

Disability Studies Conference

Lancaster University

7th-9th September, 2010



Centre for Disability Research
Bowland North
Lancaster University
Lancaster
LA1 4YN
cedr@lancaster.ac.uk

Front cover photograph of 4 Colour Sun Wheel by
Richard Shilling of Lancaster
<http://www.flickr.com/photos/escher1/>

Printed by Colin Cross, Garstang

Welcome

We would like to welcome you to the 5th 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.

This year we called for papers on current research, ideas and developments in disability studies, in particular:

- Political change - global, national and local
- War, conflict and the construction of disability
- Access to health care
- Debates about eugenics and assisted dying
- Independent living, rights and citizenship
- 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.

Hannah Morgan, Bob Sapey and Pam Thomas
CeDR Conference Organisers

Reviewing Committee

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

- Jill Anderson, Mental Health in Higher Education, Lancaster University
- Liz Ellis, Cornwall College
- Professor Eric Emerson, CeDR, Lancaster University
- Professor Dan Goodley, Manchester Metropolitan University
- Dr Chris Grover, CeDR, Lancaster University
- Professor Chris Hatton, CeDR, Lancaster University
- Dr Stephen Hodgkins, Disability LIB
- Dr Patrick Kermit, Sør-Trøndelag University College, NTNU Samfunnsforskning
- Dr Kristjana Kristiansen, Norwegian University of Science and Technology
- Hannah Morgan, CeDR, Lancaster University
- Dr Deborah Phillips, Cornwall College
- Linda Piggott, CeDR, Lancaster University
- Dr Simon Prideaux, Centre for Disability Studies, University of Leeds
- Rachel Purtell Folk.us, Peninsula College of Medicine and Dentistry
- Dr Janet Read, University of Warwick
- Dr Donna Reeve, CeDR, Lancaster University
- Professor Alan Roulstone, De Montfort University
- Bob Sapey, CeDR, Lancaster University
- Professor Carol Thomas, CeDR, Lancaster University
- Dr Pam Thomas, CeDR, Lancaster University
- Professor Nick Watson, Strathclyde Centre for Disability Research, University of Glasgow

Conference Programme

Tuesday 7 September

10:00	Registration
11:00 – 11:30	Introductions and welcome (Tony McEnergy, Dean, Faculty of Arts and Social Science, Lancaster University)
11:30 – 12:30	Plenary – Caroline Gooding (Chair: Carol Thomas)
12:30 – 13.30	LUNCH
13.30 – 15.00	Papers – Session A
15:00 – 15:30	REFRESHMENTS
15:30 – 17:00	Papers – Session B
17.30 – 18.30	Plenary - Liz Crow (Chair: Nick Watson)
18.45 – 19.45	Workshop – Janet Read, Marcus Redley and Sara Ryan
20:00	DINNER

Wednesday 8 September

09:30 – 10:30	Plenary – Ruth Gould (Chair Len Barton)
10:30 – 11:00	REFRESHMENTS
11:00 – 12:30	Papers – Session C
12:30 – 13:30	LUNCH
13:30 – 14.30	Plenary – Adolf Ratzka (Chair: Pam Thomas)
14.45 – 15.45	Papers – Session D
15.45 – 16.15	REFRESHMENTS
16.15 – 17.45	Papers – Session E
18:00 – 19:30	Posters and wine
20:00	DINNER

Thursday 9 September

09:30 – 11:00	Papers – Session F
11:00 – 11:30	REFRESHMENTS
11:30 – 12:30	Plenary – Alana Officer (Chair: Eric Emerson)
12:30 – 13:00	Ending
13:00	PACKED LUNCH

Abstracts of Papers and Posters

Lancaster University

Disability Studies Conference

7th-9th September, 2010

Kobla Agbota

Akershus University College

Influencing governmental policies and societal attitudes: The case of organizations for people with disabilities in Ghana

Influencing governmental and societal attitudes are important activities undertaken by interest organizations. This paper is about how disabled people's organizations empower their members to fight for their interests. It highlights the strategies disabled people's organizations employ to influence governmental policies and societal attitudes. The main questions to answer are: How are organizations of people with disabilities involved in policy formulation in Ghana? What challenges do they face? What strategies do they employ in influencing policies? How do they empower their members? The paper aims at providing knowledge about disabled people and their organizations in Ghana. It is also to create awareness on the needs of disabled people among policy makers and administrators. The data for this research was collected in Ghana using unstructured qualitative interviews. Four leaders representing the following organizations were interviewed; Action on Disability and Development Parent's Association for Children with Intellectual disabilities Ghana Society for the Physically Disabled & Agbelengor NGO. An interview guide was used and each interview varied between 1-1.5 hours. Tape recording was combined with taking of notes. Informed consent was acquired from informants before the interviews were granted. The data revealed the following challenges and strategies. The challenges include: Not being listened to, lack of resources, diverse disability groups, low literacy level, cultural stereotypes, organizational structure, bureaucratic and leadership problems. The strategies adopted include: capacity building, advocacy, lobbying, dialogue, networking, education and research and use of media. The concepts of power, civil society, politics and policy formulation, and relevant organizational theories will be used in discussing the main findings. Disabled people in Ghana face many challenges especially when it comes to meeting of their felt needs. They develop strategies to overcome these challenges. Whether these strategies work or not are dependent on many factors including political climate.

Embla Ágústsdóttir

Centre for Disability Studies, University of Iceland

Sexing Up Disability

This paper is primarily a non-academic personal reflection on the sexuality of disabled people, but touches on both gender and disability studies. Being disabled is in many people's mind an 'asexual' state of affairs, and the asexuality and the lack of the being regarded as a sexual being is one of the challenges facing disabled people. Traditional approaches to disability believe it is inappropriate for disabled people to have sexual desires and express their sexuality through fashion, attitudes and behaviour in the same way non-disabled people commonly do. This is the case both for people with learning difficulties who are seen as eternal children who should not have sexual desires and people with physical impairments who 'disfigure' the image of the 'sexual' rendering the association of 'sexuality' and 'disability' inappropriate. This makes the discourse on sexuality and disability awkward but this 'awkwardness' is socially constructed. From a personal perspective both my sexuality and my impairment are 'natural' facts and to experience tension or awkwardness between these two aspects of my life creates difficulties in negotiating my gender and disability identity in everyday life. Gender identity is a social construct and 'disabled identity' is equally much a social construct. This puts a disabled person in a difficult dilemma: How can an 'asexual being' have a proper gender identity? Based on my personal experience as a young disabled lesbian, I will share how I experience and negotiate society's reflection. I will also reflect on how these two communities, disability and gay community, take part in the construction and re-construction of the prejudice I face in everyday life and how I often must take on the role of the outsider or outcast in both communities.

Jo Aldridge

Loughborough University

The Participation of Adults with Learning Disabilities in Photographic Research

This paper explores the efficacy of using photographic participatory research methods among vulnerable groups, specifically adults with learning disabilities. Innovative methods, such as visual participatory techniques can help promote the inclusion of adults with learning disabilities who might otherwise be left out of research studies. The reason for their omission from such studies lies often in their marginalisation; as research participants they can be hard to reach and often do not have the necessary verbal skills and confidence to take part in conventional qualitative methods that use, for example, interview techniques. Drawing on photographic research evidence from therapeutic horticultural studies, this paper explores ethical considerations relating to the participation of people with learning disabilities in research and considers the ways in which the genuine participation of adults with learning disabilities in research can help to transform perceptions of vulnerability.

Larry Arnold

University of Birmingham

"Fully human, fully here." The impact of medical research paradigms on the conceptualisation of autism and intellectual impairment

The academic world seems not to have come very far since CP Snow's well known Rede lecture. Far from reconciling the two worlds of the arts and sciences, the fragmentation has continued so that there is now as big a gulf between the social sciences and the natural sciences. This is particularly prevalent when one juxtaposes the fields of disability studies and medical research, it seems fated that the twain shall ne'er meet, at a time when medical research is having a profound impact on both the life chances of and the popular conception of 'disability'

My argument is that the ethical procedures and strictures of medical research are insufficient to deal with the impact of that research on those being studied. My particular interest group being in intellectual and cognitive non typicality.

Coming from the social perspective I intend to demonstrate how the scientific models in themselves have the unintended effect of depersonalising the research subject with inevitable implications for the ethics of research not just in terms of how volunteers are considered but by reference to the outcomes of the research itself. I ask the question do the ethical procedures need to take more account of the social and political aspects of self advocacy.

This is an offshoot of my own research which is grounded in the educational and sociological aspects of autism, in the traditions of 'action research' and espouses the emancipatory paradigm. My aim being to highlight the often unconsidered ethical dilemmas inherent in the way which the scientific gaze has constructed the notion of what it is to be human in terms of intellectual and cognitive impairment with particular reference to autism.

I examine the historical basis on which the philosophies of mind have informed notions of essential humanity, and consent, with particular reference to I would term the hidden agenda of eugenics underlying notions of 'cure' and 'prevention'.

I theorize in particular that the construction of theory of mind deficits, insecure concepts of self, and speculations as to the nature of consciousness have an impact upon the way in which autistic and intellectually impaired subjects are conceptualised, described and related to within the research community, with the inevitable impact this has on media representation of the research.

Eiriksina Asgrimsdottir

Centre for Disability Studies, University of Iceland

Co-author: Kristín Björnsdóttir

"Are you a retard?" Disability, discourse, and non-disabled teenagers

Self advocates across the Atlantic have argued for a more valued term to describe the disability label previously named or termed mental retardation. Academics, professionals, policy makers, and carers have responded to this call and taken up the terms learning difficulties and intellectual disability. Larger society and especially popular culture are left behind and stuck in negative and old fashioned discourse where the term retard is commonly used both to describe people with and without learning difficulties. For example, the musical group Black Eyed Peas released the single Let's Get Restarted in 2004 and the demeaning term retarded was also frequently used in Ben Stiller's movie Tropic Thunder from 2008. Popular culture in Iceland is no exception from this and terms such as retard and cripple have been used in numerous TV programs and movies and representation of disability based on stereotypes and derogatory images.

This paper reports the findings of an on-going qualitative study, which explores how disability is presented in oral narratives (urban legends). In this paper we will focus on contemporary legends, which non-disabled teenagers share with each other about disability and impairment. Data was collected through focus group interviews with small groups of 13 – 15 year old students from eight Icelandic lower secondary schools. We analysed the discourse in these oral narratives in order to learn and understand how these legends are passed from one teenager to another and where these ideas originate from. The findings suggest that the stories that Icelandic teenagers share with each other are most of the time untrue fabrications, negative, and often unbelievable or even mythical. Furthermore the research findings suggest that the teenagers are highly influenced by popular culture and often use disabling and hurtful phrases like retard and cripple in their daily discourse. We argue that these research findings suggest that limited discussion about disability takes place within the Icelandic education system and the teenagers rely on popular media for information and education about disability and impairment. In the paper we reflect on these oral narratives and the interactions of culture and disability in Icelandic society.

Ruth Bailey

Access to healthcare. Clinical access

The concept of access barriers has been a key political and analytical tool used both by disability activists and scholars to deconstruct the apparent neutrality of the built environment and the social practices that occur within them (Freund, 2001). In keeping with this, my paper will explore clinical access barriers, those barriers which occur in healthcare settings. The focus will be upon what happens during an access encounter: how a barrier emerges from the relation between the embodied self and a medicalised space and how it is mediated through interaction between the disabled person and healthcare professional. All this has embodied consequences.

The substance of the paper will be two case studies. The first will be based on auto-ethnographic writings, a method chosen because it begins to capture the embodied, phenomenological detail of an access encounter which I will argue are essential to understanding access. The second is drawn from qualitative interview data collected during my PhD study of disabled people's health care encounters. A key feature of both cases is uncertainty. The disabled person doesn't know what the procedure will entail, making it extremely difficult to handle access, to ensure the embodied self's well being. The healthcare professional doesn't know how the impaired body will respond to the bodily demands of the procedure. The irony here is that even in healthcare settings, the impaired body is out of place, while biomedicine defines the impaired body as abnormal, in the process of clinical procedures it treats it as normal until proven otherwise.

The barriers which emerge in clinical setting are what can be termed micro barriers, which are context specific, including the way a particular person embodies and enacts impairment. As such, they require bespoke solutions. Hence, in order to meet its responsibility under the DDA, the NHS needs to ensure its staff has the appropriate training, resources and support to enable them to respond appropriately during any and every access encounter.

The paper will conclude by considering how the mode of analysis it uses fits with existing approaches to theorising access. By showing that some barriers are contingent upon space, embodied impairment and interaction, it quite literally fleshes out Oliver's (1990) somewhat abstract and disembodied argument that access barriers are created by the capitalist mode of production. It also challenges the idea that access barriers are just "out there", divorced from the 'attitudes and emotions we [i.e. disabled people] hold inside ourselves about our experiences of discrimination' (Finkelstein, 1996:2).

Susie Balderston

CeDR, Lancaster University

Victimised again: Systemic inequality faced by women who experience disablist hate crime and the value of Survivor interventions

This paper demonstrates how the human right to live in safety is particularly eroded, for victims of disablist hate crime. This is based on user-led research (428 respondents and participants) which illuminates barriers and stark inequalities of outcome from criminal justice and victim support systems, particularly for disabled women. The paper outlines how a further , user-led pilot in 2009 delivered a cost-effective peer advocacy approach, tackling the cultural incompetency and inaccessibility of services for excluded hate crime victims.

Comparative disaggregation demonstrates that reporting and conviction rates in disablist hate crime may be up to ten times lower than even those of racially motivated incidents. Investment in support from the Victims Fund, for victims of hate crime, averages less than two pounds per victim per year (despite the assertion of increased harm after hate crime (Iganski, 1998)). Resources are largely focused on ineffectual counselling (Rose, Brewin, Andrews and Kirk, 1999) unsuccessful empowerment (Riger, 1993), and problematic target hardening (Hope, 2008). These standard methods of victim support often fail to address the diverse needs or structural inequalities faced in hate crime work.

Feminist criminologists from the USA, however, provide evidence that co-operative approaches can be effective interventions (Chesney-Lind, 2006, p7). This paper illustrates how an EHRC funded pilot in the North East of England in 2009, successfully applied peer advocacy group methods, where intersectional approaches were employed to resist victimhood and assist service redesign. This pilot may be beneficial researchers evaluating the impact of services and policy makers planning cost-effective public services.

Phil Bayliss

University of Exeter

It's always cold in Mongolia: cultural challenges to concepts of disability

'So how does it being -36o Celsius affect you as a person with physical impairments'? Monktemuhlen thought a while and shrugged her shoulders: "It's always cold in Mongolia".

My conversation with Monktemuhlen started from exploring barriers that Mongolian environments and society created for a person with a physical impairment.

Every barrier I proposed (based on my western understanding): physical access, barriers to employment, the cold, lack of roads or suburban infrastructures of the Ger district of Ulan Bator, the levels of poverty taken from western bench marks... all of these received a shrug, a smile. 'It's not how I think of it', she said.

Is normalcy in 'the eye of the beholder'? Foucault (1970) challenges us to 'how could we think that'? The experiences of Mongolia challenge the 'taken-for-granted' nature of concepts of disability and normalcy. The paper explores Monktemuhlen's concept of 'disability' as a spiral, where she (her identity, her physical presence) is co-constituted through complex interactions between her phenomenological lived self, her social body and the given/constructed physical/social world. Such an understanding does not lend itself to a western understanding of 'disability' as a quantitative, Gaussian linear model of 'normal' (and its contradiction: abnormal). Instead, a non-linear, qualitative, context-bound and culturally dependent understanding of disability as a concept emerges.

The paper presents Monktemuhlen's story and raises questions both for the conceptualisation of disability and the process of change for people with impairments in non-western settings.

Ana Bê Pereira

CeDR, Lancaster University

(De)-Constructing the Ideal Neoliberal Subject – Thoughts from a Framework of Feminist Disability Studies

Anchored in a joint framework of disability studies and feminism, or what Rosemary Garland-Thomson has termed “feminist disability studies”, this paper aims to explore and uncover how the “ideal” neoliberal subject is, more often than not, constructed as desirably able, healthy, functional and autonomous. This paper also aims to contribute to an understanding of the role of the “normative” body in neoliberal discourses and practices. As I will argue, it is important to question and undo the ways in which the notion of ability is often taken for granted in neoliberal discourses about the body and the way bodies are more often than not thought of as being inherently able and capable.

In the first part of this paper I will situate this debate both within disability studies and feminist critiques of neoliberalism. Both traditions have developed insightful and essential critiques of neoliberalism that are important towards an understanding of the role of the neoliberal subject. In this context, I will argue that a joint framework of analysis, based on both disability studies and feminism, is arguably the most adequate and fertile ground to address some of the key issues brought forth by neoliberal practices. As I will try to argue, this joint framework allows access to a view angle that is not always present when using only one of the aforementioned perspectives. On the final part of this paper I shall, therefore, focus specifically on exploring how a framework of feminist disability studies can contribute to uncovering and exploring powerful critiques of normative corporality and the construction of the ideal neoliberal subject.

As disabled feminists and feminists aligned with disability studies have time and again demonstrated, there are many areas of common interest where disability studies and feminism can be successfully used together and contribute to a mutual enrichment. Likewise, by using both perspectives in this paper to explore the construction of the idealized neoliberal subject, I hope to be able to demonstrate how our analysis of this theme can be expanded and how both disability studies and feminism can be mutually enriched by each other’s contributions on this matter.

Angharad Beckett

Centre for Disability Studies, University of Leeds

Challenging disabling attitudes and fostering an inclusive society: the role of the primary school

Inclusive Education is increasingly seen as being about more than 'mainstreaming' alone. It is also about ensuring that schools become truly 'inclusive' environments with associated values and ethos. Addressing disabling attitudes is an important part of building inclusive school communities that are supportive of disabled young people. Arguably, efforts need to go beyond this, however, to promote positive attitudes towards all disabled people, i.e. disabled people beyond the school gates. Schools have a role to play in fostering an inclusive and enabling society.

This paper outlines the findings of an ESRC-funded project that explored disability equality in English primary schools. In particular, the study examined a) whether there is evidence that non-disabled primary-age children express disabling attitudes and b) what, if anything, English primary schools are currently doing to promote positive attitudes towards disabled people. Findings emerging from focus group discussions with non-disabled children aged 6/7 years and 10/11 years indicate that misunderstandings about disabled people abound within the primary age-group and that 'subtle prejudice' towards, or 'negative stereotyping' of disabled people is evident within some of their attitudes. Findings emerging from a survey of English primary schools and in-depth interviews with teachers indicate that progress with regard to encouraging schools to promote positive attitudes towards disabled people has been slow and 'patchy', with more than half of the schools who responded to our survey admitting that they 'could do more'.

This paper will explore the implications of these findings and outline recommendations for future policy and practice.

Dawn Benson

Northumbria University

Let's be honest: as it is the current education system is not inclusive

In 1967 Stanley Segal wrote the book 'No Child Is Ineducable' he then sent a copy to every Member of Parliament and began his campaign to influence legislation to ensure that all children received an education. Previously, those children who had learning and communication difficulties were deemed to be 'educationally subnormal' and were the responsibility of the Department of Health. That is until Segal and others influenced a change in the legislation and the new (1970) Education Act made them the responsibility of the then Department of Education and Science. Shortly after the conservative government called upon Mary Warnock to determine "...the purpose of education

...how can one justify spending very large sums of money on those who by ordinary standards will never benefit from it, and certainly never repay the money spent by contributing to society but will continue to need support all their lives" (Warnock, 1998:14).

Barton (2005) argues that Warnock (2005) is confusing the categorisation of disabled children as having 'special educational needs' with the meaning of inclusion. Defining educational inclusion is a complicated business which is often creatively avoided by many of those who write about inclusion and inclusive practice. This is not especially helpful to students, parent/guardians or practitioners who are confused about what inclusion and inclusive practice actually is.

This paper presentation will argue that when we talk about 'inclusion' in terms of education for disabled children what we are actually talking about is inclusion in the education system and not equal rights to education. It will consider the current system that disabled children are being integrated into in the name of 'inclusion' and suggest that nothing short of a complete re-structuring of that system will enable inclusion.

Peter Beresford

Brunel University and Shaping Our Lives

Co-authors: Mary Nettle and Rebecca Perring

Towards A Social Model of Madness And Distress: Findings and next steps

Theoretical and methodological ideas and debates/Independent living, rights and citizenship

At the last Disability Studies Conference in 2008, we reported some first findings from this national project which has been exploring the idea of a social model of madness and distress building on the social model of disability. The aim of the discussion was to help inform the project's development. The project report (with forewords by Mike Oliver and Tina Coldham) is shortly to be published by the Joseph Rowntree Foundation.

The findings highlight the serious concerns that mental health service users/survivors have about what they see as the continuing dominance of the medical model in mental health policy, practice and thinking. This is seen as having mainly negative effects on mental health service users/survivors, public understanding and responses to mental health problems. Yet while there is support for social approaches to understanding mental health issues, there are serious reservations about adopting a similar approach to the social model of disability.

The aim of this session is twofold.

First to share with participants the complex, sometimes contradictory findings that emerged from talking in this project to mental health service users/survivors, disabled people and people who identified with both experiences.

Second, the Joseph Rowntree Foundation has expressed a preparedness to support some additional work to follow up these findings. This session would be an opportunity to open up discussion with a wider range of people, researchers and non-researchers, survivors and non-survivors, what would be helpful next steps in seeking to take forward these findings to make broader change and to influence policy and practice. What would be helpful next steps. How can we share these findings and move on from them? The aim is to offer a safe setting for such discussion, where all perspectives will be valued and respected and where international as well as national experience will be welcomed.

Aleksandra Berg

Centre for Social Studies, University of Coimbra

Co-authors: Fernando Fontes; Bruno Sena-Martins; Pedro Hespanha

Doing Emancipatory Disability Research in Portugal: theoretical and methodological challenges

Despite the sociological interest in social inequality, the issue of disability tends to be systematically overlooked. In the UK, this tendency is being transformed by the development of a new field of studies within the Social Sciences – Disability Studies. The connections between Disability Studies and disability activism have resulted in the creation of what is commonly referred to as Emancipatory Disability Research. Drawing on the social model of disability, Emancipatory Disability Research remains accountable to disabled people and aims at challenging the social exclusion faced by disabled people. In Portugal, disability research within the academia has been restricted to the fields of psychology, medicine and education. This is related to what Robert Murphy (1990) describes as the “the body silent”, i.e., the social invisibility ascribed to disabled people in western societies. In addition, the lack of politicization of disability and the frailty of the Portuguese Disabled People’s Movement has rendered Emancipatory Disability Research invisible.

This paper draws on an ongoing research project – “From spinal cord injury to social inclusion: disability as a personal and socio-political challenge” – based at the Centre for Social Studies, University of Coimbra, Portugal, and funded by the Portuguese Foundation for Science and Technology. This study aims at articulating the empirical analysis of the life course of people with spinal cord injury with the political and theoretical insights developed through the social model of disability elsewhere. Therefore, the project intends to contribute to a cultural and socio-political questioning of the field of disability, as a way to denounce the dominance of a medical rehabilitation approach in the lives of people with spinal cord injury.

It is our purpose with this paper to offer an analysis of the theoretical and methodological challenges associated with doing Emancipatory Disability Research in the Portuguese context. As we will argue, a first challenge stems from valuing the social model’s political outcomes in a context in which they remain largely unknown, not only by public institutions and authorities, but also by disabled people. In fact, the reality of Portuguese disabled people continues to be framed by individual, rehabilitation and medical approaches, which in conjunction with other factors, might hinder the development of an Emancipatory Disability Research.

Maria Berghs

University of Leeds

Post-Conflict State and Identity Formation: Becoming disabled in Sierra Leone

In this paper, I use a social model of disability (Finkelstein 1980, 1981, Oliver 1990, 1996, Barnes 1991) as well as gender analysis (De Beauvoir 1949, Butler 1990), to access the experiences of disablement facing the ‘amputee and war-wounded’ community in post-conflict Sierra Leone. The communal identity of this group of people, was born out of common experiences during the conflict (violent biographical disruption (Bury 1982) – giving them a different moral and gendered identity from other disabled people), shared experiences of disablement in special ‘segregated’ camps, (bio) medical intervention and state control, as well as participation as a group of ‘victims’ in the rebuilding, healing and rehabilitation of the nation state.

There were three main political moments in the reconstruction and healing of the country post conflict; 1) the Sierra Leonean Truth and Reconciliation Commission (TRC), 2) the Disarmament, Demobilization and Reintegration (DDR) of ex-combatants, and 3) the Special Court for Sierra Leone (SC), and the community participated in all three of these moments. Despite the fact that the community played a crucial role in the formation of the Sierra Leonean state (identity), they were not seen as ‘development’ partners but disabled, dependent, and ‘victims’ through their participation in such political movements.

Yet, post-conflict rebuilding and healing of the nation state also brings with it new opportunities and understandings of what it means to be disabled and these can also be empowering. Intergovernmental agencies and NGOs are linked to neo-liberal ideas and transnational networks that bring with them discourses of rights and responsibilities, which have led to an increased awareness of disability rights and political activism of disabled people and DPOs in Sierra Leone. However, important gender differences linked to gaining a disabled identity during and after a conflict remain and these can be both mitigated and sustained by NGO policies and DPO actions.

John Bertelsen

Resource Centre for Special Needs Education, Denmark

Solidaric Learning Relations - education as psycho-social rehabilitation

A new and different educational regime supports Saxenhöjs educational programme, focusing on solidaric learning relations and education in a perspective of psycho-social rehabilitation.

User-led-education as an option for people with severe and complex impairment, including severe learning difficulties - is an ongoing project at the Social Enterprise Saxenhøj. It has been developed in cooperation with the Resource Centre for Special Needs Education since 2005.

the foundation of this presentation is an analysis of 150 individual education programmes which have been carried out in our own workshops and in joint ventures with external enterprises. The number of participants at any given time is about 30. The dominant forms of practice at Saxenhøj at the beginning of the project was social psychiatry and social pedagogy. These forms are supporting factors in vital areas of life. But they are also characterized by the absence of theories of learning and lack certain traditions of education. We have included contributions from discourse of special pedagogy, thereby establishing a third uniting factor in the relations of learning. The purpose here is to focus on these relations of learning, that is to say, on the content of the relations between counsellor and user. The goal of this focus is to develop processes of learning and achieve education based on user terms.

The headlines of this presentation:

1. An understanding of learning that removes the focus from simple solutions of problems, ore one-dimensional trouble-shooting, to a reflexive learning model
2. Cooperation and interdependency as social foundations for the process of learning
3. Developing a common goal, interaction, dialogue and communication
4. " When care went working" , a common but asymmetrical relation
5. learning is supported by expanded learning activity and 'scaffolding'
6. The contribution and problems of the pedagogic profession, and the joint contributions of the user to relations of learning and education

Dikmen Bezmez

Koc University, Istanbul

Institutionalized Responses to Demands for Urban Citizenship? The Emergence and Development of ISÖMs (Centres for People with Disabilities of Istanbul)

Starting with the late 1990s, “urban citizenship” emerged as a significant concept within debates on the changing forms of citizenship as a consequence of multiple processes of globalization. The general argument was that in tandem with the increasing role that globalizing cities were attaining as the nodal point of global networks, different groups were claiming their rights to the city in the form of new urban social movements. These struggles were shattering existing understandings of citizenship and paving the way for new conceptions of citizenship rights at the urban scale. A further argument was that consequently one could see the rise of various institutional arrangements at the local level, which were meant to respond to these right-claims. For instance, the establishment of various women’s departments under the roof of some local governments could exemplify such transitions. This study aims to analyze the “Centre for People with Disabilities of Istanbul” (İSÖM), established in 2008 and grown to a number of 19 branches all over the city in the following two years, within a similar framework. In other words, it asks questions such as: Does the emergence and rapid growth of İSÖMs represent the institutional aspect of urban citizenship processes in Istanbul? More specifically, what are the underlying mechanisms and power dynamics that have led to the rise of these centres? What are the kinds of services delivered to Istanbulites with disabilities through such centres? Which processes lead to the provision of these services? Who are the key decision makers? among others. The argument is that at a superficial look, İSÖMs could be perceived as institutions that reflect practices of urban citizenship that are quite similar to the their counterparts in the literature. This is especially so, when considering their time of emergence, the scale at which they function and the way they are meant to appeal to a specific group, which was excluded from conventional citizenship practices in the past. However a more in-depth study reveals that the services provided under the roof of İSÖMs are far from promoting Istanbulites with disabilities’ rights to their city as urban citizens. In contrast, the way İSÖMs are constructed and the kinds of services they deliver seem to work to reinforce clientelistic relationships, patterns of dependency and protectionism between people with disabilities and the public sector actors. Institutional, historical and cultural specificities of the Turkish context both at the local and national levels are analyzed to explain the presence of such practices in Istanbul.

Gottfried Biewer

University of Vienna

Co-authors: Helga Fasching, Oliver Koenig

Participation of Persons with Intellectual Disabilities in Education, Working Life and Research

A research project at the Department of Education and Human Development at the University of Vienna, (financed by the Austrian Science Fund FWF; stand-alone-project number P20021; duration: 1.2.2008 – 31.1.2013, short description: <http://www.fwf.ac.at/en/abstracts/abstract.asp?L=E&PROJ=P20021>), tries to analyze the experiences of participation of persons with an intellectual disability in vocational life and in the transition phase from school to working life.

The main questions underlying this research project are:

How do people with an intellectual disability perceive collected and neglected participation experiences in the phase of transition “School – Career” and in the phase “Working life”?

Is there a connection between the experience of participation and the perception of an individual and self determined design of life?

Which conclusions can be derived for the design of offers for the phase of transition “School – Career” and the area of life “Work” for people with an intellectual disability, which are orientated on the principles of self determination and participation?

The research project at hand is to be classified as an explorative qualitative basic research including a quantitative part and it is conceived as a long term study. It connects a participatory approach with a phenomenological sensitivity for the particular relevant self and world view of the analyzed people. This methodology corresponds with the social model of disability, which is represented by the Disability Studies, and the basic principles of participatory research. By the inclusion of persons with intellectual disabilities into the process of interpretation and validation of qualitative data by a reference group, the project contributes to the development of methodology in the area of participatory research.

Besides a first nationwide collection of structural data from the phase of transition from school to working life and of the labour market for persons with an intellectual disability, the investigation aims on a reconstruction of the perspective of the target group. The conference paper gives an overview of the main project outline and presents first intermediate results.

Kristín Björnsdóttir

Center for Disability Studies, University of Iceland

Co-author: Steindór Jónsson

A collaborative reflection on social justice and democracy

The deinstitutionalization of people with learning difficulties, particularly in the Nordic countries, has shaped disability policy and practices for the past 30 years. People labelled as having learning difficulties who were born in that period belong to the so-called integration generation and are the first generation in the Nordic countries that have been granted a formal right to participate in society. However, despite improved practices and disability policy in Iceland, young adults with learning difficulties lack access to social institutions and participation in areas such as politics, education, employment, religion, sports, and social networking. In this paper we will discuss the gap between formal rights and lived experiences of young Icelandic adults with learning difficulties and we draw on an inclusive qualitative research that examined how young adults perceived their social participation and how different social and cultural factors such as gender, identity and disability interacted with their social and community experience. Life histories were collaboratively constructed over a period of three years (2004-2006) with three young men and three young women who belong to the integration generation. The findings show that the social participation of the participants was often within segregated activities organized for people with learning difficulties, such as Special Olympics, segregated continuing education classes, leisure and social clubs. Furthermore, the support and services they received seemed to have many institutional qualities and they generally occupied a subordinate position in Icelandic society. The research findings indicate that negative and discriminatory social attitudes are critical barriers to social inclusion and participants' accounts revealed that they often experienced patronizing practices by professionals and carers, and generally lacked access to adult roles. In this paper we reflect on what kind of social participation is relevant for being a full member of a democracy and how people labelled with intellectual disabilities are denied the opportunity to participate in the society as democratic citizens. A non-disabled researcher and a research participant with learning difficulties collaboratively wrote this paper.

Kathy Boxall

University of Sheffield

Involving people with profound and multiple learning difficulties in research: barriers and possibilities

People with ‘profound and multiple learning difficulties’ (PMLD) have profound intellectual impairments and communication difficulties; they may also have physical or sensory impairments, mental health difficulties, or behaviours which challenge. Although a number of recent studies have involved people with mild and moderate learning difficulties in research, few studies have sought to involve people with profound and multiple learning difficulties, either as co-researchers or as respondents; this reflects a wider pattern of social exclusion in the lives of people with PMLD.

In qualitative research more generally, a range of innovative multi-media approaches have been developed to engage participants in research, explore data and present findings. These methods provide ways of involving research participants, which are potentially more accessible to people with PMLD than traditional talk- or text-based approaches. However, recent developments in research governance and ethical review in the UK, coupled with the increased complexity of ethical approval processes for people deemed to ‘lack capacity’ to consent, may be discouraging researchers from working in this area. Mental Capacity Act (MCA) guidance for social science researchers published on the Department of Health website acknowledges that this could be ‘an unintended and unwelcome consequence of the MCA’. The same guidance also suggests that responses submitted on behalf of people ‘without capacity’ should be ‘excluded’ from any general surveys which do not have MCA approval.

This paper will explore attitudinal, practical and ethical barriers to the involvement of people with PMLD in research, and ways of overcoming such barriers. It will suggest that social model analysis offers useful pointers for the development of inclusive methodological approaches. Such approaches however raise questions about the nature of people with PMLD’s participation or involvement in research and the validity of their responses. The paper will conclude by arguing that unless disability studies researchers strive to develop inclusive methodologies, the perspectives of people with PMLD will continue to be ‘missing’, since the pathologising methodologies of dominant individual/medical model approaches serve frequently to undermine even the possibility of such perspectives.

Toby Brandon

Northumbria University

Co-authors: Lawnmowers Theatre Company

Civil Courage as a Response to Disablist Hate Crime

For the last five years there has been a significant increase in the evidence for hate crime in relation to disability. However exactly what actions to take on this evidence is still unclear. This paper begins by exploring, with particular reference to people with learning difficulties, disablist hate crime compared to racist and homophobic hate crime and why 'disability' hate crime has now been renamed 'disablist' hate crime. The legal and policy framework, prevalence and practice developments around disablist hate crime are also briefly examined.

Experiencing hate crime is unique in the sense it is both devaluing to the person themselves and also to the group to which they belong. However the social construction of disablist hate crime is complex and confused. The normative perception of 'learning difficulties' being often synonymous with 'vulnerability' and the use of 'bullying', 'easy target' and 'abuse' as opposed to 'hate', 'assault' and 'hostility' is marked.

Civil courage is concerned with standing up or speaking out for others within society, this may take the form of whistle blowing on a service or intervening in a threatening situation in the street. It is more than straight forward pro-social helping behaviour, as it can involve anticipated negative social consequences as a result of defending someone who is experiencing hate crime.

The main practical focus of the paper is The Lawnmowers Theatre Company which is run by a group of people with learning difficulties based in Gateshead. Their work includes researching and performing shows around civil courage as a challenge to disablist hate crime. This paper will therefore draw upon the groups firsthand accounts of hate crime as well as their responsive theatre work.

In conclusion, the issues surrounding the structure of support and potential training of people with learning difficulties and their supporters to aid others through the use of civil courage will be examined. This is perceived as adding to the need for raising community wide awareness on the existence and elimination of disablist hate crime.

Stephanie Brewster

University of Wolverhampton

Everyday Interaction Involving People with Severe Learning Disabilities: Taking a Critical Approach.

Provision of alternative and augmentative communication (AAC) systems, such as communication aids and symbol books is designed to meet the communication needs of people with multiple disabilities and little or no speech. However, individuals' non-use of their AAC systems is a widespread problem and usually conceived of as located within the behaviour of the individuals within the interaction. This paper presents research which attempted to develop a new conceptualization of the problem of non use of AAC amongst adults with severe learning disabilities.

While existing research into the problem of AAC non-use has sought the views of AAC practitioners and users, by definition we are unable to access the views of people who do not currently have an effective system of communication. This research attempted to address this deficit by taking an ethnographic approach. Data was collected in small residential homes for adults with severe learning disabilities, and consisted of observations and videos of everyday interaction between residents and their paid carers, supplemented by unstructured interviews with staff. Some of the methodological and ethical dilemmas, such as the extent to which informed consent could be obtained within research involving people with severely impaired communication will be discussed.

The theoretical framework of Critical Discourse Analysis (Fairclough, 2001) was applied to the empirical data. Examples of natural interaction between two particular residents and their care staff illustrate the themes of turn taking, topic control and politeness. From a critically informed perspective, this data is set in the wider context of the care home (institution) and of society as a whole, drawing on the work of, amongst others, Shakespeare (2000).

What emerged from the research was a conceptualisation of interactions between residents and staff being characterised by asymmetries of two kinds, namely power relations and individual communicative competence. The theme of power is inherent in the critical approach taken and is based on the work of scholars such as Bourdieu; evidence of unequal power distribution was found in the interactions between staff and residents. AAC intervention typically aims to enhance communicative competence of the impaired person but this is not necessarily effective at reducing asymmetry of power relations. It is suggested that asymmetrical power relations inhibit AAC use and, conversely, lack of AAC use creates and maintains this power imbalance. The research demonstrates how a more political perspective can enhance our understanding of what is often rather narrowly seen as a clinical problem.

Wendy Brown

University Of Strathclyde

Poster

Micro-Meso-Macro impacts on social mobility for people with learning disabilities

Although people who experience learning disabilities occupy one of the most marginalised positions in society (Prime Minister's Strategy Unit, 2005; Turning Point, 2004), the factors and circumstances that impact their inclusion and social mobility within family, communities and wider society have not been fully explored. This PhD project, started in November 2009, aims to look at the potential and realized lives of people with intellectual disabilities from different social backgrounds. It will explore the ways in which social class and community and the different cultures they entail can impact social mobility and life trajectories for individuals with learning impairments.

The issue of social mobility and equality of opportunity, which is traditionally reflected by and reflected in occupation and educational status, will be central to this research. The factors and structures that have guided the lives of people with learning disabilities who often experience atypical education and employment will be explored. The research will identify micro-meso-macro issues that constrain or promote social mobility for this group. Using a micro-meso-macro approach as a framework for research and analysis will provide insight into the constitution of society by individuals and how they in turn shape and are shaped by society at the aggregate and individual level (Giddens, 1976; Hargreaves, 1985).

Over a twelve month fieldwork period, eight life history case studies of individuals from different familial and community environments will be developed to provide information and a clearer understanding on the lived experience of these issues.

Since research is at a preliminary stage and fieldwork is yet to begin, I propose to use this poster presentation to:

- 1) introduce the research issue and major research questions in this study;
- 2) introduce and systematize some secondary source material on the topic;
- 3) illustrate in graphic form, the major theoretical framework underpinning the ecological and socio economic environment which is being studied (micro, meso, macro);
- 4) provide delegates with an opportunity to inquire about research methods and sources of information.

Tobias Buchner

University of Vienna

Poster 1

The new Austrian Law on guardianship: Self determination in practice or only on paper? Experiences of people with learning difficulties

Background: The new Austrian law on guardianship (SWRÄG) was put into force in 2006. The reform of the law aimed on enhancing self determination of people under guardianship and “mass tailoring” the needed support on decision making. Measures for the quality of support were established (e.g. guardians have to get into direct contact with the person under guardianship twice a month at least; support has to focus on desires and needs of the person under guardianship, etc.)

Media, political decision makers and NGOs celebrated the law as best practice example and “probably the best law on guardianship in Europe”.

Since 2006, implementation of the law was evaluated focussing on different aspects, e.g. the “types of users” (Kreissl et al. 2009), number of “users” in different regions (Pilgram et al. 2009) and the experiences of judges with the law (Pilgram et al. 2007). However, all the research on guardianship undertaken so far failed to bring in the view of people under guardianship. Therefore this study aims on putting the perspective of people with learning difficulties under guardianship into focus.

Objectives: Objectives of the study were to explore the experiences of people with learning difficulties under guardianship in Austria in general and if the new law on legal guardianship had any impact on the lives of people with learning difficulties in specific.

Methods: Two focus groups, consisting of together 21 people with learning difficulties living in Vienna were held. Participants were asked about their experiences being under guardianship and if quality of support had changed after the implementation of the new law in 2006. Collected Data was analysed using the “long table” approach as described by Krueger and Casey (Krueger & Casey 2000).

Results: The implementation of the new law on guardianship had no impact on the quality of support as participants experienced no change.

Participants highlighted that it was difficult for them to get in direct contact with their guardians. If participants were successful and had “face to face”-communication with their guardian, conversations were described as hierarchical structured: guardians disrupted often, ignored wishes and concerns of people. Several participants stated that guardians communicated directly with caretakers, cutting out the people under guardianship. Being under guardianship was experienced as disempowerment and a barrier to lead a normal, self determined life

Conclusions: According to the participants of the focus groups, the new Austrian law on guardianship failed to have impact on the lives of people with learning difficulties so far. It seems that a stricter quality control of guardians is urgently needed. Austria

ratified the CRPD in 2007. Looking at the contents of Article 12, results show that there still is a lot of work in implementing the convention properly in Austria.

Poster 2

The Viennese University Training Courses on Inclusive Research

Background: In 2005 the Austrian Network on Inclusive Research was founded in Vienna. Founding members were self advocates, researchers and activists from the Austrian Independent Living Movement. In order to develop a mutual understanding of Inclusive Research, network members conducted workshops on the social model of disability, disability studies, quantitative and qualitative research methods and the history of self advocacy jointly. After that first phase of the network, the group decided to develop a university course format which would include people with learning difficulties as learners, course presenters and project leaders in inclusive research projects.

The training course: In 2007, the first cycle of the training course was facilitated at Vienna University. So far the cycle was carried out three times and evaluated. In total thirteen people with learning difficulties attended these seminars as project leaders and conducted 22 small inclusive research projects. The training courses were split into two parts: In the first phase, network members held lectures on the origins and principles of inclusive research, ethical research, research methods and how to write easy to read-texts. After that, the project leaders facilitated their research projects on the topics they were interested in (e.g. experiences with legal guardianship, bullying at work, parents with learning difficulties, quality of services and more). Students assisted under supervision of other network members. At the end of each cycle, research groups presented their work at a public event to self advocates, politicians, researchers, members of the Austrian Independent Living movement and several other stakeholders.

Results: The active participation and shaping of the university course by people with learning difficulties has led not only to an increase in awareness and methodological competences on part of the students without disabilities but also to various forms of personal and professional empowerment in the lives of the people with learning difficulties.

Discussion: In order to establish the training course at University, several barriers had to be tackled, e.g. small resources for lecturers/course leaders, a lack of physical accessibility, social barriers and many more. In this part of the presentation, authors will discuss how Universities as places consisting of exclusive environments can become more inclusive.

Jacob Bunch

Arizona State University

Poster

Social Construction and Policy Punctuation of Disability Policy in the United States

The complete repeal of The Ugly Laws in the 1970's should assume a punctuating policy position as pre-cursor to the passage of disability civil rights legislation in the U.S. because it ushered in a new era of conceptualizations of disability and the civil rights associated with it. The Ugly Laws claim their roots in the late nineteenth century (1867), beginning as a part of municipal code in San Francisco and later broadening its influence to other municipalities across the U.S. and eventually abroad. The Ugly Laws restricted citizens from public view and participation who were considered to be diseased, maimed, mutilated, or in any other way deformed.

To explain how modern-day policy agendas in the area of disability civil rights punctuated in the United States, a distinction will be made, within the context of this paper from events that were politically historical and those that were politically-significant. "Politically historical" events lacking policy punctuating capacities will be defined as those events that are (1) exclusionary to certain segments of the disabled population, or (2) instances of voluntary implementation. The opposite set of evaluation criteria will be assigned to "politically significant" events--most notably, the complete repeal of the Ugly Laws in the 1970's.

To explain the differentiation between "politically historical" and "politically significant" events on the policy timeline of the United States and the extent to which each type affects policy agenda punctuations in the area of disability civil rights within the U.S. that eventually led to landmark legislation, the following two theories will be used as a contextual framework: Social Construction as revised by Schneider and Ingram 1988, 1993; Ingram and Schneider 1990, 1991; and Punctuated Equilibrium Theory as defined by Baumgartner and Jones (1993). Specifically, Social Construction Theory will be used to explain how social categorizations and subsequent treatment of the disabled population were used and manipulated (as is typical of contender groups) to the advantage of societal members and policymakers for intentional delay in the policy process of disabled civil rights so as to perpetuate the social construction of dependency on the population.

The Punctuated Equilibrium Theory will be used to assess how sudden and dramatic policy shifts in the 1970's, beginning with the complete repeal of the Ugly Laws allowed disability civil rights policy to make a departure from incrementalism to large-scale, pattern-breaking policy changes that eventually culminated into the Americans With Disabilities Act of 1990 to create a sense of stability or stasis for the given policy area.

Marc Bush

University of Surrey and Policy & Campaigns Department at Scope

Co-author: Cristina Sarb

Shifting notion of disabled citizenship? Implications of choice, personalisation and responsibilities

This paper critically reflects on the changing notion of disabled citizenship and its relationship to the rights and responsibilities agenda; and in particular the context of choice and control. We have seen a shift in the traditional welfare paradigm from services oriented to providing a safety net to those promoting and supporting social productivity; something which comes into sharp relief when considering recent policy reform around care and support, employment and the wider personalisation agenda. This new emphasis has also been accompanied by a wider appetite around correlating rights with responsibilities, something that frequently equates to conditionality in the services disabled people and their families receive. Furthermore, this new emphasis on social productivity demands high levels of understanding, capability, and inclusion from citizens in order to realise their potential. Whilst active empowered citizenship is key to addressing many of the barriers disabled people face within society; we will argue that pursuing the social productivity agenda cannot be at the expense of providing a safety net. It is likely that the look and feel of safety net services will be very different with the advent of the focus (particularly with the rise in recognition amongst policy makers of the role that ULOs and DPOs can play) on social productivity and we intend for this paper to stimulate debate about this further as well as consider what impact this could have on disabled people and their families in the future.

Anne-Marie Callus

University of Leeds

Helping People Lead Independent Lives

The notion that these people need help, a notion which is embedded in the very definition of intellectual disability found in most texts, constructs people with intellectual disability as dependent beings who cannot act on their own behalf. The paper is based on the analysis of data from a series of interviews with people with intellectual disability and representatives of disability organizations in Malta. It starts by looking at how these interviewees define or describe intellectual disability, focusing on their references to people with intellectual disability's need for help.

The paper next looks at how people with intellectual disability become dependent on help from others, arguing that this happens not so much because of impairment-related needs, but because of the way most aspects of their lives are controlled by other adults and the fact that they are invariably financially dependent on these others. A contrast is drawn between the perceptions of many non-disabled people and that of many people with intellectual disability. While the former tend to see the need for help as a sign of deficit, dependence and a lack of autonomy, the latter very often see it as a means of asserting their rights and living independent lives as equal citizens.

The paper concludes by arguing that being dependent on help should not be seen as contradictory to being autonomous; especially if the definition of support and help is based on the way it is perceived by people with intellectual disability themselves.

Fiona Kumari Campbell

Griffith University School of Human Services & Social Work

Listening & Voice: Encounters with Memory and the Politics of Regret

In the quest to normalize disabled people the particular ways that disabled peoples' being-ness has been shaped and formed is often overlooked. Unthinking disability, relegating it to an afterthought, has meant that listening for differences, the silences and the effects of accumulated ableism has not been placed at centre stage (Campbell, 2009). Derrida points out, silence is the origin, the font of all speaking, whereby "silence plays the irreducible role of that which bears and haunts language, outside and against which alone language can emerge" (1978: 54). What is silent is that disabled people as a group and as individuals, I/you have a crip-specific history. If this history is spoken of, it is normally in terms of a history of services – but this is not the same as our history which for many has not only left indelible scars but has intrinsically shaped and formed us.

This paper is a discussion of the processes and politics of listening to difference – different histories, embracing that difference and not subsuming it into an ableist norm. In particular the paper is interested in the accumulative effects of ableism and the negotiation of private and public memory regarding disabled person's relations with the Australian State. My analysis draws heavily on the work of Connerton, 1989; Farrell, 1998; van Alphen, 1999; and the development and application of notions of 'grievability', the 'grievable life' (Butler, 2009), 'regret & guilt' (Olick, 2007; Schlink, 2009), 'muted voices' (Kuhrt & Sancisi-Weerdenburg, 1990) traditionally not specifically applied to disabled people. The challenge is to log survival in an ableist society, to grasp it's incompatibility and incomprehensibility "...between experiences and the affected person's capacity to report it due to the fact that real events do not offer themselves in the form of stories" (Reiter, 2005, 13).

It has been nearly thirty years since the commencement of the decarceration of disabled people from institutions and the embrace of a discourse of social inclusion. Drawing upon the discussion of listening and the making of 'oppositional voice', the paper also explores the politics of regret and the ways memorialisation is signified in the light of recent public apologies by government (indigenous stolen generation, English child migrants), Australian disability policy and contemporary campaigning to close existing institutions as part of the "Shut Out" campaign. Of interest is the different ways 'voice' is harnessed to negotiate the disabled past. Finally the mechanisms of accountability to the unheard and the problems of speaking for others are considered with referencing to a relationality model of disability which understands disability to be formed through faulty relations (Hamonet, 2006).

Linzi Carlin

University of Leeds

Extending the Debate: an exploration of the application of disability theory to non-disabled associates of disabled people

It is generally acknowledged that people who have a close association with a disabled person, such as parents, spouses and siblings, are affected by the same disabling social structures and forces as are people with impairments, although the ways this manifests itself and the implications for their day-to-day lives may differ. It is less clear, however, whether more specific theoretical concepts proposed by scholars within critical disability studies, such as, for example, 'impairment effects', 'disabled identity' and 'internalised oppression' also have applicability for understanding the experiences of people who do not themselves have an impairment, but are intimately associated with one who does. In the context of some preliminary work on a research project concerning siblings of people with high support needs and substantial cognitive impairment ('profound multiple learning disability'), this paper explores whether it is accurate to talk about such concepts in relation to people who do not have impairments, and if so, what an analysis incorporating some of these ideas might add to our understanding of their experiences.

Rohhss Chapman

University of Manchester

Co-author: Louise Townson

'Our support workers are very good; but like all staff, they can play up'

This paper explores the experiences of two groups of people in relation to their ideas about the role of support workers. The first group were made up of people with learning difficulties who were members of self advocacy organisations across the UK; the second group were advocacy support workers, employed by people with learning difficulties. Tensions between supporters and people labelled with learning difficulties have been recognised from the early days of the formation of the self advocacy movement.

This 3 year research project was undertaken through an inclusive process alongside the Carlisle People First Research Team. It aimed to make sense of the support worker's role and to discover whether or not the meaning and purpose of their role was shared. Findings indicated that the support worker role was contested.

People with learning difficulties and their supporters held a number of contradictory views about what support workers should do and how intensive their support should be. There was evidence of effective partnership working as well as examples of peoples' self-determination conflicting with supporter agendas. Furthermore the ownership of the groups was challenged by unacknowledged barriers, specifically in terms of access to information and the organisation of space. These inconsistencies appeared to be linked to the theoretical and value positions of the support workers.

Tsitsi Chataika

Stellenbosch University

**Disability and Development Intersecting with Postcolonialism:
Unpacking the 'ins' and 'outs' and narrowing the gap between
Southern and Northern spaces**

This presentation explores the political struggle in the disability discourse, which is about challenging oppression, voicelessness, stereotyping, undermining, postcolonisation, and moving towards narrowing the gap between Southern and Northern spaces in disability research and development initiatives. These forms of oppression are human creation whose elements have to be confronted in totality. My presentation, based on a forthcoming book chapter in Goodley, Hughes and Davis' book entitled 'Disability and Society Theory', is informed by compelling documentary and empirical evidence I have gathered through engaging with a wide range of disability and development literature and related research projects. Research evidence demonstrates that disabled people are not only almost absent from the international development discussion, but when present, they are recipients of development partners, hence reflecting and perpetuating neo-colonial discourse. I also explore the relationship/partnership between Northern and Southern disability researchers, which is often tinted by inequalities. This 'marriage of convenience' undermines the collaborative efforts between the two spaces. One is then forced to question whether Northern development or research partners see themselves as equals to Southern partners, or that they are saviours. In the presentation, I bring together debates about postcolonialism, disability and development, which are usually represented as single stand alone stories. I further unpack the 'ins' and the 'outs' in disability research and the development agenda; and how the gap between the Southern and Northern spaces can be narrowed. The presentation further follows the debate on who sets the development agenda. For example, empirical evidence indicates that if the development or research agenda is set in the North, in most cases, the Southern space tends not to benefit from the output. Does development work in the South viewed as charity work or dead aid? What single story informs the pacesetters of the research or development agenda? I will conclude the presentation with a call for a development discourse that promotes genuine collaboration between the Southern and Northern spaces, which is a 'marriage of commitment'. This calls for Northern partners not only focusing on a single story, but the many untold stories from the Southern spaces that can enrich the collaboration between the two spaces, taking into account cultural discourses.

Tsitsi Chataika

Stellenbosch University

Co-authors: Margaret Wazakili, Boniface Massah, Moses Mulumba, Gubela Mji, Malcolm MacLachlan

Poster

An exploration of disability news coverage in Uganda and Malawi

The media is the lens through which society constructs attitudes and opinions; and it is strategically positioned in influencing the public on various issues, including disability. Print and electronic media can be instrumental in educating and enabling communities to understand the nature of discriminatory practices against disabled people and what can be done to eliminate such practices. Our poster presentation is informed by disability related media articles collected from two main Malawian and Ugandan national newspapers tracked over a period of four months in 2009. The chosen newspapers in the two countries were selected primarily because of their large circulation and prominence as the agenda-setting elite media and our quest to understand what is being presented about disability in mainstream news media. The two countries are part of an ongoing three-year research project on African Policy, Disability and Development. We carried out a content analysis of the data to establish common trends in disability news coverage. Our findings demonstrated that the media has the power to foster understanding, tolerance, and respect for difference and diversity. It was also clear that negative portrayals in text media can undermine this process. We established that disability is portrayed as a deficiency, and is not linked with other categories of identity. Despite the call to put disability on the lime light, it was apparent that disabled people are sometimes 'invisible' in the media, except when the story is about sensational, 'heroic', or when the news coverage is about donations to disabled people or their organisations. In the news articles, the views of disabled people as a group or individually were seldom featured in stories dealing with common interest such as politics, economy, public transport, environmental issues or tourism. The word 'disability' often stole the limelight of any story involving a disabled person, hence increasing discriminatory tendencies. It was noticeable that lack of policy guidelines on reporting about disability issues contribute to the use of careless expressions and production of disability insensitive articles, where disabling terminology such as 'handicapped', 'crippled', or 'dumb' is a feature despite the United Nations Convention of Rights to Persons with Disabilities' call to promote, protect and ensure the full and equal enjoyment of all human rights by disabled people. We argue that disabled people should play a central role in the media industry as designers of their own images so that their lives are not constantly portrayed by other people who hold misguided assumptions about disability. We also provide specific recommendations to various stakeholders, particularly media practitioners on enabling media reporting.

Lien Claes

Ghent University

Social Geography and Disability Studies make a Good Marriage: studying 'jammed' life trajectories and creative strategies of people with intellectual disabilities and their environment.

In line with international findings, currently actors associated with support systems in Flanders (the Dutch speaking part of Belgium) formulate that they can only support people with intellectual disabilities and additional mental health problems and their environment in a very limited way. In a sense, we could state that they are 'falling between the two stools' of the care system for disabled people and the mental health care system. In this PhD research project, a medical-psychiatric discourse is considered as a dominant paradigm in conducting research on this 'population', focusing on individual problems, symptoms and treatment (without charging the context). In order to challenge this, we explore a social interpretation of these situations and questions for support.

We adopt a combination of insights from disability studies and social geography as underlying theoretical frameworks. Despite the growing interest in 'geographies of disability', people with intellectual disabilities are hardly addressed in geographical disciplines. In social geography, socio-spatial processes – regulating and reproducing social exclusion, oppression and marginalization – are explored. Although many geographers yet mapped spatial shifts in policy making and economic, social and political processes underlying these shifts, only few studies have also examined the intimate 'social and spatial worlds' of disabled people and actors in their natural and professional networks. In our research project, we focus on micro-spaces as a complementary element to the broader 'spatial scale' and aim to explore how the cross-fertilization of disability studies and social geography enables us to expose micro, meso and macro shifts and bottom-up/top-down movements.

The research methodology consists of conducting extensive case studies, in which we document the boundaries that people with intellectual disabilities and additional mental health problems and people in their natural networks experience and their creative strategies to deal with the lack of support. In order to do so, we combine a variety of research methods (such as in-depth interviews, photo-voice, observation, focus groups) and from different perspectives (the 'silent voices' of people with disabilities and people in their natural and professional environment).

This research focuses on spatial trajectories, on how 'space' constructs 'disability', on relations/interactions between people and space, and on the meaning of specific spaces and places. 'Space' and 'place' seem to be valuable indicators for an in-depth understanding of stories of migration and diaspora, of being on a 'waiting list', of being refused and put outside of care systems and institutions,... Furthermore, we seek to explore how 'mobility' - as an interdisciplinary studied metaphor - can counter the idea of 'jammed situations'.

David Cobley

University of Birmingham

Towards Economic Empowerment for People with Disabilities in Developing Countries: Examining the influence of the Social Model in Kenya

The economic empowerment of people with disabilities (PWDs) is vital to the achievement of global development targets, such as the Millennium Development Goals (MDGs). It may well be impossible to eradicate extreme poverty and hunger (MDG 1), for example, without taking into account the close relationship between poverty and disability. It is estimated, in fact, that up to 20% of the world's poor are PWDs (Elwan, 1999). One of the reasons that so many PWDs are living in poverty, in the developing world, is the difficulties they face in earning a living, due not only to particular impairments that they may have but also to a wide range of barriers that exist within society and effectively bar them from opportunities to participate as productive members of society. The 2006 UN Convention on the Rights of PWDs (UNCRPD), which is founded on social model ideology, advocates an inclusive approach to promoting the economic empowerment of PWDs. However, the continued existence of segregated training institutions and sheltered employment options in developing countries, as observed by O'Reilly (2007), suggests that not all approaches to promoting economic empowerment are based on the logic of the social model. Some analysts have even argued that fighting for social inclusion can move attention away from the more pressing needs of PWDs that are faced with high unemployment and extreme poverty. Yeo (2005), for example, suggests that the social model has encouraged the disability movement to adopt an 'upward focus', putting too much emphasis on lobbying those that seem to have the most power, rather than building horizontal alliances with community organisations that may have common aims, and be better placed to assist PWDs in their fight against poverty. These literature debates raise the question as to what extent economic empowerment strategies in developing countries are currently being influenced by social model ideology, and whether this influence really does lead to more successful strategies. This paper addresses that very question in the context of Kenya, a country which has signed and ratified the UNCRPD, thus committing itself to an inclusive approach to addressing disability issues. The paper will present the findings of a planned field trip to Kenya in Summer 2010, with the purpose of examining the influence of the social model on a range of existing economic empowerment strategies, and considering the effect of this influence on outcomes for PWDs.

Bryn Coles

Lancaster University

Co-authors: Dr Allan Collins, Dr Jackie Abell

Ideologies of Need, Dilemmas of Difference

Special Educational Needs (SEN) provision and educational reform has been debated in the UK Parliament. Initially, separate, specialist educational provision was considered the most appropriate form of educational provision for those with special educational needs (1944 Education Act). However, since the late 1970's in Britain, the education of children with SEN alongside their non-SEN peers in inclusive classrooms has been favoured (Warnock, 1978) over education in separate, specialist schools.

Within legislative documents, inclusive education is presented as an issue of rights, equality, egalitarianism and fairness. However, this legislative focus upon fairness and equality exposes political speakers to a dilemma. The category of 'SEN' implies that children have atypical learning needs, which in turn require atypical educational provision. Yet these need risks accentuating the differences between children with SEN and their non-SEN peers. The agenda for inclusion by contrast emphasises the need to treat all children as being essentially the same, but risks not meeting children's unique and individual needs. This is known as the 'dilemma of difference'. This paper considers how this dilemma is managed by speakers advocating and resisting inclusive educational reform.

Data was drawn from the Government's own on-line archives of parliamentary debates (The Hansard Debates) and taken from debates in the years in which major pieces of legislative reform were passed. Drawing upon Discursive Psychology, Critical Discourse Analysis and Membership Categorisation Analysis, it was found that all speakers are seen to support the ideals of equality and fairness in educational provision. However, speakers were also found to manipulate the notions of SEN and disability, depending upon whether or not speakers wish to support or challenge inclusive educational provision. Speakers were also found to manipulate the notions of SEN and disability in order to manage the dilemma of difference.

Findings hold implications for how the dilemma of difference may be managed in relation to SEN and disability, for how inclusion may be understood and represented in political and professional talk of inclusion and for how speakers may seek to engender support for, or resistance against inclusive educational reform.

Tabitha Collingbourne

School of Law, University of Sheffield

Administrative Justice? Realising the right to independent living

The English administrative justice system has been defined as having at its core ‘the administrative decisions by public authorities that affect individual citizens and the mechanisms available for the provision of redress.’ (Nuffield Foundation, 2007). It is through these decision-making and redress systems that law and policy are delivered on a daily basis directly to individuals, determining and influencing real-life outcomes.

People experiencing disability are more likely than others to come up against the kinds of problems that bring them into contact with the administrative justice system, and they are likely to experience more of those problems (Pleasance, 2006). Where this happens, it is likely to have a negative impact on their ability to live independently and to participate on an equal basis in the community around them (O’Grady et al, 2004). How the administrative justice system responds to their circumstances may be central to resolving such problems, and so to preserving or improving people’s independence, quality of life and opportunity.

In June 2009, the United Kingdom ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). In doing so, it undertook to ‘ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities...’ (Article 4(1)). One of those rights, as set out under Article 19 of the Convention, is the right to live independently, with choices equal to others, and to be included in the community. Realisation of this right requires, among other things, ensuring that disabled people have the opportunity to choose their place of residence and where and with whom they live; that they have access to a range of in-home, residential and other community services, including personal assistance, to support and enable inclusion; and that general services and facilities are available to them on an equal basis and are responsive.

This presentation explores the extent to which the current English administrative justice system meets the requirements of the CRPD, focussing particularly on the realisation of Article 19.

Brigit Colton

Sociology Department, Lancaster University

Experiencing it for myself: reflections on auto-ethnography in an NHS arts for mental health project

In this paper I will introduce my doctoral research project, which involves an ethnography of an NHS arts for mental health project which develops art exercises for people with severe and enduring mental health needs to work towards 'recovery'. My research draws on feminist poststructuralist theory and disability studies to critically engage with the different understandings of mental ill-health and recovery in circulation in this context. For example, it examines the kind of subjects which are constituted through current mental health discourses and arts orientated treatments. As part of the research I will be accessing the service as a service user would do. I am at the beginning of the project and I therefore want to reflect on my experiences so far in terms of setting up the project and the experience of accessing the service as both an ethnographer and a service-user. Here, I will consider what strategies I might employ to critically reflect on different stages of the experience, and move between the different positions I find myself in.

Liz Crow

Roaring Girl Productions

Liz is a writer-director working with film, audio and text. Interested in drama, life stories and experimental work, she is drawn to the potential of storytelling to trigger change. Described as “a director of real visual flair”, her work has been praised for its ability “to get under the skin of a subject”. Liz’s work has shown at Tate Modern and the British Film Institute, as well as on television and at festivals internationally. Through a four-year NESTA (National Endowment for Science, Technology and the Arts) fellowship, she explored ways to combine her creative practice and political activism. Liz is a graduate of the Skillset Guiding Lights scheme where she was mentored by Peter Cattaneo (The Full Monty).

Plenary

Resistance: transforming the future

When Liz Crow sat on the Fourth Plinth on a crowded Saturday night in Trafalgar Square as part of Anthony Gormley’s One & Other project, she sat on her wheelchair wearing full Nazi regalia to draw attention to a hidden history and the message it holds for us all today.

Selected as one of The Guardian’s Trafalgar Top Ten, Liz’s performance on the plinth was part of a larger film-based project that is touring the UK and internationally. Resistance: which way the future? explores the Nazi programme that targeted disabled people, reflecting on what this history means for us now and inviting audiences to shape things to come.

In this seminar, Liz will talk about her work and discuss what it means to create new cultural representations of disability as a tool for change.

Davey Curnow-Garland

CeDR, Lancaster University

Challenging Networks: The empowerment of individuals seeking clarification and knowledge online, and the direct challenge this poses to the medical model of disability

This paper will focus upon the MUPS (Medically Unexplained Physical Symptoms) community, and how individuals and groups/collectives of individuals use the internet as a major tool to gain both access to data and acknowledgment of their illnesses or conditions. This paper will discuss two empirical studies, one that I undertook on Veterans experiencing Gulf War Syndrome, the other, my present study, which is exploring the ways in which those with M.E/Chronic Fatigue Syndrome use ICT to enable them to continue working, studying or engaging with their everyday lives.

The key questions from these two studies that will be presented in the paper are:

- How can the design of the internet and cyberspace in itself be useful in nurturing empowerment, political activism, and the building of online ‘health communities’? This paper will use the work of Jordan (1999), Fuchs (2005), and Nettleton et al (2005) to discuss this question.
- Continuing from this point, do the cultural dynamics and experiences of disability or marginality actually make users more able to utilise the internet than other people? Are the experiences of overcoming obstacles and “thinking outside the box” making it easier to access and employ the internet? In addition to my own study, the discussion may use the work of Thomas West (1999) to give some indicators that this might be a possibility.
- How can the sharing of information be empowering? This focuses on what lessons can be learnt from Illich’s Tools of Conviviality (1973) applying it to health based communities and Embodied Health Movements and their networks, and discusses ways in which Illich’s theories on information exchange and community empowerment applies directly to the challenging of conventional wisdom or knowledge on certain illnesses.
- Finally, does the greater usage and ownership of such technology give greater hope for reducing marginality and alienation? Does the currency of citizenship and participation lie in the hopes of online activism and awareness building?

This paper will give a broad overview of these main points. It will also discuss the methodological design of the current study, the types of participants in the interviews and the questions that will be explored with them. Using data obtained from the 1st study, it will examine what may be attainable in the current research

Michelle Daley

Voices of Disabled People: A comparative study to explore the North and South experiences of Independent Living

The purpose of this study is to establish whether there is a difference in how disabled people understand the concept of 'Independent Living', whether there is a shared experience amongst disabled people on disabling barriers and finally to identify whether Independent Living can be achieved in the South.

This is a qualitative research study which has adopted the disability emancipatory research approach and has been guided by the social model of disability. This approach sets out to ensure that it did not misrepresent disabled people by depicting them as 'the problem'. Instead, it sought to identify the disabling barriers that results in their oppression and discrimination. This is different to many other research methods.

The study identified a number of key findings that result in disabled people globally being denied access to their basic needs (i.e. education, health care and employment), most notably in developing countries. In the most extreme situations disabled people are subjected to lives of abject poverty and they become voiceless.

The study also found that there is no difference in the way disabled people understand the concept of Independent Living. However, the way in which Independent Living is achieved, is largely determined by the role a State plays in protecting and promoting the rights of disabled people. For disabled people living in developed countries, there is some level of commitment made by Governments to improve the quality of life of disabled people but there are differences between people's experiences in the North and South.

Disabled people's experiences were further affected by the fact that the development agenda has largely ignored - them. This has removed opportunities for disabled people to have an input into decisions that will help to improve the quality of their lives and their living conditions.

These findings were pertinent to the study and further emphasised the need for all institutions to play a role in promoting and protecting the human rights of disabled people globally.

Finally this report concludes by drawing on the key findings from the study and presents a way forward for disabled people.

Roisin Dermody

University College Dublin

Poster

Disabled Women's access to Sexual and Reproductive Health in Ireland

In accessing general health services, disabled people encounter many difficulties. The same issues of access hold true for disabled women accessing sexual and reproductive health; however there are additional barriers in these circumstances. Not only do disabled women have to encounter the usual environmental barriers of inaccessible buildings and diagnostic equipment when accessing sexual and reproductive health services but they also have to contend with the negative attitudes and stereotypes that surround the issue of disabled women's sexual and reproductive health.

Disabled women encounter a range of barriers in accessing their sexual and reproductive health, including physical and environmental, informational and educational, attitudinal and psycho-social barriers. This study looks at disabled women's access to sexual and reproductive health in Ireland, the barriers encountered and the impact such barriers have on the lives of disabled women.

Within this study, I see the body as a socially constructed entity, through which identity discourses can develop. Such discourses take place through inter-personal relations and the social meanings ascribed to the body and what a "desirable" body consists of. It is through the body that we experience such social discourses and ultimately, social life. It is important to look at the role of the body in disabled women's fight for sexual and reproductive health as disabled women's bodies have been interpreted negatively. Such negative interpretations of disabled women's bodies have served to produce, reproduce and reinforce the psycho-social barriers that many disabled women experience. I look at how disabled women's bodies are stigmatized, medicalized and represented and how the body is idealized within popular culture. This treatment of disabled women's bodies is a primary cause of the psycho-social barriers experienced by disabled women.

In terms of grounding this piece of work within a theoretical framework, I am looking at the Social Relational Model (Thomas, 1999), the affirmative model (Swain and French, 2000), and the interactionist model (Shakespeare, 2006) to see if any of these models adequately take account of the experiences of disabled women in their fight for sexual and reproductive health. These models have begun to look at disabled embodiment and the lived experiences of disabled people, not as a "tragic victim" or "supercrip" but as ordinary people going about their everyday lives. I also look at the "new" genetic model and its implications.

John Dias

Carlisle People First Research Team

Co-author: Chloe Brownlee-Chapman

'Keeping Wartime Memories Alive': Reflections on an Inclusive Oral History Project about World War Two with people who have the label of Learning Difficulties.

The Carlisle People First Research Team has been working together for twelve years. There are currently eight members. Most members share the label of 'learning difficulties'. The main purpose of the team is to carry out work that is of benefit to people with learning difficulties. The team works in an inclusive way.

We talked to people with learning difficulties about their memories and experiences of World War Two, in an Oral History project, which was funded by the Heritage Lottery Fund.

The team expected to uncover stories which had previously been hidden. We learned that some of the people we interviewed had been a part of the war effort. Some of the women had been involved in doing the laundry for the army, based next door to their Convent. Others had worked on the farms, but that may have not been unusual. In some ways, the research uncovered the difference between people for whom the war time period was such a huge change in their independence and role in society and for those whose lives hardly changed at all. We think that this is to do with being in Cumbria. Cumbria was not targeted by 'the enemy' in the War.

We came up against many barriers in our research, such as 'Gatekeepers', clashes of priorities, people passing away, transcription difficulties and more. We have been looking very carefully at these problems since the project has finished, and we have decided to write about them.

We'd like to present what we found out from our project and tell people about the problems we encountered and about how we ran our project to help other people to improve the way they do their research.

Eduardo Díaz Velázquez

Universidad Complutense de Madrid

Co-author: M.A.V. Ferreira

Disability and citizenship: normative inclusion, substantive exclusion and corporal experience

Analyzing the access to the condition of citizenship of persons with disabilities in our societies implies not only to investigate the attainment of certain formal rights and their guarantee by the legal system, but also, and mainly, to see how those social, civil and political rights are substantively exercised by persons with disabilities, in equality with other citizens.

In Spain, access to citizenship is incomplete because of two reasons. First, because of the confluence in the legal system of advanced regulations that support autonomy and formal equality as citizens for persons with disabilities, with other protectionist and segregating laws and policies, characteristic of the formerly prevailing medical model. Second, the data confirm that, despite the normative advances, this group is still in a clear position of inequality and exclusion with regard to different spheres of citizen life, such as employment, education and/or social and political participation. Thus, to have or not to have a disability determines people's position in the social structure, and this is why it is so fundamental to analyze the processes of exclusion and social inclusion of persons with disabilities.

Dominant cultural representations of disability, coming from the domain of the health sciences, and ruled by what we could call a synecdotic disabling, play a relevant role in that inequality and exclusion because they take the part (a functional limitation that is only partial) for the whole (a false total restriction of autonomy).

This synecdotic disabling operates on a micro-social level, in the context of daily social relations between persons with and without disabilities, as well as on a macro-social level, because this persons are considered unable to access the job market or to make decisions, and because segregated environments are created on the basis of their disability with regard to employment, education, etc. With regard to this macro-social level, we can verify how the symbolic paternalist representations of disability in the design and implementation of social policies, and in the access (or lack of) of this group to certain spheres of citizenship, have the pernicious effect of limiting the decision-making ability, and therefore too, the autonomy of persons with disabilities, turning them into second-class citizens.

The study of the social inequalities and of the exclusion of persons with disabilities must be methodologically approached integrating quantitative strategies, that analyze the position of the person with disability in the social structure, and qualitative strategies that, through the analysis of corporal experience and the study of symbolic representations in our societies, investigate how the processes of identity construction and social exclusion of persons with disabilities are originated and reproduced.

Brooke Dinning

Disability Studies and Research Centre, University of New South Wales

Voices beyond the riding arena: The perceptions and experiences of parents of riders who participate in Riding for the Disabled

It has been argued that children and young adults with an impairment can be viewed as 'rhizomes', that is as 'complex phenomena tied up by a host of interconnected relationships, including impairment issues, but more crucially, relational connections with others' (Bayliss, 2004). A significant 'other' in the lives of children and young adults with an impairment is their parents/carers.

This paper is based on research that was conducted at one Riding for the Disabled centre in Sydney, Australia, a setting where parents/carers play a significant role 'chaperoning' riders to and from lessons and negotiating their children's (the riders) needs with riding coaches and volunteers. The paper is based on 21 in-depth interviews with parents of riders and is divided into three parts. The first focuses on parents' relationships with the 'professionals' of the RDA domain, the volunteers and coaches. The interviews suggested that parents/carers can have a tremendous impact on their child's experience of the RDA. Theoretical insights from Bourdieu (1976) and Lareau (2003) are drawn upon to illustrate how parents deploy their cultural capital in exchanges with volunteers in order to enhance their child's experience of the RDA. The second part of the paper explores how parents use the RDA as a space to connect with parents in similar circumstances. Previous research has made us aware that parenting a child with an impairment can be an isolating experience. This paper utilises ideas from Bourdieu (1976) and Putnam (2000) to highlight how the RDA fosters a sense of shared experience and support through which practical information about disability and advocacy resources can be exchanged. It is also a setting where many parents form important social connections that go beyond the RDA. The final part of the paper examines parents' perceptions of the impact that the RDA has on their family, in particular, what riders' siblings gain from their exposure to the RDA. The research highlighted that the RDA was perceived by parents to be an opportunity to expose their children to difference and diversity and that their family situation was not unique.

Diane Driedger

University of Winnipeg and University of Manitoba

Co-author: Nancy Hansen

How Independent Living and Literacy Work Together

This paper will discuss the findings of a three year (2007-2010) Canadian participatory action research study, entitled, "Making a Connection" Disability, Literacy and Quality of Life". Independent Living Canada, the national organization of independent living centres, (A national group of organizations run by and for disabled people promoting inclusion and equity), carried out the research in conjunction with five sites across Canada, and the two disabled university co-investigators.

It has been estimated that around 50% of disabled adults experience literacy barriers, such as lack of access to information and physical, print and verbal barriers. In addition, 20% of disabled adults have attained less than two years of secondary school education. This project defined literacy as "meaning-making" in peoples' lives. At the five local sites, in different regions across Canada, ten disabled people in each location defined their own personalized literacy goals. This included computer literacy, learning to read the bus schedule, grammar upgrading, improving numeracy skills, and taking secondary school equivalency courses. In Thunder Bay Ontario one participant has been able to secure employment as one of the goals on his literacy journey. In Saskatoon Saskatchewan, three participants achieved their secondary school equivalency. In other locations, the participants have published creative writing in writer's publications and literacy newsletters.

The Independent Living Centres in the five locations have forged partnerships with local literacy providers through the project. These partnerships have been beneficial for both the Centres and the literacy providers and will last beyond this three-year project.

This paper will report on whether disabled people improved their quality of life, which was defined by themselves, through improved literacy skills. Indications are, from early data collected (this project ends April 30th 2010) that literacy has opened up new worlds and possibilities and improved the quality of life of the project participants.

Malcolm Eardley

Carlisle People First Research Team

'The Way of Life'

The Carlisle People First Research Team started working together in the mid 1990's. We take an inclusive approach to research. We know a lot about the lives of people with learning difficulties, because we have experience of having a learning difficulty. At present we have 8 researchers on the team.

My name is Malcolm Eardley and I enjoy art, dancing, singing and sometimes swimming. I have been involved with People First for over 12 years and I am a member of Carlisle People First Research Team. I have been involved in many research projects including 'Advocacy and Autism' and 'Direct Payments'. I also have a label of a learning difficulty.

After living in Dovenby long stay hospital for 12 years I developed an interest in people's life history. I decided I would like to write a book. I received a grant to help me which I obtained myself. When I spoke about my plans, some people who have the label of a learning difficulties were very interested and wanted to be involved in sharing their stories. I researched these people's lives using an 'emancipatory' approach and I have written a book about my findings.

I would like to present at your conference to share these stories. The book is called 'The Way of Life'. Having a learning difficulty myself, I am all too aware of the stress that we can have from people calling us names and not treating us with respect and I have overcome many difficulties over the years (one being disability hate crime). I think it's important to share my story to raise awareness of issues faced by people with learning difficulties. Professionals need to know how they have destroyed people's lives.

Eva Þórdís Ebenezersdóttir

Centre for Disability Studies, University of Iceland

Co-author: Kristín Björnsdóttir

Disability in Northern European folk tales and legends

Folktales and legends are oral narratives that are told person to person and passed on between generations. Endless variations exist of these tales and legends, which are shaped by the storyteller and the time and place in which they are told and retold. Folktales and legends are complex and diverse and have arisen from people's daily lives. The tales have multiple purposes and were created for entertainment and educational purposes, to explain different phenomena and warn of danger. This paper reports the findings of a recent study, which explores how disability is presented in folktales and legends about changelings. Approximately 80 Northern European tales and legends about changelings were selected from published collections of legends and analyzed. I explore the discursive themes in the tales and legends in relation to disability and how ideas about disability and impairment were represented in the societies in which these tales were told.

The research findings indicate that there are numerous references to disability in Northern European legends about changelings. The tales have mythical overtones and the cause of various impairments was attributed to the supernatural changeling. In the paper I explore how the folk-belief in the changeling affected how disabled children were treated and cared for by their families and societies. The paper concludes by addressing the discursive themes found in the legends in relation to different disability models from a combined Folkloristic and Disability Studies point of view.

Snaefridur Thora Egilson

University of Akureyri

Parents' views of therapy services for their children

The importance of the family in disabled children's well being has been stressed in recent decades. There is evidence that providing family-centred services is associated with improvements in parents' satisfaction with services, decreased parental stress, and positive child outcomes. Key principles of family-centred services most frequently described in the literature include (1) recognizing the family as central to and the constant in the child's life, (2) acknowledging that the family is in the best position to determine the needs and well-being of their child, (3) promoting partnership between parents and service providers, and (4) facilitating family choice and decision making about services for their child. In recent years the opinions of Icelandic parents toward the therapy services their disabled child receives have been gathered through open interviews, focus groups and instruments such as the Measure of Processes of Care (MPOC). The five domains of the MPOC are enabling and partnership, providing general information, providing specific information, coordinated and comprehensive care, and respectful and supportive care. The MPOC findings indicate that, in general, parents view the therapy services as respectful, supportive, comprehensive and enabling. However, there is a distinct lack of general and specific information, such as regarding therapy goals and information sources. Parents become increasingly critical of the therapy services as their child grows older. Although the findings obtained with the MPOC indicate that, overall, parents work in partnership with therapists toward a common goal the results of the open interviews suggest that the services are frequently weakness focused rather than competency enhancing. Also, parents are often poorly informed of what takes place during therapy sessions. Most parents wish for more joint decision making in planning intervention and more collaboration with the therapy services. The overall results indicate that therapists need to put more thought into the environment of the child and family.

Eric Emerson

CeDR, Lancaster University

Co-authors: Anne Honey, Gwynnyth Llewellyn, Maina Kariuki

Left Behind: The Living Conditions of Young Australians with Disabilities 2001-2008

We used the survey of Household Income and Labour Dynamics in Australia (HILDA) to monitor trends in the 'well-being' (living conditions) of disabled and non-disabled young Australians (age 15-29) each year from 2001-2008 (a time of significant economic growth and prosperity in Australia). The UN Convention on the Rights of Persons with Disabilities was used to identify domains of well-being, with 29 indicators aligned to these domains. We examined trends over time in absolute and relative disadvantage on these indicators. On 18 indicators (62% of the total) young disabled Australians were significantly more disadvantaged than their non-disabled peers in each and every year. Inspection of trends over time indicated that: (1) decreasing absolute disadvantage was observed on five indicators; (2) increasing absolute disadvantage was observed on three indicators; (3) decreasing relative disadvantage over time was not observed on any indicator; (4) increasing relative disadvantage over time was observed on six (21%) of the indicators. Results are discussed in the context of the use of population level data to monitor progress toward the realising the aims of UNCRPD.

Eric Emerson

CeDR, Lancaster University

Co-authors: Gyles Glover, John Wilkinson, Chris Hatton

Poster

A Public Health Observatory - Learning Disabilities

In 2010 the English government established a new agency (a 'Public Health Observatory') to improve the collection and use of information on the health inequalities faced by people with learning difficulties. This agency will begin its work in May 2010. This poster will describe the work of the Public Health Observatory – Learning Disabilities and give delegates an opportunity to explore user-friendly web resources.

Emil Erdtman

Swedish Disability Federation

Co-authors: Emil Erdtman and Anne Sjöberg

From research object to research partner

Orientation: The project focuses on social research. The Swedish Disability Federation concentrates on common issues irrespective diagnosis, where as the member organizations work with research based on diagnosis. The project cooperates with its sister project - Patient Participation in Research.

Goals:

- A new research platform for the Swedish Disability Federation
- Research projects which are relevant for the disability organizations' members
- Research that cooperates with those concerned
- To be an active and knowledgeable research partner
- To discuss disability research and user participation within research
- To increase representation within research organs
- To identify research with a high level of user participation or examples of Disability Studies

Methods:

- Coordination of the work for a new research platform
- Research initiation study circles to formulate relevant research topics
- Handbook for user participation in research
- Training for the disability movement
- Survey of user participation research
- In-depth contact between the disability movement and research organs
- Influencing public opinion
- Establishment of an internal organization in order to promote the project results

Focus of speech: Sweden has a long tradition of study circles in which persons with disabilities are empowered. In this project we have developed a new form of study circle for the production of new ideas within social research. The disability movement has the initiative and invites researchers to have a dialogue about needs and ideas for future research. The result is until now more than 50 sketches of relevant research. Those have been exposed in public and commented on by the research community.

Another branch in the tree of non-formal adult education consists of the folk high schools (residential college for adult studies). In collaboration with two of those we have gathered researchers and members from the disability movement to work out criteria for participation in research. In October 2010 we plan a training course for potential researchers among our member organizations. Already educated researchers with proper impairment will take part as inspiration and role-models. Residential College for adult studies provides a suitable environment for empowerment and creative dialogue.

Miguel A. V. Ferreira

Universidad Complutense de Madrid

Co-author: Eduardo Díaz Velázquez

Embodied disability: body, rationality and citizenship

Disabled people have an existence conditioned by a two-fold imperative: un-efficiency and a-normality. Their un-efficiency is the consequence of a modern prescription about body productivity, associated to a suspicion of un-ability and uneconomic for the capitalist way of production; the a-normality is the consequence of a cultural matrix that has developed occidental culture: people with disabilities are fragile, imperfect, non adjustable to perfectibility, rationalist human canon.

People with disabilities are people with so much human bodies, because of their obvious imperfection and finitude, so much human to fit with perfectibility rationalist canons. They are the expression more evident of how human being is something more, and something less, than what our cultural tradition says that human being is: a knowledge transcendent subject with infinity and immortality power.

People with disabilities are people first, people with bodies first, and as people and bodies cannot develop a complete "human" life because we (all of us) condemned them to a-normality and un-efficiency; both conditions being embodied and produced by our own socio-economic-cultural regimen of functioning.

If we want to comprehend this body dimension, in which are situated domination strategies, also them produced by normalization technologies created by modernity, it is necessary to review our epistemological basis in order to understand disability reality. Our understanding patterns, devoted to dualisms, dichotomies and analytical procedures, contribute to consolidate these categories. From people with disabilities concrete, personal, embodied and subjective experience emerge the evidence of a field (Bourdieu) that submit them to a domination created by the permanently unfulfilled promise of curation (that is, as Bourdieu expose, an Illusion). By the same time, the structural framework in which this bodies domination is developed, is encoded by Foucauldian conception about disciplinary modern technologies, modern knowledge-power apparatus.

With this two-folded theoretical-methodological axis, it will be possible to access to a more accuracy comprehension of citizenship condition of people with disabilities in occidental societies, both in its normative-law and substantive-experience dimensions. When the normative advances trying to promote personal autonomy and formal equality are not producing and effective change in existence conditions of people with disabilities, we have to understand that effective mechanisms governing their existence are in another place.

Overcoming formal prescriptions expressed in the daily people with disabilities existence, only will be possible revealing the structural, modern and capitalist key constrictions that make these human beings non-adjustable bodies for our conventional regulations ways of functioning.

Joanna Ferrie

University of Glasgow

Co-author: Nick Watson

The Third Sector, Mental Health and Routes to Employment

The third sector has had a long history of developing and managing programmes for people with mental health problems and their journey to employment. In this paper we draw on a data collected as part of a recently completed literature review into the evaluation of the role of the Third Sector in this area. The literature examined would suggest that successful programmes take a person-centred approach, are culturally sensitive, incorporate peer support and work with employers within local communities. Less successful programmes focus only on finding work, not on sustaining placements. It is also clear that much of the work on promoting employment for people with a mental health problem is located within what is termed a 'recovery framework'. Much of the focus of the work is on changing the individual.

There is now widespread recognition that mental health problems co-exist with other societal problems and that people and policy is now developing around the concept of what is termed multiple and complex need. Factors such as stigma, homelessness, poverty, poor education qualifications show that adults with mental health problems often have interlocking needs that cross more than one social policy arena. The stigma associated with mental health problems leads many people to go to enormous lengths to hide their additional needs, thus exacerbating symptoms of stress and anxiety.

Yet rarely do these additional barriers become the focus of employment programmes. Despite a large volume of research that suggests that employers are reluctant to employ many people with a mental health problem, there is much less work in tackling and challenging the discrimination experienced by people with a mental health problem.

Further the economic downturn is likely to increase the number of people who experience poor mental health and poverty. A tightening of the public budget has also impacted negatively, limiting funding for third sector organisations. The paper will critically evaluate the current response to supporting adults with mental health problems into employment. It will highlight the challenges faced by third sector organisations and call for greater scrutiny of current programmes and to consider the wider impact of mental health problems, in order to provide successful routes to long-term employment.

Rebecca Fish

Lancaster University

Research with women living and working at a forensic learning disability service

This project will use qualitative methods to investigate women service users' experiences of being part of a minority group in a forensic learning disability service. There is very little research relating to women with learning disabilities living in secure services; the greater proportion of the literature available relates to women using mental health services. Although it has been argued that these women have similar needs, it is important that both groups are represented in the literature.

The Trust is a specialist learning disability service, which consists of low and medium secure units as well as a rehabilitation service. Women are a minority in the service – representing just 22% of the total service users. The research will be an ethnographic study of the unit, incorporating participant observation and interviews with service users and staff. Informed by the four guiding principles of the Department of Health strategy Valuing People Now (2009): rights, independent living, control and inclusion, the research will explore women's experiences, along with the staff who support them.

Fernando Fontes

Centre for Disability Studies, University of Leeds

The Disabled People's Movement in Portugal: impacts and outcomes

The development of the Portuguese Disabled People's Movement is a post-1974 reality. Despite earlier collective initiatives of disabled people dating back to the 1920s, most of the organisations were impairment specific, non-politicised and headed by non-disabled people. As with other areas of Portuguese society, the democratic revolution in 1974 signalled a shift in disability collective action. The emergence of new organisations which were politically active and the takeover of some of the previously existing organisations by disabled people laid the foundations of the Portuguese Disabled People's Movement.

Despite emerging around the same time as the Disabled People's Movements in the UK and in the USA, the Portuguese Disabled People's Movement was never as prominent and/or influential as its counterparts. Several reasons may account for that, such as the political impact of a long lasting dictatorship, the absence of a strong welfare state, the reliance on civil society to provide for social services, the fragility of Portuguese participatory democracy or the lack of politicization of disability. The Portuguese Disabled People's Movement is, thus, a localised phenomenon whose features resemble much of the characteristics of the Portuguese society. Despite the differences between the Portuguese movement and its international counterparts, its role in reconfiguring the meanings of disability, as well as the role of disabled people in Portuguese society and in Portuguese politics and policies, is indisputable.

Partially based on my PhD research about social citizenship and the Disabled People's Movement in Portugal, this paper investigates, firstly, some of the most significant characteristics of the Portuguese Disabled People's Movement and, secondly, its consequences in the lives of disabled people in Portugal. Thus, I will explore the way in which dominant perspectives about disability have impacted on the movement and on the politicisation of disability in Portugal, as well as related changes in disabled people's positionality in Portuguese society.

I suggest that the lack of politicization of disability in Portugal did not prevent the movement from developing a counter-narrative of disability based on the ideas of rehabilitation and aptitude to work. The difference in relation to the UK resides in the fact that the Portuguese movement did not opt to decentralise the attention from the body to the society. In fact, the corporality of the impairment is central for the construction of disability and of a disabled identity and, therefore, it is of paramount importance for the arguments used by the movement. Moreover, I argue that it was this new understanding of disability and of being disabled which challenged oppressing traditional views of disability and of disabled people in Portuguese society, generating social, political and cultural change.

Michael Glennon

University of Nebraska

Disability, Ideology, and the Professional Articulation of Trans-institutional Human Rights: a critical discourse analysis of a conversation between three human service professionals on an informal review of Nebraska's only short term service space for "people with developmental disabilities" in times of "behavioral" crisis.

In 2007 I conducted an ethnographic engagement with a variety of people at a number of locations in Nebraska's 40 year old "community based human service system for people with developmental disabilities (DD)". While there, I was invited by a contact, a "Program Director", to accompany her and two other human service professionals on a walkthrough. The walkthrough was an informal internal review of one of their agency's newest facilities; a facility unique to the state's trans-institutional network of private human service providers. "DIRECTION", an impossible acronym, is the name of the facility, and it is the only space in the state built specifically for "behaviorally risky" people "with DD" to inhabit and live 'between the typical group home and the institution'. It is an exemplar or epitome of the system at large, for it too spans a set of social practices and range of spaces for them situated somewhere between "the institution" and "the community".

The informal internal review, as it turned out, was in preparation for an *official* state review for licensing purposes. As such, much of the conversation during the walkthrough was tightly focused on the kinds of "rights restrictions" that remain present in the facility by way of perceived necessity, which kinds were taken out, and which kinds *they'd like to do away with* but feel powerless before other powers to act on their desiring impulse (such as the closed circuit security cameras which becomes the focus of most of the conversation). Additionally there are also to consider the kinds of rights restrictions these professional level workers their selves sanction or articulate but do not their selves necessarily detect – which is to say rights restrictions operating at a more opaque level of ideology.

While analysis will examine *critically* the disabling aspects of such discursive matters as the ethos of the facility, the agency which runs it, and the broader socio-cultural context in which they are set, it will also aim to defy a counterproductive trope found in much disability studies research on such "community based systems" and workers and professionals. In addition to reproducing disabling ideology and orders of discourse, these human service professionals also impart to their performance moments and intimations of transformative desire and a will to emancipation.

Nick Glover

National Health Service

'High Functioning Autism: A Professional and Personal Account of Working in the NHS as a Psychotherapist'

The presentation will look at the possible prevalence and situation for NHS and Social Care staff who may have Aspergers or 'High Functioning Autism'. The 'gentle research' paper will look at lived experiences and strategies for coping with Aspergers. Particularly related to those having this condition and who are working in the above 'care' settings (NHS and Social Care) for both male and female adult workers. Little has so far been written on the situation (or lived experience) of staff with 'high functioning' ASD 'disability' who work in such 'care' services. There will be a basic description of the condition, but the stress of the proposed presentation is upon revealing and thinking together about how staff / workers are affected by ASD in relation to their work, and what lessons can be learnt given the recent highlighting of ASD in the UK (with an emphasis on those working and trying to survive / thrive in care services environments).

Caroline Gooding

Equality Consultant and Special Adviser to RADAR

Caroline Gooding, is an Equality Consultant and Special Adviser to RADAR. Formerly Director of Diversity Works for London, and Special Advisor to the Disability Rights Commission where she led on the Disability Equality Duty, Goods and Services and Legislative Change. She is qualified and has practiced as a solicitor. Caroline is a long term disability rights activist and for more than ten years was Chair of the Trade Union Disability Alliance.

Her publications include Disability Rights in Europe, from theory to practice Essays in European Law (2005); Blackstone's Guide to the Disability Discrimination Act (1995); Enabling Acts Disabling Laws, Disability Rights in Britain and the United States (1994); Lesbian and Gay Legal Handbook (1992). She has also published articles on disability and equality issues in Tolley's and Equal Opportunities Review.

Plenary

"Will the new equality duty deliver progress for disabled people?"

Great claims were made for the disability equality duty when it was introduced in 2005. The race, disability and gender equality duties share a common ambition to root out institutional discrimination and change the culture of public sector organizations. Each of the three equality duties was framed slightly differently, with the disability equality duty having a greater emphasis on the involvement of disenfranchised groups and a clearer delineation of what improved equality would mean.

There were some initial indications that the disability duty had begun to deliver on its ambitious agenda. However, the duties rely on the Equality and Human Rights Commission for effective enforcement. The operational difficulties experienced by that body, coupled with its failure to provide a unifying understanding of equality for the different groups with which it is concerned, appears to have led to a faltering in the momentum.

The introduction through the Equality Act 2010 of a unified equality duty extending to sexual orientation, age and religion and belief presents a new challenge for those working to promote disability equality, with concerns that it waters down the overall requirements placed on public bodies, and fails to clearly reflect the distinctive barriers confronting disabled people.

Dan Goodley

Manchester Metropolitan University

Are we ready for 'critical' disability studies?

This paper explores the deep-rooted interconnections of disability studies with insights from class, feminist, queer and postcolonial studies. Such intersections are at the heart of what we might term critical disability studies (Davis, 2006a; McRuer, 2003), where disability links together other identities as a moment of reflection that Davis (2002) coins as dismodernism and impairment and disability are interrogated as phenomena enacted at the levels of the psyche, culture and society. While critical disability studies might start with disability they never end with it: remaining ever vigilant of political, ontological and theoretical complexity. Critical disability studies contest dis/ablism. This paper draws on two ongoing research projects and a forthcoming text (Goodley, fc2010) and will explore a number of critical disability studies themes including (i) bodies (and minds) that matter; (ii) self and others; (iii) discourses and institution; (iv) writing back; (v) resistance: Cyborgs and hybrids; (vi) disability activism; (vii) profession(al)s allied to the community

Ruth Gould

CEO DaDa – Disability & Deaf Arts

Ruth has been leading DaDa since Feb 2001 and been the driving force behind DaDaFest, an award winning Disability & Deaf Arts festival which now has an international following.

Ruth was diagnosed as having a hearing impairment at the age of six after one of her teachers realized that this was the reason she didn't talk or respond in class.

After not being able to pursue any of her desired career choices, she came upon the arts quite by accident after the birth of her first child in 1981. She gained a place in Liverpool Training in 1983 at Liverpool Theatre School and developed skills in physical theatre, dance & performing, starting to experiment with song & British Sign Language in 1986.

In 1988 she left the UK to attend the School of Creative Arts in Sydney, Australia, the next year becoming a performing arts tutor. Whilst there she developed large scale productions and later went onto deliver arts events in New Zealand, USA and Eire.

Ruth returned to Liverpool in 1992 and has since worked to develop work in Merseyside's Creative Industries sector. During this time she came across the Disability Arts Movement and is proud to now be leading a key organization within this field.

Plenary

Disability Arts: Ghetto-Blasting?

Disability and Deaf arts are a way of promoting not only 'arts for art's sake', but also to allow deeply held issues from the lives and experiences of disabled and deaf people to be articulated and expressed through creative means.

In an ever changing society, and one where social inclusion has been heralded as an achievement towards a more 'culturally diverse' Britain, the contribution of disabled and deaf communities have arguably not been elevated to the same level as other groups.

In this talk, we will touch on such things as where it has the 'movement' come from, what has been its impact, who are its audiences and more significantly, where is it going?

Anat Greenstein

Manchester Metropolitan University

Children and vulnerable adults: Risk, responsibility and exclusion in the life of disabled people.

This paper will look at how notions of risk and risk aversion are played out in the context of 'psychological development' to justify certain forms of exclusion and oppression of disabled people. "Risk society" is a term that emerged during the 1990s (e.g. Beck, 1992; Giddens, 1999) to describe the manner in which society organises in response to risk, and the ways in which the ability to take risks and to protect oneself against disaster have become means of social stratification. Another modern tool of social stratification is the psychological discourse, which portrays development as a natural and universal ascent up a ladder that leads children from a needy place associated with dependency, irrationality and vulnerability to the state of a rational, autonomous, self regulating, and responsible citizens. Under this discourse people who do not attain 'rationality' and 'independence' are pathologised and infantilised (Burman, 1994; 2006). The ways in which notions of 'risk' and 'psychological ability' interact to justify exclusion and oppression of disabled people will be examined using 3 examples: 1) The discursive shift from 'women and children' (now used mostly in contexts of humanitarian aid and the global south) to 'children and vulnerable adults' as groups in need of special treatment or protection, alongside diminished responsibility and secondary civil status. 2) The increase in identification of 'Emotional Behavioural Disorders', especially among black and working class students and their growing segregation in special education settings (OfSTED, 2004), which is concurrent with the growing prominence of the concept of 'Emotional Intelligence'. This concept, rather than admitting interpersonal and social factors to the contexts of development and participation, serves to further individualize even the most social interactions, as "Emotional Intelligence" is assumed to be a measurable trait, located within the individual and unevenly distributed throughout the population (Burman, 2009). 3) The increasing demand for CRB checks from service providers, researchers and volunteers, and the intricate ways in which they are constructed as benevolent on the one hand and dangerous on the other hand.

Samuel Grove

University of Nottingham

Co-author: Nicola Grove

Intellectual Disability and War

Highlighting the need for further research, this paper offers a preliminary review of the available information and data regarding the involvement of people with intellectual disabilities (IDs) in armed conflict. Literature searches reveal a paucity of information, with most statistics relating to disabilities which are caused by war, rather than the effects of war on people with pre-existing disabilities. The specific ways in which people with IDs may be vulnerable during war are outlined, as well as the ways in which they have been actively involved. The paper raises questions relating to the perceived status of people with disabilities as vulnerable victims, using genealogy as a framework.

Nicola Grove

University of Nottingham

Flying with the sparrow: the representation of people with intellectual disabilities in African tales

Stories connect the storyteller with his or her own life; with the listener; with others in society and other worlds; with moral judgements; with the bigger cultural narratives which influence the identities of individuals and communities. Through stories we are exposed to meta-narrative constructs about disability, which we can interrogate, challenge and change.

Openstorytellers, the first company of storytellers with intellectual disabilities, are conducting a long-term research project to explore the ways in which people with intellectual disabilities are represented in stories from different cultures. The aims of the research are to explore a range of traditional stories from different cultures that have direct relevance for people with learning disabilities; to work with storytellers and communities of people with learning disabilities, their families and professionals to develop ways of telling these stories that are empowering and positive, and to promote the cultural identity and cultural exchange of people with learning disabilities. This paper will present findings from a study tour of South Africa which included interviews with storytellers, people with disabilities families and educators. We explore the way in which negative representations are often underpinned by a more nuanced view of the causes and outcomes of disability.

Chris Grover

Lancaster University

Co-author: Linda Piggott

Disgusting! Understanding the introduction and effects of Employment and Support Allowance

This paper focuses upon the introduction of Employment and Support Allowance as a replacement for the main income replacement benefit, Incapacity Benefit, for disabled people in Britain. The paper uses the concept of disgust to explain how disabled claimants have become defined as being Other, as being part of a 'welfare class' that is economically and morally burdensome. It argues that despite its social inclusion rhetoric New Labour's welfare policy unfairly targets groups such as disabled people and is politically and socially divisive in the sense that it invites condemnation of one group of people by another. Rather than engaging in political discourse New Labour's strategy has been to use the media to promote its policies. In this context, it is argued that the media itself represents disabled people as having specific traits, such as worklessness, and invites moral judgements based upon those traits, thereby producing arguments which support measures such as conditionality as a necessary solution to the 'problem' of worklessness among such people. Hence, the paper argues that disgust is one emotion which is engendered through the media as a means of creating a conviction that conditionality, for example, is a justifiable policy solution to an economic and 'moral' problem, while in social security practice medicalised understandings of serious impairments are used to measure people's worth in relation to paid employment. In this sense, the aims of social inclusion, which should be to counteract the stigmatising of disabled people and to move beyond the idea that worth comes from the ability to labour, have become conservative measures that threaten the income and living standards of disabled people. Hence, the paper concludes that the introduction of the Employment and Support Allowance represents a retrograde development for disabled people.

Jan Grue

Oslo University College

The Discourse of Disability: Personal Narratives and Cultural Constraints

What options are available to people who present themselves as disabled subjects in a public forum? This paper centres on the analysis of a corpus of brief (approx. 400 words) personal narratives published online by a Norwegian organization for people with neuromuscular disorders. The writers' presentation of themselves as disabled subjects conventionally takes the form of narratives in which the moment of diagnosis functions as the "most reportable event", and where the return to or establishment of an everyday routine, i.e. "ordinary life", marks the end of the story.

Numerous Disability Studies scholars, e.g. Tom Shakespeare, David Mitchell and Sharon Snyder, Georgina Kleege, Henri-Jacques Stiker, and Rosemarie Garland-Thomson, have explored how narrative frameworks and conventions are available both as resources for and as cultural constraints on the representation of disability and disabled subjects in literature, film and cultural history. Two related research questions are 1) what the dynamic between frameworks and scripts and texts produced by ordinary people is, and 2) what role is played by social and medical models both in the construction of such identities. These questions have direct bearing on the understanding of disability in the Norwegian organizational community, but the results of the investigation will hold wider implications for the relationship between disability theory and identities of disability.

The paper discusses the influence of culturally conventional framings of physical disability (e.g. "the mind's heroic struggle with an infirm body") on the actual narratives, but also the creative and potentially subversive strategies available to people who engage in the public construction of identities of disability. The tools that will be used are primarily those of Critical Discourse Analysis, a school of language study associated with the work of Norman Fairclough and Ruth Wodak, though elements of rhetorical theory will be applied when relevant to issues of agency, self-representation and the strategic use of language.

Ingrid Guldvik

Lillehammer University College

Political representation among people with disabilities

The theme of the paper is political representation among people with disabilities. The data used is from studies of 767 political representatives in local politics and 50 administrative representatives. The study shows that people with disabilities are underrepresented in local political assemblies. We apply Nancy Fraser's (2003) concepts redistribution and recognition to analyse the lacking representation of people with disabilities. According to the redistribution dimension the analysis shows that neither the physical conditions nor the organising of the different meetings are particularly well adapted for people with disabilities. The recognition dimension shows that representatives with disabilities are expected to be more occupied by issues concerning disability politics than other representatives. The study underlines that there is a lack of knowledge of political participation by disabled people, i.e. how they are recruited, their influence and motivation.

Niluka Gunawardena

University of Leeds

Wounded Soldiers: Biographical disruption among disabled veterans in post-war Sri Lanka

Disabled veterans occupy a uniquely gendered position. As soldiers they experience a hyper-masculine embodiment of militarism based on physical prowess, strength, discipline, aggression and state sanctioned violence. Such embodiments are equated with heroism, honour and exemplary citizenship during times of war through discourses of nationalism and patriotism. The acquisition of impairments in conflict leads to a sudden disruption in the psycho-physical cohesion of the embodied military identity which in turn causes a crisis in masculinity. Trauma associated with war adds to this sense of cognitive dissonance thus creating 'wounded soldiers'.

This paper will examine biographical disruption among disabled veterans in terms of gender and masculinity located within the socio-political specificities of post-war Sri Lanka. It will feature the lives of several physically disabled soldiers at Ranaviru Sevana, a residential military rehabilitation facility, in their efforts to negotiate their identities and reclaim their masculinities as 'wounded soldiers'. Military rank, class and marital status have a significant bearing on the life course of disabled veterans. The gendered roles of soldier, citizen, husband, father and son are redefined in response to impairment to create new forms of masculinities. Subtle changes in views about wives, lovers and mothers are also indicative of the nature of biographical disruption. The simultaneous suspicion and celebration of women in the process of reclaiming military masculinities in response to disability illustrate the non-linear and complex process of rejection, denial, compensation, passing, adaptation and acceptance of disabled embodiments. It leads to an unexpected subversion of the hegemonic masculinities and heteronormative ideals.

The paper highlights how disabled soldiers differentiate themselves from disabled civilians by citing their superior mental fortitude and military training. Some detest being objects of sympathy given their military status or masculinity while feeling that disabled civilians should be treated with sympathy due to their helplessness or femininity. Such differentiation becomes an important aspect of re-building military masculinities. The implications of such gendered narratives for disability consciousness and identity will be explored as an overarching theme in this paper.

Following the closure of a long drawn civil war spanning 25 years, disabled soldiers were portrayed as tokens of national pride. Less than one year later they are invisible and inconvenient on account of public amnesia. In their words, they are at once heroes and burdens, soldiers and civilians, disabled and 'wounded', strong and vulnerable, normal and impaired, broken and renewed, valuable and disposable. The disabled veteran is full of contradictions that lead to uncertain masculinities and unpredictable biographical narratives. This paper will provide insights into that constant state of negotiation and renegotiation and its broader gendered implications.

Aðalbjörg Gunnarsdóttir

Centre for Disability Studies, University of Iceland

Co-authors: Kristín Björnsdóttir and Hanna Björg Sigurjónsdóttir

On the road to motherhood

In most contemporary societies, women are expected to marry and have children and being a mother is commonly perceived to be an important adult role. These expectations do however not include disabled women who are oftentimes seen as dependent, unable to care for others, and discouraged by family members and professionals from embarking on the road to motherhood. This paper reports the findings of a recent qualitative study focusing on disabled women's understanding of motherhood and reproductive rights. The study also examines how the women perceive their parenting abilities and what social and cultural factors hinder their access to motherhood. Data was collected through open-ended interviews with a small group of Icelandic disabled women who do not have children. The research findings suggest that these women want to have access to motherhood and not to be judged as unfit parents based on their impairment. In the paper we will demonstrate how society, family members, non-disabled friends, the health care system and the adoption system continuously discourages disabled women from having children. The research findings indicate that disabling attitudes and prejudice shape the research participants' perceptions of their parenting abilities, which made some of them feel defeated while other women expressed empowerment and focused on finding solution to the barriers they faced regarding access to motherhood. The paper will conclude by drawing attention to the need to revise Icelandic disability and adoption policy because it does not give disabled people access to family life as parents and contradicts the UN Convention on the Rights of Persons with Disabilities.

Rikke Gurgens Gjaerum

Harstad University College

Disability Art and Qualitative Interview Research with Informants with Learning Disabilities

Interviewing informants with learning disabilities about their own aesthetic experiences is often a challenging task for the researcher. The main issue is how to provide a comfortable environment which promotes a dynamic interview process where communication and dialog can occur naturally. The eleven steps new model of the Qualitative Research Art Interview which is based on the seven steps Qualitative Research Interview Model of Kvale will be presented. The interesting aspect of the new model, seen from the disability art perspective, is the four new elements that the researcher must take into consideration when doing field work with a disability theatre group. The first element involves categorizing the interview as a 'relational praxis' with marginal groups. In order to collect interesting 'in-depth narratives' the researcher must take on the role of the 'listener', and be extra sensitive to the wishes and needs of the informants. The process of making an interview appointment with the informant can be understood as a 'pre-phase' in the Qualitative Research Art Interview. At this phase, data is generated even before the interview actually starts. This data often helps the researcher to be able to understand the informants 'life world'. The second element of the new model is about considerations of the nature of the phenomenon under scrutiny during the interview. The third element is about the metaphoric text interpretation that can lead the researcher to creative ways of studying the field of both disability art through informant narratives. The fourth element is the interaction between the nature of the phenomenon which occurs in the interview and the metaphoric text interpretation. This interaction is at times referred to as the 'qualitative dance'. The researcher looks for the 'unique' and the 'general' in order to try to understand the informant, the disability theatre and the context where the informant lives his everyday life.

Carolyn Gutman

Tel Hai Academic College

Co-author: Yoav Kraiem

Social integration: can one size fit all?

This paper critically explores the notions of social integration and inclusion that drive social policy and practice today in the field of disability in many western countries. The conceptual framework evolved during a recent study that was conducted in the north of Israel by the national disability activist organization together with a leading academic institution in the area. The ideas expressed in this paper were conceived in partnership with the participants of this unique study.

Together with the emergence of international disabled people's movements in the 1970s and their demands for equality and full participation in social life, activist organizations and emerging inter-disciplinary disability scholarship have presented alternative theoretical frameworks that view the construction of disability from a critical socio-political lens. These developments challenge the traditional perspectives of disability that frame the social policy arena. This challenge calls for the adoption of alternative moral imperatives to be aligned to concepts of equality and social justice, namely, notions of social integration and inclusion. These new moral initiatives were, and are, viewed as being the only legitimate course for promoting equal rights for people with disability. Yet, is this paradigm really the right one to follow?

In order to address this question, we first identify the prevailing power structures that dictated the moral path underpinning the adoption of the inclusion perspective. We examine how this new ideology overturned other perspectives as being illegitimate even when they voiced the subjective will of people with disabilities. We then explore the concept of inclusion and address its goal of enabling people with disabilities to live in a milieu together with non-disabled people and to function independently and competently. And we question whether the ideal of inclusion can only be applicable to people who function totally independently in the community?

This paper will also address the universality of psychological and social identity needs for all people to be with similar others and the consequences for people with disabilities who may be involved in processes that promote the idealized inclusion. We will consider the different social policy discourses and dilemmas facing people with disabilities who are forced to choose between segregative or inclusive social, occupational and educational frameworks.

We will offer an alternative paradigm for consideration as the basis for the development of social policy related to people with disabilities. This paradigm will allow for each person to choose when to integrate and when not, in which life areas and at what points in time. The experience of belonging to either one, or both of these groups is presented as both legitimate and desirable.

Elizabeth Harkness

Carlisle People First Research Team

Co-authors: Louise Townson, Rohhss Chapman

The History of People First Project

The Carlisle People First Research Team has been working together for twelve years. There are currently eight members. Most members share the label of 'learning difficulties'. The main purpose of the team is to carry out work that is of benefit to people with learning difficulties. The team works in an inclusive way.

People First groups started up in the UK in 1984 after some people went to a self advocacy conference in America. Our own local group has been running since 1990 and has seen a lot of changes over the years.

Our history has always been important to us. We designed a 'River of History' that helped us to look at how our own organisation developed. Everything that was important to self advocacy flowed into it. From looking at the history of our own group we decided to look at the history of other People First groups in the UK.

We did this by visiting a number of groups in the UK that had been working together for over ten years. Because people were interested in this we held a national workshop about the history of self advocacy groups. We designed and ran this from Carlisle People First. It was funded by the Open University and held in Birmingham.

We found out through the workshop that people shared a lot of the same problems in their groups. These were mainly about funding and getting good support. We discovered how important it was to do things for ourselves. At the end of the workshop each group went away with an action plan about how to trace their own history.

This presentation will talk about what we found out. It will look at accessible methods that can be used by people to trace the history of their groups.

Xirong He

School of Health, Community and Education Studies, Northumbria University

Poster

Parents support deaf children in Beijing of China

Background

The issue for deaf children in choosing the right school, either mainstream schools or special schools, has created many intense confrontations among the stakeholders, including teachers and staff, parents and deaf children themselves.

China, as one of developing countries, has its different histories and perspectives from other western countries such as the United States and the United Kingdom.

Teachers and staff find it difficult to pay attention to the individual special education needs of every deaf child, as a consequence of large student-teacher ratios in China.

Therefore, it is suggested that parental involvement could positively contribute to language and academic performance in regards to educating their deaf children.

Aims:

- to explore how hearing parents provide effective support for their children with hearing impairments in mainstream schools
- to explore how to find the effective strategies of home coaching and home-school partnership

Methodology

According to my professional knowledge and the research aims, qualitative methodology will be better applied into this research proposal.

Furthermore, this proposal draws partly on the grounded theory approach and narrative approach embedded in this qualitative study on the subject of the research questions.

Method

These two approaches between grounded theory and narrative approach could generate explanatory themes of human social issues, and modify the existing theories that are grounded and narrated in the data.

On one hand, this proposal will seek various data from two main methods to address the research questions, both one-to-one interviews and focus group.

On the other hand, two main sampling techniques will be used to contact the participants who could be involved in this study: one is purposive sampling, the other is snowball sampling.

Conclusion

This research could provide unique perspectives of parental education for deaf children in mainstream schools by drawing on a part of grounded theory and narrative approach, which are applied in qualitative research.

Wendy Hensel

Georgia State University College of Law

Co-author: Leslie Wolf

Playing God: The Legality of Plans Restricting People with Disabilities from Scarce Resources in Public Health Emergencies

The threat of an international pandemic captivated much of the news media in 2009. The spread of H1N1 in the U.S. ultimately prompted President Obama to declare a state of national emergency. It was predicted that hospitals would be overburdened and shortages would occur, necessitating difficult decisions about who should get access to scarce medical resources, such as ventilators and critical care beds. Although the H1N1 threat appears to be waning in 2010, there is little doubt that similar public health emergencies will arise in the future.

In anticipation of the predicted shortages, some medical and public health groups developed recommendations to guide decision-makers during the H1N1 crisis. Several of the published recommendations explicitly exclude some patients with physical or mental disabilities from critical care treatment, even when this status is irrelevant to health outcomes. These proposals conflict with the Americans with Disabilities Act and are highly problematic. In addition to denying health care to this group, they reflect the continuing stigma of disability and the diminished status society affords to people in this population.

This paper will describe the context in which allocation decisions will be made and the recommendations that medical public health professionals have made. It will explore the legality of these recommendations and their implications for people with disabilities in the pre-planning of public health emergencies in both the U.S. and internationally.

Andy Hill

De Montfort University

Crashing the Police Barriers: Experiences of a dyslexic PhD researcher, researching the experiences of adult dyslexics, using participatory methods in Higher Education

This paper explores the author's experience of being a dyslexic former police officer working for a PhD at a United Kingdom university, researching the experiences and perceptions of dyslexic police officers across England & Wales. The research is qualitative and seeks to provide a voice to the many hundreds of dyslexic and neuro-diverse criminal justice practitioners. The research is participatory and is underpinned by the social model of disability. It sits within the critical social research paradigm and seeks to identify the multiple oppressions and barriers that dyslexic police officers experience in the UK.

The research takes place against the backdrop of the continuing debate about who has the authority to conduct disability-related research, and specifically the role and authority of the disabled researcher (Barnes and Mercer 1996; Danieli and Woodham's 2005; Barnes 2008). A wide range of issues and barriers are examined; these include attitudinal, practical and procedural challenges experienced by the researcher both in terms of process and application. The paper describes the use, adaption and creative application of assistive technology, both software and hardware. The use of QSR Nvivo 8 together with standard Disabled Students Allowance-funded mind-mapping and voice to text software is also included within the discussion. The paper offers a critical reflection as to how being a dyslexic researcher, who is researching dyslexia, can be both positive, rewarding for all involved and yet extremely difficult. Emotional and practical challenges are discussed within the context of what McLoughlin, Leather and Stringer (2002) describe as the primary and secondary (or affective) characteristics of dyslexia in adults.

The paper offers a positive and sometimes light-hearted reflection of the author's experiences as a researcher. The paper concludes with a short section on what might be described by some as 'good practice' that has been developed through the pain and frustrations of the years of study undertaken by the author. It is hoped that the paper and reflections might be of benefit to future neuro-diverse researchers studying within, or away from, the academy.

Andrea Hollomotz

Manchester Metropolitan University

Are we VALUING PEOPLE's choices NOW?

'Valuing People', the UK government's strategy that aims to improve the lives of people with learning difficulties, has shaped services for almost a decade. To promote individual's choices and independence are two of the four key principles that underpin this White Paper.

This presentation assesses the impact that these changes had on the availability of choices within service settings. It draws on empirical evidence from participant observations within day services and on interviews with a sample of people with learning difficulties.

Initially it appears that respondents are indeed able to make an increased range of decisions about a variety of aspects of their daily routine, including choices about daytime activities and about their personal relationships. At closer inspection it does however become apparent that not all of these decisions are based on an infinite spectrum of options. Under the guise of choice-based policy rhetoric many people with learning difficulties are presented with a pre-arranged 'menu of choices'. For instance, a person may be free to choose what activities they will participate in at their day centre, but they may have limited control when deciding whether to attend the service in the first place. Individuals are often acutely aware of the boundaries beyond which they cannot exercise control. Some are eager to remain within these, in order not to be seen as disobeying staff.

This presentation concludes that, although there appears to be an increase of options within the margins of a pre-arranged 'menu of choices', this change does not meet the criteria set out by 'Valuing People'. Only selections from the infinite range of options that are available to non-disabled people would promote true independence. Some people with learning difficulties may require assistance when making independent choices. Suggestions on ways in which this may be provided without infringing the range of available choices are made.

Lee Humber

Open University

From 'fixers' to technocrats: How has supporting people with learning difficulties towards employment changed over the last 30 years?

I look at how supporting people towards employment has changed since the beginning of the 1980s based on oral history interviews of people with learning difficulties and social care workers in the London Borough of Camden. Focussing on the specific in this way provides me with an opportunity to reflect on a process of local and nation political change over the past 30 years.

At the beginning of the 1980s an adult training centre in Camden offered training opportunities and paid work for a small number of people from north London. I consider conflicting accounts of life in an ATC and ask how developmental this form of employment support was.

In 1984 a sheltered work opportunity was set up in Camden by a local voluntary sector organisation, the Camden Society. Also, the Local Authority provided a small number of jobs in local government. I provide reflections from care workers and people with learning difficulties on both of these employment routes.

Since the mid 1990s the supported employment model has come to dominate. Here, central Government fund supported employment providers to source mainstream employment opportunities and support people towards and in them. I will examine how effective this model has been through an analysis of its historical development, drawing on the reflections of those involved.

I explore differences and continuities over the period. Also, I examine an older history of people supported into work by local communities and ask have the communities been 'professionalised' out of their employment supporting role?

Moritz Ingwersen

University of Cologne

This is not for you: Perception and Dis|ability in Mark Z. Danielewski's *House of Leaves*

The fifth chapter of Lennard Davis' seminal study *Enforcing Normalcy*, "Deafness and Insight", examines instances of deafness, muteness and blindness as literary representations of dis|ability. Davis' aim is to transgress the limitations of a simplistic analysis of the conventional inscription 'characters with disabilities' in favour of a more substantial disclosure of the cultural assumption that ground the designation of dis|ability in the first place. Building on Davis' vision of "Deafness and Insight" as "a prolegomenon of sorts to a future study of the complex interactions between the body, the text, and the world" I am considering a work that has been hailed as the experimental novel of the 21st century - Mark Z. Danielewski's *House of Leaves*. In terms of its audacious play with typographic form (e.g. the use of Braille and crossed-out sections), multilayered narratives, and, above all, the use of silence and blankness as major literary tropes *House of Leaves* invites the critical pursuit of Davis' concepts of the blind moment and the deaf moment as literary modalities.

In addition to being attributions of sensory deficiency, the labels 'deaf' and 'blind' have come to be imbued with signification within the epistemological dynamics of reason and unreason, knowledge and ignorance. These ideological metaphorizations of physical difference (formerly: 'impairment') will thus be scrutinized at the intersections of body, text and world, challenging not only the fundamentals of cultural criticism but the axiomatics of anthropological philosophical dogmas in general.

When Dis|ability Studies scholar Licia Carlson proposes "to think of the philosopher-as-animal in the context of intellectual disability" this evokes Gilles Deleuze's and Felix Guattari's notion of becoming-animal. One condition of the possibility of meeting Davis' call for a deep-structure analysis of literature is, in fact, the Deleuze/Guattarian becoming-other because it effectively challenges the hegemony of ontological binarisms.

The consideration of *House of Leaves* in terms of becoming-dis|abled, understood as an over-determination or diversification of sensory perception, might offer a denaturalization or deterritorialization of dis|ability, hinting at the permeability of the rupture within the contested term. I am inviting a reading of *House of Leaves* that entails the de-sedimentation of multi-sensory perception by embracing the omni-presence of absences (visual, aural, ideological) within the text as instances of 'disablement'.

Vilborg Jóhannsdóttir

School of Education, University of Iceland

Co-authors: Freyja Haraldsdóttir and Rannveig Traustadóttir

Independent Living – Lessons from Iceland

Since its origins in the US in the 1970s the Independent Living Movement has gained recognition as one of the most influential movements promoting self-determination and equal opportunities for disabled people. The independent living ideology, principles and practices have been developed internationally and have enhanced solidarity and networking among disabled people and their allies. Independent living has also been one of cornerstones in moving away from institutional care towards effective support for community living. Based on the independent living philosophy innovative practices in independent living (such as personal assistance, personal budgets, peer support and user-controlled centres for independent living) have been developed by disabled people making it possible for them to take control of their own lives. Most European countries have policies with clear statements supporting independent living and some form of independent living schemes. However, there is a wide range in how these are being practiced with some groups being excluded e.g. people with intellectual disabilities.

A few European countries lack policies on independent living altogether and Iceland is one of the countries that has no public or legal support for independent living. Only a handful of people with severe physical impairments in Iceland currently receive direct payments that allows them to hire personal assistants and these provisions are defined as “experiments”. In this paper we provide our analysis of why independent living did not take hold in Iceland when it was being adapted by other Nordic countries in the in the 1980s such as in Norway and Sweden. Independent living is based on principles of self-determination, empowerment, full citizenship and human rights and in countries where the independent living philosophy has been strong it has been one of the important tools to combat social exclusion and discrimination. This important voice has been missing in Iceland. In the presentation we reflect on what this has meant for the promotion of disability rights in Iceland.

The beginning of independent living in Iceland was manifested by a group of disabled people and their allies a couple of years ago. This group was instrumental in the establishment of the Association for Independent Living in 2009 and the first user-led cooperative on personal assistance in 2010. Iceland is currently going through multiple changes on many levels. The collapse of the banks and the many scandals around that has created political turmoil and economic hardship. In the middle of this the affairs of disabled people have been decentralized. In our presentation we will discuss some of the lessons we have learned from our study of the establishment of independent living in Iceland. The paper is based on our on-going participatory research project which focuses on independent living in Iceland in an international context and is based on involvement in the Icelandic IL movement and interviews with the leaders of the movement both in Iceland and internationally.

Bente Lind Kassah

Harstad University College

Disabled Women in Ghana: Discrimination, violence and emotional work

In most societies, disabled women experience various forms of discrimination and violence which have varied effects on their lives. The inevitable consequences are often reduced participation in private and public activities. This paper aims at providing an understanding of discriminatory practices and institutional violence which women with disabilities experience in Ghana. It is also to update knowledge on the processes that shape and reshape disabled women's female identity. Awareness creation and professional guidance to reduce psycho-emotional disability is another important goal.

Data for this paper was collected from five female workers at a rehabilitation centre in a Ghanaian city and three leading members of the following organizations; Action on Disability and Development, Ghana Society for the Physically Disabled & Agbelengor NGO after informed consent. The female workers have been disabled since they were children (2-3 years). Four of the women never married (single parents), one is divorced. Data was collected from female informants using in-depth interviews and two focus groups. The topics discussed centred on the experiences of disabled women and how they cope with their situations. The main questions to answer include: What are the discriminatory practices experienced by disabled women in Ghana? How do these practices affect their lives? How do they cope with these experiences?

The main findings are that disabled women are constantly faced with rejection and institutionalized violence. They experience discrimination from their fathers, partners, partner's family, employers and disabled peoples organizations. The informants felt being forced into atypical female roles. They are not regarded as potential housewives or attractive marriage partners. The informants are also given less priority when it comes to education and work. They experience psycho-emotional problems and depend on emotional work as a coping strategy.

Theoretical perspectives to be used in the discussions include institutionalized violence, psycho-emotional disability, stigma and social network theory.

Alexander Kwesi Kassah

Harstad University College

Children with Learning Disabilities in Ghana: On Human Rights Violations

Even though violations of the rights of disabled people are common, such issues remain mostly undocumented open secrets in many countries. The paper is aimed at creating awareness on some of the taken for granted violations of human rights of Ghanaian children with learning disabilities. The study is to discuss and provide an understanding of what constitutes and sustains human right violations and ways to minimise if not completely eliminate such violations. The study is also meant to capture the attention of stake holders engaged in efforts to empower children with learning disabilities in Ghana. The main questions to address include the following: What human rights violations do children with learning disabilities face in Ghana? Which stories and theoretical views throw light on the issue? How can violations of human rights of children with learning disabilities be reduced?

My presentation is a preliminary study based on qualitative interview data from three key informants after informed consent in Accra-Ghana. The first key informant has a daughter with learning disabilities, owns a private school for children with learning disabilities and heads an awareness creation organisation for parents of children with learning disabilities in Ghana. The two other informants are special educationists. One is a policy maker and administrator at a special education unit of the Education Ministry and the other is a deputy head of a special school for children with learning disabilities.

The interviews were tape-recorded, transcribed and stories extracted for analysis. Five of the stories are based on information from parents whose children attend the school of the first key informant. The sixth and seventh stories were collected from the second and third key informants respectively. The chosen method has its lapses as the stories were not directly from the original sources, the children and their parents. On the other hand, the method is appropriate due to the sensitivity of the study theme and time limitation. Also the stories collected are informative and credible.

Stories about the undesirability of the “unwanted other” are not new. Disabled people in developing countries have faced and continue to face various forms of human rights violations. The creation of “the other,” social order and pressure to normalise, social stigma, social devaluation among others are theoretical focuses that will be central in the discussions.

Sarah Keyes

Northumbria University

Mutual Support. An exploration of peer support and people with learning difficulties

This conference paper will present a model of 'Mutual Support' as collective support that challenges assumptions around the role and impact of people with learning difficulties supporting one another. This model formed the basis of a recently submitted PhD research project at Northumbria University. The emphasis of the presentation will be direct quotes from the people with learning difficulties whose views were central to the developing model.

Mutual Support is rooted in the self advocacy movement, building on the strength of support that has been key within the movement by exploring in depth the role and scope of peer support. The direct accounts were based on support given and received within two pre-existing settings: an Independent Theatre Company that uses Forum Drama to facilitate changes in attitudes and policy, and a course within a secure setting that was facilitated by people with learning difficulties who mentored small groups.

The research process embraced an inclusive approach to research with people with learning difficulties, prioritising meaningful research interaction that was accessible and guided by participants. Meetings with advisory groups of people with learning difficulties were intertwined with individual experienced-based narrative interviews. The outputs of the project were developed from feedback and evaluation groups within each of the settings.

The nature of support explored included practical support, emotional support, encouragement and teamwork. The idea of what makes a good supporter was also explored, as well as the role of peer support within teaching and learning. The inclusion of non-disabled allies, based on interdependence that enables self determination and empowerment, was also explored.

The model outlines the effects of peer support in breaking down barriers to inclusion: ambitions are realised; people are able to participate more fully in activities; there is a reclamation of the dignity and respect so often denied people with learning difficulties; people who have been mentored become mentors themselves; people with learning difficulties outside of the immediate context are supported; and other people are educated about issues of importance.

Birgit Kirkebæk

VIKOM and HSHS

Professional omnipotence and impotence viewed in the light of disability history research - especially in relation to people with developmental disabilities

As a researcher in disability history, it has occurred to me that during my documentation on the history of people with developmental disabilities in Denmark (from 1880 to 1987), I have never encountered reflections on possible mistakes made by professionals in the archive material (Kirkebæk 1993, 1997, 2001, 2004, 2007). This has frightened me and led me to reflect upon the roles that professionals assume in the space between omnipotence and impotence (Kirkebæk 2010). What can experiences from history contribute within our time - where the number of diagnoses is escalating and the road from diagnosis to use of a certain method is simplified as a result of the focus on (quick) results in evidence based research.

The term omnipotence refers to the "dress" of ethics and competence that the profession wears when claiming its scientific character. The term impotence refers to the "undressing" of the good intentions of professionals shown in disability history research. The concepts refer to the front and backside of interventions - to the relation between the good we want and the bad we do. Between the hope of improvement we have, and the people who have to put up with our efforts - without being asked. In the impotence of the affected, we see the face of the omnipotence. It can be impotence of those who are not seen as human beings, but rather as objects for improvement who must be adjusted, corrected and normalized. And it can be the impotence of those who do not see their good professional intentions being successful. When professional impotence becomes too prominent, professional omnipotence is just around the corner - materializing itself in the form of rigid programmes, use of certain methods and treatment manuals - without empathically considering the perspectives of those affected.

Anna Margareth Kittelsaa

NTNU Social Research

Creating meaning in a difficult situation - migrant families' experiences of having a disabled child

When families experience, either by birth or later, that their child is disabled, they have to face a variety of challenges. The research literature places such challenges into two broad categories: problems with meaning and acceptance and practical adjustments to daily living with a disabled child. This paper focuses on how migrant families with disabled children in Norway cope with their daily lives and how they create meaning in their situation. How do they understand disability? Do they face the same challenges as families with disabled children from the majority population? Do they have other or additional problems because of their status as immigrants?

Migrant families are for various reasons seldom included in studies about Norwegian families with disabled children, and there are also few particular studies about such families. Thus we have a limited knowledge base regarding their lives and experiences in our society. A dominant understanding among professionals has been that culture difference is a major challenge, but this understanding has only limited support in the literature. International studies conclude that differences in living conditions, level of education, health status and differences in housing standards explain more than cultural differences. There has also been a tendency to overlook the diversity within the immigrant population.

This presentation draws on a qualitative study with 50 migrant families with disabled children, and more than 100 professionals working close to these children. The data sampling was carried out during 2008 – 2010 in three different municipalities in Norway. Whenever necessary, professional interpreters were used when interviewing the families. Both families and professionals were interviewed with semi-structured qualitative interviews, and the children were observed in kindergarten or at school. The children are between two and twelve years of age. Most of the children have multi diagnoses, usually intellectual disability combined with physical impairments. The families have various backgrounds, with respect to nationality and language, period of residence in Norway, migration history, and living conditions. The aim of this study is to gain more knowledge about challenges in daily life for migrant families with disabled children, and to develop strategies for better collaboration between the migrant families and the service system.

Oliver Koenig

University of Vienna

Between Exclusion and Inclusion: Co – constructing life Stories of and with people with intellectual disabilities.

The presentation is part of the presenters PHD thesis which is being carried out as one part of the ongoing basis research project “Experiences of participation in the vocational biography of people with intellectual disabilities” (2008-2013) at the Department of Education and Human Development at the University of Vienna, funded by the Austrian research fund (FWF - stand-alone-project number P20021). The Aim of the PHD thesis is to examine if and how experiences of participation and/or exclusion in the (vocational) biography of people with ID shape their subjective life and future perspectives as well as their views of work, and to identify social and/or institutional as well as individual (in terms of resilience) factors and barriers which promote or impede Self-determination in various areas of life from the perspective of people with intellectual disabilities.

Within a participatory framework a qualitative longitudinal research design has been carried out conducting a series of biographical life course interviews with twenty five adults with intellectual disabilities (aged between 22 and 52 years) in diverse vocational contexts (sheltered and open employment) over a two year period. The goal of the interviews was to compile the life stories of the research participants by using an interview style that was as narrative as possible whilst employing diverse creative sources of information retrieval like self managed research diaries or one way cameras, and to document and reflect upon changes in the life situations of the research participants. The life stories are constantly being analysed based on Charmaz constructivist approach to Grounded theory, as it places a strong emphasis on mutual construction of meaning and is thus highly compatible with participatory research approaches. Therefore the presenter placed a high importance on a constant process of individual and collective Validation of the evolving concepts. The Act of collective Validation is carried out together with the project’s accompanying reference group which is composed of twelve Self Advocates who meet together with the other researchers on a regularly basis. In the reference group meetings which usually last two days the reference group members are conducting focus group discussions around central themes of the project, co-interpreting the life stories and co-constructing and upon the evolving theoretical concepts.

Within the presentation the presenter aims to focus on the PhD’s methodological orientation which tries to develop a constructivist approach to collaborative theory construction. Therefore excerpts from contrasting life stories that have been analysed with the reference group will be presented to highlight the significance of the contribution of people with intellectual disabilities to theory co-construction. The presentation will finish by giving first evidence on the overall theoretical insights and hypotheses that can be derived from the PhD thesis and its findings.

Susanne Langer

Division of Clinical Psychology, University of Liverpool

Co-authors: Michelle Collins, Vicki Welch, Emma Wells, Chris Hatton, Janet Robertson, Eric Emerson

The role of transport in enhancing the positive impact of short breaks for disabled children and their families

This paper reports on findings from research into the effect of short breaks on the lives of disabled children and young people and their families. The study was funded by the UK Department of Children, Schools, and Families and carried out by the Centre for Disability Research (CeDR) at Lancaster University.

Short breaks cover a diverse range of respite and leisure provision for disabled children and young people, including overnight stays as well as after-school clubs, leisure activities, befriending services, and holiday playschemes. Unlike traditional respite, short breaks are intended to provide both enjoyable experiences for the child or young person, and a break from caring for their primary carer. Our research showed that transport could significantly affect whether a short breaks constituted a break, or rather imposed further demands on often limited resources, such as time or money. However, transport's potential to diminish or enhance the effect of short breaks was rarely acknowledged by parents, providers or local authorities who all tended to treat transport as secondary to the short break itself. We ask why this was possible and how did it influence the provision of short breaks and their impact on the families using them?

We begin by outlining the pivotal role of mobility – a term that we understand to extend beyond transport to encompass accessibility and movement – in the lives of disabled children and young people. Disabled children and young people experience considerable difficulties when accessing short breaks, and we suggest this is a consequence of the way transport and accessibility have been framed in current policy discourse rather than a reflection on disabled children's and young people's mobility. We contrast the ideal image of the autonomously existing individual of policy discourse as it can be found in documents relating to short breaks, access and social exclusion, and young people, with an alternative formulation of personhood. Developed recently in social anthropology and sociology this approach stresses the role of relationality and of practices of relatedness in the creation of persons and therefore has the potential to highlight the agency of disabled children and young people and their families. We will conclude by asking what changes are called for to enhance the positive benefits disabled children and young people and their families can derive from short breaks.

Yvonne Latham

Lancaster University

Making Connections: ICTs, Disability and Independent Living

There are many 'voluntary sector' led attempts which use personal computers to facilitate improved participation of disabled people in social and economic life ('digital inclusion'). However, the organization and longer-term outcomes of such schemes have tended to remain under-researched. The proposed paper adopts a long-term focus on the challenges and workarounds that characterise successful or failed attempts by disabled people (typically using off-the-shelf applications for affordability and support reasons) to ensure meaningful connections.

Much of the research on 'digital inclusion' schemes of this kind tends to be conducted through questionnaires, and often suffers from a 'box-ticking' approach to issues such as 'installation' and 'ICT use' that tends to leave open questions regarding how any challenges were actually resolved (or not) in practice. Furthermore, an often extensive reliance on on-line interviews and questionnaires inevitably leaves non-users unaccounted for. Similarly, research often tends to adopt short-term approaches which overemphasise ICTs' "potential to improve disabled people's lot" (Sheldon, 2004) and thus fail to give a clear picture of what form (the hoped for) 'digital inclusion' did take in practice. Such research therefore tends to focus on end states (before/after) at the expense of questions of processes and practices.

This, the paper argues, is a critical omission since voluntary organisations which are the most common channel for digital inclusion schemes (Social Exclusion Unit, 2005) are unlikely to possess optimal equipment or support. What is often missing in this literature therefore, are accounts of how disabled people and their helpers "muddle through" the technical, support and other challenges they face.

Drawing on qualitative research currently underway with a NGO, the paper focuses on the ways in which disabled people are able (or not) to make use of information technology in their homes, and the challenges, workarounds that are involved in their successful or failed attempts at becoming 'connected'.

Accordingly, the paper engages with the following questions:

- What strategies and practices facilitate the ongoing and sustainable social connection through ICT mediated networks?
- In enacting these strategies and practices, how do disabled people, their carers and other relevant actors negotiate the problems, constraints and opportunities they encounter?
- What constitutes, for them, an ongoing and sustainable physical and social connection with and through ICT?

Bridget Tracey Leadbeater

University of Derby

Embezzling from disability studies ideology in a quest for inclusive agricultural research methodologies

The overarching aim of the research project was to study the impact of the adoption of banana tissue culture plantlets by small scale farmers, in central Uganda within the Buganda culture, particularly for women . Participation of farmers, encompassing their perspectives, inclusive of socio-political, cultural, physical and human facets of 'lived experience' seemed the most congruent approach. The study involved discussions with Non-governmental Organisations, scientists based at the National Agricultural Research Organisation, civil servants and most importantly small scale farmers, over a 4 month period.

However, during the field work, self reflection as to the role of the researcher within the process of discovery became pertinent. As a researcher with a disability, being aware of the 'uneven ground' created by the socio-political environment, the unequal acceptance of differing 'knowledges' and unbalanced power relationships caused are interwoven into my everyday life. There seemed to be asymmetry in the recognition of 'expert' and farmers 'knowledges' that needed to be addressed within which, I sat at the centre. Aware of structural and institutional patriarchy and prejudice; feeling the weight of the invalidation of people with disabilities, and that of the livelihoods of rural small scale farmer in Uganda, required genuinely inclusive, power sharing research methods.

In the presentation I shall explore the search into disability studies paradigms, the understandings extrapolated and how debates concerning the structures of disablement have shaped and influenced mainstream agricultural research techniques in the study. 'Lifeworld' methodology (Hodge 2008), an approach adapted to acknowledge the validity of experiences disabled people of varying abilities live through inspired the research ideology. Eliciting consent from farmers for the research necessitated an innovative and appropriate process made possible by exploiting new technologies and disability studies methodologies. The farmers are regarded as the experts within their context, so enabling farmers to own, in part, the research process and validate the ways of 'finding out' was vital.

The study appropriated aspects of Participatory Action Research (Chambers 1996; Mikkelsen et al 2005; Hulme et al 2007), bio-feminist approaches to enquiry (Shiva 2003; Moser and Shiva 2002; Mies and Bennholdt-Thompson 1999) and disability studies theory and research practice (Davis 2002; Shakespeare 2008). It is hoped the inter-disciplinary nature of this research highlights the benefit of more universal emancipatory and relevant research methods.

Kirsty Liddiard

University of Warwick

“There’s more than one way to skin a cat”: Disabled Sexual Stories and Gendered telling

Society de-genders and de-sexualises the lives and bodies of disabled people (Shakespeare 2000; Thomas 1999; Morris 1991). Never-the-less, sexual politics for disabled people has been sidelined within both academic and activist contexts which have instead favoured foci on more structural and ‘public’ oppressions (Finger 1992). Thus within society disabled peoples’ sexuality/ies, for the most part, remain positioned as non-existent or sexually inadequate. Where sexuality is acknowledged, it becomes dark or fetishized (sexual abuse/devoteeism), or immoral (facilitated sex/sex workers). This research, currently in its early stages, focuses on the ways that such negative constructions, which are maintained through structural, physical, social and cultural spheres, affect the lived experiences of sexuality and relationships for disabled people; and more importantly, how disabled people manage and negotiate their sexuality in the face of such constructions.

Through a narrative and multi-method approach, men and women with physical and sensory impairments have voiced their individual ‘sexual stories’ on their terms. Drawing on data collected so far, this paper examines the different ways in which women and men talk about their experiences of disability and sex, and the ways that they engage with research of this kind. This paper will then explore how disabled women and men have presented their experiences within the research; how the telling of a story is gendered, and how storytelling becomes a gendering process in itself whereby narration is utilized as a tool to (re)construct gender and sexual identities.

Ema Loja

University of Porto

Co-authors: Emília Costa, Isabel Menezes

Disability, embodiment and political identity

The dominance of the medical categorization of impaired body as abnormal, inferior and sub-human affects not only the potential physical capital vested in the disabled body, but also its cultural and symbolic value as a broken, incompetent, powerless, and dependent body (or a body without a subjectivity) (Huang & Brittain, 2006), leading to a personal narrative of 'tragedy' followed by 'heroic' efforts at self-adjustment (Hansen & Philo, 2006).

In fact, the medical model has been contributing for a hierarchy of bodies that determines the distribution of privilege, status, and power (Garland Thomson, 1997) by validating the processes in which 'normal' bodily forms monopolise physical, symbolic and social capital (Gottfried, 1998).

Despite the fact that the mark of physical disability is in the body (Stoer, Magalhães & Rodrigues 2005), embodied existence (Barnes et al., 1999; Corker & French, 1999), subjectivity and agency of disabled people (Frank, 1991; Csordas, 1994; Marks, 1999; Sullivan, 2001) are not adequately addressed. The continuous negotiation between body, socially constructed disability, and identity, lead us to the acknowledgment of the body as a crucial step toward the development of identity politics (Zitzelsberger, 2005). To bring 'bodies back in' (Zola, 1991:

This study aims to understand the way social dominant discourses about impaired bodies have been imposed, incorporated, negotiated and resisted by disabled people (Zitzelsberger, 2005), and its influence on the experience of discrimination and of political identity' construction. Our work uses a qualitative study with Portuguese adults with physical impairments, using a semi-structured interview that includes the following themes: psychosocial experience of disability, experience(s) of embodiment, political view of disability and empowerment.

Results will expand our understanding of the meanings attached to disabled bodies and their lived effects in interactions with social and built environments, namely how disabled embodiment is produced and experienced, in order to deconstruct ableism, reframe impaired bodies in a more positive way and ultimately contribute to the development of a more inclusive, pluralist and diverse society.

Sarah Long

University of Bath

Poster

“Tipping the Lens” – Focusing on visual discourses of the impaired experience. Reviewing the application of visual research method within disability studies?

This poster will outline the participatory research project “Tipping the Lens” I facilitated which involved a visual methods application. This work was presented in a series of 12 posters at the first international medical symposium on Morquio (MPSIV) (August 2008). The TTL initiative was developed to empower young people living with MPSIV to tip the lens away from the “clinical gaze”, focus on the “undesirable difference” (Mercer 2002), and notions “incompetent bodies” (Paterson & Hughes 1999) as captured in medical images and narratives. Giving participants the opportunity to define their own existence and take control of the lens to share their narratives using their own words and images. The main aspects which were chosen to be focused on where (a) what living in their bodies was/is actually like, (b) how they locate their embodied experience (Marks 1999), demonstrated through how they made sense of the world, dealt with what they defined as comfortable and uncomfortable moments and situations, (c) negotiated a sense of personhood and (d) ultimately how they wished their lives and bodies to be presented. This work was theoretically underpinned by Foucault’s bio-power concept of “subject” as demonstrated through shared themes gained from individual narratives, and importantly whilst displayed within a forum where there are dominant medical discourses. These medical and professional discourses as Tregaskis (2006) highlighted have an intense impact not just on the individual disabled young person but the whole family. Alongside gathering insightful data when evaluating the Tipping the Lens project I am left reflecting on the role of visual/sensory research methods within disability studies.

Sarah Long

University of Bath

Shades of humanity – The moral ethical maze governing the subjective narratives of impairment and/or disability.

This paper aims to explore the moral ethical maze governing the spectrum of the narratives associated with the polarisation of what I refer to as the impaired styled body and the eugenics styled body. This work explores the conceptualisations, the projective narratives and the associated socio-symbolism assigned to the portrayal of these commodities. Ultimately I have observed a human fascination (Garland Thomson 1996, 2009) and need for the notion of the “impaired body” or disability aesthetic (Siebers 2010), its projection potentially detached from real experience, with the commodity forming a hyper-reality status (Shilling 1993, Garland Thomson 1996). Being rooted in ancient narratives and reflected in contemporary societal priorities, the impaired body has become a subjective concept and/or commodity of a rejected, broken and negative image, something to control, disapprove of, ultimately detached from humanity. This sense of detachment can for example be witnessed in contemporary hate-crimes and right to life/assisted suicide media reports. The impaired body as a commodity is polarised by a eugenics body, reflecting a narrative which centralises on being beautiful, good, whole, normal, and styled as the central core of humanity. It is my supposition that the eugenic styled body is an aspirational and idealised commodity.

This work is framed within ongoing research into the interplay between the Christian Church and Disability. My research has gathered data from a range of sources including a series of interviews with church representatives and leaders from a range of denominations and personal experiences of disability. This work has begun to shape a potential contribution to a moral dimension within the sociology of impairment (Thomas 2007). There is evidence of marginalised experiences within the history of the relationship between the Church and disabled people (McCloughry & Morris 2002; Hull 2001; Eiesland 1994, Creamer 2003). This can be captured within the structure of the church as an institution and in its interpretation of the key theological concepts. Theological reflections can also provide a positive dialogue encouraging the reframing of the narrative concept of the impaired body and its commodity value to humanity (Swinton 2007, Reinders 2008). This presentation identifies some of the initial observations emerging from this study.

Heather Mack

CeDR, Lancaster University

Living with Hepatitis C: the reality of 'successful treatment'

In the UK, there are an estimated 200,000 - 600,000 people living with the blood borne virus Hepatitis C. Within the biomedical field, treatment is considered successful (i.e. virus as undetectable) in approximately 50% of those who access it. However, there is very little discussion around the experience and reality of receiving treatment, for people with Hepatitis C. This paper will present nascent ideas based on my current PhD research, which involves interviews with people living with Hepatitis C and also with the health and social care professionals who work with them. Drawing on a disability studies perspective this paper will pay particular attention to the difficulties in accessing treatment, the effects of treatment (and post treatment) in everyday life, and the lack of recognition from health and social care services about the realities of living with Hepatitis C.

Sue Mackey

Co-author: Dr GV Murthy

Using a Systematic Key Informant Method to Identify Children with Disabilities and improve access to services – an example from Rural Bangladesh

Children with disabilities and their families are one the poorest groups in Bangladesh and access to services, particularly in the rural and remote areas of Bangladesh is rare. A first challenge is finding the most effective to identify these children without incurring the high costs of a household survey, or raising expectations that cannot be met. A low cost method of identifying childhood blindness using key informant methodology (KIM) was proved to be successful in Bangladesh for childhood blindness.

This approach is now being tested for a wider range of other conditions; visual, hearing, physical and epilepsy using the same basic model but adapted for different impairments. This systematic method involves holding training workshops for volunteer key informants (KIs) from the community. A standard programme of presentations, discussion, role play with the use of illustrated flip charts and information leaflets, was adopted.

A pilot phase was completed in 2009 in the flood prone district of Sirajganj and the results look promising as 972 children listed by KIs out of 1,272 examined, had a confirmed diagnosis of disabling impairment (75%) and the majority of the others had some form of less severe impairment.

Where possible service provision is made through established or activated systems locally, or where necessary to further districts where more specialised treatment is available. It was essential to map all these services first, then contact and negotiate with providers to establish a referral network process beforehand so that the KIM assessment team had all the necessary information and contacts.

The community mobilisers have an important role in facilitating and following up with families after the assessment camps as there are many barriers to the uptake of services. Even where financial and logistical support is given, only half of the families were initially prepared to take up services and fear may often be the hidden reason.

Overall, the study demonstrated that KIM can be an effective tool in estimating prevalence for district planning, bringing large numbers of children with different impairments to the camps where referrals were made for 88%.

KIM is also an appropriate, low cost way of identification through community mobilisation using a sustainable network of key informants. The training workshops were a useful way of raising disability awareness, disseminating information and more positive messages. Links were established with local DPOs and NGOs who could learn from the process to continue the work themselves after the KIM study. A Dhaka Task Force of disability stakeholders and providers is involved with the project to take it forward and use the results for advocacy purposes.

Eva Magnus

NTNU Social Research

Time Use in Higher Education

Time use as an issue in higher education Labour market participation is strongly associated with education. Therefore higher education can be argued as of special importance to people with impairments. However, participation in higher education for persons with impairment appears to be low. The purpose of universal design and antidiscrimination legacy is to reduce environmental barriers, and increase equality and inclusion in society. This presentation will discuss how time use in studies and daily activities, can influence a student life. The material is drawn from my PhD study on disability and higher education. The intention of the study was to explore how students with impairment experience their everyday life, and how restrictions and barriers influence their studies, their possibilities for making their own choices, and for participation in student life. In all nineteen students with impairment participated. The students were asked to write a time geographic diary for one week, followed by an in depth interview, and discussions in focus groups. Data production and analysing were inspired by grounded theory. Findings showed that this group of students spent the same amount of hours in study activities as other students. They also spent more time than other students in resting and sleeping, and in doing many of their ordinary daily activities. Strategies were found to master challenges: as reducing their study progression, focus on structure and routines, prioritise what was most important to do and to give time to activities which brought joy and new energy. Despite of universal design some students with impairment still will depend on reduced study progression and individual adaptation. Even with a barrier free society time use in many ordinary activities still will represent a barrier to participation for individuals with impairment in many situations. My point is that planning for inclusion in higher education also has to bear this in mind. Universal design of the learning environment is necessary, but we still have to account for a variation in the group of students, as in the rest of society.

Pirkko Mahlamäki

University of Helsinki

The rights and obligations of air passengers with reduced mobility under the Regulation 1106/2006/EC) and their realization in Finland

The purpose of this research is to ensure the equal treatment of disabled air passengers and those with reduced mobility in accordance with recent changes in European law and regulation. In particular, Regulation 1106/2006/EC, which entered into force 28 July 2008, requires the provision of accessibility and appropriate assistance for disabled passengers. It is therefore important to determine how these provisions are being implemented in practice, and how the assistance provided can be improved and strengthened. As a preliminary for the implementation study it is necessary to conduct a detailed review of the Regulation and the obligations it imposes. What is the substance of rights and obligations for the passenger?

Of particular interest, whether the penalties meet the criteria set in Art 14: The penalties, which could include ordering the payment of compensation to the person concerned, should be effective, proportionate and dissuasive.

What effective remedies are available for the passenger in cases of infringement?

Claudia Malacrida

University of Lethbridge

Dehumanization and Its Effects: The Historical ‘Treatment’ of People with Intellectual Disabilities

In 1928, with hopes of improving services for people deemed in the language of the time to be “Mental Defectives”, the province of Alberta opened the Provincial Training School (PTS) on a park-like campus outside Red Deer, Alberta. At one time housing over 2300 inmates, PTS – which was eventually renamed The Michener Centre – operated hand in glove with the province’s Eugenics Board. Indeed, residents of Michener were the largest single group of Albertans to experience involuntary sterilization.

This talk is based on interviews with ex-inmates, ex-workers, and archival materials drawn from the official records of PTS/Michener Centre. I describe daily life inside the institution and the ways that space, time, and care were organized so as to dehumanize and devalue the people who lived there. Dehumanization was the first step toward making workers’ lives easier inside the institution, but it also acted to make institutional abuse not only possible but routine.

Understanding the history of places like Michener Centre is important: institutionalization is not dead. Indeed, large institutions continue to exist in many places in North America. Michener survivors are able to tell us why this approach is not one we should continue to pursue.

Rebecca Mallett

Sheffield Hallam University

For More Information...: Exploring the role of 'Normal' in Knowing Impairment

This paper will explore how medical diagnoses and 'impairment labels' function as solid, foundational knowledge from which other knowledge is actively deduced. It will argue that if we take impairment labels to be explanatory indicators of abnormality, and despite much being written about the role of 'normal' in the process of constructing disability (e.g. Davis, 1995), the routine recourse to labels of impairment within, for instance, literary criticism and student support, remains largely unproblematised. In attempting to disrupt this process, the paper delves into moments when medical impairment labels are mobilised as coherent categories within seemingly non-biomedical perspectives. Challenging the dichotomy between normal and abnormal, the paper specifically examines the use of what I am calling the 'normal abnormal', when typical (or 'normal') traits, characteristics or outcomes are assigned to impairment labels and act in a similar way to the exclusionary boundaries created by the 'normal normal'. In short, the paper asks, are we so obsessed with normal that the only way we can deal with abnormal is by imposing sub-categories of normal? It concludes by suggesting that the use of impairment labels as explanatory indicators to be deduced from, is a deceptive practice which demands that we question the use of 'normal abnormal' as much as the 'normal'.

Nina Marshall

Dept. of Politics, University of Bristol

Disability, development and discourse: analysing representations of the 'problem' of 'disability in development' on the World Bank website

Grounded in an empirical interest in how disability has recently been 'addressed' in international development policy, this paper explores the utility of a particular methodological approach to analysis of policy relating to disability. It is argued that this offers valuable insights into policy's productive and political nature that assist in questioning and challenging its taken-for-granted knowledge and assumptions. It is suggested that shifting our view and analysis of policy in the way operationalised in the methodology may be beneficial for those interested in critically interrogating how the 'problem' of disability is being 'addressed' through policy.

Carol Bacchi's *What's the Problem Represented to Be?* (WPR) approach (1999; 2009) rejects a view of policy as reactive to 'problems' – as problem 'solving' – instead suggesting it is inherently problem 'creating': in proposing a particular 'solution', policy therein constitutes or produces the 'problem' in particular ways. For Bacchi, policy is a problematising activity, and problematisations are central to governing processes, thus demanding our critical attention (2009: xi). She suggests that, through examining the problem representations implicit in policy propositions, we can move the focus of analysis from presumed 'problems' and their 'solution' to 'problematisations' and their effects. She sets out a six-question approach which makes explicit the problem representations contained in policy propositions, analyses the presuppositions or assumptions underlying these, explores genealogically how they have come about, considers what remains unproblematic or silenced within them, critically assesses their effects, and considers both the means through which they have become dominant and how they could be challenged.

In this paper, I explore the utility of WPR through an analysis of the problematisation of disability in international development policy, specifically using it to analyse texts published by the World Bank on and through its disability website from the late 1990s. In recent years disability has been increasingly articulated by major international development organisations as a 'problem' requiring policy attention. Particular 'solutions' – especially 'disability mainstreaming' and 'inclusive development' – have been advanced, and this 'new' focus has to date been largely attributed to a 'positive' shift in the policy response resulting from refined and improved understanding of the nature and problem of 'disability in development'. However, I suggest that applying a WPR methodological approach allows us to explore the very particular way disability is being problematised within international development policy, to discuss the conceptual logics about both disability and development which underpin this, and to consider the potential effects – in other words, to shift from focusing on the 'problem' of 'disability in development' and how to 'fix' it, to bringing into view and opening up for questioning its problematisation.

Nicola Martin

London School of Economics and Honorary Visiting Fellow at Cambridge

A Preliminary Study of Some Broad Disability Related Themes within the Edinburgh Festival Fringe

The Edinburgh Festival Fringe is the inspiration for this article which offers an initial consideration of the portrayal of some broad disability related themes (by disabled performers and by others). Comedy is covered in most detail with some concentration on a particular performer. Reference is made to other performance categories, such as drama and to some influences from beyond the fringe. Disablism, othering and the 'freak show' genre are amongst the themes which emerge from this exploration which includes consideration of whether disabled comedians can be disablist and whether Disability Equality legislation is impacting on what happens in performance. From the perspective of a disability aware audience member, unreconstructed disablism in comedy appeared to be fairly widespread within the 2008 fringe, mainly manifesting itself via the idle use of othering language such as the word 'spaz'. This paper represents a snap shot from a huge and varied festival and is presented as a starting point which has inspired future deeper research.

Lesley McIntyre

University of Dundee

Co-authors: Jennifer Harris, Jeanette Paul

'Let me show you how I get from A-to-B.....' Non-Visual Way-finding Hot-spots in Buildings: A Methodological Approach

This paper presents a multi-disciplinary doctoral research project which is based in the field of architecture. It illustrates how an innovative methodology and set of methods have gained insight into 'way-finding hot-spots' in public buildings as experienced by participants who have varying degrees of visual loss.

It will present detailed findings which generate dialogue in the design of way-finding systems suitable for people who have visual impairment, and also, people who have other forms of disability, non-reading people, young children, older people, people with language barriers and many more. During a research phase of purposeful conversation, ADAM who has degenerative sight-loss explained; "It's like a jig-saw..... I can't see very well so way-finding for me is a task of grasping at all the other information.....all the smells and everything I can touch.....then I have to add it all together to be able to find my way through it all." A building's inability to non-visually communicate direction to the visitor with visual impairment magnifies their problems of successful and pleasurable way-finding. It has a negative impact on their overall experience of that building which in turn deters further visits and creates barriers to independence and well-being.

Under a framework of Grounded Theory, the research employs a qualitative multimodal approach to identify what these 'Way-finding Hot-spots' are. Ethnographic methods and tacit knowledge gained from architectural training have been utilised to design phases of 'Way-finding Scenario'. These phases of participant input were vital to the success of the project and were sequentially integrated as;

- 1) A Purposeful Conversation based on participants existing experiences of way-finding in buildings with their visual impairment.
- 2) A Way-finding Task which involved way-finding in a public building from a starting point to a pre-determined unfamiliar destination point.
- 3) A Post-Task Conversation based on participants experiences during the way-finding task in phase 2.

This paper will discuss the logistics of the research through presenting narrative, logs and graphical trace from a participant's way-finding scenario. It will illustrate how evidence from the Way-finding Scenarios creates a case for the application of this knowledge in professional practice across many disciplines. Finally, it will discuss how such an inventive framework of methods has been vital to the success of such a multi-disciplinary piece of research.

China Mills

Manchester Metropolitan University

The tyranny of the 'normal' child: hearing voices, sly normality and resistance

This paper will explore how the statistically 'normal' child of neo-liberal developmental psychology colonises legal and 'professional' understandings of dis/abled children, drawing spatial and topographical boundaries between those within and those outside of ('normal') childhood (Rose, 1999). This trope of the 'normal' child becomes the standard by which all childhood is judged, establishing specific parameters of normality and limits of human intelligibility, constructing normative boundaries on what it means to be a 'child, to be 'normal', and ultimately to be human. Yet it is a simulacrum (Baudrillard, 1988), a model with no basis in children's lived realities, silencing childhoods that don't 'fit', and rendering disabled children as doubly diminished identities. I thus want to engage with disabled childhood as a 'state of exception', where 'the norm is in force without any reference to reality' (Agamben, 2005:36). Such norms permeate 'professional' decisions around early intervention, prevention and medical treatment, working on children to make them hyper-normal.

Drawing particularly on research with children who hear voices, this paper will engage with children's secret tactics, survival strategies and acts of resistance as meaningful, and often coherent, responses to the material and discursive violence performed on children in the name of the 'normal'. This exploration will be mobilised through readings of post-colonial and political theory, in order to tenuously explore how facets of the colonial relation are enacted within Government and 'professional' intervention, and thus how children's resistance might be understood through acts of mimicry and what I will call sly normality. This may enable some border crossing through children's 'creative lines of escape' (Reeve, 2007) into 'other worlds', serving to push professional intervention to the point of rupture.

Irma M Muñoz-Baell

University of Alicante

Co-authors: Carlos Alvarez-Dardet, M Teresa Ruiz, Emilio Ferreiro-Lago, Eva Aroca-Fernandez

Looking inside for good practice in Deaf bilingual education: A participatory SWOT analysis

Inclusive education may be defined as a process of identifying any barriers within and around the school that hinder learning, and reducing or removing these barriers as part of a wider strategy to promote an inclusive society. Deaf bilingual practices are consistent with more inclusive and equitable practices in the education of Deaf children; however, the practice of Deaf bilingual programmes varies across the countries and within societies and it seems that there remain gross imbalances throughout the regions of the world. Spain has historically played a very active role in the provision of education for Deaf people, and has also been one of the first countries to ratify the Convention on the Rights of Persons with Disabilities (UN, 2006) and develop a National Action Plan of Human Rights (2008) within the European context. This paper presents a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis undertaken to identify, from the point of view and participation of insiders, those internal and external factors around current existing Deaf bilingual practices in Spain which promote or prevent the processes through which more inclusive educational provision for Deaf children can be successfully implemented and good practice promoted. 11 schools with leading Deaf bilingual initiatives for Deaf children and a regional department of education were selected to conduct the SWOT analysis facilitated through the nominal group technique. A Facilitation Team – comprising three university researchers and two members (one of them Deaf) of the Spanish National Confederation of Deaf People – worked together throughout all the phases of the study using a participatory approach to research. 17 Deaf and hearing professionals participated in the analysis. To enable full access and on-going participation of Deaf participants, Spanish Sign Language translations and interpreting were used throughout the whole process. Our main conclusion is that awareness and understanding of these four internal and external inter-related factors are essential to assist educational communities to understand, practice and review ways of developing more inclusive practices within the current Deaf bilingual education school experiences in Spain, and can provide the starting point upon which policy-making and further research could be built. The study also highlights the importance of moving to a more participatory approach to research in the area of education of d/Deaf children and explores ways in which strategic planning can provide a practical and pragmatic tool for understanding and decision-making in Deaf bilingual education.

Chavon Niles

York University

Poster

A Comparison of regular and special education classroom teachers' perceptions of teaching students with individual education plans (IEPs)

This study employed a mixed-methods approach to examine regular and special education elementary teachers' perceptions of teaching students with Individual Education Plans (IEP). Results from this study suggest that teachers whose beliefs were grounded within the social model of disability could be classified as holding an interventionist (INT) belief system while teachers whose beliefs were grounded within the medical model of disability could be classified as holding a pathognomonic (PATH) belief system. More special education classroom teachers were found to hold INT belief systems. These findings were consistent with past findings that have investigated teachers' efficacy and beliefs using the Teacher Efficacy Survey and Pathognomonic/Interventionist interview indicating that INT teachers had mid or high self-efficacy scores. Teacher preparation in special education and their experiences teaching students with IEPs were found to contribute to their belief systems. Teachers with less years of teaching experience in this study were more likely to possess at least part one of their special education qualifications, scored higher on the P/I interview, and had higher levels of self-efficacy.

Alana Officer

Coordinator for Disability and Rehabilitation, WHO

Alana is a native of New Zealand. She holds a diploma in Applied Science (Podiatric Medicine) from the Institute of Technology in Sydney, Australia; a Master's degree in Applied Science (research) from the University of Sydney, Australia; and a Masters degree in Public Health from the London School of Hygiene and Tropical Medicine (LSHTM). Prior to joining WHO in July 2006, Ms Officer held a number of technical and managerial positions working on disability, rehabilitation and development in West and Central Africa, Europe, South Asia and the Western Pacific. Ms Officer was the Country Director for Handicap International (HI) in India.

Alana Officer joined WHO in July 2006, and is now Coordinator for the Disability and Rehabilitation Team. She oversees WHO's work on disability and rehabilitation related to policies, medical care and rehabilitation, community-based rehabilitation, assistive devices and technologies, and capacity building. She is the executive editor of the World report on disability and rehabilitation due for release in 2009.

Plenary

Research and policy working together to improve the lives of disabled people worldwide

Disability studies, which emerged from the disabled people's movement, values engagement and praxis. Yet does it reflect the needs and priorities of the millions of disabled people in the world? Does it provide evidence of what works in policy and practice? The World Health Organization, in partnership with the World Bank, is developing the first ever global report on the situation of disabled people. The World Report on Disability aims to provide governments and civil society with a comprehensive description and analysis of the importance of disability, to characterize the responses currently provided, and to make recommendations for action consistent with the Convention on the Rights of Persons with Disabilities (CRPD). The available scientific evidence suggests that disability studies is far from achieving its potential, particularly in developing countries. This talk will highlight how the CRPD provides an agenda for action, explain why the ICF offers a way forward for applied research and look at how together, we can make a difference.

Terje Olsen

Nordland Research Institute, Norway

Co-authors: Patrick Kermit, Sør-Trøndelag, Odd Morten Mjøen, Hild Rønning

Legal protection for deaf and hard of hearing people; an interdisciplinary Norwegian study

Background: The deaf Norwegian Fritz Moen (1941-2005) served 18 years in prison for the murders of two young women. In 2004 and 2006 Moen's sentences was overturned, and the following official inquiry labelled his wrongful convictions the gravest known cases of miscarriage of justice in modern Norwegian history. Tragically, Moen never lived to see himself fully exonerated. Today, a part of his posthumous compensation is funding research on disabled people and criminal justice. The study presented here is a part of this research.

Aim: The aim has been to study the way the Norwegian criminal law are practiced in those cases where people who are deaf or hard of hearing are involved, either as a victim or as a suspect/offender. Main research questions have been: To what extent – and in what ways – do persons who are deaf or hard of hearing experience barriers when it comes to reporting a crime or being a witness in court? To what extent – and in what ways – do they meet barriers either as victims or as suspects? These questions have not been studied in a Norwegian context before, and this study is meant as a first step into this topic.

Method: The methodological approach has been: a) a detailed study of 43 judicial decisions where deaf or hard of hearing people have been involved, b) ten interviews with experienced sign language interpreters, c) eight interviews with experienced police investigators, lawyers and prosecutors.

Preliminary results: The data do not indicate that deaf or hard of hearing people are overrepresented in the legal system. However, those judicial decisions we have studied indicates weak skills among judges and jury members on what deafness and hearing disabilities imply. Sign language interpreters have a central role in several aspects of the police's investigations and the proceedings of a trial. In particular, the interpreters' understanding of the legal system and legal concepts are of vital importance, and so is the practical implementation of the interpretation. The data also points to variable knowledge, understanding and attitudes among police investigators and prosecutors.

Preliminary conclusions: Knowledge and attitudes among the police seems to be essential in cases which includes deaf or hard of hearing people. As a consequence, establishing a continuing education course on disability for police investigators and prosecutors should be conceded. A general competence-building introduction for the judges and juries should be considered in those trials which include deaf or hard of hearing people. General procedures for the use of interpreters should be considered introduced in police work. A general introduction to the court's functioning and key legal concepts should be covered in the interpreter's education.

Joanne Opie

Coventry University

Co-author: Dr M.C.Taylor

The experiences of admission tutors on the admission of disabled students into the physiotherapy profession

This paper will report on an exploratory study of the experiences of admission tutors when considering the integration of disabled students into the physiotherapy profession (Opie & Taylor 2008). The emerging themes focused on the level of support available for students and staff, a perception of a lack of experience expressed by the staff and the process of educating physiotherapy students. The paper will expand on these findings and demonstrate the application of them within a physiotherapy course in order to improve the support for disabled students during the admissions process and throughout their academic studies.

Physiotherapy students are educated within the HE system, qualifying with a BSc and the right to apply for membership of the Chartered Society of Physiotherapy and registration by the Health Professions Council. Assessment of students is based on both academic and clinical ability with the requirement to meet core standards of competence as described by both the CSP (CSP 2005) & HPC (HPC 2004).

In 2001 the Disability Discrimination Act was extended to all levels of education, and in 2004 it was applied to bodies, conferring professional qualifications (Williams 2004). Consequently, the physiotherapy profession was required to consider its response to applications from prospective disabled students. The reaction of the CSP was to produce a document on supporting disabled students on clinical placements (CSP 2004). At the same time the HPC produced a document giving advice to prospective students and admissions tutors on the admission of disabled students to the thirteen professions covered by the HPC (HPC 2006). However, there was no evidence of how these documents were being utilised to guide the admissions process for disabled students and support students during their studies.

Research into the learning experiences of disabled students in HE (within the UK) implies that barriers exist in accessing the curriculum (Borland & James 1999; Fuller et al 2004). Paul (1999) suggests that these barriers may be underpinned by negative attitudes held by the academic staff. There is very little literature specifically about the integration of disabled students into the physiotherapy profession, with most of this literature pre-dating the inclusion of physiotherapy within the HE system and the introduction of the DDA (French 1988 & 1995; O'Hare & Thomson 1991). However, these articles do suggest some negative attitudes within the physiotherapy profession towards disabled therapists. The study presented in this paper focussed on the experiences of admission tutors to physiotherapy courses as these people can be seen as the 'gatekeepers' of the profession. Their responses to the DDA and opinions on the admission of disabled students will affect the integration of disabled people into the profession.

Lilja Össurardóttir

Centre for Disability Studies, University of Iceland

Coming of age with learning difficulties

The life course in contemporary cultures is constructed around socially defined events and roles and commonly divided into three sequential stages: childhood, adulthood, and old age. In modern times, an in-between stage of youth or adolescence emerged, which delayed the transition from childhood to adulthood. The reasons for the emergence of this in-between or transitional stage is e.g. a longer life-span, increased education, and young people stay longer at home with their parents and are older when they get married compared to what was customary in earlier times. Definitions of the term adult may vary between cultures and societies and is a rather complex concept and can for example be understood in terms of biology, i.e. being physically mature or as a legal term, i.e. having reached a certain age that is considered adult in the eyes of the law. Furthermore, the lines between childhood and adulthood become blurred in relation to the life course of people who have been labelled as having learning difficulties since they are commonly viewed as eternal children. This paper reports on a qualitative study conducted in Iceland with 57 people with learning difficulties including five young women 17 - 25 years old who were key-participants. Data was gathered through interviews and participant observations. The research aims to explore how the young people with learning difficulties understand different adult roles and how their understanding coincides with the ideas of life course. The findings suggest that research participants understand adulthood in terms of independence, family life, and employment. However, they have limited access to all of those three aspects of adulthood and do not occupy the same social space as their non-disabled peers, e.g. have limited options regarding education, employment, and leisure. Finally, I will discuss the social location of young people with learning difficulties in Iceland, what support they receive in order to take on adult roles, and how the key-participants perceived their coming of age in Icelandic society.

Merel Pannebakker

Cambridge Intellectual and Developmental Disabilities Research Group, Cambridge University

Co-authors: M. Redley, T. Holland

The value of a genetic diagnosis in improving health and social care of adults with an intellectual disability

In the UK, an estimated 2-2.5% of the population have an intellectual disability. Of these people, an increasing number are thought to have an intellectual disability with a genetic origin. People with a genetic syndrome can be at risk of syndrome-specific physical and mental illnesses and behavioural problems. Despite the proliferation of genetic knowledge and testing, it is hardly used in the provision of adult health and social care services. This paper reports on an exploratory study to investigate whether health and social care services should be paying more attention to the implications of person's genetic diagnoses as a means to improve health and wellbeing. The findings reported come from semi-structured interviews with 1) parents of adult children with a genetic syndrome from eleven different genetic syndromes (55 interviews); 2) chairmen, chief executives or research officers from these syndrome support groups (11 interviews); and 3) professionals with an interest in genetic syndromes within the areas of a) health care, b) social care and c) disability rights (10 interviews). The interviews addressed the extent to which these respondents saw genetic knowledge as potentially valuable in the provision of health and social care. All of the respondents knew a lot about the genetics of specific syndromes; wanted to see this knowledge implemented in adult health and social care services, but struggled to say precisely how this knowledge could be put to good use. This presentation concludes by discussing the potential of genetic knowledge to address health inequalities, promote social inclusion and champion the rights of people with an intellectual disability were it put to more use in the design and delivery of services

Deborah Phillips

Cornwall College

Co-authors: Elizabeth Ellis, Camborne Research Team (service users/carers/students)

Challenges, Choice and Change: the dynamic involved in doing participatory and collaborative research

This small scale research project centres on the theme of 'Disability and Rurality', but more specifically on the experiences of disabled people who live in a 'picture postcard' rural environment. We are interested in the barriers and benefits disabled people might encounter in relation to areas of Place, Space and Community; but more importantly how the impact of 'tourism' may shape and affect their day-to-day lives. However, the focus of this panel presentation is to explain the PROCESS of conducting this research as opposed to the final outcomes of the investigation. The panel members consist of four level 1 students on the BA Social Work degree, four local service users/carers and two academics. Our aim is to explore and discuss the ways in which we worked collaboratively and in partnership; both as a team and with the research participants.

We consider our research group to be unusual as we have a range of diverse backgrounds, interests and experiences. Yet by pooling these separate 'knowledge's' we present a unique force which not only reflects service users/carer standpoints, academic underpinnings and professional practice but also supports the interests of our research participants. This presentation will therefore comprise of our personal narrative accounts which documents the following themes:

- Setting up the project.
- Devising an epistemological and methodological framework.
- Agreeing on an appropriate interview structure.
- Conducting fieldwork.
- Experiences of analysing the data together.

Inherent in the project were a number of 'challenges' which at times impacted upon elements of choice and control; for both the research team and the participants. However, this did not distract too much from our overall goal and was indeed part of the fluid and exploratory nature of the project. In turn the investigation did expose some interesting outcomes which enabled us to answer the key research questions. Additionally the actual research process enabling us as a team of service users/carer, students and academics to be creators of knowledge as opposed to consumers.

Paula Pinto

Centre for Administration and Public Policy, ISCSP, UTL (Lisbon, Portugal) and University of York

“The Maternal is Political”: Mothering with a Disability as Feminist Empowered Mothering

In proposing a “paradoxical politics of motherhood”, DiQuinzio (1999) has argued that feminist theorizations of motherhood should focus on specific instances and specific contexts rather than aspiring to develop a totalizing account, given that motherhood is itself always differently constituted. In this paper, I seek no more than to offer such “partial” and “fragmented” theorization, one which takes into account disability and the difference that it entails. More specifically, I want to explore disabled women’s access to rights in Portuguese society by focusing on their mothering experiences. To accomplish the task, I draw on key concepts of maternal theory and the feminist ethics of care and advance a framework revolving around three interconnected themes—Maternal Practices and Thinking; the Meanings and Experiences of Mothering; and the Ethics of Maternal Care. This framework is further informed by a rights approach to provide for an assessment of women’s mothering experiences according to human rights principles and standards. I use this model to analyse 21 in-depth interviews with mothers with disabilities living in the region of Lisbon. The women who participated in this study offered accounts of mothering which resonate with the findings reported in the literature on care, motherhood, and mothering. In other words, their intimate experiences of mothering, their practices, as well as the values informing those practices are in many ways similar to those of non-disabled mothers described in the literature. But disability is also a factor of difference in these women’s lives that in small and big ways transforms and re-shapes their subjectivities and lives, including their experiences and practices of mothering. Thus, both commonality and difference permeate their stories. Importantly too, across these themes women’s narratives highlight their self-determination, resourcefulness and creativity in the face of powerful social, political, and medical discourses, which by stigmatizing disabled women as incapable of being “good mothers” have operated to exclude them from motherhood and to deny them their fundamental human rights. And thus for these women, who have achieved motherhood against all odds, mothering is a site of struggle and empowerment. For them the maternal is political.

Andrew Power

Centre for Disability Law & Policy, NUI Galway

Self-Determining Options: Lessons and Challenges from Comparative

Perspectives in Independent Living" This paper examines emerging models of Independent Living which are reshaping welfare states to give persons with disabilities more choice in self-determining their own support. These models are characterized in many western jurisdictions by self-determination, personalized support and choice in planning one's own living arrangements and support packages to become independent in the community. This is reflected in the goals of Article 19 of the UN CRPD (Living independently and being included in the community) which calls on States Parties to take effective and appropriate measures to ensuring that persons with disabilities have the opportunity to choose their place of residence, and have access to a range of in-, residential and other community support services, including personal assistance necessary to support living and inclusion in the community. Using comparative perspectives, from the US, Canada and the UK, this paper focuses on the legislative, regulatory and policy options behind some of the transformation efforts. It identifies the challenges of moving from traditional models of welfare which have enforced many people into dependency towards individualized support models which encourage independence.

Mark Priestley

University of Leeds

Politics and Strategy in the European Union

As the European Union affirms a new Disability Strategy for the next decade this paper considers where EU disability policy has come from and where it is heading. The paper draws on research and review conducted by teams in 28 EU/EEA countries on behalf of the European Commission's Academic Network of European Disability experts (ANED). It considers the key actors and drivers in the political process and pays particular attention to the mechanisms for targeting and mainstreaming disability issues in policy processes at the European level (including both 'hard' and 'soft' policy measures). Using examples from the Open Methods of Co-ordination (such as those in Employment or Social Protection and Social Inclusion) the paper highlights some of the challenges involved in 'Europeanization'. Proposals for a new policy co-ordination process to accompany the new strategy are outlined.

David Purdue

Loughborough University

Rivals or team-mates?: Conflict and consensus between disability politics and the Paralympic movement

This paper investigates to what extent Paralympic sport can play a role in disability politics by exploring the relationships and tensions that arguably exist between disability politics and the Paralympic movement. This is achieved through a sociological investigation of the organisation and format of the Paralympic Games, a quadrennial multi-sport competition for athletes with specific impairments. This paper provides a cartographic representation of, what the author terms, the 'Paralympic field'; a theoretical concept which serves to identify key individuals and groups that interact to shape the current format of the Paralympic Games. The Paralympic movement's ideological ambitions and practical actions are explored by applying Bourdieu's sociological theory to qualitative data collected from a range of stakeholders including: active and retired Paralympic sport administrators, current and former Paralympic athletes as well as social researchers of disability politics and/or disability sport. This data was gathered from in-depth, semi-structured interviews conducted either face to face or by telephone. This research represents a rare attempt to critically analyse the potential for the Paralympic movement to contribute to disability politics and vice versa.

During the presentation of this paper several key topics will be explored. The perceived capabilities of the Paralympic Games to function as a tool to educate individuals about the social concept of disability is critically analysed, in the context of whether Paralympic athletes are representative of, and self-identify as, 'disabled people'. The extent to which the Paralympic Games can empower individuals with an impairment is considered. Furthermore, whether members of the Paralympic movement can, and are willing to, act as activists to enact social change for individuals with an impairment is explored. This sociological investigation of the Paralympic movement, and the perceived suitability of the Paralympic Games to contribute to disability politics, provides a provocative insight into the complex social relations that exist between disability, sport and society. It is hoped this paper will encourage further research into how the Paralympic movement can serve the broad populous of disabled people.

Erika Puro

University of Jyväskylä

Co-authors: Helena Sume, Tanja Vehkakoski

The Identity of Special Education in the Discourse of Professors in the Field

Special education is a multidisciplinary field, which utilizes various theories and methods from psychology, sociology and medical science. As we know, the field has a long and controversial history in the education system. On the one hand, the field aims at supporting people living in marginal and promoting their rights. On the other hand, it has been accused from segregating disabled people and maintaining the unequal education system.(Sapon-Shevin 2003; Foreman 2008; Riddell 2009). Nowadays, there is a growing interest to study the nature of special education as a discipline (Nevoy 2003; Kivirauma 2004; Haustatter-Sarromaa 2004; Mastopieri 2009). Despite this, the special education researchers' own evaluations of their discipline have not been considered in earlier research.

The aim of this study is to examine how the special education professors in Finland define their own field of discipline and construct its identity. The data was collected by interviewing all Finnish professors of special education (N= 10) from five universities. The interviews lasted 37 - 65 minutes. The interviews were analyzed by means of constructionist qualitative content analysis.

The results show that the professors defined special education from two different viewpoints: on the basis of their own personal views or on the basis of the classical definitions of special education. The professors spoke about the field through five various discourses: professional, emancipatory, relativistic, autonomous and critical discourses. Most of the discourses constructed special education as an important part of the science field, although the relativistic discourse problematised the position of special education as an independent discipline. The Disability Studies perspective appeared especially in the emancipatory discourse, the main contents of which concerned human rights, inclusive education and social justice.

Rachel Purtell

Peninsula College of Medicine and Dentistry

Co-authors: Dr Wendy Rickard, Ged Bryan

What the Bones Say

Is the story of the development of a short art film, exploring whether using the raw experience of impairment and its medical treatment can be placed within a Social Model context. The film has used some of the 185 x-rays of Rachel's fractures taken during her lifetime with Osteogenesis Imperfecta (Brittle Bones) to create a piece of art. This film places the experience of impairment within an 'everyday' existence and challenges ideas of 'special' or 'brave' or 'tragic'. The film either elevates or reduces (depending on the viewer's standpoint) the experience of impairment to ordinariness. The film also confronts socially constructed views of the medical and 'caring' professions of 'normal'. The film contrasts their view of what they are trying to achieve with intervention with Rachel's own view of what is to be achieved.

Rachel Purtell, Peter Beresford, Len Barton and Simon Unsworth

Peninsula College of Medicine & Dentistry

Symposium

Issues of Death and Dying - 3rd Discussion

In 2006 and 2008, issues of death and dying were raised in discussion sessions when we posed fundamental questions about our responses to death and their implications for Disability Studies, and uncovered some pertinent issues for that need to be addressed further. Building on these two sessions, we would like once again to invite you to discuss the issues.

Generally in our culture, the issues of death and dying are rarely discussed in everyday life. Death is seen as profoundly sad, bereavement as painful and to be pitied and the process of dying is seen as tragic. Fear of death inhibits open engagement with the issues, a powerful mechanism for keeping the subject out of discussion. In the last session it was suggested that Disabled People are considered frightening because we remind people of their mortality, yet a disabled person's or disabled child's death is somehow considered less sad, less of a bereavement. The issues of death and dying cannot be separated from the issues of birth and the social position of the abortion of impaired fetuses. The rituals of death are often inaccessible to disabled people. There is a profound lack of understanding of the barriers that disabled people face when they are in need of palliative care, with a highly medicalised approach to this area taking precedence and Social Model thinking rare. More recently the media, politicians and policymakers have increasingly highlighting assisted dying, leading to growing pressure to develop legislation to facilitate this. These have particular implications for disabled people. Many of us feel conflicted, possibly agreeing that everyone should be given a choice in the manner of their death but concerned that while the pervasive and inherently negative attitude towards disabled people exists in our society it seems far too dangerous to agree to such measures. Facilitating the choice through legislation could reinforce the barriers we already face and could take all emphasis away from services meeting the needs and aspirations of the living.

If we accept even these few issues are part of the confusion that our society has around issues of death and dying, these become even more difficult for our response to the death and dying of disabled people. We require a sensitive culture of support as part of a more general concern for the establishment and maintenance of an inclusive society.

Our question is: how can Disability Studies create the culture needed that rises above the general confusion about death and dying to respond consistently ensuring the rights and interests of disabled people?

Within Disability Studies inevitably many of our scholars, heroes and campaigners have a limited time on earth so our second question is: how do we keep alive the legacy of our champions?

Adolf Ratzka

Activist for Independent Living

Adolf is an internationally renowned activist for independent living. He is known for leading the Swedish Independent Living movement. He set up the pilot project on personal assistance, which was to become the model for the Swedish Personal Assistance Act of 1994. The then Minister of Social Affairs, Bengt Westerberg, invited Adolf to Parliament when the Act made into law. Adolf was the founding chair of ENIL, the European Network on Independent Living, which works for disabled citizens' personal and political power, for self-determination and against discrimination.

In 1999 he was recognized by TIME magazine as European visionary for the new millennium, mainly for his pioneering work for cash payments replacing services in kind thereby promoting disabled people's right to self-determination and freedom of choice. Adolf received the European Citizen Award from the European Anti-Discrimination Council in 2008. Also in November 2008 he led an international conference to celebrate twenty-five years of independent living in Sweden.

Plenary

Beyond the Social Model of Disability: An emphasis on disabled peoples' status as citizens and consumers is needed for self-determination and full participation

The success of disabled peoples' struggle for self-determination and equal participation in society will ultimately depend on the model of disability to which disabled people themselves and society at large subscribe to. The United Nations CRPD and other policy documents emphasize disabled peoples' status as citizens. Adding the perspective of disabled people as consumers of services implies policies that use cash payments and demand-driven competitive markets for services where previously supply-driven government or quasi-public monopolies for services in kind existed. These developments will increase many disabled peoples' freedom of choice and opportunities for self-determination and participation.

Janet Read, Marcus Redley and Sara Ryan

Universities of Warwick, Cambridge and Oxford

WORKSHOP

Crafting Space for Conversation: An Experimental Workshop

We should like to invite interested delegates to join us for an hour in an experimental workshop which aims to encourage reflection and discussion in a way that is unusual in the context of an academic conference. We feel that within academic settings, there are ways of interacting which can be habitual, ritualistic and, sometimes, counterproductive. This is probably no less true of Disability Studies conferences than any others. We want to try an alternative format to see what happens.

The background

At a Disability Studies seminar in Lancaster last year, a group of us discovered by accident that we all liked to do stitched textiles or embroidery. Over the period of the two-day seminar, the stitchers had a series of conversations about what we made and why we did it. We all did very different things but we found that we not only took pleasure in what we created but that we were also fascinated by the way that working with our hands sometimes seemed to allow us to free-up our ways of thinking. This happened when we were alone but also when we were sitting in a group with others doing something similar. The process of stitching (or some other activity like this) in a group could enable reflection and conversation to flourish but at the same time, it could relieve individuals of the imperative to speak, take the heat off and allow them to listen and think. A number of people had also found that this made it easier to engage with issues emotionally as well as intellectually.

While this form of activity is more often associated with women and the domestic sphere, there is a long and honourable tradition among both men and women of using stitch to express identity, facilitate communication and offer resistance, particularly at times of confinement or oppression. For example, in the Pinochet years groups of Chilean women recorded scenes of their lives, First World War soldiers embroidered 'trench cards', Arthur Bispo do Rosario, fifty years in a psychiatric hospital, created stunning representations of ideas significant to him, using scavenged materials and so on. While the 'artefacts' and what they represent can be important, what happens to individuals and interactions during the process of creating something (however modest and private) may prove to be equally interesting.

What we are planning to do

We are planning to spend a relaxed hour doing a chosen activity, thinking and having conversations. The session will take place between 6.45 and 7.45 on Tuesday 7th September. We would ask those who want to join us to bring something with them to do. We're aware that so far we have referred to stitch and other craft that is not accessible or meaningful to everyone. The aim of the workshop is for delegates to actively engage in a (small-scale) physical activity of their choice that they find a little

absorbing. In addition to stitching and knitting, this could include doodling on paper or with a lap top, whittling wood, moulding clay or blu-tack, using an abacus or worry beads, making a ball with elastic bands, threading beads and so on. People might also want to think about issues related to disability that they would like to have an exploratory conversation about. Perhaps these will be prompted by things that have happened at the conference, issues that have been raised, left out or discussed only partially.

For the first five minutes we would like there to be silence as we focus on our individual activity. After five minutes (or longer) if someone would like to say something, they can. We assume that people will wish to listen and not interrupt. It may be a contribution that does not need a response from the group or it may encourage discussion. We are keen to allow space for quiet reflection and contemplation that may (or may not) lead to productive ways of thinking about disability. The intention of the workshop is not for people to perform or to produce something to show, but to shift the focus from mainly verbal interaction to creating and thinking. It is experimental so we have no idea what the hour will bring, but we hope that it will make a refreshing change and demonstrate that there are different ways and spaces to encourage academic reflection within a conference setting. We hope that though engaging in stitching or some other practical activity, people can let their guard down and in an open and respectful way begin to discuss issues that they think are interesting and important.

Marcus Redley

University of Cambridge

Co-authors: Sarah Ball, Isabel Clare, Tony Holland

The social significance of clinical interventions to help people with intellectual disabilities to eat and drink safely

Mealtimes for people with intellectual disabilities can carry a significant health risks, as dysphagia is common and can lead to chronic malnourishment, respiratory illness, and asphyxiation. These risks are managed by the provision of support, ranging in degree from observation and oversight, to ensure safe and adequate eating and drinking, to enteral feeding via percutaneous endoscopic gastrostomy (PEG). Such support, which includes modifying food and fluid consistency, correcting body posture and providing adapted utensils is provided by paid support workers and family carers, often under the direction of health professionals in specialist learning disability teams. While these interventions ensure safe and adequate nutrition they can transform meals into clinical procedures, excluding people with intellectual disabilities from the pleasures and convivial opportunities that mealtimes provide. Based upon qualitative interviews with family carers, paid support workers and people with an intellectual disability this paper presents preliminary findings focused on (i) the conflicting requirements of ensuring good clinical practice and efforts to ensure and promote choice and social inclusion, (ii) how these different imperatives are sometimes reconciled, and (iii) how that reconciliation varies dependent upon the severity of a person's disability, the nature of the support required and environment in which the person is living.

Marcus Redley

University of Cambridge

Co-authors: Jessica wheeler; Edah Maina; Julian Hughes; Tony Holland

Poster

Mental Capacity and the Right to Vote: new opportunities and new concerns

This presentation discusses the voting rights of adult citizens who due to a diagnosis of either learning disability or dementia are at risk of lacking the capacity to vote meaningfully. This is an important issue because of the rising numbers involved in democracies worldwide. Moreover, if people are denied the opportunity to vote - either because they are not encouraged to register or because voting is not facilitated - their rights as citizens are undermined; furthermore, bearing in mind that the ways to vote, and consequently to vote fraudulently are increasing, if a vote is cast for someone who lacks capacity, democracy is undermined. This paper with respect to the UK discusses the clarity of the law and guidance on voting and registering to vote; empirical data documenting voter turnout; the view, on voting, of a sample of adults with a learning disability; differences between how the voting rights of adults with an learning disability and people with dementia are being considered; a comparison with other democratic states, and concludes with a discussion of the UN Convention on the Rights of Person with Disabilities which guarantees all citizens with and without disabilities the same political rights and opportunities.

Jo Rees

School of Human and Health Sciences, Swansea University

Co-authors: Maggie Hayes and Adam Greenow

Poster

Assessment experiences of service-users of a social work team for disabled adults.

Social care assessment in the UK aims to evaluate the impact of an individual's needs on their independence and quality of life so that together the service-user and the care manager can identify appropriate support. A person-centred approach emphasises the service-user as an active partner and requires that their individual views, wishes and requirements shape this process.

Current adult social care assessment frameworks in the UK are underpinned by a co-ordinated approach to care management (Seddon, Robinson and Perry, 2010). The English Single Assessment Process (Department of Health 2002), the Scottish Single Shared Assessment Tool (Scottish Executive 2001) and the Welsh Unified Assessment Process (Welsh Assembly Government 2002) emphasise themes of consistency and effective joint working to achieve seamless and timely outcomes for service-users. In addition, a holistic approach endeavours to avoid the service-users being serially assessed by different agencies for the same purpose.

Despite these aims, an evaluation of a UK pilot local authority social model assessment team (Morris, 2004) revealed that better quality assessments may be achieved if they are underpinned by a social model approach. However, the evaluation also indicated that current assessment forms do not encourage care managers to follow a social model approach.

This poster presents key findings from the first stage of an ongoing qualitative pilot study designed to investigate the social care assessment experiences of service-users of a social work team for disabled adults in the United Kingdom. Drawing on survey and focus group data, this poster reflects the experiences of service-users, emphasises positive features and areas of good practice and explores ways in which a social model approach can be encouraged within the assessment process.

Donna Reeve

CeDR, Lancaster University

Disability hate crime and psycho-emotional disablism: Interconnections and insights

Disability hate crime is slowly starting to be recognised as a reality for many disabled people (Sin et al, 2009; Quarmby, 2008) but there are recognized problems with the UK justice system which mean that hostility towards disabled people is often labelled as anti-social behaviour rather than hate crime. The manner in which experiences of disability hate crime are 'downgraded' adds further injury to these experiences of systematic violence which are one of the five faces of oppression which minority groups such as disabled people experience (Young, 1990).

Although there are severe incidents of disability hate crime which make the national headlines, it is the daily grind of low-level incidents such as name-calling which affect more disabled people. These examples of psycho-emotional disablism which undermine emotional well-being and self-esteem are cumulative and can be affected by previous experiences of psycho-emotional disablism including internalised oppression. Quarmby (2008) offers a useful discussion of how entrenched disablism within our culture and society, enacted through language and prejudice, means that disability hate crime can exist without being recognised by such, by both victim, perpetrator and others.

In this paper I will present some exploratory ideas about how the concept of psycho-emotional disablism can contribute to theoretical understandings of disability hate crime by considering the following questions:

- What is the relationship between psycho-emotional disablism and disability hate crime?
- How might past/present experiences of psycho-emotional disablism impact on a person's 'risk' of being a victim of disability hate crime and the consequential 'hurt' that the hate crime causes?
- How might an understanding of psycho-emotional disablism affect the kinds of support offered to disabled people who experience disability hate crime?
- What can recent psychoanalytic approaches to the disabled subject (Goodley, forthcoming) contribute to understanding why disability hate crime happens and the (lack of) institutional/societal responses to these crimes?

Although there is a recent body of research which is documenting the experiences of disability hate crime, there is relatively little theoretical disability studies analysis of disability hate crime (although see for example Sherry (2000; 2003, 2010)). In the light of a growing need to address the realities of disability hate crime in the UK, it is hoped that this paper will kindle academic discussions akin to those existing in the related fields of race, religion, sexual orientation and transgender hate crime.

Katherine Reid

Seton Hall University

Alternatives to the audio guide for Deaf Museum Visitors

Technology in museums is used for a multitude of reasons such as to preserve and display art as well as to expand their audience base but is there some technology that actually leads to the exclusion of certain populations? The traditional audio guides used by many museums are one such piece of equipment that is not accessible to all visitors, particularly to those who are Deaf. Deaf museum visitors do not have as many options to enhance their experiences at museums as hearing visitors on account of their disability. The various types of multimedia technologies such as MP3 players, PDAs, and even cell phones that are mass produced and marketed would allow for museums to use to reach out to this audience. Museums would be able to create a sign language based tour or captioned videos displayed on their websites that can be downloaded onto these devices for visitors before a visit. However, there are still many hurdles to overcome financially but museums in the United States can look to the museums in Great Britain for models for Deaf accessible technology.

Museums are cautious when it comes to investing in new technology as devices may fail miserably at what their desired function is, or they may be worth the time and money spent. The Museum of Modern Art (MoMA), Los Angeles County Museum of Art (LACMA), Brooklyn Museum of Art, Walker Art Center, and Museum of Science in Boston are such museums that are taking a risk by replacing the audio guide with multimedia guides. These new multimedia guides are capable of displaying captioned videos as well as sign language tours but only the Museum of Science in Boston uses its new technology to its full advantage. Partnerships with technology companies that have Deaf clientele such as Sorenson VRS would be beneficial to those museums which have the technology capable of displaying videos or are looking for sponsorship for an exhibit and wish to diversify their audience. Museums in Great Britain, specifically the Tate Galleries and British Museum can be used as models for the other museums in terms of their technology and how Deaf visitors benefit from them. The reasons behind the funding and implementation of more Deaf accessible technologies in these British museums as well as the Museum of Science in Boston reside in their outreach to the Deaf community, as well as partnerships with experienced companies in the field of audio tours.

Ann Mette Rekkedal

Norwegian University of Science and Technology

Teachers, hard of hearing and deaf students view on assistive listening aids

Hearing aids/cochlea implants(CI), and assistive listening devices like teacher and classmate microphones play an important part of hard of hearing(HH) and deaf student's school lives. In Norway microphones for classmates are normally standard when HH and deaf students are educated in mainstream schools. In Scandinavian this is called the "Norwegian model". Teachers, classmates, HH and deaf students must daily handle the equipment. There are few studies or research, on how such assistive technology is utilized, and how it improves participation. This study examines factors that can explain the variation in teachers, HH and deaf students' attitudes towards assistive listening devices, and how it affects the use. This presentation is a part of a larger study about how assistive listening devices affect HH and deaf student's participation in mainstream schools.

The study included 154 HH and deaf students, and 167 teachers from 16 different counties in Norway. The survey was carried out in 2009, and the students answered either the survey alone, or with help of their parents or the project leader. The students were born 1992 - 1998. All students communicated orally.

Analyses show that age of getting hearing aids/CI, gender, type of hearing loss and self-confidence explain 31.5 % of the variation in student's attitudes toward hearing aids/CI. Size of classes, gender, grade of hearing loss, school motivation, and how often teacher use microphone are main factor that explain the variation in students attitudes toward teacher microphone. The student's attitudes toward classmate microphones depend on gender, school motivation, and how often the microphones are used.

Use of loudspeaker, gender, teacher's knowledge about microphone systems and hearing problems, and sort of lessons explain 32,6 % of the variation in teacher's attitudes toward teacher microphones. The amount of classmate microphones, teachers' knowledge about microphone systems, and how the microphones function are main factors which explain teacher's attitudes toward classmate microphones.

Griet Roets

Department of Social Welfare Studies, Ghent University

Co-author: Prof. Rosi Braidotti

Nomadology in Disability Studies

In this paper presentation, we situate our work in critical disability studies where translations of impairment and disability that inexorably play down ‘impairment’ into a language of pre-social ontology, social death, inertia, lack, limitation, deficit and tragedy are critically engaged with, and biological determinism and essentialism are challenged (Hughes, 2007; Price, 2007). In order to de-naturalize current understandings of impairment and disability, we explore the nomadology of the French philosophers Gilles Deleuze and Félix Guattari for disability studies; in “forming, inventing and fabricating concepts [that have to] determine its moment, its occasion and circumstances, its landscapes and personae, its conditions and unknowns” (Deleuze & Guattari, 1991/1994: 2). Their work introduces a political process ontology and a relational but asymmetrical epistemological perspective; and enables a move into an affirmative turn to embrace human difference. Based on a current ethnographic research project on child poverty, in which intergenerational dynamics in families and the real-life situations and life stories of mothers and children are explored, we attempt to unsettle current social categories of class, gender, dis/ability and childhood. We argue that approaching difference of ‘anomalous others’ who are living on the margins in a productive way can push disability studies into surprising new horizons; as “the anomalous is not merely pretty, but attractive like beauty with some kind of edge...[like] the surprising sexual energy of the apparently shy and quiet, the surprising intellectual power of the guy or the girl in leather” (Bearn, 2000, p.459).

Patrícia Roque Martins

School of Fine Arts, University of Lisbon

Art and Visual Impairment: a case study in the Modern Art Centre in Lisbon

The importance of art education to visually impaired people is to underline the value in promoting individuals growth due to the active role it plays in the production of knowledge. Deny it access to the people with visual impairments, is to waste the human potential that can reside in each one. The way that people with visual impairments use the senses to perceive the outside world, is the main difference that distinguishes them from the normal-visual person. Since visual perception is not accessible, their sensory experience of the world is qualitatively different, not quantitative, because they organize the fours senses that they have, to make the best use of them and to obtain a fairly accurate information of the world that surrounds them. In general, society accustoms to building a barrier - the omission barrier - (Smith, 2001) which means the lack of responses to the needs of a disabled person, considering that no action practicing to his favour will be an obstacle, because excluding them indirectly contributes to acquiring other kinds of incompetence since they do not have access to knowledge and information, isolating themselves socially throughout life.

This communication is based on a case study released in the Modern Art Centre in Lisbon, which aimed to demonstrate that people with visual impairment may be a part of the public of the art museums, and in particular, they may see paintings. The rapprochement between the works and people with impaired vision was developed through multisensory teaching materials in order to propose a visit to the museum which would be more expressive and appealing. In this sense, it will be focused on the methods that have proved most effective in the analysis of artworks by people with visual impairments. Moreover, it is intended to demonstrate the importance of abolishing the social barriers by the museum institutions, by creating inclusive proposals which are constant and focused on the individual differences of each person, forgetting the quantitative factors that often explain the policies undertaken for the educative programming of the museums. To take into account the particularities of each one, can contribute to increasing the quality of life in society, enhancing the performance and the information received during a visit to the museum, helping to increase self-esteem and autonomy of people with disabilities, as well as, a better understanding of the world and a more harmonious relationship between people with and without disabilities. After the end of the case study, the participants with visually impaired were cross-examined. In one of the questions: "What was the reason that took you to participate in the visit to the Modern Art Centre?" One participant responded: "See what I never saw." In this case the use of the word "see" assumed a different meaning, referring not to the visual perception but related with what was described, discussed, analyzed or felt. In this sense, it is clear that people with visual impairments are a potential audience in art museums.

Alan Roulstone

De Montfort Leicester University

You may experience some turbulence: the career concerns of disabled managers in recession times

The aspirations of some disabled people to enter positions of seniority (Shah, 2005) and the wider policy push towards work for greater numbers of disabled people (PMSU, 2005; Roulstone and Barnes, 2005) has led to circumstances where disabled people have been able to confront historical assumptions around ability, drive and organisational prowess. Legislative changes in the DDAs of 1995 and 2005 (Gooding, 2005; Lawson, 2008) add to the support frameworks in offering both legal and cultural challenges to discrimination. The extent to which disabled people can prosper long-term in economies prone to recession and countervailing 'lean processes' that refer principally to the costs of individual employees is a moot point. This paper is based on a qualitative study of 30 disabled managers across the UK and explores, through their words, the ambiguity of holding management appointments whilst often feeling disproportionately vulnerable to corporate downsizing and lean measures in a time of public and 'back room' cost savings.

Katherine Runswick-Cole

Manchester Metropolitan University

Co-author: Nick Hodge

'They never pass me the ball': disabled children's and their families' experiences of leisure

In this paper, we explore the experience of accessing leisure by disabled children and their families. Drawing on the accounts of disabled children and young people and their parents and carers, we reflect on the spaces occupied by disabled children and their families and record some of their experiences within them. Using the concept of 'ableism' (Campbell, 2009) we interrogate the data gathered as part a two-year project funded by the Economic and Social Research Council (RES – 062-23-1138) (<http://www.rhsc.mmu.ac.uk/postblairproject/>): 'Does every child matter, Post-Blair: Interconnections of disabled childhoods' and by doing so we expose the inherent discrimination in favour of able-bodied people that dominates, and excludes, within leisure facilities. We suggest that families and children occupy a mix of 'mainstream', 'segregated' and 'separate' leisure spaces. We discuss the impact of occupying these spaces and ask:

- i) To what extent are children and families required to emulate under-articulated 'norms' in order to gain access to mainstream spaces?
- ii) To what extent are 'segregated' leisure opportunities regulated and produced by a kind of 'diagnostic apartheid' (Campbell, 2009: 154)?
- iii) How might 'separate' leisure activities offer sanctuary from the power of ableism?

Katherine Runswick-Cole

Manchester Metropolitan University

Co-author: Dan Goodley

Poster

The violence of disablism: body, psyche, systems and culture

This paper explores the multi-faceted nature of violence in the lives of disabled children and their families. The accounts here have been collected as part of a two-year project funded by the Economic and Social Research Council (RES – 062-23-1138) (<http://www.rihsc.mmu.ac.uk/postblairproject/>): 'Does every child matter, Post-Blair: Interconnections of disabled childhoods'. It is our contention that violence and disability can only be understood in the context of contemporary disablist culture. In the paper we explore four types of violence; real, psycho emotional, systemic and cultural. Our aim, then, is not to individualise explanations for violence but to focus on the social contexts in which violence takes place. This paper is perhaps timely in light of growing media reports of violence against disabled people (Sherry, 2001, Sherry, 2011fc) as it challenges familiar cultural tropes which dismiss disabled bodies as mad/bad or vulnerable.

Sara Ryan

University of Oxford

'I thought if I haven't got Asperger syndrome then what is wrong with me?' Meaning, function and consequences of a diagnosis of AS

This paper, based on two qualitative research projects funded by the Wellcome Trust (2007) and the Department of Health (2010), explores the accounts of 26 people diagnosed with Asperger syndrome (AS) and builds on work published elsewhere (Ryan and Raisanen, 2008). In the analysis I follow McLaughlin's (2005) attempt to capture the depth and ambiguity involved in diagnostic journeys and explore the motivation for seeking diagnosis, the process of diagnosis and the meaning and consequences of diagnosis for participants.

The meaning of diagnosis, as understood in medical sociology, fits poorly with the experience of AS and yet 'official' diagnosis is much desired by participants. The difficulty some participants experienced prior to diagnosis, in making sense of social life and experiencing alienation and isolation, is ameliorated by the diagnosis which has significant sense making properties for them. The analysis highlights how, for the majority of participants, not getting a diagnosis would signify a serious (unknown) problem; they worried that they would not be diagnosed. Receiving the diagnosis was, therefore, largely a relief to participants.

For some, the diagnosis provided access to support, but the main consequence of the diagnosis for most participants was an acceptance of their difference and legitimization of that difference through what they described as 'formal diagnosis'.

The focus here raises contradictory and troubling questions about the concept of diagnosis which are further complicated by the proposed removal of the diagnosis of AS, and the subsuming of the condition into a more generic 'autism spectrum disorder' category in the next edition of the DSM-1V.

Ellen Saur

Nord-Trøndelag University College

Co-author: Oddbjorn Johansen

Theatre nonSTOP and the play “A cup of coffee?” Theatre for art and empowerment

In this presentation we will describe a professional theatre for actors with mental disability, focusing on the theatre as a possible arena for re-defining the common conception of “mental disability”. First of all, people with mental disabilities are often left out of many parts of the society, and lacks the possibilities that most of us have in choosing both education, work and leisure activities. The principles of empowerment often seem neglected or professionals find them difficult to carry out. In Norway, since 1991, there has been an official strategy that people with mental disabilities should be included in the local communities with the same civil rights as all other inhabitants. This still seems to be a difficult task, because it's not enough passing civil rights, the rights must also be implemented in practice. And to carry them out, both professionals and participants needs to learn how to do that. People with mental disabilities, as people with other disabilities, have often been stereotyped, and have had few arenas to examine and communicate their own stories to the rest of the world. So our concerns can be seen as 3 main goals:

- develop a theatre based on empowering communication
- establish an arena where students can learn how to participate in a dialogue based on empowerment and equality
- explore how the participants can use theatre to tell their stories about the special experiences that often are left out in the public, both represented in the content of the plays, but also to show that this group of people can create excellent and innovative theatre

Our main purpose has been to develop our own knowledge in due to create a theatre based on empowered participants. Our work is based on the values empowerment, freedom and equal rights for all people. Our claim is that knowledge is socially constructed, and developing new strategies for empowering people have to be created in collaboration between implied parts. In this paper we are exploring two ways theatre can contribute to change attitudes:

- 1) Giving the audience a possibility to experience actors with mental disabilities can in itself be a way to challenge predictions.
- 2) The theatre can be an arena to bring forward the voices of the actors themselves, through their own stories of their own experiences.

The play “A cup of coffee?” is exemplifying these two goals.

This theatre is based on the cooperation between the community council of Namsos, Nord-Trøndelag University College (HiNT), supported by the Norwegian Health Directory and the Nord-Trøndelag County Municipality

Rouven Schlegel

University of Cologne

Do bodies matter? Towards a missing category in German special needs education discourses

Not least by means of gender studies and disability studies, the category of the body has been widespread among the humanities and the life sciences to the extent that even a so-called body turn was declared. Therefore, one might expect it to be represented in the German special needs education discourse as well. A first look into recent studies on 'special education', however, surprisingly reveals an empty space. Although the history of disability and special needs education is quite comprehensive and extensive in Germany, there has been little to none academic discussion of the body as social category within this field yet.

According to German 'special pedagogy's' classics and history, the terms most often used instead of body are limb in a phenomenological, and body in a biological way. This leads to further problems, because both nomenclatures are frequently used synonymously. This problem becomes manifest when translated into English, where the two German words 'Leib' and 'Körper' are generally represented by the same single word – body. Strictly speaking, however, they do not signify the same thing, particularly not when they are compared to the body understood as a socially and culturally constructed category as it is conceptualised by disability studies. While on the one hand limb stands in a Christian tradition and is something to be experienced, body, on the other hand and according to Foucault, is the site in which and on which power works and thus is a socio-cultural construct, whereas finally the biological notion describes the body as a natural fact. Thus, these three different understandings of the body consequently imply a different understanding of disability with all its connotations. Due to the fact that in Germany the special pedagogy is still almost the sole section that investigates disability and therefore has great influence within the German disability discourse, it is of major importance to take a closer look at and to initiate a debate about these different conceptions of the body and their potential influences on the (special) educating discussion.

Hannah Scott

University of Manchester

Exploring cooperative inquiry as a means to voice, listen and critically reflect in a further education college

The voices of students with learning disabilities are so seldom heard in education, that there is often what seems like a “culture of silence” (Gibson, 2006; Whitehurst, 2006). It has been disputed that existing policy and research agendas have become too engrossed in the political and cultural processes of inclusive education, rather than genuinely listening to the voices of those currently being silenced (ibid). Consequently, there is a need to examine how these voices might be heard, in addition to acknowledging the tensions and complexities of such a process in action (refer to Shevlin and Rose, 2003; Gibson, 2006; Whitehurst, 2006; Ravet, 2007). In response, a critical cooperative inquiry was commissioned at a further education college, consisting of five student researchers, four practitioner researchers and a PhD researcher. The inquiry took place over the course of an academic year and was aimed at exploring different ways in which, the aforementioned, students might be more actively included and so empowered in their own learning. Collectively, we examined the use of a variety of different innovative methods, including body collages (based upon the theory of Multiple Intelligences), student interviews, photo voice, in addition to reflective journals and student portfolios. We also engaged in research training and cycles of reflection, where we discussed our findings and addressed challenges to put into practice about what we had learnt from the process. From this, were eager to determine whether the inquiry would be a useful catalyst, in being together both students and staff to review current educational provision. We also questioned whether it would minimise the gap created through professional-practitioner hierarchy, by providing an open forum whereby students could become consultants of their own learning. Our findings show that this was successful, to some extent at least, in alerting practitioners to the benefits of listening to the voices of students with learning disabilities. It also generated some interesting findings about the cooperative experience, student self-reflective skills, their individual learning preferences and practitioner attitudes about student capabilities

Philip Scullion

Coventry University

Towards a cautious use of a social model of disability in general nursing

This paper acknowledges that disability related discrimination is widespread and that nursing, as a profession, has had limited involvement in challenging this. It explores the instrumentality of disability models in enhancing nurses' role in challenging disability discrimination at both patient and societal levels.

First it is argued that nurses should be aware of conceptualisations and models and their own practice in relation to disabled people when they enter a patient role because of the real potential that they serve to deny full access to health care and prepare them for a social role as 'perpetual patients'.

Critique of a Social Model, the antithesis of the medical model, as unashamedly political, intending to 'legitimise one way of thinking over another' is expounded along with some of its limitations in terms of a blanket application to nursing.

Inroads and related claims of the impact this model into nursing, are outlined exposing the danger of 'thinking in one paradigm while acting in another'.

It will be argued that professional nursing faces three key issues if it is to become part of the solution to disability discrimination, rather than remaining a relatively silent partner in sustaining the problem.

1. There is a need for evidence of all kinds to show the extent and nature of the problem in nursing, since a majority view may still be that the idea that nurses could be implicated in discriminating against disabled patients would be seen as a preposterous notion
2. Disability cannot easily be viewed as both a medical condition, still the prevailing paradigm within health care professions, and at the same time an equal opportunity issue. There is a pressing need to convince those within the profession that disability should be conceptualised within a rights framework.
3. More evidence is needed to show the value or potential of models of disability in nursing and as a way of creating cognitive dissonance and thus challenging discrimination.

Advocacy has been described as little a- that which concerns itself with individuals, and big A- concerning itself with wider social illnesses or issues. This up streaming, correcting the bigger picture issues before they impact on individuals, is something an early nurse writer alluded to in suggesting that we need a model of advocacy which extends our concerns beyond the institutions walls (Folwler 1989). The possibility of nursing as social advocacy, along with other implications are examined in this paper.

Viveca Selander

Department of Social Work, Stockholm University

Challenges and dilemmas of everyday life with personal assistance in Sweden

Personal assistance was introduced as a legal right of persons with severe disabilities as a part of the Swedish Disability reform 1994. Since the introduction it has become highly valued by persons who are eligible to personal assistance. Behind the reform was a major criticism of the disability services. The criticism came from different directions. The disability organizations were critical of the lack of influence over decisions concerning one's own person and to the power of different professional groups to define problems and solutions. From market-liberal directions there was critique that the welfare bureaucracy was inefficient, costly and rigid. From an identity policy perspective there were claims that as a minority group, persons with disabilities should have the right to shape their support themselves. When the Swedish version of personal assistance finally was introduced in 1994, it was inspired by ideas from Independent Living - movement in the U.S. and experimental activities in different parts of Sweden. In comparison to how personal assistance is designed in the other Nordic countries, the Swedish model is more generous both regarding coverage and intensity: In 2008 about 18 800 persons were granted personal assistance and received an average of 108 hours of assistance per week.

Since the introduction of the personal assistance scheme various attempts have been made to reduce the ever increasing costs. At the time of the introduction, the users were seen as conscious consumers and their rights to choose or leave an assistance organizer were regarded as sufficient means of quality control. But during the more than fifteen years that has passed since the introduction of the reform, the model has gradually been adjusted and in 2010 the perspective has shifted towards a larger amount of state supervision and control. Without any legislative changes, stricter eligibility criteria are about to be introduced.

Changes in welfare systems affect people's daily lives in different ways. In a study of how families' everyday life is affected if one of the adults has personal assistance, the importance and impact of living with personal assistance is illustrated in various ways. The study is based on interviews with six women and two men with extensive physical disabilities, and with their partners and other family members including children. This paper presentation addresses some areas of the users', their partners' and the children's' experiences. Central themes include the significance of personal assistance for the non-disabled partner's opportunity to work, for the family economy and for issues of gender equality as well as how both the users and their partners handle the balance between independence, privacy and safety. The possible consequences for the informants of the recent changes of the personal assistance scheme are discussed.

Bruno Sena-Martins

Centre for Social Studies, University of Coimbra

Blindness in Mozambique: cultural experiences of disability

Grounded on a long ethnographic account of the experiences of blind people in Portugal through the Portuguese National Association of the Visually Impaired (ACAPO – in Portuguese), my research has been devoted to explore how blindness is culturally represented and experienced. On the one hand, the effort has been to understand the processes through which the hegemonic cultural values towards blindness and disability are produced and reproduced. On the other hand, the effort is to explore how those dominant values relate with the experiences of blind people.

With the goal of sketching a comparative perspective, departing from the dominant cultural representations and experiences that enfold blindness in western societies, I undertook an intensive ethnographic fieldwork in Mozambique, Eastern Africa. During three months I lived in the National Institute for the Blind in Mozambique and travelled in several provinces of the country with the support of the Association of the Visually Impaired of Mozambique (ACAMO – in Portuguese). From that analytic effort I pretend to offer some issues for discussion. Particularly, I will explain that the representations of blindness in Mozambique are strongly related to causal explanations related to sorcery: socio-spiritual narratives and interpretations that determine differently the meaning of a particular blindness. In those frames of meaning the causality of blindness depends on the relation between living social agents and the spirits - whose intervention, it is believed, permeates all arenas of experience. Moreover, I'll show that the life-histories and expectations of blind people in Mozambique are deeply related to some of the most important transformations occurred in Mozambican reality - in terms of its short and long history.

I will claim that the socio-cultural and socio-historical perspective offered by this ethnography on the experiences and representations of blindness in Mozambique contributes to the deconstruction of the hegemonic western perspectives that came to define disability vis a vis the modern biomedical notion of normality. In that sense, it is possible to establish important links between the deconstruction of disability offered the socio-cultural diversity and the deconstruction produced by the political opposition of the social movements in our societies (for instance, the social model of disability). Therefore, the epistemic deconstruction offered by different cultural contexts will illustrate the contingency in the disciplinary categories through which modern science has marginalized disabled people.

Sonali Shah

Centre of Disability Studies, University of Leeds

Has medicine changed? Medicalisation and de-medicalisation in the lives of 3 generations of disabled people

The literature of disability studies and the sociology and health and illness attributes particular significance to the role of medicine and medicalisation in producing and governing disability in the twentieth century. Particular attention has also been drawn to the colonisation of disabled people's lives by powerful health and welfare professionals. Medicine is attributed with roles in maintaining the 'normal' functioning of the individual and society, and with constraining life expectations through normalizing discourses. The prevalence of long-stay hospitals for children with impairments and diseases, before and after the Second World War, also created environments of enforced dependency that shaped the lives of patients.

This paper explores the influence of medical professionals, policies and institutions on the lives of the three generations. Developments in treatment regimes and technologies have had a substantial impact on the experience of medical environments (not least in the periods of time young people may spend in hospital). Doctors now exercise less influence over non-medical decisions that affect life choices (such as school placements) while increasing lay knowledge and patient choice have provided opportunities to resist or contest medical authority. Connecting biographical narratives (of disabled people born in the 1940s, 1960s and 1980s) with macro-level policy, this paper explores how medical authority and knowledge shaped life expectations and life pathways of disabled people (even at birth), with diagnosis and prognosis shaping parental expectations and children's upbringing.

Tom Shakespeare

World Health Organization

Mainstreaming disability: experiences from the UN system

Agencies in the UN system such as the World Health Organization, International Labour Office and the World Bank work with Member States to support the implementation of human rights and to promote development. While such international agencies are not party to the UN Convention on the Rights of Persons with Disabilities (2008), they have a duty to subscribe to the international human rights agenda epitomised by this Treaty and other international instruments. They can play an important role in developing normative tools, gathering scientific evidence and helping monitor progress towards implementation of the Convention.

Awareness of disability rights and actions to promote participation by people with disabilities in the UN system has been accelerated as a result both of the Convention and of the active participation of people with disabilities themselves in the work of these Organizations. This paper will provide a detailed account of progress towards barrier removal and mainstreaming of disability in one organization, WHO, which has created a Task Force on Disability to further these objectives. The paper will also discuss examples of progress in other UN agencies, and draw tentative conclusions about opportunities and obstacles for mainstreaming disability in the international civil service.

Yi-Ting Shih

Newcastle University

The transition between social positions

Parents have been portrayed as working along with professionals, institutions, or special schools in hiding, segregating or overprotecting their disabled child from mainstream (Barnes and Mercer, 2007; Finkelstein, 1998; Finkelstein 2001). However, it could be argued that it is the discourse of personal tragedy that shapes both researchers and parents' understanding of disability, therefore highlighting negative aspects of taking care of a disabled child. An increasing body of research emphasises parents' positive experiences of having a disabled child (Beresford, 1994), although acknowledging sorrow (Kearney and Griffin, 2001; Landsman, 1998; Larson, 1998). In addition, instead of viewing parents of disabled children as sharing same interests with service providers, research has revealed the discrepancy and controversy between parents and service providers on issues such as hope, limitation, meanings of disability, or future (McLaughlin and Goodley, 2008; McLaughlin, 2006; Green, 2003). Parents also reported difficulties while interacting, and negotiating with service providers (Todd and Jones, 2005; Todd and Jones, 2003; Brett, 2002; Case, 2000; Bower and Hayes, 1998). In this kind of research, parents and service providers are viewed as different or even contrary parties. One of the important issues in this research is how service providers could respect parents as allies or partners while providing services for disabled children and their families.

My PhD project aims to understand issues related to motherhood and meanings of disability from perspectives of disabled children's mothers. Unexpectedly, the occupations of some mothers in North East England I interviewed are more or less related to services for disabled people and their families. When the boundaries between being a service provider and being a mother of a disabled child blurred, assumptions usually taken for granted are challenged and modified.

This paper is part of my thesis and will discuss three themes. First is mothers' reflection after shifting their positions from a professional to a mother of a disabled child. It will also illustrate how mothers access resources by exercising their professional knowledge. Secondly, it will include mothers' reconstruction of meanings of disability as both a professional and a mother. Last how do the experiences as a mother contribute to their roles as a professional. Therefore, this paper suggests that although mothers are non-disabled people, their experiences can contribute to our understanding about disability.

Hanna Sigurjónsdóttir

Co-authors: Helga Baldvins og Bjargardóttir, Rannveig Traustadóttir

Disability, Family Life and Human Rights

In March 2007, the Icelandic authorities signed the United Convention on the Rights of Persons with Disabilities, and in doing so they made a commitment to abide by the terms of the Convention.

The Convention is now widely viewed as a guide in matters concerning persons with disabilities. Many nations, Iceland included, are now in the process of confirming the convention and adjusting their legal environment. The knowledge of the contents of the Convention is an essential presumption for securing equality and human rights for the people with disabilities.

This paper discusses one group of persons with disabilities—parents with intellectual disabilities and their right to a family life—as an example of a changed understanding of the status of people with disabilities in the society and the support they are entitled to. In the paper, the development of the relationship of parents to their children is traced through human-rights conventions and court-orders over the last few decades.

Results indicate that if the parents with intellectual disabilities are to receive legal protection that meets the requirements of the Icelandic constitution, the European Convention on Human Rights and the UN Convention on the Rights of Persons with Disabilities, a significant change of attitudes is necessary within those institutions that handle matters concerning persons with disabilities to ensure that parents with intellectual disabilities are equal to other parents.

Howard Sklar

University of Helsinki

Poster

Life Narratives in Graphic Form: Strategies for Enabling the “Intellectually Disabled” to Construct Their Own Stories

In this presentation, I propose an approach for helping the “intellectually disabled” to construct their life narratives. As some scholars (Whittemore et al. 1986, Couser 2002) have noted, the life stories of the intellectually disabled frequently are conveyed through the accounts of parents, with the emphasis typically placed either on their difficulties in coming to terms with the child’s needs, or on the child’s struggles to succeed in spite of his or her disability. The difficulty in this, as Goodley notes, is that “They [parents as well as researchers] have never been intellectually disabled (in the sense that they and most of us construct the term), so this is not something they can know by empathy.” Thus, Whittemore and colleagues (1986) lamented that “the lack of anything approximating an emic, or insider’s view, is perhaps the most striking common feature” of the life narratives that existed. Although some researchers have attempted to remedy this absence through the production of autobiographical materials based on interviews with intellectually disabled individuals, the “insider’s view” provided by such narratives remains relatively rare. On a personal level, this neglect seems particularly unfortunate, when I consider my own 16-year-old daughter’s interest in, and need for, ways of apprehending her own life story and its implications for her social, emotional, and psychological life. Indeed, she often attempts to tell her own story through a variety of forms: through structured discussion; through casual conversation; and through fictional stories, written entirely by her, that loosely address the concerns that she has expressed more directly through other means. Despite these efforts to convey her own experiences, she nonetheless struggles to grasp the nature and content of particular events that have occurred in her life, and often asks questions about those events as a way of understanding and constructing them in her memory. For this reason, I have become convinced that some of the difficulty that she and other intellectually disabled adolescents encounter in understanding and relating their experiences might be alleviated by having them narrate particular events in their lives and illustrate those events in “panels,” in the manner of graphic narratives. In this presentation, I will introduce this approach by first examining some of the life narratives of intellectually disabled individuals that do exist, as well as considering the obstacles that make the production of such narratives practically challenging and potentially problematic from an ethical standpoint. After considering some examples of such life narratives and the implications of these narratives for the pursuit of the truth of the experiences of the intellectually disabled, I then will show how the use of a graphic narrative approach might serve as a useful option for some intellectually disabled individuals. In order to clarify these issues, I will outline specific tasks that might be used to elicit life narratives in graphic form.

Laura Snell

CeDR, Lancaster University

The lived experiences of young adult cochlear implant users: the cyborg generation?

In the past 20 years, an increasing number of deaf children and deaf adults have received cochlear implants in the UK. The increasingly widespread use of this in-body technology has evoked diverse reactions amongst both deaf and hearing communities, and shaped the experiences of many deaf individuals. This paper is based on my (on-going) PhD research which broadly explores the lived experiences of young adult cochlear implant users. In-depth interviews have been conducted with implant users in order to explore their self-identity, community membership, and the perceived impact of the technology. This paper will draw on the research findings to date, with a particular focus on the complexities of the relationship between the human body and implant technology.

Sylvia Söderström

NTNU Social Research AS, centre for diversity and inclusion

Communicative challenges in meetings between migrant families with disabled children and healthcare professionals in Norway

Research on families with disabled children describe how these families face many challenges in their daily lives; lack of information, practical and emotional stress, and struggles with the service system. Families from non-western countries are for various reasons seldom included in these studies, and there are few separate studies about families with such a “double” minority background. Consequently we have little research based knowledge about the intersection of ethnicity and disability. However, migrant families with disabled children, professionals, user organizations, and bureaucrats indicate severe challenges in the field of service provision to these families. They describe language problems, culture differences, and lack of information about the welfare system. International studies indicate that communication problems and poverty are greater challenges than cultural and religious differences.

This presentation draws on a qualitative study with 50 migrant families with disabled children, and more than 100 professionals working close to these children. The data sampling were carried out in 2008 – 2010 in three different cities in Norway. Whenever necessary, professional interpreters were used when interviewing the families. Both families and professionals were interviewed with semi-structured qualitative interviews, and the children were observed in kindergarten or at school. The children are between two and twelve years of age. Most of the children have multi diagnoses, usually an intellectual disability combined with physical impairment. The families have different backgrounds, both with respect to nationality and language, period of residence in Norway, migration history, and living conditions. The aim of this study is to gain more knowledge about challenges in daily life for migrant families with disabled children, and to develop strategies for better collaboration between the migrant families and the service system.

I will discuss how migrant families with disabled children experience the healthcare services in Norway. Do these families face the same challenges in their encounter with the healthcare system as majority families do? Do migrant families with disabled children face other or additional barriers than majority families due to anticipations about culture and language, or prejudice and racism? The emphasis in the presentation will be on the current study’s empirical findings on the significance of language and communication in the encounter between health professionals and the families. Empirical cases of different communication challenges and of social constructions made based on insufficient or misunderstood communication will be discussed. The findings are so far preliminary. They do however indicate that language and communication capabilities, professional interpretation, and comprehensible, thorough, and repeatedly information are essential for migrant families possibilities to equal access to healthcare services.

Karen Soldatic

Centre for Human Rights Education

Co-author: Barbara Pini

The Three Ds of Welfare Reform: Disability, Disgust and Deservingness

Public policy discourses on disability frequently reference emotions such as shame or pity to describe the lived experience of disabled people. While sociological research within the emotional realm is re-emerging as a growing area of interest, little work appears to have explored the relationship of emotions in articulating notions of deservingness that are a significant part of public policy discourses on disability. This is curious, considering that normative conceptions of deservingness have been integral to the legislative process that seeks to either elaborate or constrain the rights of disabled people. Drawing on the Howard Government's workfirst welfare reform agenda as a case study, this paper explores the role of 'disgust' in constraining disabled people's rights. In particular, we suggest that the politics of disgust was drawn upon by the Howard Government to shift public notions of justice, from rights to deserving.

Per Koren Solvang

Oslo University College

Between Art Therapy and Disability Aesthetics

What emerges as art and how it is categorised is a collective process taking place in art worlds and involving a wide array of social actors. The intersection between disability and art also includes health care professionals and the disability movement as important social actors. In this paper, the relation between four ways of framing the intersection between disability and art is discussed. These are art therapy, outsider art, disability art and disability aesthetics.

Art therapy is framed by the health sciences. Its therapeutic ambitions are two-fold: to bring out suppressed feelings based on psychotherapeutic theories and to provide disabled people with a valued social practice based on social work theory. Outsider art is framed by collectors and made by people outside the art institution. The art is valued for its authenticity and for not being corrupted by the shifting fashions of high art. The most well-known artists and collectors have historically been closely related to the institutions of psychiatry, but this has changed in the last two decades with the emergence of independent collectors and gallery owners specializing in what they describe as intuitive, visionary and marginal art. Disability art is art made by disabled people identifying with the disability movement. It has emerged as a minority and activist art form alongside black art and feminist art. Disability aesthetics are developed from the position of the art critic and curator. It is both a framework for reconsidering the history of art and for giving value to disability in the aesthetic qualities assigned to works of art.

The disability art-affiliated artists interviewed were trying to balance between the ghetto and the mainstream. In doing so, they voiced a complex relation to the categories made relevant to their work and their position in the art world. Art as therapy and outsider art were first and foremost questioned regarding oppressive relations where the artist is in a patient or client role. At the same time, these institutional practices were valued for providing possibility and appreciation. Art therapy classes were the only way many pioneering disability artists could get an education and outsider art has given status to art produced by disabled people who don't have access to education and the mainstream art world. Disability art encompasses today all three phases emancipatory movements typically goes through from correcting and ridiculing the dominant disablist ideology, becoming a radical separatist movement making art only for other disabled people, and finally entering a transgressive phase where the label Disability Art is blurred and the aesthetic possibilities come into the forefront. Disability aesthetics are enacted, both by defining circus freak shows and Mexican painter Frida Kahlo (1907–1954) as ancestors of disability art, and by working with ideas of the aesthetic and relational power of disability in art.

Chris Spooner

CeDR, Lancaster University

Disabled leaders or disablist followers? Examining the reasons behind the 'Chrome Ceiling'

The 'chrome ceiling' (Medgyesi, 1996) refers to the barriers facing disabled people in their efforts to reach positions of seniority within organizations. My PhD examines to what extent impairment and the attitudes of followers (i.e. those people who are led by leaders), impacts upon the careers of disabled people. At the heart of this PhD, is an empirical piece of work, comprising a series of interviews with disabled leaders and focus groups with followers.

At time of writing, I am mid-way through my (part-time) PhD and am currently engaged in field-work. This presentation summarises my findings and thoughts to-date and highlights what I consider to be the emerging themes from my research. It draws on the interviews and focus groups which have so far been completed, and also on the concepts and theories from my literature review on leadership and disability.

My PhD is still very much work in progress and I will be looking for any helpful tips and ideas from audience members who have an interest in my topic!

Kirsten Stalker

University of Strathclyde

Co-authors: Pam Green Lister, Jennifer Lerpiniere, Katherine McArthur

Child Protection and Disabled Children - Rights at Risk

This paper presents findings from a scoping study, funded by the Sir Halley Stewart Trust, examining child protection in relation to the needs and rights of disabled children. The research aimed to scope current knowledge about this topic, review child protection policies and practice across the UK in relation to disabled children, and pilot ways of seeking disabled children's views about child protection services.

Methods included: a review of relevant research published since 1996; analysis of child protection policies in UK, along with a critical evaluation of how far these address the needs and rights of disabled children; interviews with 10 key informants – senior policy makers and practitioners in central government, the inspectorates, the police, the NHS, the voluntary sector and a Children's Commissioner Office – about the effectiveness of current policy and practice in protecting disabled children; testing out an approach to seeking the views of four disabled children, aged 12-17, using child protection services.

Findings: Disabled children are 3.4 times more likely to be abused than non-disabled children (Sullivan and Knutson 2000). Children with communication impairments, behavioural disorders, learning disabilities and sensory impairments are particularly vulnerable. The four jurisdictions of the UK share a mainstreaming approach to child protection based on the principle that all children have equal rights to protection. However, Scotland is alone in largely failing, since 1998, to address disabled children's heightened vulnerability and need for added protection in national policy frameworks. There is an opportunity to redress the balance as Scottish guidance on inter-agency working in child protection is currently under review.

Evidence emerged, from the literature and key informants, of differential treatment of disabled children in child protection systems in both England and Scotland, including lower levels of reporting and registration. Higher thresholds may be applied to this group than to other children. Some professionals were described as unwilling to believe that disabled children could be abused. Professionals often lack training, skills and experience in communicating with disabled children.

Disabled children were thought to be seldom involved in case conferences. There was little evidence of independent advocates being used to seek or represent children's views. It was reported that disabled children are often not seen as credible witnesses and consequently, relatively few cases go to court. In summary, the research suggests that disabled children's rights, under UK disability legislation, to the same level of safeguarding as other young people are not being consistently upheld. The authors are now planning a major study to investigate the issues in more detail.

Vasilica Stamatin

Babes-Bolyai University Cluj-Napoca

The present perception of disability in Romanian society

After the Romanian revolution in 1989, people with disabilities were finally seen on the streets, in the shops, in schools and in the work place. During the period of communism, we were taught that it was shameful to have a family member with a disability. So, they were hidden, or worse, they were abandoned in hellish institutions, and treated worse than animals. In 2007, Romania joined EU. It was another very important step for Romanian people, because we had to attain the European standards in almost all social areas, including issues of disability. The study is researching the present perception of disability in Romanian society, at implicit and explicit levels and the correlation of Romanian thinking, feeling and behaviour with medical or social models. Very few disability studies have been conducted in Romania, and the general level of knowledge about disability is still low. The research is an exploratory study, a qualitative one, using a phenomenology research design. To gather the data, I applied methodological triangulation, increasing the internal validity, by using focus groups, semi-structured interviews, mind mapping, and an original method called “guided empathy in disability”.

The interviews were taken in different geographical areas of the country. I used purposing sampling, and snowball sampling. Data –collection interviews continued until the topic was exhausted or saturated, that was when interviewees introduced no new perspectives on the research topic. At this stage, I got five focus groups and sixty one individual interviews. I used the same guide interview for the focus groups and the individual interviews and I’ve done the data analysis using NVivo8 program and also classic qualitative analysis.

The findings reveal that even if the Romanians have a generally positive attitude towards disability, the thinking and the approach are wrong, based on the charity and medical models. I found many similarities with the results from other disability studies, but also specific local results, as: the congruence perception of disability with disabled beggars or the phenomenon of acting as being disabled to get more money, mercy or attention, or the phenomenon of paying huge tips to authorities to buy a disability certificate, for the purpose of getting advantages (sponsorships, no taxes for cars from abroad, free transportation, priority in different social issues).

Allan Sutherland

Writer in residence, Centre for Citizen Participation, Brunel University

Transcription poetry as a vehicle for documenting the lives of disabled people.

Disability arts has long been defined as 'art made by disabled people which reflects the experience of disability.' This paper will consider some aspects of using poetry as a vehicle for disabled people's experience and of using disabled people's experience as a source for poetry, 'including technical procedures and ethical issues that can arise.

For the past five years I have been developing a way of creating poems by editing the transcripts of oral history interviews with disabled people. This has led to two major commissions from Disability Arts Online and my current Leverhulme-funded residency at the Centre for Citizen Participation, Brunel University.

The paper will describe this method of working, consider its advantages and examine issues that it throws up. It will discuss what form of transcription is appropriate to such work.

It will consider the process of editing such transcripts into poems, with particular attention to the use of techniques from scriptwriting and the formal experimentation of twentieth century modernism. It will also relate this work to a tradition of 'found art' including collage, readymades and cutup.

The paper will point out that the devices that are valuable to me in producing a literary work are potential dangers for the academic interviewer, particularly if adopted unconsciously. It will also pose the question: to what extent is the kind of truth arrived at through this work the kind of truth that is important to an academic? The paper will consider some of the issues that arise in relation to working with individuals who have impairments which affect their linguistic performance or underlying competence, such as speech impediment or aphasia. Where does truth reside? Are these elements something to be excised as stringently as possible, in order to get to the real person underneath? Or does the real person reside in the way that they speak as well as the content of that speech?

It will suggest that, at least for literary work, there exists a possibility to present both, by using the radio technique of internal monologue. It will reference such examples as Lee Evans's award-winning 'Spoonface Steinberg', the radio version of my own series 'Inmates' and 'Black Daisies for the Bride', Tony Harrison's 1993 Prix Italia-winning film made on a ward for women with Alzheimer's.

It will mention in passing the potential creative possibilities of inaccurate transcription such as might be provided by transcription software.

The paper will also consider some of the ethical issues raised by work that uses individual disabled people's personal history and words to create an end product that is much more public than the results of academic research.

Mark Swetz

Central School of Speech and Drama

Early thoughts on Blind Spectatorship

In the twentieth century, and particularly after the 1960's, British, European and American theatre has become increasingly spectacular. Fashions of practice in our lifetimes have emphasised the visual elements of performance, arguably at the expense of exposition and dialogue. Today our eyes, rather than our ears, define much of what occurs on contemporary stages.

What is the experience of the blind or visually impaired spectator in the theatre?

A brief history will be provided of twentieth century practice, exploring why and when the imbalance between text and image emerged onstage. Surveying current practice in mainstream, experimental and fringe performance one can examine the wide range of strategies in providing dramatic information through aural and visual means.

Several artists and performing art institutions are making great progress in providing a more equal encounter for their patrons. This paper will illustrate some of the strategies that are being employed to create access for visually impaired spectators. The work of specialised companies and artists, including Extant and Graeae in the UK and TBTB in the US will be cited for the practices they employ to create a shared experience with a diverse public.

This presentation is part of a larger study on Blind Spectatorship being done at the Central School of Speech and Drama in London. It is an investigation that draws on interviews with leading practitioners and experts in the UK and abroad, and also relies on practice as research. The author has over twenty years of professional experience in the theatre as a director and producer.

The paper will present the findings from the first year of an ongoing project. For those interested in learning about responses to parity for consumers of the performing arts, the speaker will provide an introduction to this topic and impressions on practical, scalable solutions to minimise or eliminate the disabling conventions of contemporary, spectacular practice.

Myroslava Tataryn

London School of Hygiene and Tropical Medicine

Co-authors: Yasmene Alavi, Vincent Jumbe, Sally Hartley, Sarah Smith, Donna Lamping, Chris Lavy

Community participation is a central tenet to community-based rehabilitation

Community participation is a central tenet to community-based rehabilitation (CBR) philosophy but the participation of local communities in such initiatives has not been adequately explored in CBR research. The pending launch of the World Health Organisation CBR guidelines in 2010, and growing international recognition of the potential of CBR in international development work, provide a timely opportunity to explore more closely the potential of local community participation in CBR. The aim of this study was to explore the ways in which local community members could support the rehabilitation of children with musculoskeletal impairments (MSIs) and their families in Malawi.

We conducted a qualitative study in 4 districts in Malawi to explore the impact of MSIs in the lives of children and their families and the role of local community members. A total of 169 participants took part in 57 in-depth interviews, focus group discussions and observations. Participants included children with MSIs (aged 2-10 years), their elder siblings, parents/guardians, teachers, community leaders, health workers, and adults who experienced MSIs as children.

Children's and parents' experiences of community support were mixed and the heterogeneity of local communities emerged in discussions. There were examples of both positive support from local communities and negative, stigmatizing experiences. Among positive roles, community members were perceived to be able to facilitate access to health care and rehabilitation services by giving advice and information, financial support, or by providing escort/advocacy, whereas negative examples emerged about some community members actively discouraging people with disabilities and their families from accessing mainstream health care and rehabilitation services.

We have identified opportunities and obstacles for the participation of community members in CBR. This information can be used in planning sustainable and effective CBR initiatives in Malawi, and highlights the need to take into account the heterogeneity of local communities.

Floris Tomasini

School of Public Health and Clinical Sciences, UCLAN

The importance of our internal life and ontological security in relation to the construction of disability

This paper looks at the importance of the concept of having an internal life and how this plays a role in our understanding the challenge of disability. Instead of looking outwardly at the problems in society, this paper examines how our inner relationship with ourselves plays a significant role in perceiving opportunities and challenges in the world. In particular I want to further develop the idea of internalised oppression put forward by Carol Thomas, by drawing on the idea of 'ontological security' (R.D. Laing) whose conceptualisation is in turn heavily influenced by Heidegger and Sartre.

Ontological security and insecurity, in simple terms, is about a basic trust in our 'being-in-the-world'. How ontologically secure or insecure we are determines how we perceive our embodiment and its challenges. To illustrate the importance of the concept of ontological security/insecurity in the area of disability I look at a wide spectrum of amputees and how they cope with the challenge of impairment effects.

I end by making the provocative claim that being 'able bodied' and deeply ontologically insecure as an amputee may be more of a challenge, in certain particular circumstances, than being 'disabled' and ontologically secure. To do this I make some comparisons between voluntary amputees (self-demand amputees) and involuntary (or traumatic amputees) and the challenges they face. While I do not wish to claim that that this holds in all comparative cases between non-voluntary and voluntary amputees, it is meant to show how significant ontological insecurity can be in understanding disability in an able bodied centric world.

Cristina Joy Torgé

NISAL, Linköping university

“The right hand helps the left”: Care in couplehood where both partners are disabled

Couplehood is an area of relationship between disabled people that is under-researched in comparison to self-evident family relationships with their parents and siblings. Although disabled people do enter into relationships with one another and there are expanding networks between disabled adults, few texts explore partnerships of love between the physically disabled. Most texts that discuss disability and relationships usually only describe spousal care by an able-bodied partner to a disabled one. It is also taken for granted that the disability was acquired after the marriage. But how does spousal care look like in a relationship where both partners are seen to be in need of help? How do the actualizations of such care change over time, over changing bodily states and with age?

This paper describes a newly started PhD project placed at the intersection of disability studies, care studies and gerontology. The aim of the project is to explore the actualizations of care between disabled couples above the age of 55, who can both look back on a long relationship together, as well as look ahead to their future. Evidently, what is of interest to the project are not couples who acquire disability with advanced age, but rather those who have acquired impairments earlier in life. The focus is on the concept of care understood in a broader meaning, which challenges notions of dependence in care.

The preliminary results of the qualitative interview study will be discussed. Interviews have been conducted with couples, where both partners have a long-term disability and have had the opportunity to live long lives together with their impairments. The dichotomy between caregiver and care receiver become less clear as partners usually take on both these roles simultaneously. Care in the relationships might also have different meanings and actualizations depending on the changing needs and bodily states of both partners.

Louise Townson

Carlisle People First Research Team

Co-authors: Rohss Chapman, Elizabeth Harkness, Malcolm Eardley.

Inclusive Research: Advocacy and Autism

The Carlisle People First Research Team started working together in the mid 1990's. We take an inclusive approach to research. We know a lot about the lives of people with learning difficulties, because we have experience of having a learning difficulty. Our research group uses a process called the 'Research Cycle'. We use methods that are accessible and build on all of our strengths.

This paper will talk about our group and then look at one of the projects we did – 'Self Advocacy and Autism'. We wanted to find out whether or not people with the label of Autism had good access to advocacy. We used lots of different methods to help us to find out the answers to our research question. For this project we worked in partnership with the National Autistic Society and the Open University.

One of the members of the Research Team was particularly concerned that people who had the label of Autism or Aspergers syndrome were not getting equal access to advocacy services, the research was very important because we knew that there were few people with the label of Autism or Aspergers syndrome attended the self-advocacy groups that Carlisle People First offered, and we felt that this was a similar situation to that of other advocacy groups.

We found out that often people suffered from issues such as late diagnosis, being given the wrong services, being passed around from service to service and being told that they did not meet the eligibility criteria for certain services. We'd like to talk about what we have found out in the hope that by getting this information out, it will improve the lives of people who have label of Autism or Aspergers syndrome.

This project came from the interest of the members of the research team, and is based on the group's values and principles. We think it's important to tell people how we do our research, as well as tell them about our research.

Rannveig Traustadóttir

Centre for Disability Studies, University of Iceland

Disabled People and Nordic Disability Studies

In most countries disabled people have been in leading roles in establishing and developing disability studies as a new academic discipline. In the Nordic countries, however, this has not been the case. Instead, it has largely been non-disabled people who have developed this new field of study. This presentation explores some of the reasons why disabled people have not been as active in the creation of disability studies and disability research in the Nordic countries as elsewhere, for example in the UK. It also examines the development of Nordic disability research in an international context and discusses the similarities and differences between Nordic, USA and UK disability studies in an attempt to explain the reasons for the lack of disabled people active in the Nordic disability studies community. Although it is not necessary to have impairment to do disability research it is essential that disabled people are in leading roles in developing disability studies as an academic discipline and are active in disability research. The paper concludes by discussing some of the strategies to increase the number of disabled people in Nordic disability studies community.

Carwyn Tywyn

Disability Law Service

Co-author: Dr Christine Goodall

A nation within a nation? Disability, civil society and nation-building in Wales

The idea of “nation-building” is common to several social science disciplines. Previous accounts of nation-building have focussed on the territorial and cultural consolidation of the central state. Particular attention has been devoted to issues such as economic and linguistic integration, and the development of “national” transport and communications infrastructures, and a national mass media (select examples from this vast literature include Deutsch (1953); Rokkan and Urwin (1982); Anderson (1983) and Billig (1995)).

The establishment of a National Assembly for Wales in 1999 has provided a further catalyst for the idea of “nation-building” in a Welsh context. Occasionally, the call for a “nation-building” project for Wales has been made explicitly (Dafis, 2003). However, the nation-building project is often to be found in more implicit terms, for example in policy documents which seek to foster greater unity between the diverse (and sometimes disparate) regions of Wales.

Recent academic work has focussed on the idea of “civil society” in Wales (Day et al. 2006; Royles, 2007). This work analyses to what extent we may speak of an autonomous civil society in Wales; to what extent the civil society underpins national unity in Wales; and the extent to which various sectors of civil society have influence with government and, by implication, to what extent these groups may be considered participants in the current process of nation-building in Wales.

In 2010, the Disability Law Service published a major report on the provision of advice services for disabled people in Wales (Disability Law Service, 2010). Whilst the report was primarily intended as a policy report, it is our view that the report has much to say about the role of disabled people in Welsh civil society and the wider idea of the “Welsh nation” itself. The co-ordination and promotion of disability rights falls on the shoulders of several separate organisations, as opposed to a unifying commissioner (as is the case with children and older people in Wales). The provision of disability advice is sparse and reflects the traditional sense of geographic disunity in Wales, rather than modern patterns of unification embodied by the Welsh Assembly Government. Moreover, disabled people are often marginalised by economic weakness and / or their belonging to an additional minority group. This paper therefore asks if disabled people are being left behind in the nation-building process in Wales.

Caroline Vandekinderen

Department Disability Studies and Inclusive Education, Ghent University

With greetings from a man who feels like no one anymore at all. Deconstructing the notion of 'psychopathology' through the lived experiences of Jimmy Sax

In the context of a current PhD research project, we embrace a collection of alternative narratives that are at risk of being disqualified and excluded in the monologue of a single theoretical frame of reference dispersed by privileged sections of western society. In this article, we explore the lived experiences of Jimmy Sax, a 49 years old man labelled as a (core) psychopath, from a critical disability studies perspective in an attempt to transgress beyond these taken-for-granted assumptions. We adapted a narrative and ethnographic research approach - embedded in interpretative research traditions – which enabled us to reappraise the singularity of Jimmy as a subject in its complexity, as subject-in-process. Throughout his life story, we analyze how the discourse of deviance and ab/normality – as a regime of power – seeks to regulate the subject and compels people collectively to inscribe these beliefs unquestioningly. The professional expert discourse, which defines 'madness' on the borders of deviant or undesirable behaviour with a reference to the social norms ("what one should or should not do"), often occupies an evident state of ultimate truth and ideological domination. We aim to expose (and counterbalance) the reductionist psychopathological view, which is demonstrated by the remarkable fact that someone's life (story) can be fitted in (and reduced to) the criteria of a contemporary's check-list based translation of the notion of 'psychopathology'. Focusing on individual behaviour, the checklist neglects the meaning of behaviour and serves as supporting evidence for the psychopathological nature of the 'investigated'. However, in order to understand his social life, we specifically deconstruct the notion of psychopathology – a widely recognized and used concept – by understanding reality as a social construction and creation. We want to demonstrate how a story can be read in the name of a particular discourse, which is not only a repository of a truth and expert knowledge, but functions as a mode of action. Our aim is to deconstruct the concept of 'psychopathology' by grasping the complexities of Jimmy's life, outside the binary logic of certainty, totality and linearity. An in depth exploration of Jimmy's complex and turbulent life story – at first sight a sequence of mental health problems, violence and imprisonment – adds a number of dimensions and disrupts the "smooth passage of regimes of truth" by revealing how power permeates the construction and the legitimation of knowledge.

Simo Vehmas

University of Jyväskylä

Does Disability Studies Need Relativism?

The disability studies perspective typically characterizes disability as a social construct. It is premised upon the notion of cultural relativism in that it assumes that the meaning and significance of disability are products of specific cultural conditions. The tenets of social constructionism have seemed to provide disability studies with an ideal basis to confront various philosophical accounts of disability that discuss disability in one-sidedly medical and individualistic terms. However, many accounts in disability studies appear to include a shift from cultural relativism to normative relativism that denies the universal validity of every moral principle and states that all moral values are equally worthy or worthless. Thus, some disability scholars and activists are not satisfied with a descriptive constructionist understanding of disability but go further and claim that impairments and disabilities that result in, for instance, physical disabilities, psychiatric problems or various forms of autism are, in fact, normatively neutral or even positive manifestations of human diversity.

Social constructionist accounts combined with strong relativist leanings raise various concerns: ontological concerns about the nature of the phenomenon; epistemological concerns about the knowledge production about it; and ethical concerns about the desirability or undesirability of disabilities. In my presentation, I will focus on the ethical issues related to a relativist understanding of disability in the light of some philosophical accounts that depict disabilities, and especially various cognitive disabilities, as conditions that undermine one's chances of leading a good life. I will argue that relativism has the danger of leading us to pointless and counter-intuitive conclusions whereas some perfectionist accounts in philosophy may result in not only counter-intuitive but also, quite literally, deadly outcomes.

Pieter Verstraete

Katholieke Universiteit Leuven

In the Shadows of Postmodernity: Reconnecting Politics with Disability History

In this presentation the methodology used by contemporary disability historians in their quest for the revelation of lost voices and suppressed experiences of persons with disabilities critically is examined and confronted with recent insights of postmodern theories. These troubling insights to a large extent have rendered the use of identity politics in emancipatory processes of persons with disabilities problematic. At the heart of these disturbing insights lies the frequently used description of emancipation as a movement from the realm of shadows towards the light. Inspired by the work of the German philosopher Walter Benjamin – especially his text ‘On the concept of history’ (1940) – and applied to the political aspirations of many of the existing disability histories we would like to suggest that the relationship between emancipation and the realm of shadows not necessarily has to be conceived in negative terms. After having shown that history itself can be seen as a collection of shadows brought about by the activity of the historian, the metaphor of the shadow at the same time enables us to restrain ourselves from embracing a historicist position – namely the belief that it would be possible to reveal how things, events or persons really were in the past – and a representation of history in terms of linear progress. This postmodern approach of history, however, not necessarily has to end up – as frequently is argued by disability scholars – in the annihilation of the political struggles instigated by e.g. disability rights movements around the globe. On the contrary, thinking about doing disability history and emancipation as vital activities which take place in and throughout the shadows actually results in an enlargement of the critical gaze of disability historians towards contemporary political processes, collective aspirations and personal wishes.

Anne Waldschmidt

University of Cologne

Trajectories and transformations in disability policy: the case of Germany

Germany was one of the last member states of the European Union to establish non-discrimination law which is in concordance with the EU directives. Why has this process taken so long in the case of this country? This presentation tries to find an answer for this question by analysing German disability policies, its development and its present state. First of all, one has to take into account that in the case of Germany we are confronted, according to Esping-Andersen's typology, with a conservative welfare regime. The German welfare state has a long history of treating people with disabilities more as recipients of welfare than as citizens with equal rights. Secondly, policies for disabled people traditionally focus on labour market integration in Germany, and other aspects tend to be neglected or are only viewed from the perspective of whether they are relevant for this area of life or not. Against this background, the presentation will start with outlining the history as well as fundamental principles, structures and laws of Germany disability policy. Subsequently, it will concentrate on the issues of education, employment, and social inclusion, in order to show that over the years transformations have been taking place, although it proves difficult to change longstanding paths. New developments such as independent living can be attributed to the disability rights movement which has become a strong player in German disability policy over the last decades. The presentation draws on reports which were written by the author acting as national expert for Germany on behalf of ANED, the Academic Network of European Disability experts, which was established by the European Commission in 2008 to provide scientific support and advice for its disability policy unit (see <http://www.disability-europe.net/>).

Nick Watson

Strathclyde Centre for Disability Research

Can a critical realist approach help in our understanding of disability?

Critical realism emerged and started to gain a momentum in social theory as a challenge to the ideas behind both materialism and postmodernism. Put simply it is a form of realism which argues that there is a real world, including a real social world which exists independently of our knowledge about it and that we can uncover the reality behind this world.

This paper will look at the underlying ideas behind critical realism and the potential it offers for disability studies and its utility as a theory for understanding disability. It will argue that it allows for both a focus on the experience of living with chronic illness and the experience of disabilism. Drawing on the ideas of Roy Bhaskar and others it will argue that materialist accounts associated with, for example, the social model of disability have not only excluded much of the experience of what it is to have an impairment but have also muddied issues that pertain to the intersection of disability with, for example, ethnicity, sexuality, gender and the different ways disabled people experience capitalism. Whilst approaches associated with postmodernism have allowed for an exploration of such differences and have sought to critically engage with the category disability, enabling a breakdown of the dualism disabled/nondisabled and how it has obscured connections between disabled and nondisabled people, they have been criticised for their lack of political engagement. Approaches associated with postmodernism have failed to offer an understanding of or engagement with improving, reforming or challenging the inequalities, injustices and misery experienced by disabled people around the world.

This paper will argue that critical realism through its use of emergence and its engagement with structure and agency has the potential to transcend these two problems and to present us with a new approach to disability that allows an analysis of both the disabling social relations experienced by disabled people and how these structures mediate but do not determine agency and the experience of living with an impairment. A critical realist approach allows us to examine how the social and the political can create inequality and through this develop a normative critique of these relations and practices,

Margaret Wazakili

Co-authors: Ratie Mpofu, Patrick Devlieger

Triple disadvantage: disability and gender sensitive prevention of HIV and AIDS through the eyes of young people with physical disabilities

Introduction: This paper explores the different ways in which disabled girls and young women are disadvantaged and marginalised in expressing sexuality and accessing HIV and AIDS prevention and care services. Disabled young men tend to have greater access to basic information on the subject because their families allow them to freely socialise with peers and learn from them. Yet for cultural and other reasons, disabled young women are prevented from doing the same. Consequently, this group lacks vital information on sexual and reproductive health and how to express sexuality responsibly. A further consequence is that disabled young women are unable to protect themselves from acquiring HIV infection or accessing treatment and care should they become infected.

Methods: A qualitative case study design was chosen as the appropriate means for achieving the aim of this study. Sixteen young people with varying types of physical disabilities, aged 15-24 years participated in individual semi-structured interviews and three focus group discussions of 5-8 participants each. Consent procedures were followed. Demographic data of each participant, in-depth interviews and focus group discussions were audio-taped and transcribed verbatim. A thematic content analysis was conducted using the Atlas.ti computer package for analysing qualitative data. Textual features of Atlas.ti were used to sort the data through coding for common meaning. Contextual features were used to group the codes into broad content categories, through which the main themes were generated.

Results: This study has shown that gender plays a crucial role in the way disabled young people experience sexuality and HIV and AIDS. While all disabled young people have limited access to sexuality education and HIV and AIDS prevention services, disabled young females are more disadvantaged, as they are confined to their parents' homes, are not allowed to express their sexuality freely and are forced to take contraceptives. Although disabled young men are allowed some freedom, they too remain misinformed about basic facts on sexuality and HIV and AIDS prevention, treatment and care services.

Raelene West

University of Melbourne

What do we mean by support for people with impairment?

The concept of support for people with impairment, rather than care, is a concept being entertained more frequently by community and support service providers. Providing support to people with impairment to enable them to live inclusively in the community, such as formal attendant care, financial, emotional and legal support, and support from accessible physical infrastructure, more effectively promotes a platform for increased choice of lifestyle, flexibility and increased capability for a person with impairment. A construct of support reduces many of the implied concepts associated with care, such as dependency, relationship imbalance (in either work or personal relationship) and need that often occur when a 'care' construct is utilised for people with impairment.

This paper thus explores the concept of support as a construct, rather than care for people with impairment. It utilises the experiences of 11 individuals that acquired a SCI (Spinal Cord Injury), and examines how support is defined and understood by these individuals. It explores the various forms of support as described by individuals, including formal attendant care, financial, emotional and legal support and support provided through accessible physical infrastructure as integral components of life once an individual has acquired a SCI.

The paper examines the way in which support as a construct, rather than care, can more effectively promote choice of lifestyle, flexibility and increased capability for people with impairment by more effectively providing a theoretical platform from which equal status, social inclusion, enhanced identity and capacity to contribute to community for people with impairment are improved. This theoretical platform of support more readily acknowledges the identity of a person as an individual with 'normal' roles in community, and contributing to community with the utilization of support, rather than someone simply in need of care or as dependent on care as their main or only identity. The construct of support is thus examined within the parameters of support and impairment.

Alison Wilde

University of York

Troubling Images: discourses of talent, courage and abjection in portrayals of disabled women

Previously occupying marginal, infrequent, yet predictable roles in popular media, disabled women have recently taken prominent places in reality television, celebrity magazines and news. The 'conditions of possibility' for portraying disabled women's lives will be explored in this paper, examining emergent tropes of disabled femininity and subjectivity. I will interrogate narrative constructions of disabled womanhood and investigate the spaces for the telling of disabled, gendered selves in these mainstream genres.

Foregrounding issues of class, talent and morality, I will briefly refer to constructions of celebrity in the personae of Heather Mills, Cerrie Burnell, Jade Goody and Alison Lapper. These will be compared with a deliberate strategy to frame new representations of disabled femininity in BBC 3's reality game show, Britain's Missing Top Model (2008)

Julie Wilmot

Quality of Life and Social Justice Research Centre, Australian Catholic University

Framing Involved Decision Making

This conference presentation will discuss first stages of this research being undertaken by the author for a PhD. Involved decision making is a priority under the United Nations Convention on the Rights of Persons with Disabilities (2006) and Victorian State Disability Plan 2002-2012. This conference presentation will explore the motivations behind the policies of involved decision making. Further, the presentation will explore the usefulness of Arnstein's (1969) hierarchical model of citizen participation for understanding involved decision making by people with intellectual disabilities.

Sarah Woodin

University of Leeds

Disability Status in Europe

This paper will consider differences and similarities in the ways that disability status is currently accorded in a number of European countries in relation to eligibility for disability benefits and entitlements. The current economic crisis is exerting a significant impact on 'public sector' finances, with important implications for disabled people.

A distinction will be drawn between those countries that use a single assessment measure to confirm or deny status and those that use multiple measures for different entitlements. Reasons for, and the implications of, the differences will be discussed in relation to current socio-economic conditions.

Stephanie Yorke

University of Oxford

A Confusion of Symptoms: a Survey of the Appropriation of the Disabled Body in Literary Theory and Discourse

Despite the rise of disability studies in the humanities over the last two decades, the disabled body continues to be the object rather than subject of most literary discourse: while interrogating the metaphorical appropriation of the racially-inscribed or gender-inscribed body has become the 'bread-and-butter' of many literary theorists, the metaphors of disability still often goes unacknowledged and unchallenged, as the disabled body is used by literary scholars to metaphorically describe the discursive degradation enacted upon other peripheral modes of embodiment. The cultural or textual symptom is continually conflated with the medical or clinical symptom, as disablement and sickness are appropriated and subordinated to catalyze literary scholars' understanding of gender, race, and the narrating psyche. Literary scholars' intellectual dependency upon objectifying metaphors of disability belies a set of analytical assumptions, and an evaluative understanding of the body, that frustrate the integration of disability discourse into the humanities generally.

In this paper, I will identify the metaphors of disablement used by several canonical literary theorists, including Gilbert and Gubar, Lacan, and postcolonial analysts, and will consider how the flaws and presumptions inherent in metaphors of disablement may undercut the value of theorists' arguments. I will frame this analysis with brief but adequate contextual explanations of the literary theorists I am considering, and will finally gesture toward the implications of metaphors of disability for disability scholars in other fields. The aim of my paper presentation will be to explicate and analyse the descriptive paradigms of disability in literature in a mode which can be translated into an analysis of common paradigms in other contexts, and to probe social implications of metaphor that extend far beyond the realm of text.

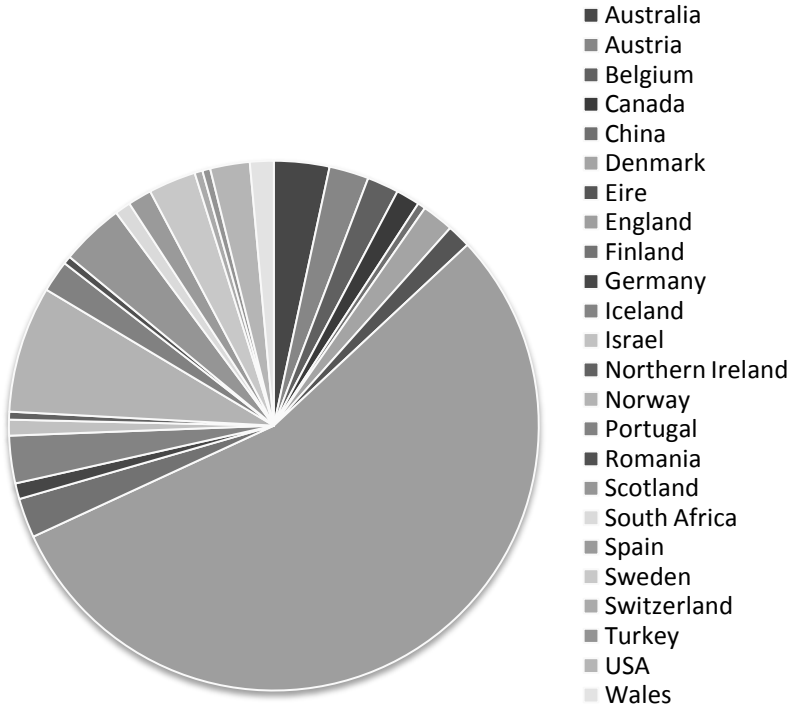
Index of Presenters

Agbota, T. Kobla
Ágústsdóttir, Embla
Aldridge, Jo
Arnold, Larry
Asgrimsdottir, Eiriksina
Bailey, Ruth
Balderston, Susie
Bayliss, Phil
Bê Pereira, Ana
Beckett, Angharad
Benson, Dawn
Beresford, Peter
Berg, Aleksandra
Berghs, Maria
Bertelsen, John
Bezmez, Dikmen
Biewer, Gottfried
Björnsdóttir, Kristín
Boxall, Kathy
Brandon, Toby
Brewster, Stephanie
Brown, Wendy
Buchner, Tobias
Bunch, Jacob
Bush, Marc
Callus, Anne-Marie
Campbell, Fiona Kumari
Carlin, Linzi
Chapman, Rohss
Chataika, Tsitsi
Claes, Lien
Cobley, David
Coles, Bryn
Collingbourne, Tabitha
Colton, Brigit
Crow, Liz
Curnow-Garland, Davey
Daley, Michelle
Dermody, Roisin
Dias, John
Díaz Velázquez, Eduardo
Dinning, Brooke
Driedger, Diane
Eardley, Malcolm
Ebenzersdóttir, Eva Þórdís
Egilson, Snaefridur Thora
Emerson, Eric
Erdtman, Emil
Ferreira, Miguel A.
Ferrie, Joanna
Fish, Rebecca
Fontes, Fernando
Glennon, Michael
Glover, Nick
Gooding, Caroline
Goodley, Dan
Gould, Ruth
Greenstein, Anat
Grove, Samuel
Grove, Nicola
Grover, Chris
Grue, Jan
Guldvik, Ingrid
Gunawardena, Niluka
Gunnarsdóttir, Aðalbjörg
Gurgens Gjaerum, Rikke
Gutman, Carolyn
Harkness, Elizabeth
He, Xirong
Hensel, Wendy
Hill, Andy
Hollomotz, Andrea
Humber, Lee
Ingwersen, Moritz
Jóhannsdóttir, Vilborg
Kassah, Bente Lind
Kassah, Alexander Kwesi
Keyes, Sarah
Kirkebæk, Birgit
Kittelsaa, Anna Margareth
Koenig, Oliver

Langer, Susanne
Latham, Yvonne
Leadbeater, Bridget Tracey
Liddiard, Kirsty
Loja, Ema
Long, Sarah
Mack, Heather
Mackey, Sue
Magnus, Eva
Mahlamäki, Pirkko
Malacrida, Claudia
Mallett, Rebecca
Marshall, Nina
Martin, Nicola
McIntyre, Lesley
Mills, China
Muñoz-Baell, Irma M
Niles, Chavon
Officer, Alana
Olsen, Terje
Opie, Joanne
Össuradóttir, Lilja
Pannebakker, Merel
Phillips, Deborah
Pinto, Paula
Power, Andrew
Priestley, Mark
Purdue, David
Puro, Erika
Purtell, Rachel
Ratzka, Adolf
Read, Janet
Redley, Marcus
Rees, Jo
Reeve, Donna
Reid, Katherine
Rekkedal, Ann Mette
Roets, Griet
Roque Martins, Patrícia
Roulstone, Alan

Runswick-Cole, Katherine
Ryan, Sara
Saur, Ellen
Schlegel, Rouven
Scott, Hannah Jeanne
Scullion, Philip
Selander, Viveca
Sena-Martins, Bruno
Shah, Sonali
Shakespeare, Tom
Shih, Yi-Ting
Sigurjónsdóttir, Hanna
Sklar, Howard
Snell, Laura
Söderström, Sylvia
Soldatic, Karen
Solvang, Per Koren
Spooner, Chris
Stalker, Kirsten
Stamatin, Vasilica
Sutherland, Allan
Swetz, Mark
Tataryn, Myroslava
Tomasini, Floris
Torgé, Cristina Joy
Townson, Louise
Traustadóttir, Rannveig
Tywyn, Carwyn
Vandekinderen, Caroline
Vehmas, Simo
Verstraete, Pieter
Waldschmidt, Anne
Watson, Nick
Wazakili, Margaret
West, Raelene
Wilde, Alison
Wilmot, Julie
Woodin, Sarah
Yorke, Stephanie

Countries of Delegates to the 2010 Conference



Notes

Notes
