1999) but it is not as yet a coherent, nationally run service. The few specialist schemes which exist are innovative, and their advocates, along with solicitor advocates, have had to develop many of their skills on the hoof hence the need to explore the advocacy process in more detail.

Following the analysis of the data, three papers were been published, as follows:

Publications

Lindley, B. and Richards, M. 2000. 'Working Together 2000 - how will parents fare under the new child protection process?' *Child and Family Law Quarterly* 12: 213-228.

Lindley, B., Richards, M. and Freeman, P. 2001 'Advice and advocacy for parents in child protection cases - what's happening in current practice?' *Child and Family Law Quarterly* 13: 167-196.

Lindley, B., Richards, M. and. Freeman, P. 2001. 'Advice and advocacy for parents in child protection cases: an exploration of conceptual and policy issues, ethical dilemmas and future directions'. *Child and Family Law Quarterly* (in press, 2001).

During the last year, Martin and I have received funding from the Department of Health to develop a model protocol about how advocates may intervene effectively on behalf of parents in such cases in the future. The first draft of this document is finished and has been widely circulated amongst policy-makers, practitioners, members of the judiciary and academics with expertise in this area for comment. It is now in the process of being revised and in October 2002 will be sent to the Department of Health and other key organisations in the field for endorsement. It will then be launched early in 2003, following which it will be available in published form from the Centre, and also on the website.

In the future we plan to seek funding to develop a model training and briefing pack for advocates and supporters respectively which are necessary components of developing good practice on this topic.

Dr Chris Mann

Visiting Research Fellow, Oxford Internet Institute April 2002 – October 2002

Focus of research at Oxford Internet Institute

Most social science and human research disciplines have well-established ethical codes for conducting 'real world' research but the situation is less clear for Internet research. International discussions concerning the establishment of general ethical guidelines for online researchers are currently underway (see the Association of Internet Researchers ethics working party report

http://www.aoir.org/reports/DraftFIVE.html). I contributed to this debate by interviewing Oxford University academics with substantial experience of 'traditional' research in a range of subject disciplines. These discussions explored the key ethical issues in each discipline and the implications of applying those issues to Internet-based research. A central focus was the challenge of designing an ethical component for graduate training courses in internet research methods at UK universities.

Menday of the stand

Indicators of Academic performance Project (IAPP)
Grants from the General Board of the University of Cambridge, 1997-2001.

Publications from IAPP.

Mann, C. 2002 'Analysis or Anecdote? Defending Qualitative Data Before a Sceptical Audience'. In Hughes, C. (ed) Disseminating Qualitative Research. Open University Press.

Mann, C. and Stewart, F. 2001. 'Internet Interviewing'. In J. Gubrium and J. Holstein (eds.), Handbook of Interviewing. London: Sage.

Mann, C and Stewart F. 2001. 'The Internet'. In C. Kramarae and D. Spender (eds.), The Routledge International Encyclopaedia of Women. New York: Routledge.

Mann, C. 2001. 'Achievement in Education'. In C. Kramarae and D. Spender (eds.), The Routledge International Encyclopaedia of Women. New York: Routledge.

Mann, C. 2001. 'Innovative Teaching and Learning Practices in Higher Education: A Thematic Review of Recent Literature. British Research Journal 27.

Guest editor (with Rehan ul-Haq). 2001. 'Qualitative Market Research: special issue Research in Cyberspace' Vol.4 Number 3.

Research Interests

Traditional and internet-based research methodologies (email interviewing and virtual focus groups), especially for qualitative research in social science and social policy. Joint author of leading handbook of internet-based research methods [Mann, C and Stewart, F. (2000) Using the Internet in Qualitative Research: A Handbook for Researching Online. New Technologies for Social Research series. London: Sage. See www.sagepub.co.uk for reviews.]

Publications on Internet research

Mann, C. and Stewart, F. (2002) 'Introducing Online Methods' in Hesse-Biber, S. and Leavy, P. (eds.) Approaches To Qualitative Research: A Reader On Theory And Practice. Oxford: Oxford University Press.

Mann, C. and Stewart, F. (2001) 'Internet Interviewing' in Gubrium, J. and Holstein, J. (eds.) Handbook of Interview Research. London, Thousand Oaks: Sage.

Mann, C and Stewart F. (2001) 'The Internet' in Kramarae C. and Spender D. (eds) The Routledge International Encyclopaedia of Women's Studies. New York: Routledge.

Mann, C and Stewart, F. (2000) Using the Internet in Qualitative Research: A Handbook for Researching Online. New Technologies for Social Research series. London: Sage.

Publications on educational research

Mann, C. (2002) 'Men accelerate, women accumulate. Undergraduate learning styles. In Journal of Science and Public Affairs, April.

Mann, C. (2001) 'Achievement in Education' in Kramarae C. and Spender D. (eds) The Routledge International Encyclopaedia of Women's Studies. New York: Routledge.

Mann, C. (2001) 'Innovative Teaching and Learning Practices in Higher Education: A thematic review of Recent literature.' British Educational Research Journal, Vol. 27:5.

Leman, P. and Mann, C. (1999) 'Research and interventions on gender inequalities in Higher Education' in Fogelberg, P., Hearn, J., Husu, L. and Mankkinen, T. (eds.) Hard Work in the Academy. Helsinki: Helsinki University Press.

Mann, C. (1999) 'Qualitative research methods raise complex issues.' Women in Higher Education, Vol. 8:5

Mann, C. (1998) 'The impact of working class mothers on the educational success of their adolescent daughters at a time of social change' in British Journal of Sociology of Education.

Mann, C. (1998) 'Family Fables' in Chamberlain, M. and Thompson, P. (eds.) Narrative and Genre. London: Routledge.

Mann, C. (1998) 'Adolescent girls reflect on educational choices' in Burgess, B. and Erben, M. (ed.), Biography and Education: A Reader. Basingstoke: Falmer Press.

Mann, C. (1997) 'Female achievement in education' in Spender, D. and Kramarae, C.

Maggie Ponder

Chairman of the trustees of the Genetic Interest Group and a Trustee of the Neurofibromatosis Association

The Genetic Interest Group is an umbrella charity that represent by genetic disorders. It represents the "patients" no other official bodies on such matters introduction of treatments genetics and " The Genetic Interest Group is an umbrella charity that represents all people affected by genetic disorders. It represents the "patients" point of view to government and introduction of treatments for rare genetic disorders, issues to do with insurance and genetics and how best to encourage and facilitate more research in the field of genetic disorders. Amongst its other activities during this past year the Genetic Interest Group has initiated an investigation of how the Human Rights Act may impact on human genetics and has a project underway to look at how ethnicity monitoring should be done within clinical genetics services.

Follow up study of participants in an epidemiological study of inherited breast cancer

This was a study initiated and overseen by Martin Richards that looked at the issue of personalised feed back of results to participants in an epidemiological genetic testing study of breast cancer. The research has shown that women did not fully understand the research objectives nor had they thought through the possible implications for themselves or their families. All would have taken part even without the option of feedback but they would all have liked more general information about the progress of the research.

The follow-up study of participants in an epidemiological study of breast cancer (with Maggie Ponder, Paul Pharoah, Sarah Everest and James Mackay) was completed during the year and the resulting paper will be published in the Journal of Medical Ethics, "Issues of consent and feedback in a genetic epidemiological study of women with breast cancer".

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Dr Ilina Singh

Implications of Ritalin for Children's Sense of Self and Personal Agency.

Research interests

Publications:

Behaviour and Social Context: The Case of ADHD. Forthcoming in *Childhood and Society*.

Bad Boys, Good Mothers and the Miracle of Ritalin. Forthcoming in *Science in Context*.

Claire Snowdon

Research Fellow, Medical Statistics Unit, Department of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, and linked to the National Perinatal Epidemiology Unit, Institute of Health Sciences, Oxford.

Research interests

Views of participants in trials, psychosocial aspects of the new genetics

Views of participants in trials

The initial study involves qualitative analysis of interviews with around 80 parents of critically ill newborn babies enrolled in a clinical trial (The ECMO Trial - Extra Corporeal Membrane Oxygenation). The research focused on parents' perceptions of the trial, the doctor-patient relationship, results of the trial and management of informed consent. This work has been developed further as a research fellow at the London School of Hygiene and Tropical Medicine, funded by Nuffield. The current study looks at the same issues with 4 perinatal trials (the INNOVO trial, the CANDA trial, ORACLE and the TEAMS trials). It involves approximately 120 interviews with staff and parents linked to these trials.

In 2001 we interviewed staff and the parents of 13 babies who were enrolled in a study of hypothermia and ECMO.

Early work at the Centre for Family Research examined the attitudes of couples carrying recessive disorders to various reproductive options (adoption, parental diagnosis, gamete donation, preimplantation diagnosis, informed consent and clinical trials).

Dr Jane Weaver

A Study of Choice and Decision Making in Caesarean Section. Sept 1999 – Sept 2002.

This project addressed the place of women's choice in negotiations with professionals (midwives and obstetricians) about whether birth should be by caesarean section. Overall it has been a success and has generated large amount of relevant data. The Report of the study's findings will be available by early 2003.

Presentations

It's a bit like the Green Cross Code man: uncertainty, litigation and caesarean section. Presentation given at the Annual Conference of the Society of Reproductive and Infant Psychology, University of Oxford, September 2001.

No. A.

Choice and decision making in caesarean section. Presentation given at Research in Midwifery Study Day, University of Salford, October 2001.

Caesarean section: who chooses and who decides? Presentation given at seminar, Department of Midwifery, Thames Valley University, May 2002.

Publications

Weaver, J.J. 2002. 'Court-ordered caesarean sections'. In A. Bainham, S. Day Sclater and M.P.M. Richards (eds.), Body Lore and Laws. Oxford: Hart.

Weaver, J.J. (2002) 'The birthing body - talking about childbirth'. Psychology of Women's Section's Special Issue on the Body. The Psychologist 15 (4) 188-190.

Weaver, J. (2001) 'In the spotlight. Obstetric preferences and caesarean section'. MIDIRS Midwifery Digest 11 (4), 516-518.

Weaver, J.J. (2001) 'Thoughts on Caesarean Section'. MIDIRS Midwifery Digest 11 (3), Supplement 2, s16-s18.

I am Treasurer for Psychology of Women Section of the British Psychological Society.

Dr Anji Wilson

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

Interests:

Genetics, inheritance and kinship; support for children and families that have experienced parental separation or divorce

Presentations and conferences attended in the last academic year

September 2001 Attended British Sociological Association Medical Sociology Group Annual Conference (York)

November 2001: Attended Annual Conference of the Human Reproduction Study Group (Northampton)

November 2001: Presented paper at Genetics and Society Meeting (Cardiff)

February 2002: Attended workshop for TEMPE (Teaching Ethics: Materials for Practitioner Education) (London)

May 2002: Presented poster at European Meeting on Psychosocial Aspects of Genetics (Strasbourg)

Responsibilities within the Centre

From January 2001 took over organising Centre Tuesday lunchtime seminars Work in progress

Report on the evaluation of in-school support for children who have experienced parental separation or divorce (project funded by Joseph Rowntree Foundation). Working with editor on final draft of report and brief dissemination document ('Findings') to be published shortly.

Analysing interviews from current study in preparation for end of project papers.



New Members (2002-2003)

Dr Bryn Williams-Jones, B.A., M.A. (McGill University), Ph.D. (University of British Columbia), Post-doctoral Fellow at the Centre for Family Research, Junior Research Fellow at Homerton College, University of Cambridge. Bryn's research focuses on the social, ethical and policy issues associated with the commercialization of genetic and genomic knowledge and technologies. He has co-edited a book on commercialization and genetic research; published articles on genetic testing and health policy, private access through the Internet, and workplace testing; and is broadly interested in the ethical issues arising from biotechnology, intellectual property, and technology development. His current research project, entitled Genomics Researchers, Industry and Commercialisation: An Evidence-based Social and Ethical Analysis, aims to provide an account of the experiences, beliefs, and values of genomics researchers (from their perspectives) in relation to the commercialisation of genomic knowledge, situated within the network of relations that exist between government, industry, and researchers. This evidence-based project will critically examine the role and influence of private financing, the place for oversight and regulatory mechanisms, and the role of the public in shaping the objectives of genomics research, in order to perform comprehensive social and ethical analysis, and contribute to more sophisticated and balanced public debate and policy development.

Dr Oonagh Corrigan (B.A. APU, PhD Essex)

Lecturer on the Social Aspects of Human Genetics and Genomics

Having completed my PhD thesis, a sociological examination of bioethics and clinical drug trials, I was awarded a post-doctoral research fellowship by the Wellcome Trust to examine the social and ethical implications of pharmacogenetics.

The ethical and socio-cultural implications of innovative genetics-based drug development. The application of pharmacogenetics in clinical drug trials: -A case study. Funded by the Wellcome trust, commenced April 2000 ends April 2003. Focussing in particular on the activities of the pharmaceutical industry, this study examines the processes, practices and ethical considerations involved in the development of pharmacogenetics.

During the past year I have presented a number of papers at national and international conferences. In November 2001 I presented a paper, 'Pharmacogenetics: The politics of consent, blood and bare life' at the Annual Meeting of the Society for Social Studies of Science (4S) conference, MIT. In December 2001 I gave a paper, 'The ethical framing of pharmacogenetics' at a Pharmacogenetics Symposium at the University of Nottingham and in July this year I presented a paper, 'Politics, profits, ethics and pills, charting the development of pharmacogenetics in clinical trials', at EASST in York. I was also invited to give a number of lectures including on the social aspects of the human genome project and have attended a number of workshops and conferences on pharmacogenetics.

Together with Richard Tutton from the University of York, I have recently been awarded a book contract with Routledge for an edited collection on the donation of genetic samples for large-scale databases.

My current post involves teaching on the Social Aspects of Human Genetics and Genomics in SPS as well as in the department of Social Anthropology. The post is being funded by the Government's new Cambridge Genetics Knowledge Park initiative and involves policy and educational work bridging academia, industry and the NHS.

Publications:

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Corrigan, O. P. (2002) 'A risky business: the detection of adverse drug reactions in clinical trials and post-marketing exercises', *Social Science and Medicine* 55 3: 141-151

Corrigan, O. P. (2002) 'The limitations of current ethical regulations' in Abraham, J., Towse, A. and Lawton-Smith, H. (eds.) *Regulation of the Pharmaceutical Industry*, London: Palgrave

Corrigan, O. P. (Forthcoming Oct 2002) 'First in man': the politics and ethics of women in clinical drug trials', *Feminist Review* 72.

Corrigan, O. P. (Forthcoming 2002/2003) 'Morality, risk and the obligation of informed consent' in Retcliffe, N. (ed.) Future Perfect: Ethnographies of Contested Moral Domains, London: Palgrave

ASSOCIATE MEMBERS

Lucy Allcock

Disabilities and rehabilitation

Because of serious medical problems for her son, Lucy has been forced to suspend work on her Ph.D. but she continues to do some supervision for the Social and Political Sciences Tripos.

Dr Andrew Bainham

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

Bainham, A., Day Sclater, S. and Richards M. (eds.), 2002. *Body Lore and Laws*. Oxford: Hart Publishing.

Bainham, A. 2002. 'Sexualities, Sexual Relations and the Law'. In A. Bainham,

S. Day Sclater and M. Richards (eds.), *Body Lore and Laws*. Oxford: Hart Publishing.

Bainham, A. (ed) 2002. The International Survey of Family Law, 2002 Edition. Bristol: Jordans.

Bainham, A. 2002. 'Can We Protect Children and Protect Their Rights?' Family Law 32: 279-289.

Bainham, A. 2001. 'Taking Children Abroad: Human Rights, Welfare and the Courts'. *Cambridge Law Journal* 60: 489-492.

Bainham, A. 2002. 'Does Sex Matter?' Cambridge Law Journal 61: 44-47.

Bainham, A. 2002. 'Unintentional Parenthood: The Case of the Reluctant Mother'. *Cambridge Law Journal*: 61: 288-291.

Andrew Bainham is acting as Special Adviser to Baroness Nicholson of Winterbourne MEP in her dual role as a member of the House of Lords and the European Parliament. He has been assisting her in particular in her capacity as Rapporteur for Romania in the European Parliament. In this role he has also been assisting the Government of Romania in the reform of that country's child protection and adoption laws.

In September 2001 he presented a paper to the World Congress on Family law and the Rights of Children and Youth in Bath.

Since January 2002 he has been acting as Chair of the Cambridge Socio-Legal Group hosted by the Centre for Family Research. He is co-editor with Bridget Lindley, Martin Richards and Liz Trinder of the Group's forthcoming book on Parent-Child Relationships and Contact. He is also a member of the editorial team planning the Group's next project on the subject of Sexuality.

He became a member in 2002 of the Advisory Group on a research project concerned with Government and Parenting being funded by the Joseph Rowntree Foundation.

Dr Shelley Day Sclater

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Reader in Psychosocial Studies and Co-Director of the Centre for Narrative Research, University of East London

I spent this year on unpaid leave from my permanent post at UeL to spend more time on my research and writing. This is what I have done this year:

Socio-Legal Work

The jointly edited (with Andrew Bainham and Martin Richards) book on *Body Law* and *Laws* was published and we held a successful launch in Oxford in February 2002.

I continued (with Felicity Kaganas, Brunel) work on the data analysis from the *Disputed Contact Cases* project (funded by the Leverhulme Trust). Our paper "Contact disputes: narrative constructions of 'good' parents" and our chapter "Contact: mothers, welfare, rights" will be published in 2002-3.

I have been editing papers for *Surrogate Motherhood: International Perspectives* (Oxford, Hart, 2003, forthcoming) with Rachel Cook (APU) and Felicity Kaganas (Brunel). We have co-authored the Introduction.

Narrative Work

I have jointly edited (with Marjatta Saarnivaara, Finland and Art Bochner and Carolyn Ellis (USA) a special edition of *Qualitative Inquiry* containing some of the papers from the conference *Arts and Narrative Inquiries* at which I gave the keynote speech in Helsinki, January 2001. I have written the "Epilogue" to the Special Issue. My keynote has been written up as "The Seductions of Narrative" and will be published next year.

I was appointed to the organising committee for the Second Tampere Conference on Narrative to be held in Finland, June 2003.

I organised a symposium on Narrative Psychology at the Centenary Conference of the British Psychological Society in Glasgow in 2001. It was extremely well-attended and there was lots of heated debate. Papers from the symposium are being published as special issues of *Qualitative Inquiry* and *Narrative Inquiry*. My theoretical paper on subjectivity - "What is the Subject" – will be included.

As co-directors of the Centre for Narrative Research at UeL, my colleagues and I have written a chapter on "Narrative Analysis" for a new volume on *Qualitative Research Practice*, edited by Seale, Gobo, Gubrium and Silverman to be published in 2003.

I have been working on theoretical work on narrative and subjectivity for a sole authored book called *Narrative Subjects* which I will finish in 2004. I intend to focus in 2002-2004 on my theoretical work on self/subjectivity/identity.

Publications

Day Sclater, S. 2002. 'Introduction'. In A. Bainham, S. Day Sclater and M. Richards (eds.), *Body Lore and Laws*. Oxford: Hart.

Day Sclater, S. and Piper, C. 2001 'Social exclusion and the Welfare of the Child'. *Journal of Law and Society* 28 (3): 409-429.

Margaret Ely

Current post S/L Medical Statistics and Epidemiology, APU

I currently teach Statistics and Epidemiology courses to students on the MSc Public Health at APU. These can be accessed as stand alone modules for those health professionals needing to add these skills to their portfolio. I provide consultancy for those submitting research applications in medical/health/social care, as well as training courses for PhD students and staff of the university.

Presentations and publications

Health Research Warning: ignoring missing data can seriously bias your estimates. Joint Conference of the International Epidemiological Association and the Society for Social Medicine, 12-15th September 2001, Oxford.

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, Ely M. (2001)

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

Wiggins 1, R.D., Ely, M., Lynch 1, K. (2001) Teaching applied multivariate analysis in the context of missing data: a comparative evaluation of current software remedies. Working paper no 51, Centre for Longitudinal Studies, The Institute of Education, University of London.

Dr Gail Ewing

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Early Motherhood and Infant Weaning. Research Associate, CFR, 1996-1999. Project Director: Dr J.M. Green, Mother and Infant Research Unit, University of Leeds. Funding: Anglia and Oxford NHS Executive.

The introduction of solid foods to infants before the age of four months is a widespread practice that carries long-term health risks. This study investigated the views of health visitors and the psychosocial context of mothers' decision to introduce solids in order to understand why this occurs. Health visitors' views were obtained via focus groups; mothers' though focus groups, interviews and fortnightly telephone contacts.

Work in progress:

Symptoms and Needs Assessment in the Provision of Palliative Care in the Community: C Todd, G Ewing, S Barclay, M Rogers, A Martin, J McCabe Health Services Research Group GP and PCRU

Funded by the Department of Health, Community Services Initiative. Institute of Public Health, University Forvie Site, Cambridge CB2 2SR

Presentations

Ewing, G. Health Visitors' Accounts of Managing Early Weaning. Paper presented to the Annual Conference of the Society for Reproductive and Infant Psychology, University of Birmingham, September, 2000.

Ewing G, Rogers MR, Todd CJ, Barclay SIG, McCabe, J and Martin, A. CAMPAS: new instrument for measuring symptoms and quality of life for cancer patients at home: measurement characteristics for anxiety and depression scales.

Paper accepted for a Poster Presentation at ECCO 11, the European Cancer Conference, Lisbon, 21-25 October 2001.

Dr Nina Hallowell

Senior Research Scientist Institute of Cancer Research, London and Royal Marsden Hospital NHS Trust

Invited seminar presentations

London Medical Sociology Group, July 2001.

Policy, Ethics and Life Sciences Institute, University of Newcastle. June 2001

The British Columbia Cancer Agency. June 2001.

Invited participant: Workshop on the 'Ethnographic research into ethical and social issues and genetics' CHSS Unit, University of Kent at Canterbury. May 2001.

Peer-Reviewed Conference Papers

BRCA1/2 testing in women previously affected with breast/ovarian cancer: reactions to, and expectations of, test results. 7th International meeting on Psychosocial Aspects of Genetic Testing for Hereditary Breast and/or Ovarian (HBOC) and Hereditary Non-Polyposis Colorectal Cancer (HNPCC) Frankfurt, September 2001

Genetic testing for breast/ovarian cancer: the experiences of affected women. 33rd Annual Conference of the BSA Medical Sociology Group. York, September 2001.

Publications

5 4 1 3

Hallowell N, Jacobs I, Richards MPM, Mackay J and Gore M. 2001. 'Surveillance or Surgery? A Description of the Factors that Influence High-Risk Premenopausal Women's Decisions about Prophylactic Oophorectomy'. *Journal of Medical Genetics*, (in press).

Hallowell N. 2000. 'A Qualitative Study of the Information Needs of High-Risk Women Undergoing Prophylactic Oophorectomy'. *Psycho-Oncology* 9: 486-495.

Committee membership

Member of the Anglia and Oxford Multi-Centre Research Ethics Committee, 1999-2002

Member of the Anglia Polytechnic University Ethics Committee 2001-

Member of steering group on Ashcroft et al.'s project "Ethical protection in epidemiological genetic research: participant's perspectives". Funded by The Wellcome Trust, 2000-2003

Eva Lloyd

Director, National Early Years Network, 77 Holloway Road, London N7 8JZ.

Professor Juliet Mitchell

Professor of Psychoanalysis and Gender Studies, Social and Political Sciences Faculty.

Public and Specialist Lectures

Looking Sideways ... Psychoanalysis and Sibling Relations. Applied Scientific Section, Institute of Psychoanalysis, London. October, 2000.

Gender and Theatre. The Glass Ceiling. Cottesloe Theatre. March, 2001.

'Did Oedipus Have a Sister?' LSE Public Lecture March, 2001.

'Attachment and Maternal Deprivation' - John Bowlby Memorial Conference, March 2001.

Publications

Mitchell, J. 2000. 'Reflections on Ethel Spector Person's The Sexual Century' in Studies in Gender and Sexuality 2(3): 243-260. New Jersey: The Analytic Press.

Mitchell, J. 2000. 'The Vortex Beneath the Story'. In P. Brooks. and A. Woloch (eds.), *Whose Freud?: The Place of Psychoanalysis in Contemporary Culture:* New Haven: Yale University Press.

Mitchell, J. 2001. 'Drogue: Un Point du Vue Psychanalytique'. In H.S. Becker (ed.) *Qu'est ce Qu'une Drogue?* Atlantica: Anglet.

Mitchell, J. 2001. Review of Evelyn Heinemann: 'Witches: A Psychological Exploration of the Killing of Women'. *Critical Psychology*.

Dr Thelma Quince

4 4 1 2

Research Fellow, Centre for Business Research, University of Cambridge.

Together with Joanna Hawthorne, I was involved in the data analysis and writing up of the final report entitled 'Anxiety in the Antenatal Clinic: The Risks and Benefits of Screening for Renal Abnormalities and Choroid Plexus Cysts' (funded by the Children's Kidney Care Fund, Addenbrooke's Hospital, Cambridge).

Dr Eileen Richardson.

Director, Centre for Women and Leadership, and Director of Studies, SPS, at Lucy Cavendish College.

I am currently writing a book with Professor Bryan Turner about how new reproductive technologies are changing social policies about families. The book is part of a broader research project elaborating our concept 'reproductive citizenship', that has so far generated several chapters, articles and conference papers.

Publications and conference papers:

Richardson, E.H. & B.S. Turner. 2002. The Medicalisation of Sexuality, Reproduction and Parenthood. Paper presented at the American Sociological Association Conference, Chicago, August 2002.

Richardson, E.H. & R. Hawthorn. 2002. 'Women and Leadership: Learning for the Future'. *Training Journal* June 2002: 22-24.

Richardson, E.H. & B.S. Turner. 2002. 'Bodies as Property: from Slavery to DNA Maps'. In Andrew Bainham, Shelley Day-Sclater and Martin Richards (eds.) *Body Lore and Laws*. Oxford: Hart, pp. 29 – 42.

Richardson, E.H. & B.S. Turner. 2001. Sexual, Intimate or Reproductive Citizenship? A Review Article. *Citizenship Studies* Vol. 5, No. 3:329-338.

Richardson, E.H. (ed.) 2001. Taking the Initiative: Women's Leadership on National Issues. In-house publication, Lucy Cavendish College, Cambridge.

Richardson, E.H. 2001. Introduction: Women and Success. In E.H. Richardson (ed.) Taking the Initiative: Women's Leadership on National Issues. In-house publication, Lucy Cavendish College, Cambridge.

Dr Deborah Thom

Newton Trust Lectureship and Director of Studies, Robinson College, Cambridge.

Publications -Forthcoming

Thom, D. 'Making War Spectacular'. In G. Braybon (ed.), Reassessing the First World War. Berghahn.

Thom, D. 'The Healthy Citizen of Empire or a Juvenile Delinquent? Beating and Mental Health in England 1900-1960'. In H. Marland and M.Gijswijt-Hofstra (eds.),

Child Health and National Fitness . Wellcome Institute Series in the History of Medicine.

Presentations

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Thom,D. Corporal punishment and the humanitarian league. April 2002 History Department Manchester University

Thom,D. 'Discipline and normality' Birgitta Forum Symposium, Vadstena, Sweden 'Normality Professions and Institutions for children: deviant children, negotiations and the transformations of childhood' 26-27 August 2002

I continue to lecture and supervise graduate and undergraduate students in the faculties of Social and political Sciences, History and the Department of History and Philosophy of Science; my leave from college teaching in the Easter term was used to make progress on the history of psychology in education in 20th century Britain and to prepare a funding application for the project on corporal punishment in Britain 1900-1982.