DISABILITY STUDIES

CONFERENCE

CENTRE FOR DISABILITY RESEARCH

LANCASTER UNIVERSITY

9TH -11TH SEPTEMBER 2014

Centre for Disability Research

Department of Sociology

Bowland North

Lancaster University

Lancaster

LA1 4YN

[www.lancaster.ac.uk/cedr](http://www.lancaster.ac.uk/cedr)

Cover image: LB Buses © Sara Ryan, 2013

Welcome

Welcome to the 7th Disability Studies conference to be held here at Lancaster University. At each conference we try to bring together researchers, practitioners, policy makers and activists from around the world, to share and debate research, ideas and developments in disability studies.

The main theme of the 2014 conference is New Directions for Disability Studies. We invited the submission of abstracts for either symposium, paper or poster presentations on current research, ideas, issues and new developments in disability studies. In particular, the reviewing committee welcomed submissions in the following areas:

• Impact of global economic changes
• War, conflict and political change
• Independent living, rights and citizenship
• Normalcy and diversity
• Madness, distress and disability
• Culture, history and arts
• The ‘Global South’: Disability in low and middle income countries
• Theoretical and methodological ideas and debates
• Assistive Technologies
• Hate crime and abuse
• Politics and policies

Peter Beresford (Brunel University) and Brigit McWade (Lancaster University) convened a conference stream on *Mad* Studies details of which can be found on p13.

A particular focus of this conference is our support of the Justice for LB campaign. Connor Sparrowhawk was a fit and healthy young man, who loved buses, London, Eddie Stobart and speaking his mind. Known as LB online, short for Laughing Boy, he also happened to have autism and epilepsy. On the 19 March 2013, he was admitted to Slade House Assessment and Treatment Unit run by Southern Health NHS Foundation Trust. Tragically, after #107days in the unit, he drowned in the bath on 4 July 2013. An entirely preventable death.

Connor’s mum Sara Ryan has been a member of this conference’s community since attending our inaugural conference in 2003. It is therefore fitting that LB and the wider campaign for justice his death sparked is centre stage at this conference. LB was an industrious gifted artist. His now iconic picture ‘Bus’ is on the front of this book and on our conference signage. The #justiceforLB campaign will also be launching LB’s Justice Quilt at the pre-dinner drinks on Wednesday. You can find out more about the campaign on their conference stand or by visiting the website <http://107daysofaction.wordpress.com/>

Hannah Morgan

Conference Organiser

CeDR: Centre for Disability Research

**Reviewing Committee**

**All abstracts submitted to the conference are subject to peer review. Members of the reviewing committee are:**

Peter Beresford, Shaping Our Lives & Brunel University

Nicola Burns, University of Glasgow,

Chris Grover, CeDR, Lancaster University

Chris Hatton, CeDR, Lancaster University

Patrick Kermit, Norwegian University of Science and Technology

Kristjana Kristiansen, Norwegian University of Science and Technology

Hannah Morgan, CeDR, Lancaster University

Brigit Morris Colton, CeDR, Lancaster University

Rachel Purtell, University of Exeter Medical School

Donna Reeve, CeDR, Lancaster University

Alan Roulstone, Leeds University

Sara Ryan, University of Oxford

Mark Sherry, University of Toledo, USA

Karen Soldatic, University of New South Wales, Australia

Carol Thomas, CeDR, Lancaster University

Simo Vehmas, University of Helsinki

**Programme**

Tuesday 9th September

|  |  |
| --- | --- |
| 10.00 | Registration |
| 11.00-11.30 | Introductions and welcome |
| 11.30-12.30 | Keynote: Jackie Leach Scully |
| 12.30-13.30 | Lunch |
| 13.30-15.00 | Paper Session A |
| 15.00-15.30 | Break with refreshments |
| 15.30-17.00 | Paper Session B |
| 17.15-18.00 | Disability & Society: Sharing New Innovations |
| 18.00-19.00 | Drink reception with an opportunity to view the poster presentations |
| 20.00 | Dinner at Barkers House Farm |

Wednesday 10th September

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| --- | --- |
| 09.30-10.30 | Keynote: Karen Soldatic |
| 10.30-11.00 | Break with refreshments |
| 11.00-12.30 | Paper Session C |
| 12.30-13.30 | Lunch |
| 13.30-14.30 | Keynote: Nicola Burns |
| 14.45-15.45 | Paper Session D |
| 15.45-16.15 | Break with refreshments |
| 16.15-17.15 | Paper Session E |
| 17.30-18.30 | Wicked Fish Performing and Creative Arts Company  |
| 19.00-20.00 | #JusticeforLB Drinks Reception  |
| 20.00 | Dinner at Barkers House Farm |

Thursday 11th September

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| --- | --- |
| 09.30-11.00 | Paper Session F |
| 11.00-11.30 | Break with refreshments |
| 11.30-12.30 | Keynote: Bill Hughes |
| 12.30-13.00 | Endings |
| 13.00 | Packed lunch available |

**KEYNOTE SPEAKERS**

**Professor Jackie Leach Scully**

**Professor of Social Ethics and Bioethics, Newcastle University**

**Engaging with the Enemy? Disability and Bioethics**

Bioethics, understood as the ethics of health care and the life sciences, has a long and difficult relationship with disability. In many ways, the disabled body – that is, the body that is variant and not ‘normal’ – is one of the central concerns of bioethics. Biomedicine, after all, is primarily about identifying, characterizing and intervening in those deviations from the bodily norm that are considered to be pathological. From this perspective, it is medicine’s job to prevent, cure or ameliorate such problematic deviations; and it’s bioethics’ job to provide some guidelines on the kinds of intervention that are ethically permissible, whether on the level of individual choice or of public health policy. Within this conceptual and regulatory framework, disability is inevitably approached as a problem to be solved. This approach provides the background for the suspicion, and sometimes hostility, that some disability theorists and activists have shown towards bioethics.

In this talk I will argue for a more constructive interaction between disability studies and bioethics. Bioethics would benefit from the capacity of disability studies to understand the body, and especially the disabled body, as a social and cultural as well as biological phenomenon. For its part, disability studies would be enriched by deeper engagement with the bioethical work on topics such as prenatal selection or end of life decisions, which are of central importance not just to disability theory but also have practical impact on the lives of real disabled people.

**Dr Karen Soldatic**

**University of New South Wales, Australia**

[**Disability Rights, Welfare Reform and Global Fiscal Austerity**](https://www.academia.edu/4701980/Disability_Rights_Welfare_Reform_and_Global_Fiscal_Austerity)

The global ascension of disability human rights has emerged with the onset of global fiscal austerity. Across nearly all Western Liberal Democracies, governments have ratified the UN Convention on the Rights of Persons with Disabilities, whilst simultaneously, undertaking broad base disability welfare retrenchment that target disability social security regimes. Australia, the UK and Canada, in particular, have progressively implemented more restrictive disability social security eligibility criteria and in turn, many people with disabilities who previously qualified for disability social security no longer qualify. Thus, despite the normalisation of disability rights at the global scale, within the national scale, many people with disabilities are no longer defined as ‘disabled’ and are being shifted onto more precarious social security payments with fewer entitlements. This paper seeks to explore this growing global contradiction drawing upon disability social policy examples from the UK and Australia. It will discuss the tension that exists between the frames of ‘citizenship rights’ and ‘disability human rights’ and how these competing political frames, between the scale of the global and the national, undermine the realisation of ‘rights’ within national disability welfare regimes.

**Dr Nicola Burns**

**University of Glasgow**

**Crossing Borders: exploring the intersection of disability and migration in Europe**

Across the globe, an estimated 1 billion people are on the move today (World Health Organization 2014). Of this number 214 million are international migrants (International Organization for Migration 2013). The social anthropologist Steve Vertovec defines the current era as the age of superdiversity, which is ‘*distinguished by a dynamic interplay of variables among an increased number of new, small, scattered multiple origins, transnationally connected, socio-economically differentiated and legally stratified immigrants’* (2007: 1024). As Vertovec’s definition suggests, individuals are moving for many reasons and in very different circumstances. Not only have global horizons expanded in the realm of work and study; global conflict and exploitation have resulted in forced migration. As a global phenomenon, migration is a political issue, one that is utilized to raise questions of identity, citizenship, diversity, integration and play upon the fear of the stranger, the ‘Other’ and difference in contemporary society (Bauman 1991; Young 1990). Such issues resonate with key debates in disability studies. Disabled migrants are a hidden population (Amas and Lagnado 2010) whose experiences are often overlooked or subsumed within wider debates around disability and ethnicity (SCOPE 2012).

Taking past work around disability and migration and recent research around migration and health as starting points; the paper considers the intersection of disability and migration in contemporary society. Theoretical and real world concerns around identity, citizenship and rights are explored in the current climate of austerity which has resulted in profound shifts in contemporary health and social care systems across Europe. From the movement of people inevitably flows the movement of ideas and the paper concludes by reflecting on the possibilities of a disability and migration research agenda furthering debate around the nature and experience of disability between global north and global south disability activists and scholars.

**Professor Bill Hughes**

**Glasgow Caledonian University**

**Invalidation: conceptualizing disability history**

Invalidation is the process that transforms impairment into disability, bodily difference into social oppression. Invalidation embodies a ‘dual meaning’ including both ‘*confinement through incapacity*’ and ‘*deficit of credibility*’ (Hughes, 2000: 558). Both meanings articulate disability from the perspective of *ableism* which is manifest in the *non-disabled imaginary*: the site of the established, hegemonic or ‘normate’ ways of thinking, feeling about and acting towards disabled people. From this *ableist* perspective disability embodies a deficit/lack of *capacity* and *credibility* where deficit is derived from an evaluation based on a comparison with normative embodiment - including ideals of humanity, human improvement and perfection.

In this paper I argue that the history of the relations between disabled and non-disabled people (it takes two to tango *in time*) is best characterised as a history of the invalidation of the latter by the former. The experience of the disabled subject in history – the disability perspective – has been ignored, hidden, suppressed, unspoken and unexamined. The possibilities of unearthing it are limited. However, the condition of disability at any given time, shows itself, sometimes in its clearest light (ironically), in the shadows of history, in the ‘spectral presence’ (Snyder and Mitchell 2007: 1) of the narratives of (or about) ‘the great and the good’ and it is visible, in the background, behind the broad shoulders of all that is deemed worthy, virtuous, beautiful and good. Invalidation is the play of these forces and their outcomes; forces that are embodied in *strategies*, *repertoires*, *processes* and *levels* of disablement. In the paper, I will outline these dimensions of invalidation to illustrate some of the ways that disability invalidation organizes social relations. In particular, I will examine the work that disability invalidation does in shaping the ‘moral economy’. My examples will come from different historical periods with a significant emphasis on modernity.

**Disability & Society: Sharing New Innovations**

Members of the Disability & Society Executive Editorial Board will be available to share new innovations introduced to expand our ambitions for the journal.  A range of initiatives have been supported by Taylor and Frances including: more issues, ‘Rapid Online Publication’,  ‘Free to View’ sections - Student Perspectives, Current Issues, Book Reviews and Doctoral Announcements; Retrospective Special Issues, Virtual Special Issues, Special Issues as Books, and a new Accessible Video for the journal’s website to improve access to articles.  New and exciting social media launches are planned and we will soon be tweeting new issues, articles and news about book reviews.

As well as showcasing more about what the journal offers at the session, we also hope to encourage contributions for our world leading publication.  Whether you're looking to equip yourself with ideas on how to get published, want to understand the different formats in which you could write for the journal, pick up tips for increasing the likelihood of successful reviews, or you would like to learn more about how the Editorial Board operates, do join us for conversation with Q&A opportunities.

And afterwards ... we are very grateful to Taylor & Francis for sponsorship of the drinks reception immediately following this session!

Professor Michele Moore

Editor, Disability & Society

**wicked fish**

www.wickedfish.org.uk

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Wicked Fish is a performing and creative arts company, based in Liverpool. The core company comprises five Disabled People, three of whom are performers who have Learning Difficulties. We work as a team to create and deliver performances, workshops and training projects in arts, community and education venues.

We have worked with partners in Portugal, Spain, Germany, Bulgaria, The Netherlands and Lithuania. Our exhibition, **From There to Here**, explored elements of the changing family, social and cultural history of People who have Learning Difficulties in Merseyside over the past 100 years. It was part of a two-year project **People Like Us**, funded by the Heritage Lottery Fund, and was at the Museum of Liverpool from May to July, 2014.

The experiences of People with Learning Difficulties are often excluded from history, so we wanted to explore and celebrate our history and culture with everybody. We combined on-gallery performances, guided tours and talks with static displays including text and images drawn from public records, portraits of all the participants and artworks commissioned by them from three local artists. Visitors were also able to watch film clips of memory and drama workshops and listen to extracts from oral history sessions.

In our presentation, we will share some of our experiences with you.

**Mad Studies Stream**



Mad Studies is about far more than the Byzantine world of psychiatry and its allied disciplines. The stakes are higher still, for to study madness is to probe the very foundations of our claims to being human. For this reason alone – and there are many more – “Mad” matters to us all. (Menzies, LeFrançois & Reaume, 2013, p. 21)

With the publication of Mad Matters: A Critical Reader in Canadian Mad Studies (edited by Brenda A. LeFrançois, Robert Menzies and Geoffrey Reaume) in 2013, Mad Studies are now gaining a higher profile internationally. We see this as a critical moment in which activists, academics, service-users, practitioners and services can come together and address integral issues in the field of madness and disability. At a time when the global north’s mental health systems are in crisis, we need to develop and strengthen ‘democratic and feasible alternatives to support our understandings of and responses to madness and distress’ (Beresford in Menzies, LeFrançois & Reaume, 2013, p. ix).

We are thrilled to include papers from Canadian scholars directly involved in the publication of *Mad Matters*, alongside activists and academics working in the field of madness and disability in the Europe and USA. The stream encapsulates the diversity of Mad Studies, with presentations on a wide diversity of topics from identity politics, collective action, representation, stigma, austerity, conceptual, theoretical and ethical concerns, and mental health legislation, policy, and practice.

We hope that this stream will offer opportunities for discussion, connection, and debate, as well as the possibility of some collective work in the future. To begin with we have created a blog where people can access the details of the stream, see the schedule and begin to add to a shared bibliography: [http://madstudies2014.wordpress.com/](https://exchange2010.lancs.ac.uk/owa/redir.aspx?C=bOl3BC3dMUKvNfxWKFwG9P2EoAYxi9EINQ664T5T1U5uwtUhh4h_-XeO4APTLnNS0rDjppvDaco.&URL=http%3a%2f%2fmadstudies2014.wordpress.com%2f)

Peter Beresford (Brunel University) and Brigit McWade (Lancaster University)

Mad Studies Stream convenors

**ABSTRACTS: PAPERS AND POSTERS**

**All presentations are listed in alphabetical order**

**David Abbott, Marcus Jepson**

University of Bristol

**'It's Not Even Gender Neutral, Gender's Not Even in There': Men with Duchenne Muscular Dystrophy and Interactions with Social Care.**

Many people with long-term conditions are living longer lives due in large part to advances in medical technology. Research tells us however that the broader social needs of this group are not always so well supported – things like help to find work, get good quality support, have help to maintain a good social or cultural life, or pursue intimate relationship. Men who live with Duchenne muscular dystrophy (DMD), a life threatening, long-term condition are one such group. Previous research suggested that once this group of men have finished at school, college or higher education, many have no meaningful day time activity and reported high levels of social isolation. The study presented here focused on gender because our hypothesis was that the impact of gender – here, male gender – is rarely addressed in planning and delivering social care (e.g. in support planning meetings, reviews, in organising and managing support workers or personal assistants).

A study funded by the NIHR School for Social Care Research (England) between 2012-2014 involved in-depth interview with 20 men with DMD study (an emerging and largely unanticipated population of male adults). Findings suggest that social care (in its broadest sense) did little to support a positive sense of masculinity or male gender. More often than not social care people and processes degendered and even dehumanised many of the men who took part in the study. Gendered needs around personal care, social opportunities, empowering interactions with social care organisations and staff, sex and sexuality were almost never addressed in assessments, support planning and reviews and in day to day practice. The men with DMD constructed interesting and diverse male identities with both similarities and differences to ideas of the ‘ordinary man’. However they were united in their view that much more could be done to support and bolster their sense of male self and that social care staff and organisations should be more aware of their gendered needs.

**Anne Abildgaard**

Aalborg University

**People with Acquired Brain Injury as Co-Creators in Product Development.**

In recent years involving end users in new forms of innovative public procurement has become a part of the agenda with more public entities. In that context this paper examines, whether it is possible for people suffering from severe acquired brain injury to collaborate with private companies in developing improved products for the social sector, and furthermore whether these collaborations could even function as a new way to underpin these people’s social esteem and expand the boundaries of what counts as a contribution to society, as well as contribute to an increased level of product innovation.

The new agenda on end user involvements sets a framework for disability studies that focus on what impact the co-creator role has on disabled people’s self-esteem, rights and citizenship.
The overall objective of innovative public procurement is to develop public welfare solutions addressing future welfare challenges within healthcare services. It allows public institutions to gain access to technical knowledge, while private companies gain access to important information about future user needs. User involvement plays a central role, which means that professional and informal caregivers as well as healthcare receivers are involved in the development processes.

Mainly inspired by the French philosopher Michel Foucault this paper explores the problematizations, power, values and identity positions that influence the meetings between actors from private companies and residents with mental and physical disabilities in a case study at The Late Brain Injury Center in the Danish Municipality of Frederikshavn. The Center is both a residential accommodation and a Living Lab where researchers and private companies develop innovative solutions in cooperation with the SCN staff and residents.

**Zoe Aitken1, Anne Kavanagh1, Lauren Krnjacki1, Anthony Lamontagne2, Andrew Beer**3**, Emma Baker**3**, Rebecca Bentley1**

**1**Gender and Women's Health, Academic Centre for Health Equity, The University of Melbourne

2School of Health and Social Development, Deakin University

3The Centre for Housing, Urban and Regional Planning, School of Social Sciences, The University of Adelaide

**Mapping the Intersections Between Disability, Type of Impairment, Gender and Socio-Economic Disadvantage.**

This paper reports the findings of a research project investigating the intersections between disability, type of impairments, gender and socio-economic disadvantage. While it is well documented that people with disabilities experience higher levels of disadvantage than their peers without disabilities, less is known about how disadvantage is patterned according to type of impairment and gender. This information is critical to informing policy and practice. The aim of the research was to gain an in-depth understanding of the socio-economic circumstances of Australians with disabilities in terms of a range of indicators, and to investigate how these associations vary according to the type of impairments, including sensory and speech, intellectual, physical, psychological and acquired brain injury, and gender. The analysis used data from the 2009 Survey of Disability, Ageing and Carers which included 33,101 Australians aged between 25 and 64 years. Indicators of disadvantage included low education, living on low income, not being in paid employment, housing vulnerability and a measure of multiple disadvantage. The findings show that, with few exceptions, women and men with any of the impairment types examined had lower education, income, and levels of participation in paid employment, and were more likely to be in vulnerable housing and experience multiple disadvantage compared to those without disabilities. There were large variations in the extent of disadvantage according to impairment type, with people with intellectual and psychological impairments and acquired brain injuries among the most disadvantaged. Gender comparisons among people with disabilities revealed similar levels of socio-economic disadvantage for women and men with the same impairment types, suggesting that among those with disabilities, there were no gender-based patterns of disadvantage. This paper emphasises the need to consider the diversity of experiences of people with disabilities and highlights the need for policy to move beyond a ‘once size fits all’ approach.

**Åsa Alftberg**

Dep. of Arts and Cultural Sciences, Lund University

**Experiences of Soundscapes for Individuals with Cochlear Implants.**

One of the characteristics of modern society is an increasing amount of sounds and noise, both in volume and scope. While various locations involve different types of sounds, not everyone has equal access to these soundscapes. Additionally, sounds are not neutral but include cultural beliefs and norms. How are sounds experienced by persons whose access to sounds is not obvious? Which cultural processes make soundscapes including or excluding?

The study’s empirical example concerns people with cochlear implants, who are hard of hearing or D/deaf. Emphasis is placed on their experiences of different types of soundscapes, in particular soundscapes associated to leisure activities, and what strategies that are used in difficult soundscapes. The starting point is that (dis)ability is a way of thinking about the body that is based on historical and cultural circumstances and always intertwined with the significance of space and place. By following individuals with different access and experiences of sound and noise, the hidden premises of the modern soundscapes are made visible.

**Victoria Armstrong**

Durham University

**Why Mad Studies Can Change What the ‘Time to Change’ Campaign Won’t Challenge.**

A review of the first year of the ‘Time to Change’ campaign demonstrated little more than a poverty of accomplishment and a falling short of the change in attitudes and successes which were hoped for. Working in a Mad Studies paradigm and using empirical interview, focus group and ethnographic material, this paper qualitatively explores why this may be the case. I suggest that tackling mental health stigma and discrimination via a campaign which insists upon exclusively peddling hegemonic notions of a biomedical model of ‘mental illness’ is inherently problematic given the stigmatising power of psychiatry and psychiatric labels. Furthermore, this paper explores how the campaign represents a ‘closing down’ rather than an ‘opening up’ of dialogue leaving meagre space to develop and incorporate a ‘social model of madness and distress’. I argue, through my empirical work, that this symbolises a typically neoliberal separation of the personal/experiential from the political to which it is, as a Mad Studies approach suggests, so closely wedded. In perpetuation of this separation we are swept away by a tide of disempowerment; accepting things we think we cannot change whilst we are concomitantly encouraged to change ourselves, tell our stories to change other people’s opinions of us, take responsibility for our own recovery and pay no heed to the structural forces which will continue to oppress us. Finally, I suggest how a critical application of the Mad Studies approach can propel us in a direction which exposes elements of the recovery model and the Time to Change campaign as a ‘neoliberal smokescreen’. This, in turn, may enable us to collectively turn our attention to a more affirmative narrative which challenges the politics of disablement of Madness.

**Larry Arnold**

The Autreach Press

**“Doing Ethics” the University Way. Is it Enough?**

“Nothing about us without us” has long been a slogan of the disability movement with respect to policy decisions and service provision, but what of research.
University researchers, who work with so called “vulnerable groups” will be familiar with the process of “doing ethics” that is getting ethical clearance for a project in order to ensure that the participants have given their consent and understand their position. It is also important that the process of volunteering does not produce harmful and traumatic results.
But what of the research itself, does ethical clearance mean that the project is ethical, or are there other considerations that ought to be made. In this paper, which forms the background and ethical position behind my research I suggest that the traditional ethics process is not enough, and that there are other issues to be considered, particularly for students whose disabilities have traditionally constructed them as having a diminished moral agency.
This paper introduces concepts such as the emancipatory paradigm, and Kathy Charmaz’ constructivist grounded theory as alternatives to the traditional research that separates observer and participant into “watertight compartments”

**Larry Arnold**

The Autreach Press

**Autonony: - The Critical Journal of Interdisciplinary Autism Studies**

Autonomy as a project grew out of one of the conclusions of my research; that there was a lack of critical engagement between the different academic fields in autism research.
Autonomy, was founded as an open access academic journal in order to address that.

The Dominant discourse in Autism is the Medical Model and there have recently been new challenges from the field of disability studies but where has the autistic voice been heard in this?

Autonomy will appeal to the widest range of the current autism research community and foster cross disciplinary discourse between the fields of medical research, education and sociology amongst others.

The emphasis will be on encouraging contributions from autistic scholars who have hitherto had limited exposure to academic publishing. Autonomy will feature papers reviewed by respected academics in the appropriate fields, reviews and also feature an opinions section which it is hoped will stimulate a lively interdisciplinary debate.

The journal was founded by myself in co-operation with a fellow doctoral researcher and an external tutor from the Autism Centre for Educational Research with the support and encouragement of my Supervisor, Dr Glenys Jones.

**Poster**

**Anna Arstein-Kerslake**

Centre for Disability Law and Policy, NUI Galway

**The Right to Sex: Legal Capacity Law and Sexual Decision-Making.**

This paper examines the right to sexual decision-making. Article 12 of the Convention on the Rights of Persons with Disabilities has spurred a re-evaluation of legal capacity law. Most attention has been given to guardianship regimes and mental capacity legislation. However, legal capacity is denied in piecemeal fashion all throughout the law. This paper will look at how legal capacity is denied to people with cognitive disabilities through laws that limit capacity to consent to sex. It will analyze these laws from a human rights perspective, looking both at status-based and functional-based denials. It will establish both as discriminatory denials of the right to legal capacity. Those based on a status of impairment or disability being discriminatory in purpose. Those based on a functional test of mental capacity being discriminatory in purpose and effect. Finally, it will propose a new model of understanding and agreement that is disability-neutral. The new model aims to provide a framework for protection of rights and protection from abuse.

**Carl Christian Bachke**

University of Agder

**Intellectual Disability and Mental Disorders: A Study of Collaboration Between Service Providers.**

The background of this paper is a joint project between one municipality in Norway and the University of Agder. It throws light on the research question: Which problem areas and success-factors do characterize collaboration between professionals in their service provisions for people with both intellectual disability and mental disorders?
Firstly, the question was illuminated by means of a literature review, mainly Norwegian publications. It showed that both problem areas and success-factors are tied to dimensions (a) within the service providing organizations, (b) the training offered, and (c) the attitudes the professionals express. Secondly, since the literature review revealed a scarcity of empiric research linked to this particular theme, and since a collaboration-reform was implemented in the Norwegian health-sector in 2012, it was decided to do a following–up study where employees on municipality level, both linked to the service-sector mainly aiming at people affected by intellectual disability and to the service-sector mainly targeting at people affected by psychiatric diagnoses, were interviewed. Likewise employees connected to the specialist-services on hospital-level are interviewed on how they do co-operate across their service-sectors on their own level, as well as with the respective sectors on the municipality level. Similarly, the municipality- informants are asked to explain how they co-operate with the specialist-services within the hospitals. The conclusions of the literature review are included in the interview guide, together with other items.
The data collection is still on-going; a new county has newly been included. This paper will focus on what success-factors do municipality-employees do experience as promoting constructive collaboration both on their own level, as well as across the level-border towards the specialist-services. The findings will be based on the statements from approximately 15 informants.

**Susie Balderston**

Lancaster University

**Assisted Suicide, Prosecutions and Advance Directives: A Problem of Policy, Practice and PACE in Europe.**

This paper argues that the Council of Europe Resolution 1859 concerning advance directives is inconsistent and problematic, given practice at individual member state level.

It is presented in the context of the removal of age restrictions for disabled children in Belgium to end their lives and the lack of convictions of family members assisting death in England and Wales, despite clear prosecution guidelines with public interest tests. The paper compares prosecution guidance and practice in England and Belgium to highlight inconsistencies and problems of inequality.

It argues that the notion of settled wishes of the individual and the public interest tests have serious implications in relation to disabled people at the end of life, given disablist media portrayals, legal aid restrictions, inequalities in hospice provisions and a lack of support to die at home.

Finally, the paper proposes how models of advocacy and education can be mobilized to protect the right to life of disabled people. This issue is timely and important for social policy and disability studies; new guidance for end of life care plans in England also bring implications of professional misconduct charges for social workers and health professionals.

**Dawn Benson**

Northumbria University

Birth Injury, Disabling Families and Enabling Human Factors.

This paper is concerned with presenting the results from a research project which looked at lifelong implications of human error that lead to injury of a child at birth, and subsequent disabling consequences for damaged children and their families. Family experience of pursuing claims for clinical negligence against maternity services for the avoidable injury are discussed alongside broader research questions which evolved in response to participant parents’ own priorities, concerning the family experience of completing litigation and the impact of pursuing litigation on relationships with professionals. Critical questions have been pursued about what professionals can learn from families in order to improve outcomes for children injured at birth.

The aim of the research was to foreground previously seldom heard voices of parents whose children have been damaged through clinical negligence in order to provide a body of evidence to influence the way professionals interact with parents of children who have been injured.

Findings show parents whose children have been injured at birth want to focus on the detail of professional error and the escalation of events culminating in damage in order to understand their own experience; not primarily with an individual blaming intention, but in the hope of identifying systems errors that could be ironed out in order to reduce risk of injury, or improve outcomes, for other babies. Parents are concerned to make sense of their experience and do this by focusing on tracking small errors, resisting complacency, seeking to understand critical edges of practice, concentrating on opportunities for personal and professional growth and working to consolidate new arenas of expertise. The data shows that parents who go through litigation come to exemplify characteristics which are essential for the maintenance of High Reliability Organisations that can minimise factors which lead to catastrophic accidents. Narratives of parents involved in the research suggest cultures in health care settings and hospitals where their children encountered birth injury were not characterised by features expected of High Reliability Organisations. Moreover, health, education and social care services parents went on to encounter also did not have in place systems for High Reliability Organisations.

The research suggests the response of parents to clinical negligence offers professionals a powerful resource for working towards High Reliability practices. The research concludes it is over simplistic to see pursuit of litigation as an instrumental manifestation of anger, distress or denial following damage to a child caused by clinical negligence. Rather, the experience of parents who pursue litigation adds considerable understanding of the complexity of disabling consequences of birth injury and how these can be minimised.

**Bente Dunker Bertelsen1, Birgit Kirkebæk2, John Bertelsen3**

1Rehabilitationcentre Söndersö – Denmark

2Historisk Selskab for handicap og Samfund – Denmark

3Forum for Skabende Arbejde

**The Concept of Dignity in a New and Historical Context – Or: The Return of the Rhetoric of Morality.**

Denmark has seen a tendential movement of the “worthy needy”-notion in the public rhetoric. It concerns the societal usefulness of people, meaning that suspicions of unworthiness have spread to everyone supported by public welfare, thus not contributing to society through labour market participation. The gaze is now fixed upon those who we consider to be “expensive” for society, and on those under suspicion for wanting to exploit the welfare system.

Specific categorizations, or exclusions, get easier to undertake when the challenges at hand can be individualized, as seen in the period described in a recent book by John Bertelsen and Birgit Kirkebæk. The book is a micro-historical study about the persons who were sent to America on a one-way ticket from an institution of forced labour in Maribo – because nobody wanted to hire them, and because of their behaviour. How did the responsible persons state the reasons for the deportations occuring between 1866-1930, and on what moral assessments were they based? How was the decision framed as a desire to help the persons, instead of being recognized as a discourse of deportation, which it was as well?

In present day Denmark, the concept of worthiness is changing. It represents 1) to have and to maintain a personal worth (dignity, self-esteem), and 2) to be worthy because one does his or her duty and contributes to the community. Recent structural changes have meant cuts in services to people in marginalized positions on the grounds that they should not base their existence on (unworthy) welfare support for life, but rather receive an education. The fact that this, to many people, means far worsened economic conditions in everyday life, and still no education because it simply is not possible for them, is basically not recognized.
In our paper, we will focus on the return of the rhetoric of morality, on the current expansion of the notion of unworthiness observable in the media, and on whether the discussion of worthiness has become dehumanized: are those who can not contribute through labour market participation conceived as useless? What role do the professionals play in this development? Dare they criticise the current rhetorics and narrowly defined ”truths”, or will they settle on debating and considering implementations of “what works” according to the established logic of evidence?

**Kristin Bjornsdottir**

University of Iceland

**Ableism, Classism, and Sexism in the Intouchables: An Intersectional Approach.**

This paper explores the (re)presentation of ableism, classism, and sexism in the French movie Intouchables through the lenses of feminist intersectionality theory, which explores the multiple dimensions of social relations in the oppression of subordinate groups in society. Social categories such as class, disability, and gender are interconnected categories of oppression and manifested in all domain of society. With intersectionality theory we are able to identify society's interconnected systems of social hierarchies that are embedded in all social institutions and experienced by members of society through everyday life and social interactions. The movie is a 2011 comedy-drama film directed by Oliver Nakache and Eric Toledano and received several award nominations and international attention. This is a story of a relationship and friendship between a wealthy disabled Frenchman and his PA who is a young immigrant with a criminal record. At first glance the film gives an opportunity to explore the relation, power and privilege, between disabled and non-disabled people. However, this movie is also about the relations between the social classes and sexes. The two men live in a class society and the disabled character is an aristocrat and therefore belongs to a higher class than his PA who come from the projects and in the paper we will explore the representation of classism and how it affects the friendship between the two main characters. The men also live in an ableist society which is designed for non-disabled people and their needs that results in an inaccessible society which often discriminates against disabled people. We will conclude by examining the representation of sexism in the movie, interactions between the sexes, femininity, and, masculinity.

**Kristin Bjornsdottir, Eiriksina Asgrimsdottir**

University of Iceland

**When Disability Becomes Taboo.**

In everyday discourse non-disabled people use words and terms such as ‘retard’ and ‘blind’ to define and describe negative attributes and behaviour for the purpose of humiliating others. This kind of derogatory language is used by people of all ages. This paper presents findings from a research conducted with non-disabled youth in Iceland which aim was to explore the meaning they contributed to different disability related terms and concepts. The focus was on the origins of their ideas and if the issue of disability was commonly discussed between them. The participants in the research were 38 Icelandic secondary school students aged 13-18 from eight different schools who had no personal experience of disability. Data was collected with qualitative focus groups. The findings suggest that the students have difficulties differentiating between disability, diseases, and inappropriate behavior (naughtiness). The students were preoccupied with the visibility of impairments, the body, everything that could be defined as different, and the opinions of others. They were also curious and wanted to learn more about the lives and experiences of disabled people, claimed they had limited opportunity to discuss and learn about disability issues at home or in school. They were told they should not look at or stare at disabled people and in general grown-ups in their lives avoided their questions. Therefore, disability had become a taboo and they are disciplined and silenced if they raise questions about disability or disabled people. Despite inclusive education and policy the students claimed they have had limited opportunities to become friends with their disabled peers and argue that disabled students have difficulties becoming full members of the school community. The students questioned the true intentions of school authorities and considered much of the inclusive efforts to be merely tokenistic and not effective in creating schools for all students. The findings suggest that there should be emphasis on awareness-rising among non-disabled youth in Iceland in order to 'foster respect for the rights and dignity of disabled people'.

**Isabel Bonello1, Anne-Marie Callus2**

1Kummissjoni Nazzjonali Persuni b'Dizabilita

2University of Malta

**Inclusive Research – A Stepping Stone on the Road to Empowerment.**

Inclusive research is research which is carried out by people with intellectual disability in collaboration with other researchers. This paper will itself be co-presented by a person with intellectual disability with experience in inclusive research and a non-disabled person who is an academic researcher. Together, they will analyse how inclusive research is useful not only because it enables people with intellectual disability to set the research agenda and have control over the research. It is also useful because it can contribute to the empowerment of people with intellectual disability, especially those who are directly involved in the research process. The paper will first outline the principles of inclusive research and present examples of how it is done. It will then describe how a group of people with intellectual disability started out by participating as subjects in a research project. The research comprised participation in monthly committee meetings and individual interviews with the twelve members of the committee. The paper will trace how the role of the committee members evolved from a relatively passive to a more active one and how this eventually led to their becoming researchers themselves in a project about sexuality and relationships. The methods used for conducting and presenting this research will be outlined and then the two presenters will discuss what was learnt in the process and how this process led to the people with intellectual disability becoming more empowered. They will also discuss the challenges to conducting fully inclusive research and the hindrances to making the process more empowering. Aspirations and possibilities for the future will also be presented.

**David Brehme**

University of Potsdam

**Discourses of Normality in a German Inclusive School: Children's Perspectives**.

The ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD; UN, 2006) by Germany in 2008 (Bundesgesetzblatt, 2008) has initiated a process of systemic change with the primary and secondary education system in Germany: children of all abilities now have the legal right to attend mainstream schools and gradually, albeit slowly, an increasing number of schools in Germany are becoming inclusive (EASPD, 2012; SoVD, 2009). Classical social psychology’s contact hypothesis (Allport, 1954) proposes that the decreased segregation of children labelled as “disabled” into “special schools” should affect how children attending more inclusive schools think about what it means to be “disabled”. Going one step further, one would expect that inclusive education also shifts how those pupils – disabled or not – come to think about notions of normality and ability (Goodley, 2011, Kumari Campbell, 2009). So how does the push towards an (more) inclusive school system in Germany today affect discourses of normality and ability?

This presentation will outline proposed doctoral research investigating discourses in normality in German inclusive schools the specific focus on its methodological challenges and strengths. Traditionally, children have been researched extensively in psychology, sociology and pedagogy, but seldom are they accepted as valid informants about their own experiences – especially if they “disrupt”, “disturb” and “disorder” adult conceptions of the “normal child”. The proposed research takes an opposing stance and asks: How do children with and without disabilities talk about disability and what is “normal” to them? Drawing on Disability Studies and ableism Studies, the proposed research will explore these questions discursively through interviews with children attending inclusive schools in Berlin, Germany.

**Ciara Brennan, Rannveig Traustadóttir**

Center for Disability Studies, University of Iceland

**Shifting Spheres of Influence: Governing Personal Assistance in Nordic Countries.**

The implementation of personal assistance law and policy is a complex and contentious process involving multiple state and civil stakeholders across several levels of government. This paper draws on the findings of qualitative inquiry with multiple stakeholders in three Nordic countries: Iceland, Norway and Sweden. It aims to explore the implications when responsibility for governing personal assistance is divided between national and local level government. Participants comprised personal assistance users, leaders of user organisations, administrators and policy makers. Findings were analysed using a multi-level governance framework. They demonstrate shifting spheres of influence between personal assistance users, local and central government, from a bottom-up, towards a top-down approach. Personal assistance users and user organisations had most influence in the initial stages of policy development. However, they are increasingly on the periphery of decision making processes. These findings are discussed in relation to the United Nations Convention on the Rights of Persons with Disabilities which adds an additional tier of governance to existing systems.

**Richard Brunner**

University of Glasgow

**Applying the Capabilities Approach to Reconfigure Social Approaches to Lived Experience of Mental Distress.**

The Capabilities Approach (CA) developed by Amartya Sen and Martha Nussbaum, distinguishes between what a person actually does (‘functionings’) and what s/he could potentially do (‘capabilities’), as a means of analysing quality of life for social groups. The CA can be used to appraise how people are constrained or supported by personal, social and structural factors in widening their achievement of capabilities, and maintains an analytical concern for both agency and wellbeing. Wallcraft suggests that by analysing the power of diagnosis and treatment to create capability deprivation the CA may reconfigure social understandings of mental distress. She also suggests that personal experience as evidence is needed to explore the actual hopes, needs and wishes for a full life of people with mental distress. Hopper argues for the application of capabilities to social recovery in schizophrenia in the U.S. due to its ability to engage agency, structure and diversity. However, Hopper’s argument is not pursued empirically. Taking up Wallcraft’s challenge to take personal experience seriously, this paper presents some preliminary findings from a current Ph.D. in which the CA has been used to structure an in-depth qualitative study exploring what a sample of people living in Glasgow and with recent in-patient psychiatric experience have subsequently been able to do and be in life. Twenty two people aged 24 to 64 were interviewed, who had been in psychiatric hospital, received psychiatric diagnoses, and been prescribed numerous psychiatric medications. Preliminary findings provide insights into how employment norms; benefit structures; mental health professionals; medication, diagnosis and hospitalisation; the effects of subjective distress; and other social relations interact in complex ways that may support or constrain what people with mental distress can do and be in life. The paper concludes by discussing the implications of using the CA for reconfiguring social approaches to mental distress.

**Emmeline Burdett**

Independent Researcher

**The Nuremberg Medical Trial and Disability Studies.**

The Nuremberg Medical Trial of 1946-7 was the US-led trial at which the principal perpetrators of Nazi medical crimes were prosecuted. The Trial's abject failure to treat the Nazi 'euthanasia' programme as a crime both reflects attitudes which were current at the time, and caused problems which remain unresolved to this day.

**Lucy Burke,**

Manchester Metropolitan University,

**Care and Dependency: *Keywords* in Disability Culture or Why Language Matters**

When Raymond Williams embarked upon his investigation of a range of ‘key words’, he did so with the intention of elaborating the historically contingent relationship between language and a range of non-linguistic transformations in a set of terms that presented what he described as “active problems of meaning”. In exploring the complex field of significations circumscribed by these terms, his project developed a form of historical semantics that sought to foreground the socially and ideologically formative powers of language. However, his endeavour to identify the range of sometimes overlapping and sometimes incompatible meanings encompassed by words such as ‘culture’ and ‘community’ was not an attempt to resolve these problems of meaning but to articulate them. Williams set out to establish the relationship between these ‘problem’ words and the historical development of other social structures (educational institutions, the intellectual traditions and development of particular disciplines, the political system, the mass media, the law etc.,) in order to map the conceptual and ideological parameters of their contemporary usage. His work might have looked like a lexicon, but it challenged the very notion that we might master the world through definition.

This paper argues that the production of an equivalent assemblage of *Keywords* for disability studies is a political and ethical necessity in order to enable us to clarify the parameters and provenance of particular debates within this field and to trace the emergence of particular modes of discourse and their effects upon disabled people. In this context, the paper will establish a methodological framework for this project and offer a provisional analysis of the overlapping and contradictory intersection of emotional, social, political and legal meanings encompassed by two key terms, care and dependency, and their use and abuse in contemporary representations of and debates around disability.

**Bronagh Byrne**

Queen's University Belfast

**Minding The Gap? Implementation of the ‘UN Convention on the Rights of Persons with Disabilities’ and Disabled Children and Young People.**

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has been welcomed with much vigour and celebration. Significant as the first bespoke human rights treaty for disabled people, we have now entered a new era where focus must shift to implementation and monitoring of States obligations; that is, from ‘rights talk’ to ‘rights action’. This paper will provide a critical assessment of the approach adopted by the CRPD towards disabled children and young people and its implications for socialising States Parties to both ‘right’ and ‘rights’ behaviour. It discusses the ways in which ‘rights talk’ for disabled children and young people, itself a relatively recent development in this context, has been predominantly needs based in its substantive content and explores whether the exacerbated disadvantage experienced by this group as a result of the particular interaction between disability and childhood is effectively addressed and given due weight by the new Convention. By way of illustration, the Concluding Observations of the CRPD to date and the UN Convention on the Rights of the Child (CRC) are drawn upon. The paper suggests that whilst the combined mainstreaming approach adopted in the CRPD has the potential to make rights ‘real’ for disabled children and young people, the double jeopardy hitherto experienced by this population group will continue unabated unless they are accorded explicit attention throughout the full range of implementation and monitoring procedures mandated by the Convention.

**Bronagh Byrne, Berni Kelly**

Queen's University Belfast

**Queen's University Belfast Disability Research Network.**

This poster presentation is about the work of the newly established Disability Research Network at Queen's University Belfast. The Disability Research Network (DRN) is a new multi-disciplinary initiative aimed at enhancing collaboration between academics, policymakers, practitioners and community and voluntary sector organisations with an interest in disability issues. It is open to University staff and postgraduate students, and members external to the University.

The DRN is hosted by the School of Sociology, Social Policy and Social Work and has members from across the University including social work, education, law, social policy and nursing. It provides a unique opportunity for members to share knowledge, disseminate findings of disability research in Northern Ireland, stimulate debate about disability issues and develop collaborative partnerships for future disability research, policy and practice.

**Poster**

**Colin Cameron**

Northumbria University

**Disability, Normality and Absurdity.**

Disabling encounters in the midst of life, occurring unexpectedly, can have an invalidating impact on a disabled person’s sense of self. We’re taken aback at what’s been said and at the assumptions being made about us. Such encounters can be annoying, upsetting, and confusing as we try to figure out where the other person is coming from and how to respond. It’s difficult, because while often (perhaps even usually) the words themselves haven’t been intended to be offensive, the layers of meaning underlying them carry a heavy weight of oppression. And yet it is during encounters like these, in the flow and flux of life, that each one of us has to choose who we are and who we want to become. In this paper I’ll attempt to make sense of what happens in disabling encounters. I’ll use ideas developed by existentialists like Sartre, Camus and de Beauvoir, by existential sociologists like Douglas, Clark and Kotarba, and by Disability Studies theorists like Reeve, Titchkosky and Michalko. I’ll use existential ideas because we are concerned with existential issues insofar as we think about what it means to be disabled; distinguish between ideas of impairment and disability; are not indifferent about what happens to us; and are not determined by our past but always have the option of acting differently. Exploring a number of accounts of disabling encounters, I’ll consider these as situations where, simultaneously, social expectations around normalcy are imposed and resisted and the absurd character of human existence is revealed. Taking issue with the interactionist Goffman, who suggested that it was for ‘the bearers of spoiled identities’ to take responsibility for people’s reactions to their difference, I’ll propose that success at living in the absurd involves adopting an affirming attitude of what Camus termed 'scorn'.

**Tom Campbell, Angharad Beckett**

University of Leeds

**Disability, Biopower, Resistance: The Social Model as Oppositional Device.**

In this paper we argue that the original social model of disability, outlined by UPIAS (1975) and key to the resistance practices of the UK Disability Movement, can be understood as an ‘oppositional device’. In defining this type of ‘device’ we draw upon the work of Michel Foucault and other theorists of biopolitics and the art theorist Brian Holmes. Positioning the model thus allows us to explore precisely how the UK Disabled People’s Movement has articulated relations of power to reframe disability as a form of oppression, rather than as individual biological deficit. We propose that as an ‘oppositional device’ the social model has a number of operations including: 1) The transformation of the individual body, via the expulsion of the personal tragedy narrative; 2) The invention of a collective body of ‘disabled people’, affirmed against the individualising forces of bio-power and capital, and allowing for the proliferation of practices of resistance; 3) The introduction of a new system of signs, allowing the activist agenda to be broadened as new sites for resistance become visible and these signs become diffused across the machinery of government. We also propose that as a device, the social model, or variants of it, have at times been employed in a disciplinary manner, as it has been adopted by a machinery of government. Our primary goal is to develop a new way into the social model debates and to attempt a reconciliation of conflicting analyses of its character and function/s. In providing a more general definition of an oppositional device as the concrete operation of technologies of power, however, we also propose a concept that may prove useful for the analysis of the resistance practices of actors involved in a wide variety of struggles. This concept may therefore have implications for wider social and political analysis.

**Bahadir Celiktemur**

University of Warwick

**Learning Disability Partnership Boards: The Unfulfilled Potential of a Deliberative Forum.**

Deliberative democracy’s demands for reasoning and preference for the force of the better argument are almost impossible to meet for those who lack the required communicative competencies. As a result citizens with communicative disabilities are rendered disqualified from meaningful participation in deliberative sites. The exclusion of up to 15% of citizens from deliberative sites poses one of the biggest challenges to the democratic credentials of deliberative democracy. This paper explores whether the UK Learning Disability Partnership Boards as deliberative forums can invigorate the political participation of the marginalised. Based on ethnographic research in two LDPB settings over a period of six months, it is argued that otherwise excluded citizens gain a civic and political consciousness through participation in these meetings. However the LDPBs’ incorporation of the voices and preferences of the disabled into political decision making mechanisms is strictly limited to disability issues and does not lead to their agency in the wider democratic arena, leading to a participation paradox.

**Bahadir Celiktemur**

University of Warwick

**Unruly Bodies: Agonising the Deliberative Site.**

Deliberative democracy is increasingly seen as the solution, the saviour where liberal democracy is in crisis around the world. However its demands for reasoning and preference for the force of the better argument are almost impossible to meet for those who lack the required communicative “competencies”. As a result citizens with communicative disabilities are rendered disqualified from meaningful participation in deliberative sites. While people with disabilities do not “exist” in deliberative democratic theory, much of the challenge to deliberative democracy has focused on the significance of passion against reason. This paper seeks to emphasize the significance of the body in deliberative sites. It suggests that the hegemony of reason de-politicises not only through leaving aside passion, but also through its neglect of the embodied experiences of subjects. This becomes most obvious in the exclusion of citizens with communication disabilities from deliberative sites. If deliberative sites are kept rational and civil by means of keeping those with disabilities outside, then the politicisation of these sites will occur through the appearance of the unruly bodies in their midst. The presence of people with disabilities is a bodily, agonistic confrontation and disruption that re-politicizes and spatializes the deliberative site that is de-politicised and de-spatialized by reason. Such an inquiry about the inclusion of people with disabilities in deliberative sites both addresses a particular democratic deficiency of deliberative democracy, and enhances deliberative theory with insights from both agonistic politics and critical disability studies.
(The paper employs insights gained through the author’s ethnographic research of two UK Learning Disability Partnership Boards over a period of six months)

**Lindey Cookson**

Northumbria University

**‘He Only Knew Before the Ceiling Above Him’: Disabled Children’s Institutional Care in Bulgaria.**

Central and Eastern European countries are reported to have high numbers of children in institutional care, with Bulgaria standing out as having the highest rates of admissions to large institutions for children with impairments in Europe (UNICEF 2012). This is despite numerous studies asserting that institutional care should be avoided for children, being particularly harmful for babies, children under 3 and children with impairments. It is widely accepted that even where institutions have good material conditions and qualified staff, the outcomes for children can be negative. Placement of children in institutions ‘raises serious concerns as to its compatibility with the exercise of human rights’ (Council of Europe, 2010).

The paper is based on the initial findings from a PhD study using Goffman’s construction of the ‘total institution’ to explore the harmful impact of collective life for children with impairments. It examines the extent to which local surrogate grannies (babas) can serve as a protective factor for the children by introducing more humane, responsive care, and challenging an overly medical model of disability. Initial findings suggest that the babas encourage attachments for the children, providing a ‘safe base’ from which the children develop further. The babas introduce care specific to the child’s needs, encourage the child’s individual identity and uphold the children’s rights as citizens of a wider community. One baba said:

“When I first took ‘Child T’ outside of the sector, he was touching the wall like that, and he was knocking on it to see what is this. He only knew before the ceiling above him.” (Baba V)

The study arose from the researcher’s experiences as a volunteer within orphanages in Bulgaria. The data from qualitative interviews with babas, orphanage staff and third sector workers will be explored here with reference to theories of disability, child development and rights.

**Lindsay Coyle**

Durham University

**Exploring the Diagnosis, Treatment and Care Experiences of People Living with Multiple Disabilities/ Illnesses/ Conditions.**

Within disability studies and the social sciences more broadly, recent work has focused on the daily life experiences of people living with long- term conditions, chronic illnesses and disabilities. For example, within the geographies of disability literature, Davidson and Henderson (2010) and Smith (2012) take a ‘life- world’ approach to understanding experiences of autism and epilepsy, respectively. Following this work, I seek to contribute to this existing literature by examining the layered and often tense negotiations people experience when living with multiple disabilities/ illnesses/ conditions.

In 2012 The Department of Health (England) reported that the number of people living with multiple long- term conditions is predicted to rise from 1.9 million in 2008 to 2.9 million in 2018. Consequently, it is important for disability studies to consider the implications of living with a wider range of bodily differences (for example, including the under- researched topic of chronic illness (Scambler, 2012)) alongside attending to people’s negotiation of multiple disabilities/ illnesses/ conditions.

To make this argument, I will use data generated from conducting 20 interviews (mainly) with people attending a mental health resource centre in Durham, U.K. It was found that participants’ experiences of diagnosis, treatment and care were shaped by the tensions and ambiguities associated with negotiating multiple disabilities/ illnesses/ conditions. For example, some interview participants noted that when accessing medical services, doctors tended to privilege the condition deemed more immediately serious, whilst neglecting other conditions. Hence, a focus on the implications of living with multiple diagnoses reveals a complex web in which the perceived differences between particular disabilities/ illnesses/ conditions are constantly (re) hierarchised. **Sue Cranmer**

Lancaster University

**What is an Assistive Technology? Convergence Across Mainstream and ‘Assistive’ Technologies.**

In recent years the gap between what is considered to be an ‘assistive’ technology and what is considered to be a mainstream technology has shifted. Tablets such as iPads have inbuilt accessibility functions whilst technologies such as speech input have been mainstreamed onto tablets and smartphones.

Keeping this in mind, this paper will report on a small-scale pilot study exploring how young people who are blind or visually impaired use digital technologies – such as the computer and Internet – alongside discrete ‘assistive’ technologies to support learning at school, home and in other environments. In particular, it will consider the relationship between mainstream and discrete ‘assistive’ technologies; how uses of mainstream technologies may be mediated through uses of ‘assistive’ technologies and the digital competences and skills needed by young people to negotiate this potentially complex relationship.

There is relatively little research which specifically examines how young people with visual impairments experience and develop their uses of digital technologies (Passey, 2013; Söderström, 2009). The paper will present detailed case studies of a number of school-age young people to explore this relationship in depth based on interview and observation data.

This project is currently work in progress. A literature review is underway alongside data collection, analysis and writing up. Data collection will be completed by June 2014 and emerging findings will be presented at the conference in response to the themes detailed above. **Helen Davies**

Lancaster University

**‘Nature Cannot be Surpassed by Art’: The Power of Prosthetics in the Body of the Soldier.**

Robert Albott’s Wits theatre of the little World (1599) argues that ‘the naturall deformity of the body, can neither be altered with sumptuous attire, colours, nor odours, but make it eyther more euident to be seene, or more doubtfull to be suspected’ (1599; 94). Albott’s identification of how an addition to the body accentuates ‘naturall deformity’ informs this paper’s investigation into the incorporation of prosthetics and early modern disabled bodies. Taking up visual disability scholar Rosemarie Garland Thomson’s work on ‘staring’ (2009; 1), I argue that the application of prosthetics to physical difference acts as a catalyst which creates an ‘intense visual exchange’ (2009; 9) between the normative and non-normative body, thus enabling a conversation on somatic difference in early modern England. With an overarching concentration on the body of the soldier, this paper turns to Rafe - an impaired soldier returning from war in Thomas Dekker’s The Shoemaker’s Holiday (1600) - to consider the response to an ocular representation of prosthetics on stage. Informed by Dekker’s later Work for Armorours (1609) and Ambroise Paré’s The Workes of that famous chirurgion Ambrose Parey (1634), I explore how prosthetic intervention can medically re-enable the soldier’s body, but taken out of the space of the battlefield the heightened visibility of deformity through prosthetics can be socially disabling. With this in mind, I conclude with an investigation into the implications of prosthetics in representations of the renowned soldier and monarch, Henry VIII. Henry’s mechanically modified body brings together issues of ‘staring’ and the medical and social implications of prosthetics that, whilst they may be biologically enabling, can transform into socially disabling fragments.

**1Hannah Donaldson, 2Karen Wood, 1Mathilde Pavis**

1Exeter University

2Coventry University

**InVisible Difference: Dance, Disability and the Law.**

InVisible Difference is an AHRC-funded 3 year research project examining the intersections between dance, disability and the law. We are a multi-disciplinary team and aim to extend current thinking surrounding the issues regarding ownership, making, value and status of work created by and for disabled dancers. InVisible Difference seeks to examine how work is made by and preserved by disabled choreographers and how the existing legal frameworks can support this process. While it is apparent that legal frameworks do exist to offer some support, for example the United Nations Convention on the Rights of Persons with Disabilities, our empirical observations have demonstrated thus far that choreographers and dancers are little aware of the legal protections in place. Not only this, but it is also apparent through our observations that while the legal protections exist on paper, they do not fully interact with the concept of the choreographer or, indeed, how disability can affect the choreographic process and final ownership.

Our poster will give a brief overview of our research questions and also discuss the preliminary findings from the empirical fieldwork that we have conducted with two disabled choreographers (one working alone, one working with a larger production team) over a period of time. We hope to raise the profile of how we value disabled dance and how this value can not only take its place within our cultural heritage, but also inform the current legal frameworks.

**Poster**

**Rosalee Dorfman**

Michelmores LLP, Scammell and Densham's Law of Agricultural Holdings

**‘Who Wants to Hire the Nutter?’ A Socio-Legal Investigation into Restricting Pre-Employment Health Checks on People with Mental Health Conditions (Equality Act 2010, Section 60)**

‘Who wants to hire the nutter?’ was a question posed by a focus group participant to illustrate the consistent discrimination against him and others with mental health conditions. This paper reveals the social barriers to recruitment through the lens of the Equality Act (EA) 2010 Section 60, the legal restriction of pre-employment health questions. The intention of the legislation was to remove the exclusionary barrier these questions created. It has failed, according to the participants in this emancipatory qualitative research – 10 people with mental health conditions, two barristers and a former policy advisor for the Equality and Human Rights Commission.

Adopting a perspective based on the Social Models of Disability and Distress and madness studies, this investigation distinguishes the alleged from the actual operation of Section 60. In addition, it utilises Michel Foucault’s theories of power and resistance to examine the liberal legal context behind Section 60 and its reproduction of the status quo. As Section 60 espouses a policy of passing as ‘normal’ to prevent discrimination and stigma, the Time to Change campaign encourages confession, ‘coming out as mad’. Although contrasting, both policies focus on the individual’s choice to disclose their condition. Yet little choice exists, in the experiences of the people with mental health conditions interviewed. The indirect and seemingly invisible barriers of accounting for previous employment gaps and absence rates and the prejudice of employers are more pervasive than direct health questions. Despite the negligible effect Section 60 has had on mental health discrimination, the emancipatory research offers concrete guidance to improve help for small employers, increase resistance and strengthen enforcement of anti-discrimination law.

**Sandra Dowling, Berni Kelly, Karen Winter**

Queen's University Belfast

**Abuse, Risk, and Safeguarding Disabled Looked After Children.**

The NSPCC reports that a fifth of all children will experience serious abuse or neglect in their lifetime. (NSPCC, 2013). Amongst disabled children this risk is reported to increase by 3-4 times (Jones et al. 2012; Sullivan & Knutson 2000). Children with communication impairments, behavioural disorders, learning disabilities and sensory impairments are reported to be more vulnerable to abuse than children who experience other forms of impairment (Stalker & McArthur 2010) Disabled children and young people are also reported to be over-represented in the overall numbers of looked after children both within the UK and internationally (Trout et al., 2009; Lightfoot et al., 2011).

Drawing on one strand of data gathered from research which aimed to profile the population of disabled looked after children in Northern Ireland, this presentation will explore the reasons for disabled children becoming looked after, their looked after status and whether child protection proceedings were implemented prior to the child becoming looked after. The presentation will also report on professional concerns about ‘risky behaviour’ and whether there is evidence of child protection proceedings whilst the children and young people were looked after.

The presentation will highlight the context of looked after disabled children’s lives including any evidence of multi-disciplinary working, placement stability and permanency planning as well as contact with birth families and therapeutic support. Data will be interrogated in relation to demographic characteristics (e.g. age, gender and impairment type) in order to highlight any contrasts or trends.

Given that disabled children are reported to be at heightened risk of abuse; that looked after children may be more likely to have experienced abuse and the vulnerability of exposure to ‘risky behaviour’ as a looked after child, this presentation will draw out key points for consideration in respect of the prevailing literature and policy context.

**Anna Dunér, Elisabeth Olin**

University of Gothenburg

**Hybrids Between Traditional Family Care and Modern Welfare Policies - A Study of Personal Assistance Provided by Family Members to Persons with Disabilities.**

Background: The right to personal assistance is intended to enable people with severe disabilities to increased influence and self-determination in their daily lives. The number of personal assistants in Sweden is estimated at 70,000, of which 20-25% consists of family members of persons with disabilities. Family members working as personal assistants are a controversial phenomenon that has traits of both traditional family care and modern disability policy. Concerns are raised about the complexity of combining informal relationships within the family with formal employment, social and economic interdependence, and how different interests are met. The study highlights the intersection between formal and informal care, the complexity of family care, and the opportunity for people with disabilities and their families to “manage” their everyday lives and to influence their living situations.

Aim: to study various aspects of the living situations, interdependence and strategies of users and providers of assistance, with different family ties.
Methods: Thematic qualitative interviews have been conducted with users and providers of assistance in four types of family ties: Parents who work as assistants to adult children; Siblings who work as assistants to an adult sibling; Spouses where one works as assistant to the other; Adult children working as assistants to a parent.

Results: In this presentation, the experiences and strategies of parents working as personal assistants to their adult children will be focused on. How is independence, dependence and interdependence negotiated? What dilemmas do they face? What strategies do they develop to deal with potential role conflicts and ambivalence?

**Tolga Duygun**

University of Kent

**Promoting Universalist Disability Policy? The Role of International Organisations and the Supranational Organisation in the Direction of Disability Policy in Turkey.**

The purpose of this study is to examine whether roles played by the international organisations and the EU are in fact reinforcing the particularist emphasis of disability policy in Turkey. The particularist orientation is characterised by a strong adherence to traditional values and the family, which constitutes one of the barriers to mainstreaming disability issues into the relevant policy areas. The initial findings of the study, which are based on a mixture of interviews with key actors (both within Turkey and internationally) and documentary analysis, suggest that the particularist approach may well have its basis in traditional value systems which militate against mainstreaming. Within traditional, close-knit Turkish family life, the needs of a disabled family member were provided for, since the disabled person was seen as one who needed to be protected and taken care of. Continuous efforts of the respective Turkish governments to adopt western culture and policies have created an interaction between traditional values and European policies. The ultimate goal might be seen as the replacement of policies based on traditional values with those based on western values and human rights. It is certain that disability policy could not develop in Turkey under its own dynamic without having the influence of the international organisations and the EU. However, the relevant government organisations in Turkey have not been able to undergo a complete process of transition from a disability policy which is centred on traditional values to contemporary European policy models. Is this because the international organisations and the EU have not exerted sufficient influence to ensure the implementation of human rights based disability policy in Turkey? Is this because the international organisations and the EU given insufficient priority to the promotion of mainstreaming disability issues into all policy areas? The end result might well be a strengthening of the current particularist disability policy in Turkey.

**Snæfrídur Thóra Egilson**

University of Iceland

**School Experiences of Pupils with Physical Impairments Over Time.**

Objectives: The aim of this study was to examine the views and experiences of youths with physical impairments in relation to their school environment and participation.
The youth’s reflections on their present and past, their current attitudes and use of strategies were in focus in order to identify changes and social processes over time.

Methods: This was a qualitative, multiple-case study based on interviews and observations in secondary school. In order to explore how things had developed for the youths, we also discussed their primary school experiences in retrospect, focusing on information gathered during earlier interviews and school visits. Seven youth with physical impairments participated. A grounded theory constructionistic approach was used for data analysis.

Results: Overall participants considered their secondary school better accommodated their needs than primary school but several contradictory examples revealed that although some things had improved since in primary school other had not. At both school levels the environmental factors contributing to participation included accessibility, flexibility, respect and support from school staff, and good communication between the school and the family. Personal factors, especially the youth´s self-determination also played a role. The pupils didn’t consider completing an activity independently or the frequency of engagement in activities as a primary determinant of meaningful school participation. Rather, the main factor was whether or not they had the opportunity to engage in selected educational and social activities alongside their peers, and whether or not they had been consulted about the implementation.

Conclusion: One of the most interesting finding of this longitudinal study is the stability versus change in the views of the youth, especially how they as adolescents interpreted school experiences compared to when they were younger. The findings highlight the importance of exploring changes associated with impairment that occur as a result of age and participation in different environments.

**Snæfrídur Thóra Egilson, Linda Björk Ólafsdóttir**

University of Iceland

University of Akureyri

**Quality of Life of Children and Youth with Autism.**

The purpose of this study was to explore how Icelandic children and youth with high- functioning autism aged 8-17 assess their quality of life, compared to how their parents assess their children’s quality of life. The study is a part of a larger ongoing research project focusing on quality of life, participation and environment of disabled and non-disabled children and youth in Iceland.

The Icelandic version of the KIDSCREEN-27 was used to gather the children’s and their parents’ perspectives on five dimensions (physical well-being, psychological well-being, autonomy and parent relation, peers and social support, school environment). Valid responses were obtained from 109 children and youth, and 130 parents. Seven children and youth participated in qualitative interviews which were used to further analyse some of the issues raised within the study, to explore the children’s reasoning and interpretation of items, and to expand on the questions and dimensions of the instrument.

The children and youth rated their quality of life in the average range on three dimensions: psychological well-being, autonomy and parents, and school environment. Lower scores were obtained on physical well-being and social support and peers. The parents rated the quality of life of their children significantly lower than did the children and youth themselves on all dimensions but autonomy and parent relations. The qualitative interviews added valuable information about the children´s responses and reasonings.

The results indicate that, overall children and youth with autism view their quality of life more positively than do their parents. Parents’ ratings may be influenced by their concerns and worries for their child or by their own experienced burdens. The findings of this study highlight the importance of eliciting disabled children‘s opinions about their everyday lives and experiences.

**Liz Ellis**

Open University

**Inclusion/Exclusion of People with Learning Difficulties in a Rural Area.**

This paper presents some of the emerging outcomes from an inclusive research project using mobile methods in a rural area of the UK. The aims of the research were generally to explore the experiences of the co-researchers, all of whom identify as having learning difficulties, and more specifically to:
• Observe if rural environments presented specific barriers to inclusion.
• See how people with learning difficulties negotiated and overcame these barriers, and finally…
• What practices within this rural context support or hinder the inclusion of people with learning difficulties.

The presentation will thus explore ideas of community, particularly in relation to the myth of the rural idyll, and how the co-researchers’ communities supported their feelings of inclusion and belonging. The ways the co-researchers constructed and maintained friendships will be discussed, especially how factors such as kinship, population density and schooling either facilitated or created barriers to friendships.

Finally there will be an attempt to expose the ways in which idealised notions of rurality and rural communities are sometimes conflated with the current post-liberal political rhetoric. I will aim to illustrate the impact on disabled people of the promotion of ‘Big Society’ ideals of individuals creating ‘connected communities’ in order to minimise the role of the state.

**Susan Eriksson**

Mikkeli University of Applied Sciences, Finland

**Deviance, Normalcy and Tales: Performances of Sexuality of Disabled People in Autobiographical Data.**

Presentation is based on autobiographical data of disabled people collected in Finland in early 2000´s. The data consists of stories written about different aspects of ordinary lives, and the analysis is focused on how sexuality is presented and performed in those autobiographical texts. Medical, institutional and other social dimensions of control are present in many areas of life in those life stories and they also reflect the morally controlled character of sexuality. With the method of intersectional analysis it is asked, how the dimensions of deviance and normalcy categorized by disability and gender organise the discourses that construct the definitions of sexuality of intellectually disabled people.

**Ieva Eskyte**

University of Leeds

**Translating Accessibility ‘Needs’: Perspectives of the Private Market and Disabled People Organisations.**

The United Nations Convention on the Rights of Persons with Disabilities (2006) recognizes access to information communication technologies (ICT) and access to consumer goods and services in the private sector as essential for full participation in society. This paper examines understandings of accessibility ‘needs’ in businesses and DPOs, placing these internalised notions in the social and policy contexts of the European single market and Human Rights.

The paper draws on qualitative data from a larger study, addressing 1) disabled customers’ experiences in the shopping process in Lithuania and the UK, and 2) various dimensions of communicative action between business and DPOs. However, the focus is on differences and similarities in predominantly internalised meanings of accessibility ‘needs’ within the industry and DPOs. Functioning within different legal frameworks, stakeholders hold different understandings of accessibility and disabled ICT users. While business treats ‘needs’ as one of the guidelines leading towards technical accessibility solutions, DPOs interpret ‘needs’ through human rights. In addition to this differing conceptualisation, disabled people are seen as ‘needing’ and non-disabled people as ‘wanting’ technologies and access to them. As a result, such practices and positions unintendedly construct a division between users with and without impairments. Consequently, this paper also critically reflects on the potential of the EU private market and accessibility oriented instruments to deconstruct this division among users with impairments.

The paper concludes that market- and accessibility- oriented EU legislation and international Human Rights instruments all play a part in constructing stakeholders’ understanding regarding people with impairments as ICT users and customers. The recommendations address several elements of Habermas’s theory of communicative action as a means for achieving more equality and accessibility within EU ICT markets.

**Delia Ferri, Jenni Kline**

NUI Galway, Centre for Disability Law and Policy

**Fostering the Production of Assistive Technologies in Europe: A Multidisciplinary Analysis.**

Assistive technologies encompass all the practical tools that support functional needs of people who experience difficulties linked to disability or ageing, from walking frames, wheelchairs, and hearing aids, to computer-based communication aids and voice activated mechanisms. Assistive technologies have attracted growing attention within the field of disabilities studies, in particular in relation to their effects and drawbacks.

Unlike other areas of disability law, the legislation that affects and impacts assistive technologies often occur at the supranational level in the EU outside the fields of health, education and equality. The laws that shape the cost, availability and development of assistive technologies occur in the area of market regulation, which is an EU competency.

This paper explores how EU policy and law contributes to the development and marketing of assistive technologies, and contrasts it with the experience of people with disabilities as recipients of it as obtained through a series of semi-structured interviews.

The paper adopts an innovative methodology merging a rigorous desk based legal analysis together with qualitative data emerging from life-course interviews to people with disabilities, in order to reach a better understanding on how the EU can better meet the need of people with disabilities through its laws and policies and helps disability rights people understand the broader scope of laws that impact people with disabilities.
The paper is the one of the output of the interdisciplinary EU funded project “DISCIT” (www.discit.eu).

**Karen Fisher, Xiaoyuan Shang**

Social Policy Research Centre, UNSW

**Employment Pathways of Disabled Young Adult Orphans leaving Institutions or Foster Care in China.**

In China, about 100,000 children are in state guardianship. Most of them were abandoned and most of them have disabilities. Before China’s economic transition starting in the 1980s, most adult orphans were provided with jobs by the government, or worked in welfare enterprises that had taxation concessions. After economic transition, many welfare factories reduced the number of employees or closed, and job placement ceased. Many adult orphans either cannot find jobs or do not have the skills to keep them, with the effect that they continue live with support provided by welfare institutions. Job placement for adult orphans is a challenge for child welfare institutions and a bottleneck for orphans. If the problem cannot be addressed, adult orphans must rely on government support throughout their life, without opportunities for social inclusion. This paper presents empirical data about recent changes to job placement experiences for the adult orphans in the guardianship of Datong Institution of Social Welfare. It analyses the impact of foster care, social networks and formal and informal employment support and concludes that adult orphans who have had the opportunity to live in a community setting, supplemented with the resource support of the institution, were more likely to have the skills and connections to find and sustain employment.

**Susan Flynn**

Equality Studies Centre, U.C.D.

**Promised Lands: Biotechnology and Cure in Contemporary Film.**

Biotechnology and disability feature increasingly in contemporary Hollywood film narratives (e.g. Elysium, 2013; Iron Man 3, 2013; Source Code, 2011; Repo Men, 2010; Avatar, 2009; Surrogates, 2009). The appropriation of the disabled body as a site of potential 'repair' is troubling in an age where the disability movement is working toward creating a society in which all forms of bodies are treated equally. This paper hypothesises that in the contemporary Hollywood blockbuster, biotechnology is employed in the service of ableism and normalcy.
This paper examines two contemporary film texts, Avatar (2009) and Elysium (2013). Both films are critical texts in terms of global reach and as exemplars of the genre that combines biotechnology and disability.

This paper suggests that both films relentlessly articulate a politics of the body; one in which the disabled body must be ‘fixed’ with the help of biotechnology. It proposes that the contemporary Hollywood blockbuster is intimately invested in the project of ableism; an ideology that sustains the ‘hegemony of normalcy’ (Davis, 1997). As the Hollywood blockbuster engages a vast audience, at once entertaining and presenting a faux-realism that is so convincing, its treatment of disability contributes to the social construction of disability. Through blockbusters, Hollywood acts as “a global transmitter of cultural pedagogy and purveyor of images and messages, which may or may not be in the interests of diverse marginalized and exploited groups across the world” (Frymer et al, 2010, p.1). Films such as Elysium and Avatar literally subjugate the disabled body with technology, in the project of creating a new, more vibrant world. By celebrating technological advances and reifying science, both in the diegetic world of the film and the film experience for audiences, these films draw the audience into complicity with the project of ‘fixing’ disability. Biotechnology’s conspicuous largesse proposes a simplistic and unrealistic ‘solution’; one that negates the agenda of the disability rights movement and propagates Medical Model ideologies.

**Fernando Fontes, Ana Cristina Santos**

Centre for Social Studies - University of Coimbra

**Disablist Hate Crime and violence against Disabled women in Portugal.**

When compared to the general population, disabled people present a higher risk and incidence of violence (UN, 2006; EU, 2011). National reports have highlighted the higher vulnerability of disabled women and people with learning difficulties either living in institutions or with their families (OPM, 2009; INR, 2010). Despite the great investment by Portuguese public authorities in programs designed to prevent violence there are no intersectional studies of violence in Portugal, emphasizing discrimination factors and highlighting the situation of disabled people in Portuguese society. Therefore the lives of disabled people are still marked by exclusion, poverty and prejudice. In a context that is particularly disabling, masculinized and male-oriented, such as Portugal, disabled women are in a particularly vulnerable position, accumulating the inequalities based on disablism and sexism.

Based on the Social Model of Disability and drawing on the research project ‘Disabled Intimacies: sexual and reproductive citizenship of disabled women in Portugal’ (funded by the Portuguese Foundation for Science and Technology - reference PIHM/GC/0005/2008) and on my post-doctoral research on disablist hate crime in Portugal (funded by FCT – Reference SFRH/BPD/80059/2011) developed at the Centre for Social Studies, University of Coimbra, this paper considers the issue of sexual violence targeting disabled women in Portugal. In this paper we begin by introducing the Portuguese context in relation to citizenship rights and outlining the phenomenon of sexual violence targeting disabled women in Portugal. The data was gathered from public reports, media coverage and original empirical data collected in biographical interviews and evidences that family and close neighborhood members constitute most of the perpetrators. We continue examining the legal dispositions already in place in Portugal in order to protect disabled women. And we conclude, assessing the effectiveness of the existing laws and exploring the potentialities of the legal recognition of disability hate crime in Portugal. **Josephine Foubert, Ronan Van Rossem, Katia Levecque**

Ghent University

**Same Consequences for Everyone? The Socially and Relationally Structured Influence of Chronic Illnesses on Well-Being.**

Introduction. Despite the evidence of the reduced well-being of people with a chronic illness or impairment compared to people without one, a big challenge remains how to explain this inequality. To get more insight, we approach disability as a process of social exclusion, resulting in a reduced well-being for people with impairments and chronic illnesses. It acknowledges that chronic illnesses affect well-being, but that disability only stems from socially reinforced restrictions. This paper examines if the influence from a chronic illness on the well-being is dependent on socioeconomic position and familial status.

Methods. The European Quality of Life Survey (2012) is used to examine our research questions with multilevel regression techniques. It allows us to identify people with longstanding physical or mental health problems or impairments. Well-being is measured by the WHO Five Well-Being Index. Several indicators of socioeconomic and familial status are included.
Results. People with a longstanding illness or impairment have a reduced well-being compared to people without one. The negative effect of having a chronic illness or impairment is different for distinct socioeconomic groups. A higher education, income and working seem to alleviate the negative effect. Same applies to being married and living in a non-deprived dwelling.

Conclusion. The detrimental effects of a chronic illness for the well-being are not equally distributed across society. This is in line with structural theories of health inequalities saying that groups in lower positions in social hierarchies have a poorer well-being, as they lack fundamental resources to cope with their condition.

**Frederic Fovet**

McGill University

**Access and Mental Health: Navigating the Conceptual Dichotomy in Higher Education Service Provision.**

The disability discourse in North America is increasingly embracing issues relating to Mental Heath in both its theoretical analysis and rights agenda. The rising prevalence of the social model has eased some of the conceptual tension which traditionally existed between both discourses in European literature. If indeed disability is to be seen not as an inherent characteristic of the individual, but rather as a construct which is interpreted as a the result of a lack of ‘fit’ between individual characteristics and expectations of the environment, then it becomes far easier to observe a degree of synchronicity between both discourses.

Disability service provision, on most North American campuses, has embraced this conceptual correlation and offers services to students under an umbrella that addresses ‘traditional’ disability as well as mental health issues. The number of service requests arising from Mental Health diagnoses is hence rising fast, and Higher Ed students facing such difficulties have come to represent approximately 25% of the overall volume of users on most campuses. Models of service delivery such as Universal Design for Learning, embodying the social model, are increasingly being adopted as a result and make little distinction between these lenses, focusing instead on triggering changes in pedagogical practices.

The hypothesis of this paper is that, despite these large systemic trends of change in disability service provision in Higher Education, professional practice has not been able to move away from the essential dichotomy that exists between the Disability and the Mental Health discourses. It will be argued that a qualitative analysis of the data surrounding current disability service provision on North American campuses reveals that, while students with Mental Health issues are being registered by these units, very little on terrain is being offered to them in terms of access tools. The discourse of service providers instead remains focused on external referrals and the notion of ‘cure’. Very little of the Access discourse in Higher Education is currently applicable to students facing Mental Health issues despite the change in orientation.

**Chris Fox**

University of Strathclyde

**Disability Abuse, Hate Crime and Social Work in Scotland.**

Instances of hate crime, abuse, and harm towards disabled people in recent years have been shown to be not only alarmingly high, but also on the increase. Under Scots and UK law, these now include criminal offences motivated by the victims’ real or perceived disability, and include verbal, sexual, financial and physical attacks against both individuals and groups. Research conducted by the EHRC estimates that approximately 1.9 million disabled people in Britain were the victims of hate crime in a recent single calendar year, yet people with disabilities are also much less likely to report crime and abuse than those without.

Social workers and other professionals addressing this issue have tended to follow a more protectionist and preventative model in handling cases of abuse and hate crime, more reflective of a tragedy or medical model of disability. This in turn has given rise to a sense of victim-blaming, rather than challenging abusers, identifying structures that create vulnerabilities and risk, or helping service users make their own decisions. There is also evidence to suggest that many social service agencies are more likely to deal with disability abuse related instances in-house, rather than working together with other agencies to design strategy and pursue outcomes.

As current research into policy and practice in this area is limited, my research hopes to raise the profile of ableist related attacks in social work. This is a three year project, consisting of a review of existing literature from disability and social work perspectives, followed by a qualitative study involving social workers and disabled people, consisting of a series of interviews and small focus groups with disabled people and social work professionals in several local authorities in Scotland about their experiences with disability related-abuse, how services are lacking, and where possible, how service provision can be improved.

**Poster**

**Peter Fuzesi**

Lancaster University

**Designing Dis/Abilities.**

I propose to approach specialist 'assistive' technologies (ATs) that aim to compensate disabled people, as a site to think about normal and disabled bodies and exclusion.

To explore how dis/abilities and user groups are defined, I focus on two central notions of AT development: compensation and population. While the notion of compensation highlights how technologies, norms, populations and individual bodies are entangled, the concept of user group calls attention to how ableist exclusion is intertwined with the design process and production of mainstream and specialist technologies.
First, I explore how different notions of the normal, self-sufficient body are shaped within the design of AT devices.The question of adequate compensation evokes the wider issue of what is an adequate body. AT and prosthetic devices can be seen as sites where historically and culturally given disabled and normal bodies are enacted. Technological devices thus offer a site to recover what is recognised as normal, and to elicit differences between distinct and sometimes contradictory normate bodies.

Secondly, as it has been argued, products and user identities are co-produced in the technology design process. While mainstream technologies are based on the assumption that there is a larger population of potential users who find the new technology useful, these technologies often simultaneously exclude disabled people, and necessitate the use of specialist ATs. While in mainstream technologies the user is implicitly understood as part of the normal population, the question of normal and disabled populations is just as indispensable in the development of ATs: Although these groups are much smaller and heterogeneous, assistive devices are also developed to meet the needs of differently defined groups of users. While these user group requirements, that are necessary in the development and evaluation of AT's to enable some; can also further exclude others within a highly heterogeneous user group of disabled people.

**Sarah Galvani, Wulf Livingston and Hannah Morgan**

University of Bedfordshire

Glyndŵr University

Lancaster University

**Cause or Consequence: Alcohol and Substance Use Among People with Sight Loss.**

The nature and extent of alcohol and other drug use by people with sight loss is not known. Anecdotal reports from front-line practitioners and social care strategic leads suggest that alcohol in particular, is a growing issue for people with sight loss. Recent research exploring the experiences of social work and social care professionals has confirmed this (Dance and Galvani, forthcoming; Galvani et al. 2011). This exploratory study, funded by the Thomas Pocklington Trust and Alcohol Research UK, was designed to collate and interpret data about the extent and nature of alcohol and other drug use (hereafter ‘substance use’) among people with sight loss.

The projects aims were to i) review existing literature and datasets to determine relevant findings about the extent of substance use among people with sight loss, ii) explore what medical evidence there is of an association between substance use and sight loss and ii) explore the meaning and function of substance use in the lives of people with sight loss. Finally, through this existing data and some newly acquired primary data, we explored how professionals in a) substance use and b) sight loss services were working with these overlapping issues and what challenges they faced. The paper will present a brief outline of the findings of the dataset analysis and literature reviews before focusing on the key findings from the qualitative interviews and their implication for people with sight loss who also use substances.

**Giulia Garofalo Geymonat**

University of Lund, Department of Gender Studies

**When Stigmas Meet. The Making of Sexual Assistance in Europe.**

Even though practices of sexual assistance for people with disabilities, under different names, have been visible in Europe at least since the 90s, only recently have they become the object of political and media attention, film production, as well as academic research. In this process, conflicts around rights, autonomy, exploitation, commercialization have become as violent as they have for sex work and trafficking – indeed, in most contexts sexual assistance is treated by the law as a form of prostitution, for it involves direct sexual contact and remuneration. As a consequence, the debate remains too often polarized, ideological and normative, with little interest for actual experiences.

At the same time, this new public attention arguably represents an opportunity for disabled activists to speak about sexuality and sexual access, and innovative alliances are built among movements working on dis/ability, gender, sexuality, and sex work. Moreover, the practice of sexual assistance is organized on grassroots level and sees not only activists, potential users and sexual assistants involved, but also doctors, families, residential institutions, nurses, all cooperating to create good experiences and shared acceptable meanings for all parts involved.
The result is the production of a uniquely rich space of negotiation of meanings around sexuality, embodiment, rights, citizenship, normalcy and diversity, which calls for an analysis of how different stigmatization processes – in relation to dis/ability, sexuality, gender and sex work – might interact, be reorganized worsen or challenge each other through this particular form of sexual encounter.

This paper is based on ethnographic work with two organizations created in 2012 by sexual assistants, people with disabilities, and professionals of psycho/sexual education and therapy. The first group fights for the recognition of sexual assistance in a country where prostitution is not legal, while the second association, which operates in a country where prostitution is legal, organizes contacts, supervisions and training courses for sexual assistants.

**Chalotte Glintborg**

Aalborg University

**Having a Brain Injury = Being Mad? Identity (Re)Construction of Adults Following an Acquired Brain Injury.**

The transition from being well and fully functioning to suddenly disabled by an Acquired Brain Injury (ABI) and having to start a rehabilitation and recovery process from disabled to participating again has a huge impact on a person’s life and, presumably, identity. However, research is still sparse on the psycho-social consequences following ABI (Teasdale, 2005, Morton et al, 1995), and there’s a lack of first person perspectives, i.e., how patients themselves perceive their situation, identity, and recovery processes following ABI (Danish Board of Health, 2011).

The present study tries to fill this gap by investigating first person perspectives on identity (re)construction after ABI and possible changes throughout the recovery process. The data is part of a larger mixed-method longitudinal study and focuses on narrative identity constructions.

Methods: Thirty-seven Danish adults aged 18-66 years with ABI were interviewed (semi structured interviews) two years post injury and asked to report how they experienced the recovery process since ABI. In addition, field notes were taken during home visits. Discourse analysis drawing on the concepts of voice and positioning (Harré & van Langenhove, 1999) was applied to investigate participants’ (re)construction of identity through self-narratives. Particular focus was given on changes and developmental processes in these self-narratives.

Results: The narrative reconstructions point to developmental change of identity in the course of the different phases of the recovery process as well as conflicting voices from society, service providers and adults with ABI. Results will be discussed in light of current identity research.

**Dan Goodley1, Katherine Runswick-Cole2**

1The University of Sheffield

2Manchester Metropolitan University

**Becoming Dis/Human: Thinking About the Human through Disability in a Time of Austerity.**

In this paper, we seek to contribute to the theoretical debates in disability studies. We are beginning to develop an understanding of the human driven by a commitment to the politics of disability, especially those of people with intellectual disabilities in a time of austerity. Our position as family members, friends and allies to people associated with this phenomenon of intellectual disability directly influences our ‘philosophical conceptions of cognitive disability’ (Kittay, 2009: 606). This has led us to begin to develop a theory of dis/human studies which simultaneously acknowledges the possibilities offered by disability to trouble, re-shape and re-fashion the human (crip ambitions) while asserting disabled people’s humanity (normative desires). We will sketch out four dis/human considerations (i) dis/autonomy, voice and evacuating the human individual; (ii) dis/independence, assemblage and collective humanness and (iii) dis/ability politics, self-advocacy and repositioning the human; (iv) dis/family: desiring the normal, embracing the non-normative,and conclude that we desire a time when we view life through the prism of the dishuman.

**Steve Graby**

University of Leeds

**Personal Assistants: A Profession Allied to the Community?**

This paper is based on interviews, conducted as part of my ESRC funded MA research, with people who played key roles in the development of personal assistance services for disabled people in the UK. In it I will critically examine the concept of 'professionalism' as applied to the job of Personal Assistant, drawing on my interviewees' opinions about the working role of a PA and the relationship between PAs and disabled employers, as well as on published accounts of the experience of personal assistance, by both disabled people and PAs, in the Disability Studies and Disabled People's Movement literatures.

By situating these in the context of Disabled People's Movement critiques of the 'helping professions' (e.g. Davis 1990), and of theoretical perspectives such as those of Illich et al (1977) on 'disabling professions' and more recent feminist and autonomist critiques of professionalism and professionalization (e.g. Adams 2012), I will assess whether PAs can or do constitute what Finkelstein (1981, 1999) called a 'profession allied to the community' (PAC), in contrast to 'professions allied to medicine' (PAMs).

In doing so I will consider how the availability of personal assistance for disabled people in the UK is affected by current economic and political conditions, including the increasing precarity of waged labour and severe cuts to state welfare provision, including funding for disabled people to employ personal assistants, and the impact that these conditions have on the status of PA work as an occupation.

**Anat Greenstein**

University of Manchester

**Radical Inclusive Pedagogy: The Disabled People’s Movement In and Out of the School.**

This paper will draw on interviews with 12 activists in the disabled people’s movement and the inclusive education movement to explore ideas of Radical Inclusive Pedagogy. First I will argue that, as both education and inclusion are political, thinking about inclusive education means thinking beyond the walls of the school and seeking social transformation. This, for Freire (1972) means education is about a process of dialogue that allows learners to explore their experiences in relation to the social context in which they occur (conscientization) and challenge oppressive structures (praxis). Adopting this view of inclusive education, I will go on to argue that the disabled people’s movement can be understood as a site of radical inclusive pedagogy in itself, as it allows activists to explore and challenge disablement.

This paper will focus on questions of identification and belonging, exploring the tensions between the need to collectivise around a shared disability identity and the will to create communities of difference in which diverse human needs and abilities are accommodated, and will distinguish between self-organisation and coerced segregation. I will conclude by exploring how insights from the movement can be applied to practices of radical inclusive pedagogy within schools.

**Alan Gregory**

Lancaster University

**"An Illustration from Nature's Book”: Showcasing the Storyteller's Spectacular Body in Hilary Mantel's The Giant, O'Brien.**

In Staring: How We Look (2009) Rosemarie Garland-Thomson identifies spectacular bodies as forms of visual novelty and exaggerations of the normative shape and scale of the human anatomy which stimulate the impulse to stare. Garland-Thomson presents an extensive consideration of a variety of spectacular bodies, including giants, while also emphasising that encounters with bodies of extraordinary scale are often the catalyst for the act of staring developing a storied quality. Garland-Thomson gestures towards the giant's status as an emblem of narrative familiarity by making reference to David and Goliath and Jack and the Beanstalk which, she suggests, contribute to cultural conceptions of people with gigantism. The literary parameters of this cultural conception also incorporate texts such as Hilary Mantel's The Giant, O'Brien (1998), a contemporary fictionalisation of the life of eighteenth-century colossus, Charles Byrne.

The Giant, O'Brien initially conforms to Garland-Thomson's conception of the spectacular body as a site of staring while challenging her configuration of staring's storied qualities. By incorporating story-telling into Charles Byrne's displays of his spectacular body and gifting the giant control of his narrative, Mantel's text initially refuses the mapping of fantastic stories onto spectacular bodies by the normative spectator. Byrne's desire to control the exhibition and narration of his exaggerated anatomy informs the conflict of the novel between literature and science. Mantel’s symbol of the medical sciences is the anatomist, John Hunter, who wishes to utilise the colossus' skeleton for an alternative, scientific spectacle. Hunter's eventual purchase of O'Brien's bones after his death is significant because it erases O'Brien's autonomous agency as a storyteller and presents the skeleton of O'Brien's spectacular body as an object of scientific scrutiny, in addition to reconfiguring it as an exemplar of staring’s storied qualities identified by Garland-Thomson. This paper is part of a proposed panel on Literary Disability Studies.

**Hrafnhildur Snaefridar Gunnarsdottir, Rannveig Traustadottir,**

Centre for Disability Studies, University of Iceland

**Violence Against Disabled Women and Access to Support and Justice.**

International research indicates that disabled women are many times more likely to experience violence than non-disabled women. Despite this there is limited understanding of this significant and disturbing aspect of disabled women's lives and efforts to prevent violence do not seem to be effective. This paper presents findings from two research projects in Iceland focusing on violence against disabled woman and specialized support services for women who have experienced violence. Participants were disabled women with varying impairments and women who work in specialized support services.

Data was collected through qualitative interviews, focus groups and a survey. The paper begins by describing the various forms of violence experienced by the disabled women who participated in the study across the life span and who were the most common perpetrators. We will also address the connection between disability and violence and outline in which places, spaces and circumstances the disabled women were most likely to be violated, including a discussion of violence within the human services designed to provide care, assistance and support to disabled women and girls.

Access to specialized support and the experience of disabled women and workers within these services will be outlined. We conclude by offering recommendations on how to prevent violence and create more effective support services, as well as discussing the importance of making it possible for disabled women to access justice when they have experienced violence.

**Nancy Hansen**

Disability Studies University of Manitoba

**Disabled Academics Reshaping the Research Landscape.**

As a disabled academic I often find the presence of non-conformist physicality often disrupts established academic practices simply by being present. As yet, there is little understanding of disabled researchers. There is limited flexibility and frequently, it is a gamble as to who and how the rules are applied or understood. Long-established fixed physical and attitudinal boundaries are slowly changing by degrees. However, in many ways, our presence in the academy remains tentative and the landscape unfamiliar. Navigating these alien spaces present numerous opportunities for research creativity that can arise at a moment’s notice.

As we embrace non-conformity in all its forms, academic research approach subject and methodology is changing .This paper documents the adventures of a disabled academic undertaking disability research. Disabled academics are shifting research perspectives in both form and content Areas are examined that until recently have had limited analysis.

I take on smaller research projects and often work in partnership with other academics both disabled and non-disabled making full use of our unique speed, space and time realities along with In many ways, we are cultural anthropologists documenting “life in the academy among the non-disabled”.

**Xirong He**

Northumbria University

**Hearing Parents Raising their Deaf Children on the Journey to Mainstream Schools in Beijing, China.**

Introduction
China is one developing country with the population of 1.3 billion, which has different culture and history from the West. China has experienced the rapid development in economy, education and society since China opened its door to the world in 1979. In the subject of disability, the development in inclusive education for deaf people has been quickly promoted by the implementation of some important laws for the disabled in 1990s.

Aim
The aim of this study is to explore how a small group of hearing parents support their deaf children to be ready for and educated in mainstream schools in Beijing, China

Methodology and methods
Within this ethnographic research design, narrative interviews were conducted with ten hearing parents in Beijing, China.

Results
Thematic analysis of interview data has identified a number of key themes, two of which are discussed in this paper presentation:
Parental attitude towards deafness: Chinese hearing parents’ attitude toward deafness was mainly affected by the medical model of deafness. In order to support their deaf child to engage in a hearing world, hearing parents decided on oral language and mainstream schools.
Parental involvement: Chinese hearing parents not only developed their deaf child’s skills in language, moral, cognition and social-emotion, but also helped their deaf child to remove the barriers to mainstream schools.

Conclusion
The results of this study have discovered the relationship between parental attitudes toward deafness and their involvement in raising their deaf child to be ready for and educated in mainstream schools in Beijing, China. Both parental attitudes and their involvement could influence their deaf child’s development in self-concept and deaf identity to some extent.

**Andy Hill**

De Montfort University

**Policing Dyslexia:  Voices from the Thin Blue Line.**

This paper is based on the findings of a recently completed PhD study in which the experiences and perceptions of dyslexic police officers from across England and Wales were explored.   The aim of this study was to provide an opportunity for the previously unheard voices of dyslexic police officers to be heard.  This qualitative and exploratory study was informed by the principles of active participation as well as the social model of disability.   Thirty current and recently retired police officers, of various ranks and from a wide range of police services, participated in this study.  Layder’s (2013) Domain theory offers an interesting and novel foundation on which this participatory social research study was developed.  Domain theory suggests that agency and structure are not discrete and flat in terms of ontology and epistemology, but rather that social reality needs to be understood in terms of four distinct but interwoven domains.   In a further break from the tradition of rejecting anything but the subjective experience of the dyslexic (disabled) person, the Theory of Domains encourages the bringing together of both objective (in a moderate form) and subjective aspects of social reality (Layder 2006:299).

In this study the social model of disability and Foucault’s concept of bio-power and the medicalization of society act as orientating theory.  An ‘Adaptive’ method linked to the Theory of Domains was used to analyse the interview data (Layder 2016).   Three key themes emerged from this study: The Dyslexic Identity, Disclosure and finally Support and Reasonable Adjustment in the operational role.  The majority of participants experienced dyslexia-related prejudice and discrimination from colleagues, supervisors and managers.  The commonality of experience reported from a range of officers of differing ranks and from across a wide range of police services suggests that discrimination is both cultural and institutional within several police services in England and Wales.    This paper will discuss the rationale and experience of using the Adaptive approach in this study.  Further, the paper will explore the key findings of this research and make suggestions for future research projects.

**Nick Hodge**

Sheffield Institute of Education

Sheffield Hallam University

**Schools Without Labels.**

The labelling of children is so embedded within educational practice that schools can no longer imagine how they might operate without them. The Academy can play a critical role in supporting schools with envisioning more enabling and inclusive structures that do not constitute children as disordered or different. Using the example of the primary school setting this paper will illustrate how education without labels might appear in practice. Professionals argue that parentcarers and staff demand answers to what is ‘wrong’ with children, that labels lead to new and more empowered understandings of children and enable access to required resources. Critics of the process position labelling within the hegemonic practice of normalcy that negates the diverse nature of the spectrum of being. This paper will demonstrate that what is critical to education is not in fact this practice of labelling but the provision of assessments of children’s ways of being that are recognisable to those who know them and the identification of related educational supports. In the school without labels children and parentcarers will be the experts at the centre of these assessments who support professionals with developing understanding of these individual modes of being. It is not labels that parentcarers or even school staff seek but a recognition and appreciation of who children are, a celebration of their abilities, recognition of their challenges and the required resources to make learning accessible to all.

**Joanne Hogan1, Maureen Horgan2, Sheila Glenn2, Kevin Southern3**

1Liverpool Hope University

2Liverpool John Moores University

3CF Unit, Royal Liverpool Children's Hospital.

**Using a Social Relational Approach to Understand Young People's Experiences of Chronic Illness.**

Introduction: A qualitative PhD study examining transition to adulthood for young people with Cystic Fibrosis (CF).

Method: In-depth semi-structured interviews were conducted with 8 males and 10 females aged 16-21 years. The study was conducted and analysed using Grounded Theory.

Results: In line with a social relational approach to disability (Thomas, 1999) the young people identified a range of problems they experienced as a direct result of their impairment (impairment effects) as well as a number of socio-structural barriers which impacted on their journey to adulthood. A social relational approach allowed consideration of the direct psychological effects of living with impairment, as well as, dimensions of disability that operate along psychological and emotional pathways and the social barriers faced by the young people.

Discussion: A criticism of the social model of disability has been its failure to acknowledge the role played by impairment and illness in people’s life experiences. The young people in this study did acknowledge the role of their medical condition in their experiences and indeed the necessity for medical attention in their lives. However, authors such as De Wolfe (2003) have argued that this does not mean social arrangement does not have a significant impact on the experience of illness and it does not mean that those with chronic illness do not experience disability in the form of social barriers. The experiences of the young people in this study add support to such arguments and highlight the need for those with a chronic illness to be able to articulate their social needs rather than having their illness construed as a purely individual/medical problem. One such way this could be addressed is through the development of the sociology of disability as a distinct sub-discipline of sociology as recently proposed by Thomas (2012).

**Ella Houston**

Liverpool Hope University

**Visual Dominance: A Feminist Disability Studies Reading of the Films ‘One Flew Over the Cuckoo’s Nest’ and ‘Girl, Interrupted’.**

This paper will critically analyse the representation of disability within the following films; One Flew Over the Cuckoo’s Nest (1975) and Girl Interrupted (1999). The lines of argument in this essay will draw upon a feminist disability studies approach, closely engaging with the theory of ‘the human stare’, as articulated by Garland-Thomson (2009). An engagement with this theory will be further understood through reflections on ‘the gaze’ (Mulvey, 1975). This theory will be used to understand how visual dominance is prevalent within both films. Foucauldian perspectives on Panopticism (1975) and Social Control (1969), will further develop this argument. A final review will draw upon how the negative representations of disability within these two films may lead to the stigmatisation of people with impairments in society, employing Goffman’s (1986) theory of Stigma, as foundational knowledge for this critical analysis.

**Rebecca Irvine**

Queen's University Belfast

**Challenging Perceptions of Disability in the Post-Conflict Environment: Who Wins?**

This paper will identify the relationship between civil conflict and disability and discuss the recognition that different groups receive in the post-conflict policy environment. Through a comparative analysis of disability policies developed in the aftermath of civil conflicts, it will explore the hierarchy that exists within the disability identity and address the differences in policies aimed at disabled veterans, victims of political violence, and people that have disabilities unrelated (or perceived as unrelated) to the conflict. Based on some of the findings of my doctoral thesis, which looked at the development and implementation of disability policies in post-conflict countries focusing on Mozambique, South Africa, and Northern Ireland, it will also draw on the experiences of other recent civil conflicts to explain the level of priority that people with disabilities have received in the reconstruction of the post-conflict state.

The paper will be divided into three parts: the first will introduce the complex relationship between disability and conflict; the second will identify who the intended beneficiaries of disability policy are; and finally it will discuss whether the policies introduced are likely to improve the lives of people with disabilities. The purpose is to determine whether the post-conflict environment, which presents great potential for social change, is being capitalised upon by drawing on the increased visibility of disability as a result of the conflict. This study is based on interdisciplinary research which draws upon disability studies, peace and conflict studies, sociology, social policy, political science, and economics. It demonstrates the potential for further collaborative work by suggesting that more research is needed to gain a better understanding of how well States, civil society, and the international community are meeting the needs of people with disabilities that have experienced violent conflict.

**Naomi Lawson Jacobs**

University of Sheffield

**Reinforcing Normalcy: Christian Churches and Faith Healing.**

The Christian churches have, historically, had a strong influence on modern discourses of normalcy. However, although churches believe that they conceive of disability through biblical and theological models, the effect of secular social thought on health, healing and normalcy is in evidence in Christian thought and practice. Ministries such as healing services and the growing 'healing on the streets' movement are influenced as much by the late modern secular normalcy agenda as by the Bible or Christian theology. The concept of 'wholeness' is particularly central to the churches' normalcy discourse, a concept which spiritualises health while associating illness and disability with deviance. A pattern can be seen in church contexts, whereby faith healing practices relate to deviance and the restoration of symbolic control, with healing services reconstituting a community and bringing deviant members back into its fold under a banner of normalcy. Healing is also linked to the faith of an individual, and to spiritual growth or 'blessedness'. Such theology draws on pre-modern concepts of the simultaneously blessed and damned disabled population, integrating it seamlessly with the late modern normalcy agenda.

This presentation will examine some examples of faith healing and exorcism ministries, looking at the ways in which they reinforce (secular) social concepts of normalcy, and considering the effect that church discourses of healing may continue to have on even a secularised society.

**Herminder Kaur**

Loughborough University

**Disability and Physically Dis-Abled Teenagers.**

This paper proposes to present a theme on disability that emerged from the findings of a PhD thesis primarily focused on understanding the use of the internet by youngsters with a physical disability. The study focused on a small cohort of teenagers with a range of physical disabilities identified by applying purposive sampling at a special educational needs school located in the East Midlands. A small number of these students were also followed into several mainstream colleges. Participants consisted of students aged between fourteen to nineteen years with physical disabilities such as cerebral palsy, brittle bones, severe ichthyosis, hemiplegia and muscle wasting conditions. By using a strong ethnographic approach including observation the researcher undertook the role of a volunteer in the school concerned and used the methods of video diaries, face to face and online interviews to provide rich data on many issues including disability.

An important theme to emerge from the thesis looks at the ways in which disability comes to be defined by participants, how this relates and contrasts with the constructions made by participant’s parents and teaching staff of young people as being physically disabled. A taxonomy is drawn from these interpretations that help to explain the different positions the participants can take and shift between in different contexts to discuss their disability. What comes to the fore is the many nuances of being a physically disabled teenager. These suggest disability is multidimensional where its complexity cannot be understood merely as a medical condition underpinned by the personal tragedy theory or simply in terms of environmental barriers. By drawing on case studies this paper concludes participants, their parents and teaching staff foster a positive view of disability that emphasises and encourages teenager’s abilities over their inability to complete normal daily activities in different contexts.

**Anne Kavanagh1, Allison Millner1, Zoe Aitken1, Tony Lamontagne2, Rebecca Bentley1**

1The University of Melbourne

2Deakin University

**Does Paid Employment Improve the Mental Health of People with Disabilities?**

Increasing participation in paid work is conceived of as central to improving the economic and social wellbeing of people with disabilities. Paid employment may have the added benefit of improved mental health for people with disabilities, perhaps over and above the benefits for people without disabilities. Despite the fact that there is a well-established literature demonstrating that unemployment and economic inactivity are associated with worse mental health there is limited understanding of whether these relationships are different for people with disabilities.

We used eight annual waves of the Household, Income and Labour Dynamics in Australia survey, a total of 2,379 people with disabilities and 11,417 people without disabilities were identified. We used the Mental Component Summary score (MCS) from the SF-36 as an overall measure of mental health. We conducted a longitudinal analysis where we assessed the effects on mental health that occur when an individual changes labour force status and examined whether the effects were different for people with and without disabilities.

We found that the effects of unemployment and economic inactivity were associated with statistically significant reductions in MCS for people with and without of disabilities but the negative effects were more pronounced for people with disabilities. Unemployment was associated with 1.9 point reduction in the MCS for people with disabilities compared to 0.6 for people without disabilities. Similarly, economic inactivity resulted in a 2.7 and 0.34 point reduction in MCS for people with and without disabilities respectively.

These results highlight the potential health promoting effects of employment for people with disabilities. Improving people with disabilities’ participation in paid, meaningful employment may contribute to a reduction in the inequalities in mental health between people with disabilities and without disabilities.

**[78] Anne Kavanagh1, Johanna Mithen1, Zoe Aitken1, Anna Ziersch2**

1The University of Melbourne

2University of South Australia

**Inequalities in Social Capital Between People With and Without Disabilities.**

This paper reports the findings of a study examining the levels of social capital experienced by Australians with disabilities compared to those without disabilities. People with disabilities are known to experience high levels of socio-economic disadvantage and social exclusion compared to those without disabilities but little is known about their access to social resources such as formal and informal social networks and social support. Access to such resources may have impacts on other socio-economic domains and people’s health and wellbeing.

Bourdieu conceptualises social capital as the resources that flow to individuals from their membership of social networks. In this paper, we operationalised Bourdieu’s conceptualisation of social capital by measuring social capital across three domains: informal networks (family and friends); formal networks (ability to access information and advice) and social support (financial, practical and emotional). We used data collected from of 15,000 Australians in the 2010 population-based General Social Survey to compare levels of social capital for people with and without disabilities and for people with different types of impairments (sensory and speech, intellectual, physical, and psychological).

The findings showed large inequalities in social capital between people with and without disabilities for all measures examined, particularly in terms of their access to formal networks and social support. There were also large differences according to type of impairment, with people with intellectual and psychological impairments faring worst for all domains of social capital.

While an overall goal of policy reform should be to improve individuals with disabilities’ levels of social capital, particular attention needs to be paid to those with intellectual and psychological impairments who are particularly disadvantaged in this domain.

**Berni Kelly, Theresa McShane**

Queen's University Belfast

**Silent Voices: Findings from a Review of Literature on Disabled Care Leavers.**

This paper will present the findings of a review of national and international research on disabled care leavers. The literature review has been undertaken as part of a current study investigating the characteristics and experiences of disabled care leavers in Northern Ireland. The aim of the literature review was threefold: firstly, to establish the extent of existing empirical research related to disabled care leavers or care leavers with mental health needs; secondly, to review the findings of previous research in this area; and thirdly, to identify gaps in knowledge of relevance to the current study.

The review of literature was guided by clear inclusion and exclusion criteria and utilized combinations of a range of search terms to identify relevant literature. The review included research focused on disabled care leavers and care leavers with mental health needs. A range of sources and publication formats were considered, with journal articles and research reports comprising the main body of literature.

The presentation will report on the methodology and explore the key findings from the review of literature, highlighting key trends and outcomes for disabled care leavers identified from the research literature. The research indicates that disabled young people are over-represented in the leaving care population; experience multiple levels of adversity and exclusion as they move into young adult life; and are likely to require continued support during transition and in young adult life. Yet there is limited consideration of their care leaving experiences in the research literature.

The paper will also critically review the range of available research in this area and key methodological approaches utilized. Finally, priority areas for the further development of research on the experiences of disabled care leavers will be presented, including the need for participatory research approaches that seek the views of disabled young people as they transition from the public care system into young adult life.

**Berni Kelly, Theresa McShane**

Queen's University Belfast

**Exploring a Social Justice Perspective for Research with Disabled Care Leavers.**

This presentation will review the theoretical models used to understand and research the experiences of disabled care leavers transitioning to adult life. These young people are over-represented in the leaving care population; are at high risk of multiple levels of adversity and exclusion as they move into young adult life; and are likely to require continued support during transition and in young adult life. Yet there has been very limited consideration of their transitional experiences in extant research literature.

The paper is based on ongoing research examining the characteristics and experiences of disabled care leavers in Northern Ireland based on existing health and social care data and case studies of their transitional experiences and outcomes in young adult life.

The presentation will provide a critical overview of the main theoretical models informing this complex area of policy and practice and explore the application of social justice as a unifying concept. The key theoretical models reviewed will include: resilience; recovery; social capital; and disability theory. The common themes of each theoretical perspective will be addressed including strengths and limitations in relation to understanding the experiences of disabled care leavers.

The use of different, if overlapping, theoretical models across different aspects of services for the same group of young people can create barriers to joint working and challenges for research, policy and practice in these interface areas. Applying a social justice perspective may help offer the possibility of a more integrated and effective theoretical foundation for understanding complexity and facilitating change in the lives of disabled care leavers.

**Patrick Kermit1, Anne Mali Tharaldsteen2, Gry Mette D. Haugen3**

1Norwegian University of Science and Technology

2Statped

3NTNU Social Research

**Adolescents with Sensory Impairments in Ordinary Classrooms - Different Notions of “Participation” and “Inclusion”.**

The paper presents a study is carried out by NTNU Social Research AS and funded by the Norwegian Ministry of Children, Equality and Social Inclusion. The main objective has been to generate knowledge about the school situation for adolescents with sensory impairments in Norway, and explore to what extent there is a correlation between the situation at school and in leisure activities. Further, the project has focused on the impact of facilitation of education regarding leisure activities for pupils with sensory impairments who attend mainstream schools.

The study focuses on three main research questions: 1) To what extent are children and adolescents with sensory impairments included in school? 2) What kind of challenges related to inclusive schooling do these children and adolescents deal with? 3) Is there a correlation between inclusive schooling, inclusion in the society in general, and in leisure activities in particular?

In this paper, the emphasis lies with the second question. The results both of the conducted survey as well as the qualitative interviews points out that “inclusion” too often is reduced to symbolic interventions where the disabled adolescent is alienated from his or her peers. For example, the still common practice of teaching disabled students in partly segregated settings on different locations than the ordinary classroom contributes to the experience of only “visitorship” (Antia et al. 1999; 2002) in the class rather than “membership” (ibid.)

All the young informants tell the story of how they themselves, to different degrees, have to strive to adapt to other students or peers in school or during leisure activities. Even though many adolescents are included in many settings, this inclusion is first and foremost the result of the adolescent’s own deliberate and unconscious efforts and management of different strategies. Some paradoxes and possible implications regarding identity formation are briefly addressed.

**Ikanshi Khanna,**

Centre for Early Childhood Education and Development Ambedkar University Delhi

**In Search of Intimacy: Experiences of Persons with Physical Disability.**

The purpose of this study was to explore the notions of sexuality and heterosexual relationships among young adults with physical disability, in relation to their perceived body image and their disability. The focus of the study was to examine the experiences of young adults in establishing an intimate relationship with a significant other and the role of family members vis-à-vis the rhythms of daily living. Data collection for the study included qualitative methodologies in which a life history approach was followed to document each individual’s life. The first group of participants for the study included 15 young adults with physical disabilities in the age group of 17 to 30 years and 11 family members. The second group of participants included 15 persons without disability, and the last group included five experts. All participants were selected using purposive sampling. Methods of data collection included active interviews, structured and semi-structured interviews and a questionnaire-aided slide presentation. Data collected were coded using open codes and themes were gleaned from the analyzed data.

Themes of the study indicated that intimate relationships of participants were influenced by their physical disabilities. Young adults with physical disability had the same sexual desires and fantasies as those of persons without disability. Secondly, data indicated that the age and onset of disability shaped the experience of disability, (3) lastly, participants with physical disability had the potential to develop feelings of attraction towards person’s without disability, but had difficulty in approaching them.

Familial concern was focused on the participants’ employment and aspirations for their future. Experts believed that sexuality and establishing intimate relationships demanded more psychological and self-effort and less of social and medical inputs. This study indicated a need for more comprehensive research in this neglected area of experiences of persons with physical disability in search of intimacy.

**Gertraud Kremsner**

University of Vienna

**“The Football Team Smells Good“ - Subalternity and the Construction of Disability in the Biographies of People with Learning Difficulties Who Used to Live in (Total) Institutions.**

In this paper I want to discuss first results of an inclusive life history research-project which focuses on biographies of people with learning difficulties who used to live in total institutions over a long period of their lives. Despite their transition into so called community-based services many of the characteristics of total institutions have not disappeared but have taken on a new and more subtle appearance. Power imbalance between people with learning difficulties (obedience, dependency) and caregivers (violence, power violations) have always been an unquestioned and unchallenged part of the lives of the first group mentioned, especially because most of them lack a background from non-professional supporting systems such as family or friends. As a consequence this influences not only the identities of persons with learning difficulties who acted as co-researchers, but also affects the construction of disability.
Therefore the author considers those people as part of what Spivak (2008) – in reference to Gramsci – called „the subaltern“. Referring to this, the paper focuses especially on language and expressions used by those sharing their life stories and elaborates „subaltern language“ as one of the few opportunities to be heard. Recollecting life stories commonly and within an inclusive, participatory process may enable an opportunity to regain the ‘lost voices’ (Atkinson and Walmsley 1999). Additionally, it challenges Spivak's critique on non-subaltern researchers who speak for someone else out of a powerful position. Hence the question is not whether the subaltern can speak, but what can be done to hear/understand it.

**Amith Kumar P V**

English and Foreign Languages University

**‘Crippling the Crips’: Imposing ‘Normalcy’ on the Disabled in India.**

Though disability studies has achieved a pivotal status in the universities of the developed economies, it is still in a nascent stage in the global south mostly constituted by low and middle income countries. A need to understand ‘disability’ in its multifarious implications and a comprehension of the diversities and dimensions involved in disability studies has not yet found identifiable significance in developing countries. In India, the ‘normal mainstream’ generally identifies persons with disability as physically handicapped. The term ‘disability’ is utilized in a very restrictive sense, mainly referring to the visible forms of disability. As Renu Addlaka has rightly pointed out, “Instead of giving rights to disabled citizens and empowering them, a culture of charity and welfare has been systematically promoted in India since the colonial period” [2011: 13].

Apart from such an act of relegation of the disabled to the social fringes in India, in the recent times one could notice certain strategies employed by the administrative powers to negate and erase the identities and rights of the disabled population. The fabrication of the Rights of Persons with Disabilities Bill tabled in the Indian parliament to suit the purpose of the state machinery, miscalculations of census data on and about disabled population, non-recognition of certain sections of the disabled population under the legislations, and negligence of the protests that demand equal opportunities and positive discrimination are a few of the recent developments in the Indian political geography. Commenting on the peripheral status provided to the disabled population in India, Roger Jeffrey and Nidhi Singhal write, “disability issues are no longer simply marginalised: now people with disabilities may well find themselves enmeshed in a kind of "surveillance society” [2008: 23]

These administrative strategies have ensured the crippling of the crips in India. Through certain administrative measures, ‘normalcy’ is enforced on the disabled sections and a retrograde move towards adopting the charity model could be seen. This is an alarming concern that needs to be understood, investigated and critiqued. The paper seeks to undertake an attempt to decipher the politics of marginalization with regard to the disabled and suggests measures to strengthen disability activism in India. To utilize a phrase from Lennard J. Davies, the paper urges the ‘crips’ to ‘strike back’ [1999: 500].

**Zoe Lambert**

Lancaster University

**‘You and Me’: Carer/Caree Narratives in Writing about Disability.**

Discourse about disability and caring in both policy and fiction can be problematic. The term ‘Care’ may invoke a long history of incarceration in institutions. The civil rights gains of independence, anti-discrimination and social inclusion are currently under political and ideological attack, as disabled people and their carers are portrayed as ‘scroungers’. Yet cuts to social security mean increasing amounts of unpaid care within the family must take place. In such a context narratives containing disabled characters often set the objectives of the carer and caree against one another.

This creative/critical paper will explore how fiction might write against the stereotype of illness/disability as personal tragedy for the ‘afflicted’ and the carer. I wish to challenge the characterisation of the disabled person as either bitter or ‘overcoming’ their disability, and the characterisation of the carer as either a bully or a self-denying angel who needs to free themselves from the ‘burden’ of caring. I will analyse the impact of point of view, narration and metaphor in writing about disability, and how narrative strategies can be used to problematise cultural prejudice, and include a short reading from my current novel and work in progress.

This paper will emphasise the social context of disability, and the possibilities of an ethical writing practice that enables inclusive representation, in which neither the voice of the carer or caree is negated or ‘othered'.

**Brenda Lefrancois**

Memorial University

**Sanism and the Mad Studies Project.**

This paper will outline the usefulness of the concept of sanism in understanding oppression and psychiatrised abjection. A term popularised by Michael Perlin, a disability rights lawyer and academic, sanism is understood as the systemic oppression and micro-aggressions experienced by people who have been psychiatrised. Sanism permeates society generally, the psychiatric regime specifically, and even exists at times within the various movements that have organised against psychiatric oppression. These issues will be discussed, along with an exploration of the usefulness of the concept of ‘sanism’ as an alternative to the limiting and problematic concept of ‘stigma’. The Mad Studies project is proffered as anti-sanist social justice based praxis, combining social activism and radical scholarship. Centering the lived experiences and analyses of psychiatric survivors and mad-identified people, Mad Studies includes critiques of psychiatry from a variety of different lenses such as from critical disability studies, critical psychiatry, anti-psychiatry as well as other forms of Mad activist scholarship. As such, Mad Studies will be discussed as an evolving project with various themes, including an anti-sanist focus.

**[114] Mark Lindsey-Halls1, Natasha Smith2, Ralphson Stuart1, John Teague, 2Liz Ellis**

1Time for Change

2Cornwall County Council

2Open University

**Walking and talking together: Inclusive research about where we live.**

* We are a team of co-researchers working with a PhD student living in Cornwall.
* We did some research together about the communities we live in.
* To do the research we went on trips which Liz, the student, recorded.
* Afterwards we talked about our trips to find out the important things we talked about and thought about the places we went to.
* We will talk about how we did the research and some of the problems we had.
* We will also talk about some of the things we think are important about what helps us to feel like part of our communities.

**Beth Lewis**

Murdoch University

**Helping Clients Rediscover Sex: The Role of the Occupation Therapist.**

Disability and asexuality are bedfellows that strip the individual of basic rights and pleasures associated with ‘normal’ occupations and activities of daily living. Many myths characterise and surround ideas of sex, disability and chronic illnesses, including; the idea that there are more important matters than sex to focus on; that disabled persons are neither desirable nor do they have their own desires; and that sexually active persons with disabilities are deviants. Scholars, disability activists and advocates have made headway in exposing these myths, and in the process are normalizing the idea of sex and disability. However, absent from the dialogue on sex and disability is the role of the occupational therapist (OT). Therefore, the question that needs asking is; what, if any part, does the OT play in delivering sexual rehabilitation for their clients, particularly clients with acquired brain injuries adjusting to an altered idea of the sexual self.
To answer this question, this study investigates the role OTs play in providing persons with disabilities sexual rehabilitation therapies, which in turn enable clients to claim and maintain healthy sexual identities. In order to understand the role of the OT in sexual rehabilitation the study considers a mix of quantitative (survey) and qualitative (interviews) data collected from OTs registered with the West Australia Occupational Therapist Association. This paper presents results from the initial stage of the project. Results suggest West Australian OTs are supportive of assisting clients, with disabilities or chronic illnesses in sexual matters. However, OTs receive limited training on sexual rehabilitation, and seldom initiate discussions on sexual matters with their clients. Further, OTs are somewhat limited with few formal or informal forums in which they may discuss their clients’ sexual rehabilitation with colleagues in the work place.

**Kirsty Liddiard**

Ryerson University/University of Sheffield

**“I never felt like she was just doing it for the money”: Disabled Men’s Intimate (Gendered) Realities of Purchasing Sexual Pleasure and Intimacy.**

Scholarly enquiry into the interrelationships of disability and commercial sex remains seriously under-represented within disability and sexuality research. This article, however, draws upon the sexual stories of heterosexual disabled men in order to explore their embodied realities of purchasing of sex, pleasure and intimacy from non-disabled female sex workers. A thematic analysis of these sexual stories revealed multiple and complex motivations for, and experiences of, purchasing of sex, pleasure and intimacy; a purchase ultimately shaped by men’s social and political positioning as disabled and, as with the motivations and experiences of heterosexual non-disabled men, by discourses of hegemonic masculinity and heteronormative sexuality. Given the dearth of research in this area, a number of questions are identified which make important contributions to transdisciplinary knowledges of disabled sexualities, commercial sex work, and disabled sexual citizenship.

**Ema Loja**

University of Leeds

**Politics of Normalcy and Body Pride.**

A ‘natural’ version of the ‘normal individual’ underpins the experience of prejudice, discrimination and exclusion of disabled people. Disability is equated to a departure from normalcy that undermines the possibility of a ‘normal citizenry’ detached from bodily, sensorial, or mental differences (Titchkosky, 2003). The pervasiveness of the medical model on interpreting impairment has been critical on devaluating disabled bodies that are seen as medical and social deviances rather than forms of human diversity (Linton 1998). Underneath, ableism allows a non-disabled society to create a world in its own able-bodied image (Hansen & Philo, 2007, pp. 494) where meanings attached to bodies influence interactions with social and built environments in everyday life (Zitzelsberger, 2005). Internalised ableism (Campbell, 2008) and norming (Davis, 1995) are some of the processes in play when disabled people interact with a society that embraces tyrannies of perfection (Glassner, 1992). As it occurred to other minorities’ struggles, the politics of disability must be considered as bio-politics (Hughes & Paterson, 2006) where bodies can be sites of resistance to social oppression.

This presentation includes a qualitative study based on embodiment theory with disabled persons where the link between body pride and the politics of normalcy is discussed. Findings suggest that much has to be done in order to achieve different ways of seeing and experiencing disabled bodies as part of a carnal and political resistance to a normalising society.

**Theresa Lorenzo**

University of Cape Town

**Reciprocal Capacity Building for Inclusive Development of Disabled Youth: Experiences from South Africa.**

A collaborative study between occupational therapy departments at six universities in South Africa and community organisations on the livelihood strategies for inclusive youth development surveyed over 1000 disabled and non-disabled youth. Strategies to increase participation in social, economic and political development were related to improved access to health and social development services, accessible public transport systems, adequate and accessible information on financial resources and skills development opportunities for gainful employment. The need for family support was identified as essential for the implementation of UN Convention on the Rights of Persons with Disabilities.

This paper will illustrate the potential of reciprocal capacity building between service providers and community disability workers to facilitate inclusion of disabled youth in livelihood opportunities. Such capacity building will increase access to information, resources and services needed for the full participation of disabled youth in inclusive and sustainable development.

**Claudia Malacrida**

The University of Lethbridge

**Sex, Lies and Intellectual Disability: Knowledge and Newgenics.**

The regulation of disabled people’s reproductive lives has been effected through both active and passive negative eugenics. In active negative eugenics in Alberta, Canada, for example, over 2300 people deemed to be ‘mentally deficient’ or ‘psychotic’ were legally involuntarily sterilized. In passive forms of negative eugenics, the broad system of asylums and institutions that arose in Canada sequestered people deemed to be ‘dangerous’, effectively excluding them from a sexual and reproductive life.

Active eugenics is no longer legal in Canada; in 1972, Alberta’s Sexual Sterilization Act was struck down, and the passing in 1986 of Eve’s Law guarantees the rights of Canadian citizens with “diminished capacity” (sic) to bodily integrity, by disallowing parents, guardians or caregivers from seeking involuntary sterilization. Similarly, the large, passive eugenic institutional settings of the 20th century have largely fallen by the wayside in Canada.

Current active and passive eugenic practices, however, operate covertly, and often fall outside of traditional rights protection. In this talk, I will examine how knowledge is used to operate as a covert form of passive eugenics. Interviews with 30 individuals with intellectual disabilities yield narratives about the effects of lack of information, deliberate misinformation, and protectionism on some disabled people’s ideas and practices relating to relationships, sexual encounters and family issues. I argue that these ways of knowing comprise a form of newgenics that has a broad reach in engendering indirect reproductive control over people with mental health or intellectual challenges.

**Victoria Mason**

Norah Fry Research Centre

**Bereavement Support for Adults with Learning Disabilities.**

Aim: There is a need to understand how people with learning disabilities are supported when they suffer a bereavement. This poster details the methodology employed in an ongoing PhD study about support workers and bereavement support.

Method: Support workers themselves are often ‘silent voices’ in research. They are frequently asked to participate in research, but are seldom researchers. The method discussed in this poster enables support workers’ views to become central to the research process.

A Bereavement Research Community has been created to carry out this study. A group of support workers and a group of people with learning disabilities are working with the author. Together the Community are running a series of focus groups and in-depth qualitative interviews with 10 – 12 participant support workers from different support settings.

Results: This poster will present emerging findings about the co-production of knowledge within a research community. The lessons learnt relate to the; a) recruitment of the community and; b) skills and interests of community members

Conclusions: Support workers are often considered problematic. This poster will discuss support workers from a different point of view; as equal partners in the co production of research knowledge alongside people with learning disabilities.

**PosterKate Mattheys**

University of Durham

**Austerity, Inequality and Mental Health.**

Programmes of austerity lead to widespread deteriorations in mental health. This effect is likely to be more marked for people who come from deprived backgrounds, who are disproportionately exposed to the psychological strains wrought by the consequences of austerity. People who have mental health problems are particularly vulnerable to the harms of the current austerity programme in Britain, including being at the sharp end of the assault on public services and welfare spending. Mental health services remain significantly underfunded, local authority social care budgets are shrinking at an unprecedented rate, and the third sector has also seen funding cuts. These cuts are disproportionately affecting more deprived areas; in areas such as the North-East, austerity is having an ever increasing impact on the lives of people who are often surviving in very difficult circumstances. The stigma attached to mental ill-health is being exacerbated by discourses of othering that label people in terms of whether they deserve (or do not) support, contrasted with others that construct people with mental health problems as passive victims. Whilst highlighting the very real damage that austerity is doing, this victim terminology may also be damaging to a survivor movement that has sought to empower people to embrace active, proud identities.

This paper will describe a current piece of research for a PhD that is using a case study of a borough in the north-east of England, to explore the impact of austerity on inequalities in mental health, how this translates to people’s experiences and how these are changing over time. The research will consider the changing impact of austerity on mental health between the most and least deprived areas of the borough. It will additionally explore how austerity is impacting on people with mental health problems, alongside both the coping strategies and strategies of resistance that people employ, to navigate their way through these most challenging and oppressive times.

**Rosaleen McDonagh**

Northumbria University

**Disabled Traveller Identity: The Affirmation Model.**

Disabled Traveller Identity within the context of the affirmative model of disability. There are over 40,000 Travellers in Ireland. We do not constitute an ethnic minority, despite being, since 1999, recognised as such in the UK. Our Ethnicity includes our tradition of language and cultural norms, including customs, which differ from settled people. The Commission for Racial Equality estimates the number to be between 200,000 and 300,000 (CRE, Common Ground, 2006).

The processes of assimilation and rehabilitation through education and accommodation policies, at national and local level, fail the Traveller community. The failure in the form of assimilation practices to change Travellers into settled people. This is because these processes deny and do not accommodate Traveller identity.

The medical model of policy making has equally failed disabled people. This model also denies identity and sees the person as the impairment. This has been effectively challenged but it still emerges in political and popular discourse. The social model does place the person at the centre of policy making. However both the medical model and the social model are problematic in that they do not encompass diversity among disabled people. This diversity includes a variety of ethnic identities within the disability community. The affirmative model can be applied to issues of gender or sexual orientation, within disability politics. Stretching the affirmative model to acknowledge and account for the experience of racism that Travellers, and other people from ethnic minority groups, with impairments live with every day. Racism and disablism encompasses passing, identity, pressures to conform, internalised oppression, conflicting Traveller/disabled identities, and simultaneous oppression.

**Mick McKeown**

University of Central Lancashire

**Alliances and Activism: Deliberative Dialogue for Framing a Politics of Mental Health.**

This paper is concerned with competing ideas for framing the theory and politics of mental health survivor identity in a context of wider disability struggles and the potential for broadly based activist alliances. The need for ideas which help bring mental health users and survivors together with the wider disability movement is increasingly important given the current threats to welfare provision and the need to defend (and sometimes extend) support, to both mental health users and disabled people. A case will also be made for the establishment of constructive alliances between movement activists and trade unions representing the health and social care workforce. Questions arise, however, over the extent to which such understandings, and the means by which they are arrived at, might foster solidarity or division within the survivor movement, and between the movement and potential allies. As with any context where ideas and strategy are as much open to dispute as consensus, there is an ever present possibility for the sort of acrimony or ‘splitting’ that can be the enemy of collective action for change. For example, in relation to questions about who is more ‘deserving’ of support or disputes regarding tactics between or within different user groups; the latter might include preferences for reformist versus direct action approaches, or, indeed, the debates concerning conceptual models of distress or disability. The potential for unsettled and unsettling relations between movement and trade union activists is acknowledged.

This paper will explore ways in which individuals and groups might take part in deliberative dialogue to arrive at a better informed politics of mental health. This should, in turn, lead to productive alliances within and between mental health and disability movements. This is not to say that separate and autonomous organising between different disability groups is always ill-advised. But what seems important to a broader politics social change, however, is developing alliances across and between these differences. This paper considers how best to frame and conduct discussions about mental health and disability in order to contribute to activism based on alliances.

**Emma Louise McKinney**

Stellenbosch University

**A Case-Study on Addressing the Disability Poverty Gap Amongst Youth with Disabilities in South Africa.**

In the past people with disabilities in South Africa were discriminated against according to their disability, race and gender. The majority of black children with disabilities were completely excluded from the education system. White children with disabilities received an inferior education in segregated special schools in comparison with those in mainstream schools. In spite of progressive policy aimed at redressing the inequalities of the previous government such as the Constitution, South Africans Schools Act, Education White Paper 6 and the Employment Equity Act, the majority of people with disabilities, especially the youth, remain unemployed and thus excluded from mainstream participation and financial independence. Currently once a child turns eighteen they are no longer permitted to remain in schooling. Due to the inferior education received the majority of youth with disabilities cannot enter into higher education. For youth with severe disabilities, many stay at home or turn to life on the streets where they do not receive the care, safety or support that they require as there are no employment bridging facilities or places of care available. This paper examines what one principal, working in a school for children with severe disabilities in a very rural area of South Africa, is doing to address this situation. This is in spite of very limited funding from the government, absence of schools fees being paid by parents due to poverty, poor resources, being located away from large towns and cities, and accommodating many children with additional barriers. These include poverty, neglect, HIV/Aids and substance abuse. This examination shows what possibilities are available if an individual sees opportunities for partnering with local businesses through corporate social investment strategies, internships, business-case and has the belief that youth with disability have the potential and ability to make a meaningful contribution to the South African economy.

**Emma Louise Mckinney**

Stellenbosch University

**The Challenge of Employment: The Struggle of Integrating People with Disabilities into the Open Labour Market in South Africa.**

In formulating the Employment Equity Act, South Africa has produced promising employment legislation regarding the integration of people with disabilities into the open labour market. However, the lack of an integrated support framework for people with disabilities including health, education, transport and labour systems in the country represents a major challenge to this legislation reaching its full potential. As a consequence, most people with disabilities in the developing economy of South Africa have not been able to take advantage of this policy, and are being denied the opportunity to access and participate in the workplace, as well as experience general exclusion from society. This inability to contribute to the nation`s economy has had a negative impact on the objective of many people with disabilities in South Africa to become meaningful members of society. It has also meant that they remain reliant on the state for their monthly disability grant. This has negatively affected the way that people with disabilities feel about themselves, as well as perpetuate negative attitudes towards disability in the general South Africa society. South Africa was one of first countries to ratify the UN Convention on the Rights of People with Disabilities. Its disability policies, in line with its constitution, are progressive and adopt the social model of disability. However, this relatively young democracy has struggled to implement legislation, particularly due to lack of resources and overall support for people with disabilities. The presentation examines the Employment Equity Act, highlighting its strengths, along with success stories of people with disabilities gaining employment. It then focuses on policy, and the lack of implementation thereof, relating to education, health and transport, exposing the lack of support for people with disabilities in South Africa. The presentation concludes with recommendations to improve the integration of people with disabilities into employment.

**Damian Milton**

National Autistic Society and the University of Birmingham

**Autistic Expertise: A Critical Reflection on the Production of Knowledge in Autism Studies.**

The field of autism studies is a highly disputed territory within which competing contradictory discourses abound. In this field, it is the voices and claims of autistic people regarding their own expertise in knowledge production concerning autism that is most recent in the debate, and traditionally the least attended to (Milton and Bracher, 2013). In this presentation, I utilise the theories of Harry Collins and colleagues (Collins 2004, 2010, 2011, Collins and Evans 2007, Collins et al. 2006) in order to reflect upon and conceptualise the various claims to knowledge production and expertise within the field of autism studies, from the perspective of an author who has been diagnosed as being on the autism spectrum. The notion that autistic people lack sociality is problematised, with the suggestion that autistic people are not well described by notions such as the ‘social brain’, or as possessing ‘zero degrees of cognitive empathy’ (Baron-Cohen, 2012). I then argue however, that there is a qualitative difference in autistic sociality, and question to what extent such differences are of a biological or cultural nature, and to what extent interactional expertise can be gained by both parties in interactions between autistic and non-autistic people. In conclusion, I argue that autistic people have often become distrustful of researchers and their aims, and are frequently frozen out of the processes of knowledge production. Such a context results in a negative feedback spiral with further damage to the growth of interactional expertise between researchers and autistic people, and a breakdown in trust and communication leading to an increase in tension between stakeholder groups. The involvement of autistic scholars in research and improvements in participatory methods can thus be seen as a requirement, if social research in the field of autism is to claim ethical and epistemological integrity.

**Teodor Mladenov**

King's College London

**Disability and Neoliberalism in the Postsocialist Region: A Three-Dimensional Analysis.**

This paper proposes a framework for critical analysis of disability policy in the postsocialist region, building on Nancy Fraser’s (2013) work. It is argued that the problems of disabled people in the postsocialist societies of Eastern Europe can be understood by looking at the three dimensions of justice identified by Fraser – economic, cultural and political. These dimensions are irreducible to each other, but are nevertheless mutually influential.

In the economic dimension, the redistribution concerning disabled people in the postsocialist region is impaired by the neoliberal retrenchment of the welfare state, coupled with the neoliberal intensification of productivism along the lines of welfare-to-work (workfare) policies. In the cultural dimension, the recognition of disabled people in the postsocialist region is impaired by disablist assemblages inherited from state socialist welfare and underpinned by productivism, medicalisation and the ‘personal tragedy’ view. The increasing ‘neoliberalisation’ of society during the postsocialist ‘transition’ challenges these assemblages but instead of enhancing recognition, it tends to substitute them with other assemblages of misrecognition underpinned by principles such as responsibilisation and market-based competition. Finally, in the political dimension, the representation of disabled people in the postsocialist region is impaired by quasi-corporatist models of political participation of disabled people’s organisation in the policy-making process, whose genealogy can be traced back to the tokenistic political representation and participation during state socialism.

The analysis in each of the three dimensions will be supported by examples of disability policy, disability activism, and everyday life in postsocialist Bulgaria. Parallels with disability policy in other postsocialist countries, as well as the UK, will also be drawn.

**Brigit McWade**

Lancaster University

**Recovery-As-Policy as a Form of Neoliberal State-Making.**

The emergence of recovery in/from serious mental health problems as a conceptual frame, and as a set of practices and policy orientations can be situated within a broader cultural shift in healthcare, from 1970s onwards, that positions patients as either consumers or citizens. In this paper I consider the beginnings of recovery as a policy object and commitment (recovery-as-policy), which can be situated as part of the New Labour government’s (1997-2010) reform of the NHS during the 2000s. Through a textual analysis of policy and legislation from this time I am to draw out a tension between contemporary ideals of choice and autonomy in healthcare and the specificities of a mental healthcare system in which psychiatrists are legislatively empowered to treat patients without their consent. It is my contention that these so-called recovery-orientated policies are practices of neoliberal state-making that make space for increasingly repressive legislation.

Drawing upon Imogen Tyler’s (2010) work, I explore how British citizenship is designed in such a way to ensure the failure of some groups of people; in the area of mental health, evidence continues to show that the people most likely to be detained under the Mental Health Act 2007 are either poor or Black (or both). I posit that exclusion and detainment are constituent elements of the ideals of neoliberal citizenship, self-responsibility and choice. As such, these turn of the century policies and legislation enact people with serious mental health problems within a paradox. Following Spandler & Calton (2009) I contend that recovery-as-policy in the era of New Labour’s third way sidesteps important questions concerning ‘what people have recovery ‘from’ [and what] people are supposed to be included ‘in’’ (p. 251), due to the socio-political-economic concerns of neoliberalism. I raise concerns about what other forms of recovery the enactment of recovery-as-policy marginalises.

**Oliver Mutanga**

University of the Free State

**Collision of Identities: An Analysis of Race, Class and Gender Among Disabled Students at Two South African Universities.**

Race, class and gender can serve as catalysts of social mobility that inspire individuals to strive for lives outside of the socially constructed norms. However, there is limited knowledge on the intricate interplay of race, class and gender in the lives of disabled students in South African higher education (SAHE) due to the erroneous treatment of these individual concepts as homogenous variables. This paper adopts a capabilities approach (CA) to disability issues and examines the decision-making processes of disabled students at two South African universities and how they negotiate different socio-cultural and institutional structures. In-depth interviews with thirteen disabled students established notions of agency, difference, values and meaning, which are significant in power relationships between disabled and non-disabled people. Irrespective of disabled students’ race, class and gender, their personal ambitions, general upbringing and attitude towards disability had positive influences in their lives and on their educational experiences at university. Study implications demonstrate the importance of CA in unmasking other disability theories, which conceal structural differences embedded in identity signifiers such as class, race and gender that explain disadvantage and social exclusion.

**Ursula Naue**

University of Vienna

**Acquiring Austrian Citizenship: Disability and the Perversity of Powerful Norms.**

Art 18 of the CRPD refers to the right of persons with disabilities to acquire a nationality.

During the last years, several cases came to light where the Austrian citizenship was not granted to persons with disabilities, because they receive welfare benefits. Until 2013, it was regulated in § 10 (1) 7 and (5) of the Austrian Citizenship Law that a person has to be equipped with sufficient means of subsistence, and that s/he does not receive welfare payments. A 2013 decision by the Austrian Constitutional Court de-legalised § 10 and the court initiated a judicial review of the Austrian Citizenship Law which led to a revision of the law. Now, 10 (1) 7 does not apply to persons with disabilities or persons with permanent severe illness. Even though the amendment of the law is a positive development, the rationale and norms behind the revision of this law are based upon an alarming logic: To impede migration into the Austrian social system, in one case, in which citizenship was not granted to a woman with disabilities, the authorities suggested that her parents (already Austrian citizens) should become her legal guardians and be responsible for her sufficiently secured maintenance as a precondition for acquiring Austrian citizenship. Perversely, in this case the right to be entitled to welfare benefits is substituted by giving up one’s independence. Starting from this case and referring to two statements by the Independent Monitoring Committee on the CRPD on the amendment of the Austrian Citizenship Law, the paper explores the underlying assumptions in Austrian society and politics that build the framework for the debate about the relationship between citizenship and disability and which are obviously not in line with the CRPD.

**Britta Nørgaard**

UCN and AAU

**What is it Like to be an Adult with Intellectual Disability? – Lifeworld Experiences Meeting a Professional World Related to Axel Honneth’s Concepts of Recognition.**

What is it like to be an adult with intellectual disability in a modern society as the Danish? This question is seldom raised in the Danish Disability Research as it is hardly constituted as a research area at all.
Through lifeworld interviews people have told me about their experiences as adults with partly invisible intellectual disability, living their lives dependent on people from different professions. These interviews are made with a phenomenological approach, and they tell stories from living a life very different from many of us. Some of the interviews are made with people born with intellectual disability – they have never lived a life as so-called “normal”. Others have got a brain damage as adults, and they have all lived a so-called normal life before. Observations in daily life and work and interviews with focus groups with different professions have given me an overall impression of the meeting between the citizen and the professional. The social philosopher Axel Honneth says that lack of recognition and infringement often can be seen outside the public eye. Often infringements are caused by people close to the person experiencing this lack of recognition or offence. We all hope to be met with recognition and understanding, and we are becoming who we are in interaction with others. It is very interesting to investigate values reflected in the professional meetings between the citizen and the professional. Is recognition as Honneth sees it part of these meetings – and can other phenomenological approaches contribute to the understanding and perhaps improvement of these meetings? These professional meetings are based on many different conditions. Economy, effectiveness and education are included in these conditions. So are policies, traditions, culture. The UN Disability Convention is signed also in Denmark, but we can still discuss if the implementation has succeeded.

**Terje Olsen1, Patrick Stefan Kermit2**

1Nordland Research Institute

2Norwegian University of Science and Technology

**UNCRPD and Rule of Law.**

By ratifying the Convention on the Rights of Persons with Disabilities (UNCRPD), nation states take on a responsibility to follow the legal standards defined in the Convention. Among other things, this responsibility includes complying to specific requirements in availability for disabled people to the criminal justice system. These principles are defined in the Articles 5, 9, 12-16.

During the later years all the three Scandinavian countries have ratified the convention. Denmark, Norway and Sweden are usually regarded as having high standards in rule of law (Al-Misnad et al 2014). During the later years, however, Norway and Sweden have had some of the worst cases of miscarriage of justice, where people with disabilities have been victims.

In this paper we will discuss the UNCRPDs potential to develop the national criminal justice systems, and the associated practices, to help making better rule of law for people with disabilities. Central questions are: What effects does the implementation of UNCRPD have on national laws in the Scandinavian countries? What potential does UNCRPD have in these matters? The discussions will take as its point of departure two particular cases from Norway and Sweden.

**Ruchi Palan**

University of Sussex

**“I seriously wanted to opt for Science but they said no”: ‘Access’ to Higher Education for Students with Visual Impairments in India.**

In the Global South, disability-related research is limited and most is focused on generating large, quantitative data on prevalence of various disabilities and establishing the usefulness of rehabilitation programmes. In India, the disability legislation provides concessions and aims to facilitate disabled students’ entry to higher education (HE); yet, there has been little effort to understand students’ experiences.

The findings reported here are from a qualitative study that mapped the experiences and aspirations of 66 students with physical and/or sensory disabilities in HE institutions in Mumbai, India. Data was collected by the author in 2012-13 using semi-structured interviews. This paper focuses on the experiences of 31 students with visual impairments. It was found that one of the main obstacles they face is access to higher education. The lack of information, low levels of awareness and attitudinal barriers on the part of staff and HE authorities often limits student choices and prevents their entry to courses that give prominence to the ‘visual’ such as economics, mathematics, science and physiotherapy. However, some participants had challenged the dominance of the ‘visual’ and entered courses of study previously thought to be inaccessible; “I just want to set an example that you can also do BMS [Bachelor of Management Studies]; it is not a big deal.”

It is argued that in India, there is a need to broaden the understanding of ‘access’ to HE for students. ‘Access’ needs to address entry for disabled students to a course of study of their choice, to the extent possible. In 2014-15, the author will be studying the UK concept of ‘reasonable adjustment’ for its efficacy and possibly, its applicability to the context of India.

**Martin Partridge**

Staffordshire University

**Including People with Learning Difficulties from Chinese Backgrounds: An Ethnography of Three Services.**

This research aims to investigate the culture of two culturally specific and one integrated service used by people with learning difficulties from Chinese backgrounds. The study was undertaken to address the lack of research currently available on the service and inclusion experiences of people with learning difficulties from Chinese backgrounds in England, to explore the importance of taking specific cultural contexts into account in policy development and service practices and to consider the importance of culturally specific services for this group of people.

This study uses a qualitative ethnographic methodology which involves participant observations, semi-structured interviews and ethnographic analysis to explore the ways in which Chinese-specific services and integrated organisations include adults with learning difficulties from Chinese backgrounds. Key informants provided specific cultural knowledge that added to the researcher’s observations and the understanding of participants’ experiences of the service they used. Participants were both men and women aged eighteen and over who were from Chinese backgrounds. In some cases an interpreter was used.

The findings reveal that the experience of people with learning difficulties from Chinese backgrounds in accessing services was different for those in culturally specific and integrated services. In particular within the culturally specific services family members were seen to be of primary importance for the person with learning difficulties accessing and using the services. However, across all the services in this study, people with learning difficulties from Chinese backgrounds experienced life as fringe-dwellers, as people who had a physical presence with limited social inclusion. The findings from the study reveal the importance of services sharing knowledge and resources in order to provide a more inclusive place for people with learning difficulties from Chinese backgrounds.

**Abigail Pearson**

LLM student at Keele University

**Reasonable Adjustment: The Golden Goose or the Cuckoo in the Nest of Equality?**

The duty to make reasonable adjustment for persons with disabilities in the UK arrived with the enactment of The Disability Discrimination Act 1995 (DDA). For the first time, there was a legal duty for employers and service providers to ensure that persons with disabilities were not placed at a substantial disadvantage compared to people without disabilities. However, this came with a caveat: adjustments need not be implemented if they could be shown to be ‘unreasonable’ in terms of cost and disruption to the nature or running of the business. Moreover, there were no legal sanctions for failure to comply with the legal duty.

In 2009, the UK ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), which protects and promotes the right to full social, cultural and economic participation. However, the duty to make reasonable adjustments and the available limitations based on undue burden remain unchanged. This may appear merely to be a consolidation of the previous exemptions to making adjustment. However, in the context of disability equality, ‘burden’ is suggestive of an inconvenient load which must be carried, a prevalent view of persons with disabilities in years gone by.
2010 saw the UK consolidate all pieces of equality legislation with the Equality Act. The requirement of reasonable adjustment remained unchanged, save for the fact that duty was made anticipatory.
19 years and two pieces of legislation since the DDA, persons with disabilities still have to justify their rights to access and participation within society as being not unduly burdensome and reasonable: parameters set by those who they do not affect.

This paper will propose that the notions of ‘reasonable adjustment’ and ‘undue burden’ should be removed completely from legislative vocabulary and replaced with the phrase: ‘assurance of rightful access.’

**Paula Pietilä, Matti Laitinen**

Threshold Association

**The Disabled Writers Challenging the Rules of Autobiography?**

In this presentation we discuss issues related to the production of autobiographies and those challenges, which concerns especially people with disabilities as autobiographers.

Our presentation draws on an ongoing research project Living with disabilities in Finland. The project is collecting a large body of autobiographical material. The autobiographies of disabled people are collected via several methods, mainly by making life-story interviews and by gathering written autobiographies in cooperation with Finnish Literature Society.

Our aim is to study the process and the results of this gathering and to provide answers to the following questions:
How the gathering was carried out?
Who participated in the gathering by sending texts?
What kind of texts the participants produced and sent to the gathering?

Some preliminary observations

By the beginning of January 2014 seventeen autobiographies were sent to the gathering. Fourteen writers were women and only two men. In one text, the writers’ sex was uncertain. The number of pages was 473 altogether. Most of life stories were short, one page or less. We can only guess, could the disability be one reason for that. We tried to assure equal possibilities to participate for giving different ways to produce an autobiography, for example to record it or using a clerk. Despite that, writers with learning disabilities were missing and two autobiographies were written by non-disabled people. Again, we have to think about, what is the difference between autobiography and biography? What are the borderlines between these two?

Who identified oneself as a disabled person and decide to write an autobiography? This question came up, because most of the writers have motor or neurological disability, despite the advertising of the gathering try to persuade people with different kind of disabilities to participate.

**Paula Pinto**

ISCSP, University of Lisbon

**Indicators for Monitoring Disability Rights: Developing a Framework.**

Article 33 of the UN Convention on the Rights of Persons with Disabilities specifically calls upon State Parties to establish a framework to monitor the implementation of the Convention. This requires a set of qualitative and quantitative indicators to measure progress in the implementation of the norms and principles of the Convention. Indicators are methodological tools of empirical basis which provide information about aspects of the social reality or the changes that are taking place in it. In the human rights field they have been defined as “a piece of information used in measuring the extent to which a legal right is being fulfilled or enjoyed in a given situation” (Green, 2001:1065). They serve as a tool for policy design and to communicate information. Both quantitative (numerical or statistics-based) and qualitative indicators are necessary to reveal how human rights are being upheld (Green, 2001).

To address this challenge, we conducted a holistic monitoring of the current status of disability rights along three strands: law and policy, social representations - through media analyses - and daily life experiences of persons with disabilities, aged 12 years and older, in Portugal. Taken per se, each of these areas is relevant, but insufficient, to understand how persons with disabilities fare in society. Brought together, however, they offer a holistic picture that enables us to examine the processes and interactions that produce disability discrimination.

On the basis of this knowledge, and a literature review on human rights and disability rights indicators, we designed a set of qualitative and quantitative indicators to monitor the CRPD. A preliminary version of this framework will be presented and discussed in this paper.

**Andrew Power**

University of Southampton

**‘Care in the Commons’: Adults with Learning Disabilities Building Welcoming Communities in a Post-Service Landscape.**

With the increased commitment towards personalisation in adult social care, allied with more ‘austere’ funding of local authority social services, support is increasingly becoming more ‘place-less’ and woven into everyday spaces within the community. Consequently, support is becoming re-framed from ‘care’ in care settings towards an effort at enabling meaningful lives nested in local neighbourhoods and mainstream community settings. This paper explores the complex relational intersections involved in delivering individualised support within this context and traces the lives of adults with learning disabilities in the wake of day care centre closures. It draws on interviews with support managers and repeat focus groups and photo diaries with adults with learning disabilities in Southampton and SW Hampshire on their experiences of negotiating support arrangements. It identifies new ‘moments of inclusion’ which are emerging, including allotments, marina’s and fish and chip shops, and examines the role adults with learning disabilities themselves play in making communities more welcoming.

**Mark Priestley, Ema Loja**

University of Leeds

**The Political Participation of Disabled People in Europe.**

This paper examines the concept of political participation as it intersects with the social inclusion of disabled people in Europe. The paper takes a broad view of political participation, situating access to voting in the wider relations of political institutions, citizenship and civil society. It arises from research carried out in 34 countries under the auspices of the European Commission and the European Agency for Fundamental Rights (FRA to support the work of the EU-level monitoring framework of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Data from this research was used to populate 43 qualitative and quantitative indicators concerning rights to full participation in public and political life, and including electoral and voting rights in European, national and municipal elections. The methods included secondary analysis of European survey data, desk research, and enquiries by national experts in each country. The findings indicated the need for three lines of action: (a) to ensure greater freedom and privacy in voting and standing for public office; (b) to make voting procedures, facilities and election materials more accessible, (c) to expand opportunities for participation in wider public and political life. Social movements as well as institutional actors have an important role to play in delivering full and equal political participation for disabled people in Europe. A compendium report was compiled and selected indicators widely disseminated during the 2014 elections to raise awareness and impact on the inclusion of disabled people in political process.

**Rachel Purtell1, Peter Beresford2, Alan Roulstone3**

1University of Exeter Medical School

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3University of Leeds

**Living and Dying in Disability Studies.**

It was eight years ago that Professor Len Barton first introduced ‘The Issue of Death’ to the Conference. Professor Barton posed a number of questions then, amongst them were: ‘How do we keep alive positive memories of colleagues who have died? What impact can this have on our lives? Given that Disability Studies is ultimately concerned with fundamental values and transformative changes, can a positive recognition of death encourage a serious critical engagement with questions concerning the purposes of our lives/work?’ In the subsequent conferences we have tried to think more about these questions and deepen our understanding. In the current climate there seems to be a real and consist threat to the founding principles of Disability Studies, Independent Living and using the Social Model as the foundation for creating an equitable society. It is therefore with all this in mind that once again we invite you to join in a discussion about how we keep alive the values and work of Disabled People who have been so important to our lives.

In this session we would like to discuss the practical ways we might keep this work alive. For both the community of Disability Studies and, perhaps more importantly, for the wider community of Disabled People.

**Rachel Purtell1, Allan Sutherland2**

1University of Exeter Medical School

2Disability Arts

**Who has the Power in your Care Set-Up?**

**A Powerful Documentary about Shifting Power to the Care User.**

The film produced & directed by David Hevey.

The care industry is set up for the care-users, yet they have the least
power. Social care is in flux and, some say, crisis. This trenchant documentary, made by critically-acclaimed filmmaker David Hevey, argues that now is the time to shift more power to the support-users, in whose name the Care industry exists. Filmed with the direct involvement of care-users, this is Hevey's personal inquiry into the state of social care in England and the lack of power among support-users. However this session will include a unique opportunity to hear about the journey of the film, the aspirations and fears of those who commissioned it and took part in it and how things have changed from when it was made just two years ago.

**Marcus Redley**

University of Cambridge

**Equal Recognition Before the Law: Article 12 of the Convention on the Rights of Persons with Disabilities and its Implications.**

Equality before the law, a fundamental principle of all human rights protections, is found in the Universal Declaration of Human Rights and the International Convention on Civil and Political Rights. Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) provides a further description of this right by focusing on (i) areas where people with disabilities are denied full legal capacity, and (ii) describing the supports and safeguards that are necessary in order to ensure that people with disabilities enjoy equality before the law. This right, as affirmed in Article 12 of the CRPD, has proved to be somewhat controversial. For the affirmation of universal legal capacity places an obligation on States to abolish all legal instruments, such as, in the England and Wales, the Mental Capacity Act and the Mental Health Act, which permit -- albeit under tightly regulated circumstances and in the presumed interests of the person concerned -- the imposition of substitute decisions where a person has a diagnosed disability and/or a severe mental health problem. This paper, responding to a recent defence of the Article 12 published by the Committee on the Rights of Person with Disabilities, will (1) explore the arguments for and against the CPRD’s affirmation of universal legal capacity, as well as any potential risks and benefits; (2) consider the extent to which the controversy over Article 12 sheds new light on how intellectual disabilities are conceptualised and (3) assess the utility of a human rights perspective for understanding the plight of people with diagnosed with a intellectually disability.

**Donna Reeve**

Centre for Disability Research / Lancaster University

**Homo Sacer, States of Exception and Zones of Indistinction: An Analysis of Disabled People’s Experience of Welfare Reform in the UK.**

This exploratory paper will utilise the liminal figure of homo sacer (Agamben, 1998) to consider the experiences of disabled people living at the sharp end of a major reform of the welfare system supporting those traditionally considered too ill to work. This is happening at a time of high unemployment and economic recession in the UK.

Two aspects of homo sacer will be discussed in this paper. Firstly it will be shown how disabled people can find themselves caught up in an ‘economic’ zone of indistinction, as a consequence of a state of exception caused by these neoliberal policies. For example, the changing of eligibility criteria for out-of-work benefits paid to disabled people has resulted in a group of disabled people who are now deemed to be fit-to-work rather than unfit-to-work. However existing barriers to paid work – whether related to the consequences of impairment or to employer attitudes – remain unchanged and so rates of employment remain low compared to non-disabled unemployed people.

Secondly, a key aspect of homo sacer is that (s)he can be killed with impunity, without the death being treated as homicide (Agamben, 1998). There have been a number of recent deaths and suicides of disabled people that have been attributed directly to benefits cuts or to the anxiety and stress caused by the work capability assessment process. The government refutes these claims and simply offers condolences to the family of the dead claimant. This ‘letting die’ of disabled people as a consequence of welfare reform could be seen as an example of the inherent structural violence associated with neoliberalism (Tyner, 2014)

This paper aims to use the figure of homo sacer to illustrate the contradictory and precarious positions that disabled people are often forced to adopt as a consequence of neoliberal welfare reform

**Ieva Reine**

Uppsala University

**Swedish Survey of People Entitled to Assistance Allowance.**

Ever since the personal assistance reform took effect in 1994, people with a substantial and durable disability have been entitled to personal assistance. To qualify for government attendance allowance, a person must belong to one of the groups predefined in the Act concerning Support and Service for Persons with Certain Functional Impairments and require personal assistance with their basic daily needs for more than 20 hours a week. In 2010 the Swedish Social Insurance Agency carried out a survey to all people (n=15,515) entitled to assistance allowance. A total of 10,200, or 67 per cent, of the responses were valid. The percentage was very high considering the potential difficulties involved for this population.

The aim of this study was to gather more comprehensive knowledge about the population that receives assistance allowance. The study was based on cross-sectional analysis involving both registry and survey data. It describes the respondents’ need for assistance, their attitude towards the assistance provider, what kind of living arrangements they have and the tasks that assistants perform. The study includes even questions about service, thoughtfulness and support on the part of assistants, as well as discrimination, financial considerations, participation and psychological variables.

A higher percentage of men are entitled to personal assistance than women, and the majority has durable physical or mental disabilities that are evidently not caused by normal ageing. Eight out of ten people entitled to personal assistance have a physical disability. Multiple disabilities are also common. More than half of the respondents had acquired their disability during their lifetime and had it for an average of approximately 18 years.

The results also showed that personal assistance is experienced by users and proxies as a valuable support that largely meets Sweden’s obligations pursuant to the UN Convention on the Rights of Persons with Disabilities.

**Melvina Robbin**

University of Strathclyde

**The ‘Gold Standard’ of Independence: A Carer and Professionals’ View of How Social Workers’ Support Black and Minority Ethnic (BME) Families Involved in Transition Planning for Young Disabled People in Scotland.**

Research investigating the role of social workers in supporting young disabled people from Black and Minority Ethnic (BME) communities’ transition to adulthood in Scotland is limited. The presentation of their experiences are implicit within this preliminary study, which aimed to uncover issues surrounding how social workers support BME families involved in transition planning for young disabled people. The operation of power within social worker-family dynamics provides a critical approach to the central issue of culture, and subsequent explanation for challenges in transition planning. This study was carried out using a qualitative design involving three semi-structured interviews with a small sample of one carer and two BME agency advisors. A thematic framework was established from the interviews using Interpretive Phenomenological Analysis, allowing for a small sample size to be used. The findings suggested that social workers fostering relationships and understanding the families’ set up, such as parents being multiple carers was important. Being culturally aware in providing services like respite care created difficulties for social workers who adopted a ‘they look after their own’ approach in supporting South Asian families. A lack of feeling entitled to services with families who had migrated to the UK, culture clashes and communication difficulties hindered transition planning. Achieving ‘independent’ status was perceived as a successful transition by social workers. The assumption that young people want to leave home based on a ‘natural’ progression is widely practised in Western culture. However Pakistani families challenged this assumption in instances where young peoples’ older siblings still lived at home. The cultural challenges, underpinned by social worker-family power dynamics appear to be partially influenced by Western ideals, imposed by professionals. This study provides a foundation for understanding how social workers support BME disabled people by considering the wider context of their family dynamics in transition planning.

**Poster**

**Bethan Roberts, Suzanne Hodge and Emma Munks**

Lancaster University

**An Exploration of the Experiences of Members of a Group Which Aims to Promote Lived Experience of Disability.**

Research suggests that involvement in health service-user groups and in advocacy groups can be beneficial to the wellbeing of members and that this is also the case for group members who have a learning disability. Previous research has often focused on groups related directly to health services and has not focused on groups such as social enterprises. These are businesses trading for social purposes that in some cases can be advocacy groups in their own right.

This study explored the experience of being in a social enterprise group for people with learning disabilities. This group trains professionals and peers on the rights of people with learning disabilities, and on improving communication and involvement between services and service-users. The study explores how membership of this group relates to the wellbeing of members. Five group members were interviewed and their transcripts analysed using thematic analysis. Five over-arching themes were identified (feeling connected; empowering to self; empowering to others; evolution; impact of external factors). The results suggested that being part of a social enterprise brought with it a sense of ownership and responsibility which contributed positively to factors linked to wellbeing. This relationship between ownership and wellbeing is discussed in relation to clinical psychology services.

**Poster**

**Alan Roulstone**

University of Leeds

**The End of Disability Voice: PiP and the Dispossessed?**

This paper focuses on reforms to the Disability Living Allowance System and the emergence of Personal Independence Payments. The DLA system has served a pivotal role in offering non-stigmatised and non-means tested benefits for disabled people. To date eligibility has not involved gatekeeper professions. Recent reforms have however been different in coalescing around the contested disabled body, ambulant performance, while erasing references to pain and fatigue which were once accounted for in disability benefits. It argues that by shifting the focus of UK disability policy towards the minutiae of bodily performativity, the consequent shifting of the disability policy may cause unprecedented hardship.

Disability and policy studies needs to re-engage with debates focused around who counts as disabled and corporeal contestation if it is to inform developments that we will otherwise profoundly regret.

**1Katherine Runswick-Cole, 2Dan Goodley, 3Val Williams, 4Toby Brandon, 5Annie Ferguson, 6Keith Bates, 7Pete Crane, 7Wendy Crane, 8Laurence Clark, 5Jodie Bradley**

1Manchester Metropolitan University

2The University of Sheffield

3The University of Bristol

4Northumbria University

5Speak Up

6Foundation for People with Learning Disabilities

7Circles of Support

8Pathways Associates

**Disability, Theory and Activism in a Time of Austerity.**

This panel session will bring together the research partners for an on-going research project “Big Society? Disabled People with Learning Disabilities and Civil Society” to discuss disability theory and disability activism in a time of austerity. We ask: how can disabled people live well in a time of austerity?
We see the cuts to services and support for disabled people, in particular, as well as the wider cuts agenda, as a clear and present danger.
This session will seek to expose these threats as well as pointing to acts of resistance and refusal in the lives of disabled people focusing on three sites of resistance: self-advocacy, ‘real’ employment and circles of support.

Accessible summary

* We are a group of people working together on a project to find out how people with learning disabilities are living with the cuts.
* We would like to come to the conference to tell people about what we have found out.
* We would like to talk about people’s experiences of self-advocacy, employment and circles of support.

**Sara Ryan**

University of Oxford

**Continuing to Get it Wrong for Learning Disabled People and their Families. Time to Stop 'Learning Lessons'.**

In this presentation I reflect on the vagaries of the personalisation agenda and the mental capacity act in the UK, and how these work in practice. I discuss how these tools can lead to the pitting of families against services and support in the negotiation of meaningful lives with, and for, learning disabled family members. Drawing on the personal experience of the death of our 18 year old son, LB, in an assessment and treatment unit in July 2013, I explore how the love provided by family and friends is typically both taken for granted, and relied upon, across the childhood of young people like LB. This changes when 'adulthood' is reached at 18 and family love, knowledge, understanding and expertise is often obscured by the bureaucratic and arbitrary workings of differing agendas around budgets, resources, 'best interests', convenience and power.

I ask how there can continue to be such a disconnect between families, learning disabled people and services given the layers of policy, procedures and practice introduced over the last few decades. Indeed, services provided often make things harder for families (a point raised by Ann Shearer in 1981). I conclude by reflecting on how measures specifically designed to improve the life experiences of learning disabled people often fall short of achieving their desired aims and advance some suggestions as to why this may be.

**Marta Sałkowska**

Collegium Civitas

**"We had to make it normal that she was not normal". Subjective Meanings of Normalcy among Mothers of Persons with Down’s Syndrome in Norway and in Poland.**

The subject of this paper is subjective meanings and definitions of normalcy, normal child, normal life among mothers (both Norwegian and Polish) of persons with Down’s Syndrome. A qualitative study was conducted (2009 – 2011) with mothers of children, teenagers and grown-ups with intellectual disability (16 Polish and 5 Norwegian). The main question asked is: what do “normal child”, “normal life”, “normal behaviour” mean? It appears that after giving birth to a child with Down’s syndrome women very often had to redefine normalcy. Normal is no longer typical, most common in the society. Statistical criteria stopped being crucial in defining normalcy. Not normal (not typical) becomes the new normal – for the mother and for the family. But it is still expected that mother would make her child as normal (typical) as possible so that others perceive her or him quite normal. What it means to have a normal child that is not normal for others? According to mothers it means to act as if she or he was normal, to treat the child the same as other children, to accept his or her needs (including the sexual needs when the child gets older), to stress those aspects that are the same as among peers without disabilities. It also means to have quite normal life – with a normal job and a normal family that needs some extra arrangements. Study participants stress that sometimes they have to prove that they are able to spend their time the same way as others. But not normal means also unpredictability. Not normalcy has both positive and negative aspects. Professionals’ role in defining normalcy is also discussed.

**Frederike Scholz**

University of Leeds

**Disability Discrimination and the Recruitment Process: Responding to Legal and Technological Developments.**

This paper focuses on research, which is concerned with the employment of disabled people in the UK; in particular, the way in which recruitment and selection may impact negatively upon those with impairments. The main emphasis is to investigate if online recruitment and selection create additional burdens or barriers for disabled people, especially for individuals with visual impairments or learning difficulties and disabilities. The Internet was supposed to be accessible for everyone; however it can lead to major accessibility barriers for disabled people (European Commission (EC), 2008).

This paper discusses the “digital-divide” which is the gap, between people in society who have already access to these Information and Communication Technologies (ICTs) and those who have no access or lack the appropriate skills to use them (Cullen, 2003; Vincent and López, 2010). It will argue that not only technical features can hinder disabled people in using the Internet, (EC, 2008), but that there are also socioeconomic barriers for individuals in purchasing, using and accessing ICTs (Vincent and López, 2010).

The paper will underline the unique contribution of this research in which it attempts to synthesise ideas and different theoretical approaches from across disciplines (work and employment, disability, ICTs and legislation), by using an innovative qualitative multi-method approach to explore different aspects of the topic. The methods adopted are ethnography, netnography (online research), and semi-structured interviews with disabled people and demonstrate an inclusive research approach in which disabled participants are not only participants, but are also involved in the research design. Overall the paper will present the initial part of the fieldwork, including different methodological approaches, and will demonstrate preliminary research findings.

**Ann Fudge Schormans, Esther Ignagni, Tania Jivraj, Self-Advocate Parenting Working Group**

McMaster University

Ryerson University

Ryerson University

Reimagining Parenting Possibilties

**Disability, Parenthood and Failing Domesticity.**

Reimagining Parenting Possibilities is an Ontario-wide community-based, participatory research initiative. Using a co-researcher model, the project attempts to privilege the voices of people labelled with developmental disabilities. Together we explore labelled people’s inclusion and participation in domesticity, specifically parenthood. Domesticity is the site where intimate citizenship is lived, future citizens are nurtured, and public citizenship ideals are fostered. Yet domesticity is a site from which disabled people have been “forcibly absent” (Das&Addlakha, 2007). In the global North, sterilization, cultural invisibility, misrecognition, de-sexualization and institutionalization have led to forced non-citizenship by denying access to systems by which citizenship is conferred. Thus Reimagining Parenting Possibilities both recognizes and positions labelled people as possessing the capacity to live citizenship in diverse and valued ways, including through domesticity. With the project underway, we confront troubling questions. To what extent are labelled people thrust into domesticity’s shadows, relegated to yet another private and marginalized space? Are labeled people, historically infantilized and constructed as incapable dependents, forced to perform a default domesticity? Must they seek inclusion without challenging ableist, heteronormative assumptions and institutions? Are they compelled to perform a privatized, depoliticized self anchored in the reproduction of neoliberal citizenship? Do they risk reproducing domestic relations in which they are consigned to be failed citizens? And what are the consequences of ‘failing domesticity’ for labeled people? We mobilize Halberstam’s (2011) ‘art of failure’ to explore moments when labelled people ‘fall short’ of domestic and parenthood expectations. These reveal the failure of social care systems to support all parents, and the failure of conventional forms of domesticity to support labelled parents. But such failings also ‘disorder’ and resist conventional domesticity and domestication. Ultimately, domestic shortfalls serve as an entry-point to imagine and enact innovative, transformative and affirming forms of parenting, kinship and domesticity itself.

**Henia Schwartz**

Center for Independent Living, Jerusalem

**The Center for Independent Living Jerusalem (CIL) - Assistive Technical Devices Workshop.**

The Center for Independent Living - Jerusalem (CIL) was established in 2003 by Disabled Now - the Movement for Rights of People with Disabilities in Israel, following a widely publicized, 70-day demonstration of people with disabilities in front of government offices. This demonstration brought the plight of people with disabilities into the forefront and succeeded in lobbying for critical financial support and a wide range of transportation benefits including wheelchair accessible vans and special driving lessons for people with severe disabilities. CIL's mission is to support, through provision of multiple services, independent living of people with disabilities in the community, and to promote social change by positively impacting upon the Israeli public's perception of people with disabilities. Over 1,200 people with disabilities receive services through CIL's programs.

Technology makes it possible for people with disabilities to have control over their lives and to attain a maximum level of independence. Assistive technical devices are very individualized and many of them must be customized in order to meet the needs of a person with disabilities. To this end, CIL operates a unique Assistive Technical Devices Workshop for creating innovative assistive technical devices for daily living such as a handle to help someone turn on a light or flush the toilet and many other exclusive devices. The workshop is managed by Mr. Elad Erenst who graduated in Universal Inclusive Design at Hadassah College in Jerusalem. Mr. Erenst has developed groundbreaking devices to assist people of all ages who are amputees, blind, paralyzed or suffer from physical disabilities that severely affect their quality of life. These devices are not available off the shelf – they are customized to each person's needs. Research that was performed shows that 100% of the people who received assistive technological devices from our workshop significantly improved their functioning and quality of life.

**Marie Sepulchre**

Uppsala University

**Experiences of Citizenship and 'Disability Identity' in the Swedish Context.**

Citizenship has become a central concept in discussions about the participation and inclusion of disabled people. Drawing upon life-course interviews with Swedish people having different impairments (difficulties in seeing, psychosocial difficulties, intellectual impairments and mobility difficulties) this paper tackles two issues. First, the interviewees’ experience of citizenship, apprehended as the ability to engage in the public arena, and, second, the issue of a ‘disability identity’. According to Ellison (2000), the contemporary societal context encourages individuals to engage in the pursuit, or defence, of particular interests and/or social rights. Citizenship is to be understood as a process of engagement, although solidarities are likely to be temporary in a fragmented public sphere. This understanding of citizenship takes into account the need to have access to power networks and resources to engage in the public arena. In a similar way, Lister’s (1998) dynamic reading of citizenship stresses agency, embedded in and shaped by social structures and relations. Lister also raises the issue of differences and warns against ‘false universalisms’, which exclude a part of the population. She suggests the concept of ‘politics of solidarity in difference’, which appreciates identities as manifold and fluid, and considers that people engage when they identify a clear common goal.

Relating this discussion to disability, this paper questions the existence of a ‘disability identity’, which brings people to engage in the public sphere about disability issues. This is a contested topic in Disability Studies; while various authors have stressed the existence of a strong collective identity as a founding element of the disability movement, others have observed that members of disability organisations do not identify as disabled, have underlined the fragmentation of the disability movement and have questioned whether people with mental health conditions should be considered as ‘disabled’.

**Marie Sepulchre**

Uppsala University

**Exploring the Meaning of 'Community' in Relation to Citizenship and Experiences of Disability.**

Starting from the observation that discourses about citizenship with regard to persons with a disability are often being linked to notions of ‘full inclusion and participation in the community’, this paper sets out to explore the meaning of the concept of community, which often remains vaguely defined. ‘Community’ is a complex concept and researchers have highlighted that communities exist both as a physical place and as a locus of affiliation or identification. Furthermore, while some understand ‘community’ as a space with clear boundaries – which can be physical, psychological, social, temporal or cultural – others view it as something fluid and without precise definition. It can also be noted that contrasting emotions are related to different conceptions of ‘community’, ranging from nostalgia to fear and envy.

The analysis brought forward in this paper begins with a discussion about the use of the concept of community in the UN Convention on the Rights of Persons with Disabilities. It continues with investigating what ‘community’ means from the point of view of persons with disabilities. The analysis is grounded in life-course interviews with Swedish women and men from three generations (born in 1950s, 1970s, 1990s) and having different impairments (difficulties in seeing, psychosocial difficulties, intellectual impairments and mobility difficulties), and adopts an intersectional approach, i.e. the analysis takes into account aspects of gender, age and impairment, with a particular attention for comparing psychosocial difficulties, i.e. mental health problems, with other types of impairments. It is argued that a discussion of the concept of ‘community’ grounded in empirical data (life-course interviews and the CRPD) brings fruitful insights for the understanding of citizenship with regard to disability.

**Mark Sherry**

University of Toledo

**The Anti-Crip.**

This paper extends on a critique of crip theory which I began in the feminist journal "Feminist Wire" - a critique which suggests that while this approach has been popular among some disability studies scholars, it is deeply flawed.

While the crip discourse may be popular among disability studies academics, it is not popular among disabled people. Ironically, however, the idea of "coming out crip" through a playful performative politics has been attractive to many nondisabled people. This paper explores some of the reasons why this might be the case.

I offer an alternative approaches to the sociology of impairment, the sociology of the body, and the sociology of identity. This approach is deeply grounded in my work with disabled people, particularly (but not exclusively) reflecting on my community work with people with brain injuries and hate crime victims. My approach
foregrounds the patterns of broader social inequality which are deeply connected with the experience of impairment, identifies and challenges disabling barriers including psychoemotional disablism, takes embodiment seriously, and also explores the complexities and ambiguities of disability identity. It relies on an amalgam of theoretical orientations and critically explores the relationships between researchers and disabled people. In terms of meeting these challenges, crip theory is a poor foundation for disability studies.

**Hanna Björg Sigurjónsdóttir**

University of Iceland

**Mirror, Mirror on the Wall.**

Children’s literature provides us with a unique opportunity to discuss disability but it demands a knowledge and understanding of the history of disabled people and the stereotypes that pervade that history. Disability is both a complex and complicated concept used to describe a large and diverse group of people and their situations, and as such all attempts to interpret the representations of disability in a particular culture are fraught with numerous difficulties. In this paper emphasis is on exploring images of disability in children’s literature available to today’s children in Iceland. This includes contemporary books, legends, fairy tales and ‘classic’ books written more than a hundred years ago. The aim is to unfold what messages Icelandic children receive about disability through children’s literature and to illustrate the relationship between representations of disability and social attitudes at any given time. In examining children’s literature, one can see that the way disability is presented has changed through the years, and that there is a clear connection between how disability is portrayed, prevailing social attitudes, and the prevailing, conventional ideas about disability at any given time.

Hanna Björg Sigurjónsdóttir is an associate professor and a chair of Disability Studies at the University of Iceland. She has recently published an edited book: Disability and culture: The Icelandic Saga in a different light.

**Jan Šiška, Julie Beadle-Brown**

Charles University, Prague, Faculty of Education

Tizard Centre University of Kent at Canterbury

**Towards Active Citizenship and Community Living - Drivers and Strategies for Change.**

Aims: The United Nations Convention of Rights of Persons with a Disability (UN CRPD), Article 19, spells out that supporting disabled people to live in the community as equal citizens is an issue of human rights. The segregation of disabled people in institutions is a human rights violation in itself. This paper will summarise the current implementation of the Convention and in particular Article 19, the explored barriers and opportunities and what the future might hold. The paper will also summarise the current state of community living, and will identify some of the trends, challenges and perceived risks around implementation of the CRPD in the countries participating in the project DISCIT.

Methods: The project DISCIT examines how different types of policies can be mutually supportive in enhancing Active Citizenship for persons with disabilities. One of the major goal of the project is to produce new knowledge about the accomplishments, shortcomings and possible gaps in existing arrangements and potentials for improvements and better synergies, both horizontally and vertically as a step towards making these arrangements more relevant and appropriate in the pursuit of community living.

Results: Overall there have been considerable developments in last decade, but with substantial progress still needed. As such, there is still a need to convey clearly the concept of independent living and the framework of the UN Convention. Challenges include issues such as the mistranslation of the CRPD, the state of the nation financially and politically, lack of flexibility and harmonisation in self-directed support for independent living. The introduction of direct payments in the social service system has not always resulted in any significant improvement and, contrary to expectations, did not always result in a decline in the number of people requesting places in institutional services. Even in some countries where deinstitutionalisation process has been completed, trends towards re-institutionalisation have been reported. Cuts in public spending and changes in public governance were amongst factors identified.

**Eiríkur Smith**

University of Iceland

**Adrift in the Mainstream: What Influences the Currents of Icelandic Disability Policy and Where is it Directing?**

For close to four decades Icelandic disability policy has been characterized by the development of group homes as substitutional service settings for larger institutions. The policy was originally rooted in the Normalization ideology but became actualized and regulated under guidance of welfare and business administration, and later on the increasing power of new public management and local government within the service structure . Despite being able to provide more adequate care and acceptable quantifiable living standards, the sociopolitical aspects that construct the patterns of everyday life and social relations, in blend with systematic reluctance to individualize staff support, spurred the group homes to take on the form of a small community institution that maintain the power and oppression of ableism, has disabling effects on the people who live there and restrict inclusion. The current form of governmental rationality in Iceland seems to have restraining effects upon the goals of the Normalization ideology. International developments in disability policy and laws, like the introduction of UN´s CRPD, have then added to the disharmony between the theoretical advancements in disability studies and the political conservatism to work against institutionalization and ableism.

This paper will bring further light to some of the many complex factors behind this situation in Icelandic disability policy and politics and, through the lens critical realist approach, explore the subtle nuances of power and governance to the future possibilities and potentialities of people with complex service needs.

**Armineh Soorenian**

Independant Researcher

**Austerity Measures and Disability Hate Crime in Disabled Women’s Lives.**

This presentation recognises that the British Coalition Government’s reform of public funding disproportionately affects disabled women, and is in breach of the Equality Act (2010). Based on a literature and policy review, I will discuss the three key disability and gender discriminatory areas of income and benefits, media representation, and disability hate crime.  According to Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) without access to financial resources, disabled people’s human rights are markedly at risk. Yet the current welfare system assumes that disability benefits/services have been ‘too generous’, reinforcing unnecessary ‘dependency’. Today, disability and income related benefits are being granted under more stringent conditions as well as imposing sanctions in order to incentivise people ‘off welfare and into work’. This specifically forces many disabled women to stay in abusive relationships and endure hardship. Furthermore, the media is reinforcing such inequalities and the prevailing prejudice by maintaining the stereotyped image of disabled women as ‘dependent’ and ‘pitiful’. By using such pejorative language, disabled people in general, and disabled women in particular, are stigmatised and falsely labeled as, at worst, outright ‘benefit scroungers’ and, at best, social burdens who are unable to contribute to society in any meaningful way.  This has contributed to a highly inflammatory atmosphere, associated with the prejudicial ideological message of demonizing disabled people, and has resulted in a number of high profile cases of disabled women being subjected to violent attacks. The climate of fear is certainly working; with some disabled women frightened to leave their homes because of physical threats and accusations of benefit frauds. The concluding remarks will highlight that the intersectionality of ‘disability’ and ‘gender’ doubly disadvantages disabled women in these three inter-related areas. The exaggerated effect of the current austerity measures is having a drastically negative impact on their fundamental human rights identified in the UNCRPD, leading to the erosion of their independence, freedom and inclusion.

**Helen Spandler, Jill Anderson, Bob Sapey**

Uclan; Asylum magazine

Lancaster University; CCrAMHP

CCrAMHP

**The Elephant in the Room: Is Being ‘Mad Positive’ enough?**

In 2011 we convened a symposium bringing together disability and mental health scholars and activists to discuss the application of the social model of disability to madness and distress (see Anderson et al. 2012), Drawing on previous work in this area (Beresford et al 2010), contributors variously explored the consequences of applying the model, from being an exercise in inclusion (Sayce, 2000) to colonization (Plumb, 1994). We have recently edited a book in which academics and activists from Europe, North America, India and Australia further consider the subject of madness, mental distress and the politics of disablement, drawing on new ideas to take the debate forward (Spandler et al. forthcoming.

Whilst disability studies scholars and activists are usually committed to developing collaborations between the psychiatric survivor and the disability movement, joint action and shared understandings are rare. In this paper, we consider the ‘elephant in the room’ - the tendency to ignore (or disavow) the tricky question of the nature of ‘madness’ itself. Madness is (by definition) relational and involves judgments about difficult, challenging or unintelligible behaviour; often experienced as damaging to the self and relationships, which can arguably preclude collaboration. Szasz (1960:114) argued that diagnoses of mental illness ‘serve only as a shorthand expression for certain types of human behavior’ which cause a person to suffer, or make others suffer. Pilgrim and Tomasini (2012) argued that being ‘unreasonable’ has consequences for the lack of unity between survivors and disabled people.

We will explore these issues from a position of solidarity with survivors
(a ‘mad positive’ stance), but equally from a desire for greater honesty, understanding and collective action. We will try to explore ‘the elephant’ (madness) and ‘the room’ (psychoemotional disablement) in order to consider strategies for a unified disability movement.

**Aine Sperrin**

Centre for Disability Law and Policy, NUI Galway, Ireland

**Access to Independent Living for Persons with Intellectual Disabilities in Post-Conflict States.**

This research examines the efficiency of rights protection afforded to people with intellectual disabilities under Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which enshrines the right to live independently and be included in the community. It focuses on the diversity of approaches to realizing this right in post-conflict states – namely Northern Ireland, Eqypt and Bosnia and Herzegovina.

Independent living is recognized as a fundamental human right in service provision for persons with disabilities. The use of disability as a non-politicised issue around which to develop cross-community dialogue in Northern Ireland will be examined. Recent years have seen the emergence of a new self-advocacy movement among people with intellectual disabilities in Bosnia and Herzegovina. The research will be limited to the periods of peace processes in Northern Ireland and Bosnia and Herzegovina during the late 1990’s and how these efforts have been affected by the standards and obligations under the UNCRPD.

While typically a predominantly patriarchal society, reports and analysis of independent living initiatives in Egypt are limited and this research will address the potential advantages if a human rights approach were to be taken in policy formation surrounding this issue. The research relating to Egypt will focus on the change in disability legislation relating to independent living in light of UNCRPD ratification in 2008.

These states were chosen because of their UNCRPD ratification status and their contemporary experiences with conflict and resolution, which I believe can contribute to a re-evaluation of human rights policies within the pillars of governance of a state.

This research aims to identify lessons to be learned by the international community in the creation of a disability inclusive society in the wake of national conflict, with a particular focus on the right to live independently.

**Monika Struck-Peregończyk**

University of Information Technology and Management in Rzeszów

**Employment Trends and Policies for Disabled People in Poland.**

Due to the introduction of the market economy in Poland after 1989 the system of sheltered co-operatives was dismantled. The Act on Employment and Vocational Rehabilitation of Persons with Disabilities of 1991 laid the foundations for forming a new system of employment support for disabled people. Poland adopted quota-levy system which used to favour sheltered enterprises. The latest changes concerning the system of wage subsidies express policy shift towards open market employment for disabled people. The quota-levy system is accompanied with different supply and demand side policies, nonetheless, it is still ineffective. Employment rate of disabled people, although it has grown for the last few years, is still very low (22.4% in case of people of working age, source: Labour Force Survey 2013), over 3 times lower than in case of people without disabilities.

It can be seen that open market is still not inclusive enough, especially for people with more severe disabilities. Recent years have therefore brought an increasing interest in supported employment, which has been successfully used by a few NGOs working with people with learning difficulties. The attention has also been turned towards the social enterprise sector as a promising source of employment opportunities for disabled people. The paper will discuss the strengths and limitations of these new trends in the current Polish socio-economic context.

**Allan Sutherland**

Edward Lear Foundation

**On Being a Disabled Carer.**

This paper looks at what it means for a disabled person to be a carer.

It considers how disabled people become carers - or how carers become disabled people. In particular it draws attention to the way that a relationship of mutual support between two disabled people can, over time, turn into a care relationship.

Drawing upon my own experience of being a carer for my partner, who has advanced MS, the paper will discuss how coming to caring from disability activism, with a good understanding of the social model, has affected my approach to being a carer.

The paper will compare the roles of carer and PA, and ask how far, when an individual’s impairment is such as to need a carer, that carer can provide the kind of independence that we are more used to associating with employment of a PA. Can a disabled carer provide a version of peer support, creating a care relationship that is empowering rather than disempowering? What are the advantages and pitfalls of a ‘mixed economy’, using both carer and PA?

The paper considers what particular expertise a disabled person brings to the work of being a carer, and how social model understandings of the power relationship between disabled person and professionals transfer to a care situation - particularly when the disabled person may be either patient or, as carer, the patient’s representative.

The paper will also draw on a recent project where I created a ‘job description’ of the responsibilities I take as a carer, which indicates that a lot of the work equates to the kind of managerial post that would draw a salary of £25-40,000 a year.

**Allan Sutherland, Michael Shamash**

Edward Lear Foundation

Middlesex University

**From Catheters to Cafetieres: Disabled People and Hospital Food.**

This paper, by the founders of the Disabled People’s Fine Dining Project, considers some less discussed aspects of the subject of hospital food.

Living with an impairment can imply intermittent admissions to hospital. A core part of that is hospital food, whose poor quality produces low morale and a lack of the nutrition needed for healing.

We place this discussion within the context of a disempowering system which treats the immediate medical crisis, but neglects the longer term needs imposed by a physical impairment, particularly where those needs are articulated, not by someone within the medical hierarchy, but by the disabled person or carer.

The idea that hospital food is poor quality is not a new one. But we argue that too much attention has been paid to the quality of the food, not enough to the overall quality of the eating experience.

We feel that there is an element of theatre to fine dining that could helpfully be brought into the practices of hospital catering, making meals an exciting event, a part of the day to look forward to.

We also argue that hospital meals follow a very old-fashioned ‘main course plus pudding’ model, whose structure remains unchanged even where attempts are being made to respond to cultural differences, producing meals that are unenticing and stodgy. We recommend looking to the many examples of food cultures which present a larger number of smaller courses: chinese banquets, meze, tapas or even the tasting menus of upmarket restaurants .  Food is not medication, but, delivered with imagination, could be just as important a part of the healing process.

The paper also outlines some simple measures that could be taken to involve carers and families in the delivery of better food, such as the provision of microwaves on the ward.

**Leslie Swartz**

Stellenbosch University

**The Return of the Freak Show: The Oscar Pistorius Trial and its Implications for Disability in South Africa.**

The shooting by Paralympian and Olympian athlete Oscar Pistorius and of his girlfriend Reeva Steenkamp in 2013 has attracted world-wide interest, and in South Africa there has been a television channel devoted exclusively to the murder trial. There are obvious parallels between this case and the OJ Simpson case in the USA. Furthermore, the negative media attention recalls ways in which media have dealt with other celebrities, including Princess Diana. These observations, however, raise the question of whether the case sheds light on issues of disability in the South African context. I suggest that some of the reactions to the case lay bare some key and pressing issues for disability rights and representation in South Africa and further afield. The bodies of both Pistorius and of Steenkamp have been discursively appropriated in various ways, recalling both freak shows in the history of disability representation, and issues of vigilantism in a context in which faith in public institutions is not strong.

**Amanda Taylor, Gerasimos Chatzidamianos**

UCLan

Lancaster University

**The Silent Corner of Mental Health and Deafness: An Interdisciplinary Dialogue.**

Background:
Deaf people have historically been marginalised. Their hearing impairment is often the sole underlying factor for not being able to access everyday information, appropriate education, or health services. Being Deaf experiencing a mental health problem leads to further marginalisation. In the UK, specialised services for this population are sparse with limited resources and underfunded. As such, most Deaf people are treated in mainstream services by clinicians who lack specialised knowledge regarding Deafness and who are predominantly unable to communicate in sign language. Deaf people with mental health problems are, in effect, overrepresented in mental health inpatient care. Reports suggest that whilst an average stay of hearing mentally ill individuals in a psychiatric unit in Flanders is 148 days, the figure for Deaf patients increases to 19.5 years.
Workshop:
This workshop will involve a dialogue between a psychology clinical researcher and a psychiatric social work practitioner exploring the challenges of the experiences of people who are Deaf in mental health services. The dialogue will be informed by the ‘Independent Inquiry into the Care and Treatment of Daniel Joseph’; a Deaf young adult with severe mental health problems who pleaded guilty for manslaughter and was sent to Broadmoor top security hospital indefinitely.
Aim:
The workshop aims to enhance our understanding of the barriers to mental healthcare provision to Deaf people with mental health problems, offer clinical recommendations and provide an opportunity for reflective practice in mental healthcare.

Resources:
You can access the ‘Independent Inquiry into the Care and Treatment of Daniel Joseph’ here. <http://www.deafinfo.org.uk/policy/the_daniel_joseph_report.pdf>

**Liz Thackray**

**Personal Troubles and Public Issues: The Implications of Public Responses for the Individual.**

It is now over fifty years since Charles Wright Mills differentiated personal troubles and public issues. Although Mills clearly recognised the interrelationship of public and personal, others have assumed a binary distinction between personal troubles and public issues that necessitate State sponsored intervention. Such a distinction locates personal troubles in private spaces and predetermines responses to individuals affected by what are deemed public issues. Public policy has placed an increasing responsibility on individuals to make provision to address their own needs as public provision has shrunk and individuals have become subject to sanctions.

An investigation of the experience of the 'struggle/fight' metaphor amongst those working with or parenting children and young people diagnosed with high functioning autism spectrum conditions suggests that although some problems may be confined to private spaces, such as the family and the family home, very often problematic issues are played out in the public arena resulting in further tensions for those immediately involved. Recognising an issue requires a public response may not lead to resolution for those concerned, but the response may have immediate repercussions for the individual and others together with potentially serious, longer term consequences.

In this presentation, I draw on the 'real life' experiences of participants in the study to consider the complex interplay between the personal and the public, focusing on the implications of practitioner actions and attitudes for individuals and families. I ask what can be learned from these experiences of participants in this study that has implications for both public policy and for practitioners in education, health and social care.

**Dianne Theakstone**

University of Stirling

**Peer Through The Keyhole: What is the Role of Peer Support Within Disabled People’s Housing Options in Scotland and Norway?**

Data from a recent international comparative study explores the role of peer support within disabled peoples’ housing options. This mixed-methods PhD research is entitled: “Building Inclusion: to what extent do the governance structures in Scotland and Norway facilitate or impede disabled peoples’ access to independent living”. Accessible housing, as will be outlined, can shape the citizenship outcomes of disabled people. The data highlighted peer support as one of the key mechanisms of empowerment in both countries which interconnects citizenship, housing and disability. By the conclusion, the author argues that formal and informal peer support play an important role within disabled peoples’ housing options and access to citizenship. However it needs to be fostered which, as the author explores, may prove challenging for the independent living movements with fragmented individual identities.

**Liz Tilly**

University of Wolverhampton/ Building Bridges Training

**Living Independently - Small Things That Make a Big Difference.**

The Convention of Rights for Disabled People (United Nations 2007) are set out by the United Nations to protect people with disabilities and their families. They recognise that they have the right to live independently and be included in the community. This includes access to and use community services and facilities that are available to everyone, and to have accessible information.

The majority of people with a learning disability however live without support, with only 11% known to learning disability services (Emerson and Hatton 2008). This group of people are particularly vulnerable as they are ‘off the radar’ of support services and advocacy groups, and not recognised as having a learning disability by mainstream services.

Building Bridges Research Group is an inclusive research group of people with a learning disability (Walmsley and Johnson 2003). The majority of members have no support from services. They have completed a year-long research project about their lives and the lives of other people in their social networks, about living with the welfare reforms and other issues relating to living independently.

The research found there were many barriers that make it hard for them to live ordinary lives. They experienced an extensive range of difficulties; these included poverty and debt, issues relating to the ‘bedroom tax’ and pressure to look for work.

They also found that small things can make a big difference. These included having a friend who can negotiate with external agencies, support from local community organisations, having front line staff who treated them with respect, and could communicate effectively and being given information in an easy read format.

The research found that local community organisations provide a range of vital roles for people who do not use formal support services and are valuable in increasing the social capital of this isolated group.

**Ann-Charlott Timander**

Lancaster University

**The Relevance of a Theoretical Framework of Disability Studies to the Study of Mental Distress and Recovery.**

One of the aims of my PhD-project is to study how people with experience of long term mental distress describe the process of identity (re)-construction in the recovery process. In this paper I examine if a disability studies approach might enhance our understanding of the process of identity (re)-construction?

When studying “mental health” through a disability studies perspective, the focus shifts from a “deviant” individual interpretation to one who encounters social oppression, discrimination and exclusion. Or in other words, we move from the study of psychiatry and medical treatment to the study of the complexity of social restrictions and social oppression that people diagnosed and labelled as “mentally ill” actually face in their daily life.

My analysis is based on semi-structured interviews with 33 men and women with experience of long term mental distress and recovery in Gothenburg, Sweden and Oxford, England - in order to explore how they describe their identity (re)-construction. This paper will draw on the research findings to date, with a particular focus on how a disability studies perspective would enhance the understanding of identity (re)-construction, by understanding how social oppression affects identity (re)-construction. I argue that social processes of oppression and discrimination are central when it comes to understanding the process of (re)-construction of identities, in men and women with experience of long term mental distress and recovery.

**Rannveig Traustadottir**

Centre for Disability Studies, University of Iceland

**Images of Disability in Mary Ellen Mark's Photographs of Extraordinary Children.**

Mary Ellen Mark is an internationally known, highly respected and influential American photographer who has received numerous awards and honors for her work. She has published 18 books of photographs and has contributed to many more. Her photographs have been exhibited world wide. Mary Ellen Mark regards herself as a photojournalist and is best known for what is usually described as her documentary photography and portraiture that captures the human condition. Her work has worldwide visibility and everything she does receives attention and, as a rule, a great deal of admiration. Most of her photographs document people on the margins of society or who have been excluded in some ways, the exotic and freakish. Examples are prostitutes in Bombay, circus people in India, Mother Theresa, women in a psychiatric ward, homeless people, street children, transgender people, identical twins and people who are extraordinary in some way, to name but a few of her projects. Mary Ellen Mark was in Iceland in 2006-2007 to photograph children in two segregated schools for disabled children. In September 2007 the National Museum of Iceland opened an exhibition of these photographs titled Extraordinary Child (the Icelandic title was Undrabörn). At the same time Mary Ellen Mark published a book of the photographs with the same title. The book was nominated to awards in Iceland and the exhibition was well received. Since 2008 the exhibition Extraordinary Child has been a "travelling exhibition" and has circled around many of the Nordic countries. This presentation will analyse the images of the disabled children in Mary Ellen Mark's photographs and the messages her photographs and her words (in her book and in newspaper interviews) send about disabled children and their place in society.

**Hrafnhildur Snaefridar Gunnarsdottir, Rannveig Traustadottir,**

Centre for Disability Studies, University of Iceland

**Violence Against Disabled Women and Access to Support and Justice.**

International research indicates that disabled women are many times more likely to experience violence than non-disabled women. Despite this there is limited understanding of this significant and disturbing aspect of disabled women's lives and efforts to prevent violence do not seem to be effective. This paper presents findings from two research projects in Iceland focusing on violence against disabled woman and specialized support services for women who have experienced violence. Participants were disabled women with varying impairments and women who work in specialized support services.

Data was collected through qualitative interviews, focus groups and a survey. The paper begins by describing the various forms of violence experienced by the disabled women who participated in the study across the life span and who were the most common perpetrators. We will also address the connection between disability and violence and outline in which places, spaces and circumstances the disabled women were most likely to be violated, including a discussion of violence within the human services designed to provide care, assistance and support to disabled women and girls.

Access to specialized support and the experience of disabled women and workers within these services will be outlined. We conclude by offering recommendations on how to prevent violence and create more effective support services, as well as discussing the importance of making it possible for disabled women to access justice when they have experienced violence.

**Caragh Hesse Tyson**

Headway Ireland

**Moving into the Community: The Barriers and Outcomes for Adults with Intellectual Disabilities in Ireland.**

The present study aimed to identify the barriers and outcomes associated with transitioning to the community from institutional settings for a group of adults with intellectual disabilities.

Participants were 26 adults with mild to profound intellectual disabilities ranging in age from 18-56 years who were residing in a large-scale residential setting. Adaptive behaviour was measured with the Vineland Adaptive Behaviour Scale: Second Edition (Sparrow, Cichetti & Balla, 2005). Quality of life was measured using the Quality of Life Questionnaire (Schalock & Keith, 2004), through proxy respondents; this was supplemented and validated with direct information from participants. An audit of transitions processes was completed including systemic, organisational and planning factors to identify barriers to transition.

Results indicate that moving to the community does not lead to an improvement in quality of life or adaptive function. Higher levels of non-aggressive challenging behaviour, having a suitable place in the community, the use of person centred planning and the use of a community support plan were associated with transitions occurring. Suggestions are made for the improvement of future transition processes.

**Ermien van Pletzen**

University of Cape Town

**Community-Based Disability Workers, People with Disabilities and their Families in the Knowledge Translation Project: Opportunities and Challenges in Three Southern African Countries.**

Knowledge translation can be defined as a process of making the knowledge produced by research available to those who use or apply it in practice. Recent research has indicated that community-based settings may require a different set of understandings of knowledge translation than clinical settings. This presentation will explore a cyclical conception of knowledge production and translation which will place community-based disability workers, people with disabilities and their families at the centre of a set of reiterative activities. Data will be presented on the life and work experiences of sixteen community-based disability workers from selected rural areas of three Southern African countries, Botswana, Malawi and South Africa. It will be argued that community-based disability workers’ experience and understanding of disability in resource-limited communities constitutes an important local source of knowledge which could strengthen processes of theory-building and policy development in the field of disability in the ‘Global South’. The presentation will further consider how such local knowledge could be channelled back into the process of translating knowledge for application in community settings. In this respect, some of the challenges that community-based disability workers, people with disabilities and their families encounter will be highlighted. The presentation will elaborate on a research design that would position community-based workers, people with disabilities and their families at the heart of the knowledge translation project as both producers and users of knowledge. In conclusion, the presentation will envisage roles and responsibilities in this particular research design for teachers, researchers and students based at institutions of higher education, as well as for other stakeholders, such as policy-makers from both the ‘Global North and South’, government officials, NGO workers, traditional leaders and community members.

**Simo Vehmas1, Nick Watson2**

1University of Helsinki

2University of Glasgow

**Towards a Normative Sociology of Impairment and Disablement.**

Previously we have argued that neither the social model nor its critiques from within disability studies, including critical disability studies, have adequately theorised the disability experience. Both the social model and critical disability studies have tended to ignore the lived experience of impairment and how that impacts on an individual’s life. The social model has opted to focus on the material and cultural environment and how these exclude people with impairments. Critical disability studies, on the other hand, has tended to emphasise the discourses that surround disability but rather than explore the lived visceral experience of embodiment, attention is placed on how corporeal difference is produced and made apparent in current sociocultural discourse. Whilst these approaches are interesting and in many ways useful, they miss key elements of the disability experience including the impact of impairment, the temporal nature of impairment and the changes associated not just with the impairment itself but also those that arise from ageing as a disabled person. It has also meant that impairment itself and what constitutes an impairment in terms of disability, where chronic illness ends and impairment begins, have gone unexamined and unexplored; disability scholars have bracketed impairment in favour of a material or cultural analysis. In this paper we seek to rectify that gap and further advance our ideas around what we have termed a normative sociology of disability and impairment, unpacking the possible intrinsic and instrumental disadvantages related to disability and impairment. We will argue that such an approach not only gives us a more complete and thorough picture of the disability experience but it is also more useful politically and will form a more constructive theoretical model in terms of equality and rights.

**Jijian Voronka1, Kathryn Church2, Lucy Costa3**

1University of Toronto

2Ryerson University

3Osgoode Hall Law School

**Making Mad Studies in Canada: process, practice, and contestations**

This symposium brings together three academic/advocates from Toronto, Canada working within the field of Mad Studies. The first paper discusses the process of implementing Mad Studies as a viable field of inquiry within a Disability Studies program; the second, the practice of teaching Mad Studies outside the field through a cross-disciplinary course; the third, raising queries as to how Mad Studies is being taken up by larger ruling regime stakeholders and asks, to what benefit and at what costs? All three presenters are also contributing authors to LeFrançois, B.A., Menzies, R. & Reaume, G. (2013) *Mad Matters: A critical reader in Canadian Mad Studies.* Toronto: Canadian Scholars’ Press.

**Mad Studies in the Academy: Staying alive? Kathryn Church, Director, School of Disability Studies, Ryerson University.**

This paper takes up what happened over a significant decade in the School of Disability Studies at Ryerson University, Toronto, to make Madness an identifiable and substantive part of our program. As a person currently situated in a management role but resonating with the activist knowledge of the Mad movement, I consider what our School has done and could do as a locus for credentialing Mad Studies. The paper highlights early curricular risks taken by faculty and instructors that enabled the program to situate Mad people’s history as a legitimate area of study for Disability Studies students and across-campus. Distance and on-site course offerings enabled other kinds of activities – including language --that present opportunities but also raise questions for diversity management leaders and their initiatives in the university. In that sense, while theory is at stake, the paper is primarily about practice/s. It draws from what continues to be an experiment-in-progress to consider some organizational actions that may be more broadly useful as well as some troubling dilemmas: both familiar and emergent.

**Bridging disciplinary divides: Teaching Mad Studies to the uninitiated. Jijian Voronka, PhD Candidate, University of Toronto and Lecturer, School of Disability Studies, Ryerson University.**

This paper is based in the practice of teaching Mad Studies in the academy through “A History of Madness,” a popular elective course offered across all disciplines at the undergraduate level at Ryerson University in Toronto, Canada. Every year over 300 students pass through the course, coming from an eclectic range of home departments: from nursing to psychology to business administration. This means that the course is often an introduction to both Disability and Mad Studies, with content often working in conflict with what they are concurrently learning about disability in their own programs of study. This paper draws on the experience of building curriculum and pedagogical practice within A History of Madness, working through conflicting discourses, and dealing with the process of unsettling both student and disciplinary beliefs about madness as a problem that needs to be fixed. This paper will focus on the particularities of teaching as a Mad instructor, facilitating students as some debate what becoming mad-identified and mad allies means to them within their professional and personal lives, and end with examples of what students produce through their final (often creative) assignments.

**Mad Studies: Fetish or freedom? Lucy Costa, Systemic Advocate, The Empowerment Council and LL.M Candidate, Osgoode Hall Law School, Toronto.**

The emergence of Mad Studies has signified an important shift and achievement in the struggle for equity and inclusion of service users. Studies in Madness, meticulously stitched together through protest, writings, and art over many decades is reflective of a body of knowledge which describes our historical, political and personal accounts. Where persons with psych disabilities once relied heavily on the refrain “nothing about us, without us,” we now grapple with what including “us” in a variety of institutions, venues and spaces *should* and *actually* entails. This presentation discusses the complexity of working with allies, departments of psychiatry, researchers of various disciplines, policy makers and other strange bedfellows who “like us” are interested in including, supporting and integrating Mad people’s knowledge into their practices. I discuss the challenges, tensions and meaning of these engagements in a political climate that paradoxically appears to be attacking redistributive social movements and public institutions that once fostered healthy dissent. Does our sharing of knowledge and engagement revolutionise, or is Mad Studies at risk for market populist and corporate culture co-optation?

**Daniel Walsh1, Trisha Suresh2, Omar Waraich2**

1British Council

2Economist Intelligence Unit

**Moving from the Margins: Mainstreaming Persons with Disabilities in Pakistan.**

When discussing Pakistan, the country is often characterised by its social, economic and political difficulties. Persons with disabilities (PwDs) remain marginalised from this discourse. Unheard and unseen, government efforts aimed at mainstreaming PwDs into society are equally inconspicuous.

Research and reports around PwDs in Pakistan have predominantly adopted the medical model; focusing exclusively on disability as a public health issue. This report will pioneer the application of the social model of disability in the country. The British Council has partnered with the Economist Intelligence Unit to study the social, cultural and economic barriers that affect PwDs in Pakistan and to propose a series of practical solutions to overcome these.

This research report aims to shed light on society’s perception of disability, the education and training opportunities for PwDs, and extent of their economic participation. It will highlight the limitations to the current legislative support for rights for PwDs. Pakistan’s National Policy, employment quotas and ratification the UN Convention on the Rights of Persons with Disabilities has had little discernible impact. The fundamental barriers to education, employment and inclusion remain. Furthermore, disability itself is considered a stigma in parts of Pakistani society. This lack of representation, access and equality perpetuates these problems.

Our analysis will cover differences by gender, socio-economic status and provinces in Pakistan. The report will not only identify barriers and challenges, but also positive developments around mainstreaming PwDs. The research will synthesise existing data. Findings will be based on detailed interviews conducted with senior policymakers, UN agencies, NGOs, and PwDs across the country.

**Jon Warren, Kayleigh Garthwaite**

Durham University

**Biographies of Place: Challenging Official Spatial Constructions of Sickness and Disability.**

Why do some localities have much higher incidence of impairment and chronic illness than others? Why to social policy initiatives and health interventions work in some areas and make little impact elsewhere? This paper will argue that a critical disability studies perspective is required in order to challenge official spatial constructions of sickness and disability. It will challenge the way in which public health researchers and geographers have tended to focus on composition or contextual effects (Macintyre et al., 2002) instead of seeking a more integrated understanding of spaces and places.

This paper will argue that there is a need to understand places as entities with specific identities which are more than the sum of their parts, and that spaces are constituted by many more factors than geographical boundaries alone. Furthermore, until this is understood progress in addressing the disability and sickness “problem” in such areas via health, employability or wider social policy initiatives will be severely limited. It will be argued that places have biographies in the same way as individuals and the intersection of individual and spatial biographies is particularly significant in understanding barriers. The discussion will draw on Mills (1959) ideas about the relationship between biography, history, and social reality. The implications of such an approach will be considered and explored via a case study of the former mining district of Easington in County Durham, North East England.

**Melaneia Warwick**

University of Brighton

**NHS Ethical Approval for Research with People with Profound and Multiple Learning Disabilities: Creative Strategies from a Participatory Arts Setting.**

The call for the inclusive participation of adults with intellectual disabilities in research has been taken up by an emerging literature advocating the same opportunities for people with profound and multiple learning disabilities (PMLD). Yet the barriers to researchers engaging with the demands and particular characteristics of the NHS ethical approval processes are well rehearsed. This can contribute to the marginalisation already faced by people with PMLD with the associated risk that the group remain under researched.

This paper explores current participatory action research utilising inclusive arts techniques with people with PMLD. It suggests that despite the challenges, engagement with the NHS research ethics process can be framed not as an isolated form filling exercise but as a reflective device presenting an on-going opportunity to gain multiple perspectives on a proposed project. It offers possibilities to collaboratively shape inclusive research design and develop an evolving consent process. Drawing on this, the paper identifies and shares the creative strategies and innovative tools that have contributed to successful ethical approval and the participation of people with PMLD in cultural activities.

**Brian Watermeyer**

Stellenbosch University

**Freedom to Read: Personal Reflections on the WIPO Treaty.**

In June 2013 member states of the World Intellectual Property Organization concluded a treaty which may reduce legal obstacles to the broader availability of accessible literature for sight and otherwise print impaired people. In best served nations of the global North it is estimated that 7% of published books are ever made accessible; the corresponding figure for the global South is 1%.

Over recent years many disability studies authors have called for increased attention to the psychological imprints of deprivations emanating from disablism. In this paper I draw on my own experience, within a broadly psychoanalytic frame of reference, to give light to the complex personal implications of the ‘book famine’. To read is to be part of the world, to be mentally and emotionally nourished, to have a share in human discourse, to be politically and socially informed; for many, to not have access to the printed word is to be more alone. Inequality is always complicated, and settles internally in the context of personal, unconscious and often malignant meaning-making. These effects have implications for our ability to remain creative and hopeful in imagining change, impacting on the negotiation of ‘disability needs’. An understanding of the impact of deprivation is of use in supporting disabled persons’ leadership in the development of policies for access.

**Grahame Whitfield**

ScHARR Sheffield University

**Power to the People? Will Choice and Control be a Reality for Older People with Personal Health Budgets - And What are the Implications for Outcomes?**

The debate about Personalisation and Personal Health Budgets seems to be becoming entrenched. Advocates argue that it will promote independence, empower people to make decisions about their lives, improve outcomes and potentially lower costs. Critics argue the model in its current form is flawed, will fail to meet the needs of older and disabled people, won’t improve outcomes that matter to them and won’t represent good use of limited funds. This ‘conflict’ exists despite a broad consensus that people should be at the heart of decision- making about their lives.
There is much debate about confidence in Resource Allocation Systems, the disconnect between RAS assessments and care planning and the potential impact of funding cuts in Health and Social Care. However, there has been relatively little discussion on how older and disabled people can be truly ‘set free’ to make decisions about their lives in partnership with professionals and managers of public services. That is, there is much on bureaucracy and little on the ‘right to control’.

Whilst there is some evidence on how some people have benefited from PHBs, there are concerns as to how this can be delivered at scale. It remains the case that there is little understanding as to how the dramatic cultural shift PHB’s represent can overcome some peoples’ reluctance to make new and innovative choices about the services or support they receive and some professionals’ resistance to change (with some at the extreme seeing PHBs as a dangerous ‘Trojan Horse’).
This paper is being produced at an early stage of an NIHR SPHR funded PhD at ScHARR. It is the author’s contention that understanding constructions of ‘risk’ and ‘good outcomes’ in the process of negotiation between people and health and social care professionals is important if we are to make progress.

**Alison Wilde**

Leeds Metropolitan University

**Masculinism, Neoliberalism and Mental Distress: Exhibit A.**

This paper examines an independent film, Exhibit A, to provide an example of how representations of mental illness can be used to problematise ableist fictions of the normal man and heteronormative, neoliberalist ideals of masculinity. In so doing, it will engage with the troubled association of violence with mental health, challenging the avoidance of such portrayals and arguing for a more critical engagement with the social and cultural contexts of violence. It will also explore the enmeshment of 'post-human' identities with technologies of self-surveillance focussing, in this case, on the use of video cameras in everyday life.

**Jane Williams1, Clair Beckett2**

1New Leaf Adventures/ The LA Buskers

2New Leaf Adventures/ Attik 360

**Turning Tides: Presented during the Poster Reception**

The 'Turning Tides' performance was the result of a creative partnership between Attik 360, an inclusive dance company,  The LA Buskers, a band who are all on the Autism Spectrum and work with Jane Williams, Music Facilitator and author of Music and The Social Model (published by JKP) and A larger group of musicians, dancers, writers and artists labelled as having learning disabilities who work with these companies.

This short film show cases some of the music, dance, poetry and art that are part of the performance and enables us to take ' Turning Tides' on tour. You're invited to see the performance and to write a review for our tour scrap book.

This presentation is linked to a paper where some of the realities of applying the Social Model will be discussed.

**Turning Tides: Paper**

This presentation is linked to a short film shown during the poster reception that enabled us to bring the ' Turning Tides Tour' to Lancaster. The 'Turning Tides' performance was the result of a creative partnership between Attik 360, an inclusive dance company, The LA Buskers, a band who are all on the Autism Spectrum and work with Jane Williams, Music

Facilitator and author of Music and The Social Model (published by JKP) and a larger group of musicians, dancers, writers and artists labelled as having learning disabilities who work with these companies.

The presentation will use anecdotal examples from the creation of

Tides to explore the process of creating a collaborative performance and the opportunities and  issues of access that this presents.

**Val Williams**

Norah Fry Research Centre, University of Bristol

**Change Theories and Disability Studies.**

Theoretical developments in Disability Studies (DS) have overtly been about changing society, rather than individuals (Oliver, 2004; 2013) and disability scholars have fought for social approaches to disability. These ideas continue to provoke debate (Shakespeare et al., 2006), largely because of the inherent complexity and differentiation of the experience of disability (Allan, 2010; Gable, 2014), with three main models or explanations of disability being distinguished by Bhaskar et al. (2006), the economic, cultural and individual-medical models. There are many tensions here. If we are to develop theories that have ‘practical adequacy’ (Sayer, 1992), clearly they have to be complex (since reality is complex). Yet, as Oliver (2004) argues, sometimes the simplest ideas can be the strongest, and the easiest to understand.

This presentation is about the possible usefulness of looking outwards from Disability Studies, towards the different frameworks and ways of approaching change. Each of these sits within a different discipline and each theory tends to be associated with different topics. For instance, Social Practice Theory (Shove, 2003; 2004; Hargreaves, 2011) focuses on the ways in which social practices are performed by individuals, and how the links and elements of existing, unsustainable practices could be broken, in order to change behaviours. I will explore some of the areas in which we know that inequities exist, and in which we know change has to happen. I will then consider some of the interdisciplinary theories of change, in order to think about how useful (or not) they may be from the perspective of disabled people, who want to lever and sustain changes towards a more equal society.

**Phillippa Wiseman**

University of Glasgow

**Negotiating an Understanding of Inclusive Embodied Citizenship Through the Lens of Public and Private Toilets.**

Toilets and going to the toilet are often seen as private and intimate and furthermore far removed from traditional understandings of citizenship, yet for disabled people good access to toilets is essential for their participation. Toilets and their use provide a useful lens through which to explore both the private/public divide and also a lens through which to understand how citizenship, inclusion and exclusion are experienced through the body.

This paper is taken from an ongoing PhD which explores the everyday experience of embodied citizenship for disabled young people in Scotland. By shedding light on the toilet as a terrain through which inclusion and exclusion are played out it allows us to better understand the everyday experience of citizenship for the young disabled people that took part. It allows a more grounded understanding of the ways in which public policies, around toileting and toilets for instance, impact on the everyday private activities of disabled people which have far reaching effects on inclusion and exclusion. Participants found that a lack of access to toilets or poor toileting provisions meant that their capacity to take part in everyday life was greatly impacted. Similarly good toilets promoted good inclusion and contributed to participants' feelings of belonging, participation and self esteem.

**Sarah Woodin**

University of Leeds

**Disabled Women's Access to Violence Support Services.**

This presentation will discuss the UK findings from an international empirical research project looking into the situation of disabled women who have experienced violence and the assistance available from specialist service providers. It will seek to expand the current focus on ‘hate’ violence in Disability Studies in recognition of the diversity of types of violence experienced by disabled women.

The scarce research to date into this problem documents that disabled women experience more violence, in a wider range of circumstances (e.g. domestic, institutional, ‘hate’ violence), compared with non-disabled women and also that they experience more difficulties gaining access to services.

At a time of austerity, statutory services are becoming scarcer. Services remaining are increasingly generic in scope, reflecting a commissioning drive towards ‘economies of scale.’ Nevertheless, our research also shows that there are promising areas for improving access and support and that these relate to the types of service provided as well as the number and the way they are managed. Issues for further investigation are identified.

**Dinara Zapparova**

Wish

**Investigating Gendered Representations of Women Within the World Report on Disability’s Articulation of Sexual Agency.**

The 2011 World Report on Disability (WRD) - published jointly by the World Health Organisation and the World Bank - has been widely discussed within the disability studies movement. However, discussions have lacked analysis of the report’s gendered content. Such analysis is crucial to interrogate whether the WRD's goals of implementing initiatives 'to the benefit of people with disabilities' (2011,xi) adequately addresses the specific experiences of disabled women. Gendered disability studies has shown that the interaction of disablist discourse with sexist discourse results in disabled women facing particular limits on expressions of sexual agency. I engage in discourse analysis to investigate the WRD’s gendered content.

I examine two instances of representation within the WRD. Firstly, I examine the WRD’s recommendation that disabled sexual agency can be achieved primarily through securing access to sexual health services. I argue that this articulation overlooks how gender mediates disabled negotiation of sexual agency. This results in the WRD ignoring how disabled females’ sexual agency can be limited precisely through the females’ experience of access to sexual health services.

Secondly, I examine how the WRD represents an example of disabled females’ access to sexual health services. Here, I draw attention to the racialised dynamics of the WRD’s location within the Global North/South relationship. I examine a conflation within the WRD discourse between female access to sexual health and a health professional’s access to the female’s body. I engage scholarship from outside of disability studies to elucidate how the WRD’s representation constructs a gendered racialised hierarchy. I then employ a gendered disability studies lens to consider how this hierarchy is inflected with a disability/ability binary. I thus consider that the report’s representation of women objectifies the disabled, non-white female target users of the WRD-recommended services.