LANCASTER DISABILITY STUDIES CONFERENCE

6-8TH SEPTEMBER 2016

BOOK OF ABSTRACTS

Conference Image: Still from *Figures*, performed by Liz Crow (2015).

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#cedr16

Welcome

Welcome to the 2016 Lancaster Disability Studies Conference. This is the eighth and largest conference the Centre for Disability Research (CeDR) has hosted here at Lancaster University. We are delighted to welcome over 275 delegates from more than 35 countries comprising post-graduate students, researchers, academics, activists and practitioners, and many who combine a number of these roles.

We would like to thank the Department of Sociology, its Head of Department Professor Corinne May, and our CeDR colleagues across the university for their on-going support for the conference and the centre.

This year the conference hosts two streams. Mad Studies, convened by Brigit McWade and Peter Beresford, returns after its inauguration in 2014 and the Mad Studies and Neurodiversity – exploring connections symposium also hosted by CeDR in 2015. The Sexuality stream convened by Tom Shakespeare and Kirsty Liddiard marks the 20th anniversary of The Sexual Politics of Disability (Shakespeare, Davies and Gillespie-Sells, 1996).

We would like to extend our thanks to the following publishers for their sponsorship: Taylor and Francis, publishers of Disability & Society, have sponsored the drinks reception on Tuesday evening; PCCS books have provided two sponsored places for unfunded delegates to attend the Mad Studies stream; Palgrave have provided two bursaries and Combined Academic Publishers Ltd have provided one bursary.

Hannah Morgan and Brigit McWade
Conference Organisers

Reviewing Committee

Peter Beresford, Shaping our Lives & University of Essex, UK (Mad Studies Stream).

Nicola Burns, Lancaster University, UK.

Chris Grover, Lancaster University, UK.

Chris Hatton, Lancaster University, UK.

Patrick Kermit, NNDR & Norwegian University of Science and Technology, Norway.

Kirsty Liddiard, Sheffield University, UK (Sexuality Stream).

Brigit McWade, Lancaster University, UK (Mad Studies Stream).

Michel Moore, Disability & Society, UK.

Hannah Morgan, Lancaster University, UK.

Alan Roulstone, Leeds University, UK.

Tom Shakespeare, University of East Anglia, UK (Sexuality Stream).

Karen Soldatic, Western Sydney University, Australia.

Carol Thomas, Lancaster University, UK.

Simo Vehmas, NNDR & Helsinki University, Finland.

Jijian Voronka, Rutgers University, Newark, USA (Mad Studies Stream).

Still from 'Figures', performed by Liz Crow (2015).

Photo Claudio Ahlers/Roaring Girl Productions

The image we have chosen to represent the 2016 conference comes from *Figures*, a mass-sculptural performance by British artist-activist Liz Crow. Liz is the Founder of Roaring Girl Productions, and has been highly influential in the disabled people's movement. She made an important contribution to developing and extending the social model most notably in 'Including all of our lives: renewing the social model of disability' (1996). Previous work includes *Bedding Out* (2012-13) and *Resistance* (2008) which included a contribution to Antony Gormely's One and Other project on the fourth plinth in Trafalgar Square (2009) where she sat on a wheelchair wearing a Nazi uniform to mark the 70th anniversary of the Nazi campaign of mass-murder of disabled people. Liz is currently a doctoral candidate at the University of the West of England focusing on the development of a humanistic methodology of activism through performance praxis.

Figures made visible the human cost of austerity and urges action against it. Liz Crow sculpted 650 small human figures, each representing an individual at the sharp end of austerity, one for each of the 650 UK parliamentary constituencies. The figures were created from raw river mud, dug by hand, and sculpted on the Thames foreshore at low tide over 11 days. Each figure differed in detail, with an individual real-life narrative of the impact of austerity published as they were made. After visiting locations from London to Bristol the figures were raised into a cairn and set alight while the narratives of austerity were read aloud. The burned and broken figures were ground into dust and scattered back to water as a poignant reminder of the human cost of austerity and a call to action.

www.roaring-girl.com
www.wearefigures.co.uk

Programme

10.00: Registration
11.00-11.30: Introductions
11.30-12.30: Keynote: Sara Ryan - What the fuckwhatery? Disability studies, activism and the continuing denial of the human
12.30-13.30: Lunch
13.30-15.00: Paper Session A
15.00-15.30: Break
15.30-17.00: Paper Session B
17.15-18.00: Disability & Society: Meet the Editors
18.00-19.00: Drinks reception including poster presentations and book launch
20.00: Evening meal

Wednesday 7th September 2016
09.30-10.30: Keynote: Susie Balderston - Are disabled people human?
10.30-11.00: Break
11.00-12.30: Paper Session C
12.30-13.30: Lunch
13.30-14.30: Keynote: Jijian Voronka - Mapping Mad Studies in movements, knowledge, and praxis
14.45-15.45: Paper Session D and Keynote: Lucy Costa - Madness, violence and other neoliberal spectacles (Mad Studies stream)
15.45-16.15: Break
16.15-17.15: Paper Session E
17.30-19.30: Sexuality Stream Film Screening: Sanctuary introduced by Len Collin
20.00: Evening meal

Thursday 8th September 2016

09.30-11.00: Paper Session F
11.00-11.30: Break
11.30-12.30: Keynote: Don Kulick - Fucked: sex, disability and the ethics of engagement
12.30-13.00: Endings & lunch

Keynote Speakers

Susie Balderston: Are disabled people human?

(Main Conference)

This presentation illuminates some of the grave and systematic violations of disabled people's basic human rights in Europe today. It explores how women are contemporarily disabled through systematic violence and State failure to defend our safety, along the continuum of sexual violence through rape, trafficking and sexual abuse in institutions. In this sociological moment of backlash against disabled people's rights and equality, the United Nations Committee on Rights of Persons with Disabilities is conducting a confidential investigation into, 'grave and systemic human rights violations' by the UK Government. The paper critiques whether women and girls disabled by, and surviving sexual violence, can benefit from human rights law and disability studies in a time of shrinking rights and poor representation.The paper recommends that we re-focus on a struggle towards the substantive equality with disabled or Deaf people and survivors at its core. The presentation proposes that supporting emancipatory, intersectional research, and survivor-led jurisprudence, can emerge as one of the most pressing and important impacts of Disability Studies in the academy today.

About Susie

Susie works to prevent and tackle disablist hate rape and institutional sexual abuse. She is currently reviewing anti-trafficking policy and interventions, in the UNESCO Gender Research Group at Lancaster University, and lecturing in social policy, disability and human rights, with a focus on addressing intersectional inequalities, improving safeguarding, equality and justice.

As Policy and Training Director of Vision Sense (a user-led organisation of disabled people) for 13 years, Susie designs, mentors and evaluates user-led pilot projects in social care, health and criminal justice in England. She was has served as advisor to the EHRC 'Statutory Inquiry into Disability Harassment' and 'Access to Specialised Victim Support Service for Women with Disabilities who have Experienced Violence' project (funded by the DAPHNE programme of the European Commission). Susie particularly loves dogs because they do not perpetrate disablist hate crime, criminalization of disabled people or preventable deaths in institutions, as far as she has noticed. Susie is proud to be a disabled woman in work; in her lifetime, she would love to be employed in disability studies and see an end to rape.

Lucy Costa: Madness, violence and other neoliberal spectacles

(Mad Studies stream)

Violence is quintessentially one of the most referenced, overused, clichéd and prejudicial "features" in discussions concerning mental health and the people who use services. This presentation explores the possibilities and opportunities for looking at these 'violence dialogues' in all their complexity - both from the individual and structural perspective and, as mitigated through the lens of our current neoliberal culture of hyper surveillance, public management, and other disasters, catastrophes and protests.

I begin by first drawing from a community organising initiative in 2011 in Toronto, Canada whereby a group of psychiatric survivors, mental health advocates, workers, and community members came together with the purpose of intervening and addressing a string of assaults targeting marginalised persons with psychiatric disabilities which resulted in the death of one vulnerable community member. Next, by providing some conceptual considerations I aim to proceed with questions for collaborative, reflective dialogue in order to engage more critically with violence as it emerges both within our communities and via the ongoing normalisation of state sanctioned violence.

About Lucy

Lucy Costa works as a systemic advocate in Toronto with the Empowerment Council promoting the rights of mental health clients as well as encouraging critical analysis about service user inclusion in the broad mental health sector. She sits on a number of advisories and has been involved in disability politics for over fifteen years.

As a member of the Psychiatric Disabilities against Violence Coalition (PDAC) she has helped produce a report on the violent victimisation of people with mental health issues, entitled *Clearing a Path: A Psychiatric Survivor Anti-Violence Framework*. She is a blog commentator for Mad in America and is co-editor of the anthology tentatively titled, *Madness, Violence and Power* due out Winter 2016.

<u>Don Kulick: Fucked: sex, disability and the ethics of engagement</u>

(Sexuality stream)

Twenty years after the groundbreaking book The Sexual Politics of Disability there is still astonishingly little social science research on the sexual lives of people with disabilities. My talk will discuss some of the reasons for that lack, and will present findings from Loneliness and its Opposite a recent comparative study of sexuality and disability in Sweden and Denmark (Kulick and Rydström 2015). I will discuss how the sexual lives of adults with significant disabilities are facilitated in Denmark, and how they are impeded in Sweden. I will argue that access to sexuality for disabled people is not a right; it is an issue of fundamental social justice.

<u>About Don</u>

Don Kulick is Distinguished University Professor of Anthropology at Uppsala University, Sweden. His books include *Travesti: sex, gender and culture among Brazilian transgendered prostitutes* (1998), *Fat: the anthropology of an obsession* (2005, edited with Anne Meneley), *Language and Sexuality* (2003, with Deborah Cameron) and most recently *Loneliness and its Opposite: sex, disability and the ethics of engagement* (2015, with Jens Rydström).

(Main Conference)

We now know in the UK that certain people hived off from the mainstream by a label of learning disability are dying on average 13-20 years before those without this label (Heslop et al, 2013). In Sweden, those labelled autistic are dying 16 years earlier and, if unlucky enough to be labelled with autism and learning disabilities, 30 years earlier (Hirvikoski et al, 2015). In December 2015 we further learned that less than 1% of the 337 premature deaths of learning disabled people that occurred in the care of one NHS Trust between 2011-2015 were investigated (Mazars, 2015). Despite state obligations under Article 2 of the Convention for the Protection of Human Rights and Fundamental Freedoms (which are particularly stringent when people deemed vulnerable are involved) for effective, prompt and diligent investigation of deaths where the right to life may have been breached, it appears that the deaths of these patients are all too readily discounted.

In this presentation I reflect on the vast body of research that highlights disparity of treatment for learning disabled people and wonder what, if anything, it has really achieved. We know what we need to know. Jim Mansell wrote a seminal report in 1993 and yet ignorance, prejudice and low expectations around what is considered to be acceptable health and social care (pre and post death) for learning disabled people continue to flourish. People are still denied their humanity and an imagined future. Drawing on the #JusticeforLB campaign, I reflect on the boundaries between 'research', academic practice and activism and ask if we are too conformist and cosy within a disability studies 'bubble' of normative academic practice.

About Sara

Sara Ryan is the Research Director in the Health Experiences Research Group at the University of Oxford. A sociologist, her work focuses on autism, learning disability and difference. More recently she has been involved in the #JusticeforLB campaign.

Jijian Voronka: Mapping Mad Studies in movements, knowledge, and praxis

(Mad Studies stream)

This paper explores how the emergent field of Mad Studies builds on Critical Disability Studies and broader critical fields of inquiry. I show the possibilities of Mad Studies as a field which attends to interlocking systems of oppression, informed not only by diverse social movement activism but also the realities of working within the everyday constraints of mental health policy and practice.

I draw on my research to show how Mad Studies, in conversation with other critical fields, needs to 'rethink inclusion' by analyzing the terms of our engagement. By mapping the conditions that manage mental health service user involvement in projects that harness diversity, participation, and cultural competency discourses, I show how peer inclusion can in effect work to retrench mental health/illness neoliberal biopolitical interventions. I explore the limits of authenticity, representational and peer identity tropes that trap us all into the elusive quest to find the 'ideal peer informant.' And I show how Mad Studies is a necessary analytic tool to be used in conjunction with other critical inquiries to elucidate how mental illness is tethered together with racial logics to justify state violence.

About Jijian

Jijian Voronka received her PhD in Social Justice Education at the University of Toronto. Her research explores the possibilities, limits, and self/management of service user participation in mental health and homeless research and service systems. She is currently working on a book manuscript, entitled *Troubling Inclusion: The value of mad labour in mental health interventions*. She is a SSHRC Postdoctoral Research Fellow in the Department of Women's and Gender Studies at Rutgers University – Newark, and teaches at Ryerson University's School of Disability Studies.

Mad Studies Stream

Conveners: Peter Beresford (University of Essex, Shaping Our Lives) and Brigit McWade (University of Lancaster).

Since the publication of *Mad Matters: A Critical Reader in Canadian Mad Studies* (edited by Brenda A. LeFrançois, Robert Menzies and Geoffrey Reaume) in 2013, Mad Studies has been gaining a higher profile internationally. In 2014, we convened the first Mad Studies stream at Lancaster Disability Studies Conference which brought together both established figures in the field and those who wanted to know more. During the last two years, there have been several UK events exploring what Mad Studies and what it might offer us in terms of critical scholarship and activism in the field of madness and disability. We are very excited to be able to convene a second stream this year, and want to thank Hannah Morgan and CeDR for continuing to support us in doing so.

We are delighted to have two keynote speakers, both closely linked to the development of Mad Studies. Lucia Costa, an activist and advocate based in Toronto, has most recently pioneered work addressing the issue of violence in the lives of people with psychiatric disabilities. Jijian Voronka's cutting-edge work addresses questions of inclusion and peer-work in mental health. Both bring excellent and concrete examples of what Mad Studies can offer us empirically and conceptually in moving the conversation about "mental health" beyond the current paradigm.

We were inundated with abstracts this year – a clear sign that there's an appetite for this work. We prioritised paper presentations that demonstrate the practical application of Mad Studies in research – showing us what Mad Studies can do - and work that is intersectional. We have a special panel session exploring the links between Mad Studies and Survivor Research, which will celebrate the publication by PCCS Books of Searching for a Rose Garden: challenging psychiatry, fostering mad studies (Russo & Sweeney, 2016). There is also a wealth of Mad Studies work being presented during the stream as posters, which demonstrates the field's diversity and also highlights many aspects of teaching or doing Mad Studies both in and out of academia.

We have worked hard to ensure those without income or funding are able to attend the stream. In light of this, we would like to extend thanks to the following people who helped us do this: PCCS Books, for providing two fully-sponsored places; supporters of our crowd-funding campaign that raised funds for three fully-sponsored places; and, both of our keynotes for generously supporting the attendance of two more unwaged and activist delegates.

It is our hope that this stream will offer further opportunities for discussion, connection, and debate, as well as the possibility of continued collective work that will actively build Mad Studies on an international scale.

#MadStudies #cedr16
@MadStudies
madstudies2014.wordpress.com
www.pccs-books.co.uk

Sexuality Stream

Conveners: Tom Shakespeare (University of East Anglia) and Kirsty Liddiard (University of Sheffield).

The foundational text, *The Sexual Politics of Disability*, was 'the first book to look at the sexual politics of disability from a disability rights perspective' (Shakespeare, Davies and Gillespie-Sells, 1996: 1). Ground-breaking in its contents and its approach, the sexual stories contained within the covers of the book – told by disabled people themselves – challenged the prevailing myth of asexuality and other tropes which render disabled people as perverse, hypersexual, or as lacking sexual agency.

Despite this scholarly activism, the sexual, intimate, gendered, and personal spaces of disabled people's lives remain relatively under-researched and under-theorised in comparison to other spaces of their lives. Rarely are disabled people themselves authors or co-producers of this work. Where austerity policies dominate, we are unsure of how this impacts the possibilities for intimacy and relationships. Conversely, we lack evidence about the impact of the UN Convention on the Rights of Persons with Disabilities. Significant gaps remain in our knowledge of disabled people's experiences of sex, love and relationships, often in marked areas.

This inaugural sexuality stream marks the 20th anniversary of *The Sexual Politics of Disability* (1996). In this stream, we will celebrate and encourage the broad bodies of work that have emerged within the ever-expanding field of disability studies, gender studies and sexuality studies. For this stream, we have prioritised papers containing original social research, as a response to the relative dearth of empirical work within the field. We also want to acknowledge, affirm and explore the methodological problems, potentialities and possibilities of exploring disability and intimate life through social research.

We are thrilled to have Don Kulick, Distinguished University Professor of Anthropology at Uppsala University, Sweden, as keynote speaker. His books include *Travesti: sex, gender and culture among Brazilian transgendered prostitutes* (1998), *Fat: the anthropology of an obsession* (2005, edited with Anne Meneley), *Language and Sexuality* (2003, with Deborah Cameron) and most recently *Loneliness and its Opposite: sex, disability and the ethics of engagement* (2015, with Jens Rydström).

#Sexuality #cedr16

Sexuality Stream: Film Screening of Sanctuary

Sanctuary (Len Collin 2016) is a feature film based on the play written by Christian O'Reilly, commissioned by Blue Teapot Theatre Company, Galway, that was conceived by, and stars an ensemble cast of actors with learning disabilities. It follows the story of Larry who bribes a carer, Tom, to arrange a hotel room that he and his girlfriend Sophie can sneak off to during an arranged group trip to the cinema. When Larry asks Tom to "Borrow a condom" he risks breaking the law. Sanctuary is unique in the respect that from its conception and throughout production it followed the manifesto drawn up by Colin Barnes in his 1992 report *Disabling Imagery and The Media: An Exploration of the Principles for Media Representations of Disabled People*. It is presented here at conference as a private screening for your consideration, thanks to Zanzibar Films. The director, Len Collin, a Senior Lecturer at Northumbria University and PhD student, will attend the screening.

Disability & Society: Meet the Editors

As in previous years, members of the Disability & Society Executive Editorial Board will be available to talk about the journal, including new innovations and ideas on how to get published or involved with our work.

As well as showcasing more about what the journal offers at the session, we also hope to encourage your ideas and papers. Whether you're looking to equip yourself with information about how to increase the chance of getting successful reviews, want to understand the different formats in which you could write for the journal, pick up tips for improving the impact of your paper, or you would like to learn more about how the Editorial Board operates and how you can play a part, do join us for conversation with Q&A opportunities.

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

Professor Michele Moore
Editor, Disability & Society
Twitter: @JDisSoc
Website: http://www.tandfonline.com/loi/cdso20#.V5H1MJOANHw

Book Launch

Disability in the Global South: The Critical Handbook

Shaun Grech and Karen Soldatic, editors

This first-of-its kind volume spans the breadth of disability research and practice specifically focusing on the global South. Established and emerging scholars alongside advocates adopt a critical and interdisciplinary stance to probe, challenge and shift common held social understandings of disability in established discourses, epistemologies and practices, including those in prominent areas such as global health, disability studies and international development. Motivated by decolonizing approaches, contributors carefully weave the lived and embodied experiences of disabled people, families and communities through contextual, cultural, spatial, racial, economic, identity and geopolitical complexities and heterogeneities.

Dispatches from Ghana, Lebanon, Sri Lanka, Cambodia, Venezuela among many others spotlight the complex uncertainties of modern geopolitics of coloniality; emergent forms of governance including neoliberal globalization, war and conflicts; the interstices of gender, race, ethnicity, space and religion; structural barriers to redistribution and realization of rights; and processes of disability representation. This handbook examines in rigorous depth, established practices and discourses in disability including those on development, rights, policies and practices, opening a space for critical debate on hegemonic and often unquestioned terrains.

Abstracts: Papers, Panel and Poster Presentations

Presentations are listed in alphabetical order by first author

<u>Doris Aigner: Madness: a Question about Power! Consequences of the ratification of the CRPD and OP-CAT for psychiatric compulsory measures in Austria.</u>

(Mad Studies stream, poster)

This paper is based on my dissertation in the field of political science combined with my practical experience as a social worker (in homelessness and in institutional care). The theoretical approach combines Critical Disability Studies and Michel Foucault´s lessons from handling madness into an argumentative-interpretative Policy-analysis, which is particularly characterized, that people with history in psychiatry have methodically and theoretically been experts during the research process.

The dissertation examines freedom restriction policies for usually so called mentally ill people. It follows the thesis that the UN Convention on the Rights of Persons with Disabilities (CRPD) and the Optional Protocol Against Torture and other Cruel and Inhuman Treatment or Punishment (OP-CAT) promote a policy-change. The paradigm shift towards a social model of disability is required by Critical Disability Studies as well as by the policy-documents/instruments (CRPD and OPCAT) and therefore the analysis of the policy-process from ratification to evaluation (in Austria from 2008 till 2014) offers the opportunity to study transformation.

The meaning of changing practices for experts by experience is a key aspect, which is illuminated interpretatively. Methodically this was made by participative observation in the club "Freiräume" in Vienna, which runs the communication forum "Trialog" and by a historical approach through work on archives of the magazine "Kuckucksnest" to reconstruct the history of the survivors´ movement in Vienna. Results show an ongoing discursive change. Human rights´ discourses challenge the medical model. Compulsory measures can now be interpreted on a continuum ranging from care to torture. The ban of cage-beds in Austria operates on more than only a symbolic level. Political Science and Critical Disability Studies/Mad Studies benefit from each other in shedding light on structures of power.

Zoe Aitken, Julie Simpson, Rebecca Bentley and Anne Kavanagh: Is the effect of disability acquisition on mental health influenced by demographic and socioeconomic factors?

(Main Conference, paper)

People who acquire a disability experience large deterioration in their mental health, and the extent of the effect varies widely. Demographic and socioeconomic characteristics may influence the mental health effect, however no single study has examined this comprehensively.We used four waves of data from the Household, Income and Labour Dynamics in Australia Survey to identify a sample of people who acquired a disability (n=294) and a sample of people who remained disability-free for all four waves (n=5721). The mental health subscale of the Standard Form 36 health questionnaire, which assesses symptoms of depression and anxiety, was compared between the sample of people with and without disabilities. We used linear regression models and applied a propensity score method to ensure the groups were comparable prior to their disability. We examined whether the association between disability acquisition and mental health was different according to prior characteristics, testing for effect measure modification by a priori identified factors that included key demographic and socioeconomic variables.

The findings demonstrated that there were large differences in the effect of disability acquisition on mental health according to socioeconomic circumstances. There were larger negative effects for people who did not complete secondary education, were unemployed or not in the labour force, were in the poorest income quintile, had low wealth, people living in public rental housing, and those who had children.

People who acquire a disability who experience socioeconomic disadvantage prior to disability are particularly vulnerable to poor mental health outcomes. While an overall policy goal should be to improve people with disabilities' mental health, particular attention should be paid to those who experience socioeconomic disadvantage.

Ali Aldakhil: Saudi Inclusive Schools and Disability Studies Theories

(Main Conference, poster)

Meaningful inclusion of disabled pupils in mainstream education underpins the overall goal of promoting full participation and recognition of disabled people in society. In Saudi mainstream schools, as in numerous schools around the globe, disabled pupils are marginalised and oppressed. They are included in the schools but excluded from quality learning based on their impairments. Drawing on theories from a range of disciplines, including educational psychology, critical disability studies and education theory, I used a qualitative approach to explore the views and experiences of Saudi disabled and non-disabled teachers regarding inclusion implemented in mainstream schools where they teach. In-depth, semi-structured interviews with 32 participants were conducted on an individualised to contextualise the data.

Thus far, my analysis has generated three key themes: incompetence, marginalisation and exploitation. My interviewees view schools' physical environment, personnel and students to be as yet unprepared for inclusion although it has been implemented. They see themselves, school staff, guardians and non-disabled pupils to have limited awareness regarding disability and inclusion. They also see themselves as untrained to deal with disabled pupils' diverse requirements, especially pupils identified as intellectually disabled. Disabled and non-disabled teachers also express pragmatic attitudes towards the effects of disabled pupils' impairments on their success in inclusive schools. Disabled teachers are annoyed and frustrated by the educational and social marginalisation that they as well as disabled pupils usually face in mainstream schools. They call for an action to be taken against this. A few participants reported stories of disabled pupils being subject to exploitation but schools took legal action against this. Participants call for reconstruction of schools with disabled pupils in mind, for deconstruction of stereotypical images, for ongoing awareness and professional development programmes, up-to-date classrooms, for increasing accountability and for putting a workable, responsible disability policy into practice.

Sándor Anikó and Horváth Péter László: I want a family too! Adoption of children with disabilities in Hungary

(Main Conference, paper)

The Hungarian Child Protection Act, according to international conventions, prefers the out-of-home care of children in families, instead of institutional settings, excluding children with disabilities, who are, referring to the international empirical data one group of the so called „hard to place" children. The aim of our state-aided empirical study (OTKA K111917) is to reveal the characteristics of the families that deliberately adopt children with disabilities. This basic research uses qualitative and quantitative approaches, in the theoretical framework of (Feminist) Disability Studies. Implementing the participatory research in various ways, member of the research group is an adoptive father of a disabled child, a leader of an NGO that coordinates the adoption of children with Down Syndrome, and a 21 year old man with Down Syndrome who lives in an adoptive family. First element of the process was a questionnaire with 52, open ended and closed ended questions. 23 answers were analysed, that is, according to the statistical database, 10-25% of the full sample. As a second step, 15 narrative interviews are made with adoptive parents and in the last sequence 7 focus groups are conducted. The focus groups involve all the relevant stakeholders of the adoption process: experts of the governmental and non-governmental organisations, parents who have place their child for adoption (and their other children), the adoptive children, and their siblings in the adoptive family.

As a result, we can get closer to the biographies of the parents who decide to adopt, and we can identify potential groups that can be encouraged to adopt. We better recognize the needs of families, their pleasures and difficulties after the adoption, that can help to establish adequate supports in their everyday lives. These empirical evidences can also lead to a legislation reform, and more children with disabilities can live in families.

<u>Ivanka Antova: Using Foucault for emancipatory purposes: governmentality and emancipatory disability research in the context of a welfare reform</u>

(Main Conference, paper)

This paper outlines a methodology used to address the long-term negative impact the ongoing welfare reform in the United Kingdom is having on the citizenship and socio-economic rights of disabled people. Since 2010, disabled people have been subjected to unprecedented in their impact changes to the social security system, including the scrapping of non-means tested disability benefits, the abolition of the Independent Living Fund and the use of controversial work capability assessments, reversing policy back to outdated models of disability. This paper understands the welfare reform as a social and political phenomenon much more complex than previously anticipated. The reform policies are not so much about managing the public budget in a more cost-effective way, as it is often suggested, but about managing the behavior of benefits claimants and transforming deviant populations into productive and responsible citizens. The social model of disability and emancipatory disability research (EDR) have been important tools for the disability movement in their struggle for equality, independent living and inclusive citizenship. Since 2010, however, the obscure tactics of controlling social deviants via reform policies have presented challenges that the familiar theoretical approaches have not been able to address fully. This paper offers a methodology where the Foucauldian concept of governmentality has been combined with EDR to illuminate the dark side of the reform as a strategy for the control of deviant populations. A methodology that understands the welfare reform policies as tactics of power that produce narratives, identities and knowledges allows for practical examples of empowerment to be discussed. This is where EDR and the work of Michel Foucault thread on common ground: empowerment through the creation of alternative 'truths', or how Foucault can be used for emancipatory purposes.

Gonzalo Araoz: Madness, De-Classification and Bricolage

(Mad Studies stream, poster)

The term bricolage is used in several disciplines, among them the visual arts and literature, usually referring to the notion of creating or constructing something using a range of objects that happen to be available. In this presentation I will outline some of the issues involved in an (eclectic) attempt to apply a bricolage approach to develop a technique to make sense and creative use of some 'symptoms' that might make up an aetiology of psychosis. I believe it should be possible to reflect upon or channel those 'thoughts', 'voices' 'feelings' in such a way that any 'symptoms' that are usually seen as obstacles (and as such deemed to be eliminated) can be used as means to allow individuals to deal with them, use them, channel and express them through creative activities.

A typically human feature is our obsession with classifying, with distinguishing different tendencies not only amongst animals but also between humans and other species and between different human social groups. We tend to define ourselves in contrast with the other, whether they are to be understood as primitive, savage, uncivilised, uneducated, uncontrolled, unconventional or just mad. The fact seems to be that all human groups have concepts of US and THEM that are based on internal beliefs and practices, and which delineate the border between what is acceptable and what is not. Those who tread along that borderline -who might do this for necessity, curiosity, boredom, creativity or any other reason- might have access to views that not many have, but might also be putting themselves at risk of being marginalised and stigmatised. In this paper I would also like to explore these ideas, based on my own experience across different sets of borders.

<u>Julia Bahner: Policy for whom? The silence of sexuality and its consequences in disability services</u>

(Sexuality stream, paper)

The law governing Swedish personal assistance services aim to provide eligible service users with the possibility to "live a life like others". What this means in terms of sexuality is not mentioned in the law and there are no related policies or guidelines – often leading to insecurity among service users and personnel whether or not sexual facilitation is sanctioned. This insecurity is further deepened as the Work Environment Law states that the personnel's working conditions must be physically and psychologically adequate – the latter giving room for moral values guiding service provision. Hence, the issue of sexual facilitation is surrounded by silence, ambiguity and normativity.

The background to this presentation are three empirical studies concerning how people with impaired mobility using personal assistance services, personal assistants and managers, experience and conceptualise sexual facilitation. In this presentation, a fourth study will be in focus; an analysis of conceptualisations around disability, sexuality/sexual facilitation and professionalism in the few existing texts dealing with these issues: two non-binding statements by the Ethics Board's Social Committee with the Swedish National Board of Health and Welfare, and a handbook by The Federation of Youth with Impaired Mobility.

Contradictions between a service user and a worker perspective are highlighted, relating to differences in understandings what can be considered "normal" sexual practices in welfare services. The presentation will discuss and problematize 1) the normative nature of policy and specifically how to balance giving room for a variety of individual approaches in line with Independent Living ideology, and simultaneously making sure these are non-discriminatory, 2) how policy can balance protecting service users' sexual rights and assistants' rights to an adequate work environment, and 3) how to influence a policy discourse where sexual facilitation is understood as an individualized and depolitized issue, with moral undertones evident.

Dawn Benson and Hannah Morgan: Disabled refugees, continence and humanitarian innovation

(Main Conference, paper)

"…persons with disabilities are often twice victimized: once by the disaster and again by the failure of the humanitarian and relief infrastructure meant to help them and protect their rights" (Hassan Ali Bin Ali, 2014).

The war in Syria has caused the biggest humanitarian crisis of our time. Over 250,000 civilians are thought to have been killed and half of the pre-war population have been displaced. Refugees continue, despite the peril of constant attacks to flee into surrounding countries. Turkey, Jordan and Iraq house the biggest refugee camps and report being overwhelmed by the sheer volume of people. Refugee populations are up to five percent more likely than other populations to experience impairment, largely though injury (WHO, 2011).

For many disabled refugees continence only becomes a concern because of the environment and circumstances they are living in. Although very little is known about the continence needs of disabled refugees reported issues include limited or no access to accessible toilets. Poor quality, or no access to, pads or continence devices and a shortage of water, all of which compromise hygiene and increase their vulnerability to infection and social isolation (Hansen, 2015).

Those disabled people who do reach refugee camps may well have lost the support of their caregivers through death or injury and or equipment, aids and medication. The needs of disabled people and women in particular, are often not considered by organisations providing humanitarian relief and when it is, continence is not prioritised. Work needs to be done to include disabled refugees and their caregivers in identifying innovations in systems, equipment, logistics and humanitarian responses. This paper will open discussion about continence and disability in the context of a humanitarian innovation project and wider disability politics.

Melisanda Berkowitz: Constructing transition to adulthood in Japan for people with moderate to severe learning disabilities

(Main Conference, paper)

Discussions of adulthood have marginalized the experiences of people with learning disabilities and presented them as unable to achieve full adult citizenship due to limited power to make and express independent choices in employment, residence and sexuality. While theory and policy statements point the way to new constructions that might increase scope for young people to choose post-school options in dialogue with carers, actually achieving increased choice calls for social environments that enable participation. This article will look at the social environment in Japan for young people with learning disabilities making the transition to post-school adult life.

Observing the transition from school to adult life in cross-cultural context can provide insights into how societies construct and shape the experience of adulthood for people with learning disabilities and suggest effective supports to increase their scope to lead fulfilling lives. I describe the situation in contemporary Japan, and analyze the Japanese construction of adulthood for people with intellectual disabilities. The majority of adults with learning disabilities participates in regular sheltered employment or daycare, funded by government and local authorities, and lives with their parents. There is little government support for independent residence. After an overview of the national situation, I focus on ten young adults who have recently made the transition to post-school life. Based primarily on interviews with the young people and their parents, I will look at how the young people actually spend their time post-school, what choices are available to them, and how they and their families negotiate those choices during the transition to post-school life.

(Sexuality stream, paper)

There is limited research that specifically addresses the sexuality of young adults with life-limiting and life threatening conditions (LLTCs). Until recently young adults with these conditions were not expected to reach adulthood so discussions about sex were often not prioritised by parents or carers during their life (Beresford, 2014). This perception is slowly changing as increasing numbers of people with LLTCs are living into their twenties and beyond.

In this presentation, drawing on the first author's PhD research and the international literature, we address the specific meanings of sex, relationships, love, intimacy and reproduction, focussing in particular, on what 13 young adults, age 17-40 with LLTCs felt were important issues to them, including choices about having relationships, the challenges that they frequently encountered from parents and carers when they expressed desires to have intimate relationships, as well as the complications that sometimes arose through the legal maze of sexual rules, both at home and in residential settings. The findings and comparisons from the same research of 10 parents and ten care practitioners will also be addressed.

The particular illness trajectory for children and young people with LLTCs may differ in relation to their social, emotional and physical requirements. The uncertainty as to when young people with LLTCs die adds a degree of complexity to their care, and the particular support which may be required for the young person during their transition into adulthood (www. togetherforshortlives.org.uk). Service priorities may fluctuate and therefore the recognition for formal, face to face advice about relationships. Intimacy, love and sex, which is not exploitative or solicited via the internet may often go un-recognised by health and social care practitioners. These issues will also be discussed.

Maddie Blackburn, Dr Sarah Earle and Dr Kirsty Liddiard: Sexuality in the shadow of death? Standards and guidance about intimacy and relationships for those working with young people with life-limiting impairments

(Sexuality stream, poster)

In this presentation, we shall explore the ethical, practical and methodological issues encountered in producing guidance about intimacy, relationships and the sexuality for young people with life-limiting or life-threatening conditions (LLTCs). This group of young people were not expected to live beyond adolescence 15 years ago (Beresford & Stuttard, 2014), although life expectancy for many may still be uncertain. There are an estimated 55,000 people aged 18-40 with an LLTC in the UK (Fraser, 2014).

We shall draw on the design and co-production of, 'Talking about sex, sexuality and relationships: Guidance and Standards for those working with people with life-limiting or life-threatening condition'. This guidance was designed, first and foremost, with young people with LLTCs, and a collaborative partnership of 15 organisations, including academics, health, social care and education professionals and authors of this paper. The resource addresses intersecting issues often regarded as 'sensitive': dying and end-of-life; sexuality; disability; and policy research with young people.

This presentation will explore the specific benefits as well as some difficulties encountered when producing this guidance for those caring for young people with life-limiting conditions (LLTCs). The overlapping and inter-relationships between research and policy with young people, sexuality, disability, dying and end-of-life will be addressed.

We address how young people contributed in producing the guidance, in particular, with people who communicated in non-verbal ways and the challenges that this sometimes presented to us as researchers. Finally, we address the complexities of co-ordinating and working simultaneously with 15 public and Civil Society organisations representing service users, law, health, social care and education professionals and academics. Each of these brought valuable but differing expertise in producing the Guidance and Standards (2015); please see our film: www.open.ac.uk/health-and-social-care/research/ sexuality-alliance/

Hanna Björg Sigurjónsdóttir and James Gordon Rice: The evidence of everyday life: parents with ID and child protection

(Main Conference, paper)

Aim: To understand the construction and application of evidence against parents with intellectual disabilities in child protection cases in Iceland.

Methods: Discourse analysis of a national sample of custody deprivation cases in Iceland from 2002 to 2014.

Results: The information collected and utilized in custody deprivation cases which served as evidence of neglect was conflicting, imprecise and misleading. A significant proportion of such evidence was in the form of numerous observations of the home and everyday life documented by child protection professionals. Combined with culturally informed assumptions and prejudicial beliefs about intellectual disability, these seemingly mundane details take on a more significant and ominous meaning in these court cases when the parents concerned scored lower on IQ tests than other parents.

Conclusion: Our analysis of the evidence suggests that there is a significant lack of critical self-reflexivity on the part of the professionals who are tasked to gather and collect information about parenting and the home, and which influences the nature of the evidence ultimately used to justify custody deprivation.

Gisli Bjornsson, Ragnar Smarason and Kristin Bjornsdottir: Can we teach gender equality?

(Main Conference, paper)

The paper is based on a collaboration between a university lecturer and two men who have been labelled as having learning difficulties and have been hired by the University of Iceland to work on an inclusive research project addressing gender equality and men with learning difficulties.

The paper describes the process of planning an inclusive research project that has the aim of exploring the access of men with learning difficulties to equal rights issues with special focus on gender equality. The research project follows an inclusive research paradigm that allows the participants to be involved in the entire research process instead of being viewed as passive research subjects. This is an ongoing research that started in 2015 and is scheduled to end in 2018. Data is being collected through semi-structured interviews and focus groups. We will describe how inclusive research traditions allow for increased participation and power by disabled people over the research process as a whole with an aim to improve disabled people's lives. Furthermore, we will describe how we planned the research, how decisions were made and how it is being carried out. The findings suggest that men with learning difficulties rely on stereotypical and hegemonic ideas about gender and gender roles. Also, the education of people with learning difficulties does not seem to address the issues of gender equality. The men have little or no access to the larger gender equality movement in Iceland but they also experience marginalization within the disability rights movement due to what we will describe as cognitive ableism. We will conclude by discussing how we will make the results available to men with learning difficulties through accessible reading material and peer support groups. This research is funded by the Icelandic Gender Equality Research Fund and the University of Iceland Research Fund.

Kristin Bjornsdottir: Educating the forever child

(Sexuality stream, paper)

This paper reports on data from a qualitative research, which explores autonomy in the lives of people with learning difficulties with the aim of identifying sociocultural factors that influence them in exercising and actualizing autonomy in their daily lives. The participants in this research were all Icelandic aged 26-46. People who have been labelled as having learning difficulties in Iceland have been denied gender and sexuality and historically treated as asexual eternal children. When treated as children people with learning difficulties are located away from ideas of femininity/masculinity, also they do not hold a status as autonomous agents and have diminished opportunities to make choices in their daily lives. People with learning difficulties have been marginalized within the discussion of autonomy, disability and femininity/masculinity. This is in part due to cognitive ableism within research, policy and practice. The favour of the interests of people who possess certain cognitive abilities against who are believed not to possess them (Carlson, 2001) will be addressed in the paper in relation to the research findings. The findings suggest that in the quest of claiming their autonomy and adulthood, the participants adopted stereotypical, hegemonic ideas of gender and gender roles and the older men demonstrated sexist attitudes. The paper concludes by suggesting that gender has been normalized in relation to people with learning difficulties and that they have been educated to be the forever child who should be blissfully ignorant of ideas such as gender equality and sexuality. They have been offered segregated educational options, lacked access to sex education, and trained for traditional women's or men's jobs.

Nele Bosch, Jo Daems, Jan Dekelver and Steven Solberg: AbleChat: A smartphone chat application for people with Intellectual Disabilities

(Main Conference, paper)

This article describes the development of a chat application (AbleChat) for an Android Smartphone. This application allows people with intellectual disabilities (PID) to chat using pictograms and caregivers to write in plain text. The Able to Include Accessibility Layer (able-to-include.com) takes care for text-to-pictograms translation. This way, AbleChat allows PID to create messages independently via the smartphone and send and receive messages in understandable way.

People with intellectual disabilities were actively involved in the design process, in the development and testing of the application (Human Centered Design). Along with PID, their caretakers were also involved. As communications partner of persons with intellectual disabilities, they are important stakeholders.

In a first phase, the context of use and user requirements were described. This was based on interviews with PID and their caregivers about the use of a smartphone. Based on these findings, a first prototype was developed. This prototype was evaluated by the caregivers. A second version of the AbleChat was tested in a pilot study by 25 PID. After six months, both the caregivers and the PID were asked to evaluate AbleChat. Caregivers were invited to fill out a questionnaire based on the "App Evaluation Rubric". Users were asked about their findings through a semi-structured interview that determined their experiences and findings.

Both the people with intellectual disabilities and their caregivers are excited about the concept of sending messages using pictograms. The prototype has the restriction that people with intellectual disabilities can only chat with their caregivers. There is a desire to extend the application and allow sending messages to friends and relatives. This feature and comments relating to the usability of the interface are integrated in the development of version 1.0.

David Brehme: Disability And Normality As Polar Opposites On A Single Continuum: A Qualitative Study With Pupils At German Inclusive Primary Schools

(Main Conference, paper)

In contemporary Western societies, disability theory suggests the concept of disability cannot be thought of without a notion of "normality" (Davis, 2013; Goodley, 2011). Is this also true in inclusive schools, where disabled and non-disabled children learn together? German ethnographic studies have shown that disability is a highly prominent social category in inclusive primary schools (Pohl, 2013; Schumann, 2014). However, we know relatively little about how normality and disability relate to each other when children talk about disability.

To investigate this question, I conducted 7 group interviews with 2-5 children each from 4 different inclusive primary schools in the state of Brandenburg, Germany. The interview transcripts were then analysed in two steps: first, a category framework was inductively created using qualitative content analysis (Mayring, 2004, 2010). Second, transcript excerpts coded in relevant categories of the framework were interpreted based on a Foucauldian discursive approach (Parker, 1992, 2013).

This paper will present the main finding from this analysis: children's discussion about disability can be understood as using the concepts of disability and normality as polar opposites on a single continuum. Here to, being disabled means to be not normal. However, the boundary between the two concepts is not strong and clear-cut but rather is better understood as a blurry and meandering transition. This then begs the question: how do children in inclusive schools draw the line between being disabled and not-disabled?

Liz Brosnan: Sanity in Mad Places

(Mad Studies stream, Survivor Research panel)

Mad Studies offers a different space to understand what it means to be entangled with mental health services. For instance many people observe the tendency for the energy of the service-user movement to get absorbed in reforming efforts: user involvement, and 'recovery focused' approaches, rather than user-directed services or alternatives beyond psychiatry. This is a different trajectory from that of the wider disability movement, who have focused on the independent living movement and helping people to get out of professionally controlled, institutional living situations.

Until now the mental health survivor movement has not widely considered launching out from under the control of psychiatry and medically dominated services, but some see the emergence of mad studies as a possible turning point. Mad Studies is a very new development in the academy, an off-shoot from Disabilities Studies, exploring many topics related to critical perspectives on the area of 'madness' including maintaining sanity in mad places.

I sit on panels and committees and work in the neoliberal university wearing the mantel of being a 'service-user'. Yet the emotional cost of this work is unrecognized, hard to communicate because of 'hermeneutical' injustice. This type of injustice refers to the inability to communicate what the problem is because it is so outside the mainstream understanding of the problem, or even acknowledging that there is a problem. Trying to articulate the luminous borderland of being the obvious 'mad person' in the room, where proceedings are guided by the unspoken rules of bureaucratic engagement, no emotional expression, no questioning of the assumption that mental health services are an industry, an unstoppable juggernaut damaging people with the canon that medication can fix problems caused by social injury. This paper will attempt to articulate the problem and engage in dialogue with other Mad Identified Scholars.

Leah Burch: The Illusionary Rhetoric and the Bleak Reality of Educational Policy: A Critical Discourse Analysis

(Main Conference, paper)

This paper exposes the conflicting influences and agendas hidden in the discourse of the 2014 Special Educational Needs Code of Practice:0-25 Years (2014 SENCoP). Employing a critical discourse analysis (CDA), this research will unpack the exclusionary rhetoric of the recent publication. Indeed, a medicalised discourse of disability and special educational needs (SEN) is exposed and positioned within the wider politics and pressures of neoliberalism. A critical deconstruction uncovers the political trajectories underpinning educational policy to challenge legislative tensions. More specifically, this research draws out the paradoxical discourses that seek to drive up the marketization of education by mystifying the terminology of inclusion, independence, and identification. To conclude, this paper suggests that an illusionary rhetoric of inclusion is cloaked by the linguistically bleak reality of 'SEN' which continues to echo a derogative discourse of prejudice that has long-legislative history. The findings of this research uncover the reluctance of educational policy to commit to inclusive education due to the pressures of neoliberalism. In light of this, it is suggested that a parallel system of education that continues to situate children labelled with SEN as 'Other' must be resisted and rejected.

(Main Conference, paper)

The book *The Madwoman and the Blindman: Jane Eyre, Discourse, Disability* was published in 2012, and is a valuable addition to previous work seeking to bring Disability Studies in general, and Cultural Disability Studies in particular. Its eight chapters comprise detailed and illuminating discussions of various Disability Studies-related aspects of Charlotte Bronte's 1847 novel 'Jane Eyre'. To paraphrase Lennard J. Davis, the publication of 'The Madwoman and the Blindman' makes it impossible to write knowledgeably on 'Jane Eyre' without taking into account the issue of disability.

Fortunately for academia, this does not mean that debates about 'Jane Eyre' have suddenly become superfluous - far from it. In this paper I shall be critiquing Julia Miele Rodas' contention, in chapter three of 'The Madwoman and the Blindman', that Jane was a character on the autistic spectrum. I will not be arguing against this contention, but rather with the way in which Rodas presented it.

Despite her laudable stated aim of using her work to reclaim autism as a legitimate aspect of human experience, Rodas tries to establish Jane's 'autism' by portraying her as defective - by, for example, using the definition of autism contained in the DSM-IV (specifically for the classification of mental disorders) and claiming that readers have very often felt that there is something about Jane which 'resists a sense of intimacy'. In this paper I will be using the writings of such successful autistic people as Temple Grandin to argue that, instead, that Jane's possible autistic traits can be seen as highly positive - her sense of 'otherness' and mental and psychological independence enable her to survive her traumatic childhood, and, as an adult, make an independent way through the world.

<u>Nicola Burns: Who has access? Exploring policy responses to communication access in healthcare settings</u>

(Main Conference, paper)

Information accessibility has been recognised as key to realising an individual's fundamental human right to health. Communication is central to effective and safe access to health and health care, raising issues of confidentiality, patient safety, informed consent and equity. In recent years there has been a growing recognition of the difficulties faced by particular groups and healthcare professionals in communicating with one another.

In the UK, the Confidential Inquiry highlighted the lack of reasonable adjustments for disabled people and their families and carers as a key factor in the deaths of a number of cases reviewed. Another group facing difficulties are non-English speakers, where the lack of a shared language raises issues to communicate can place patient and practitioner at risk of compromising key tenets of healthcare. While the barriers facing these two groups are similar- a lack of accessible information in suitable formats; lack of training; lack of resources to support accessible communication- policy responses to these two groups have differed. This paper considers the approach to accessible communication for these two supposedly distinct groups. Using normalisation process theory (NPT) and Bacchi's 'what's the problem represented to be?', key policy documents are analysed to explore the ways in which the communication issues facing different groups in healthcare settings are framed.

The paper concludes by reflecting on wider politics of healthcare considering the ways in which health justice and equity are positioned for particular groups.

Bronagh Byrne: Rights-Holders under the UNCRPD: Challenging Definitions of Disability in Human Rights

(Main Conference, paper)

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has been welcomed with much vigour and celebration.

Significant as the first bespoke human rights treaty for people with disabilities, we have now entered a new era where focus must shift to implementation and monitoring of States obligations; that is, from 'rights talk' to 'rights action'.

This paper will provide an empowering but critical analysis of disability rights discourse in the context of the CRPD. It will explore the innate conservatism and flaws of 'rights talk' when it comes to disability, and its inherent contingency upon the perceived characteristics of rights-holders. For no other population group in society are rights subject to such a range of both explicit and implicit qualifications. This 'smoke and mirrors' character is particularly evident with respect to conceptualisations of 'individualised support', 'resource availability' and 'reasonable accommodation' and their respective emphases upon the extent of individual impairment or 'deficit' rather than upon the extent of institutional or structural deficit.

Moreover, effective claiming of some of the CRPD's rights may require active self-identification as 'disabled' – on the State's terms – in order to access services or appropriate support. By means of illumination, this paper will draw on a documentary analysis of definitions of disability in State party reports and the CRPD's concluding observations to date. This paper will ultimately highlight how rights for disabled people may come to be experienced as disempowering and conditional, effectively leading to a form of 'rights disqualification'.

<u>Anne-Marie Callus: 'Children should be seen but not heard'. Does this old adage still apply for children with intellectual disability?</u>

(Main Conference, paper)

The right of the disabled child to be heard and to participate in decision-making processes affecting them is enshrined in the Convention on the Rights of the Child (CRC) as well as the Convention on the Rights of Persons with Disabilities (CRPD). The extent to which this right is realised in practice is of course another matter. The literature reporting on empirical research carried out in various countries suggests strongly that opportunities for the disabled child to exercise their participation rights in accordance with the requirements of these two Conventions are sporadic at best. The research literature also indicates that opportunities for the child with intellectual disability are even more limited than those for children who have physical or sensory disabilities. This paper first presents what Article 12 of the CRC and Article 7 of the CRPD state regarding the participation rights of the child in general and the disabled child in particular. It then presents an analysis of the results of various studies carried out in European and other countries regarding the implementation of this right in practice for the child with intellectual disability. The paper next identifies the main obstacles to the realisation of this right for the child with intellectual disability. Finally the paper presents practical suggestions about how we can go about making participation rights a concrete reality for the child with intellectual disability.

Colin Cameron: It's F***ing Wonderful Being Disabled

(Main Conference, paper)

Most people, the Existentialists tell us, would rather not think about the difficult things in life – pain and contradiction and the fact that one day they're going to die. In order to avoid having to deal with these, and to avoid having to think for themselves about the limitations of their own existence, they would rather go along with the crowd, the 'They'. Conventionality and conformity to the roles and expectations bestowed upon them – being caught up in the routines, the business, the plans, the distractions and amusements of everyday life – allow people to avoid having to reflect, and to pass through life having a reasonably comfortable time of it. The only problem with this, say the Existentialists, is its inauthenticity. The Existentialists draw on the Socratic dictum that an unreflected life is one not worth living.

Arguing against the mainstream view which holds that impairment can only be experienced as useless difference, I would like to argue that living with impairment requires us to live for real, or at least presents us with an opportunity to do so. Reflecting on impairment allows us to engage with an understanding of our own limitations.

Reflecting on being disabled reminds us of our not-at-homeness. Embracing impairment involves a practice of the knowledge of our own finitude, and allows us to become authentic in the way we relate to life. Identifying positively as disabled involves us in rejecting falling in with the opinions of the 'They'. We do not resent or aspire to be cured of impairment, but instead affirm impairment.

An Existential understanding of impairment and disability saves us from inauthenticity. It requires us to recognise the absurdity both of our own situations and of the conventionality surrounding us, and to make our own meaning and purpose.

Amy Camilleri Zahra: Enabling Counsellors: An Exploration of the Social Construction of Disability among Maltese Counsellors

(Main Conference, paper)

Counselling is generally recognised by disabled people as a valuable service. Nevertheless, disabled people form a particular client group which is often avoided by counsellors. This paper explores the social construction of disability among Maltese counsellors. This paper reports the findings of a qualitative study conducted with six Maltese counsellors, one male and five females. The data for this study was collected by means of individual semi-structured interviews and analysed using Thematic Analysis.

The findings of this study suggest that the social construction of disability among Maltese counsellors is influenced by three main forces, namely by the international and national politics of disability, the Maltese social and cultural aspect, and the counsellors' professional training and cultures of practice. The combination of these three forces creates a certain tension, which has led to contradictory discourse throughout the interviews. The over-arching theme that emerges from this study is: 'All the same but different – Contradictory discourse'. This theme is further illustrated by three subordinate themes: (i) Struggling through the politics – with reference to disability politics, (ii) 'The deserving and the undeserving' – with reference to disabled people as perceived by counsellors, and (iii) Clinging to professional ideology – with reference to the training and cultures of practice of the participants. Notwithstanding the contradictions presented in the counsellors' narratives, all six participating counsellors claimed that they would have ideally liked to receive more training about disability issues.

(Mad Studies stream, poster)

Listening for many years as a psychologist to the experiences of students studying, struggling and coping with the demands of Higher Education, I recognized an exchange in two directions. The students benefitted from the guidance and I gained insight in student frustrations, stigmatization at university and society level, good practices and proving oneself, being different but wanting to be normal and to belong. In my job at Ghent University, they expected me to be available 'to guide students in finding the appropriate study attitude and functional study skills' and to be available 'for confidential counselling for students who cope with study problems because of personal distress'. Students had to self-identify as 'distressed in need of counselling'. This self-identified 'label' was kept private between student and psychologist. If a student needed reasonable accommodation in the educational setting, he or she had to turn to another department called 'counselling handicapped students'. After providing 'medical proof' of having a 'psychiatric disability' (recorded in a governmental database), a student could negotiate about some reasonable accommodations and return for extra support.

The invisible 'Mad student' taught me this was not an easy step in life and it meant choosing between disclosing or not getting the necessary support. The fear of getting stigmatized, possible exclusion from the study career, silenced the voice of the 'Mad student'.

Endeavoring to give voice to those students, I'm beginning a PhD. Starting from literature and interviews with former students, I'll try to gather some opinions about e.g. identifying with an official medical 'mad' label, necessary support in HE, impact of studying on well-being, … before returning to the present cohort. With this paper as junior researcher, I hope to start a discussion and learn about pitfalls and interesting turns encountered by more experienced persons in the 'mad studies network'.

Sarah Carr 'Everything you make a freak': Gay liberation and mad people's history

(Mad Studies stream, paper)

In 1971 a group of radical British gay men and women formed the Gay Liberation Front. A direct challenge to psychiatry formed a key part of their manifesto:

"One way of oppressing people and preventing them getting too angry about it is to convince them, and everyone else, that they are sick. There has hence arisen a body of psychiatric 'theory' and 'therapy' to deal with the problems and 'treatment' of homosexuality." (GLF, 1971, p.5)

At the time homosexuality was classified as a mental illness. As the gay liberation movement grew in the US and Britain, activists campaigned tirelessly to remove homosexuality as a disease classification and as a mental disorder from diagnostic manuals.

This illustrated presentation will briefly explore how and why psychiatry was one of the first targets for lesbian and gay activists in the US and UK and situates the gay liberation movement within the broader context of mad people's history. It will also explore how later lesbian and gay activists formed counter-narratives to the psychiatric stories told about them, and used madness and fear of moral disease as tropes in radical campaigning.

Nasia Charalambous and Simoni Symeonidou: Investing in kindergarten teachers' professional development for inclusion: The added value of using material prepared by disabled people

(Main Conference, paper)

This paper describes the theoretical background, methodology and findings of an action research project that took place in a university kindergarten. The headmaster and staff of the kindergarten collaborated with an academic who specialized in employing disabled people's material in the curriculum. The research project has been running since February 2014. Based on the question 'In what ways can we (teachers) raise students' awareness about disability?', a plan was developed, including seminars, and reading the literature, and relevant material. The seminars familiarized the staff with the ideology of inclusive education, and the key ideas of Disability Studies (Barnes, Mercer and Shakespeare, 1999), such as the medical and social model of disability, identity, labelling, rhetoric etc. Later, the seminars focused on material prepared by disabled people (i.e. artwork, poems, songs, and articles). The staff had the opportunity to discuss with the academic possible ways of infusing disability issues in the kindergarten curriculum, without reproducing traditional stereotypes about disability, and without over-emphasizing impairment. The school staff agreed to start using the suggested material in their lesson plans and projects. The findings suggest that teachers were able to refine their approaches, and they gradually realized that disabled people's material can be used both to pursue curriculum goals that are not related to disability (i.e. disabled people's paintings can be used to develop children's fine motor skills), and to raise disability awareness (i.e. a poem or a song can be used to encourage students to campaign for all people's right to accessibility).

Taking specific examples of teachers' approaches as a starting point, the presenters (headmaster and academic) will focus on the added value of supporting teachers in their efforts to conceptualize disability as a human rights issue, and negotiating their dilemmas when it comes to the design and implementation of innovative lessons.

Desire Chiwandire: Funding mechanisms to foster inclusion in higher education institutions for students with disabilities: a critical appraisal

(Main Conference, paper)

Background: Historically challenges faced by students with disabilities (SWDs) in accessing higher education institutions (HEIs) was attributed to limited public funding. The introduction of progressive funding models such as disability scholarships has served to widen access to, and participation in, higher education for SWDs. These successes notwithstanding, little attention has been paid to potential flaws in the underlying values informing how public disability funding is allocated to SWDs. Disability funding tends to be seen uncritically as a 'good in itself'.

Purpose: In this paper the funding mechanisms of selected developed and developing democratic countries including the United Kingdom, the United States, Canada, Australia, South Africa and India are critically examined to ascertain their contribution to enhancing access, equal participation, retention, success and equality of outcome for current and potential SWDs who are funding recipients.

Methods: A critical review of the sample countries' funding mechanisms governing SWDs in higher education and other relevant government documents; secondary academic literature on disability funding; online sources including University World News, University Affairs, newspaper articles, newsletters, literature from bodies such as the Organization for Economic Co-operation and Development (OECD), Disabled World, and Parliamentary Monitoring Groups. Data were analysed using a theoretically derived qualitative content analysis in which the capabilities approach to equality was employed as theoretical lens.

Results: Barriers which place SWDs at a substantial educational disadvantage compared to their non-disabled peers include bureaucratization of application processes, cuts in disability funding, means-test requirements, minimal scholarships for supporting part-time and distance learning for SWDs and inadequate financial support to meet the day-to-day costs that arise as a result of disability.

Ganesh Chilkhe and Amith Kumar P. V.: Framing children with disabilities on the celluloid: understanding social construction of disability in contemporary marathi cinema

(Main Conference, paper)

Disability studies in the South Asian context have been an emerging area for research inquiries since the start of the new millennium. In the contemporary academic scenario, disability in South Asian economies acquires significance for two major reasons: first, disability in the countries of South Asia have been relegated to the backdrop due to an emphasis on issues of underdevelopment such as poverty, population explosion, illiteracy, and unemployment. Second, till very recently, disability had been categorized as a 'social burden' that is more a liability to the South Asian economies.

The paper focuses on the celluloid medium by engaging with the representation of the disabled child in contemporary Marathi cinema. In a country where larger issues pertaining to disability have received little critical attention, 'children with disability' is a concern obfuscated and negated by the political machinations of marginalization. The study focuses on how postcolonial manifestations are noticeable in the contemporary Marathi cinema. For this purpose, three movies have been selected: Shwaas (2004) directed by Sandeep Sawant, Aahmi Aasu Ladke (2005) by Abhiram Bhadkamkar, and Yellow (2014) by Mahesh Limaye.

The paper inquires into how children with disabilities experience "microaggression". The social construction of disability is manifested through factors such as family, charity, embarrassment/burden on the family, denied education, extra/lack of care, physical and emotional abuses, exploitation etc. These factors are significant in identifying the ways in which disabled children experience microaggression in the Marathi socio-cultural scenario. The paper also explores how experiences of microaggression add to the construction of gendered identities in children with disabilities. The inquiry into intersections of disability with postcolonialism, experiences of microaggression, politics of gendering, the assertion of identity with regard to children with disabilities would create a platform for understanding and theorizing disability in ignored regions/languages of South Asia.

Yueh-Ching Chou, Teppo Kroger, Chun-Chieh Lin, Heng-Hao Chang and Chia-Ning Chang: Semi-independent living in Taiwan: Disabled activists' perspectives

(Main Conference, paper)

Background: Independent living (IL) movement was launched in Taiwan in 2006-2007 with the establishment of the Taipei Independent Living Association (TILA). After a two-year (2008-2009) personal assistance (PA) pilot program, managed by the TILA, an experimental PA project has been granted by the central government since 2012. This study explores the meanings of IL to disabled activists and how their experiences are connected with state policy and the disability movement in Taiwan.

Methods and strategies: The research team of this study included disabled people from a DPO (TILA), disability researchers and a research assistant. Except secondary data from related documents, an interview guide was developed by the research team and used to collect primary data from 15 participants, identified as IL activists, interviewed between September 2015 and May 2016.

Findings: The meanings of IL were mostly consistent among the participants. Some moved from residential care or their family to live independently in the community; some recognized that they were able to have their own life and pursue their dreams. Most had learned to use electric wheelchairs for "going out" where they wanted to go, and to use PAs/sign language translators for "speaking out" what they needed and what they didn't like. Several had also become actively involved in work against social barriers (e.g. inaccessible public transportation and parks, unfriendly attitudes from staff of public services or private businesses, limitations of PA hours, shortage of PAs). However, the findings also revealed that if social barriers (including distrust from the family) were not removed, full IL remained unobtainable for disabled people in Taiwan.

Conclusion: Because social barriers are still rather strong, only semi-independent living is currently possible for disabled people in Taiwan.

Katharina Crepaz: The Europeanization of Minority and Disability Rights: A Comparative View

(Main Conference, paper)

Both minority rights and disability rights are relatively new fields for EU policy-making, and both are affected by the EU's diversity mainstreaming approach and its non-discrimination legislation. These policies correspond to the classic understanding of Europeanization: a "top-down" stream of influence from the European to the national and subnational levels. Europeanization "top-down" defines a degree of 'misfit' (Börzel & Risse 2003) between European and national policy preferences, leading to a process of "domestic adaptation to European regional integration" (Vink & Graziano 2004: 7). This adaptation happens in areas under the acquis communautaire, but may also have spill-over effects to non-acquis areas (e.g. minority policy, a member-state competence affected by EU non-discrimination provisions). However, Europeanization processes may also take place in a "bottom-up" direction, defined by Della Porta & Caiani (2009) as "Europeanization of and by civil society"; actors use the European arena as a forum for discourse and pursue common goals by exerting pressure on policy makers. Europeanization is a 'two-way process', encompassing both "top-down" and "bottom-up" elements, sometimes simultaneously at work on the same issue (Crepaz 2016). The theoretical framework on 'two-directional' Europeanization was developed in my dissertational project analyzing its impact on minority communities, and its further explanatory capacity will now be tested by applying it to other EU human rights policy areas. My paper therefore aims to provide a comparative perspective on Europeanization processes "top-down" and "bottom-up" in the fields of minority and disability rights, pointing out similar dynamics and patterns (e.g. civil society collaborating in transnational advocacy networks) and explaining differences consequences (e.g. disability rights having a stronger legal basis, allowing for further institutionalization of civil society dialogue). I will be conducting a process tracing analysis, drawing on official EU documents, parliamentary questions, as well as structured interviews with civil society representatives and European Commission officials.

Maria Bee Christensen-Strynø: Extensions of mobility and the mobilisation of disability awareness-raising on social media

(Main Conference, paper)

In this paper I explore potential extensions of mobility in relation to raising awareness about disability on social media. Departing from two cases – Madeline Stuart and Dear Julianna – that have each gained extensive visibility and attention, I address how social media and online communication facilitate new ways of creating disability awareness-raising, and how access to the internet and social media platforms can be seen as ways of increasing and reclaiming mobility for people living with disabilities.

Both cases are characterised by rigorous understandings of social media conventions about how to strategically convey matters on disability online. Poell and van Dijck (2015) identify how social media accelerate activist communication through advancements in mobility caused by the expansion of available mobile devices and new media platforms. This observation seems to be strengthened when considering apparent issues about limitations of accessibility and mobility in relation to new media technologies and people living with various disabilities (Goggin & Newell 2003; Ellis & Kent 2011). Tapping into discussions about how to create new critical locations for people living with disabilities, I argue that selected statements, updates and comments from the cases can be interpreted as expressions of authority (from the disability community) and acknowledgment (from their audience).

However, gaining visibility and attention on social media also raise questions about new challenges connected to online communication about disability. Consequently, I address how probable reductive idioms and styles, characteristic of social media, appear in the cases, e.g. through update-orientation, hashtagging, and inspirational/emotional statements and images. Thus the extended mobility of reaching grand crowds of audiences and users also exist on specific premises that are regulated by appropriate social media behaviour and particular modes of disability representation.

Sara Conceição: On the behalf of the working and fighting nation – National Professional Rehabilitation Services and segregationist options in the Portuguese late 60's

(Main Conference, paper)

In 1966, the Portuguese government creates the Professional Rehabilitation Service, whose primordial objective was to insure the professional readjustment of disabled workers. Through its legally assigned attributions, a national path directed to disabled workers is created for the first time in the country. This national agency defines, as one of its aims, the creation of specific services dedicated to the professional rehabilitation, with progressive correspondent specific courses, grounded in a tripartite classification system.

Mainly two kinds of arguments sustained these policies. On the one hand, moral obligations are evoked, openly associated to the need of honouring Christian values, sometimes transmuted in a shiny preoccupation for social justice. On the other, the national interest is also invoked, in a sleight of hand through which the ubiquitous rhetoric of personal tragedy is, momentarily, transformed into nation tragedy, within a context where the country leads colonial wars and the economic emigration imposes a workforce shortage.

In a double movement, in no way contradictory, the government launches the basis for the creation of a set of structures and procedures that institutionalize segregationist routes and endorses a repeated call for a change of mentality that would allow some space for the disabled. While measures that reinforce the segregation are taken, a discourse is set up that moves the heart of the question to the representational world, thus ensuring additional protection to the material organization of the society.

In this paper we will attempt to analyse the processes and mechanisms through which, in the particular political-historical context of the Portuguese dictatorship, those segregationist options were made possible and became rooted in a long-term structuring way.

<u>Nicole Cooke and Lisa Saville Young: Experiences of disabling living and experiences of disabling care: A critical psychological interpretation of case series data from the Eastern Cape of South Africa</u>

(Main conference, paper)

This paper presents findings from initial data collected as part of a broader study on the outcome and processes of a service learning programme with a small sample of caregivers and their children with disabilities living in Grahamstown East, Eastern Cape, South Africa.

Specifically the paper presents data that forms part of a a descriptive case-series design, from four caregiver-child dyads at two data collection periods over ten weeks providing, amongst other things, a rich baseline understanding of their experiences of health services currently received through the public sector. Both subjective and objective, quantitative and qualitative data are presented in a mixed methods approach to create a comprehensive and rich understanding of each case. In particular, the data tracks change processes in the subjective well being of the caregiver, the quality of the caregiver-child relationship and the functional development of the child over a ten week period of receiving public health services. The paper also presents qualitative data on the caregivers' perception of and experiences of the public services that they and their child are receiving. The findings are interpreted in light of the critical psychological literature that is concerned with the social and psychic barriers to the inclusion of disabled children and their caregivers, in this case, in their own health services. The findings, emphasizing the standpoint of the caregivers and their children in the therapeutic process, provide an important perspective on the reported difficulty in co-operation between caregivers and therapists which have been noted in previous research in LAMI countries. The paper concludes with briefly considering the implications of this interpretation of the case series data for the design of a service learning programme proposed as part of a psychology honours course.

(Main conference, paper)

This paper will investigate how disabled young people use and experience digital technologies for learning. There remains little research in this area (Passey, 2013). The paper will respond to this gap by drawing on illustrative case study data collected as part of a participatory pilot project focussed on young people with visual impairment.

Children's uses of digital technologies are often considered in isolation as individual social practices (E.g. Livingstone, 2009; Selwyn, Potter and Cranmer, 2010). Yet, this approach has neglected the important networks which underpin practices; support and scaffold them. This paper therefore will consider how communities of practice (Wenger, 1999) support disabled children's own social practices with digital technologies for learning in schools.

The paper will show the strengths and weaknesses of communities of practice for supporting digital technologies as described by young people and teachers/teaching assistants/specialist teachers. It will show the benefits for disabled young people of using tablet computers to nurture independent, self-directed learning and reduce stigma. Furthermore, how this is made possible through the interplay of young people's agency combined with support received. It will point towards future research needed in the area, particularly taking account of recent approaches developed within the field of Disabled Children's Childhood Studies which seek to view all childhoods equally and positively (Mallett and Runswick-Cole, 2014).

<u>Kim Davies: Refusing the self-evident: Dis/ability as intersubjectivity</u>

(Main conference, paper)

In this paper I will (re?)voice Fiona Kumari Campbell's (2009) call to refuse able(ness) as a refusal of "disability" itself. Starting from Campbell's preliminary call, I will present an account of a 'mother's', 'child's', 'student's', 'school's' and teacher's' experience with a diagnosis of 'Asperger's Syndrome' to consider and spotlight the social and cultural stories we tell when we narrate private and personal stories of 'ability' and 'disability'. Using Titchkosky's (2012) motif of re-arranging the relational furniture, I will turn the tables on dis/ability by relocating it as an intersubjective encounter in sociocultural space where selves are made and bodies are materialised as public conjectures rather than privatised facts of existence. I will conclude by positing the pedagogical possibilities of unbecoming and/or becoming differently that acknowledgment of our interdependent mutuality affords us all.

Lisa Davies: Who's Reading them Anyway (and Why)? An exploration of audience & disability autobiography

(Main conference, paper)

For Thomas G. Couser disability autobiography is 'a retort— to the traditional misrepresentation of disability in Western culture generally' and 'a powerful medium in which disabled people can demonstrate that they have lives, in defiance of others' common sense perceptions of them' (2010:7). But who is reading disabled autobiography and why? And what is there to be said about the potential audience for the genre? These questions are important for my PhD research which critically analyses disability autobiographies, and explores whether disability autobiographies can function as activism. The 'who' and 'why' are crucial in assessing their potential for social change. In

Harriet McBryde Johnson's autobiography she discusses some of the simplistic and stereotypical ways that disability is represented:

We are read as avatars of misfortune and misery, stock figures in melodramas about courage and determination. The world wants our lives to fit into a few rigid narrative templates: how I conquered disability (and others can conquer their bad things!), How I adjusted to disability (and a positive attitude can move mountains!). (McBryde-Johnson 2005: 2).

Johnson acknowledges that such simplistic ways of representing disability are designed to appeal to a nondisabled audience. Similarly, according to (Mintz 2007:17) they make 'disability palatable to an ableist' audience. Yet, as irritating as these representations are to some disabled people, they can also provide an opportunity for change. This particular audience may approach texts expecting to read such pervasive and reductive representations, and end up with a fresh or alternative view of disability. Audience matters even more as I write - and perform - my own disabled autobiography (provisionally entitled Fucked: Diary of a Disabled PhD Student) which will form part of my thesis.

Gemma Dawkins and Damian Milton: An evaluation of a person-centered mentoring programme for adults on the autism spectrum

(Main conference, paper)

Introduction

Specialist mentoring or coaching schemes for people on the autism spectrum are still rare, and research on the topic rarer still. A number of work training schemes, life-coaching and Access to work mentoring schemes have been initiated, yet have not been subject to good quality evaluations. This presentation reports on the development of a mentoring programme for adults on the autism spectrum. The programme involves the matching of twelve pairs of mentees and mentors, the latter having been given a day course on autism and mentoring designed and delivered by the project team with input from autistic adults on the project advisory group and within the team itself.

Methodology

The effectiveness of the mentoring programme is to be reviewed through the use of the Personal Wellbeing Index (PWI) utilised at the beginning and the end of a six month period of one session per week, as well as through qualitative analysis of logs taken of mentoring sessions and post-programme interviews. The project also uses the 'Salmon-Line' technique to track progress against three goals set by the mentee within their first mentoring session.

Results

This project is currently in progress, yet the project team would seek to present the results from the study at the Disability Conference.

Conclusion

This presentation would seek to share findings from the project regarding mentee progress, as well a reflection regarding what to include in training given to mentors to encourage a client-centred and effective relationship.

Annelies De Vliegher and Jo Daems: A customized memory game: training people with an intellectual disability in Facebook use and media literacy

(Main conference, paper)

As a part of the *Able To Include* project (abletoinclude.eu), people with an intellectual disability (PID) were trained in Facebook use and media literacy to ensure a responsible and safe environment during pilot studies. The training and follow-up of the PID was based on the 4C/ID model by Van Merrienboer, a nine-step cycle tailored to the needs of PID. The training consists of sessions to teach specific skills such as "sending a message to a friend" or "logging on and off on Facebook". An adapted memory game was incorporated into these sessions to assess the participants current knowledge about Facebook use and media literacy. The cards displayed Facebook-related symbols and additionally statement cards such as "Everyone is allowed to see what I do on Facebook" or "I have met all my Facebook friends in real life" were designed. When finding a pair, a statement card was read out loud. Participants then pointed out a green ("I agree"), red ('I disagree"), or question-mark ("I'm not sure/I don't understand the statement") card, which allowed the game leader to explore everyone's opinion and ask more in-depth questions.

The game was tried out with six groups ranging from 2-8 PID, with the presence of a caregiver. Playing this game provided insightful observations about the trainee's knowledge of Facebook related symbols, vocabulary, media literacy skills and opinions. The game is recreational as well as educational and offers a nice break from other training sessions. The PID enjoyed finding pairs, recognizing and learning symbols and vocabulary from Facebook. An educational game as described has shown to be a valuable part of a Facebook training program. Caregivers can learn a lot about their trainee's opinion in a very accessible manner through observation during the game. They can use this information to re-evaluate and continue individual training sessions.

Patrick Devlieger and Godé Mpoy: Bureaucracy and disability at the border in the African context: Vulnerable citizenship in the Great Lakes Region

(Main conference, paper)

In this paper we clarify the relationship between bureaucracy and disability as it pertains to the rules and regulations that define disabled citizenship, and its consequences in terms of advantages and exemptions, and in terms of rights and responsibilities. In the case of transborder trade in the Great Lakes region in Africa, we further explore how disabled citizenship and a state of exception and exemption in terms of customs and immigration have been applied. This has created economic niches in which disabled people as part of the group of small tradespeople have been very successful. We argue that in the region of the great lakes a balance is to be created between fluid transborder trade, public receipts, and prosperity shared by the forces of the market, a citizen acculturation that generates peace, and customs offices of a mixed nature. In such an approach, there is still space for a decentered approach and one that takes into account alterity.

Leanne Dowse and Louisa Smith: Developing a complexity approach: transdisciplinarity and innovation in critical disability studies

(Main conference, paper)

In the past decade critical disability scholars have frequently recognized disability as 'irreducible' or 'more than the sum of its parts', thereby positioning it as the epitome of complexity.

In keeping with critical disability studies' engagement in transdisciplinary debates around the epistemologies on which it rests, the presence of complexity calls for adequate theories to understand it. Complexity approaches are now proliferating at the cutting edge of new work in fields including education, urban planning, development studies, criminology, health and illness, in the scholarship of public and social policy, and in cultural and media research. As yet, there has been little work that directly and systematically engages with the complexity approach in disability.

Disability studies has to date predominantly relied on an intersectionality lens for theorising multiple forms of oppression, however this approach has fallen short as a methodological means of apprehending the synergy at play across the interactions of multiple systemic, discursive and embodied factors. The transdisciplinary lineage of theories of complexity provide the capability to capture dimensions of embodied identity in their interconnection to the mechanisms, nuances and imperatives of social responses to disability and their politics. So while intersectionality offers us a way of apprehending multiple and complex personal and social experiences, complexity provide a way of attending to them. This paper explores the promises that complexity theories have for understanding disability, utilsing a case study to illustrate how complexity theory can help build open and unpredicted understandings of disability.

Anna Dunér and Elisabeth Olin: A barrier to autonomy? Assistance users' experiences of personal assistance from family members

(Main conference, paper)

In Sweden, disabled people with comprehensive support needs have the right to personal assistance (PA) since 1994. Disabled people were expected to take on roles as experts and managers of their own on assistance and were assumed to oppose professional and/or family interference in their lives. However, official statistics show that many assistant users have PA from one or several family members, often in combination with non-family assistance, a situation we don't know much about. Thus, further knowledge is needed about family PA (FPA) and how it may promote or obstruct the possibilities to achieve the policy intentions of individual support, independence and participation in society for disabled people. In this study we have explored how Swedish PA users experience and manage having family members employed as personal assistants, with a special focus on autonomy, dependence and interdependence. We draw upon theory and research on controversies around FPA, the shifting views on disabled people from passive dependants to active agents, as well as individual and relational conceptions of autonomy. We have performed 17 qualitative interviews with users of FPA, both men and women of different ages, and who has a father or mother, a partner and/ or an adult son or daughter as FPA. Preliminary findings about 'Family as a prison or a free-zone?', 'Strategies for managing FPA' and 'Dealing with dependency' will be presented.

Alex Dunedin: Who Knows What: Locked In and Locked Out

(Mad Studies stream, poster)

What happens when the content of your voice has been written off as not being valuable? Often in psychiatry the patient voice is confined to articulating only the problems which map to the medical model which is dominantly used as a framework for action.

Typically in medicine there are recognised both signs and symptoms. Signs are externally observable and concretely measurable. A symptom is a phenomenon that is experienced by the individual affected by the disease. It is the combination of internal and external observations which is important in reaching a greater understanding of what ails the individual.

Patients commonly meet with idiosyncratic accounts of psychiatric diagnoses such as "we do not know what it is" despite encountering powerful medications which aim to "alter the course of the disease". Moving outwith normative medical practice is commonly met with cynicism or disregard as such conversations shift the bounds of agency to potentially uncomfortable and/or undesirable terrain.

In other fields of knowledge and medicine subjective perspectives are more valued as providing a route of contact with the phenomena itself. In these other spaces the personal experience of observation does not start from a point which is regarded as faulty but taken into consideration before the attempt to address bias.

Drawing from lived experience and peer reviewed science I developed a course of treatment for my mental illness as a chosen alternative to the prescription medications, however my perspective was met with silence; as a consequence I live outside of the medical system and support structures left to find the means for my own wellbeing. Patient-doctor discussions of medical interventions are too often overshadowed by doctor-patient logistics. In this presentation I'm interested to explore the differentials in agency which occur in the psychiatric space.

<u>Steven Edwards and Emma Munks: How Experience Based Co-Design can be used to create a meaningful approach to service evaluation and quality improvement for those providing and using a Learning Disability Community (Health) Service</u>

(Main conference, paper)

Background: Staff and service user frustrations with the existing approaches to service evaluation provided the starting point for this initiative. Existing methods were seen as largely quantative in nature and failed to capture the idiosyncratic emotional and psychological context faced by clients and practitioners. Experience Based Co-Design (EBCD) was identified as a method of service evaluation which allows for meaningful engagement with the experience of those receiving the service and of those delivering the service together with the opportunity for both groups to come together and co-design service improvements based on the sharing of experiences. The additional benefits of EBCD for a Learning Disability population is that it does not rely on the ability to read or write as the story of experience is captured in the first person via the use of recorded interviews and allows for the expression of experience in different formats.

What we did: We partnered with a Learning Disability Social Enterprise – Learning Together North West – to design and develop the intervention. They became our strategic partners in how to reach out to service users and carers in Lancaster and Morecambe. Outputs from this were customised materials for the Learning Disability community and an interview framework which helped interviewees share their personal experiences of the service on a DVD. Learning Together also helped with the workshops used to share the interviews on the DVD and co-design our actions in response to the key themes we identified.

We also held a roundtable with staff from Learning Disability services in Lancaster and Morecambe and used their feedback to identify priority areas for improvement.

The paper will explore the strengths and weakness of EBCD as a methodology for evaluating the quality of Learning Disability services and the insights it offers for those commissioning and delivering these services.

<u>Laraine Epstein: Welfare Reform - Why reduce Access to Work support when you want to keep disabled people in work?</u>

(Main conference, paper)

Access to Work is a government programme set up to support people who face barriers to employment as a result of their health or impairment. Access to work plays a crucial role in supporting people in employment, it is estimated that half of the people using the scheme would not be in employment at all without it. It has been suggested that the disabled person is a master of adaptation therefore the main benefit of Access to Work's philosophy is to assist the disabled person to adapt, remain and thrive in the workplace (Siviter 2008).

However, from October 2015 the Government are making cuts to Access to Work which means that individuals will not be able to claim support worth more than one and a half times the national average salary which at current rates would be equivalent to £40,800. The newly implemented cutbacks make it more difficult for people to qualify for resources from access to work thus threatening the disabled persons right to work.

 Independent Living (2015) report that the Government benefit financially from Access to Work as for every £1 that the Government spend on Access to Work, £1.48 comes back to the Exchequer in tax, national insurance or savings to the benefits bill). Moreover, disability spending seems to be unbalanced as the Government spends around 20 times as much on out-of-work benefits for disabled people compared to spending on specialist disability employment support (£7 billion compared with just £330 million).

Paper aims:

Discuss the new implemented Access to Work cutbacks

Explore the new implemented Access to Work cutbacks impact on disabled workers

Review whether the changes assist or hinder individuals to stay in work

Susan Eriksson and Veli Liikanen: "You don´t need legs to skate – you need friends" – the status of disabled young people in youth sport cultures

(Main conference, paper)

Research dealing with disabled people is often dominated by medical understanding of disability, especially when it comes to issues of body. For example, the studies considering sports activities of disabled people are often based on concepts and theories of rehabilitation, which are established and institutionalized as official social policies.

Our research project deals with the status of disabled young people in youth sport cultures. The aim of the research is to enhance knowledge about the status of disabled youth among their peer groups and promote their opportunities to participate in sport activities. It is asked in the research, what kind of meanings sport has in the lives of disabled youth, what kind of opportunities of choice they need in order to have sports as a hobby and how they are able to join in the different youth sport communities. The data consists of ethnographic observations, interviews and a survey.

Theoretical framework is combined with critical disability studies and theories of youth culture. Within the approach we try to give disabled young person a status of an ordinary citizen or ordinary young person, who has certain leisure time interests. The research focuses on analyzing, what kind of means or mechanisms of social inclusion, exclusion and social differentiation these young people use, when it comes to their abled or disabled peers. In order to discover those mechanisms, we look at language use, spatial arrangements and other forms of social order within the gatherings of young people.

The aim of this presentation is to scrutinize some theoretic and analytic possibilities to study the position of disabled youth in the ordinary life cycles of young people in general.

Alison Faulkner: Mad Studies: A View from Outside the Academy (sort of)

(Mad Studies stream, Survivor Research Panel)

This paper will explore some of the opportunities and challenges offered by Mad Studies from the perspective of an independent survivor researcher working predominantly in the voluntary and community services sector. Challenges include the high walls of the ivory towers and the complexities of the communities we work with, including intersectional issues; also the dominance of mental health clinical academic ideology (particularly the biomedical model and its implications for mental health research) in much UK survivor research. Opportunities include the broader perspectives on mental health and distress from the different disciplines that come together in Mad Studies; the richness of these different perspectives and the opportunities they afford to step outside of the mental health service-dominated ideology. How are we to remain grounded in survivor knowledges in all their complexities and bring marginalised communities along with us? What does it mean to be a survivor researcher - and are we essential to the establishment or embodiment of survivor knowledge inside the academy? How are we to bring ideas in and out of the academy to ensure that the breadth of survivor knowledge reaches what we have come to call 'Mad Studies'? The author is currently doing a PhD by prior publication at City University on 'the role and value of experiential knowledge in mental health research' so she currently has a toe inside the academy.

Charmaine Agius Ferrante: An Insight Into Students' School Experience Through The Social Model of Disability Lens

(Main conference, paper)

This paper presents some of the outcomes from the experiences of students attending a Maltese school that decided to embrace the philosophy of inclusion using a Case Study Methods. This was both a quantitative and qualitative study based on interviews, focus groups, observation and questionnaires with students from primary through to the end of their secondary Education. A thematic analysis supported by descriptive statistics was used within an interpretative approach of hermeneutic phenomenology. Most schools in Malta claim to include 'inclusive' settings. The aims of the research were to explore the whole school experience of all students in one school who claimed to provide inclusive education following the social model of disability and more specifically to:

1.   Observe if the school had reduced the barriers to education for all learners.

2.   See how the various stakeholders negotiated and overcame these barriers.

3.   What practices within this model support or hinder the inclusion and education of all students in a mainstream environment.

4.   Whether or not and if so, how disabled students are participating active members of the school.

Finally there will be an attempt to expose the idealised notions of the fundamental principle of 'schools for all', social justice, disability equality and human rights issues that underpin the social model of disability are being responded to within the 'Special' Education discourse creating exclusionary practice and inequalities within education.

(Mad Studies stream, paper)

This paper will explore the ways in which digital new media platforms enable new ways of articulating distress, through a focus on the ways in which selfies are mobilised by victim-survivors of trauma as activism, protest, self-care and community. As Engin Isin (2009) has argued, recent times have seen the emergence of new ways of claiming citizenship, with new media and social networking constituting important sites of struggle and enabling new acts of citizenship. Central to the activist potential of victim-survivor selfies is this facilitation of action, in a context that positions sexual violence as unspeakable: activist selfies allow for speaking out, but on one's own terms. This is important because, as Tanya Horeck (2004) argues, the figure of the 'rape victim' is at once invisible and hyper-visible: rape is imagined as private intimate, yet media and popular culture are saturated with images of sexual violence ranging from the eroticised and sensational to 'issue-based' representations including soap storylines, middlebrow mainstream cinema, and the proliferation of popular survivor narratives in publishing and TV. In this context, selfie activism constitutes a way of articulating victim-survivor citizenship that resists the overwhelming cultural imperatives that construct this term as a binary (you are either a victim, or a survivor), or as a narrative of linear progress through 'recovery' (you start out as a victim, but through personal effort, become a survivor). In this sense, victim-survivor selfies speak to Adi Kuntsman's (2015) reminder that selfie activisms work by mobilising the intimate and personal to political effect: in capturing the rage, sadness and trauma that may surface in a single moment, they are acts of citizenship in that they refuse the need to become-citizen through survivor-hood, and instead draw attention to the actual experience of the vast body of citizens who are also already victim-survivors.

Rebecca Fish: They've said I'm vulnerable with men: Sexuality on locked wards

(Sexuality stream, paper)

In intellectual disability services, women's sexuality has long been considered a problem, with women being removed from their residences and segregated from men as a form of protection. This paper draws on ethnographic research based on a secure unit for people with intellectual disabilities in England. It suggests that staff and clients are concerned about the client mix on the unit, and that staff feel protective towards women service-users. Physical contact on the wards is highly regulated and all spaces are described as 'public', therefore women are not afforded privacy to explore their sexuality. During interviews, many of the women disclosed experiences of childhood sexual abuse and some were unsure about their sexual orientation. This paper argues that life on the locked ward positions intellectually disabled women as both sexually vulnerable and as fundamentally asexual, which may prevent women from learning the skills needed to make informed choices about sexual partners. Despite this regulation, many women found ways to enjoy intimate relationships.

Tracey Fleming and Lisa Saville Young: Analysing students' talk on childhood disability: Describing a psychosocial analytic approach within service learning research

(Main conference, paper)

In this paper, we describe and demonstrate a psychosocial analytic approach to interview data with university students participating in a service learning programme with children with disabilities and their caregivers. The aim of this methodological approach is to traverse the traditional psychological-social dualism in childhood disability literature, through capturing the ways in which students' narratives of their service learning with disabled children are both socially constructed and emotionally laden. In other words, the analytic approach conceptualises students' narratives as drawing on socially shared meanings of disability in order to serve psychic functions at the individual, interpersonal, and societal level. We present a series of analytic questions that attempt to achieve these aims by moving from a focus on the discourses students employ to construct their service learning with disabled children and their caregivers, to possible reasons for students' emotional investments in these discourses. Within this psychosocial methodology, we argue that employing the concept of mentalisation is a useful analytic tool specifically when mentalising is conceptualized as a process located in, and facilitated or shut down by, the relational and sociocultural contexts in which the students are located. We conclude by reflecting on the relevance of this psychosocial methodology to childhood disability studies. In particular, we reflect on its potential to build on the gains of the social model of disability while holding on to the emotional processes occurring at individual, interpersonal and societal levels that impact on the construction of disability within but also outside of service learning processes.

Susan Flynn: Economic recession and children with intellectual disability: Applying an affirmative non-tragedy framework to the issue of austerity

(Main conference, paper)

"A society cannot be equitable unless all children are included, and children with disabilities cannot be included unless sound data collection and analysis render them visible" (UNICEF, 2013, p.63)

This paper begins with a summation of the author's PhD research. The research investigates the impact of the economic downturn on children with intellectual disability, and their families, within the Republic of Ireland, using a Biographical Narrative Interpretative Method (BNIM). As the research is in progress, the paper will not present findings but rather offer a critical exploration of the literature on the topic through the application of a framework derived from an Affirmative Non-Tragedy Model. In doing so the paper makes the presenter's subjectivity clear in drawing a number of core themes from the literature in order to highlight some of the serious concerns and practical challenges which now face children with intellectual disabilities and their families, as a result of austerity.

First is considered the socio-economic position of children with disabilities, and their families, and their distinct predisposition to poverty. Next, funding cutbacks to the service and support infrastructure is examined. Finally, the impact of the recession on quality of life and opportunities for progression and inclusion are addressed.

Prior to literature review, the paper makes explicit its position with regard to its use of terminology and rationale for the adoption of an Affirmative Non Tragedy lens as a conceptual optic for literature review. Throughout, the paper also critically considers the relevance of an explicit human rights approach in the face of stringent cutbacks to services and supports.

<u>Lauren Foster Mustarde and Tanya Buynovskaya: Addressing the rights and needs of children with disabilities in the international development context: Perspectives from Eastern Europe, Central Asia and the former Soviet Union</u>

(Main conference, poster)

Individuals with disabilities, particularly children, remain a highly marginalised group in most countries of Eastern Europe, Central Asia and the former Soviet Union. This marginalisation occurs at multiple levels of society; at the community level due to stigma, isolation and poor access to services, at the state education level due to exclusion from educational opportunity, and at the policy level due to poorly mobilised advocacy to promote their rights and needs.

Despite such challenges, this is a unique time of progress in these regions. Catalysed by global developments in the area of human rights of persons with disabilities, local momentum and commitment to change is underway in many countries, at both Government and community levels. Many countries have now ratified the major international treaties which safeguard the rights of children with disabilities, namely the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

But what do these commitments mean in practice? How are they operationalised within the context of international development? How do international agencies work with local Governments and partners to inform attitudes, practice and policy related to disability?

This poster will address these questions, by describing our extensive experience in this area. HealthProm is a small international NGO that works to ensure that vulnerable children, even in the most remote and impoverished areas, have the best start in life. We currently operate in Afghanistan, Belarus, Moldova, Russia, Ukraine and Central Asia. We work to promote the needs and rights of children with disabilities through improving access to health and social services, promoting inclusive education, mobilising advocacy and strengthening families and communities.

Peter Fuzesi: What do user/s do?

(Main conference, paper)

Technology appears as an unstoppable juggernaut, as a force of nature inevitably disrupting existing patterns of social lives and identities. Increasingly, as devices organise daily life especially in countries of the Global North, the world is becoming populated by users.

Existing literature on the relationship between disability and technology has explored its dis/ empowering impact (Goggin and Newell, 2003, Thornton, 2007, Harris, 2010, Cumming et. al, 2014) risks and potentials (Ellis and Kent, 2011), issues of access and voice (Johnson and Moxon, 2011) and how identities and imaginaries become entangled with digital technological devices (Meekosha, 1999, Kafer, 2011). My paper attends to the figure of the user, as a site of subjectification, to connect what has been so far discussed as disparate concerns.

Hence, the paper is an invitation for trespassing the boundaries of technology and social and to ask and contest what forms of subjectivities are implied in technological devices, and naturalised in the figure of the user (Leigh Star, 1991). Drawing on insights from Science and Technology Studies, I try to open up the literal and metaphorical box of technology, to understand becoming a user as a disciplinary practice (Akrich, 1992) that often entails disabling effects. Framing someone as a user is an intervention in itself, and it works in relation to other forms of subjectivities such as citizens, clients, consumers and patients. Further, for one to become a user specifies expectations, and very often has individualising effects.

But as other disciplinary practices, technology also can be, and has been subverted and hacked. I take inspiration from the category of service user (Beresford, 2010); both to resist the individualising tendencies, inherent to the figure of the user, and to open up and preserve an ongoing discussion on the norms and limits of how technology should be used.

Mariela Gaete-Reyes, Luis Campos, Rebeca Silva, Lorenzo Berg, Max Aguirre and Antonio Sahady:
Cultural imaginaries of inclusivity in contemporary architecture in Chile

(Main conference, paper)

The issue of inclusivity has gained visibility in Chile lately, due to the recognition that cities in this country are unequal, not only in socio-economic terms, but also in their built environment. This has encouraged initiatives such as Law N°19.284 about the Social Integration of Disabled People (1994) that sought to create equal opportunities for them, through enabling their access to the built environment. This Law modified the Chilean building regulations "Ordenanza General de Urbanismo y Construcciones" (Gaete-Reyes, in press). In addition, Law N°20.422 on the Regulations to provide Equal Opportunities and Social Inclusion for Disabled People ("Normassobre Igualdad de Oportunidades e Inclusión Social de Personas con Discapacidad", 2010) includes Article 29, which mandates the Ministry of Housing and Urban Planning to develop special subsidy programmes to acquire and adapt dwellings to be permanently inhabited by disabled people.

However, the built environment of Chilean cities is still highly inaccessible. Moreover, the still scarce inclusion initiatives for disabled people do not have an equivalent for other forms of inequality related to gender, ethnicity and age. This paper focuses on the early stages of a research project that aims to examine the cultural imaginaries of inclusivity present in the discourses that have guided the architectural production in Chile in the last 50 years. The paper discusses the conceptual framework and the methodological approach undertaken in the research and also presents early findings of the project.

Annicia Gayle-Geddes: Transnational Disability and Inequality: Socioeconomic Social Policy Imperatives in Jamaica

(Main conference, paper)

The paper examines the nexus of disability and inequality in the global South through the triangulation of quantitative and qualitative data from Jamaica. It discuses socio-economic deficits evident in the marginal socio-cultural disability identity, poorer education/training, and labor market outcomes of persons with disabilities (PWDs) compared to persons without disabilities. Multiple risks and overlapping vulnerabilities such as gender, geographic location, type and severity of disability are deconstructed. Further, an evidence-based, theoretically grounded and implementable public policy Framework of Key Determinants for Political and Socioeconomic Inclusion of PWDs is recommended. The framework advances anti-discrimination legislation and a twin-track policy schema with six interconnected enablers of development. The public policy imperatives of the framework are applicable for Jamaica, the Caribbean as well as developing countries with similar characteristics - many of which are signatories to the Convention on the Rights of Persons with Disabilities.

Vibeke Glorstad: How can the practice of political citizenship be explored among people with learning disabilities?

(Main conference, paper)

This paper aims to explore the notions of and tendencies in the political citizenship among persons with learning disabilities/intellectual disabilities in Norway. The UN Convention on the Rights of Persons with Disabilities describes in article 29 the Rights for Participation in the political and public life; which relates to participation in political and public life directly or indirectly through representatives and non-governmental organizations. Generally the notion of social citizenship has been the focus in the citizenship discourses related to persons with learning disabilities – how can they reach the juridical and ethical level of support and inclusion that make sense related to general human rights? These discussion and practices are evolving. By extending the discourse to the political citizenship the focus is on political participation generally, but also on other areas that are considered as political participation; organizational work and actions (Strømsnes 2003, Schur, Shields and Schriner 2003, Waldschmidt 2013). Political citizenship can also be related to the double conception of justice (Fraser 2003) as both accessibility and recognition/ respect. Newer research in Norway see people with learning disabilities generally more included in society - especially the younger generation (Sandvin and Hutchinson 2015; Morlandstø and Sandvin 2014). This relates to inclusion in user- involved research and the media; where they are also representing themselves as actors in the cultural and political life and not only as spokespersons relating to lacks in social / educational /work opportunities. And the practices of advocacy organization as The Norwegian Association for Persons with Developmental Disabilities (NFU) are increasingly using peer advocates and notions of self advocacy among persons with learning disabilities. This paper will explore the concept of political citizenship and how it can be understood and explored in relation to people with learning disabilities.

<u>Sarah Golightley: Disabling Madness: Disrupting Mind Body Dichotomies</u>

(Mad Studies stream, paper)

This presentation will examine the problematics of theorising mental 'health' and 'distress' as a separate function from physical disability; of Mad Studies when it is detached from physical disability; of Mad Studies when it is detached from a critical disability politic. The presentation seeks to disentangle institutional Western philosophies of the mind-body divide, by drawing from personal experience as an activist and academic with multiple, overlapping, forms of physical and psychological disabilities. I will discuss how Anti-Psychiatry and Mad Studies approaches that reject neurobiological basis of mental health often do so through the reification of mental health's difference to presumed measurable and objective medicalisation of physical aspects of the body.

I will discuss how a mind-body dualism is in and of itself an oppressive construct that compartmentalises complex experience. Within Mad Studies there has been prolific writing on the limitations of psychopharmacology and coercion within the medical industry. Without minimising the importance of this, we must also examine what a rejection of medical treatment implies for those who are campaigning for improved and increased access to adequate medical care, including people with physical disabilities, and trans people.

If Mad Studies can claim that all people on psycho-pharmaceutical medication are necessarily coerced and harmed, this functions to speak over the experiences of Mad people. I argue that to enhance Mad Studies we must be open to the complexities of health experiences and listen to the multitude of ways people themselves interpret these experiences. Moreover, Mad Studies needs to be intersectional in order to challenge oppressive structures that compartmentalise our personal experiences as well as our academic and activist liberation movements.

Dan Goodley, Hannah Morgan and Katherine Runswick-Cole: 'Disability Studies: A Roulestoneian perspective'

(Main conference, panel)

In this 1 hour panel we bring together contributions from colleagues in disability studies to discuss the contribution of the work of Professor Alan Roulstone. Alan, who has retired from full time academia this year, has made major interventions into the field of disability studies in ways that have substantively shifted the paradigm for the better. This panel will include a number of friends and colleagues who will offer their perspective on a Roulestoneian approach to Disability Studies.

Dan Goodley, Katherine Runswick-Cole and Kirsty Liddiard: A Dishuman Manifesto

 (Main conference, panel)

ProjectDisHuman is a collective of activist-researchers committed to rethinking the category of the human through disability. We have been working together for a number of years but came together in 2015 to explicitly articulate our DisHuman manifesto which:

Unpacks and troubles dominant notions of what it means to be human;

Celebrates the disruptive potential of disability to trouble these dominant notions;

Acknowledges that being recognise as a regular normal human being is desirable, especially for those people who been denied access to the category of the human;

Recognises disability's intersectional relationship with other identities that have been considered less than human (associated with class, gender, sexuality, ethnicity, age); Aims to develop theory, research, art and activism that push at the boundaries of what it means to be human and disabled;

Keeps in mind the pernicious and stifling impacts of ableism, which we define as a discriminatory processes that idealize a narrow version of humanness and reject more diverse forms of humanity;

Seeks to promote transdisciplinary forms of empirical and theoretical enquiry that breaks disciplinary orthodoxies, dominances and boundaries; (http://dishuman.com/dishuman-manifesto/).

In this panel of three papers we seek to extend, explain and advocate the potential affirmative offerings of our DisHuman manifesto for the development of critical disability studies now and in the future. We will address a number of key questions including:

1.   What are the dangers and potentials of challenging the human category?

2.   How does disability extend humanness and human worth?

3.   In what ways do crip theory and humanist theories rub up against one another in productive ways?

4.   How might our manifesto be exploited to intervene in debates around the intersections of class, race, sexuality and gender?

<u>Flick Grey: Borderline mad?</u>

(Mad Studies stream, paper)

This paper explores experiences that tend to get labeled as Borderline Personality Disorder

 (BPD) within the mental health system, and their complicated relationships with madness, trauma and the broader consumer/survivor movement.

Just as madness studies is often situated as peripheral within disability studies, BPD experiences have often been situated as peripheral within madness studies, including: accounts that conflate madness with psychosis (e.g. Read et al 2004); political critiques of the mental health system that locate involuntary treatment as the sine qua non of psychiatric injustice, whereas many (but by no means all) people with a BPD diagnosis experience systemic exclusion and neglect, rather than (or in addition to) coercion – Epstein 1996 captures the paradox of how injustice is experienced differently within the consumer/survivor movement; alternative models that offer space for people with experiences that would be labeled as 'psychotic' by mainstream services – e.g. the Hearing Voices movement and some descriptions of Open Dialogue.

The liminality of BPD is reflected in the community more broadly, where common-place ascriptions of "madness" are typically associated with psychotic experiences, and community-level "mental health literacy" campaigns tend to privilege schizophrenia and depression (and anxiety and bipolar), ignoring BPD altogether (e.g. Mental Health First Aid).

The BPD diagnosis is deeply contested, with many proposing a focus instead on trauma. However, this can (re)inscribe hierarchies of trauma (Epstein and Grey 2012), in which profoundly painful experiences like neglect and misattunement can become marginalized, or leave a residue of people for whom the language of trauma does not resonate.

Drawing from crip theory, the author's own doctoral research into 'Benevolent othering' and auto-ethnographic observations, this paper explores how we might collectively formulate a 'rigorous conjunctural analysis that leaves no form of identity behind.' (McRuer 2006:viii).

<u>Nora Groce, Maria Kett, Tom Shakespeare and Ellie Cole: The Disability and Development Gap: examples from health and education</u>

(Main conference, paper)

International development efforts up to and including the Millennium Development Goals have improved the lives of millions of people over the past 15 years, through significant advances in health, education, economic development, communication and human rights However in this presentation, we argue that there has been little attention to the systematic inclusion of the world's one billion persons with disabilities in these initiatives – and because they have not been included they have lagged behind their non-disabled peers. This 'lag' has created in many countries what we term here a 'disability and development gap', where the socioeconomic status of persons with disabilities has remained stationary while the well-being of many of their fellow citizens has moved ahead.

In this presentation, drawing on examples from health and education, we argue that unless specific measures are taken to ensure the inclusion of persons with disabilities in current and future international development efforts, including the new Sustainable Development Goals (SDGs), the 15% of the world's population who live with a physical, sensory (i.e. deafness, blindness), intellectual or mental health disability are at risk of continuing to live in poverty and social isolation, remaining poorer in both relative and absolute terms as their non-disabled peers rise out of poverty. Inclusion of persons with disabilities in the SDGs offers new promise, but we will posit that unless there is serious commitment to the monitoring and evaluation of this potential inclusion, people with disabilities run the risk of facing even greater disparity and marginalisation over the coming years.

Laurine Groux-Moreau: Supporting Young Autistics in Building their Identity

(Main conference, paper)

This paper seeks to explore autistic identity-building. Indeed, autistic children and young people are often starved for role models who are autistic themselves, making it more difficult to understand their place in the world.

During childhood, parents and services are often focussed on therapies, and do not necessarily seek out autistic adults' expertise.

During adolescence, autistic young people may also not have the ability to meet with other autistics. As adolescence is a crucial time for the construction of one's identity, it can be suggested that more opportunities for autistic young people to meet with other autistic peers and adults can be extremely beneficial.

On the other hand, how can autistic adults best support autistic youth? How to suggest positive ways of being autistic in the world while letting young people form their own opinions and their own identity, without seeming to push a particular agenda?

In this paper, I will look at possible ways to approach this issue, and suggest ideas that can help autistic youth build an identity in their own terms, while being supported by other autistics. I will use my expertise as a Disability Studies researcher, disabled activist, youth club leader, and ex-special needs teacher.

Chris Grover: Disabled people, less eligibility and changes to Employment and Support Allowance

(Main conference, paper)

The first budget by a Conservative government in Britain for 18 years announced that from April 2017 the work related component of Employment and Support Allowance (the main income replacement benefit for disabled people) would be withdrawn. This move denotes a reduction of nearly a third (28.4 percent) of the level of weekly Employment and Support Allowance for those people deemed fit enough to engage in work-related activity in the hope of hastening their (re) entry into wage work. This announcement was part of a wider package of austerity measures that were supposed to deliver £13 billion per annum savings in social security spending by 2020/21. The paper will examine this development in the financial support of disabled people. It will demonstrate that the justification for the changes to Employment and Support Allowance – that it recipients are disincentivised from competing in open wage work markets – reveal the ideological nature of cuts to social security benefits since the 'age of austerity' started in 2010. The paper will argue that the cuts to Employment and Support Allowance should be understood in a tradition in British social security policy, framed by economic liberal and moral concerns with the potential of income replacement benefit to disincentivise workless people from taking wage work. In this sense, the cuts to Employment and Support Allowance can be understood as means of reasserting less eligibility – the idea that the experience of claiming income replacement benefits should be felt as being more economically uncomfortable than doing wage work. The idea, therefore, is to further impoverish disabled people in the hope that this will encourage them to do wage work, an approach that ignores the social basis of the labour market disadvantage of disabled people.

<u>Abir Hamdar: The Living Martyr: Disability in Middle Eastern Visual and Media Culture</u>

(Main conference, paper)

In contemporary Lebanon, Sayyid Jawad, a veteran Hizbollah fighter who was left severely disabled during a battle with the IDF, is popularly known by the intriguing name 'Al-Shaheed Al-Hayy [the living martyr]'. It is a nom de guerre that has been applied to a number of disabled war veterans from the Middle East over the last 40 years. This paper explores the trope of the 'living martyr' in Middle Eastern nationalist and Islamist discourse. Through an analysis of a selection of posters, promotional videos and television programmes, it uses the trope as a means to explore the representation of disability in modern Middle Eastern culture in times of heightened conflict. What are the key ways in which disability is conceived and communicated in visual and media culture of both nationalist and Islamist parties from the Middle East? Do representations of the disabled fighter exacerbate the stigma of disability or do they glorify it? To what extent does the 'living martyr' affirm or deconstruct key signifiers of national or religious sacrifice?

Heng-Hao Chang and Jingyi Wang: From the Handicapped to the Disabled: A Content Analysis of Disability Labels and Discourse in Taiwanese Newspaper

(Main conference, paper)

Disability stigma and label has been the political agenda in Disability rights movement. This research uses content analysis to explore the impact of renaming disability label from "cán jhang"（the handicapped） to "shēn xīn zhàng ài" (people with physical and mental disabilities) and the transformation of disability discourse in Taiwanese public discourse from 1953 to 2014. We examine the images of disabled people, newspaper model and typology of newspaper content in different disabled label and historical period, divided by the renaming of the law in 1997 and 2007 into three periods: 1953-1997, 1998-2007, 2008-2014. We use we use systematic sampling to collect data come from the United Newspaper data base from 1953 to 2014.

The results show that the change of disability label by law did not change the model of newspaper narrative but partly transforms the images and the content of disability newspaper reports. There are more images of care burdens and more newspaper coverage on care issues under the label "cán jhang." Comparing disability in different historical periods, there is no significant different in model of newspaper narrative, but there more and more images of helpless disabled people. In addition, there are significant more disability charity events in newspaper after 2008. Finally, we discuss the content of the charity event, where disabled people are always the subject of being helped and their voices are usually unheard.

We argue the relabeling of disability in Taiwan were mainly advocated and promoted by scholars and politicians and lack of social movement mobilization and social consensus. In addition, under the pubic-owned and private managed social policies, service oriented non-profit organizations increases significant and compete for resources. Thus, news discourses of charity model increased after 2008.

Stefan C Hardonk and Hanna Björg Sigurjónsdóttir: Raising a deaf child in a high-tech society: parents' discursive positioning and agency

(Main conference, paper)

Research about deaf children and their parents has paid attention to among other issues discourses about deafness in relation to the children's identity and their parents' decision-making processes. Early research departed mainly from a classification of hearing versus culturally deaf identities and discourses, and later on the bilingual-bicultural discourse was also included. Empirical studies have analysed the experiences and decision-making processes of parents of deaf children in terms of the different discourses and the role of educational settings and hearing aid technology. Conceptual work by authors like Ladd (2003) has pushed the boundaries of the discursive approach by opening up the concept of deafness – termed "Deafhood" by Ladd – to account for diversity and agency of deaf persons themselves as well as for the historic perspective of the Deaf community. Nevertheless, the positions of the predominantly hearing parents of deaf children who engage with different options regarding education, language, hearing aid technology, community life and other fields are not conceptualised in a way that accounts for their multiplicity. There remains an opportunity for research that considers the subject positions and identities of deaf children and their parents from a poststructuralist perspective, emphasising their multiplicity and changeability. We have adopted this approach in a multiple case-study of three Icelandic families with congenitally deaf children between 2 and 15 years old. We used a critical discursive lens to uncover the parents' subject positions and the subject positions that they assigned to their deaf children. The results indicate that although the child's best interest was a central concept in all parents' representation of their experiences and decision making, the parents occupied different subject positions which related in a new manner to the traditional discourses about deafness, and also to elements in the wider social context such as community life, family and recreation.

(Main conference, paper)

Aim: This paper presents disabled young people's accounts of participating in child protection decision-making in three English local authorities

Method: A narrative approach was used to analyse data from in-depth qualitative interviews with 16 disabled young people, aged 11-17, who took part in the author's doctoral study. All participants had experienced significant professional involvement relating to suspected abuse or neglect.

Results: Many young people understood, and some agreed with professional concern for their welfare. However young people reported carers and particularly professionals, were usually more concerned with their protection and impairment-related needs, than involving them in decision-making and enabling them to make choices that were important to them. How young people made sense of and responded to these experiences varied. Some, despite feeling frustrated, struggled to express their views, and identified others' negative perceptions of their impairment and vulnerability as affecting their confidence to speak up. While others responded by attempting to defend their right to self-determination, resulting in conflict and a lack of engagement with professionals and services. A third group of young people had greater confidence expressing their views and being taken seriously in decision-making. These young people spoke about professionals and carers taking time to engage with their overall interests and priorities, not just their vulnerability or impairment.

Conclusion: Disabled young people who have experienced or who are at risk of maltreatment represent an especially vulnerable group. In responding sensitively to their complex support needs professionals and carers need to ensure that young people's right to have their views valued and respected in decision-making is upheld alongside their right to protection and support with impairment related needs. Critical realist theoretical perspectives that promote a holistic approach to how disabled people make sense of their lives and impairments have much to contribute to improving practice in this area.

Juho Honkasilta: Cultural need for pathologizing human diversity – Families living 'with' ADHD

(Main conference, paper)

The existence and realness of attention deficit hyperactivity disorder (ADHD) has been an ongoing ontological debate during the past decades. This discourse study asserts that ADHD exists in an abstract space of text and becomes real in the concrete space of practice. It studies meanings given to and built around ADHD in the context of the compulsory schooling in Finland by conducting interviews for 13 young teens (aged 11–16 years) diagnosed with ADHD and 18 mothers of diagnosed children.

The paper corresponds with earlier arguments on the school's role as a catalyst for the growth of ADHD diagnoses and persistence of the phenomenon. The decision to start the ADHD diagnosing process was constructed as an outcome of normative cultural and social processes that foreground the clash of norm expectations and maintain the contemporary values of what it means to be a 'normal' student and parent. For mothers, ADHD label was laden with the promise of recognition. It was expected to promote the match between the child and school and translate as a mediator between parents and teachers. Youth, on the other hand, constructed adherence to psychomedical discourse as potentially impeding the process of identity building. Instead, they constructed themselves in relation to ADHD, and vice versa, in the vortex of discourses providing deeply embedded varying and contradictive cultural meanings.

The results question the uncritical use of a psychomedical interpretation frame in educational practices. Understanding ADHD phenomenon cannot be reduced to knowledge domain of medical science since, clearly, the prevalence and cultural need for deviance labelling is constituted in contemporary institutional, social and discourse practices. The structures (policies, power relations etc.), conventions (laws, rules, traditions, principles etc.), and ideologies and related discourses and practices widely integrated into the daily activities of homes and schools construct the deviant, disabled individual.

Ann-Marie Houghton and Georgia McCrone: 'More than just Jenga and X-box, evaluating a transitional programme for University students on the Autistic Spectrum'

(Main conference, paper)

Many young people on the autistic spectrum now attend university (NAS, 2015). Institutionally and nationally there has been a dramatic increase in the numbers of students disclosing a social communication / Autistic spectrum disorder (SC-ASD), with an increase of 911% in the past ten years, from 260 undergraduates in 2004/05 to 2,630 in 2014/15.

Existing research (Cooper, 2013), policy guidance 'Think Autism' (HM Government, 2014) practitioner experience and student feedback suggests that students with autism may have intensive support needs especially at times of change and transition. In response some universities are developing pre-university programmes that will enable students with ASD to live independently and to improve their opportunities for social activity (Hastwell, et al., 2013, HEFCE 2015). These programmes typically involve a number of 'transitional events' (Hastwell, et al., 2013) designed to maximise these opportunities.

This paper reports on a programme of OFFA (Office for Fair Access) funded activities designed to facilitate the transition of SC-ASD into University Life. The programme includes a three day pre-term residential with structured activity for first year students, a weekly group mentoring session opened to all students with SC-ASD and the introduction of a peer mentoring system.

Research is informed by a commitment to social model of disability and responsive to wider debates regarding an inclusive curriculum and higher education experience (Morgan and Houghton, 2013). Data includes observations, interviews and focus groups with students, student ambassadors, parents and staff involved in the development and delivery of the programme.

This paper will discuss the evaluation of the project to date, key observations made during the project and recommend possible strategies for improving access and participation for ASD students in their first year and university. We will speculate on the continuing benefits during their university career and future employment opportunities.

<u>Ella Houston: Disability and Subjective Wellbeing: Challenging notions of normalcy</u>

(Main conference, paper)

Wellbeing literature largely stems from psychological, health research and socio-economic journals. Research on individual or collective wellbeing dominantly focuses on personal/external aspects of happiness, motivation and feeling of 'value' in the world (Fox, 1997). Research in this area tends to focus on the relationship between perceived significant factors in a person's life and affect on levels of happiness, contentment and security. Subjective wellbeing is defined as an individual's levels of personal and emotion fulfilment and positive regard for their own value in the world.

In her research examining disabled people and wellbeing, Edwards (Edwards and Imrie, 2008; Edwards, 2013) draws attention to the wide range of wellbeing literature that has typically discussed wellbeing, disability and impairment from a 'non-disabled' point of view. Edwards and Imrie (2008) show scepticism of individualising trends in wellbeing, suggesting that emphasis on 'individual empowerment' and wellbeing is typically interpreted as self-reliance and self-motivation – ableist concepts that have traditionally stigmatised disabled people.

Edwards (2013) explains that much of the literature focusing on disabled people's subjective wellbeing, such as Dan Moller's (2011, in Edwards, 2013) paper on the differences between subjective and objective wellbeing reports of disabled people, tend to homogenise disabled people and infer that certain services are useful to disabled people, without having explicitly consulted disabled people's opinions.

It is my argument that narratives surrounding subjective wellbeing, disability and impairment are often constructed by non-disabled people who do not seek to prioritise disability 'voice'. Moreover, an absence of critical disability studies aims, issues and theory leads to stereotypical assumptions regarding the lives and 'happiness' of people with impairments. Therefore, the risk that subjective wellbeing literature presents disability is an anthesis to positive reports of wellbeing is oppressive and over-reliant on myths of 'normalcy'.

Sachiko Hosoya: Ethical discussions on Iran's National Prevention Program for Genetic Diseases: from the Experiences of People with Thalassemia

(Main conference, paper)

The purpose of this study is to investigate the ethical discussion on the implementation of a social policy, which 'prevents' a genetic disease called Thalassemia, from the experiences of people with Thalassemia and their self-advocacy under this national policy in Islamic Republic of Iran. Thalassemia is a recessive hereditary hemoglobin disorder, with high prevalence in the region called Thalassemia belt. The Iranian national prevention program of Thalassemia is highly praised as a successful example of implementation of genetic medicine. However, although the Iranian government carefully avoids any portrayal of the policy as 'eugenic', ethnographic research of the Thalassemia community shows some ethical dilemmas in the application of genetic medicine.

In this paper, the ethical discussions of premarital carrier screening, prenatal diagnosis and selective abortion will be explored, along with the context of the legalization of 'Therapeutic Abortion Law' (2005) in Iran. From the viewpoint of Western theories of bioethics, mandatory carrier screening could be recognized as a eugenic policy, but Shi'a Islamic jurisprudence interprets it as lawful. While western disability rights activists accuse it as excluding the existence of people with genetic diseases from society, the theory of public health policy for lower-resource countries considers it economically legitimized.

Additionally, in order to understand the discussion of 'public good' and 'personal choice' in Iran, an ethnographic approach is taken, and the choices of people with Thalassemia will be analyzed. The detailed emic data, including their reproductive behavior such as selection of the marriage partner, choices of having or not having children, practice of sterilization surgery, and self-advocacy movements will be discussed in relation to the Iranian national Thalassemia prevention program.

As a conclusion, the concept of eugenic policy and self-advocacy of people with genetic diseases will be reconsidered, with the emphasis of the potential efficacy of ethnographic studies.

Esther Ignagni and Eliza Chandler: Thinking with 'Chemical Stories'

(Main conference, workshop)

This workshop will engage dialogue around "Thinking with Chemical Stories," an exploratory research project centered on people's accounts of how they interact with 'chemicals' in their everyday lives. In this project, we treat 'chemicals' as a relatively empty category to be filled by participants' language, meanings and practices (Smith, 2005); chemicals could be anything from medication, to household products, to airborne toxins, ranging from perfumes to pesticides. This project employs a dialogical approach intended to discover the types of stories that are readily shared, the language participants use in conversation, the tensions and conflicts that may arise in sharing chemical stories and social relations are appear in and contour dialogue (Diamond, 2009).

After a brief description on this project's framework, a brief review of how 'chemical stories' have been taken up in the fields of disability studies, feminist theory, and Indigenous Studies, and an account the chemical stories we have engaged so far, this workshop will bring a focused discussion on the role of chemicals in our lives, specifically how chemicals both energize and deplete the future. Questions for workshop attendees will include:

How do you interact with chemicals in your everyday lives?

How do interactions with chemicals capacitate some and incapacitate others (Erevelles, 2011; Fritsch, 2013)?

What kind of (crip) futurity do chemicals allow for (Kafer, 2012)?

The workshop will consider how 'chemicals' form and manifest disabling environments, shaping and maintaining particular subjectivities, embodiments and lives marked by difference, debility and exclusion through both mundane and extreme interactions. In this way, we will draw on and contribute to growing disability studies literature that interrogates how disability and impairments are socially produced within the environment by and through interactions with toxins, workplace hazards, and war.

Kay Inckle: A Cripp(l)ing Blow: Disability, Sexuality (& Sport)

(Sexuality stream, paper)

This presentation intersects three strands in the sexualities stream: identities and imagery, (masculinities and femininities); pleasure, sensuality and desire; sexual and bodily esteem, and it incorporates theoretical contributions from queer, feminist and crip theory.

It draws on a qualitative research project which gathered narrative accounts from men and women who became disabled as a result of spinal cord injury. The main research project explored disability identity in the contexts of disability sports. However, sexuality was a significant emergent theme in the research as the participants attempted to understand themselves as sexual beings in the context of their acquired disabilities.

This presentation takes a critical feminist and queerly crip perspective on the constraints and possibilities for developing a positive sexual identity post-spinal cord injury. It follows the experiences of three participants, two men and one woman (all heterosexual) as they navigate the gendered norms and bodily ideals of heteronormative sexuality and disability. It explores how (hetero)normative representations of disability as failures of (normative) masculinity and femininity constrain possibilities of sexual exploration and sexual pleasure in two of the participants narratives. In contrast, the third narrative highlights the potential for disability to queer body ideals and (hetero)sexual norms in productive ways, and demonstrates the more pleasurable identities and experiences which emerge from a non-normative paradigm. These themes reinforce many of the findings of earlier studies on disability and sexuality in terms of the negative impacts of heteronormative and disablist body ideals and sexual norms, and the radical potential for sexualities and corporeal identities which emerge from outside these frameworks.

<u>Naomi Lawson Jacobs: Uncovering the Roof: Inclusive Research into Disabled Christians' Experiences of Churches in the UK</u>

(Main conference, poster)

There has been very limited research on religions and disability in the UK, and none focused on the experiences of disabled people in churches. Christian disability theology is shaped largely by non-disabled theologians with no connection to the disability movement, who have sometimes been overtly hostile towards disability activism. There are no formally organised user-led groups of disabled Christians; the few informal user-led networks which do exist are unfunded and have little influence in the churches. This study aims to begin to fill this research gap by investigating the experiences of a range of disabled Christians.

30 disabled people were interviewed about their experiences of UK churches, while 3 case study observations took place in churches with disability ministries. An inclusive methodology aimed to include any participants who were interested; a mix of focus groups, one-to-one interviews, Skype interviews, text interviews, and participant observation in churches allowed people with a range of impairments to take part. A research advisory group of disabled Christians has met regularly to guide the focus and methods of the study. Initial findings are focusing on theologically-motivated concepts of normalcy, healing theology and practice, and barriers to entry to leadership roles faced by disabled people.

In line with the aims of the dissemination plan, which the research advisory group helped to form, the majority of dissemination of this research is aimed at disabled Christians and churches. However, it is also important to disseminate the research results in academia, where the influence of religion on concepts of disability and disability social policy is rarely discussed. The poster will present the context, aims, methods and initial findings of the study. It will include an easy-read version of the full poster content.

Naomi Lawson Jacobs: Panel: Normalcy in Academia: The Exclusion and Oppression of Disabled Academics Today

(Main conference, panel)

19 years ago, Mike Oliver and Colin Barnes questioned why a growing emancipatory research agenda was not increasing the numbers of disabled scholars in disability studies (Barnes & Oliver 1997). Today the problem remains: only 4% of academic staff declare a disability (HEFCE 2015).

While many writers have discussed the issue of whether non-disabled people should do research in disability studies (e.g. Stone & Priestley 1996), there has been little discussion of the experiences of disabled researchers and the normalcy agenda we face in the academic environment, and how it prevents us from participating in disability studies. However, the issue is increasingly being discussed among disabled people in academia, who name many barriers to participation in academia, from the need for high levels of (sometimes international) employment mobility, to poor funding for support needs. The twitter tag #academicableism is very active; the PhDisabled and Conditionally Accepted blogs regularly feature stories of exclusion by disabled scholars. The government's austerity agenda and the increasing marketisation of academia are only set to increase the difficulties that disabled academics face.

Fiona Kumari Campbell has recently reimagined the debate about who should do disability studies, focusing on the importance of 'nothing about us without us' and asking what is preventing disabled scholars from engaging in disability studies (Campbell 2009). On the whole, however, this issue is not widely debated in disability studies.

This panel invites disabled scholars to discuss the structural barriers and dis/ableism they face in academia. The panel is chaired and introduced by Naomi Lawson Jacobs, a disabled PhD candidate who campaigns for better access for disabled scholars in academia.

<u>Nicola Jones: The Impact of Personal Assistance on relationships between disabled parents and their children</u>

(Main conference, poster)

Although accurate statistics are not available, it is widely agreed that there has been an increase in recent years in the numbers of disabled parents. Estimates suggest that 1.1 million UK households with dependent children have at least one disabled parent (Morris and Wates 2006). With the increase in uptake of personal budgets, more disabled people are employing personal assistants (PAs) within the home, yet little is known about the impact of PA support upon parenting. The researcher's previous (2014) study into the relationships which exist between disabled people and PAs suggests that the challenge of managing this already complex dynamic increases with parenthood.

This poster will provide an outline of an ongoing PhD research study based in East Anglia. This qualitative study will explore the significance, influence and meaning of the PA role in the intimate arena of family life by examining the interaction between disabled parents and their children. Working with local user groups of disabled people to promote recruitment, the project will have a sample of approximately 30 participants; these will be divided into three equal study population groups – disabled parents, children, and PAs. Views of participants will be gathered by means of conducting semi-structured interviews. Face-to-face meetings will be held with disabled parents, and discussions with children will be based around age-appropriate activities. Telephone interviews will be held with PAs. Findings will be analysed thematically.

Outcomes for this study include to develop a more detailed understanding of how PA support operates in the lives of families with disabled parents. It is anticipated that both positive experiences and areas of tension/difficulty may be uncovered. An accessible guide will be produced to disseminate findings and share best practice.

Alexandra Kaley, Christine Milligan and Chris Hatton: More than words: The use of video in ethnographic research with people with intellectual disabilities

(Main conference, paper)

People with intellectual disabilities (ID) comprise one of the most marginalised groups in the UK; are often subject to inappropriate or discriminatory health care provision and typically experience poorer physical and mental health than the general population. Yet people with ID are often excluded from actively participating in research that directly concerns them and there continues to be an over reliance on the views of health and social care providers (as well as family members and carers) in evaluations of the services that people with ID receive. Whilst participatory research approaches are on the rise, these are generally limited to interviews and focus groups. Yet a focus on the spoken or written word in service user research can present a challenge for those who may prefer to use alternative forms of communication. This paper examines the use of video in ethnographic research with people with ID and its potential to engender participatory approaches that actively engage participants in the research process. I reflect on experiences from my PhD research conducted with intellectual disabled people engaged in nature based (or 'green care') therapeutic interventions for health and wellbeing. I argue that the use of video in ethnographic research values non-verbal means of communication and encourages participants to use their whole bodies and material environments to show, rather than tell of their experiences. If used within carefully negotiated relationships and viewed as a set of collaborative performances (rather than distanced or objectified claims to knowledge) I conclude that ethnographic video has the potential to destabilise hierarchical power relations and gives voice to people with ID.

Mikael Karlsson: To care for your child's sexuality. Gender, disability and kinship in the light of the transformation of the Swedish welfare state

(Sexuality stream, poster)

This project is going to focus on sexuality, gender, disability and kinship. The aim of the study is to reach a deeper understanding of how male family members of people with intellectual disability construct and manage disability, sexuality and gender.

Since the 1960s, the big institutions for the disabled have been closing down. Instead the focus has been on the principle of normalization, meaning that lives of people with disability as far as possible should resemble the life of everyone else. Therefore, the role of the family has become increasingly important.

Most research about disability and sexuality has focused on how staff members working with people with disability deal with the sexuality of the service user. Only a few studies focus on the role of the family members. Furthermore, most of the studies focus on the mother of the disabled child. Very few studies have focused on the role of male relatives in relation to disability and sexuality. Since divorce rates are high in families with an intellectually disabled child, it is most often the mother who cares for them, but that is the more reason to study the male relatives who take responsibility for the child.

Previous studies show how sexual norms in Sweden are more repressive for young men with intellectual disability than for intellectually disabled young women. The men are being de-sexualized because of a fear of uncontrolled male sexuality. In addition to this, the majority of the caring staff are women. Most likely, most of the non-disabled men that disabled young people meet will somehow belong to their kin. How do male family members of people with intellectual disability view disability, gender and sexuality? What influence do they have on the young person with disability? How does the idea of the able-bodied child relate to masculinity?

Grietje Keller: Mad Studies Reading Groups in the Community

(Mad Studies stream, poster)

Foundation Perceval – a service user initiated organisation in The Netherlands- offers since 2014 Mad Studies reading groups. A group of twelve participants reads and discusses during ten meetings Mad Studies texts. The majority of the group are service users. Through the texts the participants are exposed to words and ideas that describe our experiences with other vocabularies and concepts then that of the dominant medical discourse of psychiatry. Mad Studies gives us a treasury full of words, theories and new ideas. This enables us to question and critically view the dominant views on madness. It is a laboratory for the participants to construct new identities outside the bio-medical discourse.

There is this idea floating around that mad people can not think or should not think too deeply. These groups are challenging these unspoken ideas.

There is a need for these reading groups. The groups fill up easily and the participants are very enthusiastic.:"Through this group I experienced that madness is not only a problem, it is also an interesting subject to read and discuss about."

My paper will be on one the context and pedagogy of the groups. And I will expand on one or more of the successes and challenges we face: the attempt to de-centre whiteness in our groups; how to make a Mad Studies community; what about shy people; racist and sexist talk by participants, supporting other Mad Studies groups; making money and the co-optation that may bring; privacy of the members; diversity in intellectual disability.

Berni Kelly: The experiences of disabled care leavers: a social justice perspective

(Main conference, paper)

This presentation is based on the qualitative phase of a three year study which examined the experiences of disabled care leavers in Northern Ireland. This phase of the study involved case studies of 31 care leavers which included reading their case files, interviewing care leavers up to three times over the course of a year and, where appropriate, interviewing their birth parents and/or carers and social workers.

The care leavers involved in the case studies were aged between 17 and 24 years old during the course of the study, and were defined by service providers as having a range of mental health needs and/or learning disabilities including some who had a clinical diagnosis and others who were considered to have borderline impairments. These young people had a range of leaving care experiences based on the care settings they left, the accommodation they moved to and the level of support they could access.

This paper will draw on Fraser's (2000) social justice framework with a dual focus on distributive and recognitive justice to present the findings from these case studies. The presentation will address structural and relational aspects of care leavers' experiences to explore issues of status subordination, inequality and misrecognition. The findings highlight how, within this context, disabled care leavers negotiate their post-care identities and navigate their way through difficult familial and social dynamics towards young adult life.

Based on the findings of these case studies, the relevance of social justice to the experiences of disabled care leavers will be explored including the need for a redistribution of resources coupled with efforts to promote recognition for disabled care leavers at personal and cultural levels of society.

Maria Kett, Ellie Cole and Richard Ngafuan: Examining the wellbeing of persons with disabilities in Liberia

(Main conference, paper)

Measuring development from a solely economic standpoint has significant limitations. Economic measures risk failing to capture important and valuable aspects of people's lives. Therefore, the concepts of multidimensional poverty and wellbeing are increasingly prioritised by the international development community as a way of measuring development that takes into account levels of life satisfaction and the different ways in which people experience poverty beyond solely economic measures.

This paper presents the preliminary findings from a 3-year research project undertaken with persons with disabilities in Liberia. The country ranks 175th on the Human Development Index, but attempts are being made to improve the lives of persons with disabilities in line with broader rights-based approaches, including in Poverty Reduction Strategy Papers. The government has placed great emphasis on the rights of its citizens, developing a National Human Rights Action Plan in 2013.

However, to date, the impact that this progress has had on the lives on persons with disabilities has not been measured. This research seeks to redress this to by examining the comparative wellbeing of persons with and without disabilities in five districts in Liberia. The survey assesses wellbeing across different domains including employment, health and community. Households with persons with disabilities are surveyed and matched with non-disabled households within the same community. Comparative analysis enables differences between the two groups to be explored, including specific factors that affect wellbeing. Conceptions of Ebola are explored, as its impact on the lives and wellbeing of persons with disabilities is not widely understood. This research is a timely opportunity to explore this further.

The results of this research will contribute to the limited literature on wellbeing of persons with disabilities, and provide greater understanding of the political and institutional factors that can affect the effectiveness of poverty reduction programmes in reaching persons with disabilities.

<u>Joshua King: The peg leg and the lambskin arm: how did experiences of disability vary between different sorts of people in early modern England?</u>

(Main conference, paper)

According to Elizabeth Bredburg, an absence of experiential accounts of impairment perpetuates a 'depersonalised' history of disability. By exploring personal narratives such as William Hay's essay 'Deformity' (1754), and vignettes of lived experience available in the letters, journals, newspapers and court proceedings of early modern daily life, this paper draws attention to the intensely individual nature of 'disability' and emancipates disabled characters from reductive stereotypes historically and today. A comparative study investigates how the experience and reception of physical defects such as limb loss and facial disfigurements varied between different socio-economic groups and genders in late C17 and C18 England. For example, to whom was deformity more problematic: women, whose ugly visage jeopardised success in the sexual economy, or men, whose lameness threatened supremacy of the household? What social anxieties were expressed in the different types of body technologies available, and what was it like to hobble around with a clunky, wooden peg leg compared to 'life-like', lambskin prosthetics?

Given the inevitable disablement of old age, was elderly impairment treated more favourably than lameness in youth? And how does William

Hay explain the day to day variations in people's reception of his hunchbacked form? By exploring these issues, we develop a more nuanced appreciation of the 'disabled experience' and shed light on the factors that contributed to difficult living in early modern England.

Antonios Ktenidis: Media representation(s) of people with restricted growth: Perpetuating or challenging the dominant discourse?

(Main conference, paper)

This paper explores the media representation(s)–films, documentaries, reality shows- of people with restricted growth (RG) in the 20th and 21st century. The significance of their representation results from the invisibility of the population (it is not common to come across a person with RG) and the visibility/availability of their media portraits. Drawing on critical discourse analysis, it attempts to answer the following questions:

1.   Are people with RG depicted as human beings or as something else (e.g. freaks, oddities) and what are the repercussions of these media depictions on people with RG?

2.   Are there any alternative representations of people with RG, which could be perceived as resisting practices to the dominant discourse?

In order for the above questions to be addressed, this paper starts by looking into the cultural representations of people with RG in different centuries (e.g. ancient Greece and Rome, Medieval era), with a strong focus on the 19th century, when freak shows emerged and the commodification of people with RG became popular. I argue that the majority of the media representation of people with RG either reproduces prior representations of them (childish and naïve or mean and evil characters, spectacles to be laughed at) or constitutes a contemporary, "civilized" format of the past freak shows, which intends to satisfy the curiosity of the spectators and reinforce their human identity by the process of "othering". Nevertheless, there is a minority of media depictions which struggles to resist to and deconstruct the stereotypical representations of people with RG by claiming their human identity and the normative aspects of human life.

Yvonne Wechuli: Dis/Ableism and Heterophobia

(Main conference, paper)

This contribution examines the question of acceptance of an open society as promoted by struggles for inclusion. In Germany, it was shown that a big proportion of the population holds fears against diversity (Heitmeyer 2011). Now, heterophobia as the fear of persons who are defined as "the other", is expressed more openly against some groups in society as compared to others. In the given historical-cultural context, strong moral restrictions can be assumed for attitudes which devalue persons with disabilities. Still, utilitaristic attitudes are shared by a considerable part of the population, dividing people in those adding value and those causing costs (Mansel & Endrikat 2007, 21).

The above mentioned findings are interpreted against the background of an ableist society (Goodley 2014). In this understanding the expressed (and unexpressed) fears are not to be understood as an individual or political attitude but as part of an overall, institutionalized power structure in society. Factors that are stabilizing a dichotomist organisation of this kind are thus the focus of attention.

Recent engagement with emotions (such as "fear") in the cultural and social sciences accepts the following premises: Emotions are a socio-cultural product not only in their expression but also regarding the content. Norms underlying historical change determine how which emotions are expressed but also what one "should" feel. In this understanding, emotion and cognition cannot be divided (Hitzer 2011). The proposed contribution seeks to bring these strains together into a critique of current (German) society to make potential risks of exclusion for persons with disabilities visible.

Birgit Kirkebæk and John Bertelsen: Different accounts different truths

(Main conference, paper)

According to the Norwegian Professor Barbro Sætersdal the public diagnosis is more done in moral terms than in Medical. She builds her statement on an technologic collection of accounts, where the eldest informant was born in 1896, the youngest in 1980 (Sætersdal, 1998, p. 163-174). her point is that public diagnosis in spite of the wording is more inclusive than the medical.

We have in our book Unwanted in Denmark - shipped to America in the same way as Sætersdal found examples of folk accounts about - and constructions of - so called different people, but we have not to the same degree as her found these constructions inclusive - and certainly not from the leading persons in the poor commissions and in the parish councils in the individual parishes. (Bertelsen and Kirkebæk 2014). In our material, which is a reading of journals and prisoner´s letters from a Forced Labour Institute in Denmark in the period of 1867-1930, it seems that both the Institute Inspector and the representatives from the parish councils used the public form of diagnosis.

From our research it appears as if, about the same time there are two different diagnostic systems in use in Denmark: a public and local and a Medical and governmental, which appears in relation to the Institutions for Mental Retarded. There is also two different constructions practiced. One is the moral failure and laziness of the different person; the second is that the person has an ailment that manifests in poor morale. The behavioural descriptions of the unwanted are identical for both groups, but the cause of desire cravings, a lacking ability to persevere in a employment relationship, drunkenness, begging and deviant social behaviour is constructed differently.

Gertraud Kremsner: Power, violence and the "Philosophy of Praxis": experiences with institutionalisation in the biographies of people with learning difficulties

(Main conference, paper)

In this paper I want to present selected results of my PhD-project which focusses on experiences of institutional structures in the biographies of 6 "people with learning difficulties". The term used to describe this group already refers to one of the main results considering learning difficulties as a consequence from institutionalisation.

The inclusive research team, consisting of the same 6 people who had been interviewed and myself, soon identified power and violence as key factors in the biographies collected. Instead of mere description of what has happened during a life in institutions, we decided to rather focus on the reasons why it had come to institutionalisation: a question which scrutinises the society we live in.

Antonio Gramsci's Philosophy of Praxis turned out to be an appropriate theoretical framework, as it not only helps us to understand institutionalisation as a hegemonically produced social necessity but also offers new approaches to the process of research production.

(Main conference, paper)

Based on post-structuralist feminist and critical disability studies approaches our presentation focuses on the life narratives of mothers who after positive prenatal diagnoses gave birth to fetuses being stigmatized as having Down-syndrome. Today, reproduction is almost entirely embedded in the discourse of biomedicine. The practice of prenatal screenings and pertinent legal regulations are aimed at doing away with the so-called genetic abnormalities. Based on the standard of normality the fetus stigmatized as disabled gets to be deemed deviant as an element of the functioning and maintenance of ableism. At the same time, all of this is done with the intention of minimizing the social costs brought on by disability, cutting out undesirable conditions and normalizing bodies. Due to the normative and exclusive nature of scientific knowledge huge pressure is put on expecting women after a positive diagnosis.

While the responsibility rests with them, women's autonomous decision-making is largely limited by societal pressure. In our research we are conducting and analyzing narrative interviews with women who gave birth to their children regardless of diagnosis. The Deleuzian framework of the rhizome informs our analytical approach we, therefore, consider the self as a rhizomatic story in which along the lines of flight the becoming-subject is continuously constructed.

While tracing the interactions between personal life (micro) narratives and cultural (macro) narratives, our primary goal is to reveal and understand those cultural and social mechanisms and power dynamics that influence the mothers' decisions to either keep or terminate fetuses diagnosed as disabled. We would also like to find out how these women construct themselves in the context of available cultural, social, institutional discursive frames.

Jonathan M Levitt: Introducing the empowered model of disability

(Main conference, paper)

The empowered model focuses on the effects of the actions of disabled people on their own disabilities. These actions include self-help, using support groups and deploying assistive technology. Although models focus on the effects on disability from society (social model), the disabling condition (medical model), the `social identities' of disabled people (Swain and French's description of the affirmative model, 2000) and the 'personal traits' of disabled people (Samaha's description of the social model, 2007), no current model focuses on the effects on disability from the actions of disabled people. I seek to fill this gap, by introducing the empowered model.

This model is timely, because several developments, over the last two decades, have substantially increased the scope for disabled people to reduce the constraints of their own disabilities. Firstly, the Internet provides many more opportunities for disabled people to self-help (e.g., through understanding their disabilities).

 Secondly, the rapid growth in the number of disability support groups, and the development of more effective assistive technology have increased the opportunities for disabled people to decrease the impact of their disabilities. Finally, reductions in societal barriers have increased opportunities for disabled people to take actions to limit the impact of their disabilities.

In my presentation, I will: (1) describe the limited role of disabled people in current models of disability, (2) outline journal research findings on the effects of self-help, support groups and assistive technology on disability, and (3) relate the empowered model to other models. Smart (2009) wrote 'Diversity in models has the potential to be both strengthening and enriching.' I suggest that models can complement each other and that new models can facilitate the understanding of disability. My assertion that actions of disabled people can reduce the impact of their disabilities is in keeping with my experiences of visual impairment.

<u>Kirsty Liddiard:</u> "I'm a lie-back-and-think-of-England type of man": Imagining the Posthuman
<u>Dis/sexual Subject</u>

(Sexuality stream, Poster)

In this talk, I critically imagine the possibilities of a posthuman disabled sexual subject (Braidotti 2013). In rejecting the routine linear interconnectedness of sexuality and humanness in Western cultures, I suggest that disabled, or rather Crip sexualities – which can be non-normative, inter/dependent, radically relational, queered, unpredictable, technologised and cyborg – are already resolutely posthuman.

Yet, I purposefully complicate this transformative imagining by positioning it within the lived realities of disabled people's "everyday" experiences of sexual and intimate life. Telling their own intimate sexual stories, disabled people in my research forcefully asserted a (naturalised) sexual subjectivity and made claims only for normative sexual citizenship, locating their rights, access, agency and embodied experiences of sexuality as central to their very humanness (Liddiard 2012, 2013, 2014). Desiring (and labouring towards) a normalised, autonomous, independent, and bounded sexual reality was a viable (but precarious) means through which to humanise the self and served, for some, to gain entry into mainstream sexual cultures. Such labours were purposeful, then, towards feeling and enacting "human" in the context of lives and selves consistently devalued and dehumanised.

Utilising Goodley and Runswick-Cole's (forthcoming: pagination unknown) recent articulation of the dis/human position, through which it becomes possible to 'recognise the norm, the pragmatic and political value of claiming the norm' while always seeking to disrupt and contest it, I conclude by calling for what I call the Dis/ sexual. To do so, I locate the very dis/human moments in disabled people's sexual stories, sketching out the dis/sexual as a transformative space through which disabled/Crip subjects can claim their humanness through conventional modes of sexuality and gender, yet simultaneously defy, crip and exceed such boundaries.

Heidi Lourens and Michelle Nell: The use of an existing poem to facilitate painful storytelling: a collaborative autoethnography

(Main conference, paper)

Background

Critiques hold that disability studies' analyses have too often lacked insight into the embodied and psychological ramifications of disability experience (Watermeyer, 2012). After all, it is our subjective bodily experiences that connect us to the world and make it meaningful and real. And, when we are able to communicate our experience of disability authentically to others, we become more real and internally whole (Watermeyer, 2009).

In this paper, we explore and make sense of some of our embodied and psychological disability experiences. We also reflect upon the ways in which these experiences are shaped by the confluence of society and/or our disabled bodies.

Method

Looking through a collaborative autoethnographic lens, we unravel the complexities of living with a sensory impairment within a largely uninhabitable world. Simultaneously, but not unrelated, we demonstrate the effective ways in which existing poetry can facilitate the telling of delicate, potentially sensitive and hitherto unheard lifestories.

We use a published poem to help us think and write about our personal and sometimes painful stories. We selected "I know why the caged bird sings" by Maya Angelou, since it resonates so closely with the ways in which we experience life with a disability. Using verses from the poem as prompts, we reflect honestly and unapologetically upon our vulnerabilities, frustrations, fears and alienating experiences. The poem moved us to underscore our stories with diary and Facebook entries and examples from our lives.

Our stories

We focus on three themes from our lives. Firstly, we tell of the experience of limited options; exacerbated by living in a poorly resourced country. Secondly, we show how limited options/ lack of freedom detracts from our power and threaten to silence our voices. Lastly, we discuss the psychological effects of socially constructed limitations and, simultaneously, make sense of our resilience.

Heidi Lourens and Leslie Swartz: The perceived influence of help on relationships: a phenomenological account of visually impaired students from one South African University

(Main conference, paper)

Introduction

Some authors stated that friendship lies at the heart of the student experience. Friendships between disabled and nondisabled students strengthen the self-concept of disabled students, influence their persistence in higher education and, on a broader level, challenge their exclusion. In the studies where visually impaired students reported positive and meaningful relationships with their nondisabled peers, they often referred to the latter as an invaluable source of emotional and practical support. This support included finding books in the library or taking notes during class-time.

This paper will shed light on the helping experiences and perceptions of 15 visually impaired students at one South African university. It will show that they believe that help always have an influence on relationships, albeit it positive or negative.

Method

Data was collected through two focus group discussions and analysed according to the interpretative phenomenological approach.

Findings

The students had two different opinions on the way in which help influenced their relationships with sighted peers. Some believed that accepting help, even in instances where they did not need it, served as a gateway for sighted peers to get to know them and that nondisabled persons also obtain psychological gain from helping them. Others believed help establish a power-imbalance without any room for reciprocity. They furthermore believed that sighted persons will feel "trapped" if they are obliged to help their fellow blind students.

Even those students who found help beneficial for the formation of relationships concurred that it was only beneficial if they were not helplessly dependent on a sighted person's help for everything.

Conclusion

Help influenced relationships with sighted persons. In managing their relationships, they sometimes had to be untrue to their needs, which meant that they did not necessarily accept help when they needed it or refused it when they did not need it.

Jack Lukkerz: An empty arena – on attitudes to and experiences of sexuality education among special school and habilitation service staff in Sweden

(Sexuality stream, paper)

Young people with intellectual disabilities (ID) grow up in environments strongly influenced by parents' and staff's values on gender, sexuality and disability. This may create barriers in promoting the youth's knowledge about their bodies and possibilities to sexual expression and sexual health. In this study, Swedish special needs school teachers and habilitation staff participated in nine focus group interviews, and shared their views and experiences of working with sexuality education. The data were analysed using the theory of Social Representations in order to capture the staff´s everyday knowledge on sexuality and sexuality education. The data points to attitudes expressed both explicitly and implicitly, found on an individual as well as a structural level. E.g. sexuality among people with ID is largely seen as problematic and risky while pleasurable aspects are made invisible. Young people with ID are expected to take responsibility for possible risks in their surroundings while their sexuality is seen as different from others'.

Stereotypes about gender and sexual expression are significant. Non-heterosexual persons with ID are present, although seen as a challenge to the daily work. Parents of the youth are seen as obstacles in the implementation of sexuality education. The professionals also express a lack of education and practice regarding sexuality education. Furthermore, they emphasize the need for leader support in order to establish professional self-esteem, as well as to allow for creativity and independence in the implementation of sexuality education. A norm critical (e.g. awareness of own values regarding gender, sexuality and disability, as well as a critical approach to current perceptions among colleagues or in society in general), more equivalent sexuality education that includes both risk reduction and positive and enjoyable aspects of sexuality, and a clear framework of the subject of sexuality education are recommended.

Eliah Lüthi: <u>Introducing the Psychiatric Complex: Towards an Intersectional Understanding of Psychiatry</u>

(Mad Studies stream, poster)

In this presentation I introduce the concept of the Psychiatric Complex, as a visual model of the psychiatric area of influence in interdependency with societal power relations. This concept is constructed on the following two discourses: Firstly, recent studies in Mad Studies have highlighted ways in which psychiatric influence and sanism intersect with societal power relations such as racism, gender-based discrimination and classism. The aim to incorporate intersectionality in a conceptual understanding of psychiatry is the starting point of the Psychiatric Complex. The second discourse essential for my conceptualisation of the Psychiatric Complex arises from the field of research and activism which deals with the shifting influences of psychiatry due to reforms and social psychiatry.

In the model of the Psychiatric Complex, I work with the imagery, or metaphor of an islandscape, inspired by Foucault's Archipel Carceral. In addition to the previously mentioned discourses, the concept is thus shaped by the idea of Governmentality. The Psychiatric Complex understands psychiatry interdependently with intersectional power relations as a network of different actors, including media representations, diagnostic processes and manuals, social services, the pharmaceutical industry, academia, family, the subject and much more. These actors (or islands) are connected through shared (psychiatric) norms, which are symbolised by the sea floor, which is mostly invisible from above. Intersectional power relations are symbolised by the water, which connects and shapes the islands. It thus refers to the ways psychiatric influences and actors (for example diagnostic manuals and psychiatric institutions, or media re_presentations) are shaped by intersectional power relations. In my presentation I will give some short examples, how the interdependency of intersectional power relations establishes itself in different fields of psychiatry.

This model aims to expose the often inscrutable and complex workings of psychiatric influence and violence. In addition, it might be used to find ways to challenge and intervene in psychiatric structures from the many different points of entry to this network.

Bente Lilljan Lind Kassah and Frøydis Helen Andersen: Cooperation Strategies of Parents of Youth with Learning Disabilities in Norway

(Main conference, paper)

Even though the cooperation among members of care management groups (parents/social care providers) for people with disabilities is encouraged in Norway, there is limited research on the strategies that parents adopt when co-operating with service providers. Cooperation between parents and service providers are necessary, but can be conflict-laden as the two groups often have different backgrounds, experience, and knowledge (one formal and the other informal) about how to meet the felt needs of youth with learning disabilities. We generated data for the study conducting in-depth qualitative interviews with eleven parents of youth with learning disabilities. The use of thematic analysis was the basis for processing and discussing the data. The data revealed that the informants use trust promotion, praise-giving, bridging and counter-power as strategies. Theoretical views on power, trust and social capital among others, are instrumental in discussing the different strategies the parents adopt to ensure cooperation with service providers.

Mick McKeown, Will Aindow, Amy Scholes and Fiona Edgar: Stories of recalcitrance, resistance and legitimation

(Mad Studies stream, paper)

Faced with psychiatry as the only show in town, any person who resists mental health services, especially more coercive forms and associated diagnostic labelling and medication, is compelled to take on the identity of recalcitrant. Numerous stories gleaned from a variety of research studies demonstrate that recalcitrance is both a pejorative appellation in the hands of staff, or can be positively claimed by patients themselves. We present such material elicited in studies of our own (McKeown et al. forthcoming). For some individuals subject to psychiatric coercion resistance erupts in violence and quite literally fighting against institutional regimes and the staff who service them. Reflections upon relational struggles and tensions framed by notions of recalcitrance can help us to better understand mistrust within the psychiatric system: staff do not trust the sincerity of patients' cooperation when it occurs, and patients mistrust staff claims to care about their welfare.

The term recalcitrance has also been deployed in the context of movement activism and opposition to the vicissitudes of neo-liberalism (Clarke 2007, Law & Mooney 2006). As such, relevant critical thinking, actions and reactions, speak of profound issues of legitimacy. In this paper we attempt to theorise recalcitrance in terms of resisting the psychiatric episteme and, in these terms, as a legitimate and rational response to compulsion and coercion. Democratised alternative forms of support may offer one means of negotiating a way out of these crises of care and legitimacy. Similarly, Mad Studies and Mad Activism can be represented as recalcitrant enterprises, and Mad Activists located as a particular band of recalcitrants.

<u>Emma Louise Mckinney: Love, hate, need: life with full time carers</u>

(Main conference, paper)

In order to live a full life some disabled people require the assistance of full time carers. This paper explores the complexities of dealing with and managing carers. It shares the experiences of a South African couple, Vic who has C4 quadriplegia, his wife Emma and their two children. While his carers are an extension of Vic's arms and legs, giving him the independence he needs to navigate through daily life, there are many complexities that are not often thought about but can have a huge impact on day to day living as a family. These include managing relationships, egos and emotions, to having someone blow your nose, button your shirt, and get you to the labour ward to watch your children being born. The presentation examines the ripple effect on family privacy and couple dynamics. These include having to manage spousal rows, disciplining children, breastfeeding privacy, other peoples treatment and over-compensations, hero-worshiping, picking up and comforting your baby when he falls, to dealing with theft and body odour.

Peter McTigue: "I refuse to see myself as a disabled person" - The interaction between people living with HIV/AIDS and disability identity

(Main conference, paper)

The nature of discrimination against people living with HIV/AIDS ("PLHA") is rooted in deeper stigmatisation than discrimination against other groups. One reason for this is the marginalised nature of the vast majority of PLHA, e.g. their status as injecting drug users, men who have had sex with men or members of ethnic minorities. Another is the characteristics of the virus itself i.e. the fact that it is currently a potentially fatal infectious disease with no cure. In light of this heightened level of stigma, for more than a quarter of a century the legal system of the

United Kingdom attempted to formulate a coherent response to discrimination against PLHA.

Recently UK law has been amended to ensure that PLHA are now classified as "disabled" from the point of diagnosis for the purposes of discrimination legislation. Using qualitative data obtained through 21 in-depth interviews with a number of PLHA living within the UK, this paper investigates whether the decision to classify PLHA as disabled is an adequate response to the unique and multi-faceted discrimination faced by PLHA. The paper examines the reasons for PLHA's identification (or non-identification) as individuals with disabilities. It examines resistance from PLHA to being defined as disabled and also suggests possible approaches to improve legal protection from discrimination against not only PLHA but all individuals with disabilities.

Kirsten Maclean, Anne O'Donnell, Lili Fullerton, Shirley Anne Collie, Sue Phillips, Lin Cochrane, Esther Fraser, Alison Robertson, Elspeth Morrison and Siobhan Forsyth: Finding our way back out - taking Mad Studies back out into the community

(Mad Studies stream, poster)

"Find your way into the university…find your way around…make alliances…bring in Mad students and teachers too… then you have to find your way back out into the community again" David Reville (2014)

Community and movement building are important impacts of Mad Studies. Within the first term of the "Mad People's History and Identity' course at Queen Margaret University (QMU), a regular community get together was set up. It was from these meetings, facilitated by CAPS Independent Advocacy, that we, a group of people who have been lecturers and students on the course at QMU, decided to take this work forward. We developed an inclusive, democratic methodology to create a curriculum to be delivered in the community.

We have recently completed the very first 'Mad Matters' (borrowed from the book of the same title) 5 week course at a community mental health centre in Edinburgh.

In this presentation we will discuss our methodology, how we delivered the curriculum and what our plans are to develop the course, taking it to more people and places. We'll explore why this transformative education is important, how it intersects with university based Mad Studies, what impacts it can have on our grassroots communities, how we can use it to build solidarity and alliances in times of welfare cuts and austerity.

Bryan Matthews: Mobility Benefits and the Benefits of Mobility: what can welfare economics tell us about the economics of welfare?

(Main conference, paper)

Mobility benefits, in the form of welfare payments or subsidies to enable and promote personal mobility amongst disabled people, are coming under severe pressure in Britain as a consequence of recent welfare reforms. Reports indicate that 14,000 people in Britain have lost the support they received via Disability Living Allowance towards their Motability vehicle, following their re-assessment for Personal Independence Payments. The link between disability and mobility has been formally acknowledged within the welfare system for decades, in the form of Mobility Allowance; and this enabled the Motability scheme to develop from its inception in 1977. The link is also acknowledged within the narrative surrounding concessionary public transport fares. In the face of current policy, however, it is timely to re-examine the understanding of mobility benefits and the benefits of mobility.

Whilst arguments tied to economic cost are used to help drive the welfare reform agenda, arguments tied to the economic benefits arising from personal mobility appear somewhat neglected in the welfare reform debate. Understanding of the economic benefits linked to personal mobility, in terms of the ability to access employment and other opportunities, building social capital and promoting health and wellbeing, have received growing attention in academia and there have been some attempts to quantify them. It is widely recognised, however, that personal mobility for disabled people can be problematic. Statistics show disabled people's levels of mobility to be suppressed, limiting their opportunity to derive the benefits of mobility, and data demonstrates lower levels of employment, social inclusion, and health and wellbeing amongst disabled people.

We seek, in this paper, to assess how well current research enables a holistic economic assessment of costs and benefits to be made, what the available evidence implies for policy and what remains to be done – in terms of research and practice.

(Main conference, paper)

One of the key ways in which visual impairment impacts on people is the way it affects them getting about as a pedestrian. Problems include a lack of confidence in going out alone or to unfamiliar places, obstacles in the environment that make navigation more difficult, and fears about busy traffic. Consequently, for a lot of visually impaired people, fear of getting around means they do not go out as much and/or that they spend more on taxis as a means of overcoming the need for mobility on foot. This leads to suppressed levels of social inter-action and physical activity (with consequent knock-on negative impacts on health and wellbeing) and reduced levels of disposable income.

Much effort has gone into developing technological solutions to enhance mobility for visually impaired people over the past two decades and this has presented exciting opportunities for enhanced mobility. There are, however, reasons to be cautious; where technological solutions rely on users equipping themselves with devices that can be expensive, complex to use or even unwanted by the user, there are natural concerns regarding levels of uptake.

This paper starts with a comprehensive review of these developments, including specialist GPS devices, 'smart' white canes and 'smart' glasses. This is then supplemented with outputs from a series of interviews with experts to explore visually impaired people's mobility, the challenges of orientation and navigation and the inter-action with vehicular traffic such as is encountered at road crossings and in Shared Space streetscapes. We then seek to assess the upcoming opportunities and threats posed by technological interventions to improve visually impaired people's mobility and, in particular, the scope for a greater degree of engagement of users in the research and innovation process.

Victor Mckinney and Emma Louise Mckinney: From self-imposed exile to ejaculation: the personal relationship and sexual journey of a C4 quadriplegic

(Sexuality stream, paper)

Vic McKinney is a C4 quadriplegic paralysed from the shoulders down as a result of a road accident in 1987. This accident occurred when he was a 19-year-old and a fine art student at the University of Cape Town, South Africa. Unfortunately, Vic's father was also killed in the same accident and he and his mother battled to come to terms with life after he was discharged from hospital and sent home. In that sense, Vic felt like a burden to his mother. Furthermore, while attracted to other woman, Vic felt that he could not be in a relationship as you would be a burden to any partner. They could not imagine he would ever be in a relationship or even have a future and he did not envisage living past the age of 30. However, after remaining single for the first six years after his accident, he suddenly found himself in a series of relationships that changed his way of thinking and confidence about himself. Over the years his ability to feel sensation returned. There was also an increase in the ability of his body to perform sexually, reaching a point where he discovered he could ejaculate naturally 15 years after his accident. Vic discusses this journey in his presentation and reflects on how his changing relationship with his own body and his partners influenced his confidence, sense of well-being and even his dreams towards living and being in relationships. Today, Vic has been married for 6 years to Emma and they have 2 sons.

Grainne Meehan: Towards exploring the sexuality-related experiences of Deaf and Hard-of-Hearing Women in Ireland

(Sexuality stream, paper)

This paper introduces the topic of my PhD research which explores the sexual health and sexuality-related knowledge, experiences and needs of Deaf and hard-of-hearing (D/HH) women in Ireland. D/HH women have been described as, "a silent minority whose health needs have been overlooked" (Steinberg et al., 2002: 730). It is argued that achieving good sexual health is contingent on a number of factors, in particular, access to information (Curtin et al., 2011).

Worryingly, it is reported that sexual health related knowledge amongst Deaf people remains poor (Job, 2004). Furthermore, research indicates that Deaf women experience inequalities and gaps in accessing healthcare services and information (Ubido et al., 2002). International research, albeit limited, suggests the need for this topic to be examined in the Irish context, where there is a distinct dearth of research in relation to D/HH people and sexuality. The topic is also influenced by my own work and personal experiences as a Deaf woman.

This research is the first in Ireland to seek the views of D/HH women solely, on their sexual health and sexuality-related experiences and support needs. Applying a feminist disability lens, this paper reviews the current Irish knowledge base of the health related experiences of D/HH women. Given minimal previous studies with Deaf women and sexuality it draws on research exploring D/HH women's general health, and in particular, maternity and reproductive related experiences in Ireland. Through unpacking the health experiences of Deaf women in Ireland, it works to reveal and highlight potential impacts for Deaf women's sexuality-related knowledge and support needs. In presenting these ideas this presentation aims to conclude by expanding on this conversation to spark reflection and discussion on the PhD research topic.

(Mad Studies stream, paper)

This paper examines depression and other mood disorders as responses to living a precarious existence. I focus on the various ways precarity foments psychological states of vulnerability by presenting ethnographic data from my work with Mexican survivors of gendered violence. I argue that the various forms of psychological distress that these women suffered and seek to cured from were often intensified by the process of becoming subjects worthy of U.S. legalization or subjects worthy of being thought of as belonging in the U.S. but also sustained and made constant by "doing the work" of economic survival. As a result, the work of economic survival often compels mujeres to subscribe to neoliberal ideas of citizenship, while remaining uncritical of the many contradictions that they face when doing so.

This presentation is also an auto-historia (a term by Gloria Anzaldua that urges the writer to weave in her own lived experience with that of other Chicanas) to understand emotional vulnerability and distress in the context of existing and surviving in a world that places women of color to experience different forms of dispossession. The collective narrative that I share also captures how the ideological construct of the American dream and others myths surrounding the idea of an U.S. nation affected the psychological conditions that these U.S. women of Mexican descent conceptualized as depression and anxiety. The crossing of affective and material fronteras leads these women to eventually learn the dimensions of this dream: the temporary, character-building struggle with different forms of dispossession described by earlier immigrants as part of their journey towards happiness and success becomes a permanent feature in the journey of non-European White immigrants. The latter eventually realizing that the Texas-Mexico border wall is not the only barrier obstructing them from their hopes and dreams.

Reetta Mietola: What's rocking Ella? (Re) conceptualising action of a person with profound learning disability in the course of ethnographic research process

(Main conference, paper)

The paper discusses interpretation of action when considering a person with profound learning disability. It asks how action can be grasped theoretically and methodically: how different theoretical approaches work in the process of conceptualising and theorising action of a person with profound learning disability. The paper reports analysis of data produced in ethnographic research project 'People with PMLD and good life'. Common theoretical approaches to action appear somewhat problematic when considering action of a person with profound learning disability. At the same time these approaches are self-evidently present, offering conceptualisations already in the process of making observations and writing fieldnotes. One such dominant theoretical concept, discussed in the paper, is agency. Alongside the critical traditions of agency theory the paper asks, who gets to be positioned as an agent, and what kind of theoretisations of agency are workable when interpreting action of such 'unlikely agents' as people with profound learning disabilities. While the paper aims to discuss different theoretical approaches, focus of the paper is on how to apply these in empirical research, in the process of building interpretation of action of a person with profound learning disability. This is done by representing ethnographic fieldwork and how researcher's perspective and understanding of the research participant was formed and changed in this process. The data used in the paper focuses on one research participant and one specific feature in her action, namely rocking. This 'symptomatic' action is focused on in order to demonstrate how certain understandings of action and agency close and open up possibilities for detecting specific qualities of action.

Sonja Miettinen: Autonomy in the lives of persons with profound learning and multiple disabilities

(Main conference, paper)

Recent changes in disability services have brought about significant improvements in disabled people's opportunities for self-determination in many countries. However, the extent to which this progress has touched persons with profound learning and multiple disabilities (PLMD) is unclear. Needing extensive support in their daily lives, and using only non-verbal forms of communication, they are particularly susceptible to the stereotypical idea of cognitive impairment completely undermining individual's capacity for decision-making.

This presentation discusses the opportunities of persons with PLMD to exercise autonomy in their social contexts on the basis of ethnographic material collected in an ongoing Finland-based research project "PLMD and a good life". The material of the study is collected by participant observation of the lives of six persons with PLMD in the contexts of their everyday life and interviews of their caring staff and family members. Theoretically, the research project draws on Martha Nussbaum's capability approach.

This presentation focuses on the question of autonomy that is central to this approach, discussing preliminary findings about how this capability is currently fulfilled in the lives of persons with PLMD in Finland, and how it could be interpreted in this context. Fieldwork material is used to shed light on the individual ways in which the participants of the study expressed their needs and wishes and how their self-determination was supported or restricted by their environment, care relations in particular. This discussion addresses also the question about the relationship between autonomy and care. Instead of viewing them simply as opposites, a more complex understanding of the ways in which care can both undermine and promote autonomy may be needed to secure fundamental human capabilities for persons with PLMD.

Damian Milton: Educational discourse and the autistic student: a study using Q-sort methodology

(Main conference, paper)

With some notable exceptions (e.g. Jones et al., 2012), current guidance regarding best practice for the education of children on the autism spectrum often reflects a medical / behavioural model approach that seeks to remediate perceived deficits (Cumine et al., 1998; Hanbury, 2005; Hewitt, 2005; Worth, 2005; Hagland and Webb, 2009). Such advice can be contrasted with that given by autistic writers (Sainsbury, 2000; Lawson, 2010) often situating itself within a social model of disability. This presentation would report on a study that utilised Q-sort methodology (n = 60), followed by qualitative interviews (n = 6) to investigate the ideology and priorities of differing stakeholders, including autistic adults, parents of autistic children, practitioners and academics working in the field, and those occupying multiple positions, regarding the education of autistic pupils of secondary-school age. Eight factors were extracted through the PoetQ application for analysis. Two of these factors were dominant within the data-set. One represented a critical radical pedagogy frequently favoured by autistic adults, the other an approach akin to a Positive Behavioural Support (PBS) model often preferred by non-autistic parents. Practitioners and academics were found to hold a less-defined eclectic approach between these two main factors.

The presentation concludes with a reflection regarding this 'three-way dispositional problem' and offers a number of recommendations for future research and practice.

Damian Milton: How is a sense of wellbeing and belonging constructed in the accounts of autistic adults?

(Main conference, poster)

This small-scale exploratory study sought to examine how a sense of wellbeing and social belonging are constructed in the narratives of adults on the autism spectrum, investigating potential contributory factors to these lived experiences, in order to inform further research regarding this topic and service provision for adults on the autism spectrum. A thematic analysis was employed in order to investigate issues relevant to adults on the spectrum expressed through an analysis of articles within twenty-one editions of Asperger United magazine, with particular attention given to references made to factors that have influenced, either positively or negatively, an individual's sense of wellbeing or social belonging, as well as any links made in narratives between these two themes. Four main themes were identified from the data: meeting personal needs; living with the consequences of an 'othered' identity; community connection and recognition; and personal relationships. The themes identified highlight the many barriers and challenges faced by people on the autism spectrum in achieving well-being and a sense of belonging and supports previous studies, which highlight the need for support networks, effective professional support and autistic 'friendly' environments.

Yasushi Miyazaki: What does it mean being developmentally disabled in the news discourse on economically developed world?: Quantitative textual analysis in Japanese news

(Main conference, paper)

This paper uses Japanese news discourse and its correlation with social policy to examine semantic components for "making sense" of developmental disabilities/disorders (in Japanese, Hattatsu Shogai). In recent decades, several changes in Japan's social welfare and special education policies have increased public attention to developmental disabilities, and news coverage similarly increased in the first decade of the 21st century. Although the news coverage has since stopped increasing, the public attention continues. Several scholars, reporting on the social construction of developmental disabilities, argue that an industrial category shift requires more "cognitive labours". Such discussion, however, lacks a linguistic perspective on the construction of the disabilities. With respect to Foucauldian attention to the linguistic discourse on mental conditions and Bakhtin's attention to the relation between texts and the social world, this paper aims to discover which linguistic components of newspaper texts are affecting the construction of this public discourse.

Critical Linguists and Critical Discourse Analysts have discussed public discourse primarily from a qualitative perspective. While having great respect for these research precedents, this paper tries to better understand how we can "make sense" of developmental disabilities in Japan using a quantitative text analytics approach. Applying Principal Component Analysis, cluster analysis, among other methods, this paper tries to answer the following research questions for five major Japanese newspapers:

1.   Does the news ideology represented by each major paper in Japan differ diachronically as evidenced by a change of the positive/negative expressions of disabilities?

2.   Who is responsible for raising public awareness about developmental disabilities, known as "the newer disabilities" in Japan?

3.   What is the linguistic mechanism of the semantic change seen in the construction of Japanese public discourse on developmental disabilities?

4.   The answers show a correlation of psychological development and economic development among the social factors constructing disability discourse.

Teodor Mladenov: Disability and 24/7 capitalism

(Main conference, paper)

In a radical critique of contemporary capitalism titled 24/7: Late Capitalism and the Ends of Sleep (first published in 2013 by Verso), Jonathan Crary characterises our technologically interconnected world by the injunction to perform in ways that serve a global profit-generating machine. This injunction of performativity incorporates people into homogeneous space and time of uninterrupted and constantly accelerating production and consumption. Crary regards sleep as the last frontier before the total submission of humans to the profit-making imperatives of the globalised techno-capital. He conceptualises sleep as a 'vulnerability' that defies the instrumental calculus of what Crary calls the '24/7 world' of contemporary capitalism: 'Sleep is the only remaining barrier, the only enduring "natural condition" that capitalism cannot eliminate.' (Crary, 2014: 74)

Considering this understanding of sleep, it is remarkable that Crary has disregarded disability. Disability's resistance to instrumentalisation, although far from 'natural', has nevertheless been widely explored within disability studies and in this regard is very akin to Crary's sleep. In this talk, I provide some reflections on the place – or anti-place – of disability in 24/7 capitalism that fill the void in Crary's account. I conceptualise the 24/7 world as a world of technologically mediated hyper-ability and I argue that: (a) in the dimension of economic redistribution, the world of hyper-ability tends to eliminate the disability category, which enhances commodification of human labour; and (b) in the dimension of cultural recognition, the world of hyper-ability tends to universalise the norm of self-sufficiency, which enhances devaluation of human interdependency. I consider disability as bearing a potential to disrupt the instrumental imperatives of 24/7 capitalism in ways that exceed the disruptive potential of sleep.

Cristian Montenegro: The rise and fall of an (im) probable engagement: Different voices reconstructing the early collective agency of users in the context of the institutional modernisation of the Chilean mental health sector

(Mad Studies stream, paper)

Generally, Chile's community-based organization of mental services is considered one of the most advanced in Latin America. Particularly laudable has been its de-institutionalization process, described as a technical and democratic achievement in the modernization of the mental health sector after dictatorship. But there's one aspect that complicates this picture: the lack of a recognizable, organized "voice" from service users or, more generally, a "users" movement. How can this disjuncture be untangled?

This paper presents the results of a qualitative study into the creation of ANUSSAM, the first user-lead national-level advocacy organization in Chile, conducted in the context of a broader research project around the contemporary entanglements between user's organizations and the mental health system. It's based on 20 interviews with users and family activist, former professionals, policy makers, and international policy advisors that had a stake in the process, and on related legal and policy documents produced during this period.

Results suggest the need re-describe a unitary narrative of democratic modernization into a multi-tiered process, experienced and observed in different ways by different groups engaged in the process, with no unitary "truth" behind the accounts. The way in which the mental health system observes and validates the voices of users responds less to the concrete status of users' organizations than to the contingent dynamics and transformations of the mental health system.

Karen Mogendorff: Where is the person in 'personalisation'?'

(Main conference, paper)

Disabled people's participation in disablist society in part depends on their capacity to deal with bureaucratic institutions that control access to benefits, auxiliary aids and services. Disabled people's dealings with institutions are fraught with tensions, contradictions, interests and emotions. Application and (re)assessment processes tend to be presented as rational, objective, standardized, just and/or fair neglecting the emotions that implicitly inform processes, decisions and outcomes. The myriad effects applicant-gatekeeper relationships produce for the actors involved and society at large tend to be understudied. A complicating factor is that not all consequences of changes in bureaucratic processes such as adjustments in eligibility criteria are understood, foreseen or provided for resulting in distress, uncertainty and upheaval.

This paper seeks to discuss plans to setup a larger study to investigate bureaucratic processes in different institutional contexts with a focus on implicit consequences and underlying emotions in encounters between applicants and clients on the one hand and gatekeepers and controllers on the other hand. Several assumptions inform the proposed research: (1) emotions play a much larger role in bureaucratic processes and in the disability-society relationship than tends to be acknowledged; (2) addressing underlying emotions may help participants in bureaucratic processes to cope with and manage its various material and immaterial consequences, (3) a better understanding of the emotions that inform the disability-society relationship may be of help in transforming the disability-society relationship.

A so-named vertical slice approach is proposed to investigate disabled people's applications processes drawing upon applicants' experiential knowledge and expertise and professional and formal knowledge of gatekeepers and civil servants involved in relevant bureaucratic processes.

Lyte Moon: Identity, Self-Terrorisation Limitation and Freedom. [a perspective on tyranny, labels & language or/ How Life became a Thing]

(Mad Studies stream, poster)

Through a Lens of Metaphor and Story, archetype and Fable, image and other language, alongside more formal reference and an eclectic range of academic influences, this enquiry is about issues of the purpose and value of 'identity'.

In challenging - and questioning - normative introjects, the issue of shifting identities is raised, allowing enquiry into the phenomenological; the personal; subjective. Outside of the limitations of language live Fields of Influence uniquely personal; and Fields of Influence archetypal, social or cultural.

Because conventional thinking in the West relies upon 'thingification' and labels, I question how deep re-framing can occur. Identity/identities arise, and are lost and are imposed and accepted. Hidden agendas abound in the normative fashion-ridden consumption of people 'as objects', 'as signs', 'as quarry', 'as chess figures' in a game of alienation.

Language plays its part in limitation and control of 'self-concept'. Society as a whole becomes a place of subtle and not so subtle terrorisation, alien to the human Spirit of collaboration and expansive connected growth into new forms and evolutions more able to support the beauty and potency of life. Self-terrorisation and Psycho-Emotional Disablism will be conceptually linked to the means whereby survival in an alienating culture takes priority over genuine well-being. Exploration will move always with threads of metaphor and the sensory: language beyond 'language' towards opening discourse, dissolving limitations that had purpose but now hold us back from the power and expression of ourselves-in-service to the co-creation of entirely new and life-enhancing paradigm for the future. Paradigm, paradoxically, that must self-destruct once, should we do so, we move closer towards life of Life.

References will be made to the work of others, to those whose creative exploration, thought, academic work and life activities/expression have been of particular influence in informing the development of the paper.

(Main conference, paper)

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was passed in 2006 and came into force in 2008. South Africa is one of the few countries that have signed to and ratified both the Convention and Protocol.

The Convention spells some core principles and values, including dignity, individual autonomy, non-discrimination and, full and active participation and inclusion of people with disabilities in their communities. Article 24 of the Convention outlines one of the most complete provisions of the right of persons with disabilities to education ever to be articulated in an international human rights treaty. Although Article 24 is recognised as an important step in providing the foundation for building dignity and self-worth, there are challenges in achieving this. The underpinning values of a quality education, reasonable accommodation and the criminalisation of the exclusion from the general education system on the grounds of disability are important, but potentially leave out some students with disabilities at disadvantaged positions. It also present challenges and dilemmas for those involved in supporting roles within the South African Higher Education (SAHE) especially with regards to students with learning difficulties.

This article examines human rights approach and disability in SAHE in the wake of the UNCRPD's Article 24, which is viewed to be central to the struggle for recognition of people with disabilities in education. Using 14 narratives of students with disabilities from South African universities, I assess the potential and limitations of CRPD in general and Article 24 in particular to the struggle for social justice for students with disabilities in SAHE. I argue that in as much as human rights approach to disability is important, the experiences of students with disabilities in SAHE lie outside the reach of human rights approach and calls for an interactional approach to disability.

<u>Sumaira Naseem and Rebecca Lawthom: Open doors and safe spaces - including everyone in events</u>

(Main conference, workshop)

Issues of access affect ways in which people enter and participate in spaces. These spaces can be academic, informal, community and involve everyone. The disability studies community is often more attentive to processes of access and has an inclusive ethos. From an earlier community psychology festival, drawing upon principles of stewardship, diversity and community , we developed a participative pledge. The process affirmed criticial issues benefiting all potential participants at events. Given the increasing neoliberalisation of universities and other organizatons, conferences are often commodified requiring business cases. This access costs messages point to the cost of accessibility, although this rests upon faulty logic that these costs are located in or belong to disabled participants only. We are reminded of Titchosky's point that as soon as we talk of inclusion we highlight exclusion.

We propose a workshop on accessibility for the inclusion for all delegates and we want to address access issues that could affect all. We use participatory methods such as drama as well as critical vignettes as contributions. We draw on our expertise as disability activists, theorists and community practitioners recognising that all participants will have something to offer. We want to ensure that the workshop space itself is inclusive and that participation occurs in accessible ways.

We will explore creatively vignettes which detail access issues at the individual, group and institutional level. In responding to these, we critically consider developing best practices. An exemplar may be how the visual is dominant and often exclusionary in settings.

This workshop will generate best practice and be shared following the workshop. We would like to continue to develop a manifesto for change which allows for people to engage in ways they are confident in and provides tools for hosts. We invite delegates to pledge their support.

Ursula Naue: Lost in translation?! The challenges of translating the Convention on the Rights of Persons with Disabilities (CRPD) into German

(Main conference, paper)

There are six official languages of the United Nations. But what does this mean for countries where other languages are spoken? The paper will discuss this question with regard to the translation of the CRPD into German. An existing German translation of the CRPD – shared by Germany, Austria, Switzerland and Liechtenstein - was formulated more or less without the participation of persons with disabilities. Resulting from this, a 'shadow translation' was formulated by Netzwerk Artikel 3 e.V. (German association for human rights/equalisation of persons with disabilities). Whereas the first translation reveals grave mistranslation of important terms (i.a. inclusion, accessibility, participation), the second has not been accepted as an official translation.

In 2013, the Austrian Federal Ministry for Europe, Integration and Foreign Affairs initiated a new translation of the CRPD into German. Starting in 2014, a working group – including i.a. persons with disabilities, their organisations, and the Independent Monitoring Committee - met five times for translating the CRPD. In the context of a Disability Studies approach, the paper is based upon the argumentative turn in policy analysis, arguing that "our language does not simply mirror or picture the world but instead profoundly shapes our view of it in the first place" (Fischer&Forester 1993: 1). Arguing with Eco that "[T]ranslations do not concern a comparison between two languages but the interpretation of two texts in two different languages." (Eco 2001: 14), the author understands translation as a process of socio-political-cultural construction, which makes it necessary to question differing meanings behind certain terms. Currently, the new German version of the CRPD is in the phase of consultation; until mid of February, written statements by diverse political actor groups are possible. The still ongoing discussions about the translation reveal the socio-political debates about the role of persons with disabilities in Austrian society.

<u>Ghasem Norouzi: Physical and environmental barriers for disabled people in Iran</u>

(Main conference, paper)

This paper discusses findings of analysis of the research question 'Are the current physical and environmental factors of buildings suitable for disabled people?' through using quantitative method consisting of 120 structured questionnaires, completed by researcher who visited all 120 locations in a city in the West of Iran and was undertaken through SPSS analysis.

The findings of the research illustrated that irrespective of Iran's Act for Supporting Disabled people (IASD), which provides guideline to all building designers, architectures, building owners, governmental and private organisations to pay attention to needs of disabled people when constructing buildings, most buildings in this study are not accessible for disabled people due to physical barriers.

The findings showed that out of 80 public buildings, most of them (62.5%) were governmental and 37.5% were private. The outcome of this study indicated that most of the buildings (83.8%) were without lift. In addition, none of the buildings had disabled access elevators. The results showed that most of the buildings (62.5%) had no bathroom for disabled people. Moreover, most buildings (71.2%) had no ramp and amongst the buildings which did have ramps, most of the ramps were sharp and not suitable for use by disabled people.

The results of this study demonstrated that physical barriers including stairs, doorways, hills, roads and pavements prevented disabled people from accessing into the buildings and public places. Therefore, these environmental barriers limited disabled people activities and affected their abilities to contribute in the society. This study suggested some ways of overcoming physical barriers including: enforcing legislations for good implementing act; rewarding accessible buildings for disabled people and providing punishments for organisations not implementing legislations. Changing the negative attitudes of people towards disabled people by providing suitable disability awareness training is another way of overcoming physical barriers for disabled people.

Joseph Ocran and Dan-Bright Dzorgbo: Disability in Mass Culture: A Study of Ghanaian Movies

(Main conference, paper)

This paper examines how disabled people are represented in Ghanaian movies. Disabled people are often constrained, oppressed and struggle to access opportunities, resources and privileges that non-disabled persons have access to within the same society. The imagery of disabled people as handicapped, laughable, pitiable, and objects of curiosity is depicted and reproduced through the mass cultural media such as advertising, television and newspapers. The media, being a significant instrument in social interaction, a powerful reference point in society and an influential agent of socialization, contributes to the differentiation of disabled people, from non-disabled people. Ghanaian communities have strong traditional beliefs about disability, its aetiology, manifestation and consequence. Whiles it is true that some of the conservative perceptions, discrimination and prejudice about disability and disabled people have given way to some degree of social acceptance, there are serious indications that disabled people are persistently perceived and treated differently, compared to non-disabled persons. These differences are often manifested and mirrored in the representation of disability in movies made in Ghana. Using the multiple case study approach, this paper focuses on Ghanaian movies and examines the representations of disability, the reproduction of disability stereotypes and the characterization of stigma in the movies. To this end, Ghanaian movies that feature people with physical and/or mental disabilities will be purposively selected and analysed. An analysis of how disability and disabled people are represented and the varying social contexts within which they are created will be done. An understanding of the dynamics of disabling imagery will lead to better management of disability issues in Ghana and beyond.

Patrick Ojok: Barriers and facilitators to implementing disability policies in developing countries: Experiences of and Lessons from Uganda

(Main conference, paper)

Domestic legislation is critical for the realization of the rights and the full inclusion of persons with disabilities in society. Uganda is among the developing countries that have taken significant strides by enacting legislation that firmly anchor disability as a human rights and sociopolitical issue. However, Uganda appears to be at crossroads with regard to translating its well-intended laws to practice. The primary goal of this paper is to share first persons' perspectives on the factors that influence the implementation of a Uganda disability law in relation to employment. A total of twenty five macro-level policy stakeholders drawn from disabled persons' organizations and public entities were qualitatively interviewed between March and August, 2014. Overall, there was an unsuccessful attempt to implementing the law, and, a bill has been tabled in parliament to repeal and replace the law even before it has been tested in practice. The barriers and facilitators to the law's implementation aligned into three overarching themes: policy-oriented factors, process-oriented factors and tractability. The experiences from the failed attempt to implement the Uganda disability law indicate that superficial support and commitment to disability rights is inadequate. As well as enacting disability laws, individual countries must take additional steps such as allocating financial resources to ensure that disability laws are effectively implemented. This paper argues that the promises espoused in domestic disability laws of developing countries are at best symbolic and rhetorical aspirations unless such laws are effectively implemented.

Dr Lisa O'Leary, Laura Hughes-Mccormack and Professor Sally-Ann Cooper: Life expectancy and causes of death of people with intellectual disabilities: a systematic review

(Main conference, paper)

Life expectancy of people with intellectual disabilities (ID) has increased in recent years, but is still considered to remain lower than that of the general population. It is thought that the causes of death in the ID population differ to the general population. A systematic review was undertaken in order to evaluate this evidence. Five electronic databases were searched for keywords relating to intellectual disability AND death. Titles and abstracts were assessed using strict inclusion/exclusion criteria (5% were assessed by a second researcher). Full papers were assessed for eligibility. Study information was extracted, tabulated and reviewed. N=17,828 potentially relevant articles were identified from database searching. N=40 studies met the inclusion criteria. N=22 of these studies were comparable. Therefore their findings were synthesised. N=18 studies were incomparable, as they were exclusively comprised of specialist populations such as individuals with feeding problems. These studies were excluded from the synthesis. Narrative analysis of the comparable studies revealed that individuals with ID had lower life expectancy than the general population.

Higher mortality rates were pronounced in specific subgroups such as individuals with severe/profound ID. Standardised mortality rates were higher for females than males with ID, demonstrating a greater inequality for females compared to the general population.

Respiratory and circulatory diseases were the leading causes of death for the ID population. This was followed by cancer. People with ID had a different cause of death profile than the general population and were more at risk of avoidable causes. Most studies were limited by reliance on death certificates, administration data and by not undertaking age matched comparisons with the general population. Further population based and age matched cohort studies are needed in order to ascertain life expectancy and causes of death of the entire ID population. The Scottish Learning Disabilities Observatory is investigating this further.

Meghann O'Leary and Liat Ben-Moshe: Homage to Spencer: The politics of "treatment" and "choice" in neoliberal times

(Mad Studies stream, paper)

Our argument is framed by a personal narrative of the first author's experiences with the mental health system, including hospitalization, medication and psychotherapy. Meghann: "I am now 35 and have been an active consumer in the mental health system, since I was 19, when I was first hospitalized due to what was diagnosed as a manic episode with extreme psychosis, characterized by delusions, hallucinations and paranoia. My first serious boyfriend, who I was not yet dating at the time, was going through a similar experience in terms of symptoms and hospitalization. He committed suicide at the age of 23. When our two stories are compared dominant societal discourses assume that I survived and even flourished due to my adherence to a medication regimen and therapy while my ex-boyfriend's death resulted in his refusal to comply with treatment. In this scenario I become an example of neoliberal triumph, someone who overcame their "illness." My ex-boyfriend becomes an example of what happens when people who are "mentally ill" do not take responsibility for themselves and adhere to prescribed treatment."

Such individualized notions of treatment and success ignore the complex ways in which society marginalizes and discards individuals with little access to social and economic capital and are also psychiatrized. The narrative frames a larger discussion of the neoliberal and capital governance of psychitarized bodies and souls. We ask such questions as – what do concepts like 'consumer' or 'choice' mean under a violent socio-economic structure that already restricts (certain) people's life chances? How is psychiatry embedded in the violent carceral state in the U.S. and what effects does that have on individual bodies and minds/ souls who are pathologized as violent? And finally, what does treatment or recovery mean in a racist, capitalist regime, which remains unchanged but requires individuals to transform themselves?

Terje Olsen and Patrick Kermit: Rights and Intellectual Disability – a Review Study

(Main conference, paper)

Background: The reform putting an end to "total" institutional care for persons with intellectual disabilities, and closing down the big, segregated institutions in Norway, has worked for about 25 years. The reform was driven by the ambition of improving living conditions and legal safety for persons with intellectual disabilities.

The main question in this study is: What do we know from international and Nordic research about legal, civil or political rights, special rights or human rights in the context of intellectual disability?

Method: This is a review study. Searches in a range of international and Nordic research databases were conducted. The searches were designed to identify research articles, reports, papers and books tropicalizing intellectual disability in the context of legal, civil or political rights, special rights or human rights.

Results: The search resulted in approximately 1000 publications with potential relevance. In the next step 198 original references were distilled through different processes of elimination. The 198 references were evaluated manually and eventually; 57 publications were included in the study. The 57 publications presented topics summarized under the following headlines: abuse and protection from violence (18), guardianship (7), physical restraint procedures in care facilities (13), criminal justice, interrogation and incarceration (9) and other (10).

Discussion: The paper presents and discusses the content and tendencies within each of the above mentioned headline themes. In addition, some remarks are made concerning general tendencies within the context of intellectual disability and different types of rights.

<u>Łukasz Orylski: Disability and symbolic capital: a Polish case</u>

(Main conference, paper)

The aim of the presentation is to analyse the methodological potential of such categories as: habitus, symbolic capital and symbolic violence, in the field of disability research. The category of symbolic capital, according to P. Bourdieu, denotes the specific form of different kinds of capital possessed by individual, groups or social classes that the mentioned capital assumes in order to be recognized as the legitimate one. In many social diagnosis concerning the disability community, the diversity of symbolic capital inside this community is not taken into consideration. As a result, the trajectories of the life careers as well as limitations of the emancipation processes concerning people with disabilities cannot be understood properly.

According to the presenter's opinion, "the culture of able-bodied persons" which is the theoretical construct shared by many persons with disabilities, is treated by them as the only legitimate kind of culture. That is the reason why the vast majority of people with disabilities from the global North tend to be more submissive to the cultural practices that comprise in "the third dimension of power" in a meaning given by S. Lukes.

The dominant discourse created for people with disabilities (and partly by them) in the Polish reality limits the sense of every life activity to adaptation to the conditions created by the social majority and to prove their rights to be the social actors.

This hypothesis was proved by the discourse analysis of Polish magazines and web pages addressed to people with disabilities between 2010 and 2015.

<u>Maria Pallisera, Judit Fullana, Gemma Díaz-Garolera, Carol Puyalto and Maria Josep Valls: Between dependence on institutions and independent living: the views, desires and criticisms of self-advocates with intellectual disabilities in Spain</u>

(Main conference, paper)

Article 19 of the Convention on the Rights of Persons with Disabilities(UN, 2006) establishes the right of people with disabilities to decide where they want to live and with whom, and to access supports that allow them equal access to community resources. In Spain, which ratified the CRPD the 2007, a new law was enacted in 2013 (Law on the rights of persons with disabilities) to articulate support for people with disabilities in accordance with that set out in the Convention. This law calls for progress in transforming the traditional model of service provision based on the institutions, which had a very significant influence in Spain, towards a model of distributing support focused on the needs and demands of the individual.

In order to examine the extent to which this progress has taken place, a study was carried out which focused on the opinions and experiences of people with intellectual disabilities. A total of 12 focus groups were conducted in Catalonia (Spain), with the participation of 94 self advocates. The following topics were discussed: current options with regard to independent living; the role of professionals and organizations; the role of the family; the role of the persons with disabilities themselves; perceived barriers to fulfilling that set out in art. 19 of the Convention; and the support model they would like to see in place to help them construct their own personal life project.

The results obtained allow us, in addition to looking at participants' views in greater depth, to compare their experiences with the theoretical discourse employed in the political sphere and by organizations. In addition, we are also able to highlight the major challenges facing organizations, professionals and people with disabilities in making progress with the construction of plans for independent living aligned with the Convention.

Gabor Petri and Agnes Turnpenny: Deinstitutionalisation in Hungary: a critical policy analysis

(Main conference, paper)

Background:

Large residential institutions still remain a common form of service provision for people with intellectual and psychosocial disabilities in many European countries. There are approximately 1.2 million people living in residential institutions in the Member States of the European Union (EU) and Turkey (Mansell et al. 2007). More recently governments in Central and Eastern Europe have started implementing institutional closure programmes and developing new, community-based services for people with intellectual and psychosocial disabilities.

Method:

This study explores the development and implementation of deinstitutionalisation policy in Hungary from a critical perspective focusing on content as well as context, actors and processes (Walt & Gilson 1994). It uses qualitative methods: discourse and thematic analysis of policy documents and interviews with 11 actors, including policy makers, representatives of disabled people's organisations and civil society, as well as service providers.

Results/Findings:

Deinstitutionalisation policy in Hungary is mainly context-driven by the availability of EU structural funds to support the implementation of the UN CRPD and the development of social care services in a policy area characterised by decades of underinvestment and inadequate infrastructure.

The content of the policy is unclear and reflects the "fuzzy" nature of policy planning and a lack of consensus among stakeholders on what "deinstitutionalisation" should look like in Hungary. Relationships among the actors are considered by distrust and conflicts over the allocation of resources.

Conclusions:

We will discuss the implications of the findings for future deinstitutionalisation policy and people with disabilities, and put forward some lessons and recommendations for countries embarking on similar programmes.

Paula Pietilä and Matti Laitinen: Challenges, Changes and Complications: Experiences of disabled people in working life

(Main conference, paper)

According to statistics about 15-20% of disabled people participate into working life In Finland. It is much less than average population, which employment rate is about 69,5%.There is estimation, that 15.000-30.000 disabled people being able to work are outside from the labour market. (Mahlamäki 2013.)

Our data consist of fifty five biographical interviews, made during 2013-2014. In almost all of them, the working life is one important aspect. The most of interviewees have a physical disability and a few are sensory or intellectually disabled. Majority of interviewees are women, men have not adequately been represented within our research.

Most of the interviewees have had difficulties to find a job. Many had met negative attitudes and even discrimination, already during recruiting process. It was a common experience that if you mention something about disability in the application, you don`t get invitation to an interview. Some of the interviewees shared experience that they have to prove to the employer that they are capable to the work.

There was little evidence in the stories that interviewees had got much career counselling during their compulsory education. A number of interviewees have long, scattered educational path and seldom work for the profession, they have education for. Working on a fixed term contracts, part time or doing voluntary work was a common experience of the interviewees. It was ordinary that disabled people often got assisting jobs, which were underpaid, short term or part time jobs. There was also evidence that disabled people may be first to get unemployed during a layoff and the lasts to get a permanent positions in their work. This with other factors mention makes the employment process vulnerable and uncertain for disabled people.

Tom Porter, Tom Shakespeare and Andrea Stockl: 'You get sick of people, you do, and they get sick of you': understanding and avoiding conflict in PA relationships.

(Main conference, paper)

This paper reports on ongoing ESRC-funded qualitative research with personal assistants (n=30) and personal assistance users (n=30) in the East of England, exploring themes of ethics, power and emotions in PA relationships, through interviews and observations.

A theme of particular importance in the study is the breakdown of relationships, how this occurs, and what can be done to avoid this. In our research, we have encountered examples of theft, exploitation, unrequited love, labour market problems, unreliability, lack of professionalism, as well as everyday misunderstandings and tensions. Problems are more likely to occur at the beginning of PA relationships, prior to PA users developing skills and strategies to avoid conflict in the relationship.

This evidence raises the question of how far personal assistance should be professionalised, and subject to a code of ethics, and whether more training should be provided to both workers and users. We believe we can learn from the skills and strategies of PAs and PA users, to develop training which can ensure that other PA users avoid problems.

<u>Konstantina Poursanidou and Lisa Morriss: Struggles and opportunities in co-teaching trainee Approved Mental Health Professionals: Links to Mad Studies?</u>

(Mad Studies stream, poster)

This paper is a reflection on our experiences of co-teaching trainee Approved Mental Health Professionals (AMHPs). Our different backgrounds

– Dina being a service user academic/researcher and Lisa a registered social worker and social work academic/researcher - resulted in differing experiences of our collaboration and of the struggles and opportunities it entailed. Lisa will talk about her struggle with anxiety and guilt pertaining to the likelihood of Dina becoming distressed or unwell, as Dina was asked to re-visit times of acute mental health crisis to provide the AMHP trainees with opportunities for knowledge development. Lisa will also comment on how she struggled with the unsettling and uncomfortable nature of some of the material used in the co-teaching, whereas at the same time felt privileged for the opportunity to learn from such material, highlighting the 'lived contradictions' characterising 'mad-positive, engaged academics' (Church, 2013; Cresswell and Spandler, 2013). Utilising the notion of service user involvement in practitioner education as a 'paradoxical space' (Rose, 1993), Dina will talk about the identity struggles, tensions, contradictions, paradoxes and deep ambivalence implicated in negotiating her double identity as an academic educator/researcher and a mental health service user. Discussing her struggle with being expected to stay incessantly connected with 'difficult, troublesome and dangerous' (Pitt and Britzman, 2003; Cooper and Lousada, 2005) knowledge (i.e. mad knowledge) and the discomfort this can generate, Dina will also raise crucial questions concerning how to manage the emotional labour and profound emotional cost of using one's lived experience as a knowledge tool in mental health practitioner education. At the same time Dina will reflect on critical autobiography as mad activism to consider the transformative and subversive possibilities associated with placing survivor counter-narratives at the heart of learning. We will conclude by examining whether our collaborative work can be deemed to be 'doing' Mad Studies.

Andrew Power and Ruth Bartlett: Peer-advocacy in a personalised landscape: the role of peer support in a context of individualised support and austerity

(Main conference, paper)

While personalisation offers the promise of more choice and control and wider participation in the community, the reality in the UK has been hampered by local council cuts and a decline in formal services. This has left many people with intellectual disabilities feeling dislocated from collective forms of support (Needham, 2015).

What fills this gap and does peer-advocacy have a role to play? Drawing on a co-researched study undertaken with and by persons with intellectual disabilities, we examined what role peer-advocacy can play in a context of reduced day services, austerity and individualised support.

The findings reveal that peer-advocacy can help people reconnect in the face of declining services, problem-solve issues and informally learn knowledge and skills needed to participate in the community. We argue that peer-advocacy thus offers a vital role in enabling people to take up many of the opportunities afforded by personalisation.

<u>Yuanyuan Qu: An alternative space? Digital inclusion of disabled people in China</u>

(Main conference, paper)

This paper draws on data from on ongoing PhD exploring disabled people's use of the internet and new social media in China with a particular focus on employment. This use is mapped onto reforms China launched in the late 1970s, which shifted work from a collective right to an individual struggle in a highly competitive market. This shift has seen the marginalization of disabled people in employment. Based on interviews with disabled internet users in China the paper examines the employment and inclusion through digital technology in the contexts of China's rapid globalisation and digitalisation. It suggests:

1.   Internet has been used as an effective tool in job-seeking, for both 'mainstream' jobs in

the free market and disability-related, welfare approached jobs.

2.   More importantly, internet has been developed as a public sphere where new jobs are created and more opportunities are provided. Disabled people are more likely to be included in this barrier-reduced digital environment.

3.   However, most disabled employees were taking low-skilled 'labour' jobs online, like 'water-army posters' and 'game player substitute'; only a few were doing 'mainstream' highly rewarded work, such as running online shops or IT works. Disabled people were mainly located in the bottom of this alternative digital market.

By presenting various forms of digital employment, I argue that the internet in China has to some extent empowered disabled users by reducing physical barriers and providing more accesses to the job market. It, however, has also reproduced or even re-enforced the oppressive structure by locating disabled employees in disadvantaged positions. The internet itself cannot change disabled people's situation without digital welfare services and supports.

<u>Anni Rannikko and Veli Liikanen: Disability in the body cultures of sports media</u>

(Main conference, paper)

Media influences people's conceptions of what is deemed normal in different areas of human activity. For perceptions of normality in sport, media coverage of athletes can have a big influence. In our presentation, we examine what kind of portrayals of disability are produced in media texts covering disabled athletes, especially in descriptions concerning body and bodily functions. The analysis leans on a mix of conceptualisations from both sociology of sport and critical disability studies. Research material consists of volumes 2010–2015 of a major Finnish newspaper. Material is analysed using dialogic thematization.

Articles covering disabled athletes show power relations and social hierarchies that are based on distinctions between normal and deviant. These become visible especially in the depictions of body. In the articles, disabled athlete's body is portrayed in mechanistic ways and using heroic narratives. Disability is understood through body and its capacity, or through narration of survival, where disability is conquered and the athlete reaches top performances despite of her/his disability. The depictions of disabled athlete's body are presented without any societal context: newspaper articles approach disability not as a social phenomenon but as stories of the individual.

<u>Stuart Read, Sue Porter, Joseph Webb, Wendy Merchant, Nicola Reynolds, Victoria Mason and Val Williams: Tackling disabling practices: A panel supporting inquiry in the service of change</u>

(Main conference, panel)

We know that disabled people experience a number of barriers that restrict their ability to engage and participate in society. Yet, attempts to change existing social practices are limited, and rarely include the voices of disabled people as part of this process. The 'Getting Things Changed' programme is an ongoing, large study funded by the ESRC and aims to work with disabled people to explore current societal barriers, and how meaningful change to social practices can be achieved. This symposium includes five talks largely from 'new voices' in the research teams in separate strands of the programme, each describing a different social practice, and explores two important questions: first, what is currently going wrong for disabled people, and second, what changes are needed to rectify these problems. The first talk focuses on exploring the micro approach to communication which can help us see how disabled people may be enabled to learn to be in control of their own personal assistance. Talk Two describes how disabled students and staff, acting as co-researchers with the research team, can help highlight and change the current barriers that exist within the university environment. The third presentation explores the current provision of reasonable adjustments for disabled people when accessing hospital care. Talk four focuses on current practices in place to assist parents with learning disabilities when there are concerns around child neglect. Finally, talk five, led by Disability Rights UK, ends this body of work by describing how disabled people can be part of a drive for 'user-driven commissioning'. Taken together, these series of talks reveal how we might be able to understand better the way in which disabled people can be excluded or disadvantaged by various social practices. However, their direct experience and action can provide valuable insight and opportunities to advocate change.

Marcus Redley and Isabel Clare: Full and Equal Equality: an exploration of the Convention on the Rights of Persons with Disabilities and the controversy surrounding people labelled as having an 'intellectual disability'

(Main conference, paper)

The avowed purpose of the UN Convention on the Rights of Persons with Disabilities (CRPD), as stated in Article 1, is to "promote the, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities". When applied to persons labelled as having an intellectual disability, this progressive agenda has raised intense debate. Disagreements have taken place over: (i) the merits of promoting the legal autonomy of persons whose judgments may be challengeable, and (ii) how best to ensure, when supported to exercise their legal capacity, that support is free from undue influence and conflicts of interest. Left largely unexamined in these debates is any consideration of such key terms as "disability", and "intellectual disability". In effect, the conceptualisation of intellectual disability has gone unexamined, as has the wide range of skills and needs associated with the term. This presentation, in response to the controversy provoked by the CRPD's "paradigm change" reviews how men and women labelled as having an intellectual disability can be homogenised and/ or divided depending on their position (medical, legal, welfare, and political) with the welfare state, in order to ask: (i) whether we really know what we are talking about when we speak of "intellectual disabilities"; (ii) the irony of labelling a population as different in order to promote their inclusion, (iii) the responsibilities, if any,that the general population has towards the identified group so labelled, and (iii) whether an exploration of these issues can help us to better understand and address the controversy surrounding the promotion of 'full and equal equality' (Art. 1,CPRD).

Donna Reeve and Mèlani Halacre: Mind the Gap: Exploring the creative intersections of disability studies and counselling theory

(Main conference, paper)

It has long been recognised that disability as a diversity issue is still largely absent from counselling theory, practice and training (McLeod, 2013). Similarly, disability studies has been reticent to engage with the psychological ramifications of living in a disabling world. One of the difficulties of bridging these two disciplines is that of bringing a social model view of disability to bear on what is often viewed as an individualised, personal experience of the world. This is particularly relevant when disabled clients bring issues to therapy which are a complex muddle of individual (impairment) and social (disability) effects. The relative absence of disability within counselling training means that counsellors are often ill-equipped to understand the complexity of these issues and their impact on the disabled person. Hence counselling may be at best ineffective, or at worst, yet another disabling experience for the client.

This intertwining of individual and social aspects of disability and impairment causes a theoretical challenge for counselling and disability studies theory alike, a tension which needs to be resolved if disabled people are to have access to effective counselling.

In this paper, we explore the potential of using Thomas' extended social relational definition of disablism (2007) as a way of reducing the gap between these two disciplines – through a collaboration between an experienced counsellor who has worked with many disabled clients and a disability studies theorist with a life-long interest in this area. We consider the following questions:

How useful is the concept of psycho-emotional disablism for helping counsellors better understand the lived experience of disablism within contemporary UK society?

How does a counsellor support their client to make effective changes in the face of intertwined disabling barriers and impairment/ impairment effects?

What challenges does this raise for disability studies and counselling practice alike?

Melvina Robbin: Social Worker Interactions with Black and Minority Ethnic Families Raising Disabled Children and Young People in Scotland

(Main conference, paper)

Research investigating social worker interactions with Black and Minority Ethnic (BME) families raising disabled children specifically in Scotland is limited. Within the last two decades, however, there have been waves of recurrent research investigating BME families' experiences of social work and service provisions for disabled children and young people within the rest of the UK.

Through focusing on anti-oppressive social work practices within social worker to BME family and disabled children interactions, a more detailed understanding of these interactions has developed. The conceptual understanding and demonstration of anti-oppressive practice by social workers provides a critical approach to issues regarding normalcy and diversity: in this instance 'race' and disability.

This study is currently being carried out using a qualitative design that is underpinned by descriptive phenomenology. The lived experiences of qualified social workers, social work students, and BME families with disabled children and young people are presented within the preliminary discussions of this study. An initial thematic framework has been established from semi-structured interviews, focus groups with a small subsample of respondents, and textual analysis of social work curriculums within the central belt of Scotland.

The initial inferences suggest that attitudinal barriers linked to stereotypical beliefs about BME communities exist among qualified social workers. Issues specifically relating to 'oppression' and 'race', do not feature specifically within social work curriculums, but is referenced implicitly in anti-discrimination discourse. The cultural challenges, underpinned by social worker-family dynamics within interactions appear to be partially influenced by western ideals: imposed by institutions and perpetuated by practitioners.

The final outcomes of this study will provide a foundation for understanding how social workers interact with BME families raising disabled children and young people by considering the wider context of family dynamics; the challenges and good practice examples within social work education, training and practice in Scotland.

Chrissie Rogers: Being human and Intellectual disability: developing a care ethics model

(Main conference, paper)

Imagining care and social justice in the context of intellectual disability is challenging when, by comparison to physical disability, far less has been written about this heterogeneous group. They are not considered full citizens and at worst, are left to die. In response, as a sociologist, and a mother with an adult intellectually disabled daughter, I develop a care ethics model of disability. I propose three spheres of caring that are currently populated with care-less spaces. The Emotional Caring Sphere, where love and care are psycho-socially questioned. The Practical Caring Sphere, where day-to-day care is carried out relationally, and The Socio-political Caring Sphere, where social intolerance and aversion to difficult differences are played out. These spheres interact in complex ways, and are grounded in social and political relations. Challenges arise when powerful others make decisions based on attributes such as, rationality, language, physical and mental capacity, as rudiments for participating in citizenship. This clearly excludes many from contributing to, and participating in, civil society, and this is dehumanising. Stories and images about intellectual disability and exclusion, heroism, violence and vulnerability are often interpreted in relation to inequality, injustice and humanity. For intellectually disabled people, their story is one of horror. The irrational, erratic, slow and unintelligent '(sub)human' is to be feared, as reason and rationality are revered. 'The person with a stigma is not quite human' (Goffman 1990: 15), and there are many who suggest that disabled people are better off dead or better still, not born. Intellectually disabled people are stigmatised, but the assumed worthlessness of life, based on levels of pain, discomfort and everyday disadvantage, seems to be enough to suggest that they might be better off dead. I propose we enable a care ethics model of disability in transforming social and political responses for intellectually disabled people.

<u>Cath Roper and Vrinda Edan: Growing critical consumer perspective over the bricks of the ivory tower</u>

(Mad Studies stream, Survivor Research panel)

Both authors are consumers occupying roles within academia at two different universities in Victoria, Australia. Our positions are located within health sciences/clinical contexts against a backdrop of increasingly competitive and conservative institutional functioning. It has taken decades of hard work by consumers and our allies for consumer perspective to gain a foot hold in existing teaching and research activity within the academy. As consumers, we speak/write/ think from a discredited position. So, what does it take to secure a sturdy enough rung to foster the development of our own 'critical' discipline - from which to critique existing ideas and practices, generate new ones and influence contemporary thinking and practices?

The authors have two inter-related aims: first, to generate provocative questions about framing their own work in the academy as 'mad knowledge' and second, to celebrate the growth and sustainability of local 'consumer perspective' thinking by discussing innovative strategies and sharing examples.

We examine the fit between belonging to a socio-political movement and traditional ideas about what an 'academic' is. We debate how/whether to reframe our thinking and discipline development as mad knowledge in our particular contexts: would it be foolhardy – would we be further marginalised? Would our allies be likely to join with us? Or would it be the greatest boon to our creativity? Will we lose vital connections with our movement if we don't speak of mad knowledge?

We discuss examples of work contributing to our discipline development such as the Psych Action and Training (PAT) group that has been meeting since 2002, the documentation of oral/ conversational knowledge for easy sharing, and the development of our own theory, concepts and repurposing of the conceptual work of others for our own field.

Katherine Runswick-Cole, Fran Rodgers, Gilly Bryerley and Vicky Ackroyd: The meaning(s) of value: Measuring the Impact of Creative Activities upon children and young people with learning disabilities

(Main conference, paper)

Current research exploring the impact of arts education lacks engagement with disabled children; it fails to explore directly, or, indeed, to reference or to differentiate, how the learning of disabled children might differ from that of non-disabled peers in the context of arts education.

Traditional 'success measures' for understanding the impact of arts practice on learning inevitably exclude the experience of children with complex impairments. Overwhelmingly, the research methods developed and used for these studies are designed with children in mind for whom communication is both 'normative' and 'verbal' and so exclude children with complex impairments from the research. This paper begins to address the indirect discrimination existing in literature focused on the impact of the arts on learning and practice that intrinsically excludes disabled children. Through collaboration with Purple Patch Arts, as part of their arts education work in schools, we describe how we are developing collective knowledge and deepening understanding of the impact of arts practice on learning. This research is guided by the principles of disabled children's childhood studies (Curran and Runswick-Cole, 2014). As such, it seeks to expose and to challenge the exclusion of disabled children from cultural life and to explore the radical potential of disability arts practice as a counter hegemonic space (Goodley and Runswick-Cole, 2011).

Drawing on new materialist methodology, we focus on assemblages: human and non-human, animate and inanimate, material and abstract, as well as the affective flows within them, and so draw on emotional and sensory data within the social inquiry (Fox and Alldred, 2015).

<u>Jasna Russo: Moving towards a first-person-defined model of madness: prospects and challenges</u>

(Mad Studies stream, Survivor Research panel)

Any attempt to initiate a new, non-oppressive discourse about madness faces the dominance of the biomedical model on the one hand and the stigma and prejudice around lay understandings of madness on the other. People who have been labelled mad and/or subjected to psychiatric treatment struggle to find words and concepts that are true to the multitude of their experiences. The word 'mad' intersects with our social, economical and political positions and impacts differently on our unequal lives. There are also pressing questions about who presides over language and has the power to name and who defines whom and for what purpose. In contrast to the often self-serving academic debates over the 'right' terminology, I will highlight the potential of language to restore, connect and remake realities.

Building on my PhD research so far, I want to explore how Mad Studies can extend beyond participation and co-production and ensure the long overdue leadership of people who have experienced madness in the process of theorising their experiences. I will discuss the prospect of people who have been labelled mad, mentally ill or disordered working together to reach our own understanding and develop our own theoretical framework for thinking madness. My contribution will focus particularly on the question of how to research madness, the task of undoing the biomedical model and the role of individual and shared identities in generating knowledge.

Jens Rydstrom and Don Kulick: Marxism and Sexual Rights in 1970s Scandinavia

(Sexuality stream, paper)

The paper will explore Marxist discourses of disability and sexuality in 1970s and 1980s Scandinavia and analyse ideological differences and similarities with the radical disability movement in England, with special regards to their discussions about sexuality.

At about the same time as UPIAS activists formulated their ground-breaking and highly influential analyses on disability and impairment in England, similar yet different claims were made in Scandinavia. New groupings of young activists broke with the old reformist movements that in their eyes had sold out to well-meaning, able-bodied bureaucrats and care workers, and, inspired by socialist discourses of their time, built up a whole new way of conceptualising disability. Independently of the UK movement, but in many ways similar to it, Swedish and Danish activists took issue with the old liberal, charity-based disability movement and reformulated the movement's demands in ways that would change the history of disability politics.

What were their demands, and how were these compatible with claiming sexual rights? How did the activists formulate their criticism toward the established movement? And how did they understand the failures of the welfare societies of the time? Departing from an analysis of membership publications of the socialist groups, and with the help of memory interviews, the paper will shed light on an important period in the history of European disability movements and provide an understanding of the ideological currents that have formed contemporary disability politics and activism.

The paper will focus on Scandinavian groups, but also provide a tentative comparison with the UK development, and it will invite to a discussion of the ideological undercurrents of today's activism.

Alice Scavarda: "Normal, different or something in between": self perceptions of young people with High Functioning Autism and Down Syndrome

(Main conference, paper)

People with learning difficulties have been rarely involved as protagonists of a study and as experts of their condition, but there rather has been a reliance on parents and carers for insight into their children's experiences. However, when directly addressed, they express original interpretations of disability and impairment, based on their experiences and interactions with others (Kelly 2005). Nonetheless, dominant discourses, as well as conceptions of significant others (parents, siblings and health professionals) affect the construction and re-construction of their identity. The paper discusses some findings of the author's doctoral study, a three-year comparative qualitative study carried out in Italy, based on about 60 in-depth interviews to young people (aged 14-20 and 21-27) with High Functioning Autism and Down Syndrome and to their parents.

In line with Carol Thomas' relational model, the interviewed show the effects of both structural and psycho-emotional barriers in their everyday life, but the second ones have a strong influence on the self-identity and self-esteem of learning disabled young people. Moreover, the main strategies of stigma management developed by parents, namely medicalization and normalization, are generally interiorized by their children. Most of the Down young people highlight their "normalcy", with the annulment of all the traits ascribable to the syndrome, while the majority of autistic young people are aware of their difference, consisting in a lack of social skills. However, a scant group of interviewed suggests a positive image of their condition, which represents neither normalcy nor difference, rather "something in between", namely a variation of human diversity with specific strengths and weaknesses.

Marie Sepulchre: Blogging to claim rights and challenge the ideal of citizenship: the case of Swedish disabled people

(Main conference, paper)

The concept of citizenship is widely used in disability research, politics and policies. Yet, little is known about what citizenship means and how disabled people engage as citizens. This paper defines citizenship as membership in a community and draws on previous research that observed that the traditional ideal of citizenship corresponds to the situation of an able-bodied male citizen. This ideal is not fixed or solely elaborated by politicians however, but citizenship is continuously being reworked by groups of citizens claiming their right to full participation in society. As a case-study, this paper explores an online blog initiated by Swedish disabled people seeking 'full participation now'.

A content analysis was conducted to investigate what the bloggers write about, how they draw on citizenship to make their claims and whether there is a difference between women and men's engagement in the blog. Preliminary results indicate that bloggers denounce discriminatory practices at socio-structural level and heavily criticise the fact that they are both 'invisible' and 'pointed out' in a context of austerity measures.

It appears that female and male bloggers differ in the topics they raise (and do not raise). Furthermore, the bloggers do not claim special rights but position themselves as ordinary citizens who have the right to participate in society on the same basis as others. Finally, the analysis shows that the blog posts are underpinned by an ideal of citizenship that corresponds to a traditional (masculine) conception of citizenship emphasizing independence, control and access to the public sphere. A key difference, however, is that the bloggers challenge the disembodied notion of citizenship assuming that citizens are disconnected from their bodies.

Leen Sevens, Ineke Schuurman, John O'Flaherty, Vincent Vandeghinste and Frank Van Eynde:
Pictographs to the Rescue! Social Media for Functionally Illiterate Users

(Main conference, paper)

In order to be included in today's society, it is becoming increasingly important to be able to use the current available technological tools. The number of apps is growing exponentially, but very few are really accessible to people with Intellectual Disabilities (ID). However, users indicated very clearly their desire to interact with their friends and family on social media. The Able-to-Include project seeks to improve the lives of people with ID. Able-to-Include is creating a context-aware Accessibility Layer based on three key technologies that can improve the daily tasks of people with ID and help them interact with the Information Society.

These technologies are a text simplifier, pictograph translation technologies, and text-to-speech funtionalities. The integration of this Accessibility Layer with existing ICT tools will be tested in different pilots in Spain, Belgium, and the UK.

Within the Able-to-Include project, KU Leuven is responsible for the development of the Text-to-Pictograph and Pictograph-to-Text translation tools. The Text-to-Pictograph translation tool translates Dutch, English, and Spanish text into a series of Sclera or Beta pictographs. Additional to a shallow source language analysis, we use WordNets to link pictographs to groups of synonyms and retrieve appropriate or semantically related pictographs in the translation process. The system allows social media text to be converted into pictographs with a single tap.

The Pictograph-to-Text translation system provides help in constructing Dutch, English, and Spanish textual messages by allowing the user to introduce a series of pictographs and translates these messages into natural language using WordNet synsets and a trigram language model. So far, we have developed two different input methods. When using social media websites, users have access to the Accessibility Layer to construct pictograph messages using a pictograph hierarchy and a pictograph predictor. Their messages will be converted to text, which can be posted on the website.

Sonali Shah, Lito Tsitsou and Sarah Woodin: ʻI can't forget': Experiences of Violence and Disclosure in the Childhoods of Disabled Women

(Main conference, paper)

Violence against children is a human rights problem that cuts across gender, race, geographical, religious, socio-economic status and cultural boundaries. The risk of violence towards disabled children during their lifetime is 3-4 times greater than towards non-disabled children. It starts in early childhood, is more severe and linked to disablist structures in society. Violence is perpetrated by individuals and through institutional practices that are part of disabled children's everyday life. Violence is often misdiagnosed as related to individual impairment, and not recognised by professionals or the victims themselves. Presenting disabled women's reflections of childhood violence, help seeking and responses to disclosure, this article seeks to raise an awareness of violence towards disabled girls and the need for these to be recognised as a serious child protection issue to be included in official definitions of child abuse.

Tom Shakespeare and Sarah Richardson: "I don't feel quite as different": participants from The Sexual Politics of Disability, twenty years on

(Sexuality stream, paper)

This paper reports on follow up with eight participants in the Sexual Politics of Disability study (Shakespeare et al 1996, twenty years after the original research. Participants generally felt more confident about their identity, and their place in the world. As they aged, our participants felt more comfortable with their changing bodies, and contrasted this to their peers, who were only now experiencing limitations and discomforts of ageing, and were becoming less confident in their bodies. This reduced the salience of impairment as a difference. However, there was still stigma attached to disability, particularly to mental health conditions. Most participants had achieved relationships and intimacy over the years, whether or not they were currently single. The internet offered some additional possibilities for sexual contact, and was experienced as equalising. People felt confident in their sexuality and relationship choices. Several had widened their horizons in terms of potential partners or rejected traditional monogamous relationship models. All respondents expressed concern about how welfare changes had undermined people's choices and wellbeing, and considered that attitudes to disability were still problematic. Overall, the follow-up research confirms the claim of the original book, that the problem of disabled sexuality is not so much 'how to do it' as 'who to do it with'. However, the message from these respondents is that over time, disabled sexuality itself becomes less of a problem, as people in their fifties become more confident and comfortable with themselves.

Emma Sheppard: Kinked and Crippled: chronic pain and BDSM

(Sexuality stream, paper)

This paper will present findings from my PhD thesis research, which explores experiences of pain for disabled people with chronic pain who also engage with BDSM play. The research situates chronic pain as challenging and disrupting ableist, normative understandings of pain. Pain is often considered to be an individual experience, but also a universal one – and there is very little to differentiate "normal pain" (acute pain, the pain of intentional wounding or accident) from chronic pain; the two share a name and therefore must be the same, only with chronic pain lasting longer.

The paper will focus on the emerging theme of controlling pain – not just in terms of the neoliberal regime of self-control, but also how non-normative sexual practices can be a part of controlling pain – and how practices of controlling pain can be cripped, exposing normative constructions of appropriate reactions to pain.

<u>Mark Sherry: Human Trafficking and Disability</u>

(Main conference, paper)

Human trafficking is barely on the radar of the disability movement, disability studies, or human trafficking campaigns, and that is a travesty. This injustice means that when disabled people are the victim/survivors of human trafficking, the cases are almost never reported to authorities. In this presentation, I want to do four things: identify some of the common features of the trafficking of disabled people, by looking at the details of some convicted traffickers; discuss some of the reasons why these crimes are not reported; discuss the role of the fetish industry in the human trafficking of disabled people; and outline some of the ways practice and policies may need to change to include disabled people in human trafficking responses more effectively.

<u>Satnam Singh, Samantha English and Maxine Wood: Claiming, fighting for and surviving on benefits</u>

(Main conference, paper)

About us

Building Bridges research group is an inclusive research group of people with a learning disability who live in the West Midlands. Most members have no support from services, except for minimal tenancy support.

The group have been involved in researching their lives and the social barriers they face since 2010, Their research enables others to have a better understanding of these challenges so they can make changes that make a real difference to their lives.

Our research presentation

We are going to talk about our experiences of the welfare benefit system and how these have affected us. We claim a variety of benefits;

Job Seekers Allowance and ESA, DLA and PIP. Many of us have recently had assessments and reassessments by nurses to see if we are still entitled to the benefits we claim. Not all of us have health or medical problems, and the outcome of these assessments have been different for each of us. We have reflected on these experiences and we will share about the experience of living on benefits, being assessed and how we cope with the anxiety and stress this gives us.

Many have had benefit sanctions for failing to show they are actively looking for work and fear of sanctions on benefit payments is an ongoing stress. We are fed up of being forced to look for jobs. This is made worse by other benefit related problems such as paying the Bedroom tax.

We are also under pressure to get a bank account ready for Universal Credit, so we can pay bills in a different way. This is hard for us when we often don't have the right documents to open a bank account, don't know how to use them including cash machines so we want to keep our Post Office accounts.

<u>Satnam Singh: Disability football – from the coach's perspective</u>

(Main conference, paper)

I am from Building Bridges Research Group for people with learning disabilities. I am also a football coach for Smethwick Rovers, teaching people with learning disabilities to take part in football. We currently play in the Birmingham Ability Counts League, it runs September to May ‑ we play monthly games. We also sometime go to different football tournaments with Special Olympics. We train every week in the local park.

At the moment we only got about 7 players and 1 team which is growing every year. We get between 20 to 30 spectators at our tournament matches – they are parents, carers and friends.

It is important for people with a learning disability to have a full part in their communities, and do things with non-disabled people. But there are times when special opportunities have to be made to give people the chance to do the things they want to do.

Many people with a learning disability wouldn't be able to play in non-league football teams with non-disabled people because their football skills aren't good enough. Because of this people with learning disabilities don't have many chances of playing competitive football and do regular training.

The team is only for people with learning disabilities because it is easier for them to play in the same level with other people who got learning disabilities. The good thing is that it gives them chance to play the sport that they like. It also helps them to keep fit and meet up with and make new friends.

Jenny Slater and Kirsty Liddiard: "Like pissing yourself isn't the most attractive quality, let's be honest" Learning to contain through youth, adulthood, disability and sexuality

(Sexuality stream, paper)

Abstract: In this article, we (re)conceptualise containment in the context of youth, gender, disability, crip sex/uality and pleasure. We begin by exploring eugenic histories of containment and trace the ways in which the anomalous embodiment of disabled people (Shildrick, 2009) remains vigorously policed within current neo-eugenic discourse. Drawing upon data from two corresponding research studies, we bring the lived experiences of disabled young people to the fore. We explore their stories of performing, enacting and realising containment: containing the posited unruliness of the leaky impaired body; containment as a form of (gendered) labour (Liddiard, 2013a); containment as a marker of normalisation and sexualisation, and thus a necessary component for ableist adulthood (Slater, 2015). Thus, we theorise crip embodiment as permeable, porous and thus problematic in the context of the impossibly bound compulsory (sexually) able adult body (McRuer, 2006). We suggest that the implicit learning of containment is therefore required of disabled young people, particularly women, to counter infantilising and desexualising discourse and cross the 'border zone of youth' (Lesko, 2012) and achieve normative neoliberal adulthood. Crucially, however, we examine the meaning of what we argue are important moments of messiness: the precarious localities of leakage which disrupt containment and thus the 'reality' of the 'able' 'adult' body. We conclude by considering the ways in which these bodily ways of being contour both material experiences of pleasure and the right(s) to obtain it.

Roddy Slorach: Class and Disability in the Neoliberal Era

(Main conference, paper)

Has anti-discrimination legislation improved the lives of all disabled people? Claims of greater equality have been undermined by the neoliberal policies embraced by successive governments, further exacerbated by the more recent international consensus in support of austerity.

The disability movement has repeatedly split over the issue of civil rights legislation, with leading figures opting to work for change "inside the system". The evidence, however, suggests that change has been both slow and piecemeal, principally benefiting those with greater means and resources to enforce their rights.

The Americans with Disabilities Act and the UK's Equalities Act, championed across the world as model legislation, can best be described as 'free market civil rights'. The UK government in particular proclaims a wish to reduce dependence and help more disabled people into work. Cuts and deregulation in public and voluntary sector jobs and services, however, have led to increased poverty for "the 99 percent", with growing numbers of those still in work reporting worse mental and physical health.

This paper aims to show that a class-based analysis is more necessary than ever in order to confront the increasing impoverishment faced by most disabled people.

Helen Spandler: Mad and Queer Studies: What's love got to do with it?

(Mad Studies stream, paper)

The emergence of Mad Studies has some echoes with Queer Studies, another notable critical field of enquiry and activism. The 2016 Lancaster Disability Studies conference, marked by the co-occurrence of Mad Studies and Sexuality streams, offers an ideal opportunity to explore some interconnections - and tensions - between Mad and Queer studies.

This presentation will be based on a guest post written by Helen Spandler and Meg John Barker for the International Mad Studies Network blog (https://madstudies2014.wordpress.com/2016/07/01/mad-and-queer-studies-interconnections-and-tensions/). It will explore points of dis/connection within and between Mad and Queer and identify some mutual learning and key challenges. In doing so, it asks some difficult questions such as: Is sanism 'equivalent' to homophobia? Are there limits to our psychological and sexual expression? If so, who decides? and how? Ultimately, it will foreground a prefigurative politics based on practices of mutual kindness, understanding and consent. Achieving this, however, is a continual work in progress.

<u>Jill Smith: The affective economies of special school classrooms: how labelled children disrupt</u>

(Main conference, paper)

In this paper I use storytelling to suggest a productive turn to Ahmed's affective economies (2004) in research around dis/ability, childhood and autism. In reflecting upon the affective economies at work in the story of a labelled child biting a teacher, I analyse the ways in which emotions serve to produce particular ways of knowing and relating to children in a special school classroom. Emotions here are not individualised, internal, psychology but understood as being produced and moving between bodies. Particularly 'sticky' emotions circulate around the bodies of labelled children in which discourses of 'challenging behaviour' are read through small acts (a bite) and are cyclically read as being both signifier and consequences of labels such as autism.

These 'sticky' emotions conceal the affective economies at work which moralise the bite as wrong and produce a single, natural response; punishment. I explore what happens when the work of affective economies in the classroom is exposed and the implicit discourses concealed within them, disrupted. I suggest that thinking about how the emotional responses to such acts work to subjectivate labelled children can be an opportunity to explore how children resist and disrupt such processes through their everyday interactions. It may be that children, individuals, are always coming to be and be known within a 'scene of constraint' (Butler, 2004) but as the exploration of this bite reminds us, where there is power, there is always resistance (Foucault, 1979).

Janikke Solstad Vedeler and Terje Olsen: Hate speech targeted at disabled persons

(Main conference, paper)

British and American research has examined the phenomenon of hate speech and disability (e.g. Beadle-Brown et al 2014, Corker 2000, Shelly 2003). This body of knowledge shows that disabled persons are the target of hate speech and hate crime to a larger extent than other citizens. Being a victim of hate speech may cause serious personal problems as well as limitations in a person's life.

Furthermore, hate speech may create a political situation of "oppressive silencing" (Corker 2000) in which particular groups of citizens withdraw from societal participation in fear of stigmatizing and discriminatory utterance and practices. Experiences of hate speech towards disabled persons have so far not been examined in the Nordic countries. Our study examines the following questions: To what extent are disabled persons exposed to hate speech? What types of hate speech do they experience and in what contexts, and what are the consequences of experiencing such utterances? Which preventive measures could be implemented?

To shed light on these questions, the study includes a survey and qualitative interviews that will be implemented in the spring of 2016. The survey is partly based on the British questionnaire developed by Beadle-Brown and colleagues (2014). The survey will measure the scope and types of hate speech towards persons with different forms of disabilities. Interviews with disabled persons who have experienced hate speech will explore more in-depth their understandings of this phenomenon as well as explore their personal experiences. Interviews with representatives of disabled persons' organizations and other relevant milieu will be carried out in order to address preventive measures.

The presentation will provide preliminary results, with a particular focus on comparison of the Norwegian results with those obtained in Beadle-Brown's study. The results will be discussed in relation to a social justice framework as outlined by Fraser (2003).

Astridur Stefansdottir: Is the possession of language necessary for autonomy?

(Main conference, paper)

The discussion on the autonomy of those who are commonly labelled as severely disabled and use alternative methods of communication, has been marginalized in the literature. They are frequently excluded from the ethical discussion on autonomy on the ground that they cannot be autonomous since they do not possess the necessary abilities. If the definition of autonomy is solely based on personal qualities of the individual like reason and language, those labelled as severely disabled can be marginalized ethically. In this lecture I will argue that this view is a form of "cognitive ableism", and therefore unjustified.

It is important to develop a concept of autonomy that can be interpreted more universally. I begin by discussing the meaning of autonomy as an ethical value. Then I will outline the idea of relational autonomy and how that concept can be used as a way to recognize and enhance the autonomy of those described above. In doing so I will draw on the ideas of Laura Davy in her article: "Philosophical Inclusive Design: Intellectual

 Disability and the Limits of Individual Autonomy in Moral and Political Theory". The ethical basis of my discussion is the view that if we are to regard autonomy as an important ethical value it has to be understood more universally. Conceptualizing autonomy in this way is important because it can enhance the quality of life of those labelled as severely disabled. It also gives the necessary means to interpret important agreements like the Convention for People with Disabilities in such a way that it includes those that are most vulnerable instead of marginalizing them further.

Guðrún Stefánsdóttir: Postsecondary education for students with intellectual disabilities - Lecturers' views and experiences of the diploma programme

(Main conference, paper)

Post secondary education for students with intellectual disabilities is almost unheard of in the Nordic countries, but several colleges in America, Australia, and Europe offer such programs. These colleges seldom offer inclusive education services; since 2007, however, the University of Iceland has offered a Vocational Diploma in inclusive settings for students with intellectual disabilities. In this lecture the focus will be on qualitative research carried out in 2013 among 16 lecturers who have taught inclusive college courses. The courses are inclusive, i.e. offered to disabled and non-disabled students at the School of Education studying at the undergraduate level. The lecturers described the inclusive courses as positive both for non-disabled and disabled students. Since the diploma students have not completed the matriculation examination they are not eligible for undergraduate study at post secondary level. Therefore, student evaluation was the factor most often mentioned as most challenging aspect of the inclusive courses. A few of the lecturer thought the students have earned their PSE credits even though their evaluation was adapted. Other felt it was not reasonable to expect the diploma programme to be based on PSE credit. The lecturers also claimed that the experience had positive impact on their own perceptions of people with intellectual disabilities and their ability to contribute to society. The findings suggest that, despite some reservations, there seems to be a common agreement that this initiative is an important part of improving the access of disabled people both to education and society.

(Main conference, paper)

Background

Disability research as an academic field was established in1960s and 1970s in the Nordic countries as in the Anglo-Saxon world. Disability research was studied within the medical model, e.g. in medical and rehabilitation studies, while disability studies became a part of the social model, e.g. in social and psychological studies. According to a Nordic context disability was mainly studied within medicine, social science and special education (Roulstone, 2013). It has been a lack of theoretical perspective in disability research and according to that a discussion of theoretical approaches in disability studies has been raised during the recent years (see e.g. Gustavsson, 2004; Bhaskar & Danermark, 2006; Söder, 2013).

Aim

The aim of this paper is conceptually to describe and illustrate how vertical and horizontal knowledge integration appears in disability research, with an example from a study within brain injury.

Results

Vertical integration is an understanding between different levels on a biological, psychological and social level. Horizontal integration is an understanding across varying disabilities. The study indicates that vertical and horizontal integration in disability research are useful for a broader and deeper understanding of the phenomena. It also indicates that different theoretical perspectives has been more common in disability research during last years and fill an important need in the development of disability research as an academic field.

Magdalena Szarota: "An open house": Polish disabled women activists challenging the intersection of disablism and sexism

(Main conference, paper)

The intersections of disability and gender are proven by sociological research to cause greater discrimination and socio-cultural insignificance in the case of disabled women in comparison to disabled men or non-disabled women. Similarly, research and insights based on first-person narratives find that disabled women claim that they do experience particular kinds of systemic disadvantages both in private and public spheres. This means that disabled women are less likely to succeed educationally, economically, politically and socially and that existing stereotypes render them as passive, dependent, incompetent and helpless members of society. In consequence, those problems on the one hand, have been taken up by feminist disability scholars and were theorized (and critiqued) with the means of various concepts such as: double discrimination, the rejected body, invisibility, and on the other hand, they contributed to disabled women led-activism and disabled women organizations. However, most of the knowledge in disability studies about the lived experiences of disabled women and their activism concerns (predominantly) the Anglo-American 'case studies' as well as it's framed by the Western notions of 'activism', 'empowerment'. Hence, my autobiographical paper shifts the focus to the post-socialist context to examine why and how Polish disabled women activists have problematized and represented gender and disability in the public sphere. My analysis concerns the first webportal in Poland devoted to those issues. "An open house" was both: an interactive platform for disabled women and their families/allies and a website aimed at the general public to bring awareness about disability as a human rights issue as well as to challenge stereotypes about disabled women. I seek to find out in what ways those attempts and their further (re)interpretations by the media can broaden understanding of the challenges (and possibilities) that disabled women activists face when addressing disablism and sexism in a particular culture/country.

Danny Taggart: An illuminating triptych? Multifaceted perspectives on the issue of childhood sexual abuse

(Mad Studies stream, Survivor Research panel)

As the issue of childhood sexual abuse dominates the news cycle, academic and clinical psychology interest in the area continues to grow. With increasing recognition that psychiatric diagnoses are often merely discursive fig leaves covering up underlying childhood trauma, psychology is revisiting it's troubled past with victims of childhood sexual abuse. However their services are often poorly resourced in managing the chronic, complex mental health difficulties that can afflict this group and the move towards brief interventions mean that often survivors of abuse are abandoned in times of need.

It is in this context that the author considers his own distinct perspectives on the topic. He is a survivor of institutional childhood sexual abuse, a clinician working with victims of similar forms of abuse and an academic studying the ways in which these experiences can inhibit adult development. On the one hand these multiple perspectives offer the possibility of an illuminating triptych through which the perspective of each can clarify and sharpen the image of the others, even offering the possibility of a synthesis of views into a coherent whole. However this tripartite perspective also risks alienating him from the different vested interests of which he is part member. On the one hand taking up a survivor perspective risks rejection from academic enquiry that emphasises objectivity, while on the other the authenticity of the survivor voice may be compromised by the privilege afforded through professional status. This risks illuminating nothing and being situated nowhere. What conditions need to be met for this multifaceted perspective to be utilized in a way that can be helpful both to victims of sexual abuse and those charged with helping them? This question and the dilemmas that precede it will be discussed with relevance to others who have similarly pluralistic positions in related areas.

<u>Bethany Taylor: ʿMoving on': exploring the end of co-residence for people with learning disabilities and their family members</u>

(Main conference, paper)

Following developments in accommodation arrangements, the number of people with learning disabilities leaving the family home has increased over recent decades and this rise in prevalence is expected to continue.

My PhD research provides an in-depth exploration of this 'moving on' experience from a family perspective, recognising that the roles and expectations of family relationships fluctuate over the life course and particularly during transition periods. Generally, the available literature has concentrated on the planning phase of leaving home yet this research captured the temporal nature of this transition by involving families from various stages, spanning the entire process. Storybooks were co-constructed and creative methods were incorporated into narrative interviews undertaken with people with learning disabilities and their family members.

 Supported by a Prezi presentation, I will briefly outline this research, its rationale and the methods used. Moving on to consider research findings, I will explain and discuss the active role of both people with learning disabilities and their family members during this 'moving on' process.

Focusing on the active role of people with learning disabilities; developing new interdependencies, taking on responsibility in the new residence and asserting agency during this process, will each be considered. The significance of this active role in renegotiating interdependencies between family members will then be placed within the context of the current political framework. Implications for future research, policy and service practice will be highlighted.

Katharine Terrell: Interpreter, Carer, Teacher? Support workers and the sexuality of people with severe/profound learning difficulties

(Sexuality Stream, paper)

People with learning difficulties are subject to "troubling discourse" in relation to their sexuality (Winges-Yanez, 2014). This paper explores the way support workers have the potential to help remove disabling barriers that people with "severe" or "profound" learning difficulties face in expressing their sexuality. People who do not use verbal language to communicate rely heavily on support workers to interpret their communication (e.g. through gestures or eye gaze). This research is based on in-depth, semi-structured interviews of a small sample of support workers in the UK, which were qualitatively analysed using a phenomenological approach. This paper shows that the ubiquitous "person-centred" approach (Kaehne and Beyer, 2014) sites disabled people's difficulties within their person, rather than in social disabling barriers such as taboos around sexuality, preventing support workers from recognising and addressing potential barriers. Additionally, because people with learning difficulties are constructed as "vulnerable", support workers see their role as balancing clients' freedom of choice with safeguarding them from harm. These two concerns are seen as opposing forces, rather than part of one continuum (Hollomotz, 2011). Finally, this paper shows that even when support workers are willing to support their clients' sexual expression, their time is taken up with three types of activities: supporting basic needs (such as eating and personal care), administrative tasks, and pre-decided, limited activities, leaving little room for spontaneity, including people with learning difficulties choosing to be alone and to explore their sexuality. This inflexibility can be seen as part of a neo-liberal concern that disabled people live lives that are as "normal" as possible. Thus approaches to supporting non-verbal people are generally reactive, not proactive, and do not do enough to seek the desires of "service users", rather than simply respond to so-called "challenging behaviour" which is put down to the person's learning difficulty (Goodley, 2005).

<u>Liz Tilly: The outcomes and impact of the transfer from DLA (Disability Living Allowance) to PIP (Personal Independence Payment) for people with a learning disability</u>

(Main conference, paper)

The DWP started to replace DLA (Disability Living Allowance) with PIP (Personal Independence Payment) in 2013. Currently and until the end of 2017 people with a learning disability who claim DLA will be reassessed for PIP by an independent healthcare professional, however there is a slightly different criteria and assessment process for the two benefits. There is no replacement for the low rate of care in PIP, which could mean that people with a mild learning disability lose the care element of their benefit, resulting in a loss of £1133.60 a year of this benefit income. This group already face financial hardship due to the combined effect of living long term on welfare benefits and having poor budgeting skills.

This qualitative research project seeks to establish;

How many people have had a change in disability benefit income due to the reassessment and transfer of DLA to PIP?

Is there a pattern indicating that the level and type of support throughout the reassessment process affects the assessment outcome?

How did claimant experience the reassessment on a personal/ emotional level

How has a change of income affected their daily lives and the ability to live a full life in the local community

In the first stage of the project 50 people with a learning disability who live in the Black Country were recruited. The participants were asked to complete a questionnaire about their personal circumstances, welfare benefits including DLA and PIP rates and the support they receive.

In the second stage of the research project approximately 10 people from the first group who elect to, will be interviewed after the outcome of their PIP assessment is known. The presentation will share emerging findings from the research project.

Liz Tilly: Issues Relating to Using a Co-productive Approach in an Accessible Technology Project

(Main conference, paper)

This presentation discusses accessibility to being online and using social media for people with a learning disability, and the challenges to using a co-production approach in an accessible technology project. Ongoing developments in information and communication technology are changing all aspects of life. Access to the internet contributes to social inclusion; it can help people with a learning disability to keep in touch with others and reduce social isolation (Holmes and O'Loughlin 2014;

Caton and Chapman 2016), learn new skills, and gain access to information in a more accessible format, and provide visual rather than written information.

The Able to Include project aims to enable people with a learning disability to understand simple written text through the creation of an open source context aware accessibility layer using three technologies; text simplification, text to speech and text to pictograms tools (Able to Include, 2016). This presentation focuses on the Text2Picto technology, co-developed by partners KU Leuven, it provides a text-to-pictogram and a pictogram-to-text translation, which are standardised image-based representations of words or concepts.

The Able to Include project engaged people with a learning disability as active partners to test and feedback on the use and development of the pictogram app. The project was delivered in two stages. The first was to gauge internet and smart device access and use, through questionnaires and pilot groups, exploring the participants' current use of the internet, IT, smartphone devices and social media.

The second stage used feedback and observations from group-work sessions piloting the Able to Include app on tablets.

The challenges mainly related to the feedback needing to be sent electronically to the partners; there was only minimal contact with them and no face to face contact. The paper also outlines how other challenges were overcome to enable genuine and meaningful co-production.

<u>Ann-Charlott Timander: The (re) construction of positive identities in men and women with lived experience of long term mental distress</u>

(Main conference, paper)

Research suggests that people who experience a mental distress crisis often face an identity crisis as well. Furthermore, how they are perceived by others might also be dislocated. The (re) construction of a positive identity therefore becomes a core component of the recovery process. The main and general research question was to study whether and how Swedish and English men and women with experience of long term mental distress reclaim and (re) construct positive identities, following experiences of oppression on the grounds of mental distress and gender.

Research participants in this qualitative study were 33 Swedish and English women and men who took part in an in-depth interview about their experiences of recovery. Thus, this study was developed from a first person perspective on disability. The data were analysed using framework analysis.

By using a theoretical framework drawn from British disability studies (Thomas, 1999, 2007, 2010), it was possible to establish that both the women and the men experienced 'disablism' and 'gendered disablism', and that their experiences of oppression affected them in a negative way both psychologically and emotionally. However, by conceptualising identity from a minority studies perspective, it was also possible to establish that the participants exercised agency and resisted the experience of oppression, and reclaimed and (re)built positive identities. Social factors could either become a barrier to or a facilitator of these processes of recovery. In addition, processes of recovery were found to be to a certain extent gendered, although no significant differences could be found in the description of the recovery process and in the experiences of oppression between Swedish and English participants. This research adds to the call for Western societies to learn to validate and celebrate 'social difference', and to begin to explore innovative and creative ways of thinking about experiences of mental distress and recovery.

Svjetlana Timotic and Veronika Mitro: Sexuality of Women with Physical Disability from Vojvodina

(Sexuality stream, paper)

Organization for the support of women with disability ...IZ KRUGA – VOJVODINA from Novi Sad (Serbia) conducted qualitative study on Sexuality of Women with Physical Disability from Vojvodina in 2014. With this study we gave women with disability a possibility to talk about their sexuality and be actively involved in the research. The empirical data has been collected by means of focus groups and interviews. A total of 45 women with physical disability from various places in Vojvodina, ages 19 to 65, took part in the study. The study describe and analyze the experiences of women with physical disability in Vojvodina regarding sexuality: sources of information; physical changes during puberty; menstruation; intimate personal hygiene; going out, dating, first kiss, first sexual experience; gynecological exams and contraception; masturbation; relationships and marriage, pregnancy, giving birth and raising children.

Floris Tomasini: Overcoming disablism through embracing vulnerability

(Main conference, paper)

This presentation mines some conceptual ideas from Brené Brown (2012) and Andrew Solomon (2014) and explores how they may operate in challenging the psycho-emotional disablism (Thomas, 1999, 2007) of shame.

Andrew Solomon critically examines the relationship between shame and identity, pointing out that, "when we're ashamed, we can't tell our stories, and stories are the foundation of identity." One of the antidotes to shame, according to Brown, is embracing the power of our vulnerability: the courage to embrace our shadow and our light.

Shame, in Brown's words again, "corrodes the very part of us that believes we are capable of change." For Brown vulnerability has been mistakenly taken for weakness and something that needs to be covered up. Instead, Brown understands vulnerability as an authenticity to accept ourselves. In her words, "vulnerability sounds like truth and feels like courage. Truth and courage aren't always comfortable, but they're never weakness." (2012)

In short, vulnerability is the courage to forge the meaning of who we are. For Solomon this is only a single step of battling psycho-emotional disablism of shame. Solomon's mantra involves a second step: "forge meaning and build identity". Elaborating on the subtle difference between the two steps, he explains that "forging meaning is about changing yourself. Building identity is about changing the world." To illustrate these ideas, the presentation ends with the Vicky Lucas story. She has a facial disfigurement called Cherubism. She decided that it wasn't her face that she wanted to change, but social attitudes." Lucas is not saying 'I am here but I have cherubism'. She is saying 'I am here and I have cherubism'. She is 'forging her meaning and changing the world.'

<u>Zoe Troxell Whitman and Kathryn C. Oleson: Motivated Disclosure Patterns: Disability Identity Management in the Higher Education Environment</u>

(Main conference, paper)

This investigation is part of a larger study focused on disability-based disclosure patterns in college students within the higher education environment. It applies psychological theories of identity management and disclosure disconnects to understand students' motives for disclosing their disability. In addition, academic variables, overall life satisfaction and disability-based demographics were explored. The sample consisted of 57 college students representing a wide range of American colleges and disabilities. In this paper, we first focus on motives for the disclosure or nondisclosure of a disability status as a strategy in disability-based identity management, examining both the antecedents and outcomes of disability-based disclosure. Second, we articulate the relationship between disability identification and life satisfaction. Finally, we apply the theory of disclosure disconnects to the use of disclosure decisions as an identity management strategy among the college student sample. Furthermore, we posit that the disclosure of a disability-based identity, and motive source for disclosing, will generally predict positive outcomes for the individual, specifically a sense of overall life satisfaction and disability identification. Our results suggest that the identity management strategies used by college students with disabilities are highly correlated with an individual's overall life satisfaction and disability identification. The findings indicate that positive outcomes are related to this disclosure; this trend is amplified with regards to socially-motivated disclosure, thus demonstrating the use of disclosure as an effective identity management strategy. In contrast, nondisclosure is far less likely to produce the same positive benefits, and may in fact be harmful.

We conclude by discussing the implications of these results and their application to the higher education environment in supporting students with disabilities.

Maria Tsakiri: Disability Film Festivals; the spaces where crip killjoys take action

(Main conference, paper)

It was not until recently that Disability Film Festivals came on the scene with a view to offering a close-up of disability. Their main aim has been to promote changes in how disability is viewed.

In their depathologizing analysis, Mitchell and Snyder (2008) claimed that "disability film festivals provide alternative 'contexts for reception' and operate as active filters for forging new ways of 'being disabled' in the twenty first century."

My paper will attempt to outline some of the characteristics and functions of Disability Film Festivals which turn them into spaces where collective voices find ground to flourish. In my analysis, I will be looking at Disability Film Festivals as cross-cultural and cross-disability spaces where disability aesthetics (Siebers, 2006) and the politics of atypicality (Mitchell & Snyder, 2008) are introduced to the audience.

Disability Film Festivals also promote the action of "crip killjoys". Johnson and McRuer (2014) drawing on Ahmed's (2010) work on feminist killjoy and willfulness created the idea of crip killjoy and crip wilfulness. Crip killjoys refuse to fake satisfaction and happiness to justify social norms that are actually oppressive for disabled people. Disability Film Festivals give space to crip killjoys through the filmic representations and also by bringing together a community consisted by viewers, artists and activists with disabilities. Disabled people act as crip killjoys when they claim and stand for the places they wish to have in society. In this setting disabled people raise their voices against the oppression of compulsory normalcy which is reinforced also by neoliberal practices.

Drawing on documentary films where crip killjoys take action and on further educational and political actions of disability film festivals, this paper suggests that disability film festivals are the agonistic spaces for collectivity and creativity where visual activism works towards inclusion and social justice.

Anne-Marie Tuikka: Tackling the problems faced by families with autistic children in Finland

(Main conference, paper)

Finland is often defined as one of the Nordic welfare states, which aims to provide high quality healthcare and social care to their citizens (Lehto 1999). Alongside other groups of Finnish citizens, disabled people have a right for these services and to other services which are assessed based on their personal needs. However, the objectives of Finnish disability policies are not always met in the reality. (Miettinen & Teittinen 2014.) Thus, I have started to study, how the rights of autistic children and their families are met in Finland in the spirit of participatory action research (Kemmis & McTaggart 2005).

At this stage of the study, I have visited four parental support group meetings meant for parents of autistic children and discussed about possibilities for future collaboration. In these meetings, parents have discussed about the social and health care services they or their children have received.

In these discussions, parents from different municipalities noticed that they have received different kinds of services for their children. They also noticed that sometimes the application procedure for similar type of service varied across municipalities.

The variation in the content and in the accessibility of services is not surprising in Finnish context because Finland has decentralized social and health care service structure. To understand better the inequalities experienced by parents of disabled children, I will interview approximately 10–15 parents of autistic children during spring and summer 2016. I will also search court rulings related to social and health care services offered by the municipalities.

This article aims to define, which kind of problems parents of autistic children experience when they apply or receive social and health care services. This articles also describes, how parents of autistic children tackle the problems they experience while applying or receiving social and health care services.

Agnes Turnpenny, Beckie Whelton, Lisa Richardson and Julie Beadle-Brown: Use of information on outcomes and quality of services in decision making about services for people with intellectual disabilities and autism

(Main conference, paper)

Background:

User choice has been at the centre of government policy on social care. Information on the quality and availability of services is central to user choice. This study aimed to explore decision-making – particularly the role of quality information – about services for adults with learning disabilities or autism.

Method:

Semi-structured qualitative interviews were conducted with 11 service users, 12 family carers, eight care managers and four advocates. Interviews were transcribed and coded using a combination of a priori, emergent and in vivo codes. The segments were analysed using Attride-Stirling's thematic networks tool. Basic, organising and global themes were identified by groups of actors and their experiences compared and contrasted.

Results/Findings:

Global themes that emerged were related to the type and sources of information, the decision-making process, barriers to choice, and the emotional aspects of the process. Many individuals and families had limited access to information, which in turn restricted choice. Care managers strived to offer options to individuals, but this could be restricted by availability, urgency of the move or other challenges.

Conclusions:

This study supports existing evidence that suggests low awareness and limited use of quality information among users of social services and their families in England. Care managers had access to a broader range of sources of information and were often gatekeepers for this information. Implications for commissioners, care managers, the Care Quality Commission, families and individuals themselves will be highlighted.

Natalia Valencia and Juan Camilo Celemin: Research results of a program on inclusive education for persons with disabilities

(Main conference, paper)

The Saldarriaga-Concha Foundation has been developing, for the last six years, an applied research-strategy to include students with disabilities in the Colombian educational system. The initial proposal was constructed based on evidence of other experiences, such as New Brunswick, Canada; and on an extensive literature review. The initial four years of implementation served as a laboratory to identify what works and what does not, since we have to adapt the international initiatives and experiences to the Colombian public education context: crowded classrooms, poor-trained teachers, lack of relevance of courses contents.

In those years, we built a training process with more than 3000 teachers, in 200 schools, from more than 30 regions spread all over Colombia. We also included an advocacy and technical support component to formulate and promote inclusive policies with the authorities that manage public education.

The work developed with students, parents and teachers to promote the understanding and acceptation of living in an open and inclusive environment at mainstream schools; taught us that education is a process presents in all the contexts in a human being life. It also showed us that either, inside and out; of the classroom to promote inclusive practices there are five principles that should be consider: equity, relevance, accessibility, flexibility and participation.

The fifth year the program was adjusted and the final proposal focuses its work in the promotion of policies, culture and practices, which recognize the diversity and allow to devise strategies for participation and learning.

This program aims at developing a flexible and innovative proposal to access to education for children and adolescents in Colombia, in an inclusive setting, without any discrimination. We hope that our findings can be used for societies within the global south, where public education still struggles with quality and inclusion.

Simo Vehmas and Ben Curtis: Social Constructionism Refuted

(Main conference, paper)

In the disabilities studies literature, the following question is often taken to be of central importance: Are impairments objective features of individuals who have them, or are they socially constructed?

There are three possible answers:

1:      Objectivism: They are entirely objective, and not even partly socially constructed.

2:      Constructionism: They are entirely socially constructed, and not even partly objective.

3:      Hybridivism: They are partly objective, and partly socially constructed.

In this paper we consider the meaning of this question in a more explicit fashion than is usual, and argue that it should be framed in terms of necessary and sufficient conditions. We argue further that if we do so frame it, and get clear about what the question involves so framed, Objectivism can be seen to be true. We thus place ourselves in opposition to most in the disabilities studies literature, as Objectivism is almost universally rejected. We defend our account by showing that although Constructionism and Hybridivism contain germs of truths, the underlying positions are confused, and once one gets a clear view of this, one can see that those truths are not relevant to the question of disability as a social construct. Our approach, by contrast, offers a clear view of the question of social constructionism and how it relates to other important issues in disability studies. In addition, it provides a way of making clear progress in practical matters of improving conditions for disabled people.

Shruthi Venkatachalam and Parthiban Babu: Contesting practices and spaces within the criminal justice system: case on disabled women based in Tamil Nadu, India

(Main conference, paper)

The present era marks a paradigm shift within disability discourse that calls for human rights approach to be espoused to address inequalities and discrimination against disabled citizens which is in response to the United Nations Convention on Rights of Persons with Disabilities which India ratified in 2007. At the same time, the concerns of the neglected intersectional subjects within the disability population began to surface as a result of academia and activism. Yet, some of the disquiets of these intersectional subjects get obscured in the larger struggle for establishing and affirming equal rights as being citizens. One such marginal section is the disabled women who are much more vulnerable due to their twofold status of gender and disability that has constructed an undesirable outlook towards them on the grounds of socio-cultural norms and practices in the country. Consequently, the concerns of disabled women are found insignificant and their experience of fierceness and abuse goes unrecognised in any struggle for change Considering the existence of marginality and exclusion of disabled women in the mainstream discourse on violence, this paper envisions to understand the experience of disabled women who have been afflicted with violence and further who have experience of confronting the criminal justice system in search for justice. The typology of violence is narrowed down to sexual violence to stabilise the focus on the experience of disabled women within the criminal justice system. Using qualitative enquiry, the case study method involving critical incident technique is used to capture critical interactions of disabled women with other agents like lawyers, police, and social activists within criminal justice system. Thus, this paper enables to comprehend various practices and spaces in terms of social relations and attitudes of the various agents that the disabled women encounter in quest for justice within the criminal justice system.

<u>Lotta Vikström, Erling Häggström Lundevaller and Helena Haage: Untimely deaths and death causes among women and men with or without disabilities in 19th-century Sweden</u>

(Main conference, paper)

This analysis explores more than 500 individuals with disabilities over their lifespan to examine the risks of dying and causes of death in 19th-century society. We make use of Sweden's 19th-century parish registers (digitized and hosted at the Demographic Data Base, Umeå University) to identify people the ministers defined as disabled, and to construct a reference group of non-disabled persons. These sources enable us to conduct quantitative life course analysis of individuals' death. Our first findings indicate that disability increased substantially the risks of dying among women and men, and in particular of the latter, hence men paid a 'higher' price for their disability than did women. There is also statistical evidence that some types of disabilities cut the length of life more than others. To gain a deeper understanding of the diverse mortality risks in relation to gender and different disabilities, we analyse the death causes reported in the registers. Making account of the gendered expectations at the time and by combining deviance theories from sociology studies with historical sources and demographic methods, we obtain new insights into how and why life ended untimely for people with disabilities.

In all, our mortality results both reflect and differentiate how disability and gender worked to shape individuals' health and survival chances in history, or, their 'liveability', to put it differently. Our historical results further serve as a relief of interest to compare with recent mortality findings on people with disabilities.

<u>Hannah Ware: Migration and Disability: Searching for constructions of identity and experiences of belonging in the narratives of Eastern European migrant children identified with SEND in England</u>

(Main conference, poster)

Children identified with Special Educational Needs and Disabilities (SEND), particularly those with a migrant status, are often marginalised within society. Their voices are unheard within academic discourses and they are especially underrepresented on their own terms. This research-in-progress aims to bring the narrative voices of Eastern European children identified with SEND living in England to the fore. Taking an inclusive and participatory narrative approach this work (re)searches the children's stories for constructions of identity and experiences of belonging. This methodological approach is guided by Oliver (2002), who argues that epistemologically research must reject the notion that it is investigating the world and rather replace it with an understanding that 'research produces the world'. In testament to this understanding, this research seeks to elucidate the unequal power relations in society by taking an approach that allows the children to express themselves autobiographically, as far as possible, on their own terms using creative art based methods including: video voice, self-portraits and life mapping.

<u>Brian Watermeyer: Disablism, identity and self: Discrimination as a traumatic assault on subjectivity</u>

(Main conference, paper)

Having, to a great extent, been informed by historical materialism, the international disability movement has tended to eschew investigation of subjective and emotional aspects of disability, warning against the danger of psycho-pathologization. Yet, it is becoming unarguable that the socially engendered trauma of disablism must leave impressions on subjectivity. Drawing loosely on ideas from psychoanalysis, this paper explores the effects of symbolic assaults often associated with the disabled identity, thus connecting intra-psychic and socio-political arenas. The conceptual ideas employed emerged from psychoanalytically oriented group psychotherapy with severely physically impaired adults performed by the first author. The authors argue that the ongoing nature of socially engendered trauma suffered by disabled persons perpetuates marginality, through internalization of self-punitive psychological defences which corrode the entitlement necessary for an assertive political movement. Surviving in a world which continually questions one's belonging leaves little personal resources for debunking oppressive social phenomena. Discursive as well as material changes are essential if internal life is to be reclaimed, overcoming internalized relational inequalities.

<u>Jay Watts: Mad Women and the History of Advice</u>

(Mad Studies stream, paper)

Since the nineteenth century professionals have been preoccupied with telling women what to do for their own good. This professionalisation of advice was often a way of co-opting lay advice and selling it back to women. For example, the medical profession in America was formed when it became obvious 'heroic medicine' was violent, and the soft practices of witches, midwives and healers more effective. Advice has often been a way to de-politic social movements, and maintain the status quo. The radical Human Potential Movements of early feminists, for example, became twisted into the individually focused, self-help culture that so serves a neoliberal ideology today. In this paper, I will take us through a brief tour of the changing shape of advice in the past centuries to see how we have landed in today's predicament - one where responsibility for taking 'good' advice is injected into the subjectivities of women. I will focus on how such 'psychocentrism' has come to locate madness as genderless in psychiatric spaces, and how this individualisation divorces women from the embodied socio-political experiences which constitute madness. I will argue that we must find new feminist ways of understanding mad experiences, less in individual therapies and more in intersectionist movements to reconnect the personal and the political in a way digestible to digital generations.

Magnus Wiberg and Dimitris Michailakis: Problematic Online Gaming Among People with Disability: Troubles or Issues?

(Main conference, paper)

This paper utilizes C. Wright Mills' distinction between private troubles and public issues as a theoretical point of departure. Video gaming has become one of the world's most common pastime. According to certain estimates there are more than half a billion people all over the globe who are playing video games for more than one hour each day. The previous prejudices surrounding the 'gamer' discourse have been questioned due to the fact that more or less everyone in the West plays games nowadays, including people with intellectual or cognitive impairments. While some consider the growing minority that chooses to renounce their family, friends, and occupation in order to play games as a social problem in the making, the same people disregard the vast diversity of the people that are included in this group, not to mention the complexity of their social situations and their own accounts. This paper proposes that the phenomenon could be explained by connecting the distinction "private troubles and public issues" with other relevant concepts as formulated by C. Wright Mills. These concepts will be applied in an analysis of seven semi-structured interviews with representatives from the three main disability rights movements that represent persons with neuropsychiatric impairments in Sweden. While the situation seems to stem from certain private, or even widespread, troubles, the process of translating private troubles into public issues has hitherto been somewhat tardily. The use of a critical sociological perspective on disability and concepts such as social inclusion and embodiment open up for radical and creative implications that will contribute to the refinement of the concept of disability.

<u>Alison Wilde and Stephen Millett: We accept her. One of us: Belonging, difference, and identity in the discussions of young people watching 'Freaks'</u>

(Main conference, paper)

We showed the film Freaks (1932) to three groups of thirteen year old young people, as part of a research project on 'disability films' and identities. All the films discussed facilitated discussions of integration, rehabilitation, independence/autonomy and belonging, but only Freaks encouraged the participants to question conventional discourses on acceptance and tolerance and to reveal the ideological character of the concept of tolerance.

The marriage scene, of non-disabled 'gold-digger' Cleopatra to Hans, a man with restricted growth, exemplifies the mimetic strategies employed within the film to expose the contents of the disabling gaze/stare. The young people's discussions of this scene allowed them to perform a group-based 'ethical encounter' (Hadley, 2014) with a very different solidarity-based perspective of disability which inverted the normalcy-centred dialogue on tolerance and belonging. Alongside this, the freak-show style vignettes of disabled actors carrying out difficult tasks, provided opportunities for 'staring' which, in turn, facilitated discussion of previous assumptions and fascination with 'extraordinary bodies.' Overall, not only did Freaks allow them insights into the limited conditions of possibility of the cultural representation of disabled people; the inversion of discourses of tolerance began a process of questioning hierarchies of privilege and what it is to belong and to be human.

Val Williams, Sue Porter and Jon Symonds: Three or four ways of mentioning the toilet: a conversation analysis of live recordings of social care assessments

(Main conference, paper)

UK social care policy has for many years enshrined the principles of personalisation (DH, 2005 onwards) whereby services should be tailored to individuals, but English social work has for several years been striving to find a place which is less about 'power' and certainly less bureaucratic in process (DH, 2012; Lymbery, 2012; Williams & Porter, 2014).

This paper reports on research carried out about social care assessments with disabled adults, just after the implementation of the Care Act in April 2015. The assessor's task is to help identify the outcomes which the individual client wants, and then to determine whether those outcomes will attract funding. However the overt concern is also to establish a good relationship with the client. The project as a whole was co-produced with a disabled people's organisation, the West of England Centre for Inclusive Living. This presentation focuses on seven 'naturally occurring' recordings of assessments in action, which were transcribed and analysed using the tools of Conversation Analysis (CA) (ten Have, 2007; Heritage & Clayman, 2010). It turned out that practitioners did 'friendliness' as a way of being personalised, and getting to know the individual. However, that could result in problems when faced with the interactional task of getting through the questions which had to be addressed during the meeting. The interactional problem for both assessor and assessed is this: given the need to relax the formality of the assessment process, and to get to know the person on their own terms, how then can outcomes, need and wellbeing be jointly negotiated – particularly when it comes to deeply individual matters of personal care?

(Main conference, paper)

This presentation will explore issues arising when working at the boundaries of Disability Studies and other established fields of social sciences academic research. Disability Studies is frequently described as interdisciplinary but the scope of this interchange is often limited to working with like – minded colleagues in other academic disciplines. This is understandable in a situation where crossing over into other fields has often resulted in a reception characterised by indifference, misrepresentation and / or misunderstanding. These are facets of the endemic marginalisation of disabled academics throughout academia.

Nevertheless there are indications that engagement with other fields may be worth the effort. Arising from the nascent work of an international group of academics working in Sociology, this presentation will offer some possible ways forward in challenging established orthodoxies in other fields. Issues covered will include: the complexities, challenges and strengths of working with multiple approaches, (e.g. drawing on medical and Critical /Disability Studies), and resistance to the marginalisation of disabled academics. The value of working on multiple issues with a group of like – minded colleagues, rather than simply on one problem as an individual, is discussed.

Eda Yesilkaya, Allen Thurston and Bronagh Byrne: Decision making and power in primary schools for visually impaired students

(Main conference, paper)

This research project reports two case studies of visually impaired students in schools in Northern Ireland. The case studies will show that approaches to decision making surrounding social and academic inclusion and adaptations to physical spaces in the school can vary dependent upon where the schools see power residing. Past research has shown that vision loss may affect visually impaired children's adaptation process and socio-emotional skills, thus visually impaired children might respond to the environment in different ways (Fraiberg, 1977; Teplin , 1983; Brambring, 1993; Tuttle &Tuttle, 2004; Campell, 2007). A case study approach was used to explore the experiences of two visually impaired students at home and primary school. Data was collected over a 6-month period using observation and interviews with students, parents and school staff. Data indicated that schools took widely differing approaches to inclusion. One school ensured significant involvement of the family in school planning. The views of the young person were taken into account and they were encouraged to be independent around the school. Excellent liaison with parents included regular face-to-face meetings to discuss progress and next steps. The other school took responsibility for all decision-making. This often included making decisions about adaptations to the environment that would not have been optimal the child. Contact with parents was limited and tended to be information giving from the school. The differences in where power resided seemed to lie at the heart of decision-making in each school. Flatter power distribution and inclusive decision making, that took account of the student view, was successful in promoting social inclusion, physical mobility and academic performance in one case study. A high power differential (school high: parent/student low) in the other case study led to assumptions being made about the need that did not always appear optimal to the observer.

Engin Yilmaz: The Phenomenon of Disability Perception in Blindness

(Main conference, paper)

The present study aimed to investigate the perception differences of blind people about their blindness, the determining factors of those differences and their possible consequences. For this purpose a qualitative survey was conducted on 36 blind participants, 22 men and 14 women.

The findings revealed 5 perception levels from affirmer participants to normalizers. It is found out that, while affirmers and partial affirmers view blindness as a part of their identity, a difference and are not eager for a possible cure, for negative perceivers and normalizers, blindness is certainly a deficiency and is the main causes of their troubles in their lives. Independent living skills and equal interrelation with both blind and sighted people were observed as the most determining factor of perception of disability. The role of schools for blind had dualistic effects. While they provided independence skills, they had inhibitory effects in the lives of the participants. The impact of sight degree, family atmosphere, employment area, technology and blind related NGO's as facilitator or inhibitory factors were also discussed. The findings showed that people with more positive blindness perception had more active roles on both blind related and other NGO areas.

Karen Young: Where is the person in 'personalisation'?

(Main conference, paper)

The policy shift towards the personalisation of social care aims to enable those who receive care services to exercise choice and control over their support arrangements. However little is known about how personalisation is actually experienced by people with learning disabilities and their families. In Glasgow, personalisation has been seen as a means to reduce social care spending within the context of austerity and its implementation has coincided with the cutting of support services for people with learning disabilities. These changes impact upon the daily lives of those who have learning disabilities and their families, many of whom have been faced with making alternative arrangements with limited funds.

In this paper I discuss the initial findings of my PhD research, which seeks to explore the experiences of people with learning disabilities and their families in Glasgow as they negotiate these changes and how they interact with complex issues of dependence and interdependence within family care relationships. Utilising feminist research methods, underpinned by a critical realist/social model understanding of disability,

I carried out semi-structured family group and individual interviews with 18 families. Drawing on feminist care ethics which recognise human interdependency and the relational aspects of care, I will present initial insights gleaned from the stories of families whose daily lives, routines and relationships have been affected by austerity and policy change.

Dongchul Yu and Sekwang Hwang: Disabled people's Movement in South Korea: past, present and future

(Main conference, paper)

This paper aims to critically reflect the status and future directions of disabled people's movement in South Korea (hereinafter Korea) to examine i) value and purpose ii) motivation iii) tensions since 1980s.

Unlike how disabled people's movement developed in Western countries, the Korean disabled people's movement started with the democracy movement under the military government, and began the political strike to achieve freedom for disabled people from oppressions since Seoul Paralympic games 1988. Disabled people's organisations expressed anger that the budget for the Paralympic games was unjustly about 5 times higher than that of disability support services. Disabled people saw no alternative than to get together and they organised a public protest against the government to get protection for care, education and employment. In this period, the main leading groups were educated people with physical impairments and professionals such as lawyers and academics. However, disabled people were still poor and their rights were consistently ignored.

From the 2000s, the focus of disabled people's movement moved to human rights, especially in terms of mobility and independent living. At that time, the consumerist approach in service user involvement was introduced. Interestingly, the less educated and severely disabled became the leading group of the movement and disabled people's organisations made strong relationships with voluntary organisations led by non-disabled people. As a result, many new legislations and policies such as Disability Discrimination Act were introduced or enforced.

The disabled people's movement has enormously influenced the values, norms and system of Korean society, but we found there are serious tensions that prevent the development of disabled people's movement: 1) disability classification system, 2) relationships between professionals and disabled people, 3) a shortage of services and a provider-orientated delivery system, 4) political identity and transversal politics, and 5) lack of disability studies theory.

Nordic Network on Disability Research (NNDR) conferences brings together researchers, policy makers, activists and practitioners to share scholarship and ideas, and provides a forum for Nordic and international collaboration in disability studies. The conference welcomes a wide range of contributions applying social, cultural, historical and philosophical perspectives to the study of disability. Its next conference will be held in the city of Örebro a town in the heart of Sweden, May 3 – 5, 2017.

IMPORTANT DATES

Call for abstract: 15 August 2016

Abstract deadline: 1 November 2016

Abstract confirmation: 15 January 2017

Conference registration opens: 15 January 2017

Conference registration deadline: 15 March 2017

NNDR 14th Conference: 3-5 May 2017

Welcome to NNDR-14th conference at Örebro 2017 !

Further details can be found at: www.oru.se/jps/nndr2017