

DISABILITY STUDIES
CONFERENCE

LANCASTER UNIVERSITY

11TH-13TH SEPTEMBER, 2012

Centre for Disability Research
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Front cover photograph of *Honeywort*

Printed by Colin Cross, Garstang

WELCOME

We would like to welcome you to the 6th Disability Studies conference to be held 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 conference in 2012 is *Disability, Poverty and Neo-Liberalism*. We invited the submission of abstracts for either symposium, paper or poster presentations on current research, ideas and 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
- Professions allied to communities
- Normalcy and neuro-diversity
- Madness, distress and disability
- Eugenics and assisted dying
- Culture, history and arts
- Theoretical and methodological ideas and debates

We hope that you will be able to participate in the conference as much as you wish and that the debate and discussion will be rigorous and polite. We especially hope that this event will help each of us to develop our understanding and knowledge so as to support the social and political changes that are necessary for the creation of an inclusive society.

CeDR Conference Organisers

REVIEWING COMMITTEE

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

- Professor Dan Goodley, Manchester Metropolitan University
- Dr Chris Grover, CeDR, Lancaster University
- Dr Patrick Kermit, Sør-Trøndelag University College, NTNU Samfunnsforskning
- Dr Kristjana Kristiansen, Norwegian University of Science and Technology
- Hannah Morgan, CeDR, Lancaster University
- Linda Piggott, CeDR, Lancaster University
- Rachel Purtell Folk.us, Peninsula College of Medicine and Dentistry
- Dr Donna Reeve, CeDR, Lancaster University
- Professor Alan Roulstone, De Montfort University
- Bob Sapey, CeDR, Lancaster University
- Dr. Sonali Shah, CDS, University of Leeds
- Dr Karen Soldatic, University of New South Wales, Australia
- Dr Helen Spandler, University of Central Lancashire
- Professor Carol Thomas, CeDR, Lancaster University
- Dr Pam Thomas, CeDR, Lancaster University
- Professor Simo Vehemas, University of Jyväskylä, Finland
- Professor Nick Watson, Strathclyde Centre for Disability Research, University of Glasgow

PROGRAMME

Tuesday 11th September 2012	
10.00	Registration
11.00-11.30	Introductions and welcome
11.30-12.30	Plenary: Chris Grover
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
17.15-19.00	Drinks reception with an opportunity to meet the editors of <i>Disability & Society</i> and view poster presentations
20.00	Dinner at Barkers House Farm
Wednesday 12th September 2012	
09.30-10.30	Plenary: Sonali Shah
10.30-11.00	Break with refreshments
11.00-12.30	Paper Session C
12.30-13.30	Lunch
13.30-14.30	Plenary: Kristjana Kristiansen
14.45-15.45	Paper Session D
15.45-16.15	Break with refreshments
16.15-17.15	Paper Session E
17.30-18.00	Pre-Theatre drinks
18.00-19.30	Telling Lives by Cul-de-sac Theatre Group
20.00	Dinner at Barkers House Farm
Thursday 13th September	
09.30-11.00	Paper Session F
11.00-11.30	Break with refreshments
11.30-12.30	Plenary: Rob Imrie
12.30-13.00	Endings

KEYNOTE SPEAKERS

DR CHRIS GROVER

Centre for Disability Research, Lancaster University

SOCIAL (IN)SECURITY, DISABILITY AND NEO-LIBERALISM

This presentation will explore the main conference themes examining relationships between disability, neo-liberalism and poverty. The presentation will examine the concept of neo-liberalism before going on to discuss how in recent years in Britain social security policy for disabled people has become structured by the imperatives of neo-liberalism and the impact that this has had on such people.

Although acknowledging neo-liberalism as a form of cultural political economy providing the discursive context for change to the social security regime for disabled people in Britain, there will be a particular focus upon neo-liberalism as an economic project. As such, it will be argued that neo-liberalism is not so much concerned with the de-regulation of economies, and labour markets in particular, but the embedding of economic and social structures in ways that are consistent with the central themes of neo-liberalism related to particular notions of freedom and responsibility, and the promotion and extension of markets.

In this context, the presentation will focus upon changes to the ways in which the 'disability category' is being redefined in social security policy, alongside the commodification of both the labour power of disabled people and, in the search for new 'welfare markets', their bodies. The material consequences of these developments in terms of the living standards of disabled people will then be discussed.

PROF. ROB IMRIE

Kings College London

UNIVERSALISM, UNIVERSAL DESIGN AND EQUITABLE ACCESS TO THE BUILT ENVIRONMENT

The concept of universal design has acquired global significance and become orthodoxy of what is presented as the very best of design practice. This is despite limited evaluation of the theoretical content of the concept. This paper seeks to redress this shortfall in knowledge by providing a critique of the theoretical and conceptual components that underpin the principles of universal design. As I suggest, the content of universal design appears to be reductive and functionalist, with an appeal to discourses of technical flexibility, or the notion that the problems confronting disabled people by poorly designed products, places, and material artefacts may be redressed by recourse to technical and management solutions. Universal design is characterised by its advocacy of the marketisation of access as the primary means to ensure the accessibility of products, including the built environment. This has the potential to reduce the 'right to access' to a right to be exercised through a market presence or transaction. There is also lack of clarity about what advocates of universal design understand universalism to be, as illustrated by evidence of some ambivalence towards specialist or particular design solutions. The conclusion is that universal design provides a useful, yet partial, understanding of the interrelationships between disability and design that may limit how far inequalities of access to the designed environment can be overcome.

PROF. KRISTJANA KRISTIENSEN

Norwegian University of Science and Technology, Trondheim

THE ONTOLOGY OF INSANITY: WHOSE VERSION IS REAL?

This presentation starts with personal reflections about my work and my life in Norway which led me to the research to be presented. The central research questions concerned exploring what everyday life is like for people diagnosed with schizophrenia, with a focus on what problems and needs should be addressed. Exploring everyday life for vulnerable groups has long-established traditions in Norway, and is used as a socio-political tool to unveil and then address inequalities. In this study, service recipients (survivors) and service workers (paid) were interviewed in two phases about what is/should be happening, and eventually led to the sub-title of 'two versions of reality', since the findings show a stark contrast between the two views. This was then compared with national Norwegian living conditions data and existing/planned service development plans, in an attempt to understand and clarify whose version of reality might be 'real'. Issues of representation and power are fundamental in such efforts, where ontological, epistemological, ideological, clinical, and related methodological themes intermix, and these will be presented as possible explanations, unfinished discussions and remaining questions.

DR SONALI SHAH

Centre for Disability Studies, University of Leeds

ASPIRATIONS TO SUCCESS: THE WINDING ROAD OF EMPLOYMENT FOR DISABLED PEOPLE

Choices are the building blocks of the individual life course, shaped by an interplay of macro structures, private resources and personal agency. One of the most important life decisions adults need to make concerns their occupational and economic role. In British Capitalist society, work and employment have been viewed as crucial both to the economy of society, and to the identity, health and prosperity of the individual. While it is important for financial survival, supporting an escape from poverty, the act of working has also been widely recognised as providing other life opportunities such as access to social capital and networks, an occupational identity and a respected position in society. In doing so, work satisfies psycho-social needs necessary for mental health and well-being.

The relationship between structural employment and social inclusion has received much attention in disability policy making since the 1940s, being recognised as having a significant impact on how disabled people are made known in public places and over time. Further, this was a central part of UPIAS' ground breaking discussion on the Fundamental Principles of Disability in the 1970s. The argument maintained that the fluctuation of the labour market, from economic boom to economic recession (and vice versa), has been a determining factor in the inclusion and exclusion of disabled lives in different historical worlds. However, this does not altogether explain the different career pathways travelled by disabled people, reasons why some disabled people meet their aspired goals while others are forced to follow alternative trajectories, and how this may vacillate over historical time. In order to fully understand the complexity of disabled lives, it is necessary to examine the ways public policies impact the construction of private lives and identities via structuring social spaces, relationships and individual life course expectations.

Using examples from the lives of people with physical impairments from different generations, this presentation illustrates how contextual factors (policies, environments, institutions and interdependent relationships) and individual factors (personal and familial agency, resistance and resilience) work together to shape their life course choices and trajectories, and the critical turning points they encounter along the way. These examples also demonstrate the value of the biographical lens in social research, not only to bring historically marginalised voices to the forefront of debate about their own lives, but also as a tool to observe social and cultural change in the employment of disabled people over time. Such observations can be used to inspire and inform future generations about employment careers and strategies for success.

CUL-DE-SAC THEATRE

PRESENTS

TELLING LIVES

WRITER: ERIC NORTHEY

DIRECTOR: SUE WOMERSLEY



In 1914, Prestwich County Asylum held 3,000 patients. It provided real care for the mentally ill. In Brechtian style, with songs, dance and drama Telling Lives presents the stories of patients, doctors, nurses; of the mad ideas and hopes they shared, before the First World War shattered more than illusions.

ABSTRACTS: PAPERS, POSTERS AND AN INSTALLATION

All presentations are listed in alphabetical order.

ARNOLD, LAURENCE

University of Birmingham

THE SOCIAL CONSTRUCTION OF THE SAVANT.

Ever since 'The Rainman', the notion of the 'autistic savant' has gripped the popular imagination. The savant makes appearances in both fiction and in documentary, and Pat Howlin has estimated that some 10% of autistic people possess the trait. I approach this phenomenon from the sociological perspective as a constructed role which fulfils a certain desire or need in the popular imagination and attempt to locate the role in historical archetypes. In so doing I ask questions as to what is a Savant? Who is in or out? When did the association of Idiot leave the picture and why? Why for example are the skills of classical Organist Loius Vierne, who started to play the piano by ear at age 2, and his friend Marcel Dupre who could perform the entire organ works of Bach from memory, not included in the canon. Is this because they do not have that additional component of low IQ that has traditionally been included in the popular definition or because they have otherwise not fulfilled the social role and inducement of wonder that the examples to be found in the pages of Treffert and Sachs do. Is it necessary for the Savant to be an outsider, to play the role of an exotic other, distanced from the nuanced gaze of the casual observer and how is this trope exploited to the potential disadvantage of that class of people reputed to possess these traits in some measure. These are problems I shall attempt to address in this paper which will take a critical stance against the medical freakery of current studies and in so doing examine just what the construction of the Savant means to the ordinary autistic individual.

ASKHEIM, OLE PETTER

Lillehammer University College

Guldvik, Ingrid

PERSONAL ASSISTANCE: WHAT HAPPENS TO THE ARRANGEMENT WHEN THE NUMBER OF USERS INCREASES AND NEW USER GROUPS ARE INCLUDED?

During the last 25 years personal assistance has become a growing and integral part of the welfare services in many countries. Persons with physical impairments still make up the great majority of users, but in many countries the arrangement has been extended to wider groups, including persons who are not able to act as managers of the arrangement on their own. Using data from two representative surveys among the users of personal assistance in Norway carried out in 2002 and 2010, the paper will examine developments and consequences of the strong increase of users and the extension of the target group. The data shows that there is more heterogeneity among the users in 2010 compared to 2002: Users with mobility impairments still dominate, but the proportion of people with intellectual impairments, brain injuries and sensory impairments have increased, and the age of the users is more varied. The average number of hours of personal assistance received has been reduced from 2002 to 2010. The "new" users seem to be allocated fewer hours compared to those who received personal assistance at the early stages of the arrangement. Still, most users experience an increase in their welfare arrangements, as compared to the situation before they received personal assistance. The user control of the arrangement seems to be preserved, but it takes more different forms. For a higher proportion of users, one of their relatives or a guardian acts as manager of the assistance.

AUTIO, ANU

National Institute for Health and Welfare (THL)

Ojala, Matti, Nurmi-Koikkalainen, Päivi

E-HANDBOOK ON DISABILITY SERVICES FOR SOCIAL WORKERS AS A WAY TO PROMOTE EQUALITY IN SERVICES AND NEW DISABILITY POLICY

The Handbook on Disability Services is intended for people working in the field, for use in support of client work and decision-making. The e-handbook is available in Finnish, and some sections are translated into Swedish. The purpose of the e-handbook is to improve the nationwide equality in services for people with disabilities, and to improve service quality and promote a new approach to disability policy, giving people with disabilities more right to self-determination and better opportunities for participation. The handbook gathers more than 9000 visitors monthly. The handbook is divided into the following sections:

- The front page contains news and events, consulting questions and answers, links to key legislation and the latest court decisions.
- The section on support for independent living contains descriptions of services and assistance.
- The section on administration and policies contains information on the provision and monitoring of services and information on disability policy.
- The section on legislation contains links to relevant legislation and to court rulings.
- The section on the service process describes the stages of the service process and the procedures involved at each stage.
- The section on tools contains tools for use in client work, such as assessment methods.
- The section on contacts contains information on the relevant authorities and NGOs, together with their contact details.

The handbook also contains a wealth of links to further information on the subject. The Service System Development Unit at the National Institute for Health and Welfare (THL) is responsible for the content and maintenance of the handbook. The content has been constructed together with over 60 professionals nationwide. NGOs of people with disabilities are closely connected to the construction of the handbook. The quality of the handbook is monitored by an editorial board.

<http://www.sosiaaliportti.fi/en-GB/the-handbook-on-disability-services/>

POSTER

BAILEY, RUTH

**DOING IMPAIRMENT: TOWARDS UNDERSTANDING
DISABILITY/IMPAIRMENT AS EMBODIED ACTION**

There has been ongoing debate within and between Disability Studies and Medical Sociology about how impairment/chronic illness should be conceptualised. This paper will contribute to this debate by exploring the insights gained by using the concept of “doing impairment”, which refers to the everyday practices that the embodied self has to “do” to the body-as-object in order to live (and live well) through and with an impaired body in a disabling world. The concept was used to analyse data generated from qualitative interviews with 27 disabled people about their experiences of healthcare. This revealed that participants’ everyday life included mundane tasks in which the impaired body was implicated and these necessitated participants doing a range of physical, emotional and cognitive acts. Particular attention was paid to what influenced this doing. One of these influences was the enactment of impairment, the way impairment affected movement, function emotion and cognition. But other conditions of the body, such as age, biography, social status, also influenced doing. Similarly, as the embodied self is always experienced in a context shaped by social structures, context influenced both the tasks that had to be done and the doing of them. Thus the doing impairment concept understands impairment as embodied action, which is shaped simultaneously by agency and structure, thus avoiding the over-socialised approach of some within Disability Studies and the individualised approach of some within Medical Sociology. It is also rooted in a non-normative view of the body which in turn is fleshy but always experienced through the social.

BALDERSTON, SUSIE

CeDR, Lancaster University

WHAT WORKS? INTERVENTIONS WITH DISABLED WOMEN AFTER HATE CRIME AND RAPE

This paper explores the efficacy of interventions with disabled and Deaf women after disablist hate crimes and rape in the UK. There is an evidenced need for accessible interventions; disabled women may be between twice (Smith, 2008) and four times (Martin et al, 2006) more likely to experience sexual and domestic violence than non-disabled women, with greater harm after hate crimes (Iganski, 2008). Given the escalating nature of these attacks and the costs of domestic violence (Walby, 2004, 2012), prevention and early intervention are crucial (Resnick et al, 2005). Yet, significant institutional barriers and structural inequalities (Young, 2009) often result in further harm and exclusion of disabled women from standard interventions after domestic violence (Hague et al, 2010) and hate crime (Roulstone, Thomas & Balderston, 2011). Mainstream interventions for victims in the UK are predicated on troubled neo- liberal, individualised provision, with ineffectual counselling by volunteers (Rose et al, 1999) and problematic target- hardening (Hope, 2008). But the heavily invested public services after rape may be less independent, less victim- focussed and less successful in gaining convictions than third sector interventions in the UK (Robinson & Hudson, 2011). Familiar constructions of vulnerability and safeguarding in policy can lead to disabled people being further excluded and institutionalised after violence in the community, leading to further risks of violence and neglect. In contrast, lower cost, grass roots advocacy models can be appropriate with disabled women after hate crime and rape, bringing additional protective outcomes of pride that can resist vulnerability (Balderston, 2012). This quantitative and qualitative work in the North East of England gives useful transferable learning for the design of projects in other regions where poverty is a significant factor. In user-led, accessible and culturally competent spaces, disabled and Deaf Survivors have compellingly shown how they can take their own agency and move on after violence to independent living, inclusion (Lowicki and Pillsbury, 2004) and social happiness.

BAUMBERG, BEN

SSPSSR, University of Kent

INCREASING JOB STRAIN AS AN EXPLANATION FOR RISING INCAPACITY BENEFITS CLAIMS IN BRITAIN

Over the past three decades, the number of incapacity benefit claimants in the UK has trebled. To the public and most politicians, this rise self-evidently cannot reflect 'real' incapacity; Britons are perceived to be healthier and jobs less physically demanding. The academic consensus is that rising incapacity claims reflect a lack of jobs in certain areas, with incapacity concealing 'hidden unemployment'. In this paper I consider an alternative explanation: that rising incapacity claims are partly because work has deteriorated since the early 1990s. The hypothesis is not that work has caused greater ill-health, but rather that the changing nature of work has made it more difficult for those with impairments to stay in work. I test this in two stages. Firstly, I look at whether work has improved or deteriorated, using repeated surveys covering the whole workforce from 1992 to 2006. Perhaps counterintuitively, there has been a decline in levels of control at work, despite the rhetoric of the 'knowledge economy'. This has come alongside the job intensification seen across most high-income countries, and – again surprisingly – with no change in the physical demands of work in the past twenty years. Secondly, I test if these working conditions matter, investigating whether people in high-demands, low-control jobs are more likely to go on to claim incapacity benefits. Taking account of a large number of other possible explanations, I find no effect of job demands, but an apparent effect of job control. Combining this with trends in the nature of work, I estimate that if job control had not declined over the 1990s, then around one-sixth to one-quarter fewer people would move from work to incapacity benefits in any given year. I conclude by drawing together the implications both for policy and for public understandings of 'incapacity'.

BÊ PEREIRA, ANA

Lancaster University

THE ROLE OF ABLEISM AND DISABLISM IN PEOPLE'S EXPERIENCES OF CHRONIC ILLNESS

This paper will explore how ableism affects the lives of people living with a chronic illness as well as their experiences of disablism, discrimination and exclusion. Findings will be based on my current research about the daily experiences of people living with a chronic illness, namely fibromyalgia, chronic fatigue syndrome, myalgic encephalomyelitis and multiple sclerosis, in England and Portugal. This research is situated mainly in disability studies, feminist perspectives, sociology and critical and cultural studies. Previous research about chronic illness, particularly from a sociological perspective, has tended to focus on personal issues such as how people cope with the illness and how they experience 'biographical disruption' but the importance and impact of social and institutional realms has been less explored. My research participants, on the other hand, were very keen to highlight a myriad of issues that influence their experiences of living with a chronic illness. Some of these issues are related to impairment effects whilst a great deal of other issues is situated in the social sphere. This paper will focus on their reported experiences of disablism such as: the lack of state support and difficulty or impossibility of access to benefits; the difficulty for other people to understand and recognize the impact of the illnesses; the difficulty in being able to obtain proper accommodation at work and the role of institutional practices at state level and in other institutions such as universities and schools. These areas will be particularly scrutinized and, in addition, I will argue that the role of ableism, the importance of neoliberal practices in contemporary societies as well as the importance of normalcy and normative constructions of embodiment all play an important role in the lives of people living with a chronic illness.

BEAUCHAMP-PRYOR, KAREN

Swansea University

Simoni Symeonidou, University of Cyprus

PURPOSE, PROCESS AND FUTURE DIRECTIONS OF DISABILITY RESEARCH

The content of this paper stems from the experiences of an international network of 'new' researchers with an interest in researching disability: each researcher had recently completed doctoral research. The network provided an opportunity to share experience and to contemplate on the purpose, process and future directions of disability research. Whilst approaches and experiences of researching disability differed across countries and contexts, the network was unified by an underpinning desire to explore ideas about researching disability. A range of factors which directed research projects and the decisions reached were identified and examined. The significance of individual interests, motives and values were addressed and their subsequent impact on research projects considered. Moreover, each researcher reflected upon whether their beliefs were validated, challenged or changed during the research process. As part of the process, the network was united in furthering debate about power relationships and the marginalisation experienced by disabled people and the exchange of ideas reflected the importance of enabling unheard voices to be heard. Theoretical debates about the meaning of disability and the way they shaped the direction of research projects were explored, questioning whether original research positions changed. The appropriateness of methodological choice was re-visited, together with the decisions made over directions taken. Network members explored their moral and political position as researchers and the potential ways in which it might have influenced the validity of their findings. Issues about dissemination and the impact of findings were also deliberated. Developing these ideas the network shared their thoughts and dilemmas about future research aims and challenges.

BERESFORD, PETER

Brunel University

ASSISTED DYING: IS ANY COMMON UNDERSTANDING POSSIBLE?

This proposal's aim is to offer a safe space for discussion of assisted dying to see whether it is possible to identify any common ground among people with different, even opposed views on the subject. It aims to provide a rare neutral forum which can test out the possibilities of creative discussion including people opposed to, in favour of and without fixed views on assisted dying. The issue of 'assisted dying' or 'assisted suicide' has gained very high and increasing profile internationally over a period of years, with little likelihood that this interest will diminish. The term 'assisted dying' refers to both assisted suicide and voluntary euthanasia. The most recent expression of concern over this issue in the UK has been the setting up and reporting of the Demos Commission on Assisted Dying in England and Wales. The focus of the Demos Commission, like much discussion before it, was on changing the law regarding 'assisted dying'. It is not only the scale of interest which the issue of assisted dying has commanded which distinguishes it. It also engenders highly polarized and conflicting views. It has been particularly associated with a number of high profile spokespersons calling for assisted dying for themselves or those close to them, as well as generating powerful opposition, particularly associated with the disabled people's movement. There seems little likelihood of the issue of assisted dying diminishing in importance. At the same time, it does not seem likely that there will be an early resolution of the controversy surrounding it. The UK Demos Commission pulled together valuable evidence, but it has certainly not put an end to or reduced the controversy surrounding assisted dying. The aim of this session is not to dampen but to encourage safe discussion in a spirit of supportiveness and sensitivity.

BEVAN, JULIE

University of Sheffield

WHOSE ATTITUDE IS IT ANYWAY? IDENTITIES, MODELS AND IMPAIRMENTS

WHOSE ATTITUDE IS IT ANYWAY? Identities, models and impairments
This poster introduces the topic of a PhD research study which will investigate how disabled people's attitudes towards impairment or disability are formed, developed or changed by their experiences. By focussing on individual perspectives and understandings about who or what has made a difference, I hope to gain an insight into why contrasting attitudes exist and how they can contribute to theoretical debates surrounding the promotion of awareness, inclusion or empowerment. The study plans to utilise an ethnographic, participatory action research methodology involving a diverse group of participants re-counting their experiences through interviews, narratives or focus groups. A flexible approach will promote the principles and practices of user-led research by encouraging participant involvement at all stages. A grounded theory analysis will primarily attempt to identify themes or similarities within the data and then, secondly, associations with a model (or models) of disability. The results could indicate how specific individuals or events can be instrumental in framing participants' attitudes or identities and the relevance of models within the context of the lives of people with impairments or disabilities. They may confirm or challenge established assumptions and expectations by identifying strengths and weaknesses in disability-related training, education, treatment and support, or in the planning, allocation and provision of services. This study is currently in its early stages, so this poster aims to generate interest in the research. The idea has stemmed from my own personal and professional experiences, so any constructive feedback on the concept, topic and methodology would be welcome. I would also be particularly happy to hear from people who may be interested in participating in the research.

POSTER

BOXALL, KATHY
University of Sheffield

SOCIAL MODEL UNDERSTANDINGS OF INTELLECTUAL DISABILITY

Drawing on people with learning difficulties' own contributions to social model discussion, this paper will explore the contradictions and tensions of a university researcher without learning difficulties developing social model understandings of 'intellectual disability'. The term 'learning difficulties' is preferred by many self-advocacy groups but, despite the stated preferences of many people with learning difficulties, the 'field' is defined and controlled by those responsible for research, policy and practice in this area. Academic researchers have moved towards terminology which can be recognised internationally, preferring the term 'intellectual disability' (Schalock et al. 2007). Within the UK, the Department of Health report Raising Our Sights: Services for adults with profound intellectual and multiple disabilities (Mansell 2010) has also adopted 'intellectual disability' terminology. However, there does not appear to be a general trend towards use of the term 'intellectual disability' within UK policy and practice, where 'learning disability' remains the preferred term. 'Intellectual disability' is nonetheless increasingly being used by UK academics in publications intended for an international audience. Shared terminology and understandings are also essential for international research collaboration; for example, the International Association for the Scientific Study of Intellectual Disability has developed guidelines on international multicentre research involving people with intellectual disabilities (Dalton and McVilly, 2004). The international research community's naming of people's experience in this way raises ethical issues and concerns. This paper will explore these concerns and the path negotiated by the author between the preferences of people with learning difficulties and the demands and requirements of the UK academy and international research in this area.

BRANDON, TOBY

Northumbria University

BETWEEN A REC AND A HARD PLACE: THE ETHICAL CHALLENGES OF CONDUCTING EMANCIPATORY ACTION RESEARCH WITH MENTAL HEALTH SERVICE USERS AND CARERS.

This paper is based on a research project funded by the NHS which explores whether there is a pathway to mental health 'recovery' through care coordination. Mental health service users and carer researchers have driven this project; setting the aims, designing the tools to be used, generating and analysing the data and disseminating the findings. The original design and continued progression of this project has faced ethical challenges and the presented work explores the tensions that exist between conducting emancipatory research and the consequential systemic ethical requirements. The work utilising key social theory will explore two questions, firstly if a project is designed and led by service users and carers does it in some sense make it 'better' ethically? Secondly how in mental health research is 'vulnerability' conceptualised and enacted upon? Issues considered include gate-keeping and the role of the Research Ethics Committee (REC), egalitarian and political commitments and how to conduct 'authentic' service user/carer work. Ultimately the research attempts to blur traditional boundaries between participants and researchers and enable co production within an open inclusive design. The cultural contrast between risk averse, hierarchical, tightly structured ethical protocols and the continuously evolving, loosely structured, power sharing nature of emancipatory research will be reflected upon and conclusions drawn around ways forward in both theory and methods.

BREHME, DAVID

Edinburgh Napier University

THE ROLE OF NORMALITY IN THE DISCOURSE OF LEARNING DISABILITY: A LACANIAN DISCOURSE ANALYSIS

In contemporary Britain, 'learning disability' is legally defined through a medical understanding of Disability (Equalities Act 2010). Disability is conceptualised as a direct effect of physical or mental 'impairment', leaving the idea of Normality unquestioned because of its assumed self-evident nature (Skully, 2002: 48). Extensively criticising the medical perspective, the social model of disability has been pivotal in pointing out the socially constructed nature of Disability and the particular notion of Normality that underpins it (Goodley, 2011: 11). However, the social model too, has failed to examine the notion of Normality fully by relying on an empiricist understanding of 'impairment' (Shakespeare & Watson, 2002).

Using a case-study approach, this paper examines the notion of Normality within the discourse of learning disability from a post-modern perspective through the work of Lacan (1966/2006; 1991/2007), and that of Lacanian scholars such as Davis (1995; 2002), Seshadri-Crooks (2000) and Verhaeghe (2008). I present selected parts of a transcript of my interview of family with a child with learning disabilities in Edinburgh and interpret them through a psychoanalytic-social-constructivist discourse analytic framework based on Lacanian theory (Pavón Cuéllar, 2010). Given that all experience is linguistically mediated, this kind of analysis allows an exploration of the subjects' perspectives on learning disability without claiming to 'uncover the truth' of the discourse. With this case study I argue that, the notion of Normality is a master signifier in the discourse of learning disability and that the suspenseful relationship between subject and master leaves the subject in an impossible position, stuck between anxiety and desire. The particular strength of the Lacanian perspective taken in this paper lies in its power to account for how a certain understanding of Normality has come to underpin the contemporary discourse of learning disability in the UK, without reducing it to an individual pathology but rather locating it within a socio-economic and historical context.

BROWN, WENDY

University of Strathclyde

CONTACTS AND CULTURE: THE IMPACT OF SOCIOECONOMIC DERIVATION ON THE LIVES OF PEOPLE WITH LEARNING DISABILITIES.

Where socioeconomic circumstances have been investigated in relation to the lives of people with learning disabilities, there has been a tendency for research to focus on children and education, health outcomes, the social determinants of intellectual disability, or the poverty associated with living with a disability. Existing studies have been mainly quantitative, often derived from data sets with other primary research objectives. Whilst studies in these areas have been invaluable in helping to determine how people with disabilities are affected by poverty in our society, they have not provided an understanding of the mechanisms through which life opportunities can be impacted by socioeconomic derivation. Taking Bourdieu's theory of cultural/social reproduction as a theoretical framework, this research attempts to unveil the impact differential access to social, cultural and economic capital (the mechanisms of social production) can have on life opportunities and outcomes for people with learning disabilities. Using concepts of field, habitus and capital, the research takes an in-depth look at the lives of 8 individuals with a variety of cognitive impairments who are from different social backgrounds. Analysing their current practices and social background, it attempts to explore the ways in which habitus and capital have both structured life outcomes and have been structured by the individuals' social position. Findings are based on semi-structured, naturalistic interview data, photo and activity diaries, neighbourhood and relationship maps, and individual PATH plans. Research data varies between each participant according to their ability and willingness to participate in different types of research activity. This poster presentation will:

- Sketch the broad theoretical outline of the study
- Compare 2 case studies of individuals from diverse socioeconomic backgrounds
- Present preliminary findings of the study drawing upon the two case examples.
- Illustrate the significance of these findings for current learning disability policy and practice.

POSTER

BRUNNER, RICHARD

University of Glasgow

HOW MIGHT THE CAPABILITY APPROACH ENHANCE UNDERSTANDING OF LIVED EXPERIENCES OF MENTAL DISTRESS? A REVIEW OF LITERATURE.

Increasingly predominant in social sciences theoretical and policy discourses, Sen's capability approach distinguishes between what a person actually achieves ('functionings') and what they could potentially achieve ('capabilities') to understand inequalities between social groups. It maintains a focus on both agency and wellbeing. In developing an original framework for evaluating social justice, Sen successfully argues for human diversity, disability and health differences to be accounted for. However, no analysis is made of the implications for people with experience of mental distress. In her prime disability and capability text, Nussbaum's acknowledgement of mental distress is marginal whilst incorporating normative judgements about a life that is worth living, good health, dignity and rationality. Both authors underplay issues of power and the role of the state which are significant in shaping the agency and wellbeing of people with mental distress, especially those who have received diagnoses. Little literature yet applies the capability approach to mental distress. It has been suggested that it might form a useful model for examining recovery in schizophrenia, and has been used to justify a claim that psychiatric diagnoses invariably have a negative impact on capabilities and functionings, both questions begging empirical exploration. This review shall evaluate the ways in which the extant empirical and theoretical capabilities literature interprets lived experiences of mental distress. It will argue that the capability approach allows for a model of exploring mental distress that may address human rights, autonomy, and basic flourishing, core issues for further development of a social understanding.

BRYANT, WENDY

Brunel University

Laura Cresser, Stephanie Tempest

ACTION RESEARCH TO DEVELOP RECOMMENDATIONS TO IMPROVE THE CENTRE FOR CITIZEN PARTICIPATION WEBSITE

The Centre for Citizen Participation at Brunel University is focused on user involvement in research and policy development. A user advisory group was set up two years ago and initial discussions indicated that online access to information about the Centre could be improved. Members wanted more information and an opportunity to shape research agendas outside of group meetings. Funds were obtained from the university's Knowledge Transfer scheme and an action research project initiated. The project took place from January to July 2011, involving seven people with varied interests and knowledge of research, websites and access to online resources. They all had direct personal experience of long term health problems. They were recruited from the user advisory group, who oversaw the project. An MSc occupational therapy student acted as convenor for the group, facilitating access and participation. Five meetings took place, with people working together for most of the day to identify issues in accessing the website, discuss possible solutions and agreeing action to gather relevant information and other resources. Each meeting started with a reflection on what had been achieved since the last meeting. The group created recommendations to substantially improve the content and presentation of the existing website, which were discussed with the user advisory group. Many of the recommendations were implemented and this presentation will explore those, as well as accounting for those which were not implemented. The project offered all involved an opportunity to learn more about the needs of different populations in accessing online resources, the academic context for research and how action research works in practice. These aspects will also be discussed, taking a broader perspective on user involvement in theory and practice. Successful user involvement is the essential basis for the development of relevant research which can positively impact on people's lives.

CALLUS, ANNE-MARIE

National Commission Persons with Disability

DO "ANGELS" HAVE A RIGHT TO INDEPENDENT LIFE?

This paper is based on the social model of disability (with its clear distinction between impairment and socially-created disability) and the individual model of disability (which subsumes various approaches that focus not on disabling barriers but on the individual's impairment). One such approach is the charity model of disability, which is based on religious notions of helping those who are considered to be weak and vulnerable. The pervasiveness of this model emerges particularly clearly in writing about people with intellectual disability in Malta. This paper is in fact based on an analysis of such writing in Maltese newspapers, and newsletters, magazines and other literature produced by organisations that work with people with intellectual disability. One of the significant characteristics of these writings, it is demonstrated, is the frequency of references to them as "angels", "gifts" from God or a "cross" that has to be borne. This is perhaps not surprising in a culture steeped in Catholic tradition and which retains religiously marked idiom even in more secular times. But, interestingly these images are very often interwoven with arguments in favour of the rights of people with intellectual disability to independence, community inclusion, education and employment, leading to contrasting patterns of rhetoric and exhortation in the field. The paper investigates whether it is possible for the language and notions of the social model, with its emphasis on disabling barriers created by society, on the rights of disabled people rights and on independent living, to co-exist easily with the charity model, with its use of religious imagery, or whether the two are perforce at odds with each other and should remain separate. In the process, conclusions are drawn on how the Maltese experience may be generalised to other more international contexts of disability rights.

CAMERON, COLIN

Northumbria University

THE AFFIRMATION MODEL: WHAT IS IT AND DO WE REALLY NEED IT?

The affirmation model: what is it and do we really need it? In distinguishing between impairment as 'physical, sensory, emotional and cognitive difference to be expected and respected on its own terms' and disability as 'a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those identified as normal', the affirmation model gives us something the social model didn't. This is unsurprising and uncontroversial, as the social model is simply a tool to be used in focusing on structural conditions that shape society's responses to people with impairments. While the social model defines disability as a restrictive social relationship, allowing us to identify what disabled people are prevented from doing and becoming, the affirmation model defines disability as a productive relationship, enabling us to recognise what they are required to do and become instead. In a context where debate around the validity of the social model continues, however, rather than being proposed as an alternative or a replacement, it is suggested that the affirmation model be regarded as a confirmation, an extension and a development of the social model. Rather than being 'just another model', developed for the sake of extending theory, it is a new tool designed for a different, practical job – which includes making affirming sense of the lived experience of impairment in the face of oppressive assumptions of tragedy; and making affirming sense of the innumerable invalidating encounters experienced by disabled people in the midst of everyday life. As a framework within which disability can be understood as the ontological price paid by people with impairments for the relative security of identity of the 'normal', the affirmative model establishes a basis for refusal to be cowed by cultural expectations of conformity.

CAMPBELL, TOM

CDS, University of Leeds

**RESISTING DISABLEMENT BIOPOLITICALLY, OR, IS
THE SOCIAL MODEL THE BEST TOOL WE HAVE FOR
INVENTING THE COMMON?**

When bio-politics has been operationalized as a mode of analysis in disability studies (and aligned disciplines) it has concentrated on how bodies are subjectivated; how an identity is assigned to an individual, particularly through the mechanism of the norm that results in the constitution of particular impairment categories, work that I myself have begun to undertake and consider to have great value. However, despite Foucault's warnings to refuse all attempts of understanding power negatively, work on bio-power and bio-politics throughout the social and human sciences typically carries a negative tone. In this paper I wish to explore whether the disabled peoples movement's positive re-articulation of difference and singularity on their own terms, re-imagining their own bodies and the bodies of others, contra to tactics of power that have hitherto been articulated onto them, should be considered as example of the invention of the 'common' as understood by Judith Revel. The paper will explore how the Disabled People's Movement in the UK and the social model of disability has allowed for the re-invention of both singular and collective bodies and possibly begun the invention of the common, through the reframing of disability as a social process of discrimination linked to the material conditions of societal organization, rather than resulting from individual biological deficit.

CARTER, IRENE

University of Windsor, Canada

Judy MacDonald, Dalhousie University and Roy Hanes, Carleton University

DISABILITY SCHOLARSHIP, LOCATION AND PLACE WITHIN NORTH AMERICAN SCHOOLS OF SOCIAL WORK

Throughout the past decade, a small group of dedicated scholars within Canadian social work programs have been diligently trying to raise awareness about disability rights, educational access/accommodations for students with disabilities, and curriculum development re disability policy and practice. The group's primary aim is to transform post-secondary social work education into an accessible, inclusive and welcoming environment for disabled persons. This paper will begin by sharing some of the trials and tribulations this group experienced in the process of bringing about structural change. A key component of the structural change process involved a survey that was dispersed to all accredited schools of social work in Canada (n=36), which yielded a 75 percent response rate (Carter, Hanes, and MacDonald, 2012). Deans and Directors were asked questions about their policies and practices pertaining to students, faculty and staff with disabilities, with particular focus on recruitment, admissions, academic and field accommodations, curriculum, retention/graduation and best practices. The findings from this research were shared with the Canadian Association of Social Work Education (CASWE) through conference presentations and discussions (Carter, Hanes and MacDonald, 2010; Dunn, Hanes, Hardie and MacDonald, 2003), policy recommendations re Educational Policy and Accreditation Standards (CASWE, 2011, 2009) and scholarly publications (Carter, Hanes and MacDonald, 2012; Dunn, Hanes, Hardie, Leslie and MacDonald, 2008; Dunn, Hanes, Hardie and MacDonald, 2006). Key elements of this engagement process will be highlighted within the paper, along with preliminary findings from extending the survey to the 700 accredited schools of social work in the United States. Through extending the survey to schools of social work within North America, it is anticipated that progressive and innovative practices, policies, and curriculum will emerge shaping recommendations for an inclusive environment that fosters disability scholarship, location and place.

POSTER

CASEY, HELEN

Division of Health Research, Lancaster University

Dr Jane Simpson

Using a social model of disability perspective to enhance understanding of psychological difficulties in people with Parkinson's disease: A literature review

Research investigating psychological difficulties associated with Parkinson's disease (PD) is dominated by individualistic neurobiological and psychological perspectives. Therefore this literature review draws on a social model of disability, Thomas' (1999; 2007) social relational approach to disablism, to offer an alternative way of conceptualising psychological difficulties experienced by people with PD. This narrative review explores the ways in which socially imposed restrictions and stigma can contribute to psychological difficulties by using Thomas' (2007) concept of psycho-emotional disablism. As such, quantitative and qualitative research exploring the relationships between social oppression, disability and psychological difficulties associated with PD is presented to demonstrate that people with PD can be subject to psycho-emotional disablism which may contribute to psychological difficulties such as depression. The review concludes that further attention to the social dimensions of disablism in PD is needed in both research arenas and clinical practice.

POSTER

CHATAIKA, TSITSI

University of Zimbabwe

Margaret Wazakili, Gubela Mji, Kudakwashe Dube, Mac MacLachlan

REALISING THE RIGHTS AND POTENTIAL OF PEOPLE WITH DISABILITIES IN AFRICA THROUGH INFLUENCING POVERTY REDUCTION STRATEGY PAPERS

There is documented evidence suggesting the link between disability and poverty, and yet, disability issues still struggle to feature in most strategies targeting poverty reduction. In this presentation, we report findings from a three-year qualitative research project (2008 – 2011), which aimed at documenting and analysing research evidence on the extent to which disabled people engage in national and international development policy initiatives targeting poverty reduction, particularly the Poverty Reduction Strategy Papers (PRSPs). The study took place in Malawi, Sierra Leone and Ethiopia. The study employed a series of five qualitative data collection methods namely key informant interviews, focus group discussions, critical incident technique, nominal group technique, and force field analysis. The study confirmed that disability issues are minimally included in PRSPs because of the gap between policy and practice. Also, people with disabilities are not meaningfully involved in the PRSP processes. Consequently, they struggle to access basic services such as education, health, and employment. Specific facilitators of disability inclusion in poverty reduction strategies, which can be applied by various stakeholders, including policy makers, civil society organisations, and development partners were identified. Also, the study identified prohibitive factors that negatively impact on disability inclusion; hence the need for all stakeholders to work together to reduce the negative impact of these factors. Strengthening the facilitators and minimising the prohibitive factors, will enable governments to uphold the rights of people with disabilities, and work towards attaining the Millennium Development Goals. Specific skills for ensuring disability inclusion in development strategies were also identified.

COLLINGBOURNE, TABITHA

University of Sheffield

**ANALYSING PARADIGM CHANGE: THE UN
CONVENTION ON THE RIGHTS OF PERSONS WITH
DISABILITIES AND POLITICAL DISCOURSE THEORY**

The phrase 'paradigm change' is frequently used in connection with the UN Convention on the Rights of Persons with Disabilities. But what does it mean? How might it come about? And what techniques might we use to assess progress – or otherwise – in the desired transformation in understandings? This presentation suggests that the political discourse theory of Laclau and Mouffe may provide some relevant tools. It will attempt to illustrate, using implementation of the right to independent living in England as example, how this 'viewpoint' may help to illuminate such developments as the re-articulation of understandings through (neo-liberal) policy, or their dislocation in the face of unforeseen economic events; the shaping of systems of social relations through law and administration; and the play of identity in the formation of and response to such discursive dynamics.

CROOKS, VALORIE

Simon Fraser University, BC

Michelle Owen, University of Winnipeg; Sharon Dale Stone, Lakehead University

CHRONIC ILLNESS AND THE KNOWLEDGE WORKER: THE ROLE OF THE BODY IN SHAPING THE PRODUCTION OF ACADEMIC WORK

Academics are knowledge workers who are known for their intellectual outputs. Although these outputs are often attributed to their minds, it is flawed to think that their bodies are not essential to their knowledge work despite the prevalence of a neoliberal regime that reinforces mind-body separation in the production of labour. In other words, a disembodied view of the production of academic work is an incomplete one. In this presentation we examine the role of chronically ill academics' bodies in shaping the production of their academic work. Drawing our collective backgrounds in geography, sociology, and critical disability studies, we focus specifically on the experiences of Canadian academics who have multiple sclerosis (MS), a chronic illness that is characterized by symptoms of pain, fatigue, and neurological impairment. We report on the findings of 35 phone interviews conducted with full-time, part-time, and retired Canadian academics with MS. In this study we set out to understand if and how academics with MS who work at Canadian universities negotiate the socio-spatial workplace after onset and explicate the ways in which systemic institutional barriers and enablers inherent in this workplace shape the experiences and employment outcomes of this group of workers. A key finding pertains to the complex ways in which participants' chronically ill bodies mediated, shaped, and regulated the production of their knowledge work. We expand on this finding in this presentation through discussing five themes:

1. the changing body;
2. the accommodated body;
3. the fluctuating body;
4. the present body; and
5. the absent body.

We critically examine the relationships between these five bodies and the production of academic knowledge work. We conclude by discussing the pressing need for creating an embodied view of academic work, and knowledge work more generally, in both research and practice.

DERMODY, RÓISÍN

FROM PRENATAL SCREENING TO "AFTER BIRTH ABORTION"

Abortion is a highly contentious issue when the debate focuses on a woman's right to choose and the right to life of the unborn child. However, when the decision to abort is based on the detection of an impairment during prenatal screening, the debate takes on a whole new perspective. And now, we are asked to consider the case of "After birth Abortion".

In this paper I shall examine the arguments in favour and against aborting a foetus on the grounds of impairment detected during prenatal screening.

I will deploy a feminist disability studies lens to analyse these arguments and their meanings in context. Abortion can be a contentious issue but even more so when there's an impairment involved. The argument is less centred on the rights and wrongs of abortion and more focused on the `suffering` caused by bringing a disabled child into the world; the burden of care` to both the family and the state; and whether or not it would just be better to abort and start again. Therefore, as an Irish disabled feminist, this issue presented me with a number of concerns, not least of which is the legal position of abortion in Ireland. I will try to explore these concerns while bearing in mind the complexity required to approach this issue. I will argue that a pro-choice position and a disability rights position can be reconciled and don't have to be mutually exclusive. I will also discuss how right wing discourses have co-opted the issue of disabled peoples right to be born and the dangers this discourse can have on our lives.

And to conclude, I shall consider the recent publication of an article by Alberto Giubilini and Francesca Minerva on the 23rd February 2012, in the online edition of the Journal of Medical Ethics, which advocates for "after birth abortion".

ELLIS, LIZ

Open University

RURAL SPACES, THERAPEUTIC PLACES?

This paper primarily draws upon the outcomes from a participatory research project. The research team comprising of academics, social work students and service users explored the themes of Disability, Rurality and Tourism with two distinct social groups, older people and people who identify as having mental health distress. This paper focuses upon the latter group. Additional outcomes from my Master's thesis will also be drawn upon. There has historically been a strong link between 'therapeutic' sites of treatment and rural spaces. For economic, psychiatric and social purposes, people who are considered to be lacking in reason, either temporarily or permanently, have found themselves in (usually) forced rural formal communities. This paper will explore the historical precedents of these types of community and critically examine the burgeoning modern 'care farms' movement. The paper will then investigate some of the tensions between the supposed therapeutic benefits of rural spaces, notions around the 'rural idyll' and the reality of living in a rural environment. The paper will also explore the pressures people with labels of mental illness face to 'act normal' for tourists and the resistance offered to the drive to normalise actions and appearance. Using the perspective of people labelled with mental health distress and/or learning difficulties, there will be a discussion of the ways the respondents negotiate a tourist environment and their drive to find a place of sanctuary located in 'magnificent isolation'.

EMERSON, ERIC

CeDR, Lancaster University

Alan Roulstone, University of Northumbria

DISABILITY HATE CRIME IN BRITAIN

For consideration for WHO round table on violence This paper will present new analyses of data collected in the UK's Life Opportunities Survey on crime and hate crime experienced by disabled adults in Britain. It will include information on the overall prevalence of crime and hate crime, types of crime reported and the association between reporting of crime and hate crime and age, gender, type of impairment associated with disability and indicators of socio-economic position.

EFFECTIVE CONSUMER POLICIES FOR DISABLED PEOPLE IN THE PRIVATE MARKET

The situation of disabled people as active consumers in the private sector is not new but remains a little researched topic. On one hand, often disabled people are seen as passive consumers of social and medical services; on the other hand, the majority of research concerning disabled people in the market are oriented towards identification of the technical features of specific products or disclosure of experienced problems. The research project 'Effective Consumer Policies for Disabled People in the Private Market' is oriented towards the identification of what needs to be done in Europe in order to 'ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities' (CRPD Article 9). The main focus is on Information and Communications Technologies (ICTs). This research collects data from two countries (United Kingdom and Lithuania) and at the European level, involving: document analysis, lived experiences and interviews. The synergy of different methods (photography, lived experiences, focus groups, interviews, and legal documents and complaints analysis) allows the identification of key- stakeholders positions, experiences and views (disabled children and adults, DPOs, ICT producers and sellers, policy makers). This is crucial as this research seeks not only to reveal the current situation about legislation and mechanisms of enforcement but to identify what should be done in order to encourage private companies to improve their activities and become more fully accessible for disabled people. Giving voice to all key-stakeholders will enable the development of mutual dialogue as more equal partners. The research aims to provide recommendations for the development of EU disability law and policy reform in the light of the UN CRPD.

FERRIE, JOANNA

University of Glasgow

Nick Watson

MND, CORPOREALITY AND DISABILITY STUDIES: A RE-ENGAGEMENT WITH FEMINIST UNDERSTANDINGS OF PRIVATE SPACES

Disability Studies and the disability movement have campaigned, or informed campaigns for equal access to public spaces and opportunities. The political strengths of this position are evident in the infiltration of the social model into public policy rhetoric. Nevertheless, the social model has been critiqued for marginalising the private experiences of impairment; for example the theorizing of impairment effects and psycho-emotional disablism as a pathway to gain deeper understanding of intimate experiences. The former are the restrictions or limitations imposed upon a body relating to an impairment which are distinct from the social relational barriers whilst the latter refers to the social processes and practices which place limits on the psycho-emotional well-being of people with impairments. Impairment effects and disabilities are inter-related so that the whole person can not be subjected to a dualist approach. Work by Donna Reeve has significantly informed this paper as we examine data drawn from interviews with adults who have motor neurone disease (MND) and focus groups of family members who have supported someone with MND to explore how living with a terminal, chronic condition can be explored from a disability studies perspective. The data suggest people facing chronic and life-limiting illnesses may be less concerned with 'public' disabling barriers as they are faced simultaneously with 'private' impairment effects that grow in number and severity. The psycho-emotional consequences of living with a condition that will end one's life, on average within 18 months, and with particular symptoms will be discussed. Particular attention will be given to the loss of verbal communication ability, fear of asphyxiation, a lack of medical awareness among front line medical professionals and the need to accept an identity of disability in order to access particular resources and benefits. The paper ends by re-engaging with feminist literature to critically assess how the social model can incorporate experiences of private spaces.

FONTES, FERNANDO

University of Coimbra, Portugal

THE LONG RUN FOR DISABLED PEOPLE'S CITIZENSHIP IN PORTUGAL: DOMINANT MODELS AND IMPACTS

The increased variety of social conflicts in the post-1960 years led to the extension of the individual's participation in the state's activity which was mirrored by the formation of New Social Movements and the expansion of the notion of citizenship. From the initial tripartite model of citizenship suggested by Marshall (1950, 1963) – comprising civil, political and social citizenship – there has been a demand for new forms of citizenship, ranging from sexual or intimate citizenship to ecological or green citizenship. As Phelan states, "the category of citizenship seems to open up under the pressure of multiple desires to identify with its promises." (2001: 13). New groups of people have emerged claiming citizenship rights. This has been the case of disabled people in most Western countries since the late 1960s and 1970s including Portugal. In order to do this, disabled people started to coalesce into uni- and multi-impairment groups and organisations to denounce their exclusion and oppression from civil society and from the state and to call for their rights as citizens. In fact, citizenship defines the relationship between the individual and the state, as well as between individuals within a given society, and may prevent equality between citizens. Partially based on my PhD thesis about social citizenship and the Disabled People's Movement in Portugal, this paper investigates, firstly, the dominant model of citizenship in Portugal and the idealised citizen assumed by this model, and, secondly, the notion of citizenship promoted by the Portuguese Disabled People's Movement. In this paper, I will also discuss the implications of different models of citizenship in the lives of disabled people and in the exercise of their citizenship rights.

FOVET, FREDERIC

McGill University

TWO VOICES, ONE DISCOURSE? NEO-LIBERALISM AND MINORITIES RIGHTS APPROACHES TO DISABILITIES IN HIGHER EDUCATION: AN UNLIKELY COMPATIBILITY.

The Neo-liberal and Minorities Rights approaches to the management of Disabilities issues are traditionally perceived as antipodean: one wishing to apply and ride market forces in the management of individual needs; the other intent on carving out a voice and an advocacy space for individuals with Disabilities. Yet, current strategies and models in Higher Education – with the adoption of Universal Design in particular – are currently, and for some time to come, blending these two theoretical perspectives into one path on the field. The hypothesis of this paper is that circumstances and considerations, that are as varied as contradictory, in the sphere of Disabilities in Higher Education are creating an extraordinary conjuncture in which both theoretical discourses seem to find satisfaction in terms of practical outcomes. The paper surveys current documentation and literature developed and used by post- secondary Disabilities service providers in North America and carries out a qualitative analysis of their major themes and concerns. It will be shown that there is indeed great theoretical contradiction in the discourse used but a surprising unified voice with regards to pragmatic on terrain expectations. The discussion session of the presentation will draw parallels between the theoretical contradiction observed in this domain and similar recent observations made through literature on Neo-liberalism and minority voice, particularly in the sphere of minority languages.

GAETE REYES, MARIELA

King's College London

**WOMEN WHEELCHAIR USERS' AGENCY AND
RESISTANCE IN THE CONTEXT OF MOBILITY AND
MOVEMENT**

Popular media and other publications tend to portray disabled people as passive victims of the socio-spatial environment. This paper develops the argument that disabled people in general, and women wheelchair users in particular, are not passive victims, or what Allen (2000: 52) refers to as 'physiological dopes'. Rather, disabled people have active agency and they are able to create strategies of resistance that enable them to challenge, to some extent, poor access, immobility, and cultural stereotyping (Young, 1990). The paper uses Bourdieu's (1986; 1990; 2005) notions of habitus and capitals, and also, de Certeau's (1984) idea of the strategies of the powerful and the tactics of the weak in everyday life, to examine the experiences of women wheelchair users. It explores how they seek to overcome the physical obstacles that they, daily, confront in the built environment, and it also focuses on their political efforts to campaign for better access and how they resist cultural stereotypes. The paper concludes that disabled women ought to be (re) conceptualised as, potentially, active agents with the capacities to create social and material change.

GARTHWAITE, KAYLEIGH

Durham University

Clare Bamba, Jon Warren

**I DON'T WANT TO PUT MY HAND UP AND SAY 'I'M
DISABLED': EXPLORING IDENTITY AND STIGMA WITH
LONG TERM INCAPACITY BENEFITS RECIPIENTS**

The receipt of incapacity benefits is currently a high profile topic in the UK attracting much political, public and media attention. Reducing the number of people receiving incapacity benefits has long been a priority of successive governments and remains a high priority under the Coalition government's agenda. This has brought with it notions of 'deserving' and 'undeserving' which have re-emerged in policy responses to unemployed sick and disabled people, marginalising them as 'scroungers' and 'workshy'. However, what is less often heard are the voices of those experiencing life on these benefits. Through qualitative interviews with 25 chronically sick and disabled people, the study explored the lived biographical reality of receiving long term incapacity benefits. This paper emphasises participants' stories of experiencing chronic illness and how they relate to identity and stigma. Questions of how identity formation and reformation are affected by the onset of a chronic health narrative will be explored, and also how identity is affected by populist discourse which labels sickness benefits recipients as 'scroungers'. Finally, this will include a discussion of the acceptance or rejection of a disabled identity in relation to peoples' narratives.

GLENNON, MICHAEL

University of Nebraska at Omaha

“IT IS TRULY A FIGHT TO SALVAGE HUMAN THOUGHT FROM DESPAIR”: THE POLITICS OF AFFECT, YOUTUBE, AND THE BECOMING MINORITARIAN OF NEURODIVERSITY

“Erecting the figure of a universal minoritarian consciousness, one addresses puissances of becoming that belong to a different realm from that of Pouvoir and Domination. Continuous variation constitutes the becoming-minoritarian of everybody, as opposed to the majoritarian Fact of Nobody” (A Thousand Plateaus, p. 118). This paper reports on portions of a virtual ethnographic research within autistic liberation discourse communities; in this case an analysis of YouTube viewer comments responding to a video by a woman who uses her channel to transmit her autistic perception – a sense of her sensation and movement – to the viewer, and then using speech synthesis to argue autism is her native language. Comments come from parents, educators, care workers, autistic people, and many others. They are analyzed as affective artifacts left along the many passages through the video. Together they reveal a hunger and awe for autism as a continuous variation of human becoming.

GOODLEY, DAN

Manchester Metropolitan University

Katherine Runswick Cole

BORDERLINES: DISABLED CHILDREN AND THEIR BOUNDARIES

Curti and Moreno (2010) have argued that boundaries and borders are nothing if not the different relational and durational articulations of bodies and spaces. These entangled boundaries include borders between parent and child; culture and body; school, families and child. Through analysing the ways in which these borderlines are continually re-composed and re-constituted we are able, following Curti and Moreno, to reveal their relational and embodied articulations. In previous work we have explored the ways in which disabled children disrupt normative orders associated with school, family and community (Goodley and Runswick-Cole, 2012). In this paper we take up the concepts of boundaries and borders to explore their relational and embodied articulations with specific reference to stories collected as part of an ESRC project entitled 'Does every child matter, Post-Blair: the interconnections of disabled childhoods'. First, we explore the notion of 'disabled families' and 'cripping families'. Second, we examine 'school exclusion' and 'school revolution'. Third, we consider the 'body-as-disability' and the 'body-as-possibility' (sic). Through this analysis we offer ideas for new psychologies of behaviour through the sighting disabled children at key borderlines which may offer loss or capacity, though drawing us to affirmative theoretical ideas from geography, philosophy and critical psychology including the work of Deleuze, Guattari, Braidotti and Shildrick. We ask; how can we re-imagine, re-think and differently practice – that is revolutionize – key borders and boundaries of education in ways that affirm the lives of disabled children.

GOODLEY, DAN

Manchester Metropolitan University

Cate Fisher, Katherine Runswick-Cole

RE-POSITIONING RESILIENCE: RESPECTING DIVERSITY AND INTERDEPENDENCE IN THE LIVES OF DISABLED PEOPLE ACROSS THE LIFE COURSE

This paper draws on an on-going research project, Resilience in the lives of disabled people across the life-course, that is being carried out in collaboration between Scope, the UK disability charity, and Manchester Metropolitan University. The aim of the study is to understand what 'resilience' means in the lives of disabled people, adopting a critical psychological disability studies approach in order to inform policy and practice. In this paper we argue that resilience is a problematic concept in the lives of disabled people. Resilience is often understood as the ability to develop or to live normally, despite adversity. This means that disabled people have often wrongly been considered to lack the bodies and minds needed for resilience to emerge. On the other hand, because impairment is seen as a 'risk factor' to resilience, a disabled person who lives 'normally' is automatically considered to have overcome their impairment to be 'resilient'. Crucially here, while social constructionist approaches have begun to challenge understandings of resilience that are tied to what is normal in specific nations and cultural contexts, little attention has been paid to the conceptions of resilience that are tied to ableist cultures that diminish lives that are judged to differ from the norm (Campbell, 2009). Our aim in this paper is to draw on the life stories of disabled people at each stage of the life course to reposition the concept of resilience in ways that reject normative, individualistic models and respect diversity and interdependence and disabled people as active agents of change.

GRABY, STEVE

University of Leeds

NEURODIVERSITY: BRIDGING THE GAP BETWEEN THE DISABLED PEOPLE'S MOVEMENT AND THE MENTAL HEALTH SYSTEM SURVIVORS' MOVEMENT?

The Disabled People's Movement and the Mental Health System Survivors' Movement have evolved in parallel, both as grass-roots liberation movements and creators of scholarly theory, from origins in the political alliance of institutionalised `service users` to broad and diverse coalitions today. Both movements have used diverse tactics ranging from direct action to lobbying and from emancipatory research to consciousness-raising arts, and have diverse ideological influences from Marxism and feminism to post-structuralism and libertarianism. These movements may appear to be natural allies against the hegemony of medical professions and the `medicalisation` of individual experience (Marks 1999; Garland-Thomson, 2006), but there have been tensions and contradictions between them, such as disagreements on whether mental distress should be considered as an impairment or mental health system survivors as `disabled` within a social model of disability (Plumb 1994; Beresford 2000), and differing attitudes to concepts such as `illness` and `treatment`. More recently, the neurodiversity movement has been developed by people with diagnostic labels such as autism, AD(H)D, dyspraxia and dyslexia, which have been classified under umbrellas of both `mental illness` and `disability`. Focused on de-pathologising such conditions and arguing for their recognition as fully valid `ways of being in the world` (Meyerding 2003), this movement has drawn on the theory and activism of both the DPM and the MHSSM, and on other bodies of thought such as feminism and queer theory (Singer 1999; Sinclair 2010). In doing so it has revealed new and challenging perspectives on the boundary between the biological and the social. I will examine the similarities, differences and porous boundaries between these movements, and consider whether the emergence of the neurodiversity movement can resolve tensions between the DPM and the MHSSM, and/or lay the groundwork for a wider synthesis of all these movements and others concerned with human diversity and the oppression and potential liberation of those who diverge from hegemonic social norms.

GRABY, STEVE

University of Leeds

WORKING IT OUT: WAGE LABOUR, DISABILITY AND AUTONOMY

In the 1960s-70s neo-Marxist groups such as the Situationists in France and the Autonomists in Italy developed strong critiques of waged labour as a principal means of organising necessary work in society (e.g. Vaneigem 1967, Berardi 1970). While they drew on older traditions including 19th-century anarchist and `utopian socialist` thought (e.g. Kropotkin 1913[1990], Morris 1884[1983]) and peasant struggles against industrialisation and proletarianisation, their work has been highly influential on a wide variety of critical perspectives on capitalism, including those of feminists concerned with domestic labour (e.g. Mies 1986, Federici 2004) and political ecologists (e.g. Gorz 1982). The historical analysis of many of these authors draws close parallels with that of foundational writers within Disability Studies (e.g. Finkelstein 1980, Oliver 1990, Gleeson 1999). However, for the most part, the attitude to wage work of such authors has been very different, with many regarding participation in the formal labour market as an essential precondition for the inclusion of disabled people in modern society. One major exception has been Paul Abberley, whose critiques of classical Marxist theory and the centrality of paid work in disabled people's movement discourses (1997, 1999) draw potentially fruitful parallels with anarchist and autonomist thought. In this paper, I will examine these parallels in the light of current political conditions in the UK, in which disabled people are demonised as `workshy` or `scroungers` by government and popular media, and slogans such as `Right to Work` are used by the activist opposition to government austerity measures (in contrast to US-based disabled activist Sunaura Taylor's 2004 call for the `right not to work`), and argue that a radical reconsideration of the concept of `work` and its social organisation, as currently conceptualised by both capitalists and socialists, is necessary for genuine social inclusion for disabled people.

GREENSTEIN, ANAT

Manchester Metropolitan University

DRAWING LESSONS FOR INCLUSION FROM A SEGREGATED UNIT: IS THAT A DANGEROUS THING TO DO?

The imperative for inclusive education is widely promoted by disability activists, academics and the educational policies of the former government, with arguments ranging from economic, social and educational advantages (e.g. Excellence for All Children: meeting special educational needs, DfEE, 1997) to the politics of disablement and enablement (e.g. Barton, 1997; Skrtic, 1995; Slee, 1997). However, the new green paper- 'Support and Aspiration: a new approach to special educational needs and disability'- aims to fulfil the coalition government's pledge to "remove the bias towards inclusion" (ibid, p.5) in disabled children's education. In this context the paper will describe the moral dilemmas of conducting research in a segregated SEN unit in a secondary school in the North West of England. The convergent data from observations, interviews with teachers and administrators and creative group activities and discussions seemed to suggest that, although segregated, this unit offers its students a sense of belonging and community and enables learning and achievement. Gabel (2002) asserts that the first question regarding education should not be whether a student is in an ability diverse inclusive classroom, but whether the student is where wants to be s/he is and whether s/he is supported to live a self constructed life as much as possible. But in the current political climate, dominated by a sense of urgent struggle to protect the limited and partial achievements of the disability movement, what is the politically committed researcher to do? Is promoting the idea of inclusion as belonging regardless of the diagnosed "abilities" and "needs" of classmates a dangerous thing to do?

GREGORIUS, STEFANIE

Loughborough University

**USING MULTIPLE QUALITATIVE METHODS TO
EXPLORE LIVELIHOOD STRATEGIES, SOCIAL AND
HUMAN CAPITAL OF YOUNG PEOPLE WITH
DISABILITIES IN ACCRA, GHANA**

Young people with disabilities, especially those in the Global South, remain marginalised from mainstream debates about geography, development and broader social science, and little is known about their lived experience as well as how they make sense of their lives and perceive them in social and economic terms. The project fills this gap by focussing on individual perceptions and experiences of the everyday lives of young people with disabilities in the particular case of Accra, Ghana. The paper critically discusses the researcher's experience of using different qualitative methods to explore how disability, in interaction with other factors, is influencing livelihood strategies, education and social networks of young people. It is argued that the use of different qualitative methods including life-story interviews, photo-diaries, written-diaries, video- recording and participant observation allows the researcher to gain in-depth knowledge about the lives, identities and experiences of young people with disabilities. The research will contribute to geographical and social science literature about young people with disabilities in the Global South and has the potential of informing global understandings of disability. Furthermore, through investigating the everyday lives and livelihoods of young people with disabilities, the study seeks to shed light on the opportunities available to those young people. Making their voices heard has the potential to contribute to the development, implementation and evaluation of inclusive policies and programmes.

GRUE, JAN

University of Oslo

THE REJECTED CATEGORY: ME, CFS, AND THE THEORIZATION OF DISABILITY, IMPAIRMENT, AND CHRONIC ILLNESS

Is there a lack of fit between current conceptions of disability, impairment, and chronic illness? In Norway, as in many other countries, the national disability organizations function as umbrellas that cover direct membership organizations dedicated to particular diagnoses. Although members of such organizations may be disabled both for all most purposes and according to most definitions of disability theory, discourse produced by both the organizations and their individual members may avoid mention of disability entirely. Myalgic encephalomyelitis (ME), often used synonymously with chronic fatigue syndrome (CFS), is a case in point. Debates on the etiology of and treatment for these highly controversial diagnoses are rife and frequently acrimonious. A salient feature of the ME/CFS controversy is its fraught relationship with disability. The Norwegian ME association is part of the national disability umbrella organization. Nevertheless, it very rarely discusses ME/CFS explicitly in the context of disability. The same applies to many if not most of the Norwegian ME bloggers, who are among the most audible public voices on what is effectively disability issues. A decade and a half after the publication of Susan Wendell's *The Rejected Body*, which explicitly invokes ME/CFS as a test case for the development of disability theory, this is a problematic state of affairs. Do the interests of chronic illness communities with the interests of disability communities? Has disability theory failed to provide a satisfactory approach to chronic illness as opposed to impairment, and if so, can a satisfactory account be provided?

GUSTAVSEN, ANNELIN

Nordland Research Institute

Cecilie Anvik

'IF I WAS SITTING IN A WHEELCHAIR, PEOPLE WOULD HAVE SEEN ME.' YOUNG PEOPLE WITH MENTAL HEALTH PROBLEMS AND CHALLENGES TOWARDS EDUCATION AND EMPLOYMENT.

This paper is based upon a research project which investigated the challenges young people with mental health problems encounter within the educational and employment system in Norway. Almost six out of ten young people between 18 and 39 who are on permanent disability benefits refer their disability to mental health difficulties, and for many young people with such illnesses, the illness or its symptoms make it impossible to maintain steady employment. However, previous research shows that many of these clients dream about living a life where a steady and rewarding job is an essential component, and in previous studies, we have met young people who missed opportunities to contribute to the workforce and to complete formal education. Knowing that there is a lacuna in the research which investigates young people's own experiences with the system, we take a user-perspective in our study, and ask young people with mental health difficulties to describe three daily life scenarios: one, which describes a normal day in their lives, one, which describes a 'moral' day, or how they think a normal day should look like according to their parents and society, and one, which describes a dream-day, or how their daily life would be if it was only up to them. In addition to asking the informants to describe their experiences, hopes and dreams in qualitative interviews, we conducted an electronic survey among the target group to investigate whether there were common experiences with the social and psychiatric care systems which explain why so many young people experience that mental health problems equal obstacles to maintaining employment, and what they think can be done to render this situation.

GUTMAN, CAROLYN

Tel Hai College

Yoav Kraiem

SLEEPING WITH THE ENEMY? THE CO-TEACHING ROLE IN CRITICAL PEDAGOGY

A major dynamic emerging from disability activism and the development of disability movements has been the demand for articulating the “voice” of people with disabilities. This voice is increasingly being heard through the involvement of service users with disabilities in the UK and elsewhere, including in academia, medical and welfare settings. While service user involvement is often examined through its impact on professionals and students, this paper explores the impact of involvement in professional education on identity issues for the service user. Tracing the development in Israel of a co-teaching pedagogic model in which social work students engage with a co-teacher with disabilities, we identify dilemmas concerning his role in the class setting. One focal question emerging from the accumulated collaborative experiences of both educators in this new pedagogy relates to the influence of academic knowledge on the unique voice that the co-teacher with disabilities brings to the classroom. Does the academic setting taint the distinctive power of this voice? And if so, what is lost in the process? This paper will address important issues surrounding the multiple identities of the service user co-teacher in the classroom, as activist, consumer and educator. At the same time we will offer insights into the potential interaction between the co-teacher’s involvement in academia with the broader social aim of furthering equality and inclusion of people with disabilities in Israel.

HAKALA, KATARIINA

Finnish association on intellectual and developmental disabilities

ANONYMITY - PROTECTION OR EXPLOITATION IN INCLUSIVE RESEARCH?

The paper discusses challenges in doing life historical and ethnographic research with individuals with learning disabilities. The study is conducted within the research and development project "RATTI - Solutions to challenging situations in individual housing for people with intellectual disabilities". The research focuses on the service system and social networks of the collaborating individuals. They are living in residential services within traditional institutions of care where professional practices structure peoples' living quite heavily. Researcher has visited their homes, had a life history interview with them and observed their everyday environment by following their days and meeting their closest social network alongside with the individuals. This has been documented by audio taping discussions, photographing, and writing fieldwork diaries, memos and correspondence with the individuals. Researcher has written stories in a single print book about the process with photographs and given them for each individual personally. The negotiations about publishing the stories with the individuals themselves as well as with the people and institutions involved in the process are on the way. The research is based on feminist poststructuralist theorization on the construction of subjectivities in cultural and historical discourses which in this research are situated in the institutional practices of care, help and support for the people with intellectual disabilities. The presentation is to focus on questions of naming actors, organizations and places in the research publications. The methodological, ethical and epistemological aspects of anonymity as taken for granted practice in research are to be considered.

HAMBROOK, COLIN

Disability Arts Online

Colin Cameron

DISABILITY ARTS/DISABILITY STUDIES: A SYMBIOTIC RELATIONSHIP?

Disability Arts/Disability Studies: A Symbiotic Relationship? If the disabled people's movement is, as represented by Jane Campbell, a jigsaw, each part necessary in order to understand the big picture (Campbell and Oliver, 1996) there is suggested a symbiotic relationship between the different parts, by which each is given meaning, value and clarity through its connection with the others. Parts of the disabled people's movement include, for example, the independent living movement, the direct action network, self-organised coalitions and campaigning organisations, the disability arts movement and disability studies. Focussing on the relationship between disability arts and emerging theory within disability studies, this paper will explore the value of disability arts in illuminating and validating the lived experience of impairment in disabling social contexts and in pushing forward theoretical perspectives on the meaning of disability. Specifically, this paper will relate to the affirmation model, a framework distinguishing between impairment (as physical, sensory, emotional and cognitive difference to be expected and respected on its own terms) and disability (as an invalidating personal and social role)(Cameron, 2011). Having emerged initially as a descriptive summary of the spirit or essence of disability arts (Swain and French, 2000), the affirmation model is a theoretical tool addressing ongoing issues of debate within disability studies around experience, subjectivity, agency and structure. The aim of this paper is to explore the question whether, in turn, the affirmation model, as a theoretical abstraction, can be used by disability artists to give fresh perspective and insight into their own work and reasons for working.

Cameron, C. (2011) 'Not Our Problem: Impairment as Difference, Disability as Role' *The Journal of Inclusive Practice in Further and Higher Education*, 3:2, pp.10- 25

Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding Our Past, Changing Our Future*. London: Routledge

Swain, J. and French, S. (2000) 'Towards an Affirmation Model'. *Disability and Society* 15(4) 569-582

HANISCH, HALVOR

Oslo University Hospital

CASPAR DAVID FRIEDRICH AND PHYSICAL IMPAIRMENT

When disability scholars reconstruct the history of Western art – including, among other art forms, landscape painting – the 18th century is often seen as crucial. This historiography has had different frameworks: economic (focusing on the 18th century as the emergence of industrialist capitalism), cultural-conceptual (focusing on, say, “the enforcing of normalcy”), or many others. This array of frameworks suggests that it is of particular importance to examine artworks which were important in that historical context, and in particular those which retained an important Wirkungsgeschichte through the 19th and 20th century. One of these is the German romantic landscape painter Caspar David Friedrich (1774-1840). Given that disability often is used as a “prosthesis” - in literature and art, as well as in the everyday maintenance of the implicit subject position one refers to as the normate – it is necessary with close examination of the “prostheses” if we are to describe the larger “operating” accurately. Hence, the paper presents a “close” interpretation of Friedrich's work, investigating how typical Friedrich themes, in particular self-transcendence, vulnerability and religion, emerge in specific works. The paper traces a certain trajectory in Friedrich – or, more precisely, in three of his influential works – which display a certain trajectory of disability. Three questions is asked: 1) To what extent does the trajectory dovetail with the so-called “personal tragedy theory of disability”? 2) To what extent is the representation of disability part of 18th and 19th century religious sentimentality (as in, for instance, Wordsworth or Dickens)? 3) Are these two orders of disability representations – personal tragedy and religious pathos – really so intertwined that the analyses of disability scholars arguably tend to assume?

HANISCH, HALVOR

Oslo University Hospital

Eivind Engebretsen, Per Koren Solvang

DISABLED CHILDREN IN NORWEGIAN SCHOOLS; FREEDOM, CLOSENESS AND DISTANCE

This is not really a poster, but an installation. The installation displays photographic documentation of the school everyday of two girls with severe impairments, one attending a `special` school, and one attending an `ordinary` one. The focus is on participation in general, but in particular on forms of freedom and community/closeness. The installation is interactive, allowing the spectators to make choices which in part mimic policy choices. The photographic documentation is combined with - or put in dialogue with - an academic/theoretical argument.

INSTALLATION

HANSEN, NANCY

University of Manitoba

LS LOWRY THE CRIPPLES DISABILITY IN SPACES OF CULTURE

Over two years ago now and quite by accident, I came across `The Cripples` on a site seeing visit to The Lowry and it was love at first sight. This paper is an exploration of LS Lowry's painting `The Cripples` (1949) as a case study mechanism for examining depictions of disability in spaces and places of mainstream culture. Using a combination of journal articles, reflections from gallery personnel, patrons Disability Studies scholars, writers and artists an interesting picture emerges illustrating how understandings of disability impact on perception and place.

HATTON, CHRIS

CeDR, Lancaster University

Vicki Welch, Michelle Collins, Emma Wells, Susanne Langer, Eric Emerson

CHANGE AND CONTINUITY IN THE USAGE OF SHORT BREAKS BY FAMILIES WITH A DISABLED CHILD

Short breaks for families with a disabled child continue to be a high profile policy issue, although relatively little is known about how families experience short breaks over time or how short breaks are allocated. We conducted a postal survey of 214 family carers with a disabled child at two time points, 10 months apart. The survey included information on family demographics and socio-economic indicators, family usage of and satisfaction with short breaks, main carer health and well-being, and child well-being. There was no change in the total number of hours of short breaks received by families from Time 1 to Time 2, but there were reductions in the range of types of short break used by families, and the number of families using leisure short breaks and getting NHS funding for short breaks. The number of families privately funding short breaks increased over time although the number of families using unpaid carers for short breaks reduced. There was considerable fluctuation in family short break usage from Time 1 to Time 2, not predicted by any characteristics of children or families at Time 1. Family usage of more total hours of short breaks at Time 2 and of centre- based short breaks were predicted by characteristics of the disabled child at Time 1, largely older children with more complex health and physical needs and severe learning disabilities. Overall, families are experiencing a fluctuating, reducing and seemingly random allocation of short breaks, based at best on a narrow range of child characteristics.

POSTER

HAWKESWORTH, MARIAN

Independent

SUDDEN INCAPACITY: TECHNIQUE, TECHNOLOGY AND THE SIGNIFICANCE OF THE LIMB OBJECT

Using a narrative approach, this paper explores the interrelationships between a stroke episode and the (im) mobilisation of the human body. In the event of a stroke, the person is often unable to move, beset by paralysis or loss of muscle function and sensation, typically, on one side of the body. The alternative to walking is to mobilise the body by using a machine, usually a wheelchair. The paper begins by discussing Haraway's (1991: 208) observation that 'corporealizations are mixed up with other things including technology'. I relate this understanding to the active, actant, role of the wheelchair as constitutive in the (re) making of a stroke survivor's subjectivities. The paper seeks to define the wheelchair as, after Le Corbusier, a 'limb object', that is, an extension 'of our limbs and adapted to human functions that are type-needs and type-functions'. I explore the complex ways in which the wheelchair, as limb-object, is conjoined to the human subject, and I describe and evaluate how the situated, and specific, nature of impairment is involved in a field of tensions with technology and technique as part of a process to remake the body.

HEAP, DAN

University of Edinburgh

MAINSTREAMING DISABILITY BENEFIT CLAIMANTS INTO THE 'ACTIVE' UK AND DANISH WELFARE STATES

Benefits paid on the grounds of reduced capacity for work have become a major site of welfare reform in a number of countries in recent years, with policymakers seeking to make them more 'active' and to provide clearer routes to employment. Although there have been a number of studies of individual policy changes like the increased conditionality of such benefits and more stringent access criteria, less work has been done in looking at what kind of welfare- to-work regimes such changes result in, how the disabled benefit claimant's relationship with social security authorities is being redefined and what the consequences of these shifts are. 'Mainstreaming' is a useful way of conceptualising these changes. Firstly, they assert that it is now reasonable for claimants not to be exempt from the requirements that have long been made of claimants of unemployment benefits. Secondly, pre-existing models of activation – measures to increase the claimants employability most notably – are being applied to incapacitated claimants. Thirdly, many disabled claimants are being reclassified as ordinarily unemployed and increasingly access unified welfare-to-work programmes which make no formal administrative recognition of a claimant's disability. Whilst providing more employment- focused support to disabled benefit claimants and on the basis of a personal judgement rather than a benefit category may be a welcome move, the UK's particular approach is concerning – the system into which disabled claimants are being mainstreamed appears to lack the capacity to help claimants who may need more resource-intensive and longer-term support and so risks applying a work- first approach to claimants for whom it is not appropriate. A comparison with Denmark – which is pursuing a mainstreaming strategy underpinned by a much more nuanced understanding of the disadvantage that workless disabled people face – is made in order to highlight what policy alternatives exist.

HIETALA, JUHA

Finnish Federation of Hard of Hearing

HARD OF HEARING PEOPLE - DIFFERENT BUT ACCEPTED?

Even though almost one-fifth of the European population has hearing impairments, scientific studies concerning hard of hearing (HOH) have not largely been conducted from the social or cultural perspective. Scarce empirical studies have shared a common problem: overgeneralization and lack of group analysis. There is not consensus in society whether or not HOH people could be considered as disabled people. Non-accessible environment disables temporarily even those HOH persons whose impairment is not severe. In this context, the social model of disability is useful approach paying attention to environmental barriers. A study carried out by the Finnish Federation of Hard of Hearing found that workplace adjustments are rare and the importance of accommodation for HOH people is not widely understood among employers. If HOH people are not wholly accepted in the group of disabled people a difficult question arises: what consequences follow from this exclusion? In a larger scale hearing impairment is detected among working age individuals and this creates a challenging situation. The strong sense of belonging to majority and fear of being stigmatized may discourage from developing an HOH identity. The unclear phenomenon of hearing disability may lead to a situation in which HOH people are not seen disabled enough to be entitled to support. The importance of the environment is not widely understood and thus attention is focused merely on person's physical or psychosocial abilities. The politics of normalization have a counter side: is it allowed to be different and accepted?

HODGE, NICK

Sheffield Hallam University

AUTISM, RIGHTS AND THE CHALLENGE OF PEOPLE BEHAVING BADLY.

Autism is often associated with the phrase 'challenging behaviour'. Many organisations are responding to counter-normative expressions of behaviour through an embracement of approaches such as 'positive handling'. Although these philosophies often focus on an avoidance of physical engagement the ways in which organisations practise them mean that people on the autism spectrum can experience an increase in unwanted bodily contact and restrictions on their personal freedoms. This paper explores the relationship between positive handling, locations of the 'problem' of behaviour and the negation of the rights of disabled people. Prouty's (1976) principles for pre-therapy from the field of counselling are evaluated for their potential for helping to meet the challenge of behaviour. It is suggested here that pre-therapy's focus on really looking and seeing behaviour (Prouty, 2001) can lead to more developed understandings of different ways of being. Practising the techniques of pre-therapy can then engender an empathetic appreciation of how those with autism are often surrounded by people who behave badly but without the resource of team coercion to exercise control.

HOLLER, RONI

The Hebrew University

**POLICY TOWARDS THE INCLUSION OF PEOPLE WITH
DISABILITIES IN THE ISRAELI LABOR MARKET:
HISTORICAL DEVELOPMENT AND SHAPING FACTORS**

Throughout the years of its existence, the state of Israel has developed a system of laws and institutions, aimed at promoting the well being of individuals with disabilities in various ways, including some pertaining to aspects of their employment. However, the development of this system of laws and institutions has been characterized by a number of principal anomalies, including above all a deep hierarchy that discriminates the disabled people on the basis of the circumstances of their disability. The aim of the proposed presentation is to explain the formation of this hierarchy, by focusing on the disability employment policy which was introduced during the era of the founding of the Israeli welfare state (1948-1965). This historical analysis is based upon two broader theoretical fields: the social model of disability and the modern welfare state theory. As for the former, the social model of disability, with its rejection of the static, `objective` and medical inquiry, has been successful in providing fresh and fruitful analytic lens through which scholars can analyze the post-war welfare arrangements. Similar to the feminist lens, it enabled scholars to challenge the common view of disability as a non-problematic category, and offered some powerful insights on the various ways in which the modern welfare state itself participated in the `disablist` society. Despite this successful use of the category of disability as an Explanandum, the lens of the social model has, so far, been less successful in analyzing the subtle mechanisms through which the disability social policies themselves evolved. Based on the case of the Israeli employment policy, I argue that the use of welfare state theories can contribute to the social model analysis. More specifically, I will seek to demonstrate the ways in which institutions, political agents and ideas, all took part in the historical process of the construction of the Israeli disability employment policy.

HOLLINS, HEATHER

University of Leicester

EMANCIPATORY RESEARCH: A CHALLENGE TO MUSEUMS' CORE PRACTICES?

Over the past 15 years the museum sector in the UK has become more aware of the communities that are marginalised or excluded from accessing heritage, culture and the arts. Within this debate however, disabled people rights and needs have not always been at the forefront of discussions. Much of the practice around inclusion within museums is tokenistic and placed at the margins of organisations, with an emphasis being placed on outreach and project work, rather than direct challenges being made to core services and working practices. In 2009 the Holocaust Centre, Nottinghamshire, launched a new exhibition and education programme which aimed to discuss children's experiences of the Holocaust. The first exhibition of its kind in Europe to focus on Holocaust education with primary aged children, a key aim of the exhibition was that it would be accessible to children with physical, sensory and intellectual impairments. Before the exhibition's development, although the Holocaust Centre had socially conscious core aims, the reality was that on a daily basis disabled people had difficulties accessing the site and its programme, due to a lack of awareness of disabled people needs. This was in a place which discussed issues of prejudice, marginalisation and exclusion. This paper will focus on a longitudinal ethnographic PhD study which aspired to follow emancipatory principles in its planning and delivery. It will explore how the use of emancipatory research was used as a tool to enable a group of young disabled people to challenge the Centre to develop an inclusive approach to its services and the development of the new exhibition. It will also explore the impact that being involved in the research had on the young people's lives, and the wider implications for changes needed to museum practice.

HOLLOMOTZ, ANDREA

University of Leeds

**TIME TO ENGAGE WITH THE 'UNDERDOG': WHAT
CRITICAL CRIMINOLOGY HAS TO OFFER TO
DISABILITY STUDIES**

A range of activists and scholars have discussed how intersectionality between disability and other aspects of one's identity, such as class, gender, sexuality or ethnicity, interplays and can further oppression. This presentation will highlight that a similar debate is long overdue in respect to disabled offenders. For instance, we know that offenders with learning difficulties are over-represented amongst the prison population. This group is at increased risk to manipulation by the police and other inmates. Their needs are often poorly met within the criminal justice system, which leads to their further social exclusion. These issues should thus be of interest to social researchers. Yet, a comprehensive mapping exercise of the literature on sex offenders with learning difficulties exposed that sociological studies or those that give individuals the opportunity to provide first person accounts are largely absent from the literature. This presentation will argue that we need to engage with our 'underdogs', in order to inform more effective and accessible criminal justice provisions for offenders by highlighting amplified risks and disabling barriers to rehabilitation services. It is shown how critical criminology and disability studies can be brought together, in order to enable research that can expose the intersectionality between disability and the label 'offender'.

IGNAGNI, ESTHER

Ryerson University

PRODUCING FRAGILE CITIZENS: THE PROMISE AND PERILS OF PARTICIPATORY DIGITAL VIDEO ARTS RESEARCH WITH DISABLED YOUNG PEOPLE.

In this presentation the digital construction of disability rights claims is investigated, and the implications for disability activists, advocates, and researchers engaged in participatory digital media projects are considered. Limited and negative portrayals of disability in the formal and informal publics, including the media, contribute to the continued marginalization of disabled people. Eager to transform and broaden these restrictive images, disability rights movements have recently redirected its efforts into a politics of visibility, looking to digital video and other new media forms to control, innovate and re-imagine the representations of disablement and disability. These re-constructed images are central to the movement's claims- making for equitable treatment and amelioration of the social and material conditions of disabled people everywhere. This presentation is based on the analysis of data collected through digital video-making workshops with disabled young people that formed part of a larger participatory policy review of personal support provision. Disabled young people successfully produced videos offering a non-normative 'disability perspective' commenting in various ways on 'support'. Paradoxically, in doing so they required significant supports from others to access digital technologies. The presentation documents the challenges they faced in securing such supports and their efforts to address these challenges. The presentation will focus on young people's activation of philanthropic discourses in order to mobilize support resources and explores the consequences these efforts had for their subsequent 'claims-making'. Far from achieving the full voice and equal participation promised by participatory methods utilizing such digital media, the concessions made by young people in support interactions produced what could best be described as a qualified and fragile rights claims. It is argued that research involving digital image production, participatory methods and disabled people must allow for inter- dependent expression, and that researchers must recognize the power relations that often organize practices of accommodation and support. Working through these issues involves bringing Disability Studies, digital media arts and accessibility concerns into dialogue.

INFANTE, MARTA

Pontifical Catholic University of Chile

VULNERABILITY IN CHILEAN PUBLIC SCHOOLS: (RE) IMAGINING SUBJECTS

This presentation addresses the problematics of subjectivities' production in a scenario where educational public policies are becoming more sophisticated and imperceptible. Neoliberalism as a force that transform educational services into a logic of market system allows Chilean educational system to produce biopolitical technologies that problematize and interpellate students' subjectivities. Particularly, disability and vulnerability concepts are masked in discursives' representations with specific effects in students' educational and life experiences. I draw attention to the ways in which Chilean public schools display their governmentality processes, subjectivities' emergence in and through educational discourses, and how practices and discourses inform disability and vulnerability ideas. With the intention of problematizing these ideas, I use Chilean public policies in education and students' narratives (oral and visual). Specifically, narratives emerge from 15 students who attend 8th grade at schools that have high rates of immigrant population, inclusion projects, and high vulnerability indexes. Methodological approach includes a qualitative approach and a critical discourse analysis with an emphasis on Michel Foucault contributions (2002). Therefore, I introduce at the center of our analyses, discourses' political views and social implications regarding disability and vulnerability within (re)production of power practices and subjectivities in Chilean public school.

POSTER

JOHNSEN, BJORN-EIRIK

Harstad University College

**INMATE EXPERIENCES FROM A CLOSED DOWN
INSTITUTION MEANT FOR PEOPLE WITH
INTELLECTUAL DISABILITIES**

In Norway institutionalised care for people with learning disabilities is a closed chapter. The aim of this paper is to describe and discuss the living conditions of people with learning disabilities at Trastad Gard, an institution for people with learning disabilities. Trastad Gard was established in 1954 and closed down in 1990. The paper is based on data collected by the use of retrospective qualitative interviews. Six former inmates, six former members of the staff and eight parent/siblings were interviewed. The data revealed that none of the inmates were happy about their relocation into the institution. The stories confirm dishonourable, poor and difficult living conditions, but also how the inmates acted inventive to cope with the hush environment they were submitted to. They developed and explored different possibilities and performed creative and productive resistance against the degrading use of power hidden in the firm routines and strict rules handled by the staff. I will in this paper highlight these understandings with the help of Klara, one of my informants, and discuss some of her experiences by use of Goffman Foucault and Deleuze.

JOHNSON, CONNIE

University of Edinburgh

DISABLING BARRIERS IN THE CLIENT/COUNSELLOR RELATIONSHIP

Psycho emotional effects of disability have been identified by writers in Disability Studies (Reeve, 2002; Thomas, 2007) and it has been suggested (Shakespeare, 2006) that many disabled people experience difficulties in relationships as a direct result of their impairments. In this ongoing PhD research, I draw on existing literature on disability and counselling to problematise counselling as a resource for disabled people and to contest the view that counselling is inherently oppressive (Goodley, 2010). I argue that discussing the psycho emotional effects of disability on relationships in the context of counselling can be beneficial to some disabled people.

Adopting a qualitative, reflexive approach, I am researching

- disabled people's adverse experiences in relationships ('relational barriers')
- how these occur between client and counsellor where both are immersed in a disablist society
- how all of this is addressed in counselling
- how the process of counselling can enable clients to develop a sense of agency through increasing confidence; personal, social and political awareness; effective communication skills and emotional literacy.

The research is being conducted in two phases. The first phase, now complete, consisted of interviewing disabled counsellors who had been clients and the second phase will involve a series of in-depth interviews with disabled clients.

The following themes, based on findings so far, will be discussed:

- Why the effects of a disablist society on the client/counsellor relationship can be difficult to unravel.
- How experiences of relational barriers vary according to type of impairment (sensory, cognitive or physical, visible or hidden) and the client's stage in life.
- What disabled clients experience in terms of the limitations and benefits of counselling.
- How unravelling difficulties in the client/counsellor relationship and discussing relationships in client's everyday lives can have a positive impact on the client's social interactions.

KASSAH, KWESI ALEXANDER

Harstad University College

EXPERIENCES OF FORMER INMATES OF TRASTAD GÅRD

Experiences of former inmates of Trastad Gård By Alexander Kwesi Kassah and Bente Liljan Lind Kassah Institutionalised care for people with learning disabilities was abolished in Norway getting to the end of 1990s. This paper is to describe and discuss the experiences of former inmates of Trastad Gård, the only large institution in Northern Norway for children and teenagers with learning difficulties. Qualitative interviews were conducted with six former inmates after informed consent. The questions asked centres on what the informants remembered from their time at the institution. Four main but interconnected issues evolved from the interviews with our informants. These include information on their experiences on coming to the institution, feelings of homesickness, loneliness and stringent expectations/lessons to learn. The experiences were discussed, with reference to perspectives including discipline, punishment, self-esteem, power and power relations. The paper aims at giving the former inmates the opportunity to make their experiences known as they are aging and will soon be unable to tell their stories. The paper also seeks to keep alive the issues on the experiences that preceded the closing down of large institutions to serve as a reminder to policy makers to avoid policy initiatives that segregate, rather than integrate people with learning difficulties in Norway. Key concepts: People with learning difficulties, institutional care, personal experiences, power relations

KATA, PRACHATIP

AISSR, University of Amsterdam

AMBIGUOUS CITIZEN, BIOPOLITICS AND BARE LIFE: THE IRONY OF SOCIAL MOVEMENT OF DISABLED PEOPLE IN THAILAND

This paper is based on ethnographic fieldwork conducted among blind singers and groups of musicians working in the streets of Bangkok, analyzed texts such as available literature, public policy, and law documents relating to disabled people, and interviewed governmental and non-profit organizations. My paper shows that disabled people in Thailand live their lives in an ambiguous world. They are 'people', but because they are denied access to social resource and welfare they are not 'citizen' in the full sense of the word. They also lives in a double ambiguous situation: between the citizens and non-citizen, or between able body and disabled body. The ambiguous citizen situation was constructed by Thai neo-liberal state's ideology in each era. The disabled people became to be problematized in the field of political thought as moral-political subject, of the observe of techniques of power of Thai modern state in each era. This technology of power, this biopolitics, was essentially centered on the body, on the dis/abled body. Their dis/abled body are excluded by means of an inclusion through power of state mechanisms in many ways. It is not only to secure power of politics and economy of state but also maintains morality of society. Base on social model of disability and human rights approach, social movement of disabled people in Thailand tries to change their ambiguity through law process. However, the social movement is based on emancipation agenda, social construction of disability and minority group approach denies diversity of disabled people's live experiences and confirms predominant medical model of disability that they need to struggle. Moreover, although disabled people in Thailand become to be 'citizenship' under law rights but they still difficult to be 'human being' in everyday life.

POSTER

KATSUI, HISAYO

Institute for Human Rights at Åbo Akademi University

POLITICISING HUMAN RIGHTS DISCOURSE IN THE GLOBAL SOUTH

From the global perspective, one important remark to make about the new Convention is that "International Cooperation (Article 32)" was included as a stand-alone provision, which was not the case for the Conventions for the rights of women and children. That is, transnational obligation is stipulated. This Article has various implications, particularly towards participation of persons with disabilities from the South. It "provides a comprehensive normative framework, as well as specific guidance, for mainstreaming disability (United Nations Economic and Social Council, 2009:17)." For instance, major international agencies and Northern countries have rapidly made "dynamic change" into their policies and programmes to include disability in their international cooperation and development aid policies and also practice to some extent reflecting on the Convention (Lord. et. al. 2010: 31). That is, international cooperation has been highlighted to support national efforts in this field. However, its role is yet to be widely recognised and more research is needed on its role of international cooperation (United Nations Human Rights Council, 2010). Is human rights discourse automatically legitimized with the ratification of the Convention? Or does it need to be politicized to question Eurocentric and individualistic approach of human rights to be operationalized in Southern contexts that are significantly different from the North? Is international and development cooperation a form of cultural imperialism? Does human rights make sense in the South at all? This paper tries to answer these questions with a case study on Uganda.

KAWASHIMA, SATOSHI

University of Tokyo

WHAT CAN JAPAN LEARN FROM THE UK EQUALITY ACT 2010?

What can Japan learn from the UK Equality Act 2010? The Japanese government signed the Convention on the Rights of Persons with Disabilities in 2007. It established the Panel of Experts on Disability Discrimination Act in the Cabinet Office in 2010 in order to ratify the Convention. The Panel has been drafting the framework of the Act. In this process, it is necessary for Japan to learn from other countries' experiences, including the UK Equality Act 2010 (EA). In this paper, I clarify what Japan can learn from the EA. The EA adopts two general axioms: X) like cases should not be treated differently; and Y) different cases should not be treated alike, in order to promote and protect fundamental values such as inherent dignity, individual autonomy, social inclusion and equal opportunity. The axiom X is embodied into "direct discrimination" and the axiom Y into "indirect discrimination," "discrimination arising from disability" and "reasonable adjustments." The EA introduces these four forms of disability discrimination to comply with, to greater or lesser degrees, the following five requirements: a) to strengthen and harmonise the existing legislations; b) to implement the proposed EU Directive; c) to restore the Novacold approach and deny the Malcolm judgment; d) to establish appropriate balance between the rights of disabled persons and the duties of other persons; and e) to tackle the four dimensions of disablement: 1) micro (subordinated group status); 2) meso (disabled sub-groups); 3) macro (disabled individuals); and 4) hybrid (disadvantages of a combined impairments and other characteristics). The last two requirements (d and e) are relevant to the anticipated Japanese Disability Discrimination Act. The Japanese government has to pay attention to the four dimensions of disablement as a starting point to achieve a balance between disabled persons and other persons under the Act.

KELLY, BERNI

Queen's University Belfast

**“WHAT A DIFFERENCE A DECADE MAKES”:
EXPLORING RIGHTS AND CITIZENSHIP IN YOUNG
ADULT LIFE**

This presentation will present findings of a study which aimed to explore: the life experiences of young adults with cognitive impairments; the impact of family context and service provision on their young adult lives; and, the intersections of impairment, rights and risks. This ten year follow up study of involved ten young adults with cognitive impairments aged 18-29 years. A qualitative approach was adopted including: semi-structured interviews with young adults incorporating pictorial and photographic life stories; reading social care case files spanning 10 years; and, semi-structured interviews with their parents, social care professionals and policy makers responsible for adult disability services in Northern Ireland. Findings of the study illustrate how young adult participants re-negotiate their sense of self across various settings, including day care, home, and work/college. Most participants described a sense of citizenship grounded in interdependence and the significant roles of others, including parents, friends and service providers. Some had dreams and hopes for young adult life that have not yet been recognised or attained. These young adults were often restricted by lack of knowledge of their adult rights, limited post-school options, experience of social exclusion and the surveillance of non-disabled adults. Key challenges for parents and service providers were managing changing roles and responsibilities as young people move into adult life and negotiating issues of care, risk and protection. The interplay of these dynamics has the potential to either enable or diminish the realisation of the rights of young, disabled adults and the opportunities for self-determined life choices and positive self-identities in young adult life. Drawing on life course and disability theory, this study provides insight into the transitional life experiences of young adults with cognitive impairments that can inform our understanding of rights and citizenship issues at this life course stage and enhance policy and practice initiatives aimed at improving outcomes for disabled young people.

KIM , KYUNG MEE

Soongsil University

Dong Chul Yoo, Dong Ki Kim , Yu Ri Shin

HOW PEOPLE WITH DISABILITIES EXPERIENCE SOCIAL EXCLUSION IN KOREA

People with disabilities have experience exclusion through whole their life. This study aims to explore how they experience social exclusion in Korea. Data was collected to conduct 8 times focus group interview. Total 31 people participated in the focus group and their types of disabilities were varied including physical and mental disabilities. The main themes of social exclusion were two: economic/structural exclusion and social/cultural exclusion. 1Economic/structural exclusion has two sub-themes: material and social right. Social right includes the physical accessibility, opportunities, and choice. The theme of social and cultural exclusion consisted of social capital and the level and type of social participation. Moreover, cultural exclusion was represented as social belongings, and social attitudes toward people with disabilities. The social exclusion of people with disabilities enabled us to consider complex aspects of social structure, environment, culture, and interpersonal relations that influence the experience of disability. The research suggested theoretical, political, and practical implications.

KIRKEBÆK, BIRGIT

Journal of Disability History

John Bertelsen, Resource Centre for Special Needs Education,
Denmark

NOT WANTED IN DENMARK - DEPORTED TO AMERICA

Poverty, non-employability, and "deviant behaviour" are societal challenges that have been addressed historically through various initiatives. These initiatives were meant to prevent "spreading the disease", social unrest, and unfortunate reproduction. The means included detention, forced sterilisation, and subjectification to lifelong measures of state control. One of these means has been more or less disregarded in a Danish context, namely the phenomenon of deportation. People were sent to America on a one way ticket. The money for the journey was raised in the local parishes in order to avoid the return of these individuals to the local community from various asylums and institutions of forced labour. The management of the local poorhouses and the local poor law authorities agreed: a return to the community was not desired. The authorities had the right to deny the return to the community because of the nature of "administrative placements", and because the parish itself was in a position to accept or refuse the release of the individuals. It would frequently be the manager of the asylum or the workhouse that would suggest deportation to America. The question is: how can we understand this strategy? Is it to be considered as deportation per se, or as a way of providing a "last chance"? An act of solidarity or one of ultimate rejection? Our research focuses on 25 men and one woman that were sent to America from the institution of forced labour (workhouse) Saxenhøj in Maribo from 1867-1929. Some of these individuals managed to get a life in America. Others returned to Denmark, and some we are not able to track. One of the individuals who managed in America was Charles Luchow. He died in Minneapolis in 1916. Until 1910 he was a gardener, and before that a police officer. He married a Norwegian immigrant in 1886, which was 6 years after coming to America from Denmark. His name in Denmark was Carl August Luchau, and he was condemned to forced labour in 1878, to be served at the Maribo Asylum and Workhouse. The year after that he served another sentence for begging and excessive drinking. His parish of origin did not wish for his return after served time. The management of the workhouse and the parish arranged for him to go to America on a one way ticket. He was provided with a new set of clothes and a little money. The archives show the discussions leading up to the deportation. The police was part of the collaboration and escorted him to the steamboat in Copenhagen. Luchau is just one of the individuals who were deported in a joint venture between the poor law authorities, the police and the legal system. Our presentation reflects, firstly, a historical account of the deported individuals seen from a disability perspective. A large part of the rural population on the Southern Danish

island, Lolland, where Maribo is located, emigrated during the mentioned period (the majority to America). At the same time people immigrated to Lolland from other parts of Denmark, from Sweden and Poland. Many persons were needed for farming, but at the same time, the individuals not suited for this purpose had to be pacified and subordinated, forced to work or deported. Secondly, the presentation is a consideration of social history, reflecting on the relationship between the society and the individual. What is the nature of the measures that we implement, past or present, to encapsulate or cast out individuals that are considered dangerous to public safety? How can we explain (and defend), that persons not wanted in Denmark due to their "being a threat" were sent to America with the aid of the police? We portray "the unplaceables" by way of archive research. What kind of gaze are they submitted to from various authorities, and what financial considerations are brought forward? What can we read from the letters of the individuals themselves? We provide an insight in the legal framework, and critically review the double punishment applied to these individuals, as they went from imprisonment to forced labour in an asylum or workhouse. In reality, they were outside the legal system, since the various placements would be a result of political and administrative practices rather than legal processes. Such a view relates to a discussion of "homo sacer" in the present, about the people forced to live on the edge of society.

KIUPPIS, FLORIAN

Lillehammer University College, Norway

HETEROGENOUS INCLUSIVENESS - ON UNESCO'S SHIFTING UNDERSTANDING OF WHAT SPECIAL (NEEDS) EDUCATION SHOULD BE

This paper examines the history of UNESCO's disability related work and specifically investigates the role its unit for Special (Needs) Education played while it was responsible for the follow-up of the "World Conference on Special Needs Education" (held in 1994 in Salamanca). The paper begins with an examination of the contributions made by Gunnar Dybwad, former Director of the "Mental Retardation Project" of the International Union for Child Welfare, a person that is regarded as having "planted the seeds" in 1964 for UNESCO's focus on „the problems of exceptional or handicapped children". The paper then goes on to trace the development and eventual decline of UNESCO's unit for Special (Needs) Education. In doing so, it contrasts the organization's current disability related work — today considered one of seven facets of Inclusive Education — with its work prior to 2000 when Inclusive Education was still primarily focused on people with disabilities. The paper reveals that there have been chronic tensions in the relationship between UNESCO's Special Education program and the Education for All-agenda. This has resulted in various shifts in understanding both what Inclusive Education is all about and for whom it is intended. The arguments put forth in this paper make up part of a case study I have been leading that reconstructs the diversification of meanings around selected programs of education for marginalized minorities (e.g. Education for All and Special Needs Education). My data comes from archival materials housed at the headquarters of UNESCO and includes unpublished reports, memoranda, letters, faxes, e-mails, and notes. Using in-depth content analysis, the larger study as well as the paper analyze the symbols, myths and decision-making processes that various actors – some even embedded in multiple institutional environments – have used to interpret their institutional environments and to develop common or related agendas.

KOCA-ATABEY, MUJDE

University of Leeds; Tubitak-Sobag

CHANGING NEEDS OF DISABLED STUDENTS: THE NEW SUPPORT STRATEGIES FROM DISABILITY COORDINATORS

The study aims to investigate the university support structure towards disabled students. Disability coordinators from a certain UK university are interviewed. Content analysis is conducted in order to reveal the support-related themes regarding disabled students. The results reveal that the characteristics of disabled students are continuously changing and there are new needs which need to be addressed. The issue is dynamic in nature. The demographic structure of disabled students is changed in the last five years. The new disabled student has less severe impairments. There are more students with psychological impairment and dyslexia than before. The students are competent in using technology. The new support strategies of disability coordinators are discussed. The coordinators should be more active than before. They should be ready to provide faster solutions for higher expectations. Together with policy implications the results are discussed in accordance with the equality perspective.

KOLAROVA, KATERINA

Charles University, Prague

POVERTY OF DISABILITY THEORY IN THE NEOLIBERAL CZECH REPUBLIC

The paper follows two lines of argument: Firstly, it explores the triangulations of disability-poverty-neoliberalism in relation to the recent austerity measures in the Czech republic. Not only are the disabled populations made the most vulnerable to poverty and existential anxieties in the wake of such "reforms" (read: cuts) of the Czech welfare system, simultaneously the neoliberal governance is, as I want to highlight, rhetorically and discursively utilizing the 'disabled' to legitimize and construe the necessity of these cuts. In Neoliberalism as Exception Aihwa Ong lays out the paradoxical and yet definitional relationship of neoliberalism and exception: neoliberalism as exception and exception to neoliberalism by which the figure of 'exception' lends itself flexibly to contradictory policies: both to include as well as to exclude. I follow Ong's proposition to explore the hinge between the two figurations of exception to analyse how locating the disabled subject into the (conditioned and extremely precarious) location of exception and thus supposedly "privilege" that exempts the disabled subject from the requirements the neoliberal citizens, serves in the post-socialist Czech(oslovakian) context the ideological definition of neoliberal capitalism as a synonym to democracy and freedom which in its turn establishes the homo oeconomicus and responsible citizen of privatized responsibilities as the moral norm. Against this thesis, I then develop my second theoretical argument and discuss the (apparent) absence of radical and openly politically engaged disability critique, or—to put it into provoking terms —'poverty of disability theory'. I look to the above-described culturally constructed exceptionality of disability on the one hand and the affective attachments to ideologies of freedom (imagined as free market economy) on the other to offer an explication why radical disability and crip theories seem not to provide a culturally intelligible and morally attainable position for disability critique and movement. This, however, to follow E.P. Thomson's work that I refer to in my title, does not preclude specific forms of disability theory and critique to arise and be articulated.

KRAMER-ROY, DEBBIE

Brunel University

Esha Morjaria, Tricia Antoine, Susan Fosythe

THE SOCIAL MODEL OF DISABILITY AND RELIGION: EXPLORING MUSLIM STUDENTS' PERCEPTIONS OF DISABILITY.

This poster presents the outcomes of an MSc project, undertaken as part of the researchers' MSc in Occupational therapy, in which 3 of the co-authors explore the perceptions of Muslim students in their university about disabled people and their social inclusion in their community through qualitative interviews and focus groups. The research is supervised by Dr Debbie Kramer- Roy, whose participatory action research project (Kramer-Roy, 2009) with Pakistani families with disabled children found that their lived experience was strongly influenced by their religious and cultural background. Whilst they acknowledged that they encountered a significant level of stigma and exclusion from cultural and religious occupations, they also described how their own faith in God enabled them to accept their disabled child as a blessing and to develop an adequate response to the negative attitudes encountered in their community. The current project seeks to explore the way religion may affect ones perceptions of disability in further depth by inviting participants to reflect both on their own perceptions and those they observe within their communities. In particular participants are asked to consider to what extent disabled Muslims' participation in religious and cultural occupations is affected by their impairments and/or other Muslim's attitudes towards them, and how this influences their health and well-being. The researchers use a Social Model perspective throughout the research process and part of their analysis and discussion considers to what extent Social Model theory incorporates religion / worldview in the understanding of the lived experience of disabled people. The poster seeks to invite conference delegates to reflect on both the positive influence of faith and religion in disabled people's lives, and the challenges arising from potential misconceptions based on religion. The project is still in progress and will be completed in July 2012 when the dissertations are due for submission.

Reference: Kramer-Roy, D (2009). Exploring the support needs of paksitani families with disabld children: a participatory action reserach project.

PhD Thesis, Brunel University, London.

Available:<http://bura.brunel.ac.uk/handle/2438/4377>

POSTER

LAST, EMILY

Independent Researcher

THE GOVERNANCE OF ACCESS: FROM RIGHTS AND RESPONSIBILITIES TO THE BIG SOCIETY.

This paper presents some evidence, arguments and future directions from research about the relationships between disability, access to the built environment and public participation. It begins by suggesting that the complex organisation of policies, programmes, practices and people involved in the provision of accessible environments at different scales of government and civil society might be characterised as the governance of access. The governance of access has implicated disabled people, sometimes problematically, in the provision of accessible environments, through the articulation of a rights and responsibilities agenda that requires, in specific ways, the expression of their citizenship in relation to access. One way in which this is occurring is through the commodification of access (Last, 2010), in which new forms of access expertise have arisen around the legislative provisions of the DDA (1995; 2004) and now the Equalities Act (2010). Here, access consultancy and insurance services position disabled people simultaneously as manageable risks and choice-making consumer-citizens, and their access needs are framed through the duality of risk (Clarke et al, 2007; Imrie and Street, 2009; Power, 2004). The commodification of access involves problematic conceptions of disabled people's access rights and responsibilities. Nevertheless, disabled people's citizenship around access continues to be reworked in unexpected ways. The final part presents some preliminary evidence which suggests disabled people are continuing actively to develop innovative approaches to creating accessible environments that extend the role of the consumer-citizen. These range from online access guides and digital inclusion products to social enterprises dealing with accessible transport or housing, coupled with other social or environmental concerns. The paper concludes by considering, briefly, how far these developments in and around the governance of access might be seen as part of the coalition's Big Society.

LAST, EMILY

Independent Researcher

DISABLED PEOPLE'S PARTICIPATION IN THE GOVERNANCE OF ACCESS: NORMATIVE DISCOURSES AND STRATEGIES FOR RESISTANCE.

Drawing on research about the relationships between disability, access to the built environment and public participation, this paper compares and contrasts the ways in which disabled people and their access groups work into and out of the development process and the structures and processes of local government that deal with access issues. It begins by expanding upon the central concept of the research, which is that the organisation of people, policies and practices around access, at different scales of government and civil society, could be thought about as the governance of access (Last, 2010). One aspect of the governance of access is the co-option of disabled people, as a hard-to-reach group, into the development process (DCLG, 2006). Here, their knowledge and experience of socio-spatial exclusion is used to inform and legitimise the policies and procedures of planning and the normative discourses of participation around access (Brownhill and Carpenter, 2007; Bochel et al, 2007). The values and practices of officials involved in the governance of access may be irreconcilable with those of disabled people seeking a greater say in decisions, and often involve reductive, idealised or instrumentalised conceptions of participants and their deliberative role (Barnes et al, 2007; Imrie, 1999; Imrie and Hall, 2001). The final part suggests that the role of public participation in creating accessible environments goes beyond outcomes to speak about the nature of disabled people's citizenship and the constitution of their identities in relation to access (Newman, 2001). It describes how, at the intersection of local government with grassroots organisations, disabled people are able to resist the constraints of official forms of participation to tackle socio-spatial exclusion through more radical, embodied forms of participation in situ.

LATHAM, YVONNE

Lancaster University Management School

B P Bloomfield, T Vurdubakis

DISABILITY, TECHNOLOGIES AND SOCIAL EXCLUSION

Policy makers throughout the 'first world' frequently emphasise the role that contemporary information and communication technologies (ICTs) can play in overcoming various forms of social exclusion (e.g. Social Exclusion Unit, 2005; BECTa, 2008). Yet longitudinal research pertaining to issues of digital inclusion and exclusion in the context of disability remains relatively scarce. The proposed paper draws upon an ongoing longitudinal study of a group of participants in an ICT based NGO funded 'social inclusion' initiative in NW England. This paper aims to draw upon and contribute to a number of different literatures. There is what we might call the policy oriented literature on 'digital inequality' and 'digital inclusion'. In addition, there is a growing body of work that explores the 'domestication' of technologies. The term 'domestication' is here used as shorthand for the processes through which technologies are adapted to everyday life but also the processes through which everyday life is adapted to technology (e.g. Aune, 1996; Silverstone and Haddon, 1996; Habib and Cornford, 2001). However this literature has largely failed to engage with the specific issues raised by disability, and relatedly, with the sociology of the body. Within the fields of Disability Studies, but also Technology Studies, Sociology and Organization Studies, there is by now extensive literature that explores the ways in which abilities and disabilities emerge and are allocated within specific social and material arrangements, settings and situations (e.g. Winance, 2006; Moser, 2005; Moser and Law, 2001; 1999; Law, 1994). Scarry's (1985) sociology of the body for instance, highlights the ways in which technological artefacts tend to take as their referent particular (culturally situated) understandings of the nature and limitations of the human body. In order then to understand how disabled people engage with the technology, we need to appreciate the ways in which the intended users of technology are already 'inscribed' (Akrich, 1992; Woolgar, 1991) in the technological artefact –and the ways in which actual users may fail to 'match' these inscriptions. This work thus provides an important set of tools for understanding the processes of negotiation (sometimes involving considerable discomfort and pain) and bricolage that often take place in order to allow disabled individuals to make use of ICTs. The paper accordingly proposes that a major limitation of extant research on 'digital inclusion' initiatives directed at disabled people is what Cooper and Law (1995) call a shared 'distal' focus. That is an almost exclusive focus on end states (before/after) and a consequent lack of focus on questions of processes; an emphasis on the 'what' at the expense of 'how'. By contrast, this research adopts what Cooper and Law (ibid) call a 'proximal' approach. It focuses on how the computers' integration into, (and transformation of), disabled peoples' circumstances occur, or fail

to occur. How do disabled people and their helpers “muddle through” with the technical, support and other limitations they encounter? Indeed, it is precisely these sorts of muddling through processes that can tell us something about the aforementioned broader issues. This is particularly relevant given that limited resources typify the voluntary organizations which have, as the Social Exclusion Unit (2005) report acknowledges, traditionally been the most common channel for digital inclusion initiatives.

LEIULFSRUD, ANNELIE

IDEALS VERSUS PRACTICE - A QUALITATIVE STUDY OF SPINAL CORD INJURED PERSONS EXPERIENCES OF PARTICIPATION AND INTEGRATION IN NORWAY

The aim of this article is to study participation and integration in every day life for persons with spinal cord injury (SCI) and to further develop our theoretical and practical understanding of participation and integration. The data used is based upon 31 in depth interviews with persons with SCI in Norway, initially designed to study participation and integration within the theoretical framework of ICF. This is the Norwegian part of a comparative project on participation and integration of people with SCI in Europe. Activity and engagement, autonomy, equality and contribution are general responses, in line with a global human right perspective. Contrary to the idea of a universal understanding of participation it has to be related to peoples varied roles, life situations and social situation. This is also in line with an argument that the concept of integration into society as a whole, is not always telling us the full story whether persons are socially included or not. The interviews show that the meanings of participation and integration are in the eyes of the beholder. i.e. related to individual and personal circumstances. Their understanding of participation confirms the idea that this both include activities to be carried out and to share and join in with others. It also reveals a stronger social dimension than that found in standard interpretation of participation in recent health research.

LID, INGER MARIE

Oslo and Akershus University

STREETS FOR PEOPLE: RIGHT TO THE CITY" AS A RIGHT TO URBAN LIFE "

The UN Convention on the Rights of Persons with Disabilities (CRPD), article 9 Accessibility, states that people with disabilities should be ensured access on equal basis to "buildings, roads, transportation and other indoor and outdoor facilities". In this paper I interpret the urbanist Henri Lefebvre's notion Right to the city (1968) as a right to participate in urban life and thus a dimension of equal citizenship on a very concrete level, a right to use the streets. Public streets are of great importance for the opportunity to be a part of urban life. Susan Schweick documents in her book *The Ugly Laws* (2009) that people have been excluded from public areas because of appearance and disabilities. Enforced by new legislation this has changed. However, accessibility is not yet recognized as an important characteristic by good urban design. In this paper I discuss how disability as human condition can inform urban planning. Drawing upon the CRPD I argue that this convention provides a useful tool towards equal accessibility and to include perspectives from people with disabilities in urban planning processes. Universal Design as a strategy together with accessibility, can contribute to more inclusive urban environments, motivated by acknowledging people's right to have rights. Planning processes are practices that involve power and knowledge. Therefore it is necessary to develop accessibility and universal design as part of the knowledge base in urban processes. I use an urban redesign project in Oslo, *Oslo Alive*, as a case. In this project a disability perspective is integrated in terms of user involvement. However user involvement is not easy to carry through, due to differences in knowledge and power. Involvement in urban planning processes from rehabilitation may strengthen the disability perspective. In the discussion I draw upon perspectives from Hannah Arendt, Iris M. Young and Martha Nussbaum.

LIND, BENTE LILLJAN

Harstad University College

DISABILITY AND INCLUSIVE EDUCATION: CHILDREN WITH INTELLECTUAL DISABILITIES AND SPECIAL SCHOOL EDUCATION IN GHANA

Disability and inclusive education: Children with Intellectual Disabilities and Special School Education in Ghana By Bente L. Lind Kassah and Alexander Kwesi Kassah The 1992 constitution and 2006 disability laws of Ghana emphasise the need to mainstream disabled people in all aspects of life including education. This is also in line with UN's efforts to end segregation of children in special schools. In Ghana, most disabled children are still being educated in special schools where they have little or no contact with non-disabled children. The questions to answer are: Why are special schools still in operation in Ghana despite government's policies to include people with disabilities in mainstream schools?

- The main goal of the research is to unearth and discuss the factors that sustain special school education for people with learning disabilities in Ghana. It is also my desire to provide information that can make it possible for stakeholders to develop inclusive educational programs for people with learning disabilities.
- Qualitative in-depth interviews were used in acquiring data for analysis in this research. Accra, the capital of Ghana is the research universe. Twelve informants were selected after informed consent from three special schools (5), the Special Education Unit of the Ministry of Education (5), an organization of parents (PACID) (1) and Ghana Society for the Physically Disabled (GSPD) (1) participated in the research. The informants were questioned on continuous reliance of Ghanaians on Special Schools as institutions for educating people with learning disabilities. Information gathered was transcribed and subjected to phenomenological analysis.
- Quality of care, cultural stereotypes, knowledge and dedication, education of parents and families, networking with other schools, learning aids, are some of the reasons assigned for maintaining special schools. Theoretical views including cultural conceptions, inclusion, integration, segregation, stigma, devaluation and network are employed in the discussions.

LINDQVIST, ANN-MARIE

University of Helsinki

CITIZENSHIP FOR PERSONS WITH INTELLECTUAL DISABILITIES WITH EMPHASIS ON PARTICIPATION AND DECISION MAKING IN EVERYDAY LIFE

BACKGROUND After many years as a social worker, I did in my licentiate dissertation (2008) a description of participation for people with intellectual disabilities. The following step in the research process is to go from understanding the person's experience to explain the mechanisms that enable and limit citizenship. Therefore, critical realism mainly by Bhaskar and Archer seems to be a useful ontological and epistemological basis for the dissertation which is a form of practical research. **AIM** The aim is to identify the structures that enable or hinder citizenship for people with developmental disabilities.

METHOD In three studies I examine citizenship on three levels: the societal level, within a human services organization and in everyday life. The first study (2008) was conducted as a qualitative participatory research involving people with learning disabilities by participating in a research group, as interviewers and informants. The participants came up with issues directly related to the disability policy with the result that the second study reveals mechanisms at the community level to understand everyday life. I do a critical discourse analysis of the laws, policy documents and newspaper contents from newspapers to get an idea of how citizenship is mediated and the roles and positions they convey to people with intellectual disabilities. The results are reflected in the third study which studies decision making in everyday life through observation in a housing unit and qualitative interviews with users and professionals.

RESULTS Critical realism gives tools to understand how the different levels interact and the underlying mechanisms that hinder or enable citizenship. The challenge is to create an analytical framework for the empirical materials from the three studies, and to provide results that can influence the practice.

CONCLUSION How can critical realism be applied as an analytical framework for the material from the three studies?

LONG, SARAH

University of Bath

THE CHURCH – A EUGENIC MORAL CODER?

In this paper I aim to discuss how the Church traditional hegemonic practices disenfranchise disability in the context of a faith, through the institutional infrastructure, theological teachings and socio-symbolic engagements (Betcher 2007). In my PHD exploration of the Church and Disability I have been able to explore the socio-cultural nature of an institution defined through the interpretative understandings of Church leaders. This work has exposed institutional forms of alienation present in philosophical and institutional infrastructures (Davis 2002). These can be associated with the capitalist agenda governed by modernist priorities as it manipulates the impaired body to symbolically signify otherness, thus alien to acceptable conceptualisations of existence (Hughes 2002; Quayson 2007). As an institution the Church therefore constructs an impairment aesthetic that forms a hyper-reality status upon which socio-economic and moral agendas can be applied (Baurillard & Glaser 1994; Garland Thomson 1996). The traditional attributes of such actions are cemented into the moral framework of contemporary society (Gillibrand 2010). For the implicit means of naturalising subjectively the concept of the impaired body into a passive symbolic metaphor provides means through inference of highlighting the dislocating processes present within contemporary society (Bauman 1989; Armer 2004). Where political agendas and societal fears are being ascribed to the disabled populous (Quarmby, 2011). The relationship between the Church and socio-cultural constructions of certain moral codes that govern the right to life and with it an understanding of a quality of life can be exposed to be a eugenic process. These means of subjectivity have been identified as in need of challenging for they impact on the development of esteem, community involvement and institutional participation (Morris 2008).

LUNDQUIST ÖHRN, MARIANNE

Rehabilitation Center, Kristianstad, Sweden

Birgitta Johansson

PARENTS WITH INTELLECTUAL DISABILITIES AND THEIR CHILDREN

A Presentation of a 3-year Project Parents with intellectual disabilities have a great need for help in their role as parents. If you are a social worker/welfare officer it is important to be aware of these needs. When you start an investigation it is crucial to have basic knowledge about intellectual disabilities, to be able to provide the best possible support to the families. During this 3-year project we have focused on how to cooperate with different parts of society, how to get in touch with the parents and how to work together in different constellations to facilitate their role as parents. Through scientific studies as well as our own experiences we know that these parents have a lot of difficulties, such as parenthood, complex family situation, low income (if any income at all), bad homes/surroundings, unemployment, relationship problems, crime and domestic violence. In their backgrounds there are often lots of social problems, that have been going on for generations. Solutions are hard to find if there is not cooperation between society and the parents. During these years we have made some progress and found the following points to be important: -knowledge about the disability, parenting, children and their development -increased cooperation among professionals and finding methods to accomplish this -groups for professionals meeting regularly - individual support to parents - support groups for parents These approaches need to be implemented in all areas that in some way work with parents, regardless of whether the children are living with the parents or not. The individual circumstances of the parents as well as the children need to be taken into account. The methods can be applied across the whole country, since knowledge in the field is well spread and the methods are generalizable. Birgitta Johansson Marianne Lundquist Öhrn

MACK, HEATHER

Lancaster University

**IT WOULD HAVE BEEN A LIABILITY. BUT PHYSICALLY, I WOULDN'T SAY IT WAS A DISABILITY' -
DISCLOSURE, BLAME AND RESPONSIBILITY: THE
EXPERIENCE OF PSYCHO-EMOTIONAL DISABLISM
AMONG PEOPLE WITH HEPATITIS C.**

This paper will present ideas drawn from my PhD research (currently being written up) which involved qualitative interviews with 21 people in the UK, who were living with (or had lived with) hepatitis C. Although the virus currently affects between 200,000 and 600,000 people in the UK, the support afforded to people with hepatitis C has been minimal, with responses focused on reducing the spread of the virus and increasing diagnoses and numbers of people in treatment. This enacts hepatitis C as a disease which needs to be eradicated, reflecting public health priorities, and shaping personal ones, especially since the possibility of cure - although increasing - remains uncertain (Fraser and Seear, 2011) and the effects of the treatment [expressed as being like chemotherapy (Hopwood et al., 2006)] were described as worse than the effects of hepatitis C itself, and can extend beyond the end of treatment. The frequent conflation (Harris, 2005) between hepatitis C and injecting drug use means that stigma (Goffman, 1963) has been a key focus for research among people with hepatitis C. Whilst this is clearly a useful concept, this paper will argue that the concept of stigma does not go far enough in illuminating the complex facets of the experience of people with hepatitis C and that the experience needs to be viewed through the lens(es) of disability studies, specifically the experience of psycho-emotional disablism and internalised oppression. Discussion will explore the application of the concept of psycho-emotional disablism to the experiences of people with hepatitis C, in particular the pressure participants felt to answer questions concerning their hepatitis C (treatment), the responsibility and blame associated with hepatitis C diagnosis and the way hepatitis C has been shaped in relation to other high profile illnesses including tuberculosis, leprosy, cancer, and HIV.

MAGUIRE, ROSEANN

Strathclyde University

A METHODOLOGICAL FRAMEWORK FOR LOOKING AT THE IMPACT OF CLASS IN YOUNG DISABLED PEOPLE LIVES: DISABILITY, SELF-IDENTITY, INDEPENDENCE

Class has been acknowledged as a particularly powerful determinant of the disability experience (Shakespeare, 1996) however little is known about the impact of class on the daily experiences of disabled children and young people's lives (Priestley, 1998) although recent work from both disability studies (Watson, 2010; Wickenden, 2010) and poverty studies (Ridge, 2009) has drawn attention to this gap. Through an exploration of the lived experiences of a group of young disabled people from different socioeconomic backgrounds this Phd research project seeks to examine how young disabled people's social location intersects with their experience of disability and also how it influences their construction of self identity and negotiation of independence. Fieldwork for the project will be conducted during 2012. The poster presentation focuses on the theoretical framework of the study. My theoretical framework identifies the common ground between dimensions of disability theory, particularly the social relational model of Carol Thomas, and that of social justice theorist Nancy Fraser and I suggest that this offers a useful way to think about and address disablement. Reflecting upon the redistribution recognition debate of Honneth and Fraser I side with Fraser's assertion that injustice needs to be addressed at both an economic and cultural level and highlight how her concept of participation parity and Thomas's concepts of barriers to doing and barriers to being offer a useful lens for looking at disabled young people's accounts of their lives. I suggest that the biographical approach from youth studies (Furlong and Cartmel, 2007), incorporating Giddens (1991) concept of the self identity narrative is not only a useful way to examine the interplay between structure and agency in disabled young people's lives but that it also provides us with a way to explore and talk about the impact of psycho emotional barriers experienced by both disabled and disadvantaged young people.

POSTER

MALLET, REBECCA

Sheffield Hallam University

**NEGOTIATING 'NORMAL': EXPLORING NEO-LIBERAL
IMBRICATIONS OF NATIONAL IDENTITY,
LEADERSHIP AND IMPAIRMENT IN THE WEST WING**

The West Wing was a hugely popular U.S. TV drama series, which ran from 1999-2006. Its immense public popularity and international critical acclaim has been met with be considered critical analysis within Cultural/Media Studies (e.g. Parry-Giles and Parry Giles, 2002; Holbert et al, 2005). However, despite various impairment/illness aspects of the drama series being considered by those interested in health communication (e.g. Zoller and Worrell, 2006), there has been little said on The West Wing from a Disability Studies perspective. This paper aims to fill this gap by utilizing perspectives on the cultural representation of 'impairment' to explore what The West Wing can tell us about the role of impairment in our contemporary moment. In particular, it explores the neoliberal imbrications between a 'normal' body/mind and national identity, suggesting that ability, capacity and rationality are bound up, not only in ideas of 'good' citizenship, but also, and crucially, in ideas of 'good' leadership. It will discuss moments when characters engage in negotiating such imbrications, and suggest that this offers a valuable insight into the often banal, pervasive and significant impact such notions of normalcy have in the lives of disabled people.

MARKS, GENE

University of Ballarat

KNITTING A MOEBIUS STRIP: TOWARDS AN EVOLVING PARADIGM OF INCLUSIVE AND TRANSFORMATIONAL DIS/ABILITY RESEARCH

Research in the field of intellectual disability has traditionally excluded the involvement of people with disabilities themselves. While there has been some move away from this idea in recent times, it has still been argued by researchers in the field of dis/ability research that it is not possible for participatory research to be both inclusive and transformational, let alone emancipatory. In this paper I challenge that notion, and posit that in order for such research to be emancipatory, researchers and theoreticians in the field must develop new and eclectic ways of framing the problem, so that our work is truly transformational. This paper draws on a wide range of perspectives and theories, including work on: Mestizaje and Borderland Theory (Anzaldúa, 1987; Pallotta-Chiarolli and Lubowitz, 2003); Pagtatanong-tatong (Pe-Pua, 1989); 'outsider belonging' (Probin, 1996); the pedagogy of hope (Freire, 1994); hope as a new philosophy for change (Zournazi, 2002); disability as social apartheid (Goggin & Newell (2005)); as well as Campbell's (2009; 2010) work on ableism, and on the disabled flâneur. Citing recent co-research with people with intellectual disability, I present an evolving paradigm that, while applying specifically to dis/ability research, may be generalised to wider contexts of diversity, difference and culture. Building on these principles, I present inclusive and emancipatory dis/ability research as taking the form of a (knitted) Möbius strip, that somewhat curious geometric construction that appears to have no beginning and no end, where the non-orientable surface winds and returns, twisting on itself. If research is to be truly transformational, then it is not possible to have researchers on the one side and participants on the (O)ther. This is no flippable coin, but rather a complex and beautiful enigmatic construct, within which the threads of those traditionally empowered and disempowered become interwoven and indistinguishable, moving round an endless iterative spiral, moving towards the construction of a paradigm that challenges the status quo of research in the area of intellectual disability. This paradigm confronts the way research is traditionally done on, rather than with, people with intellectual disability, and looks to a future where co-research enables people with intellectual disability to become empowered in unexpected ways, and move into new phases and levels of adulthood, citizenship and belonging.

MARRA, ANGELO D.

Gruppo di Ricerca Disability Studies e Inclusione (GRIDS)

Simona D'Alessio, Roberto Medeghini, Giuseppe Vadalà

DISABILITY STUDIES IN ITALY: CURRENT DEVELOPMENTS AND CHALLENGES

Over the last two decades the emergence of Disability Studies in the US and the UK did not always correspond to the emergence of similar studies in Southern European countries. Such evidence is particularly visible in Italy where it does not exist (at least until today) any Disability Studies publication or academic discipline in line with the works produced by the UPIAS movement in the UK (1976) or the American Society of Disability Studies (1982). With this in mind, the paper will present a critical analysis of the early developments of Disability Studies in Italy with a focus on the historical analysis of the reasons that seem to have hindered the development of this discipline in Italy. The paper will also discuss some of the current debates concerning the different interpretations of disability and their implications for the perpetuation of forms of exclusion in Italy. Despite Italy is celebrated, and rightly so, as one of the fewer countries in the world with progressive anti-discriminatory policies (for example in education and employment sectors), forms of marginalization are still perpetuated due the way in which disability is conceptualised and the way in which society, policies and services are structured. The paper will show the many challenges that need to be addressed in order to support a paradigmatic shift from a deficit model of disability that locates the problem within the person to a social model of disability that supports systemic changes and fights against a dominating disabling culture. Unless a shift in thinking in approaching disability is promoted and structural changes are undertaken, exclusion will still be in place even in those countries with the longest tradition of integration in education and anti-discriminatory legislation. For more information please visit our website please visit the following link:

<http://www.milieu.it/DisabilityStudiesItalyEN/DisabilityStudiesItalyEN.html> For information about the Italian Journal of Disability Studies please write to: simonadalessio@yahoo.it

MARTIN, NICOLA

London School of Economics

THE C WORD

Differences between disability and serious illness are considered in the light of a diagnosis of cancer received by a 24 year old young man in November 2011 (my son). This paper rethinks ideas such as 'hierarchy of impairment' and medical, social and post social models. Notions of stigma are discussed with reference to the work of Susan Sontag. Treatment will be ongoing at the time of the conference. It is possible that my son will present the paper with, or without, me. It is also possible that he- we may not feel able to present at the conference. Sometimes only a cure will do.

MARTINUSSEN, INGER

Harstad University College

BEING IN OPPOSITION OR FIGHTING FOR ONE'S DIGNITY

Rehabilitation is a process where rehabilitation service receivers and providers cooperate in rebuilding a person's life after a disease or injury. Investigations, however, show that there are gaps between what users and professionals consider vital in a rehabilitation process. My research shows that medical perspectives of a user's situation may be scientifically appropriate, but may still be in conflict with what is important to the person. One of the participants in my research was a young man paralyzed from his neck and down after a spinal cord injury. His first aim was to mend his disrupted life and get back to his 'free life-style' with parties, drugs and alcohol. Because his view of life could endanger his possibilities of rehabilitation, it created a major challenge to his service providers. Difficulties transformed into crucial conflicts between the parties as their goals turned out to be opposite. While the professional's most vital goal was to make the young man understand the importance of the principles of good health, he had no interest in health issues. He claimed that 'I am the same person as before. I am just paralyzed. I intend to live just the way I did before'. During this presentation I will emphasize the importance of relation and communication in crossing the gap between service receivers and providers. My research showed that without a common understanding of each other's definition of the situation, they were not able to relate to each other in a way that could benefit the young man, and the Convention that should be an instrument of his human rights were just wonderful ideas out of reach of them all.

MCCANN, ALESS

University of Leeds

EXPERIENCES OF DISCLOSING "SPECIFIC LEARNING DIFFICULTIES" IN HIGHER EDUCATION

This paper will discuss the results of a recent Disability Studies MA dissertation investigating the experiences of students deemed to have a 'Specific Learning Difficulty' who have disclosed their impairment(s) in a Higher Education Institution. The paper will look at the findings of the study including what factors led to students disclosing their impairment, what changed as a result of disclosing and what impact they thought disclosing had on their and other students' experiences of higher education.

Disability and impairments have negative connotations in higher education (Borland and James, 1999). Reasons put forward for students choosing not to disclose impairments include an expectation of stigma and socially awkwardness (Green, 2009), fear of discrimination during the admissions process and inequality once at university (Equality Challenge Unit, 2012). Higher Education Institutions work hard to encourage students to disclose; examples of how they do so include having a key contact for disclosures, a commitment to disability awareness training and publicising previous positive experiences and results of disclosure (Stanley et al., 2007). This paper will look at University students' own experiences of disclosing their impairment(s), what they think the barriers to disclosures are, ways they can be removed and if/how disclosure can be encouraged amongst students with hidden impairments.

McCARTHY, PATRICIA

Trinity College, Dublin

FROM THE INSIDE: THE ACCESS ACCOUNTS OF BLIND/VISION IMPAIRED PEOPLE WITHIN THE IRISH EDUCATION CONTEXT

Until recently in Ireland the educational provision for blind/vision impaired people occurred primarily within the special educational system. The restructuring of the education system began in the 1990s and led to many changes in special education including a language of inclusive education within policy initiatives. This research seeks to explore the educational and life choices of people who are blind/vision impaired within this context. The research questions examined in this study pertain to the educational experiences of people that are blind/vision impaired, the factors that impact on these experiences and, the issues that impact on transition choices and opportunities. In-depth unstructured interviews were conducted with twenty three participants over a number of time points. This study is qualitative in nature and a life history approach was utilized. Participants are the key players in life history research as their life stories are the primary data. Life history research recognizes the integrity of the individual and acknowledges their experiences as valid. My ontological position as a disabled researcher has been central to the development of this research. Some pertinent findings of this research concern: levels of participation with the school/college curricula; challenges encountered when accessing the school/college curricula; and; effective/ineffective experiences of transition choices and opportunities. Findings indicate a continued gap between the rhetoric and reality of inclusion at various levels of society for people that are blind/vision impaired and suggest that exclusion and limited participation can still be common experiences.

MICHALKO, ROD

University of Toronto, Canada

CULTURE'S PROBLEM WITH THE PROBLEM OF DISABILITY

What disability_ is_ stems from how we define and thus understand it both individually and collectively, locally and globally. These definitions, sometimes explicit and at other times implicit, are themselves rooted in largely unexamined interests and projects. Nonetheless, these definitions cultivate an understanding of disability and are thus tacit ways we have of making disability what we need it to be. This paper examines a dominant understanding of disability that circulates around the globe today. This understanding is captured well by David Mitchell's formulation that "...nearly every culture views disability as a problem in need of a solution..." For many interests and projects today, disability needs to be a problem in order that we may conduct our projects with the understanding that they represent solutions to the problem of disability in whatever way such problems are formulated. This paper critically examines Mitchell's formulation of disability, not with the aim of correcting it (although this may happen), but with the aim of understanding what problem of disability Mitchell is suggesting that "nearly every culture" is imagining and thus addressing. I will show how Mitchell's formulation is itself an implicit solution to some problem that we take disability to be. I end by demonstrating the collective power invoked to make disability what we need it to be and thus to demonstrate how we define disability in order to imagine and proceed with our particular interests and projects.

MILTON, DAMIAN
University of Birmingham

THE NORMALISATION AGENDA, AND THE PSYCHO-EMOTIONAL DISABLISM OF AUTISTIC PEOPLE.

Within the dominant discourse of the medical/behavioural model of autism, the autistic person is framed as being incapable of 'self-surveillance', a potentially dangerous individual 'lacking in empathy', and in need of external and potentially coercive techniques in order to manage and control their 'challenging behaviour' (albeit with the caveat of attempting to instruct the autistic person to be able to 'manage their own behaviour' more 'appropriately'). This paper explores the philosophical underpinnings of the 'normalisation agenda' (whether implicitly or explicitly manifested) in the treatment of autistic people, and the disabling effects this agenda has had on the 'invasion and occupation' of the autistic 'lifeworld'. Beginning with an exploration of the diversity of 'dispositional social equilibrium' that neurodiversity represents, and how attempts to 'normalise' autistic behaviour to non-autistic standards could send the autistic person into a state of personal 'disequilibrium' and alienation (anomie) from oneself, with resultant affects on 'problems in living' and psychological ill-health, this paper continues with a deconstruction of the use of 'Applied Behavioural Analysis' (ABA) as a technique utilised in the education of autistic people, and the political divide this has created between some parents of autistic children and autistic self-advocates. The paper concludes by utilising the notion of 'psycho-emotional disablism' (Reeve, 2002, 2004, 2011) to investigate both the internalised oppression of autistic people attempting to 'pass as normal', and the strategies employed just to be credited as someone capable of the social agency to resist. This paper concludes by arguing that the 'personal tragedy model' and resultant 'normalisation agenda', supported by some of the world's largest autism charities, and the resultant need induced in parents of autistic people to 'behaviourally modify' them, has not only led to the psycho-emotional disablement of autistic people living in society today, but also their families.

MUNOZ-BAELL, IRMA M

University of Alicante

Carlos Alvarez-Dardet, M Teresa Ruiz-Cantero, Rocio Ortiz-Moncada, M Luz Esteban, Emilio Ferreiro-Lago

BRINGING SIGN BILINGUAL EDUCATION INTO FOCUS: AN INTERNATIONAL DELPHI STUDY

Deaf sign language users are especially vulnerable in the areas of education and health. However, inclusive and school health-promoting education programmes often fail to cover the needs of many deaf children, or do so unsatisfactorily. The underlying reason behind this problem is that schools are only effective as healthy, inclusive environments for deaf children when they are able to respond in a satisfactory manner to their linguistic and cultural rights as members of deaf communities, specifically recognizing their right to receive an education of quality including the acquisition and use of sign language. Sign bilingual education programmes view the education of deaf children from a new perspective and are in accordance with the Convention on the Rights of Persons with Disabilities. In this study, a two-round Delphi survey was used to identify, rank, and rate international megatrends in sign bilingual education whose effect is to promote or hinder the change towards this educational approach. The expert panel consisted of 41 experts in deaf education (9 deaf, 32 hearing) from eighteen countries. The process revealed 6 main essential elements of the international implementation of sign bilingual education and 9 main barriers against it. The top three promoting forces in that list in order of priority were: (1) societal and political changes towards a growing acceptance of diversity and deaf issues; (2) growing deaf activism, self-awareness and empowerment; and (3) scientific research in sign linguistics and bilingualism. The top three hindering forces included: (1) the view of deafness as a medical condition with a technological solution; (2) phonocentrism and societal resistance to the unknown; and (3) educational and deaf educational policies. Our results reveal that social/political changes towards a growing acceptance of diversity and deaf issues, and a medical/social model of deaf people's health can promote or limit deaf people's educational options much more than changes within the education system itself.

MURPHY, ESTHER

Dublin City University

**DESTRUCTIVE OR CONSTRUCTIVE NETWORKS:
UNPACKING 'CULTURAL BAGGAGE' FOR VISUALLY
IMPAIRED MIGRANTS IN IRELAND**

This paper will present findings from an overall PhD study which qualitatively examined the lived experiences of the visually impaired migrants in Ireland. It is the first time visually impaired migrants have been involved in research in Ireland. 22 semi-structured interviews with service users and providers were conducted employing a grounded theory approach. Findings presented in this paper relate to core categories which emerged from the data namely; cultural perceptions of disability and support networks. Case studies are presented to illustrate service users experiences of sight loss in the host society. In addition, service provider accounts are also analysed to examine their experiences working with migrant service users. Findings demonstrate the influence of 'cultural baggage' related to cultural perceptions of disability to dictate the levels of support received in host society. Recommendations are made to improve access and engagement with disability services for migrants. This paper draws attention to the additional strain on migrants coping sight loss who are separated from family or most alarmingly experiencing psychological social exclusion from their own communities due to their disability status. Consequently, service providers are recommended to be alert to migrant service users' compounded vulnerability and when necessary link migrants with appropriate psychological support.

NAUE, URSULA

University of Vienna, Austria

**THE AUSTRIAN NATIONAL DISABILITY ACTION PLAN
2012-2020 IN THE LIGHT OF THE UN CONVENTION
ON THE RIGHTS OF PERSONS WITH DISABILITIES,
OR: WHAT IS PARTICIPATION?**

In 2008, Austria ratified the CRPD. Since then, officials and politicians repeatedly refer (red) to an already initiated and implemented paradigm shift from the medical towards the social model of disability in Austrian disability policy (e. g. formulated in the Report of the Austrian Government on the situation of persons with disabilities 2008/2009, but also in the First State Report of Austria on the CRPD from 2010). To implement the CRPD, Austria decided to develop a National Action Plan 2012-2020. At least in the light of the development of this Action Plan, it becomes obvious that the paradigm shift has not yet taken place. An indicator for a change of attitudes towards persons with disabilities is to facilitate full and effective participation of persons with disabilities and inclusion in society (as postulated in Art 3 (c) CRPD). The development of the Action Plan shows the opposite: After one event in February 2011, where persons with disabilities and their organisations were invited to participate, one year of silence followed. During these months, the Federal Ministry of Labour, Social Affairs and Consumer Protection formulated a draft of the Action Plan. In February 2012, another event took place where the draft was presented to the public. Although in parts based upon the working groups' work in February 2011, the draft reflects the ministry's understanding of how to do what and when (and does not implement Art 4 (3) CRPD). The Action Plan has not been developed in a participatory manner. Also, the Action Plan as such addresses participation in a rudimentary way. The paper explores the ministry's argumentation regarding participation as information instead of cooperation. It is the aim of the paper to discuss the impact of this strategy on the implementation of the CRPD and hence, on persons with disabilities' full inclusion in society.

NEE, JEAN

University College Dublin

SUFFERING, THE ILLNESS CONSTELLATION MODEL AND PSYCHO-EMOTIONAL DISABLISM: FACILITATING COMMUNITY PARTICIPATION OF PEOPLE WITH SERIOUS MENTAL ILLNESS

As a team member of a study on the supported socialisation of people with serious mental illness (SMI), I have been researching the difficulties that people with SMI have in participating in the larger community. As part of this study, I am examining the idea that such participation may be inhibited by an emotional factor related to loss and/or suffering; while this emotional factor may arise due to SMI, it is not part of the illness. In investigating the idea that suffering may affect one's community participation, I explore the applicability of the illness constellation model (Morse & Johnson, 1991) in which suffering is conceptualised as a comprehensive concept that incorporates acute and chronic pain experiences, the alienation of social exclusion, the trauma of institutionalisation, and uncertainty in anticipating the implications of an illness. Minimising suffering, the core variable in the illness constellation model, underpins the entire process of the illness experience for both individuals and their significant others; it is viewed as a basic social, psychological, physiological process used to reduce physical and psychological discomfort, the social distress of changes in roles and responsibilities and the uncertainties of the future. Recently, I have started to study the concept of psycho-emotional disablism. As explained by Reeve (2011), disablism consists of two strands: (1) structural disablism (disabling barriers, operating at the public level, such as discrimination and inaccessibility, which restrict what people can do) and (2) psycho-emotional disablism (disabling barriers, operating at the private level, for example, stares and comments, that restrict who people can be). In this paper, I examine the idea, proposed by Reeve, that how someone deals with current psycho-emotional disablism may be influenced by previous experiences and will outline the usefulness of the illness constellation model in facilitating who people can be.

OGDEN, CASSANDRA

University of Chester

WHEN LEAKAGE SEEPS INTO NORMALCY; IMAGINED FUTURES AT THE END OF LIQUID LIFE.

Possession of a body which finds controlling bodily fluids difficult or impossible is met with repulsion and exclusion and yet paradoxically only does in public what every body does in private. A symptom of a neo-liberal regime is the promotion of individual efficiency over practicality and control over nature contributes to a more economically viable, hygienic and 'better' way of living. The project of ableism (Campbell, 2009) a key ally of neo-liberal ideology promotes its vague, elusive concept of 'normality' and 'others' and oppresses specifically those with impairments. In interrogating the oppressive talons of ableism through experiences of leaking bodies, this paper will show how 'othered' realities can challenge normalising discourses and remind its subjects of their corporeal existence. Furthermore this paper will locate the world as liquid modern (Bauman, 2007) characterised by fluidity causing a great deal of ambivalence and insecurity with little time to form permanent bonds. An acknowledgement of living beyond static identities and structures is necessary alongside the development of sophisticated and appropriate framework to ensure sociology is able to imagine future freedom. Through the exploration of ableist agendas the focus moves from the 'othered' to wider society which better grasps (albeit fleetingly) connectedness between bodies and beings and hence offers the potential alleviation of oppression. If the liquid modern can be seen as potentially emancipatory its instability can be played to the advantage of those being othered. Normality is less likely to be clearly defined in liquid modern times and leakage will occur between dis/abled communities. In uncertain times the ableist project is vulnerable and disconnected thus a good opportunity to introduce dis/ableist alternatives is upon us.

OLLI, JOHANNA

University of Turku

Salanterä, Sanna, Vehkakoski, Tanja

THE REALIZATION OF DISABLED CHILDREN'S AGENCY IN A HOSPITAL SETTING

Disabled children often spend much time in institutions and with professionals of different fields. Their opportunity to act as agents may however be compromised in these settings due to the adults' power to choose who are entitled to express agency. According to the earlier research, significant facilitating and hindering factors in the realization of agency seem to relate either to professionals' attitudes and communication or to the structural and cultural factors of institutions. The old professional-centered and paternalistic ways of thinking seem to especially live on in the practices of the health care of disabled children. The aim of this study is to make visible how the agency of disabled children is constructed in social interactions with nurses in a children's neurological ward. The analysis is focused on the children's interaction initiatives and the ways in which nurses support and respond to these initiatives. The research data has been collected by videotaping three 3-5 years old children and their four nurses on one Finnish children's neurological ward during eating and play situations (N = 6 situations). The data has been transcribed verbatim and will be analyzed through conversation analysis method. The results of the study will be discussed from the viewpoint of the social model of disability and children's rights.

OLSEN, TERJE

Nordland Research Institute

Patrick Kermit, NTNU, Tr, Odd Morten Mjøen, Møller Trøndelag Resou,
Hild Rønning, The Norwegian Police

SIGN LANGUAGE, TRANSLATION AND LEGAL PROTECTION – DEAF PEOPLE’S EXPERIENCES FROM ENCOUNTERS WITH THE CRIMINAL JUSTICE SYSTEM IN NORWAY

Background: In a previously published study (Olsen et.al. 2010; Kermit et.al 2011) we have shown that deaf people in Norway are under-represented in criminal court cases as victims, witnesses or the accused/convicted. This points to higher lingual barriers, although sign language interpretation services are well distributed. Interpreters understanding of the legal system and legal concepts are of vital importance for the outcomes, and so is the practical implementation of the interpretation. Our data shows variable knowledge, understanding and attitudes to deafness among police investigators and prosecutors. Aim: The aim of this study is to discuss whether or not deaf people are treated equally to other (hearing) people when facing the criminal justice system. We approach this by studying deaf people’s experiences from the police stations and court rooms. Particular interest is put on interaction, mutual understanding and the outcome of these cases. Method: The methodological approach is open-ended, semi-structured interviews with five deaf people who have recent experiences from encounters with the criminal justice system. Preliminary results: Our informants refer to lack of control over information given to police in episodes where crimes have taken place. In cases where the police investigate and prosecute crimes, informants express a lack of understanding and information about the proceedings they take part in. The role of the translators is of vital importance both to the outcome of the process and to the informant’s feeling of coming to terms with the outcome. All deaf informants report that they must mobilize their bilingual and bicultural competence in order to take part in proceedings. A similar bilingual and bicultural competence among the professionals within the criminal justice system is, however, neither requested nor reported. Preliminary conclusions: Although Norway has a well-distributed system for sign-language translation there are several aspects of criminal court cases where deaf people experience a substantial lack of control. Such experiences undermine the legitimacy of the criminal justice system and violate deaf people’s right to equal access.

OWEYA, EZEKIEL

University of Cape Town, South Africa

DISABLED YOUTH; ENABLING SUSTAINABLE LIVELIHOOD IN KENYA.

People with disabilities are grossly under-represented in poverty reduction strategies (PRSPs) and encounter major physical and social barriers when trying to access employment services. The paper explores the involvement of youth with disabilities in poverty reduction strategies in Kenya. Drawing on a study which examines the existence of social, human and financial capital among disabled youth and aims to facilitate their participation in development opportunities, the paper suggests that one of the greatest risk factors affecting the disabled youth population after primary education is the lack of sound sustainable livelihood programmes. Using Rakodi's (1999: 316) definition of livelihood as "comprising the capabilities, assets (including both material and social resources) and activities required for a means of living", this descriptive study examines the different aspects of sustainable livelihood in Kenya. Qualitative research methods were used employing a case study design. The study was conducted in three main cities of Kenya: Nairobi, Mombasa and Kisumu. Using key informants, a snowballing technique was used and a sample of 30 youths with disabilities (18- 35 years) was recruited covering all forms of disabilities. Each focus group comprised of 7-10 participants in each city. Preliminary findings indicate that disabled youths in Kenya lack competitive livelihood opportunities due to non-existent human, social, physical and financial capital. Disabled youth also suffer discrimination on the basis of employment opportunities, inaccessibility and societal attitudes. The paper will conclude that there is a need to build both human, social, physical, financial capital and to mainstream disability in all sectors of development.

PARKER, LANI

Birkbeck, University of London

EVERYWHERE AND NOWHERE: CONSTRUCTIONS OF WHITENESS IN THE LIVES OF PHYSICALLY IMPAIRED/DISABLED PEOPLE

This paper will be based on empirical research carried out with disabled people in North London, as part of a Masters programme in Culture, Ethnicity and Diaspora at Birkbeck, University of London. Critical Whiteness studies has focused on the construction of whiteness as hegemonic and normative and has underlined the importance of deconstructing whiteness in order to eliminate racism. Thus, it is useful to look at how visibly disabled people construct themselves as disabled people and as white people in order to gain insight into how the dominant discourse of disability is racialised. In this paper, debates arising from the fields of Critical Whiteness studies and Disability studies will be used as a theoretical framework to explore the construction of white disabled people's identities in order to open up debates around people's perceptions of themselves as racialised subjects, to look at the patterns of how white, disabled people as racialised subjects both reinforce and resist racism in the context of wider power structures in the everyday, and to look at the interaction between racism and disablism. I will argue that manifestations of whiteness in white, disabled people's identities may be similar in some ways to hegemonic manifestations of whiteness, for example whiteness as invisible, pervasive and a signifier of white privilege. However, physically disabled people hold specific positions in society as part of a subordinate group, and I contend that because of this positionality, their "whiteness" will be inflected by the experience of being disabled.

PAX, RAFAELA MARIA

University Kassel, Germany

"SPECIAL RELATIONSHIPS" - EVALUATING A MENTORING PROGRAM FOR FEMALE STUDENTS WITH DISABILITIES"

The `MentEva` researching group, at the university of Kassel, Germany, evaluates the first nationwide `Mentoring program for female students with disabilities` in a three year longitude study. My presentation is divided into three sections: I will inform about the mentoring program as well as the qualitative research projekt and offer some insights of the early outcomes, researching the very special kind of promoting relationships between academics with and without disabilities.

POSTER

PETERS, RUTH

VU University Amsterdam

RESISTANCE IN CHANGE PROCESSES AND WAYS FORWARD IN A LEPROSY PROJECT

The importance of disability is more and more recognized in the development sector and aligned with several new policies, projects and other initiatives that aim to mainstream disability. On a larger scale, disability and leprosy projects with either top-down or bottom-up approaches are implemented. Both regularly do not achieve the goals they expect but not because there is a lack of technical guidelines, principles or project descriptions. So what is missing?

In this paper we analyse our experiences and in particular the main resistances and challenges that arose when starting up the SARI project. With the SARI project we aim to bring change by implementing three promising stigma reduction interventions for people affected by leprosy including, i) counselling, ii) contact between people affected by leprosy and the community, and iii) socio-economic development in Cirebon, Indonesia. The interactive learning and action approach is the guiding methodology. From January 2011 onwards, initial activities such as hiring staff, introducing the project in Cirebon, building a network with local organisations, training research assistants (including persons with impairments and people affected by leprosy) and an exploratory study took place.

The aim of this paper is not about how to avoid resistances. On the contrary, resistances will inevitably emerge and could actually be seen as windows of opportunity for learning. We make several suggestions how to deal with resistances in such a way that it shapes and prepares a team or organisation for the remaining work.

PHILLIPS, DEBORAH

Cornwall College, Combined Universities of Cornwall

A DISABLING INVASION? THE IMPACT OF TOURISM AND COLONIALISATION ON OLDER DISABLED PEOPLES SPACES, PLACES, AND RURAL ENVIRONMENT

This paper draws on the outcomes of a recently completed research project which explored the themes of 'Disability, Rurality and Global Tourism'. We questioned how the influx of tourists impact and shape the daily lives and lived experiences of disabled people who live in a rural environment. This presentation will focus on a group of older people who attended the same Day Centre. Drawing on their narratives accounts we documented the reflections and upheaval they experienced during our time with them. As a means to conceptualise and underpin this narrative data collection, this paper draws mainly on the work of Bauman (1995, 2011), Bourdieu (1984) and Davis (2003) For many participants the arrival of tourists represented an 'invasion' of traditional public places and spaces. This consisted of beaches, harbour fronts, streets or eating establishments. All of which were considered 'local' yet in fact were clearly and historically marked as classed and gendered spaces where some could enter or be entertained. The tourists of 'yesteryear' tended to reinforce these boundaries whereas the 'invading hordes' and 'superdrys' of today disrupted them. It was acknowledged by the participants that tourism economically supported the community and brought about a certain 'carnival like', atmosphere. Yet this conflicted with the drain on local services, health and care provision, transport, housing and employment. All of which compounded and created disabling barriers in their lives. Inherent in this conflict was the struggle for disabled people to retain and maintain personal and public 'spaces'. Therefore we suggest these stories illustrate a shift in class, gender and moral values: from modernity to postmodernity. As well as providing an example of dismodern colonialisation and global imperialism. In the current ideological and economic climate these basic facilities and human rights become available to 'others' and at the expense of local older disabled people.

PIEPER , MARIANNE

University of Hamburg

Haji Mohammadi, Jamal

“NOT TO BE GOVERNED IN THIS WAY...”

**THEORETICAL AND METHODOLOGICAL PERSPECTIVES
OF ‘CRITICAL ABLEISM STUDIES’: ASSEMBLAGES OF
NEO-LIBERALISM AND LINES OF FLIGHT**

In the framework of ‘Critical Ableism Studies’ and ‘Critical Occidentalism Studies’ on the one hand we aim to discuss the intersection of multiple forms of discrimination concerning dis/ability, ethnicity, age, class and gender in the period of the Neo-Liberal project and its global economic transformation processes. On the other hand it might be misleading to examine dis/ability and the other forms of discrimination exclusively in terms of exclusion, viewing actors simply as victims in the regime of ableism, occidentalism, and neo-liberalism. Current modes of ableism and racist practices are defined not only by binary differentiation and processes of exclusion but primarily through processes of limited inclusion due to the bio-political strategies of the neo-liberal project in the North-Atlantic societies. Based on findings of our EU-project on ‘Participation of multiple discriminated people’ (www.wiso.uni-hamburg.de/cepar) we propose the theoretical and methodological perspective of ‘assemblage’ in the sense of Deleuze’s/Guattari’s ‘agencement’. With this term we aim to investigate the intermingling of ableistic, occidentalistic, and economic power relations and strategies of the regime of Neo-Liberal governmentality with bodies, discourses, affects, and a multiplicity of human and non-human actors. In this meaning assemblage functions as emergent and contingent versatile fabrics of rhizomatic becoming where new lines of flight can appear. Investigations should not, however, stop at a description of the restrictive nature of regimes and their immanent contradictions and by determining the dominant ‘interpellation’ of a ‘symbolic order’. We cannot start from the assumption that subjects merely reflect the ‘relations’, that they are exclusively their ‘victims’. That would be to ignore that the processes establishing subjectivity within these ‘assemblages’ are a social field of conflict in which micro-politics and the desire for other, better life projects express themselves.

PIGGOTT, LINDA

Lancaster University

LEARNING DIFFICULTY, INDEPENDENT LIVING AND ADULT SOCIAL CARE

Reduced adult social care budgets have resulted in diminished support for adults with learning difficulty living independently. Packages of care have been reduced as a result of assessments made by social workers using tighter eligibility criteria, despite needs not having changed. This is a case study relating the experiences and outcomes of one service user and one parent who challenged the decision, the journey that was taken to produce a positive outcome and the insights gained into the relationships between provider, purchaser, care manager, family and service user in relation to adult social care. The National Health Service and Community Care Act 1990 introduced a 'mixed economy' of in-house, private and voluntary sector providers and transferred funding from central to local government. Demand for adult social care in Britain is increasing, partly due to an aging population. As part of the perceived need to reduce public spending the Coalition government has encouraged local authorities to reduce spending on care packages for adults with Learning Difficulty. As a result social services across Britain have embarked on a programme of reassessment of need where adults with Learning Difficulty have packages of care. Assessment is often used explicitly for gate keeping purposes, leaving the aims of encouraging independence, extending user choice and promoting quality care behind. Social work is no longer about helping people with Learning Difficulty to achieve maximum quality of life - the emphasis is on resource allocation, leaving families carers and advocates to negotiate services themselves. There is a new inequality based on lack of access to services and failure to recognise the basic difference between consumers in a free market economy and users of public services with social and political rights. There are significant local variations as to who is eligible for what kinds of support, and a host of complicated local and national rules that apply to the funding of different elements of social care services, essentially leaving the spending decisions open to challenge. This case study focuses on the often fragmented web of connections between the services, the service user and family during their challenge to an assessment that led to reduced care funding. It uses participatory research and shared experience to illuminate the social context of policy making.

POSTEK, NATALIA

University of Vienna

**WHERE IS CRITICAL THEORY WITH ALL THAT
CRITICAL STUFF? OR: UNDERSTANDING OF
SOCIALISATION AND EDUCATION WITHIN THE
CRITICAL THEORY AND ITS POTENTIAL FOR
DISABILITY STUDIES.**

The recent discourses in Disability Studies increasingly use the term critical in their description. Examples for the use of this term are: "Critical Special Education" (Danforth 2009), "Critical Paedagogy" (Gabel 2002) or "Critical Disability Studies" (Goodley 2011). Social Theories that are used to explain the construction of disability and disabilism are different and vary from Freire (Gabel 2002) to Haraway (Goodley 2011). Interesting in this discourse seems to be that this term seldom is used in German speaking discussions about disability. As the term "critical" is used in English scientific community in a big variety, it seems that within the German community the term is mostly associated with the critical theory of the Frankfurter School around Adorno, Horkheimer and Marcuse. Therefore the paper will try to fill the gap of critical theory in the disability studies. The question that will be asked is which additional values can be achieved for Disability Studies by examining critical theory of the Frankfurter School, especially their understanding of socialisation and education. Through this exploration, actual discussions about inclusive school settings and the construction and internalisation of disability in exclusive school settings, can be extended.

POWER, ANDREW
University of Southampton

**FULFILLING THE 'RIGHT' TO INDEPENDENT LIVING:
A CASE-STUDY OF SERVICE MANAGERS NEGOTIATING
REFORM**

The independent living agenda has become dominated by a rights focus which has helped drive national level shifts in setting norms and changing mind-sets. This paper is concerned with examining how rights are utilised by service providers in the process of facilitating independent living. Drawing on an empirical case-study of providers in Ireland, the paper identifies the strategies being used to put rights into practice. The findings show that in the process of creating a well-managed support arrangement for each individual, providers often take a delicate approach to using rights, and sometimes dilute their guiding principles when engaging in on-going complex negotiations between individuals, families, staff and volunteers.

PRIESTLEY, MARK

University of Leeds

INDICATORS OF DISABILITY EQUALITY IN EUROPE? THE CHALLENGES OF MONITORING AND MEASURING PROGRESS

This paper is based on the findings and ongoing development of new public resources and tools for comparing progress on disability equality between European countries. It outlines one methodological strand within a seven year programme of work under the auspices of the Academic Network of European Disability experts (ANED) focused on the scoping and development of qualitative and quantitative 'Indicators of Disability Equality in Europe' (IDEE). The paper's main aim is to demonstrate the new tools in action, to discuss the opportunities these new knowledge resources provide for researchers, activists and policy makers to develop deeper critical analysis, and to consider the strengths and limitations of using indicator methodologies in the disability field. The two key resources include (a) an online database tool describing 1,500 selected public policy instruments, relevant to implementation of the UNCRPD, in European countries and the EU institutions (43 in 34 countries); (b) a selection of quantitative indicators based on available European data and statistics for the 27 EU Member States. The paper will describe the context, rationale and method for development of the indicators and demonstrate the functionality of the pilot data and tools. It will discuss the implications of future development within the context of European policy processes, such as the EU2020 Strategy, the European Disability Strategy 2010-2020 and the Open Methods of Co-ordination associated with these.

PURTELL, RACHEL

University of Exeter

Professor Peter Beresford, Professor Len Barton

LEST WE FORGET: KEEPING THEIR WORK ALIVE AT LEAST:

With such an emphasis on issues such as assisted dying and the cost of Social Care within British Society there is a real fear and concern that the role disabled people have played in past and do currently, will be forgotten. Disabled Scholars, we mean scholars in the widest sense, have built the foundation for independent living, civil rights and have created a world where many of us can now study and work and live in ways that they could not. But inevitably the nature of impairments means as a community we suffer the loss of many of our scholars and stalwarts. The pressure of academic culture is to go to the new and modern, this poses a real problem for the work of our passed scholars and though interpretation is always needed there is a threat that we will lose the essence and meanings that underpinned their work. In this session we want to ask three questions: Do we need something that is particular to keeping the work of dead disabled scholars alive: What is the something? What do we need to make it happen? The outcome from this session will inform conversations with, amongst others, the Disability Archive at Centre for Disability Studies, University of Leeds.

PURTELL, RACHEL

University of Exeter

WHO HAS THE POWER IN YOUR CARE SET-UP? A POWERFUL NEW 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 new 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.

FILM

RAVNEBERG, BODIL
University of Bergen, Norway

ASSISTIVE TECHNOLOGY AND DISABLING BARRIERS REVISITED

There is little research from disability studies scholars or from STS (Science, Technology and Society) - scholars about the role of assistive technology in the relationship between private households and public service providers, or about how users experience assistive technology in their daily life. In special, there is little research on assistive technology in an actor-network perspective with a focus upon the use of technology analyzed as a process. This contribution strives at combining STS-perspectives with disability studies perspectives on the use of AT in order to grasp the connection between disability as a social phenomenon and technology as a social actor. Within disability studies the main focus has been on what constitutes barriers for peoples' participation, equality and inclusion in society. Approaching technology as an actor in itself and studies of how design and aesthetics shape (dis)ability, have not been major topics. From an STS- perspective, technological devices are not only important partakers in people's lives - they are viewed as actors in themselves. This approach facilitates a sharpened focus upon the crucial role of AT alongside the human aid in (re) habilitation processes. The devices are not seen as neutral, nor are they taken for granted, neglected, or seen as finished or "dead" products. More precisely, AT products, while seen as non- human actors, are looked upon as social constructions that are partaking in negotiation processes. This important contribution from STS-studies brings life to the non-human actor and facilitates a scrutinized look upon the relationship between devices, human aid and users in different ways.

RAY-BARRUEL, GILLIAN

Griffith University

PROVIDENCE AND PENURY: THE ROLE OF LITERARY REPRESENTATIONS IN THE ECONOMIC MANAGEMENT OF INTELLECTUAL DISABILITY IN NINETEENTH CENTURY ENGLAND

The management of intellectual disability historically has been marked by profound discrepancies in treatment according to one's class and gender. The rise of the novel as a literary form coincided with the advent of industrialisation and became progressively more popular as literacy increased, particularly among the middle class. The formative power of the novel to impart middle-class values and mores coincided with increased social control in all aspects of daily life. Recent cultural disability studies scholars have highlighted the ubiquity of disabled characters in nineteenth-century fiction and proposed interpreting disability in literature as a defining feature of Victorian anxiety about culture. In an era when the worth of an individual was measured in terms of productive capacity, and political debates about the economic and social merit of the working-class fuelled fears of the decline of British supremacy, people with mental impairments became embroiled in the maelstrom of evolutionary and degeneration theories. This paper explores the contribution of literary representations to the economic management of people with intellectual disability in nineteenth-century England.

REDLEY , MARCUS

Cambridge University

**HEALTHCARE FOR MEN AND WOMEN WITH LEARNING
DISABILITIES: UNDERSTANDING INEQUALITIES IN
ACCESS**

Globally healthcare for men and women with intellectual disabilities receives little or no attention during medical training and is an area where a large gap exists between the health needs of this population and the provision of services. This is true in the United Kingdom where the often complex health needs of people with intellectual disabilities - known locally as learning disabilities - were largely overlooked until the publication of 'Death by Indifference' (Mencap, 2007). This report not only prompted a public inquiry and an investigation by the Health Ombudsman, it also led to a new policy initiative designed to improve this population's access to healthcare. The publication of 'Death by Indifference' and the subsequent political attention this has brought to the health of men and women with learning disabilities makes it imperative to consider both the beneficence of the medical profession, and how best to ensure the health rights of this population are promoted and protected. Charting some of this neglected territory this presentation, in four parts, will briefly describe the challenges of providing healthcare to men and women with learning disabilities; review 'Death By Indifference' and its aftermath; presents findings from a small-scale interview study of access to healthcare, and close with an assessment of whether or not access to healthcare for men and women with learning disabilities is likely to improve.

REDLEY , MARCUS

Cambridge University

**THE RIGHT OF ADULTS WITH INTELLECTUAL
DISABILITIES TO VOTE: REFLECTIONS ON THE
CONVENTION ON THE RIGHTS OF PERSONS WITH
DISABILITIES AND THE SITUATION IN KENYA AND
THE UNITED KINGDOM**

Worldwide some 200 million people are living with an intellectual disability. Irrespective of whether they are living in the global south or the more economically developed north, people with intellectual disabilities experience discrimination and stigmatisation. Furthermore, their continued exclusion from opportunities for education, employment and healthcare represents a denial of their fundamental human rights; rights that the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) aims to promote and protect. The CRPD has been described as a “paradigm shift”. No longer are people with disabilities to be viewed as objects of medical intervention, charity and social protection; rather they are to be respected as both holders of rights, and as active members of society. Across its 50 articles, the CRPD addresses prejudicial attitudes and environmental barriers as well as guaranteeing political rights - Article 29 - and the opportunity to enjoy them on an equal basis with others. With respect to the right to vote Article 29 raises an important question, because voting rights have long been associated with beliefs about the ability to reason and act independently, how, and to what extent can people identified as having mental disabilities - impairments in the functioning of the mind or brain - meaningfully participate in this quintessential democratic activity? This is the question considered here; first, by reviewing arguments that have commonly been used to deny voting rights to people of “unsound mind”; second by considering the practical steps that have been taken in Kenya and the UK to support and promote the rights of adults with intellectual disabilities to vote, and third by discussing of two very different answers to this question.

REEVE, DONNA

CeDR, Lancaster University

Soldatic, Karen

THE ARRIVAL OF THE 'BROWN ENVELOPE': THE GENDERED EMBODIED EXPERIENCE OF WELFARE REFORM IN THE UK

Within the UK, the restructuring of disability social security measures under the Cameron Government welfare to work agenda has received considerable attention within the mainstream media. Frequently, we are exposed to a range of discourses and discursive practices that seek to morally, politically and socially justify the on-going withdrawal of disability social entitlements via the realm of disability benefits such as the Employment and Support Allowance (ESA). While there has been a growing body of work that has sought to identify the significant material and stigmatising effects of the Cameron Government's disability welfare to work agenda, thus far, there have been few studies that have directly drawn upon the rich narratives of disabled women who have directly experienced the coercive administrative procedures of the government's welfare to work agenda. In this paper, we begin to fill this significant gap in the literature. Our point of analysis seeks to understand disabled women's emotionally embodied experience of receiving information from the administrative department responsible for notifying disabled ESA recipients of welfare assessments and other mandatory requirements such as job centre appointments that form part of these reforms. We argue, that exploring disabled women's embodied experience of the arrival of the 'brown envelope', the envelope containing welfare reform administrative requirements for ESA recipients, provides a critical window into understanding the nascent forms of psycho-social embodied disability that emerges under such coercive disciplining regimes. Further, through the use of narrative methodologies, we show that the disabling effects of such administrative processes not only affect the 'emotional wellbeing' of the individuals concerned, but have far greater consequences for the processing of their legitimate claims to disability social entitlements.

RICE, JAMES

CDS, University of Iceland

THE DISABILITY CONCEPT IN THE FIELD OF POVERTY RESEARCH: A DISCUSSION FROM ICELAND

This paper will explore some of the analytical issues that can arise when the concept of disability is analysed in conjunction with poverty. The research on which this is based was a 10-month study entitled 'Poverty and the Social Conditions of Disability Pensioners,' funded by the Icelandic Ministry of Welfare and the Organisation of Disabled in Iceland (ÖBÍ). From an intersectional perspective, it was analytically problematic to disentangle such factors as gender, parenthood, socio-economic class, ethnicity/nationality and impairment from the analysis of either poverty or disability. In this project, the diverse group of research participants shared little in common other than low income and a bio-medical evaluation of 'disability' for the purposes of the pension system or other kinds of entitlements and services. Furthermore, the disability focus in Iceland of late has been on factors of independent living and user-led services. These are of course critically important issues, but they primarily concern a group of people in Iceland who are situated somewhat differently from the research participants in this study. It is important to retain the category of disability for research, activism and the promotion of rights-based frameworks such as the CRPD which depend upon the disability concept. But this paper will seek to spur discussion on the utility of the disability concept as the key analytical framework in research fields such as poverty in which disability intersects with other competing factors.

RICHARDS, MICHAEL

Manchester Metropolitan University

CHALLENGING THE LABEL OF 'LEARNING DIFFICULTIES': A COMMUNITY PSYCHOLOGY APPROACH IN TACKLING THIS LABEL AND IMPROVING MEN'S HEALTH AND WELL BEING.

Community psychology is a radical and action orientated paradigm that aims to work in unity with community members who are oppressed and marginalised by social, economic and cultural structures. It places the problems people with learning difficulties face in their contexts, not in their brains, which psychology traditionally sets out to do. In this paper, I want to analyse the commonalities and advantages of combining community psychology and disability studies together and what it can bring to people with learning difficulties. I will use my recent research to explain some of the visual and creative methods I have used to challenge the label of 'learning difficulties' and improve the health of men. These methods included producing films, photography, art and craft, poetry, story writing, debate, sculpture and drama. The men's work was celebrated in a six month exhibition in Manchester in 2012. The research has so far found that using these methods has been a good way to challenge people's perceptions of learning difficulties and are good ways to challenge their health attitudes or to learn new ways of thinking about their health, with the aim to change. In conclusion, community psychology is the best approach in psychology to realistically start to make a difference in the lives of people labelled with 'learning difficulties'. Instead of judging them, we aim to celebrate their talents, skills and contributions to society, on their terms. Men's health can be improved by using strategies of change that empower the men to see for themselves their particular health issues and finding ways prevent or change these issues.

ROBERTS, HAZEL

Lancaster University

Susannah Baines, Chris Hatton, Sue Turner

EXPLORING THE ADVOCACY LANDSCAPE FOR PEOPLE WITH LEARNING DISABILITIES

Valuing People (2001) and Valuing People Now (2007) helped to strengthen advocacy for people with learning disabilities and the introduction of Independent Mental Capacity Advocates have meant help for the most vulnerable people. However this focus on statutory advocacy may be at the expense of other types of advocacy, including self advocacy. Previous research has found that many people with learning disabilities are not getting access to the advocacy services they need and has argued that independent advocacy should be seen as an essential service by commissioners (Action for Advocacy, 2011). The Improving Health and Lives: Learning Disabilities Observatory carried out a research project in 2011/12 to focus on the extent and nature of advocacy services for people with learning disabilities in England, to consider the impact of potential changes to funding and identify gaps and barriers in the provision of advocacy. The research used online surveys of advocacy organisations and local authority commissioners of advocacy as well as in depth case study work with three self advocacy organisations selected through the survey. 88 advocacy organisations and 78 advocacy commissioners responded to the survey. 81% of advocacy organisations thought that they would find it more difficult to get money for the following year (2012/13). Commissioner data suggests that while total advocacy spending has increased since 2009/10, the proportion of spending on self advocacy has decreased during this time. For both advocacy organisations and commissioners the top reason for funding advocacy services was to give people with learning disabilities a voice. Given the priority of this aspiration within current learning disability policy it seems clear that advocacy for people with learning disabilities, and particularly self advocacy, should be prioritised by commissioners.

POSTER

ROBERTSON, JANET

CeDR, Lancaster University

Hatton, Chris, Emerson, Eric, Mohammed Taghi Yasamy (WHO)

THE IDENTIFICATION OF CHILDREN WITH OR AT SIGNIFICANT RISK OF INTELLECTUAL DISABILITIES IN LOW AND MIDDLE-INCOME COUNTRIES: A REVIEW

At least 85% of children with intellectual disability (ID) live in low and middle- income (LAMI) countries. The World Health Organization Mental Health Gap Action Programme (mhGAP) identified developmental disorders as one of the priority areas for intervention within child and adolescent disorders. The development of mhGAP involved commissioning four systematic reviews of evidence in relation to children with ID, which were undertaken under the auspices of the International Association for the Scientific Study of Intellectual Disability (IASSID). These reviews form a special section in the Journal of Applied Research in Intellectual Disabilities, 25, 96-154. One of these reviews, carried out by the Centre for Disability Research, looked at the identification of children with or at significant risk of ID in LAMI countries. Developmental monitoring of children is an important strategy for the early detection and management of ID in high- income countries. The review looked at the approaches that are available to enable primary or secondary healthcare functionaries to identify children with or at significant risk of intellectual disabilities in LAMI countries. Electronic literature database searches were conducted to identify relevant articles in the English language published since 1980. Requests for information were also sent to membership of IASSID and relevant organizations in selected LAMI countries. A total of 37 articles were identified for inclusion in the review, the majority of which concerned validation of specific screening tools. Information is presented on sensitivity, specificity, positive predictive value, negative predictive value and reliability of identified screening tools. Evidence relating to the validity of specific approaches to identifying intellectual disability in children in LAMI countries is of low quality. Studies were mainly concerned with identifying child disability per se. Research and development should develop specific approaches to identifying ID among children in LAMI countries.

POSTER

ROBERTSON, JANET

CeDR, Lancaster University

Emerson, Eric, Hatton, Chris, Mohammed Taghi Yasamy (WHO)

EFFICACY OF COMMUNITY-BASED REHABILITATION (CBR) FOR CHILDREN WITH INTELLECTUAL DISABILITIES IN LOW AND MIDDLE-INCOME COUNTRIES: A REVIEW

At least 85% of children with intellectual disability (ID) live in low and middle-income (LAMI) countries. The World Health Organization Mental Health Gap Action Programme (mhGAP) identified developmental disorders as one of the priority areas for intervention within child and adolescent disorders. The development of mhGAP involved commissioning four systematic reviews of evidence in relation to children with ID, which were undertaken under the auspices of the International Association for the Scientific Study of Intellectual Disability (IASSID). These reviews form a special section in the *Journal of Applied Research in Intellectual Disabilities*, 25, 96-154. One of these reviews, carried out by the Centre for Disability Research, looked at the efficacy of community-based rehabilitation (CBR) for children with ID in LAMI countries. CBR was developed in the 1980s, 'to give people with disabilities access to rehabilitation in their own communities using predominantly local resources' (<http://www.who.int/disabilities/cbr/en/>). The review summarises evidence on the efficacy of CBR for children with ID in LAMI countries. Electronic literature database searches were conducted to identify relevant articles in the English language published since 1980. Requests for information were also sent to membership of IASSID and relevant organizations in selected LAMI countries. Thirteen studies contributed to evidence on the efficacy of CBR for children with ID. Few studies focused specifically on the efficacy of CBR for children with ID and the quality of evidence that does exist was 'very low'. The little evidence that is available presents a mixed picture. This does not mean that CBR is ineffective. At present, we simply do not have sufficient evidence of sufficient quality to form a judgement with regard to efficacy, effectiveness or efficiency. Improving the quality of the evidence base will require greater investment in the evaluation of CBR and addressing the marginalization of people with intellectual disabilities in CBR.

POSTER

ROBERTSON-RIECK, PHILLIPPA

University of Glasgow

**“MOVING THE GOALPOSTS”: CUTS, CONTINGENCY
AND EMBODIED CITIZENSHIP.**

This paper is drawn from an ongoing PhD based on interviews with disabled young people. In this paper I draw on data that examines how young people live their everyday lives and explore their accounts of being a disabled young person. These young people have grown up in a very different world to that of older disabled people. For them legislation such as the Disability Discrimination Act, along with the growing mainstreaming of services, has meant that they have grown up in a society where the right to inclusion is, on the whole, accepted and expected. However, the population has moved into ‘the age of austerity’ and as such the level of citizenship that disabled young people have come to expect and enjoy is being challenged and is now pivoted on the social production of contingency. For the young people who took part the future is uncertain and their experiences of public and private spaces are being re-imagined through the proposal of cuts to services and provision. This paper will, therefore, explore the ‘contingency’ of rights and of citizenship for these disabled young people; this will be achieved through an analysis of the changing landscape that young people now have to negotiate. The data documents how the threat of ‘cuts’ have altered the way in which the participants perceive themselves, their rights and their position in society. It will explore the concept of embodiment as the site of citizenship in our everyday lives and how the contingent nature of citizenship impacts on our corporeality and our embodied selves.

ROULSTONE, ALAN

Northumbria University

VIC FINKELSTEIN AND PROFESSIONS ALLIED TO THE COMMUNITY: AN UNFINISHED PROJECT

Vic Finkelstein, writer, activist and practitioner provided a ground-breaking challenge to pre-existing practice and their underpinning assumptions about disability and disabled people. Finkelstein questioned the roles of 'professions allied to medicine' and their dependency-perpetuating impact in 'confirming' disability as a para/medical problem. Finkelstein, both a practitioner and service user forged ahead with an intellectual and practical critique of what he called the 'helper-helped' relationship. The social model of disability had a key role to play in his thinking but his views were however optimistic that professionals, if allied to disabled people, were a necessary and potentially enabling force. Rather than see this critical approach to disability as outmoded, arguably the project to get more professionals allied to disabled people and free from medical hegemonies remains incomplete. This paper will pay tribute to Finkelstein's contribution to disability studies and practice and will argue that recent discussion of a movement towards a 'critical disability studies' risks overlooking fundamental achievements that went before it and which in a post structural relative 'soup' risk being reversed in an era of austerity.

RYAN , SARA

University of Oxford

GLOWING OR GLOOMY ACCOUNTS OF PARENTING DISABLED CHILDREN; WHAT'S THE STORY?

In 1990, West published a paper exploring two qualitative studies of parenting a disabled child; his own PhD research, in which parents produced gloomy accounts, and Voysey's classic study, in which glowing accounts emerged. For West, the difference was explained by the status and validity of the two accounts; Voysey generated 'public' (ought-type) accounts using single interviews, while he was able to generate 'private' accounts through a mixed method approach involving multiple interviews (with skeptical questioning) and observation. Opposing accounts of parenting disabled children are apparent in the broader literature, although it is possible to trace a shift towards more glowing from gloomy, in line with changing understandings of disability and impairment. Much of what I call the enlightened literature is written by mothers of disabled children (for example, Sara Green, Gail Landsman, Chrissie Rogers and Catherine Runswick-Cole) and could reflect a particular stage in the development of a new social movement. An over-emphasis on the positive is necessary to facilitate a shift in thinking, and establish a credible foundation for examining the experiences of parenting a disabled child outside of a tragedy model, before the difficulties and challenges can be brought back in to the arena. The enlightened literature could, alternatively, reflect the position of the 'mother researchers', who apply a particular lens to their work. In this paper, I return to data from a study involving interviews with 45 parents of children diagnosed with autism and explore in-depth the types of accounts the parents generate. Using a bracketing technique, I analyse both the content of the narratives, and critically explore the co-construction of the accounts, focusing on the interaction between myself, a researcher, and a mother of a disabled child, and the participants.

SAGEN, LINE

Harstad University College

INTELLECTUAL DISABLED CHILDREN AND THEIR RIGHT TO EDUCATION: HOW DOES THEIR POSITION AS "BEINGS" CONTRIBUTE TO THIS RIGHT?

Since the 1990ties there has been a change in the perspective on childhood. This from focusing at children's development and value as future adults ("human becomings"), to regarding children as competent social actors with rights and value on their own ("human beings"). In the last decade this change in focus is also reflected in an increasing political focus at securing the interests and needs of children through legal rights, including their right to education. According to the Norwegian Educational Act of 1998 all children have a right to education, and to be included in democracy, learning and social activities at school. The paper discusses and questions whether the sociological theories on the constructions of children as "beings" contribute in securing the educational rights of children with intellectual disabilities. The discussion is build on qualitative fieldwork, based on qualitative interviews (N=55) and participant observations in lower secondary school in Norway (children aged 13 - 16 years). The study examined how the schools catered for pupils' with intellectual disabilities and their opportunity to take part in democracy, learning activities and social interaction. The interpretation of the interviews and field notes were inspired by hermeneutic principles. The research was approved by the Norwegian Research Ethics Committee and the necessary informed consent was acquired before the interviews. The data on intellectual disabled children's everyday life in lower secondary school tell that intellectual disabled children in the Norwegian education system only to a limited extent are treated as "beings" and/ or "becomings". Sometimes the teachers use the dichotomy in a manner that increases the exclusionary processes towards this group of children.

SAUR, ELLEN

Norges Teknisk Vitenskaplig Universitet

Oddbjørn Johansen

CAN THEATRE CONTRIBUTE TO REDESCRIPT THE UNDERSTANDING OF LEARNING DISABILITY?

The main subject of our paper is whether theatre can contribute to redescrptions of the understanding of learning disability. Redescription is a concept from the philosophy of Richard Rorty (Rorty, 1989). The concept learning disability is being constructed when special associations and emotions are connected to it. Different ways of understanding learning disabilities creates or deprive people with learning disabilities of possibilities to act in the society. We want to look into how establishing and creating theatre can contribute to extend the understanding of having a learning disability. The paper is based on our experiences with a theatre for 15 people with intellectual disabilities. Namsos Municipality is the host of the theatre. This is a municipality with 12906 inhabitants, and is a part of Nord- Trøndelag County (131555 inh.), Norway. These 15 people are employed at Namsos Municipality in a professional theatre; Theater nonSTOP (www.teaternonstop.no) based on principles from community theatre (Johansen & Saur, 2010; Nicholson, 2005). The theatre collaborate with professional artists; musicians, dancers, choreographers and directors and has produced four different performances so far. We will discuss if such encounters can contribute to a changed understanding and challenge existing prejudice. To deal with this complex situation which involves developing the theatre in artistic, organizational and political ways, we have chosen to do an action research approach, leaning on the emancipatoric and critical pedagogy of Paulo Freire and Augusto Boal (Boal, McBride, McBride, & Fryer, 2008; Freire, 2000) Action research is chosen as research method because this is an approach suited for research where the researcher can make a difference by initiating changes (McNiff & Whitehead, 2006). The research is exercised together with the partners in the project, and this article is based on interviews with the partners in order to evaluate the theatre so far. The focuses of the research are theatre, disability politics and education.

SAYRAFI, IMAD

Birzeit University, Palestine

THE GAP BETWEEN RIGHTS AND REALITY; AN ASSESSMENT OF THE RIGHTS OF PEOPLE WITH DISABILITIES IN THE OCCUPIED PALESTINIAN TERRITORIES, AND THEIR INTERACTION WITH THEIR COMMUNITIES

Can people with disabilities (PWD) in the Occupied Palestinian Territories claim their rights and entitlements in accordance with the rights and laws pertaining to them? What are the barriers they face towards the achievement of equal rights? The reality on the ground shows that there is a notable lack in the implementation of the rights of PWD and many barriers facing PWD towards accessing rights and services. These barriers are studied through the implementation of the ongoing 42-month project "Empowering PWD to Claim Their Rights and Entitlements" which is funded by DfID and implemented by the Center for Development Studies- Birzeit University. The project adopts a rights based approach in studying the reality of PWD in their communities and supports them in creating interventions aiming change the reality in their communities. This paper focuses on alarming discrepancies between rights and reality and depends on data gathered throughout field work carried out between September 2010 and March 2012 studying the situation of PWD in these communities, in addition to a community accessibility mapping carried out by a core group of PWD working within the project, and the reflections of this group on these findings. The paper argues, that there is a prominence in attitudinal, institutional, and environmental barriers that prevent PWD from accessing rights and services within the target communities. These barriers, are normalized, even by people of disabilities themselves within these communities. The normalization of these barriers presents a challenge for PWD in claiming their rights, and present insight towards the design of the next stages of the project which aim to advocate towards changing the reality in these local communities.

SEALE, JANE

University of Plymouth

THE ROLE OF SUPPORT WORKERS IN ASSESSING AND MANAGING THE PERCEIVED RISKS OF TECHNOLOGY USE BY PEOPLE WITH LEARNING DISABILITIES

The focus of this paper is the use of educational technologies by people with learning disabilities and the aim is to critique the discourses surrounding this use and the implications this has for how access to technology is facilitated by support workers. The discourses surrounding technology and disability have long been influenced by notions of risk. Three risk discourses are particularly prevalent: an "at-risk" discourse associated with using technologies to teach people with learning disabilities basic literacy and numeracy skills; a "risk minimising" discourse associated with using technologies to teach independent skills that optimise personal safety and security and a "risk management" discourse associated with teaching safe use of online social and communication technologies. Reflected across all three discourses is a neoliberal construction of risk, where groups or individuals who are considered incapable of managing their own risk are subject to surveillance and treatment by service providers and the support workers employed by them. This is predicated however on the assumption that support workers can appropriately assess and manage the perceived risks of technology use by people with learning disabilities. This paper will draw on research literature and case examples to critique the validity of such an assumption.

SHAKESPEARE, TOM

World Health Organization

Alana Officer, WHO; Aleksandra Posarac, World Bank

WORLD REPORT ON DISABILITY: FROM EVIDENCE TO ACTION

The WHO/World Bank World report on disability brings together the best available evidence on disability at the global scale, with the aim of enabling governments to remove barriers and achieve the human rights of persons with disabilities. The World report thus supports implementation of the UN Convention on the Rights of Persons with Disabilities. This talk will describe the participative process which generated the report, highlight the main findings, and outline the recommendations for promoting participation. One headline finding was the new disability prevalence estimate of 15% of the global population (one billion people with disabilities). The talk will conclude with a discussion of the need for more research on disability in low and middle income countries. Full text, summary and accessible versions of the World report on disability can be found at:

www.who.int/disabilities/world_report

SHAMASH, MICHAEL

Allan Sutherland

FISH AND CRIPS: TOWARDS A CULINARY MODEL OF DISABILITY

This paper seeks to launch a discussion about disability and food. We live in a world that has become seemingly dominated by food. You only have to open a newspaper or turn on the television and there is an article or programme about food. Cookbooks are bestsellers and chefs are media stars; yet disabled people are invisible in this process. Cooking is an activity that disabled people can do and eating out is a sedentary experience that can be totally inclusive. Yet there is little thought given to disabled people and their relationship with food and eating. It is clear that many aspects of the disabled person's relationship with food are worthy of serious consideration. These include: the medicalisation of the eating experience, based on an assumption that for disabled people food is about nutrition, not sociability, a process in which expert decision-making outweighs personal choice and culture; the effect of institutionalisation and hospitalisation on our culinary experience and expectations; the fear of being conspicuous and ill at ease whilst eating in a public place; physical access to the kitchen or dining room; cultural issues that exclude disabled people from participation in the creation or consumption of food; issues of self-worth, particularly in relation to fine dining; and the nature of food poverty and the response of disabled people. It is easy to regard lifestyle issues as trivial, but food embodies culture, and we feel that disabled people must have a part in that process. It is time for the sociable model of disability.

SIGURJÓNSDÓTTIR, HANNA

CDS, University of Iceland

INTELLECTUAL DISABILITY AND MOTHERING: (DIS)ABLING SOCIAL AND CULTURAL CONTEXTS

This paper explores how social and cultural factors shape the experiences of mothers with intellectual disabilities. It is based on a long-term involvement with 20 mothers with intellectual disabilities and their children. The data is qualitative and is based on participant observations and interviews over an extended period. Drawing on a social understanding of disability the aim is to explore the structural context of women with intellectual disabilities and mothering. A life history approach is used to trace the experiences of the 20 mothers from the time they were growing up as little girls to the time they have become mothers, and their accounts of raising children. The paper explores the ways in which most of them were discouraged from having children, how their impairment exposes the expectations of mothering, assumptions about disability and how society is disabling and disempowering of mothers with intellectual impairments. The life histories demonstrate that the women grew up in an environment that did not expect them to become mothers and tried to prevent them from having children. Almost all had negative reactions to their pregnancies, experienced threats of having their children removed and raised their children in debilitating fear of losing custody of their children. In short, their major obstacles in having and raising children were negative and prejudice reactions from the environment including family members, professionals and others who they came in contact with. Based on the mothers' experiences the attitudes and practices the mothers found supportive and empowering will be outlined.

SKOGMAN, EVA

Mälardalen University, Sweden

INDEPENDENT LIVING WITH PERSONAL ASSISTANCE IN SWEDEN - TWO BOYS, THEIR FAMILIES AND VERY DIFFERENT LIFESTYLE CHOICES

Kim and Max are two boys with multiple disabilities in their primary school years. Both boys are quadriplegic and wheel- chair users. They both communicate with small gestures. Both Kim and Max live with their families and they both have personal assistants, around the clock, employed by an Independent Living cooperative which stresses the importance of self-determination and a life like other children. Kim goes to school in his local community and his class is located in an ordinary primary school. This means that he, with assistance, can participate in play and interaction with other children during breaks. At school Kim participates in circle time but spends the rest of the school day with his assistant which means that Kim gets hardly any teacher- led lessons. Kim enjoys listening to music, playing drums and watching TV with his family and he spends little time doing physical therapy or other training. Max, on the other hand, goes to school far away from his home. This school provides him with both intensive teacher- led lessons as well as physical training. Max has a special schedule that he follows every day. Apart from his school work the schedule contains different training programs for different parts of his body. In fact, Max has no leisure-time at all and spends all waking hours, with the help of his assistants, training. Max never gets assistance in playing or interacting with peers or family. Kim's and Max's lives are very different due to lifestyle choices. The choices of schools also reflect this. These choices can both be contained within the Independent Living values. Data was collected by participant observations for 2-3 months for every child and is part of a more extensive project.

POSTER

SLATER, JENNY

Manchester Metropolitan University

**STEPPING OUTSIDE OF NEOLIBERAL NORMATIVITY:
WHEN YOUTH AND DISABILITY MEET, THE CASE OF
JODY MCINTYRE**

Disabled activist, political blogger and journalist, Jody McIntyre, was 20 when in December 2010 he was pulled out of his wheelchair and dragged across the floor whilst demonstrating against educational cuts in the UK. Caught on camera, the video soon became a YouTube hit and reached the national press. Responses to the video were furious and wide-ranging. There was outrage that the police would treat a 'cerebral palsy sufferer' in this way. Rather than condemn police violence *per se*, however, another reaction was to paradoxically treat the incident as a mark of equality: YouTube user comments suggested, for example, that a protest was no place for a disabled man, and that as McIntyre put himself in that vulnerable position he should expect police brutality. Other responses were nothing less than overt disablism. I stand in solidarity with Jody and others fighting public sector cuts and condemning police brutality. However, in this paper I will not debate either issue. Rather I focus on the resultant (confused and contradictory) rhetoric emerging as a result of Jody's police treatment. I argue that Jody, as a politically active young disabled person, disturbed discourses of passivity which surround disability. In welfare cutting Britain, young, like disabled people, are deemed lazy, unproductive, scroungers, burdens (Garthwaite, 2011; Giroux, 2009). There is a Neoliberal push for activity... but 'activity' is only defined in relation to economic productivity. Politically active young people are deemed volatile, dangerous, neurologically unstable: rioters. I argue the frenzied responses to the Jody McIntyre case result from 'disability' stepping outside of the 'innocent' 'passive' 'good' disabled person we believe in, and confusing us by meeting head on with rhetoric of dangerous and volatile youth.

Garthwaite, K. (2011). 'The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform. *Disability & Society*, 26(3), 369-372.

Giroux, H. (2009). *Youth in a suspect society: democracy or disposability?* New York: Palgrave Macmillan.

SLEPICKOVA, LENKA

Masaryk University, Brno

CONTEXTUALIZING DISABILITY WITHIN THE CZECH REPUBLIC: BETWEEN INVISIBILITY AND INCLUSION

Full acceptance and low level of prejudice towards people with disabilities in the context of formal and non-formal relations is a necessary precondition for the successful inclusive process within all types of institutions. Our paper aims to analyze the context of inclusive processes in the Czech Republic through researching attitudes of the general public towards people with disabilities to find out where on the road between their „invisibility“ and „inclusion“ we are. The situation of people with disabilities in the course of the second half of the twentieth century in the Czech Republic has been strongly affected by political situation in the region. The communist government and administration (1948 – 1989) spread the ideology of “healthy, strong and uniform society,” kept people with disabilities invisible and offered only basic services in segregated residential settings. More than twenty years after the collapse of the totalitarian regime and beginning of democratization processes, the situation of people with disabilities remains peculiar. Despite significant changes in legislation, administration, education and social services, despite striving for more just and inclusive society, prejudice in the sense of subjective-affective dimension of attitudes still prevails. In our research, carried out in December 2011, we administered an adapted version of Bogardus scale of social distance to a representative sample of Czech population. The questions were aimed to provide information about various types of disabilities. The analysis will look closely at the level of acceptance in educational settings and also at focus on generational comparison. We will focus on the connotations of different types of disabilities and their impact on the level of social acceptance.

SLORACH, RODDY

St George's University of London

DISABILITY IN THE AGE OF AUSTERITY

Disability in the Age of Austerity Disability activists sometimes make comparisons between the current assault on benefits and services and the treatment of disabled people under the Nazis – a regime whose rise to power was made partly due to the scale of the Great Depression of the 1930s. Today, wider comparisons between the global recessions of then and now are increasingly commonplace. What then is the relationship between disability and economic recession? Why are disabled people among the 'hardest hit' by government cutbacks during such downturns? Does the severity and durability of the current crisis mean that disabled people are likely to face much worse attacks? The precarious position of many disabled people makes them particularly vulnerable to such cutbacks. In this session, however, I wish to argue that there are important differences in the place disabled people have in current society compared to that of the 1930s. These include the provisions of a welfare state (albeit weakened in recent years), the increased visibility of disabled people in both the community and the workplace, and the related gains made by the disability movement. These differences have clear implications for how current and future attacks on disabled people can be resisted.

SMITH, EIRÍKUR

CDS, University of Iceland

TEENAGE ANGST AND REBELLION: SHAPING IDENTITY IN DISABLING MODERN SOCIETY

The teenage years are often described as times of turmoil and distress, driven by emotional yearning to “fit in” and be accepted, while holding on to “the uniqueness” of one’s own personal identity. During this transition from childhood, greater access is given to the space and dynamics of a market-driven society, where it is believed people, as consumers, have unrestricted freedom to choose who they are. This paper presents findings from a qualitative study on the perspectives of young disabled people in modern Icelandic society, with special focus on their attempts and negotiations to shape their identity. It addresses the difficulties disabled teenagers have in attaching to the so called “market of opportunities” and how they feel pressured to find their consumerism and lifestyle channelled to more un-acceptable and segregated options, drawing all attention to their “undesirable” personal difference. Furthermore, the images used in presenting the marketed options are built on ideals of body perfection, being self-sufficient, economical and comfort which, in relation to ableist cultural imagery, is normally not related to disabled people. In that way, disabled teenagers feel that they are forced to take up a pre-described identity that goes against their will. This process of restrictions and “othering” can cause lot of anxiety and insecurity, which often goes unnoticed or interpreted as a natural attribute of being disabled. Challenging it calls on stronger and prolonged form of rebellion.

SNELL, LAURA

Lancaster University

THE COCHLEAR IMPLANT JOURNEY: THE EXPERIENCES OF YOUNG ADULT COCHLEAR IMPLANT USERS

In the past two decades there have been significant and rapid developments in the field of cochlear implants, and in the UK an increasing number of profoundly d/Deaf children and adults now routinely receive implants on the National Health Service. The widespread use of this implant technology has evoked diverse reactions amongst both d/Deaf and hearing communities, and consequently shaped the experiences of many d/Deaf individuals. This paper is based on my PhD research which explores the lived experiences of young adult cochlear implant users (aged 18 – 30 years old). In-depth interviews have been conducted with implant users in order to explore their self-identity, socialisation, their perceptions and experiences of implant technology. This paper will draw on the research findings in order to highlight participants' experiences of living with and using cochlear implants as part of their everyday lives. There will be a specific focus on the cochlear implant journey - from the initial decision making undertaken by the participants, to the practical realities of learning to adapt and live with the technology, to the participants' experiences of managing and negotiating the cochlear implant in their everyday lives.

SPOONER, CHRIS

CeDR, Lancaster University

**“YOU’D HAVE TO LOOK A CERTAIN WAY TO FIT IN
AND BE GROUP MANAGING DIRECTOR OF THIS
COMPANY” EXAMINING THE IMPORTANCE OF
‘AESTHETICS’ IN THE CAREERS OF DISABLED LEADERS**

‘...all bodies are not created equal when it comes to aesthetic response. Taste and disgust are volatile reactions that reveal the ease or disease with which one body might incorporate another. The senses revolt against some bodies, while other bodies please them’ (Siebers, 2010). Siebers has referred to ‘the aesthetics of human disqualification’ arguing that impairment is a marker of otherness that is viewed, not as an acceptable or valuable variation between humans, but as a dangerous deviation, a natural inferiority which becomes the justification for unequal treatment. This argument is redolent of Campbell’s (2009) notion of ableism which has produced ‘the corporeal standard’ against which all bodies are judged, measured and evaluated and which casts disability as ‘a diminished state of being human’. This presentation draws on my on-going PhD research and introduces the idea that aesthetic considerations may play a role in the career outcomes of disabled people. In particular I look at how aesthetic judgements may influence choices about leaders and also the level to which followers will decide to support or reject their leader.

STALKER, KIRSTEN

University of Strathclyde

HOW WELL HAS THE POSITION OF PEOPLE WITH LEARNING DISABILITIES BEEN THEORIZED WITHIN DISABILITY STUDIES?

The aim of this paper is to assess how far, in what ways and how effectively the position of people with learning disabilities has been theorised within Disability Studies. In some respects, the 'strong' social model appears to fit well, for example in relation to its materialist analysis of the social and economic exclusion of disabled people and the impact of external social and communication barriers. In other respects, the social model fits less well. There is, then, a need for further theorisation but more energy has been spent debating who is eligible to theorise about learning disability rather than doing it. It has been suggested that emancipatory research, Disability Studies' preferred approach, is less easy for people with learning disabilities, and some pioneers of inclusive research have avoided developing theory because they believed that to do so would exclude colleagues with learning disabilities. Different theorists have argued that learning disability is a social construct although difference does exist; that learning disability is totally socially and discursively created and that no differences exist between those with and without this label; and that the idea that impairments are simply matters of representation and discourse which can be eliminated through a process of re- or deconstruction is untenable. Rather than adopt a dualistic approach which sees biological reductionism as the only alternative to social construction, perhaps the way forward lies in a more complex and nuanced position which takes account of both the real and the social. This might be achieved by adopting critical realism as the 'grand theory' of DS with a sociology of impairment (Thomas 2007) as a mid- range or substantive theory.

Thomas C (2007) *Sociologies of Disability and Illness* Basingstoke: Macmillan

STICKINGS, MARTHA

European Union Agency for Fundamental Rights

CHOICE AND CONTROL – THE RIGHT TO LIVE INDEPENDENTLY AND BE INCLUDED IN THE COMMUNITY

The opportunities and support for people with mental health problems and people with intellectual disabilities to live independently vary across the EU. Disabling barriers and systems – whether in the form of long-term care institutions, lack of daily living support, inaccessible workplaces and services, stigma and discrimination or restrictions on legal capacity – operate to exclude them from the mainstream of community life. In 2011 the European Union Agency for Fundamental Rights (FRA) carried out fieldwork research in nine EU Member States to capture the lived experience of people with mental health problems or intellectual disabilities in the area of community living. Their testimonies highlight the obstacles which impede their ability to live independently and participate in community life, but also offer examples of good practice from across the EU. Many persons reported being unable to choose where or with whom to live, their options limited by a lack of support for community living and by the continuing presence of institutions and institutional regimes. Similarly, a lack of support for daily living, in terms of access to both mainstream services and specialised support, contributes greatly to restrictions on individual choice and autonomy. Employment on the open labour market, particularly, is out of the reach of many people as segregated education makes the transition from education to employment particularly difficult, employers fail to make reasonable adjustments and discrimination on the grounds of disability remains prevalent. Restrictions on the ability to make decisions add to the lack of choice and control people can exercise over their daily lives. While this research was not designed to provide representative results or a comprehensive picture of the lives of persons with mental health problems or intellectual disabilities across Europe, it informs the debate about human rights by relaying the experiences of people whose voices are seldom heard.

STICKINGS, MARTHA

European Union Agency for Fundamental Rights

WORK OF THE EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS IN THE AREA OF DISABILITY RIGHTS

The European Union Agency for Fundamental Rights (FRA) is mandated to provide evidence-based advice to the EU institutions and EU Member states when they implement EU law. FRA works across the human rights field, including discrimination on the grounds of disability. In December 2011, the Agency was nominated to be part of the EU level monitoring framework required for signatories of the CRPD under Article 33. It will independently collect and analyse relevant data concerning CRPD implementation in areas of EU competence. FRA's work so far in the area of disability covers social and legal comparative research, indicators development and awareness raising activities. As part of its project on the rights of persons with mental health problems and persons with intellectual disabilities, FRA has already published comparative legal reports analysing the right to vote and the protection of persons with mental health problems under non-discrimination law. Further socio-legal reports, which draw on the results of fieldwork research in nine EU Member States, cover the issues of the right to live independently and participate in the community, involuntary placement and treatment, and legal capacity. In 2012, FRA is launching a project focusing on the experiences of children with disabilities in relation to discrimination, inclusion and hate speech. This will include pilot interview-based fieldwork research with children with disabilities. In addition, the Agency is working to mainstream disability across all its projects, and to make all its events and management processes fully accessible. All FRA's work in the field of disability is framed by the CRPD and its underlying principles of equality, participation and inclusion. Taking a participatory approach, FRA works with actors key to the effective implementation of the CRPD, including EU institutions, the Council of Europe, National Human Rights Institutions, Equality Bodies, disabled persons' organisations and other civil society representatives.

STRUCK-PEREGOŃCZYK, MONIKA

University of Information Technology and Management, Poland

THE FACTORS HINDERING AND PROMOTING THE WORK PARTICIPATION OF YOUNG DISABLED PEOPLE IN POLAND: AN EMPIRICAL STUDY.

The paper will discuss the current labour market in Poland and present findings from the study on the reasons for low work participation of young disabled people. Internationally, both youth and disabled people are seen as being at special risk of unemployment. However, general programmes for unemployed people are rarely tailored to the needs of disabled people, as well as programmes for disabled people seldom include the specific needs of the youth. Young disabled people are therefore in a particularly difficult situation – as a body of research suggests, they are more likely to be unemployed, underemployed or employed at a lower wage (Walker 1982, Burchard 2004, Groce 2004). As a result, unemployed youth with disabilities have become and remain a group at risk of social exclusion. This phenomenon can be evidenced in Poland as well. After 1989 and the introduction of market economy, the level of work participation of disabled people dropped drastically. Nowadays, only 35% of young disabled people are economically active – in comparison to 67% of non-disabled people at this age. The study encompasses a survey conducted on the group of young disabled people and in-depth interviews with the representatives of governmental and non-governmental institutions involved in employment policy and education, as well as employers of disabled youth. The study explores some of the factors that promote and hinder the work participation of young disabled people, e.g. the potential of the local labour market, effectiveness of legal regulations and employment policies, qualifications of young disabled people, educational opportunities and vocational training, the attitudes of employers, the role of institutions and family support. As will be argued in the paper, it is crucial for the government to explore and address these issues as current situation may result in further disadvantage and a lack of social cohesion.

SUTHERLAND, ALLAN

A SHORT HISTORY OF HUNCHBACKS

A Short History of Hunchbacks From Shakespeare to Disney, hunchbacks have played a significant role in Western culture. This history is unremittingly negative, yet differs from the kind of stereotyping we normally consider in discussions of the representation of disabled people, for the reason that it is based more on myth than on genuine physical impairment. To the idea of abnormal spinal curvature, (kyphosis), is added the idea of the hump, a grotesque supernatural appurtenance that marks its bearer as an outsider. The hunchback is the archetypical example of the 'twisted mind in a twisted body': dark, distorted, malicious and always male. This paper traces this myth through literature, popular culture and cinema, with key examples including Shakespeare's Richard III, Mr Punch and the various incarnations of Quasimodo in fiction, silent and sound film and Disney animation, plus secondary figures such as the moneylender Quilp, in Dickens's 'The Old Curiosity Shop' and the gunman Wild (Klau Kinski) in Sergio Leone's 'For a Few Dollars More'. The paper also considers whether other representations of disabled people should be considered as being based on false construction rather than stereotype.

SYDENHAM, KATHERINE JANE

University of Michigan

Saikat Chatterjee, Joyojeet Pal

**INFORMATION SHARING ON THE GLOBAL STAGE:
UNCRPD IMPLEMENTATION THROUGH THE LENS OF
REPORTING ON FUNDING**

This paper examines reporting trends by United Nations Convention on the Rights of Persons with Disabilities (UNCRPD/Convention) signatory countries on funding allocations for domestic initiatives to implement the Convention. Six countries' status reports detailing implementation of the Convention are analyzed for references to funding and quotas: Argentina, Australia, El Salvador, Peru, Sweden, and Tunisia. Analysis reveals divergence between the themes for which these countries submit funding information and those that are singled out by UNCRPD reporting guidelines as requiring attention. This paper also shows that the six countries, despite constituting a range of per capita GDP levels, generally report funding allocations on a handful of common themes. Additionally, some articles of the convention receive no mention of funding by these six countries nor are they singled out for attention in the UNCRPD reporting guidelines. Countries show a preference for reporting funding toward education, women's initiatives, childcare, medical care, employment, and a number of other similar topics, rather than on topics related to freedom from torture, freedom from risk, liberty of movement, privacy, and other human rights. This paper uses concepts from organization studies and information science to provide a framework for understanding why these reporting trends may occur in an organization of the Convention's size and mandates. It also aims to elucidate some of the complexities of comparing information from these reporting documents, and provide those in the UNCRPD community of practice a frame of reference with which to engage in analysis of other countries' reports on topics other than funding allocations.

TANAKA, JUNKO

Kawasaki University of Medical Welfare

RETHINKING ARTS ACTIVITIES IN THE MEDICAL WORLD: FROM "ARTS ACTIVITIES FOR THE DISABLED" TO "DISABILITY-INCLUSIVE ARTS"

The purpose of this study is to rethink arts activities in the medical world like occupational therapy (OT), in addition to propose a new perspective in arts activities.

I have made a comparative study on the various artists' attitudes when they suffered from problems or disabilities. The result shows that some more unique attitudes of artists to their problems can be found. We may understand how they are distant from the medical viewpoint.

For example, a British free improvisation guitarist, Derek Bailey refused an operation for his carpal tunnel syndrome for his own original performance pertaining to his disability; an American composer, Robert Ashley utilized his involuntary voices caused by Tourette syndrome for his composition "Automatic Writing"; the Japanese performance troupe, TAIHEN, with various handicapped people, performs with their disabled bodies to accomplish new forms of performance art. They all have mobilized their disabilities as expression for their works. And all these examples show the existence of the gap regarding the view of arts between the art world and medical world.

In contrast, the influential OT definitions in the world reveal that the purpose of present OT is "enabling the people to do something". It means that OT has a tendency to fall into so called "overcoming narrative" which is basically close to meritocracy.

The concept of "disability-inclusive art", which I am proposing, is to conceptualize these artists' activities, which is quite a different idea from the medical way of thinking where disabilities have to be accepted and overcome.

"Disability-inclusive art" is for reconciling those artists' work with today's medical work and is what I would like to point to for further development.

TILLY, LIZ

University of Bristol

MONEY, FRIENDS AND MAKING ENDS MEET; COPING DAY TO DAY WITH POVERTY AND LEARNING DISABILITY

Financial and social exclusion affects the most vulnerable people in our society, including those who have a learning disability. Poverty is often linked with other experiences of social deprivation and crisis, and has a negative impact on mental and physical health. This research project explored the lives of a group of people with a learning disability who do not receive specialist services, with a particular focus on the strategies they used to cope with day to day living, their experiences of poverty, and the support received from their social networks and social capital. The research project also explored issues of identity and labelling and enabled this excluded group to have a voice and raise awareness about what life is like for people with a learning disability who live without support services. The research participants exist on welfare benefits, operate solely on a cash budget and are more vulnerable to loss or theft. Some are not eligible for disability welfare benefits, and other concessions such as travel passes, and they find the concept of budgeting very difficult. They are far more likely to use the alternative credit market and pay interest many times that of a standard personal loan, often contributing to spiralling debt. Some have also been taken advantage of or financially abused by friends, family and neighbours. Many have cash flow crises before their next benefit payment is made, and have to resort to loans from others and using pawn shops and facilities such as Cash Converters. The fieldwork took place from summer 2010 to summer 2012, data was collected from;

- People talking about their friends and networks in focus groups.
- People researching their own lives and experiences, especially about friends and networks and money problems through in-depth interviews to develop life stories.

POSTER

TIMANDER, ANN-CHARLOTT

Lancaster University

**THE RELEVANCE OF A THEORETICAL FRAMEWORK OF
DISABILITY STUDIES TO THE STUDY OF
RECONSTRUCTION OF SELF-IDENTITIES IN MEN AND
WOMEN WITH EXPERIENCE OF SEVERE MENTAL
DISTRESS.**

Title: The relevance of a theoretical framework of disability studies to the study of reconstruction of self-identities in men and women with experience of severe mental distress. One of the aims with this ongoing PhD- project is to study how people with experience of severe mental distress describe the process of self-identity reconstruction in the overall recovery process. How could a theoretical framework of disability studies enhance the understanding of the process of self-identity reconstruction? When studying "mental health" in a disability studies perspective, one would orient the research from the "deviant" individual to processes of social oppression, discrimination and exclusion instead. Or in other words from the study of psychiatry and medical treatment to a focus on the complexity of social restrictions and social oppression that people diagnosed as "mentally ill" actually face in their daily life. In this research project, in-depth interviews have been conducted with men and women with experience of severe mental distress and recovery in Gothenburg, Sweden and Oxford, England, in order to explore how they describe their self-identity reconstruction. 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 self-identity reconstruction. How do ongoing social oppression and discrimination affect the self-identity reconstruction? I would argue that social processes of oppression and discrimination are central when it comes to understand what promotes and what impedes reconstruction of self-identities, in men and women with experience of severe mental distress in the overall recovery process.

TITCHKOSKY, TANYA

University of Toronto, Canada

DISABILITY AND THE POVERTY OF IMAGINATION IN NEO-LIBERAL TIMES

There are various forms of interactions, events and structures that make it seem as though disabled people are not born free and equal in dignity, liberty and security and are, instead, regarded as less-than-human. Rather than exploring how conceptions of disability lead to the precarious status of less-than-human, my paper will ask how conceptions of "human" have managed to enact disability as such a precarious status. Edward Said (1994: 44) suggests that a key task for us today is "...explicitly to universalize the crisis, to give greater human scope to what a particular race or nation suffered, to associate that experience with the sufferings of others." I aim to universalize what the UN has called the "silent crisis" of disability by turning to the question of the "human" in human rights discourse especially as it is located within projects that make claims to include disability as a human rights issue. I will analyze human rights discourse oriented to solving this crisis of disability as a way to understand how an impoverished neo-liberal imagination currently controls the concept of "human." My paper represents a disability studies approach that claims that "disability" is best understood as a complex social scene where interpretations regarding the cultural production of the meaning of the human can be encountered, engaged, and re-thought. I end by suggesting that the recognition of the appearance of disability, as a provocateur of the social imagination, could help pry open the question of human that has unimaginatively excluded so many from its confines. Thus, this paper explores the idea that more imaginative relations to the appearance of disability in everyday life can provide a greater human scope to humanity.

**AT THE INTERSECTION OF DISABILITY AND
POVERTY: EVERYDAY LIFE ON A DISABILITY
PENSION**

This paper reports the findings of two research projects which focused on the complex intersection of poverty and disability. The aim of the research was to gain an in-depth understanding about the everyday lives and experiences of disability pensioners from their own perspective. Qualitative methods were used; individual and focus group interviews with disability pensioners. Participants were a diverse group regarding age, impairment, education, housing and other factors. In this paper I discuss some of the findings from these two studies. The first theme discussed is financial: the inability to maintain a surplus. Linked to low pension levels, low wages, pension claw-back measures, high taxation and cost of living issues, the inability to maintain a surplus was repeatedly cited as a prime difficulty in making ends meet and which had clear implications for future security. The second theme focuses on the survival strategies research participants engaged in, and which illustrates that their ingenuity played a key role in keeping them out of poverty. The third addresses a prominent theme of ethnographic poverty research—the importance of social networks—but also their limits in addressing and preventing poverty. The last theme looks closely at issues of stress, insecurity, depression and mental health issues. The findings reflect that the labour market left to its own devices will not correct the vulnerable positions facing some disabled people. The findings also highlight the creative survival strategies on the part of many research participants, challenging the negative stereotype of disability pensioners as passive victims of political and economic forces. The paper concludes by discussing how an attention to the strategies of disabled people to sustain themselves can offer insights into possible ways in which support programmes, services and policies can be revised to support such action.

VEHMAS, SIMO

University of Jyväskylä

DISABILITY AND DISADVANTAGE: SOME CRITICAL REMARKS ABOUT CRITICAL DISABILITY STUDIES

Critical disability studies (CDS) is a research trend that is based on criticism of the materialist understanding of disability, and that opposes, for example, binary accounts of human diversity. Thus, theoretical accounts that in any way categorise people on the basis of their characteristics are seen ontologically false as well as ethically harmful. I will discuss in my presentation the ethical challenge proposed by CDS, namely: how to engage with bodily diversity in a way that is not reducible to the binary of either sameness or difference? I will argue that while CDS has offered various useful insights for disability studies, it has so far failed to address properly the various external and internal sources of disadvantage. Examining and eradicating disadvantage is an ethical and political challenge that is of uttermost importance for disabled people and disability studies. This challenge includes various issues, such as measuring and prioritizing disadvantage, that simply cannot be managed properly with the theoretical and political tools of deconstructionism. Putting justice into practice requires, among other things, (re)distribution of goods, and this cannot be done without some criteria, and some categories, about people's social circumstances and their individual characteristics.

WALTZ, MITZI

University of Birmingham

VIOLENCE, ABUSE AND THE CATASTROPHIC MODEL OF AUTISM

There is a dark side to campaigns for “autism awareness,” if the true impact of these is to place people on the autism spectrum as objects of fear, distress, and disproportionately high social/financial cost in contrast to uncontested norms. In this presentation, I will provide evidence of ways this has been done through discussing my recent research on charity images of autism, as well as problematic constructions of autism in professional literature and popular media narratives. I will then link these representations to public policy decisions and parent/practitioner discourses that have resulted in abuse and violence towards individuals with autism. This has ranged from acceptance of dangerous “therapies,” drugs and interventions to defense of parents who have murdered their autistic children by media outlets and some parent groups.

WATSON, NICK
University of Glasgow

WHAT'S SO CRITICAL ABOUT CRITICAL DISABILITY STUDIES?

Critical Disability Studies (CDS) in taking a post structuralist/post modernist approach to disability presents a challenge to the predominantly Marxist/materialist line found in more conventional disability studies. Developed to contest the binary approach found in disability studies it has drawn on a variety of different sources as it has attempted to de-stabilise many assumptions about disability. Whilst the various theorists who write in this area have all taken slightly different directions there are a number of key ideas within CDS. First is the importance of embodiment, corporeality and impairment, second is the role of culture, third a denial of categories and finally fourth a recognition of the importance of emotions. CDS has been a useful and interesting development and it has also encouraged a critical review of the category disability and the ways in which binary distinctions suppress the experiences of certain groups of disabled people and deny the diversity of the disability experience. There are however a number of dangers in this approach including its ability to provide an analysis that can examine the links between disablism and capitalism as well as the relationship between disability, misrecognition and maldistribution. It is hard to see how a theory that denies the existence of basic categories can promote the development of communities of resistance. Further CDS has tended to focus on cultural texts rather than 'real' life, and the way it employs the term embodiment is not really embodied in the fleshy sense in terms of the reality of living with an impaired body. Whilst there is much to commend CDS this paper will argue that it cannot be translated into a viable critical theoretical framework that would enable the emancipation of disabled people. The paper will suggest an alternative framework using Nancy Fraser's concept of perspectival dualism, arguing that we need an approach that both recognises diversity and equality but at the same time promotes the redistribution of resources.

WICKENDEN, MARY

Centre for International Health and Development, UCL

ASK US TOO! INITIAL FINDINGS FROM PARTICIPATORY RESEARCH WITH DISABLED CHILDREN IN SOUTH ASIA FOCUSING ON WELLBEING AND LIVELIHOODS.

This paper will present initial findings from a pilot study using participatory methods with disabled children in India and Sri Lanka. In parallel with discourses in Disability Studies about participation, there is currently much discussion in the Childhood Studies arena about the benefits of the meaningful participation of children themselves in research. Previously approximations of children's views were acquired only through proxies such as parents or teachers. Participatory approaches are increasingly being used to explore the lives of children in low income countries and in diverse cultural contexts and situations. So far however disabled children have largely been excluded from these initiatives. This may be because they are often assumed to have nothing to say or because of perceived methodological problems in including them. Thus their voices are generally absent.. This pilot study aims to explore the children's lifeworlds and in particular their perceptions of their present and future wellbeing as well as their suggestions for possible change and improvement in their lives and those of their families. It will focus to some extent on the issues of livelihoods and poverty. The children's data will be contextualized with that from their parents. The study aims to use innovative methods to include children with a wide range of impairments, rather than privileging the voices of those who are easiest to ask. Therefore a discussion about methodological issues may form part of the presentation.

WILDE, ALISON

Bangor University

DISABILITY, DOXA AND THE CULTURAL LIMITS OF SCHOOL INCLUSION

This paper investigates the role of habitus in students' negotiations of 'special needs' identities (on 'school action' plans) within an 'inclusive' secondary school. Focussing on their lived experiences of relationships with peers and teachers, we examine the 'conditions of possibility' for hearing the voice of children attributed with 'SEN' within school cultures and research findings. Using a vignette-based method of fictional scenarios we investigated the value of this method focussing in particular on the ways it helped students to consider disabling processes and relationships within the doxa of school culture and wider social expectations. The data discussed suggests that disabled young people continue to face considerable degrees of exclusion. Despite the overarching principles of inclusion guiding the management of this school, the students' experiences speak of oppressive environments and processes founded upon rigid and exclusionary ideas of academic competency and capabilities. Examining gaps between their performances of identity and opinions on inclusion, questions about their perceptions of their future roles in education and society will be raised.

WILLIAMS, JANE

University of Exeter

Rachel Purtell

MUSIC AND THE SOCIAL MODEL AND OCCUPATIONAL THERAPY: A RESPONSE TO PAUL ABBERLEY

Music and the Social Model: An Occupational Therapist's approach to music with people with learning difficulties "Before you read another word in this book if you have never read Paul Abberley's article : "Disabling Ideology in Health and Welfare- The case of Occupational Therapy"(Abberley P. 1995) I'd strongly advise you to read it now." Occupational Therapy (OT) is often reduced to assessment of functionality and the supply of "daily living aids". The professionalism of the role OTs is defended with the development of standardised tools and ADL (Activities of Daily Living) Labs. Yet the skills and craft of OTs can be used within a Social Model Approach as a useful and powerful tool in barrier reduction when this is the purpose it is put to. In this forthcoming book OT models and the Social Model are used to create a practical and meaningful guide to open up music to those who are traditionally excluded because of the perception of the severity of their impairments. This is not about music as 'therapy' but as a human occupation that should and can be open to everyone. In this session we ask questions about why OT and the Social Model in their respective disciplines are so estranged and how we might bring them back together.

POSTER

WILLIAMS, VAL

Norah Fry Research Centre, University of Bristol

WHO HAS CAPACITY? THE BLURRED EDGES OF ASSESSMENTS OF CAPACITY UNDER THE MENTAL CAPACITY ACT

The Mental Capacity Act (2005) (MCA) in England and Wales lays out the legal basis, both for supporting autonomy and also for protecting the best interests of those who are deemed to lack capacity to make a particular decision. Although it can affect any of us, it impacts particularly on those with known 'impairments of the mind', including those with intellectual disabilities, mental health problems and dementia. This paper draws on a study of best interests decisions by professionals in England, funded by the Department of Health (2010-12). We will explore here the issues reported by professionals in assessing capacity, which is an essential pre-requisite for making a best-interests decision, and therefore has a profound influence on the rights of the person deemed to lack capacity. Data will be presented from the online survey of 385 responses, as well as telephone and in-depth interviews. The findings show that decision makers favoured joint assessments, and were acutely aware of the subjective, fluctuating nature of capacity to make a decision. However, there were many confused areas, including the problem of distinguishing 'unwise decisions' from lack of capacity. The drive to protect the individual from risks frequently took precedence, and led to some circular arguments about lack of capacity. We will discuss these findings in the light of what it means to make a decision, and the collective nature of decision-making for everyone. At best, the MCA can provide a person-centred and balanced approach, ensuring that autonomy sits alongside protection. The paper will conclude with some examples to promote thinking about the tensions underlying the notion of mental capacity: what do the words 'choice and control' mean in this context? How does the policy of personalisation interlock with the legal framework of mental capacity, and what does this mean for the lives of disabled people?

WOODBURY, ESTHER

University of Otago

**INDEPENDENT, PRODUCTIVE MEMBERS OF SOCIETY:
HOW THE RIGHT TO MOBILITY IS UNDERMINED BY
FUNDING MODELS FOR DISABLED DRIVERS.**

Mobility is a basic human need, which provides people with the capability to live lives that they value. People with mobility impairments live in a disabling world, where constraints on mobility affect their activity, well-being, identity and social and economic opportunities. Government programmes that focus on increasing access to mobility for disabled people are politically contested; while disability activists seek to expand access, the global economic crisis has increased the economic pressure on these programmes. This presentation will use New Zealand as a case study to explore the contradictions between a governmental disability strategy which acknowledges the social model of disability and the reality of government funding systems. The 2002 New Zealand Disability Strategy recognises mobility as necessary to meaningful participation for disabled people and its statement on 'quality living in the community' specifically includes 'moving around the community'. However, my recently completed doctoral research on the experiences of disabled drivers in New Zealand highlighted how New Zealand government funding does not support the mobility of all disabled drivers but instead discriminates based on the origin of impairment(s) and on employment status. The research also revealed how disabled people's conceptions of mobility are at odds with the values of government funders. This presentation will examine both the ideological implications of this fracture between stated values and reality, and the effect it has on disabled people's lived experience.

WOODIN, SARAH

University of Leeds

CUTTING PARTICIPATION IN THE UK

User involvement in public services and research has substantially increased in recent decades the UK. The UK government has also signed and ratified the United Nations of the Convention on the Rights of Persons with Disabilities (UNCRPD), which includes Article 29 on 'Participation in Political and Public Life'. With a new strategy document underway, the consultation has given particular prominence to the UNCRPD. However, this presentation will provide examples of the impact of austerity measures affecting local services for people with learning difficulties in many parts of England and Scotland. Opportunities to participate in mainstream political and public life are now being reduced compared with non- disabled people. Fourteen interviews with people with learning difficulties were carried out between March and April 2011, at a time when local authorities were setting budgets for voluntary organisations. Most participants had received support for their participation in local policy bodies and they described how this was jeopardised by withdrawal of funding and the implications of this. At the same time, in wealthier parts of the country and where people with learning difficulties were engaged with more 'mainstream' policy work, there was less discernable impact. Overall, the data highlights the lack of adjustments and safeguards for the participation of people with learning difficulties and the tenuousness of support mechanisms. Continuing inequalities between different parts of the country are also evident. The presentation will illustrate the existence of a clear disjuncture between international, national and local policies and actions.

WOODIN, SARAH

University of Leeds

THE EXPERIENCE OF VIOLENCE BY PEOPLE WITH LEARNING DIFFICULTIES IN THE UK

This paper will reports on the experiences of violence of fourteen people with learning difficulties living in England and Scotland. The data is part of a larger EU qualitative study that investigated the situation of people with learning difficulties and people with mental health conditions with regard to fundamental human rights. Violence was a recurring theme, affecting all participants to varying degrees and at times through their lives. Despite persistent evidence about violence experienced by disabled people, data remains limited overall (Hughes et al. 2012). The problems associated with definitions (Roulstone et al, 2011) and estimating levels of violence and crime have been well documented and there is scope for further research on access to justice. However, participants in this study consistently reported greater levels of violence in certain living situations and circumstances, in particular in institutional living arrangements and where they faced lack of control over assistance and support. Violence in local community settings (experienced by all participants) is also discussed, with some environments presenting greater. Finally the paper offers some ideas about prevention that are suggested by the data on risks and that might be suitable for further investigation.

Hughes, K., Bellis, M., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mickton, C., Shakespeare, T. and Officer, A. (2012) 'Prevalence and Risk of Violence against adults with disabilities: a systematic review and meta-analysis of observational studies', *The Lancet* 28.2.12

Roulstone, A., Thomas, P and Balderstone, S (2011) Between hate and vulnerability: unpacking the British criminal justice system's construction of disablist hate crime, *Disability and Society* Volume 26, Issue 3, 351-364

YTTERHUS, BORGUNN

Norwegian University of Science & Technology

QUALITATIVE LONGITUDINAL FIELDWORK ON EVERYDAY SEGREGATION AMONGST DISABLED CHILDREN IN NORWAY

This presentation will focus on strengths and weaknesses in qualitative longitudinal fieldwork. The presentation focuses on everyday life segregation mechanisms in childhood. Face-to-face encounters among children made us aware of social inclusion and exclusion mechanisms due to informal interaction rules negotiated and practiced by children. Due to a qualitative longitudinal fieldwork during twelve years these rules become identified and developed as changing social structures during childhood. A total of 60 - 100 children were involved at different points of time, 7 - 9 of them were disabled. Children not able to identify the nuances, signs and symbols in these rules become marginalized. Intellectually impaired children struggled to grasp the nuances without translators and support, and their challenges increase with age. Children with mobility difficulties did succeed both due to the rule's developing processes and substance, and their practical problems due to time and space decreased during childhood.

NOTES

