A Sexual Health Research and Practice Symposium

Friday 25th November 2016

The Open University, Camden
(1-11 Hawley Crescent, Camden Town, London NW1 8NP)
# Programme

<table>
<thead>
<tr>
<th>Time</th>
<th>Session/Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 – 10:30</td>
<td>Coffee and Registration</td>
</tr>
<tr>
<td>10:30 – 10:35</td>
<td>Welcome to the Conference – Lesley Hoggart</td>
</tr>
<tr>
<td>10:35 – 10:50</td>
<td>Introduction to the Conference – Alison Hadley</td>
</tr>
<tr>
<td>10:50 – 12:50</td>
<td>PANEL 1: Pleasure and Intimacy</td>
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<tr>
<td></td>
<td>Ann Furedi <em>Birth Control, pleasure and intimacy: a matter of personal choice or public health?</em></td>
</tr>
<tr>
<td></td>
<td>Rebecca Jones <em>Positive visions of queer ageing and sexual relationships</em></td>
</tr>
<tr>
<td></td>
<td>Peter Keogh <em>Pleasure and intimacy in HIV research</em></td>
</tr>
<tr>
<td></td>
<td>Claire De Than <em>Supporting the human right to have fun</em></td>
</tr>
<tr>
<td>12:50 – 13:30</td>
<td>Lunch</td>
</tr>
<tr>
<td>13:30 – 15:30</td>
<td>PANEL 2: Developing inclusive sexual health services</td>
</tr>
<tr>
<td></td>
<td>Jon Hastie <em>Reflections on sexuality as a man with a disability</em></td>
</tr>
</tbody>
</table>
Eleanor Formby Supporting young LGBT+ people’s sexual health

Alison Cooke A Hospice Approach to the Management and Support of Young People with Issues Relating to Sexuality for Young People with Palliative, Life Limiting and Life threatening conditions

Ester McGeeney The good sex project; tracing research impact over time

15:30 – 16:00 Tea and Coffee with Poster Display

16:00 – 16:30 PANEL 3: Research into practice

Carrie Purcell Working toward destigmatising abortion services in Scotland

Dan Baker How do young gay and bisexual men navigate their online identity as part of their adolescent sexual identity development?

Mathijs Lucassen That’s [not] so gay: Computerised therapy for sexual minority youth with depression

16:30 - 17:00 Multimedia Session

Lesley Hoggart, Louise Bury and Victoria Newton Hearing women’s voices: can abortion films challenge abortion stigma?

Susan Walker Creating evidence based resources for busy practitioners

17:00 – 18:00 Conference close with wine and cheese
Programme Outline

As part of our commitment to continuous knowledge exchange within the academic, policy, and practice communities we are arranging a symposium to focus on two areas in sexual health where such knowledge exchange can be challenging.

- Delivering/developing innovative, non-stigmatising, non-judgemental sexual health services.
- Factoring pleasure and intimacy into sexual health.

The symposium will bring together invited experts from the world of social science research, policy and practice to address these issues under the following topic headings:

- LGBT+
- Reproductive control
- HIV
- Sexuality and disability

Panel 1: Pleasure and intimacy

Sexual health services tend to focus on morbidities (for example sexual dysfunction or sexually transmitted infections) or reproductive outcomes. Accordingly, the role of sexual function and sexual pleasure and intimacy remain underdeveloped in sexual health services. Moreover, for some groups such as lesbian, gay, bisexual and transgender individuals, people with disabilities, older people or people with long-term conditions, sexual pleasure, intimacy and functioning are very poorly understood.

The oppressions experienced by disabled people in their sexual and intimate lives are frequently over-looked. Whist a growing literature indicates that people with physical, sensory and/ or learning difficulties want to discuss and have intimate relationships, irrespective of sexual orientation or disability. It is recognised that health and social care practitioners often find it difficult to discuss and support disabled people with sexuality issues. In the area of reproductive control, questions of sexual relationships, pleasure and intimacy are not necessarily at the forefront of practitioners’ minds when engaged in contraceptive counselling, or in designing sex and relationships education, despite research that points to the importance of understanding, for example, how contraceptive choices may be influenced by conceptions of sexual pleasure and intimacy. Similarly, STI prevention and treatment services traditionally focus on negative
outcomes of sexual risk whilst rarely considering people’s experiences of intimacy and pleasure and the role this plays in sexual decision-making and behaviours.

Panel 2: Developing inclusive sexual health services

Questions of stigma in sexual health services remain relevant. This can be stigma associated with identity, for example being lesbian, gay, bisexual and/or transgender, or diverse in terms of sex and gender; or with sexual practices or behaviours (for example women seeking abortion, or those whose sexual practices are considered to be non-normative). Moreover, there is significant stigma attending sexual pleasure, practices and desires of people with disabilities and those with long-term sexually transmissible conditions such as HIV or Hepatitis. Such stigma profoundly influences how services are delivered and received, what services are commissioned and who receives sexual health services.

Panel 3: Research in practice

In Panel 3, presentations will focus on the ways in which research has been translated into practice across our sexual health areas. In particular, presenters will consider the ways in which pleasure and intimacy have been designed into services and ways in which services are made more inclusive and non-judgemental.
Abstracts

Positive visions of queer ageing and sexual relationships
By Rebecca Jones

People find it hard to imagine themselves growing old. Previous research has shown that, despite the increased variability and diversity of (post)modern life courses, people still tend to project normative life courses, centring around marriage, childbearing and grandchildren. It has been argued that this tendency, combined with the scarcity of representations of older queer people, creates particular difficulties for younger queer people in imagining later life positively. This paper presents findings from a study where members of a bisexual community used creative methods to imagine their futures. Predominantly, they created positive and non-normative futures.

Birth Control, pleasure and intimacy: a matter of personal choice or public health?
By Ann Furedi

This session will explore why women in Britain, a country that the UN regards as having universal contraceptive provision (and an uptake of over 80%), continue to require abortion. The most effective means of preventing pregnancy (LARCS) remain unused, to the puzzlement of family planning practitioners and frequently women report a pregnancy to be unplanned. Is it that women are uneducated, ill-informed or chaotic? Or might they be rejecting the values of public health professionals when they make their private choices about sex?

Pleasure and intimacy in HIV research
By Peter Keogh

Social and intervention-based research on HIV prevention and support does not generally focus on pleasure and intimacy. Rather it is usually driven by epidemiological imperatives and investigates knowledge, beliefs and behaviours or sexual functioning or focuses on sexual risk reduction. In this presentation, I will discuss research from over 20 years in the UK and consider what the place of pleasure and intimacy has been and why it has not come to the fore in such research. I will then ask how we might research and integrate pleasure and intimacy into HIV research and intervention development in this new era of pharmaceutical HIV prevention.
Supporting the human right to have fun
By Claire De Than

Everyone has a human right to have fun of their choosing, alone or with others who consent. This paper will consider how to work within the complex mesh of relevant criminal law, safeguarding and human rights law, using practical examples and case studies.

Reflections on sexuality as a man with a disability
By Jon Hastie

As an adult I have required round-the-clock social-care support since I was 18. Diagnosed with Duchenne muscular dystrophy at the age of three and given a life expectancy of just 16 years, at age 35 I am now part of an unforeseen generation of people living with Duchenne Muscular Dystrophy (DMD). My mobility is severely limited and I rely on a ventilator 24/7 to breathe. I am entirely reliant on a team of personal assistants whom I employ directly to meet my needs. As a gay man, this has presented me with unique challenges around expressing my sexuality and realising my needs around sex and relationships. Having very little privacy, I did not feel comfortable enough to come out about this until age 30 and I have missed opportunities as a result. Often left to navigate my own path without any guidance, it was only through creating a global network of adults living with Duchenne that I was able to obtain any meaningful support. Still now, I'm charting new waters learning how to live with my condition, manage a care team, and find a way to have anything approaching a love and sex life. In this presentation I will outline the challenges I've faced and the physical and practical dilemmas involved in managing a care team as a disabled gay man.

Supporting young LGBT+ people's sexual health
By Eleanor Formby

Drawing on a range of previous research with LGBT people, this talk will focus on the development of inclusive sexual health services. In particular, it will look at some of the experiences and concerns raised by young LGBT+ people, and examine their wishes and needs within a broader context of learning about sex, and sexual and gender identities. This includes considering how and where support for sexual health may be accessed if and when sexual health services are deemed to be inaccessible, inappropriate, and/or unsupportive. In conclusion, implications for policy and practice will be addressed.
In 2012 Rainbows Hospice for Children and Young People worked with Helen and Douglas House Hospice to host a two-day conference, in relation to issues surrounding sex and sexuality for young people with palliative, life-limiting and life-threatening conditions. Douglas house was and remains a well-established hospice for young adults. Following agreement with England’s regulator, the Care Quality Commission, in 2012, Rainbows extended its services to support young people up to the age of 30 years. Issues of sex and sexuality had become a growing area of interest and concern as children and young people were now living into adulthood in growing numbers and it was becoming increasingly obvious that it was not acceptable to ignore these needs.

The conference was a great success and attendees were committed to ensuring that more would be available to support young people in this aspect of their lives. A major concern for those present was the need to balance the care of young people with the need to ensure that boundaries were not crossed and that care and support remained within the confines of the law.

The Sexuality Working Alliance was set up with a view to developing guidance for professionals working with young people and their managers. Following the publication of Talking about sex: guidance and standards for those working with people with LLTCs (December 2015 and July 2016) Rainbows has taken a proactive approach to ensuring that robust systems are in place to ensure that young people and staff both feel supported in addressing and discussing intimacy and relationship matters in their daily lives. Within the hospice, training has been delivered, a policy has been developed and the hospice has identified key staff to become ‘Sexuality Champions’ to ensure that young people can feel confident in asking questions regarding what is often regarded as a sensitive subject without fear of rejection or embarrassment. The work has been underpinned by firm commitment from senior managers to ensure that staff feel supported and confident in taking their roles forwards.

This has been and continues to be an evolution, not a revolution in care. With the ongoing commitment of those involved, Rainbows is confident that the hospice will continue to break down taboos and provide the support that young people need.
The good sex project; tracing research impact over time
By Éster McGeeney

For over three decades researchers and practitioners have noted the absence of discussions of pleasure and desire from sexuality education and sexual health services and have argued for their inclusion in these domains. More recently, researchers and practitioners have started to document strategies for including pleasure in education and health domains and sharing examples of best practice. This paper contributes to this recent body of work and shares an example of how doctoral research on this topic has been used to support education practitioners at a large UK based sexual health charity (Brook) to develop a ‘sex-positive’ approach to their work and create safe spaces for discussion of pleasure, intimacy and desire.

This paper shares findings from the ‘good sex’ project – a one year knowledge exchange project that used original research on young people’s sexual cultures to inform and influence practice at Brook. The project was based on a four year doctoral study that explored young people’s (16-25) understandings and experiences of ‘good sex’ and sexual pleasure and that was co-funded and carried out in collaboration with Brook and the Open University. The ‘good sex’ project extended this collaboration and involved a team of researchers at the Centre for Innovation and Research in Childhood and Youth at the University of Sussex, staff at Brook, independent artists and young volunteers. Over a one year period the project team staged a series of participatory film-making workshops and training sessions for staff with a view to supporting education staff at Brook to engage young people in work around pleasure, intimacy and desire. Reflecting on the ‘good sex’ project two years after its completion, the paper will document ways in which the research has come to influence practice at Brook over time, as well as highlighting some of the challenges to achieving this.

Working toward destigmatising abortion services in Scotland
By Carrie Purcell

This paper outlines a number of research studies which have, in recent years looked at the provision of and attitudes toward abortion in Scotland. These have addressed women’s experiences of more than one abortion; of later abortion; of medical abortion under nine weeks; providers’ experiences; young people’s attitudes to abortion; GPs’ views on their role in abortion provision; and media representations of abortion.

Each of these projects was designed in response to a specific challenge, be it one identified by the Scottish Government, service organisers, or as a direct result of previous studies. And each has either informed service provision (including immediate reorganisation of clinic procedures); service organisation or
policy (for example via the new Scottish Government Pregnancy and Parenting in Young People strategy); or identified areas in need of further research. A key theme running through findings from each study has been the stigma associated with abortion – for those who provide or undergo the procedure – and how this might be reduced. Outputs from the studies have aimed to address this stigma in a range of ways including via new/more accessible forms of information provision, such as video testimonies from women who have previously undergone the procedure.

Moving forward, a future challenge will be to consider what shape an intervention might take in order to effectively address abortion stigma in Scotland, in a way which would see it more readily framed as a routine component of reproductive healthcare.

*How do young gay and bisexual men navigate their online identity as part of their adolescent sexual identity development?*
*By Dan Baker*

The latest phase of my own PhD research ‘How do young gay and bisexual men navigate their online identity as part of their adolescent sexual identity development?’ involved collecting data through online focus groups with a total of 17 young gay and bisexual men across England.

The focus group conversations showed young guys using the internet for four main purposes: exploration, connection, information and experimentation. Their assessment of online resources included feelings of release from offline limitation, the ability to manage their coming out and a range of responses to sexual material ranging through thrill, obsession and danger. Further inductive analysis of data showed the pressures and risks of online sexuality exploration which dominated young men’s experiences, as well as some autonomy to navigate online spaces with a critical and independent energy.

METRO Charity run youth groups for lesbian, gay, bisexual, transgender and questioning (LGBTQ) young people where sessions include discussion of a range of non-procreative sex. These discussions present more relevant information to young people, allowing them to learn about sex in a safe environment, so they can explore sex more comfortably and confidently. Youth group sessions also facilitate LGBTQ friendships and relationships. For young gay and bisexual men, these opportunities run parallel to dating / sex apps, cruising spots and some bar / club culture which can present risks for wellbeing, sexual health and safety.

METRO also delivers workshops for pupils and training for staff which seek to address the common absence of LGBTQ voices, identities, sex and issues within the confines of a largely heteronormative school culture.
That's [not] so gay: Computerised therapy for sexual minority youth with depression
By Mathijs Lucassen

Sexual minority youth disproportionately experience depression and have difficulty accessing help for emotional worries. Rainbow SPARX is a form of computerised therapy, and it is a 3D role-play program designed to treat depressive symptoms. The program was co-developed with sexual minority youth. This short presentation will summarise the results of a mixed methods open-trial of Rainbow SPARX amongst 25 sexual minority youth.
Lesley Hoggart is a Senior Lecturer in the Faculty of Wellbeing, Education and Language Studies at the Open University. She specialises in qualitative research, and spent many years working in the qualitative research group at the Policy Studies Institute. Her research interests are focused on reproductive health, abortion policy and politics, teenage pregnancy and sexual health. Her recent publications include: 2015. Hoggart, L. ‘Abortion counselling in Britain: understanding the controversy’ Sociology Compass, Volume 9, Issue 5, pp. 365–378; Hoggart, L. and Newton, V. ‘The contraceptive implant: understanding how experiencing side effects may challenge bodily control and lead to removal’, Reproductive Health Matters, 21(41) pp.196-204; Hoggart, L., Newton, V. and Dickson, J. (2013) ”I think it depends on the body, with mine it didn't work”: explaining young women's decisions to request subdermal contraceptive implant removal.' Contraception. Lesley is currently looking at ways of challenging abortion stigma.

Alison Hadley OBE is the Director of the first Teenage Pregnancy Knowledge Exchange at the University of Bedfordshire. Prior to this role Alison led the implementation of the previous Government’s Teenage Pregnancy Strategy for England, which reduced the under-18 conception rate by 34% to the lowest level for 40 years, and helped improve maternity and postnatal support for young parents.

Rebecca Jones is a Senior Lecturer in the Department of Health, Wellbeing and Social Care, at the Open University. She has used a variety of broadly narrative and discursive approaches in her research to investigate a range of topics including: age discrimination, how people imagine their own ageing and later life, normative and non-normative life courses, the ageing of lesbians, gay men, bisexual people and transgender (LGBT) people, LGBT issues in health and social care, and especially ageing and bisexuality.

Ann Furedi has led the abortion provider and advocacy charity bpas as its chief executive, since 2003. Her previous career was mainly in policy, communications and crisis management. She has recently published The Moral Case for Abortion (Palgrave Macmillan). She lives in Kent and is Chair Elect of MidKent FE College.

Peter Keogh is Senior Lecturer and Head of Reproduction, Sexualities and Sexual Health Research Group at The Open University. His background is in applied social research in the areas of HIV, intimacy and sexual risk. For many years, Peter worked at Sigma Research and more recently at NatCen Social Research and the University of Greenwich. He also holds an Honorary Senior
Lectureship at the London School of Hygiene & Tropical Medicine. Peter is interested in how people with HIV and those at risk for HIV manage their sexual, intimate and social lives as the epidemic unfolds. In particular, he is interested in looking at the ways in which biomedical and governmental processes interact with sexual and intimate lives and with questions of identity, citizenship and community/collectivity. Most recently, Peter has been exploring, with others, processes of biomedicalisation of HIV - a period which commenced with the introduction of highly effective antiretroviral treatments in 1996 and recently led to the introduction of pharmaceutical HIV prevention technologies.

Claire De Than is Co-Director of the Centre for Law, Justice and Journalism at City University, London, having previously held appointments at 2 London University colleges. She is a Law Commissioner (Jersey). The author or co-author of more than 15 books, including de Than, Criminal Law (OUP 2016), de Than and Heaton, Criminal Law (OUP 2014) and de Than and Shorts, International Criminal Law and Human Rights (Sweet and Maxwell 2004), she has over 80 legal publications in total, including chapters in leading legal monographs and edited collections, such as Reed and Bohlander, Substantive Issues in Criminal Law (Ashgate, 2011) and articles in a variety of national and international journals, including the Modern Law Review. Her research fields include criminal law, human rights law, media law, and disability law. She has been an expert for the Law Commission of England and Wales on two recent criminal law projects. A regular keynote speaker at legal and medical conferences, she has advised several governments and many organisations on criminal law, human rights and law reform issues, with specialisms in comparative human rights, the law of British Overseas Territories and Crown Dependencies and in the law of consent.

Jon Hastie is 35 years old and has Duchenne Muscular Dystrophy. He is from the UK and lives in his own flat in Shoreham, West Sussex, having moved out from the family home some years ago. He is supported by a team of carers who provide his personal care 24/7, funded by a Personal Health Budget from NHS Continuing Healthcare. Jon has very little mobility throughout his body, requires 24/7 non-invasive ventilation and can eat only soft or puréed foods.

Despite his complex care needs, he has worked in a variety of roles since leaving university, including at local disability charities and as a local government Political Assistant. He now works part-time at DMD Pathfinders, a user-led charity he founded in 2014 to provide advice, guidance and support to adults living with Duchenne. He tries to find time to enjoy a good glass of wine or two with friends down the pub, and enjoys cinema, theatre and comedy shows.

Between 1999 and 2007 Jon lived independently at the University of Essex in Colchester. Over a period of eight years, he gained a Bachelor’s Degree in Politics and International Relations, a Master’s degree in Environmental Studies and finally a Ph.D. in Government. He has been involved in a number of research
studies in a freelance capacity, exploring the role of social care in meeting the needs of adults with long-term life conditions.

**Eleanor Formby** is a Senior Research Fellow at Sheffield Hallam University. Her research interests focus on lesbian, gay, bisexual and trans (LGBT) wellbeing, and on young people’s learning about sex and sexualities. She has published a range of journal articles and research reports in these fields and is the author of a forthcoming book, *Exploring LGBT spaces and communities* (Routledge). For more information see: www4.shu.ac.uk/research/ceir/eleanor-formby.

**Alison Cooke** qualified as a children’s and adult nurse in 1984 and as a health visitor in 1987. She has a degree in Health Studies and a Master’s Degree in Medical Ethics and Law. Alison has worked in palliative care for over 25 years, with experience in both children’s and adult hospices. In 2002 she became the first Care Development Manager for the Association of Children’s Hospices, (now part of Together for Short Lives) from where she moved to become Clinical Lead for Children’s Community Nursing Services in Coventry. She took up post as Director of Care at Rainbows Hospice for Children and Young People in Loughborough in 2006. Alison lives with her family in Leicestershire.

**Ester McGeeney** is as a youth researcher and practitioner, currently working for the young people’s sexual health charity Brook. Previously Ester has worked on a number of research and public engagement projects in the fields of youth and sexuality research. This includes the ESRC funded ‘Good sex’ project, which set out to develop sex-positive approaches to sexuality education using original doctoral research and the ‘Sounds of Sexology’ - a participatory research and song-writing project that formed part of the Wellcome Trusts’s Sexology season. Prior to this Ester completed a PhD with Brook and the Open University exploring understandings and experiences of ‘good sex’. Ester has a background in youth advice and community work and has worked with young people and their families in a range of education, health and community settings.

**Carrie Purcell** is a qualitative researcher with a background in sociology, and research interests in abortion, and young people's sexual health. She has published on a range of aspects of the provision of abortion in Scotland, including the experiences of service providers and users. Carrie's current research relates to an NIHR-funded trial of a school-based peer supporter intervention to improve the sexual health and wellbeing of young people.

**Dan Baker** has been Head of Integrated Youth Services at METRO Charity for 2 years. METRO Charity is a leading equality and diversity charity providing health, community and youth services across London and the South-east. Dan’s role sees him managing a network of 8 youth groups for lesbian, gay, bisexual, transgender and questioning (LGBTQ) young people, delivery of workshops and training in schools and colleges and targeted work together with boys and young
men to improve their knowledge, attitudes and behaviour in respect of relationships and sex.

Dan previously led the METRO Youth Chances research project which surveyed over 7,000 young people across England and is the largest ever UK survey of LGBTQ young people and their experiences across a range of areas including school, health and community participation. Dan has also worked as a manager at education charity IntoUniversity and is CELTA-qualified teacher of English as a foreign language having taught in France and Spain.

Dan is currently completing a PhD at the University of Greenwich which examines the role of the internet in the sexual identity development of young gay and bisexual men.

He enjoys swing dancing (currently taking classes in balboa) and is set to do the Brighton half marathon in February 2017.

**Mathijs Lucassen** joined the Faculty of Wellbeing, Education and Language Studies at the Open University in August 2015. Mathijs originally trained as an occupational therapist, and worked clinically in mental health services in both England and New Zealand. Immediately prior to starting work at the Open University he worked as a lecturer and research fellow at the Department of Psychological Medicine, School of Medicine, University of Auckland.

**Susan Walker** is a Senior Lecturer in Sexual Health at Anglia Ruskin University and a member of both the British Medical Association and the British Sociological Association. Her research interests lie at the intersection of sociology and health. She is particularly interested in the effects of gender and sexuality upon health behaviours. She has researched attitudes, knowledge and beliefs about the body and towards contraception. She has also led projects which examined the impacts of education and training upon the healthcare workforce.
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To find out more about the school please visit our website at http://wels.open.ac.uk/overview/school-health-wellbeing-and-social-care or follow us on Twitter @ou_hwsc.
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The Open University, Camden
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By Bus: Routes C2, 24, 27, 29, 31, 46, 88, 134, 168, 214, 253, 274

By Rail: Camden Town Underground (Northern line) is 250m away and Camden Road (London Overground) 650m.

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