Medical and Scientific Understandings of Childhood Difference: Framings, Representations and Imaginaries Symposium

PEALS Spring Symposium

Thursday 23rd & Friday 24th February 2012

Great North Museum, Newcastle upon Tyne

Newcastle University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

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Leave by 5pm

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http://www.gustorestaurants.uk.com/restaurants/gusto-newcastle

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Katie Featherstone

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Juliet Chenery-Robson
Mimesis 3: Visualising the invisible illness M.E.

Alienation, social exclusion, loss of identity and controversy lie at the heart of my photographic research. Often referred to as 'the disease of a thousand names' ME affects over 250,000 people in the UK, with at least 65,000 of these being children. Despite this fact ME remains misunderstood by many health professionals, with some still believing that it is 'all in the mind'. Emily was 10 when she developed ME: *"Negative attitudes from doctors and teachers can destroy your confidence in both yourself and the world around you. Being told that your health problems are psychosomatic isolates you from the people you turn to for help."*

Following my own daughter's diagnoses of ME when she was 13 in 2004 I began working with ME sufferers and medical researchers in 2007 to find ways of creating a visual interpretation of this devastating illness. Being a complex disease with no visible signs of illness, but rather a collection of symptoms, photography cannot simply be used to record ME, but rather has to be thought of in terms of metaphor. So by combining a methodology based on action research and interpretive phenomenology I am currently attempting to find ways of providing a 'visual voice' by which ME sufferers can 'speak' to varied audiences about their lived experience of illness.

Professor Julia Newton, a Clinical Professor at Newcastle University's Institute of Ageing & Health: *"People often have preconceived ideas about people with ME and Juliet's photographs challenge many of those negative views. It was interesting for me to see my patients in their own surroundings rather than in a stark, brightly lit room and it even made me look at them in a different way."*

Emma Clavering
Children and young people's encounters with genetics: Through an ethnographic lens

When health and development questions about a child lead to genetic investigations, new issues can surface for people close to that child and the child themselves. Even when questions around a possible medical condition lead to a chromosomal diagnosis, new questions may be posed around potential future opportunities and challenges for the child, and implications for possible future children. Technical medical language around genetic knowledge, that may appear to be in a state of constant revision, can make these issues seem even more difficult to grasp and deal with. How do children and young people engage with such troubling and potentially personally risky questions, along with the new set of possible scenarios they are presented with?

In the study, *Kinship and Genetic Journeys* we aimed to explore what it was like for family members and close friends, including children referred and their siblings, to enter the world of genetics. A total of 26 families participated in the study – 17 of these families were followed from their first referral to the paediatric genetic service while the remaining 9 families had been referred to the service several years earlier and were asked to reflect back on their experiences. The children and young people in these families came into the study in a number of ways. 27 children and young people, aged between 5 months and 18 years, were included in observations of consultations in clinics and everyday live contexts. 9 children and young people, aged between 9 and 18 years, took part in in-depth interviews. Of these 5 had been referred to the genetics clinic and 4 were siblings.

The research approach encouraged the children and young people to work with the researcher on their own terms as much as possible. This posed a number of challenges for the researcher, which will be explored here to identify moments of connection and also dislocation between adult researcher and child participant. The close analysis of these junctures offers insight into what it can be like for children and young people entering unfamiliar and daunting worlds.

Stuart Derbyshire
The problem of infant neurodeterminism

Recent political and scientific commentary on parenting has concentrated on the importance of the first three years for appropriate brain development. It is proposed that necessary brain circuitry for cognition and also empathy and concern develop in the first three years. Stress, deprivation, poor parenting or poverty, even at relatively mild levels, are suggested to hinder brain development and thus undermine learning and moral development. Furthermore, there is no means to later compensate for the loss of learning and moral development because permanent changes in brain organization and brain chemistry greatly reduce the impact of any further educational efforts. Extreme abuse and deprivation can certainly affect brain development, and can cause behavioural problems, but there is little evidence that milder neglect can have negative consequences on the brain or behaviour. There is also no evidence that the brain areas involved in empathy and concern, for example, become fixed during the first three years and much evidence that the brain retains plasticity throughout life. The extreme pessimism of infant determinism is simply unwarranted. In general, the evidence linking negative childhood circumstances with permanent changes in brain function is limited while the evidence for children overcoming serious deprivation, and even frankly abusive environments, is very good. Nevertheless, discourse on the catastrophic consequences of not providing an enriched early learning environment means that parents are instructed to make Herculean efforts to 'wire' their children's brains in the first three years. Such instruction is intrusive to normal family life and is unnecessary.

Katie Featherstone and Paul Atkinson
Creating conditions: the making and re-making of a genetic syndrome

This paper explores the multiple sites and versions in which one medical condition – Rett syndrome - is enacted and represented. This rare condition provides us with an analytic window onto wider issues in the sociology and anthropology of medical conditions, notably those with a genetic basis. Rett syndrome continues to be diagnosed based on the observation and adjudication of key clinical features; however, genetic medicine has entered the field. A key moment in the trajectory of this entity is the association of a gene with the syndrome and Rett syndrome therefore provides us with a snapshot in time, allowing us to follow the implications of this technology as it occurred. We provide a detailed case-study of the effects of genetic knowledge on this syndrome and what it is thought to constitute.

Our multi-sited ethnography traces the syndrome from the local clinical and scientific team to the international field and back again via families caring for a daughter with Rett syndrome. We follow the work of clinicians, scientists, activists, parents, and others in the construction of Rett syndrome to map out some of the multiple sites and versions in which this medical condition is enacted and represented.

Ellen K. Feder
Protecting vulnerability: An imperative of care

Surgical management came to define the standard of care for children born with ambiguous genitalia beginning in the 1950s. Following the revelation of the physical

and emotional harms individuals had suffered, the standard has seen significant changes over the last decade. Despite these changes, the number of normalizing surgeries has not substantially decreased. Where in the past, surgery was undertaken by physicians who understood themselves to be responding to a "social emergency," these same surgeries are performed today because physicians report that this is what parents want, even what parents insist upon, intent, as they are, on relieving their children from the stigma attached to atypical sex anatomies.

I have argued elsewhere that an ethics of care provides the ground for ethical inquiry into the violation entailed by the standard of care through attention to the vulnerability of parents charged with making decisions on behalf of their children. In this paper I explore the possibility that Foucault's concept of "care for the self" provides a way forward in promoting ethical practice in the clinical care of children with atypical sex. Ethical reflection grounded in this notion of care for the self involves relocating a common sense notion of parental duty to make one's children invulnerable, to a duty to preserve their freedom, as Foucault understands it. In developing this analysis I rely on the reflections of a mother who decided to forgo normalizing surgery for her daughter. In her account we find an exemplary model for appreciating the rewards and challenges this "care of the self" involves.

Ruth P Fitzgerald, Michael Legge, Susan Wardell, Kristin Clift, Martha Bell, Julie Park

Endangered Kiwis? Contradictions, endorsements and concerns around genetic testing and terminations in Aotearoa/New Zealand communities

This paper draws on ethnographic interviewing and critical discourse analysis of relevant public media to map out the contested cultural terrain surrounding the medical and scientific creation of childhood difference through prenatal genetic testing, screening and the use of PGD between and within various New Zealand communities. It presents emerging findings from an ongoing three year Marsden funded project which explores the everyday ethical thinking of people who are experts (through life experience) at living with genetic difference and its associated reproductive decision-making. Our research includes the views of families with inherited deafness who are members of the Deaf Cultural Community, and activists from the Savingdowns group comprised of families with children who have Down Syndrome, and their supporters. At the more complexly networked social level, we draw on interviews with members of large and well established New Zealand support and advocacy groups such as Parent to Parent (a group committed to peer support for the raising of children with genetic difference) and NZORD (an umbrella group for rare disorders that holds complex medicalised views of certain genetic differences as preventable pathology). We also consider the meanings of childhood difference created through the Ministry of Health sponsored National Screening Unit publications. All of these discursive positions are then analysed against the backdrop of a selection of local men and women's accounts of their own moral reasoning strategies for terminations undertaken for a variety of reasons including genetic difference. Our analysis demonstrates the complex and situated framings of fetal life and personhood which these various communities produce and assesses the power and relevance of these framings in the reproductive decision-making of individuals confronted with the possibility of terminating a pregnancy.

Dan Goodley
Disabled children and the normative imaginary: The psychopathology of the 'non-disabled'?

We know from recent research that disabled babies and children – and their families – are subjected to a whole host of responses to disability from society. What we perhaps know less about are the reasons why 'the non-disabled' imaginary responds to disability in terms of the often contradictory processes of fear/fascination. In this paper I want to explore the normative imaginary through the stories of parents and disabled children. Adopting a social psychoanalytic account – including the work of Freud and Lacan – I will consider the ways in which disabled children's bodies and lifeworlds become wrapped up in responses of the non-disabled. I will make, employ and evaluate the concepts of the 'uncanny' and 'disavowal' with specific reference being made to scientific and medical contexts and discourses.

Annette Hames, Alex Henderson, Jeremy Parr
New developments in autism spectrum disorder genetics and parental perspectives about clinical genetic testing

This session will focus on how new technology is leading to opportunities for genetic testing in families of people with autism spectrum disorders (ASDs). ASDs are common neurodevelopmental disorders, and considerable efforts have been made over the last 15 years to investigate their genetic basis. The recent finding that Copy Number Variants have a role in the development of ASD has led to opportunities to test for potentially causal variants. 'Consensus statements' have been made suggesting tests that can identify copy number variants should replace chromosome testing in clinical practice. However, there is currently debate about:

1. whether our current level of scientific knowledge justifies testing in clinical practice
2. the value of clinical genetic testing, and how this could be delivered in a publically funded healthcare system
3. whether parents and people with ASD would like testing to be available

This session will focus on the opportunities presented by new and emerging technologies, the challenges and potential impact of using them in clinical practice, and following the largest survey of its kind to date, parents' opinions about clinical genetic testing.

Eva Feder Kittay
Forever small: The strange case of Ashley X

I explore the ethics of altering the body of a child with severe cognitive disabilities in such a way that keeps the child "forever small." The parents of Ashley, a girl of six with severe cognitive and developmental disabilities, in collaboration with her physicians and the Hospital Ethics Committee, chose to administer growth hormones that would inhibit her growth. They also decided to remove her uterus and breast buds, assuring that she would not go through the discomfort of menstruation and would not grow breasts. In this way she would stay "forever small" and be able to be carried and handled by family members. They claimed that doing this would ensure that she would be able to be part of the family and of family activities and to have familial care. But the procedure has raised thorny ethical questions. I wish to explore these questions philosophically by bringing to bear my own experiences as a mother of a grown daughter with severe cognitive impairments.

Joanna Latimer

Portraiting the genetic: The family, the body, children and persons in dysmorphology

In this talk I am going to present some of the key themes of the book that I am currently finishing writing, *The gene, the clinic & the family: Medical Dominance in the 21st Century.* The book is based on a case study of a sub-discipline in clinical genetics, *dysmorphology*, or the study of abnormal forms. Focusing on one particular aspect – what I call dysmorphology's portraits – I explore the kinds of bodies, children, persons and families that process and practice in dysmorphology, and the interaction between the gene, the clinic and the family, performs.

Ellie Lee

Prejudice masquerading as research: Brain science and British social policy

A set of Government-commissioned documents have recently been published by English politicians, setting out what is presented as a radical programme of action to address social problems, centrally poverty and 'social mobility'. These include The Foundation Years: preventing poor children become poor adults, authored by Frank Field MP (Dec 2010) and Early Intervention: the Next Steps (Jan 2011) / Early Intervention: Smart Investment, Massive Savings (July 2011) by Graham Allen MP. A core theme of these reports is that neuroscience leaves us with no uncertainty that 'poor parenting' is the main cause of social problems. Allen's reports even features images of brain scans of children on its front cover, which, we are told, 'illustrate the negative impact of neglect on the developing brain'. This paper will offer a reading of this policy approach / programme, centring on the way 'nature' and 'nurture' are represented in such documents. This will draw attention to the surprisingly high degree of primacy placed on the significance of 'nurture' and consider where this leads in regards to constructions of social problems, social mobility, and 'the family'. The conclusion will be drawn that this policy agenda is driven less by uncontrovertable 'scientific evidence' than by a commitment to (or prejudice that) recasting the relation between 'the family', 'parents' and the State is the key to a better society.

Janice McLaughlin

The co-location of digital imagery and embodiment in paediatric genetics

Paediatric genetics involves multiple visually based diagnostic processes (alongside other elements including exploring the family tree). While dysmorphology focuses on the potential for external features to provide clues to genetic variation, biochemical analyses of the blood concentrate on displaying the chromosomes themselves in order to visualise variations such as deletions and translocations. The level of magnification and detail which is now able to be captured via technologies such as FISH (Fluorescence In Situ Hybridization) and Array-CGH (Comparative Genomic Hybridization) is allowing for new patterns of variation to be 'seen' and possible diagnosis to be made, which was not possible before. However, this generates questions about what kinds of diagnosis and what version of the body is produced via such visualisations. Some writers have suggested that new disorders and new disordered bodies are being produced via such visualisations, which do not require a link to symptoms of illness to carry social significance. This presentation, drawing from ethnographic research in a paediatric genetic clinic, which uses both dysmorphology and biochemical analyses in diagnosis processes, cautions giving too much power to digital imagery to define disorder and the child. It does so by arguing that the imagery is co-located, in different spaces and moments, with the body whose DNA it is capturing and this co-location means that the meanings formed for what that body is and contains are also therefore co-produced.

Rayna Rapp and Faye Ginsberg

Screening disabilities: Visual fields, public culture, and the atypical mind in the 21st Century

In an age dominated by media imagery, we argue that the citizenship of people with disabilities encompasses more than legal or judicial rights. Our work asks what it means to be a visual citizen by examining the interocular fields that place, circulate, and reposition young people with a range of diagnoses involving atypical cognition. Children and young adults labelled with cognitive diagnoses are becoming increasingly visible through the proliferation and circulation of media representations – from laboratories to the internet --- that embrace a cultural model valorizing "all kinds of minds." Drawing on our current multi-sited fieldwork in NYC, we examine the construction of these subjects as public actors across diverse visual fields: the use of fMRI scans in neuroscientific labs studying cognition; the creation of targeted media in the educational world to represent the needs of non-normative learners; the emergence of independent film and activist documentary projects that generate models for a new social landscape on and off-screen via advocacy campaigns for inclusion; and d.i.y/social media that use irreverent humor and parody to upend social hierarchies and suggest alternative regimes of value. This process is inherently ambiguous, as the expansion of democratizing visual representations of neurodiversity are entangled with forms that seek to categorize and regulate cognitive difference.

Sara Ryan

"Well I thought if I haven't got Asperger syndrome, then there really is something wrong with me"; exploring autistic people's reflections on childhood and diagnosis

Autism spectrum conditions (ASC) challenge conventional understandings of the dynamic relationship between diagnosis and identity. Singer, drawing on her personal experiences as a person with ASC, suggests that ; "whereas the traditional image of 'diagnosis' is of something reluctantly sought, dreaded, resisted and imposed from outside, people with "marginal" neurological differences clamour at the gates, self-diagnosed and demanding to be let in."] Singer seeks to capture the peculiarity of the medicalisation of autism in that, for her, ASC is ontologically linked to personal identity; it is not a condition that people have, but rather an identity that people are.

In this paper, drawing on data from a qualitative interview study, I explore the ways in which autistic adults reflect on their childhoods and being diagnosed with ASC. The narratives offer fascinating insights into both the historical context and the social construction of ASC, as participants position their autistic selves in relation to the emergence of the diagnostic categories of ASC.

Nineteen participants (out of 37) were diagnosed in adulthood and for some of this group, the diagnosis marks a radical redefinition of self, offering answers to longstanding social and emotional puzzles, tensions and difficulties experienced since childhood. For others, diagnosis simply confirms and legitimises an identity they may have already assumed - though not necessarily disclosed. Eighteen participants were diagnosed as children and while their recollections of childhood (where relevant) have some similarities with the first group, they also demonstrate how their autistic identity has a greater legitimacy, level of acceptance and certainty than that of those diagnosed in adulthood.

Beverly Searle

Innovations within the genetic analysis of children with unexplained phenotypic differences: the challenges and opportunities they present and the work of Unique in supporting the children and their families

For families of children with unexplained developmental delay and disability, rapidly evolving genetic analytical techniques offer the tantalising prospect of a diagnosis. The recent roll out of array CGH analysis across the NHS has more than doubled the rate of diagnosis of rare chromosome disorders in this cohort of children and for some children have witnessed the emergence of new pathogenic copy number variants including novel microdeletion and microduplication syndromes. For many children, their new diagnoses are ultra rare, if not unique, with no other cases recorded with which to compare. In addition, the prospect of routine genome sequencing, with its ability to detect the most minute genetic differences, is fast becoming a reality.

I will explore the reasons why families seek a diagnosis and the challenges and opportunities they face on being given a diagnosis of a rare or even unique chromosome disorder using these new technologies. I will discuss the work of Unique in helping these families understand and come to terms with their child's diagnosis, including:

- Unique's comprehensive database detailing the holistic lifetime effects of individual rare chromosome disorders
- Development and maintenance of Unique's innovative and extensive range of evidence-based, professionally-reviewed, family-friendly information guides on specific rare chromosome disorders, including the more recently identified microdeletion and microduplication syndromes, and on related topics
- The ways in which families and, where they are able, children receive and make use of these resources
- Support for those families whose child's chromosomal diagnosis will always set them apart as being unique

Nick Watson
Theorising disability in childhood

The ideas that have emerged from within Disability Studies, in particular the Social Model, saw emergence of what were then new approaches in the study of disability in childhood. The focus shifted from an exploration of impairment to one that prioritised the social with an emphasis placed on the material. Recent work from within the discipline has challenged the over materialistic approach of the earlier social model theorists but has in the main supported its focus on barriers. More recently ideas that have emerged from what has been called Critical Disability Studies have attempted to take the study of disability in childhood in a slightly different direction with a focus more on culture and the representation of disability. This paper examines how disability studies and critical disability studies have influenced the research agenda and their impact on childhood research on disability and explores their usefulness for providing an understanding of the lives of disabled children. The paper finishes with recommendations for future research in the area.

Participant Biographies

Juliet Chenery-Robson

Juliet is currently a full-time PhD AHRC (block grant) funded student studying practice-based Photography in her second year at the University of Sunderland. The title for her PhD is 'The visualisation of the invisible illness M.E.'. In 2008 she was awarded a Photography MA with distinction and selected by Axis to be one of their MA Stars. In 2009 she received a grant from the Arts Council to develop the project she began for her MA and is continuing to research for her PhD. Prior to this Juliet worked as a photographer, writer and editor for national and regional publications and organisations.

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Dr Emma Clavering

Emma's research interests engage with current socio-cultural debates around notions of 'the family' particularly associated with perceptions and experiences of health, illness and disability. She draws on in-depth ethnographic research tools to explore those narratives and gain insight into ways in which people (such as clinicians, parent/carers, and children and young people) makes sense of their worlds. She has recently completed working on the project: 'Kinship and Genetic Journeys', and is currently undertaking a number of roles across research and teaching at Newcastle University.

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Dr Cathrine Degnen

Cathrine Degnen is Lecturer in Social Anthropology at Newcastle University. Trained in medical anthropology and ethnography, her research interests include the everyday experiences of ageing and selfhood, with a particular emphasis on the intersection of narrativity, memory and place. A second strand of her research has been on public understandings of genetically modified food, exploring how people without a vested interest in the technology grapple with its broader social and cultural implications. Recent publications include 'Years in the Making: Ageing Selves and Everyday Life in the North of England' (forthcoming in summer 2012 with Manchester University Press) and 'Animals and Science: From Colonial Encounters to the Biotech Industry' (2010, with Maggie Bolton). Current research projects include 'Regarding Beauty: Transnational Understandings of Ageing Bodies, Beauty and Emotions' (with Dr Mónica Moreno Figueroa) and 'Ageing Creatively: a pilot study to explore the relation of creative arts interventions to wellbeing in later life' (MRC funded, 2011-2013, PI Eric Cross).

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Dr Stuart Derbyshire

Stuart is the Director of Pain Imaging at the University of Birmingham and a Reader in Psychology. He is currently funded by the Medical Research Council to investigate functional pain using neuroimaging combined with a novel analgesic technique called 'offset analgesia'. He is Associate Editor of Pain and Psychosomatic Medicine. He has authored or co-authored papers on medicine, psychology and philosophy for the British Medical Journal, Bioethics, European Journal of Neuroscience, Pain, Psychosomatic Medicine, Neuroimage, Gastroenterology and psycCRITIQUES amongst others. Current research involves both theoretical and empirical research on the nature of pain and the possible causes of a rising incidence of pain or other somatic illness in the absence of identifiable pathology and in the context of improving health and longevity.

Before arriving in Birmingham he was a member of research faculty at the Universities of Pittsburgh and California, Los Angeles.

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Dr Katie Featherstone

Katie is a Senior Lecturer and Director of Postgraduate Studies in the School of Nursing and Midwifery Studies at Cardiff University. Her expertise is in the sociology of biomedical knowledge, with particular emphasis on the social consequences of genetic technologies. She has produced a body of ethnographic work examining: kinship and disclosure in the context of genetic risk information; the classification of genetic syndromes and their social consequences; the technologies of health service evaluation and clinical guidelines; the diagnosis and classification of medical entities. The recurrent theme of this work is the production and translation of biomedical knowledge and the interaction between the laboratory, the clinic, and patient populations.

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Dr Ellen K. Feder

Ellen is Associate Professor of Philosophy in the Department of Philosophy and Religion at American University. She is the author of *Family Bonds: Genealogies of Race and Gender*, and co-editor of *The Subject of Care: Feminist Perspectives on Dependency*, as well as *A Passion for Wisdom: Readings in Western Philosophy on Love and Desire*. She is currently completing a book manuscript which examines ethical questions raised by the medical management of children born with atypical sex anatomies.

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Dr Ruth P Fitzgerald

Ruth is Senior Lecturer in Social Anthropology, in the Department of Anthropology and Archaeology, University of Otago, New Zealand where she teaches graduate and undergraduate courses in medical anthropology and the ethics and politics of visual ethnographic techniques. She is Chair of the Editorial Board of Sites, a journal of social anthropology and cultural studies. Her research interests include contemporary ideologies of health care; innovative medical technology and embodied moral reasoning both in New Zealand and in Utah society. Her current research focus "Troubling Choice" is a collaborative ethnographic study of the everyday ethical thinking of New Zealanders who have had personal experience of struggling with the issues of choice, reproduction, and genetic difference. It is supported by the Marsden Fund Council from Government funding, administered by the Royal Society of New Zealand.

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Professor Faye Ginsberg

Faye is Director of the Center for Media, Culture & History; and Co-Director, of the Center for Religion and Media at New York University where she is also David B. Kriser Professor of Anthropology. She has a longstanding interest in cultural activism, from her first multiple award winning book, *Contested Lives: The Abortion Debate in an American Community*. She is completing a book on her longstanding work on indigenous media, *Mediating Culture: Indigenous Identity in a Digital Age,* and is actively engaged in research on cultural innovation and learning disabilities with Rayna Rapp. Their most recent joint publication is 'Reverberations: Disability and the New Kinship Imaginary', in Anthropological Quarterly, Spring 2011.

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Professor Dan Goodley

Dan Goodley, PhD, is Professor of Psychology and Disability Studies at Manchester Metropolitan University in England. His research and teaching aims to shake up dominant myths in psychology as well as contributing, in some small way, to the development of critical disability studies theories that understand and eradicate disablism. Recent publications include Disability Studies: An interdisciplinary introduction (Sage, 2011).

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Professor Erica Haimes

Erica Haimes was the Founding Executive Director of the PEALS (Policy, Ethics and Life Sciences) Research Centre (1998-2008) where she is now Professorial Fellow; she is also Professor of Sociology at Newcastle University, UK. Her research interests include: interdisciplinary research on social, ethical and legal aspects of the life sciences; reproductive and genetic technologies; socio-ethical aspects of the provision of human tissue for research, and the relationship between states, families and medicine with a focus on assisted conception. She founded the PARTS (Provision and Acquisition of Reproductive Tissue for Science) International Research Network.

Erica has been a member of various policy and practice advisory bodies including: the RCOG Ethics Committee; the Ethics and Governance Council for UK Biobank; the MRC's International DNA Banking Advisory Committee; the Nuffield Council on Bioethics Working Party on the care of premature babies, and was a co-opted member of the Ethics and Law Advisory Committee of the Human Fertilisation and Embryology Authority. She is currently a member of the Ethics and Public Policy Committee of the International Society for Stem Cell Research (2009-ongoing). She is on the Advisory Board of the UK's Economic and Social Research Council (ESRC) Genomics Research and Policy Forum at Edinburgh University and on the International Advisory Board for the NIH-funded Centre for Genetics Research, Ethics and Law at Case Western Reserve University, USA.

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Dr Annette Hames

Dr Annette Hames is a consultant clinical psychologist, who works in Newcastle's Community Team, Learning Disability. She has worked with children with learning disabilities, and their families for over 25 years. She recently spent one year working with Jeremy Parr and Alex Henderson, on a project investigating family members' attitudes towards potential clinical genetic testing for ASDs.

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Dr Alex Henderson

Dr Alex Henderson is a consultant clinical geneticist, who sees families referred to the Northern Clinical Genetics service

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Professor Eva Feder Kittay

Eva is Distinguished Professor in the Department of Philosophy, Stony Brook University, New York. Her areas of expertise include feminist philosophy, feminist ethics, social and political theory, metaphor, and disability studies. She has taught and published more generally in philosophy of language and normative ethics and social thought. She is a Senior Fellow of the Stony Brook Center for Medical Humanities,

Compassionate Care and Bioethics and an Affiliate of the Women's Studies Program. Her most recent books include *Blackwell Guide to Feminist Philosophy*, edited with L. Alcoff (Blackwell, 2007), *Theoretical Perspectives on Dependency and Women*, edited with Ellen Feder (Rowman and Littlefield, 2003), *Love's Labor: Essays on Women, Equality, and Dependency* (Thinking Gender Series, Routledge, 1999); and *Cognitive Disability and Its Challenge to Moral Philosophy*, co-edited with Licia Carlson (Blackwell, 2009).

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Professor Joanna Latimer

Joanna is Professor in the School of Social Sciences and the Centre for Economic and Social Aspects of Genomics (CESAGen) at Cardiff University. Her research interests include: biomedicine, the body and personhood; the place of the non-human in the ordering of social relations; ageing, science and older people; care; contemporary Social Philosophy. Current projects include: the ESRC project 'Ageing and Biology'.

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Dr Ellie Lee

Reader in Social Policy
Elllie's research and teaching draws on constructionist theories of social problems and sociological concepts such as 'risk consciousness' and 'medicalisation' to analyse the evolution of family policy and health policy. Her work explores why everyday issues, for example how mothers feed their babies, or their feelings when pregnant and following birth - turn into major preoccupations for policy makers and become heated topics of wider public debate. She is the Director of the Centre for Parenting Culture Studies based in SSPSSR at the University of Kent https://blogs.kent.ac.uk/parentingculturestudies/ and regularly discusses her research in the media and other public forums.

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Dr Pauline McCormack

Pauline has interests in disability, patient inclusion and empowerment and the ethics of translational research. She is concerned with work which challenges existing power structures, communicates ideas and fosters greater understanding of paradigms and standpoints, between scientists, health professionals and patients. She is currently working on two projects: exploring the social and ethical issues around clinical research for rare, childhood disease; and investigating patient experiences of failed metal-on-metal hip joint replacements. In all her work she operates in close collaboration with patients, healthcare professionals, scientists and engineers.

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Dr Janice McLaughlin

Janice is Executive Director of PEALS. Her research interests are in the areas of health and disability and her approach is influenced by ideas from within medical and social anthropology, social studies of technology and critical disability studies. Her work revolves around examining the construction of meaning and identity within various engagements; in particular those varied engagements that occur between service users, professionals, social actors and technology. Janice's current work includes 2 ESRC projects, the first is an ethnography of paediatric genetics, exploring kinship and identity; the second is a project examining issues relating to embodiment, disability and pain from the perspective of disabled young people. Recent publications include: Families Raising Disabled Children: Enabling Care and Social Justice, published in 2008 by Palgrave and Contesting Recognition in 2011, also with Palgarve..

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Dr Jeremy Parr

Jeremy is a clinical senior lecturer and consultant in paediatric neurodisability at Newcastle University, UK. He has been involved in ASD genetics research for over 10 years, and now leads the International Molecular Genetic Study of Autism Consortium, which is one of the major groups participating in the Autism Genome Project Consortium. Jeremy works as part of a regional clinical service that sees children and young people where a question about ASD diagnosis, or management has arisen.

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Professor Rayna Rapp

Rayna is Professor of Anthropology and Associate Chair in the Department of Anthropology at New York University. Her research interests include gender, reproduction, health and culture, science and technology, and disability studies. Significant books include Testing Women, Testing the Fetus: the Social Impact of Amniocentesis in America. Routledge (1999), and Conceiving the New World Order (co-edited w Faye Ginsburg). She is actively engaged in research on cultural innovation and learning disabilities with Faye Ginsburg. Their most recent joint publication is 'Reverberations: Disability and the New Kinship Imaginary', in Anthropological Quarterly, Spring 2011.

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Dr Sara Ryan

Sara Ryan is a Senior Researcher at the Health Experiences Research Group, University of Oxford. Sara's research at the Health Experiences Research Group has largely focused on autism spectrum conditions. Her research interests are disability, difference and issues around trying to include particular groups in research. In 2011, Sara began a five year fellowship as part of a Department of Health funded Quality Outcomes Research Unit with colleagues at the LSE and University of Kent. The aim of this unit is to improve health and social care for people with long term conditions through high quality evidence about need, quality and outcomes.

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Dr Beverly Searle and *Unique*

Based in Surrey, *Unique* is a UK-registered charity with an international reach, providing information, networking and support for families with a rare chromosome disorder (RCD) and for the professionals who work with them. Founded in 1984 as a parental self-help group, *Unique* membership has expanded to include well over 8,860 member families, representing more than 12,000 individuals with a RCD. As diagnoses of RCDs increase with the roll out of array CGH analysis, membership of *Unique* is increasing rapidly, with more than 100 new families joining each month at January 2012. Central to the group's work is its comprehensive database which facilitates documentation of phenotype/genotype correlations, publication of a growing list of accessible information guides on specific RCDs and linking of families and researchers. Beverly Searle gained a PhD for her work on the genetics and biochemistry of yeast. Now *Unique*'s CEO, her professional and personal lives collided with the birth of her daughter with a RCD who, until her premature death in December 2012, was profoundly disabled and medically complex.

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Dr Jackie Leach Scully

Jackie is Reader in Social Ethics and Bioethics at Newcastle University, and a Co-Director of PEALS. Originally trained as a biochemist she developed an interest in the social effects of science and its regulation, and in 1997 joined an interdisciplinary unit for bioethics at the University of Basel. There she was able to follow her research interests in the regulation of genetic and reproductive medicine, and in more general areas of bioethics, disability, the social construction of moral issues, and in feminist and psychoanalytic approaches to understanding moral processes. Her most recent work is on the ethics of bodies that are anomalous in different ways -- disabled, missing, fragmented -- and the role of legislation and regulation in shaping public moral imagination.

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Professor Nick Watson

Nick is a Professor of Disability Studies in the School of Social and Political Sciences and Member of the Institute Health and Wellbeing at University of Glasgow. Research interests include: disability and childhood, disability theory, identity, the role of impairment, care and personal assistance, disability and technology and disability history. Current research projects include disabled people's experiences of and access to woodland; the provision of home care; the experiences of young people in receipt of home ventilation and their transition to adulthood; the impact of the new single equality body; and an in-depth examination of public bodies' experience f implementing the disability equality duty

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Dr Simon Woods

Simon Woods is a Senior Lecturer at the Policy, Ethics and Life Sciences Research Centre (PEALS), University of Newcastle (UK) where he is Co-Director. Simon has a longstanding interest in the ethics of research; he is vice-chair of an NHS research ethics committee (REC) in Newcastle and is a member of the National Research Ethics Service National Ethics Advisors' Panel. Simon's early career was in the NHS in oncology nursing where he gained experience of adult stem-cell transplantation research. Simon holds bachelor and doctoral degrees in philosophy and over the past 10 years he has pursued a career of teaching and research within bioethics. His recent research concerns the ethical and social implications of early human development research, medical nano-technology and translational research for rare genetic disorders.

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