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Vulnerable Normality: Popular Neuroimaging and the discursive logic of the (dis)able(d) brain

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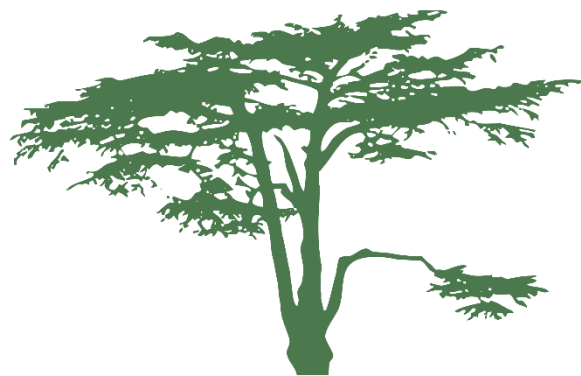
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LANCASTER DISABILITY STUDIES CONFERENCE
#CeDR18

Centre for Disability Research (CeDR)
Lancaster University

11-13th September 2018



CENTRE FOR DISABILITY RESEARCH



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Cover Image: Mosaic by Raana Salman (2008)

Index

Welcome	3
Reviewing Committee	4
Mosaic by Raana Salman	5
Programme	6
Keynote Speakers	7
Critical Neurodiversity Stream	15
Craftivism Workshop	16
Disability & Society: Meet the Editors	17
Book Launch	19
Abstracts:	
Papers, Panel and Poster Presentations	20
Symposia	212

Welcome to the 2018 Lancaster Disability Studies Conference. This is the ninth conference the Centre for Disability Research (CeDR) has hosted here at Lancaster University. As in previous years there is great diversity amongst our delegates who hail from over 26 different countries and bring experience as disabled people, activists, post-graduate students, researchers, academics, practitioners and many who combine a number of these roles.

I would like to thank the Department of Sociology, its former Head of Department Professor Corinne May-Chahal and current Head, and CeDR stalwart, Dr Chris Grover for their on-going support for the conference and for the centre.

This year Dr Damian Milton convenes a Critical Neurodiversity stream which he introduces on page 15.

We would like to extend our thanks to Taylor and Francis, publishers of Disability & Society, who have sponsored the drinks reception on Tuesday evening. Liverpool University Press, publishers of Journal of Literary and Cultural Disability Studies who sponsored a delegate bursary.

Looking ahead the tenth Lancaster Disability Studies Conference in September 2020 we are exploring the possibility of a linked and overlapping conference with our Lancaster colleagues from Centre for Mobilities Research (CeMoRe). This will open up exciting opportunities for dialogue between the fields and also an opportunity to make the conference, its debates and discussions more accessible to those not able to join us in Lancaster. We will keep you posted!

Hannah Morgan
Conference Organiser

Reviewing Committee

Nicola Burns, Lancaster University, UK

Rebecca Fish, Lancaster University, UK

Chris Grover, Lancaster University, UK

Chris Grover, Lancaster University, UK

Patrick Kermit, NNDR & NTNU, Norway

Damian Milton, Tizard Centre, University of Kent, Participatory Autism Research Collective (UK)

Michele Moore, University of Oxford, UK

Hannah Morgan, Lancaster University, UK

Helen Spandler, UCLan, UK

Simo Vehmas, Stockholm University, Sweden

Mosaic by Raana Salman (2008)

The image we have chosen to represent the 2018 conference shows a piece of art by Raana Salman, Mosaic.

Raana, 29, has fragile x syndrome, the most common form of inherited learning disability. She created the 60x60cm varnished collage when she was at a specialist college studying organic horticulture and taking part in art workshops. Inspired by the natural environment, Raana developed the intricate work over several weeks. From designing the maze-like pattern to sourcing and sorting photographs, magazine cuttings and coloured paper by shade and tearing them into hundreds of tiny pieces, Close up, the tiles show a variety of materials and objects including flowers, pebbles, stone and grass.

Mosaic is one of the most elaborate pieces of art Raana has created. The artwork reflects what people can achieve when they have the freedom to pursue their interests and the kind of support that enables their creativity to flourish.

Raana's sister Saba Salman is lucky enough to have the piece hanging in her home. Saba is a freelance social affairs journalist who writes for the Guardian; she has a particular focus on learning disability. Raana has influenced Saba's forthcoming book *Made Possible*, a crowdfunded collection of essays on success by high achieving people with learning disabilities. *Made Possible* aims to shatter stereotypes about learning disability and challenge the negative narratives that currently exist.

* Conference participants wishing to order *Made Possible* can enter LANCASTER10 at checkout before 30th September to receive 10% off: <https://unbound.com/books/made-possible/>

Programme

Tuesday 11th September	
10.00	Registration with refreshments
11.00-11.30	Introductions
11.30-12.30	Keynote: Esther Fox -
12.30-13.30	Lunch
13.30-15.00	Paper Session A
15.00-15.30	Break with refreshments
15.30-17.00	Paper Session B
17.15-18.00	Disability & Society: Meet the Editors
18.00-19.00	Drinks reception including poster presentations and book launch
20.00	Evening meal

Wednesday 12th September	
09.30-.10.30	Keynote: Niklas
10.30-11.00	Break with refreshments
11.00-12.30	Paper Session C
12.30-13.30	Lunch
13.30-14.30	Keynote: Phillipa Wiseman
14.45-15.45	Paper Session D
15.45-16.15	Break with refreshments
16.15-17.15	Paper Session E
20.00	Evening meal

Thursday 13th September	
09.30-11.00	Paper Session F
11.00-11.30	Break
11.30-12.30	Keynote: Damian Milton
12.30-13.00	Endings Packed lunch available to take away

Keynote Speakers

Niklas Altermark Crip Solidarity: Vulnerability and Political Struggle

Esther Fox Reframing Utopian Futures: How can disabled activists problematise the pro-screening debate?

Damian Milton “Said the autistic endorsed autistic informed academic”: Neurodiversity, Academia and Activism.

Phillippa Wiseman Embodied citizenship, disability and the public/private divide

Niklas Altermark

Lund University (Sweden)

Crip Solidarity: Vulnerability and Political Struggle

In this keynote, I will argue that the insight that vulnerability is a defining characteristic of all human lives can revitalise our understanding of what solidarity is. The purpose is to revive this concept from its zombie like existence at the margins of political discourse by infusing it with disability theory.

To start with: Why should we engage with the suffering of others? Why should we act politically to better their situation? What are the grounds of political alliances between oppressed groups and those not directly affected? Mounting problems such as austerity politics, discrimination of groups perceived as deviant, and xenophobia being the standard response to what is called 'the migration crisis', all underscore the need for critical analysis and political struggle. Within critical theory and activism, there seems to be a broad consensus that these political battles need to be fought by alliances - of directly affected groups and their allies as well as by coalitions of groups that are oppressed by interlinked structures of power. However, in a time that is commonly characterised as 'hyper-individualistic', it is hard to see what the basis of such alliances might be. Political engagement today often appears to stem from sentiments of empathy or even pity, leading to a form of activism that resembles charity. As has been noted by disability activists and scholars, as well as critical thinkers concerned with other issues, this tends to reproduce inequalities between the oppressed and their benevolent helpers. At the same time, such political responses to oppression and suffering are often individualistic in nature; the solution to the 'migration crisis' becomes sending worn out clothes to charity organisations and the answer to the social exclusion of disabled people might for example be programs tailored to help members of the group enter the labour market. Meanwhile, the structures that create the problems in the first place are left intact.

Historically, another way of responding to oppression and inequality has been through solidarity - not for the oppressed but with them. However, as I will argue, our present notion of solidarity is utterly unprepared to spark political alliances as well as critical analysis. Tracing how the meanings of solidarity shifted throughout the 20th century, primarily within the labour movement, I show how this

concept has transformed from being a way to talk about social struggles and power to become a notion of national unity and a legitimisation of the welfare state. Solidarity was tamed and depoliticised. Furthermore, the transformation of 'solidarity', which was intimately associated with the formation of the welfare state, also resulted in a strengthened emphasis on the obligation to work, in turn justifying disciplinary measures against those perceived as unable to. In our present time, the very same moral of 'work as duty' is used to legitimise the destruction of welfare systems targeting groups that for some reason cannot. And at present, we do not have a conception of solidarity that help us muster resistance.

Now, I argue that the necessary theoretical resources for a revitalisation of 'solidarity' are to be found within critical disability studies, disability activism, and feminist political theory, in the idea that all human lives are characterised by precariousness. Within disability theory, this has served as a powerful tool to deconstruct the idea that disability politics is of interest only to a separated group of unfortunate individuals and to question the boundaries separating 'normalcy' from 'deviance'. My argument is that it can also be a foundation of political alliances and a motor of political struggle. Indeed, the insight that we are all fragile runs as an underlying ethos in much of the disability movement's resistance against austerity, at least in the Scandinavian context. By this view, the reason why people that are perceiving themselves as non-disabled should care about disability cutbacks is that they share with those directly affected the predicament of being vulnerable. Every single one of us can at any time find ourselves in a situation where we are dependent on the welfare systems that are being slashed. Therefore, the disability movement is not merely fighting for their own rights, but for the rights of all of us.

In other words, vulnerability ties us together and can serve as a platform to build political alliances from. Nevertheless, it is almost completely absent in academic as well as activist discussions explicitly addressing the meanings of solidarity. Rather than understanding progressive politics as a project of transforming members of oppressed groups to become self-determined, independent, and autonomous rational beings, we need to start by asking how we are to make politics of the fact that none of us can take our bodily or cognitive functioning for granted. We need to understand the question of how we should respond to precariousness as the most fundamental problem of politics. I contend that the answer of solidarity is that we should embrace vulnerability by building alliances that are committed to fight

for a society where we carry our shared precariousness together,
equally and as equals.

Esther Fox

Accentuate (UK)

Reframing Utopian Futures: How can disabled activists problematise the pro-screening debate?

I am interested in how looking towards genres outside of medical science, such as socially engaged arts practice, film and digital gaming, can enable an alternative critique of utopian arguments. In my keynote I will be discussing three interconnecting issues: (1) new eugenics, (2) science fiction and Gaming and (3) contemporary socially engaged arts practice. My purpose is to problematise the pro-screening debate; in order to reposition and reframe pro-screening as a dystopian movement, but one that 'passes' as utopian.

In medical discourse genetic screening is only described in positive terms, as beneficial for society, a mechanism to eliminate suffering. However, I would propose that it is essential for the pro-screening debate that it is sanitised in this way. Science Fiction offers us a lens to see what could actually be at the heart of the race to eliminate disability; and that is fear (of the unknown, of the unsightly, of the unproductive). Medical science subsumes all other views within its orbit, yet it is ill equipped to predict the wider sociological impacts which may occur with the reduction or abolition of genetic "abnormality".

Science Fiction affords us a freedom to reveal what often goes unsaid within "mainstream" society. Taken to its conclusion "Eugenic Logic tells us that we can avoid disability and even eliminate it from the human condition. This understanding of disability as somehow detachable from human life rather than essential to it fosters the idea that disability does not have much to do with us unless we have the misfortune of having it descend upon us". Garland-Thomson. *Bioethical Inquiry* (2012) p342

Science fiction enables us to imagine the future before it happens: an early warning system outlining inherent dangers in those prophecies, or in contrast, the promise of benefits and enhancements. The exposure of these societal constructs demonstrated through films such as *Gattaca* could give disabled activists an alternative method to problematise the Utopian pro-screening debate.

Socially engaged arts practice also offers an opportunity to engage the wider public in the ethical issues relating to screening that otherwise

may be seen to be too difficult to broach. In this presentation I will discuss my collaboration with Dr Felicity Boardman (University of Warwick) and how as a result of this collaboration, I created a new piece of sculpture “Pandora’s Box”, exhibited at the Science Museum (2016). Currently through the AHRC funded D4D project I am exploring how new technologies (particularly virtual reality) and gaming, can open up immersive experiences that can encourage the public to challenge their views on value, categorisation and order.

Damian Milton

Tizard Centre, University of Kent, Participatory Autism Research Collective (UK)

**“Said the autistic endorsed autistic informed academic”:
Neurodiversity, Academia and Activism.**

The neurodiversity movement can be said to have developed as a form of activism directly opposed to the way academics and clinicians had defined particular groups of people purely in terms of pathological deviations from an idealised notion of normalcy. Such a positionality and resultant ethos has been particularly prevalent within the autistic community, and has borrowed heavily from social model (or variations thereof) activist and academic perspectives. In this presentation, I reflect upon my own position as a scholar-activist working within and between the neurodiversity movement and the academy. Traditionally the field of autism studies has been dominated by biological and psychological research, and yet power differentials can impact upon critical sociological work reflected in the formation of niche subcultures. In this presentation, I also comment upon the precarious position of being an ‘endorsed insider’ (and simultaneous opposite) scholar-activist, the potential pitfalls, the expectations and tensions that can come about from others one interacts with, and what can be done to navigate such terrain.

Phillippa Wiseman

University of Glasgow (UK)

Embodied citizenship, disability and the public/private divide

That the bifurcation of, so called, public and private spheres has shaped and structured the lives of women is well understood- its impact is less well theorised or empirically examined in the lives of disabled people. The relegation of bodies, in everyday life, and in the academy, to the 'private' sphere (and thus being of lower status) has arguably removed intimate experiences from constructions of citizenship and so has led to the pervasive and ongoing hidden inequalities that disabled people face every day. By working towards a notion of embodied citizenship, I aim to place everyday lives and felt experiences, intimacies and bodily practices at the centre of what it means to belong and feel of value - feeling states and ways of being that claw citizenship out of abstraction and have the potential to make hidden inequalities visible. Central to this is the need to bring attention to the everyday intimacies that challenge the public/private divide. I will focus on my ongoing research on (inaccessible) toilets as sites of (non)belonging and citizenship and the spaces where everyday inequalities are played out and felt. Similarly I will draw on my research with young disabled people and their experiences of relationships, sexual health and body management.

In locating belonging as central to embodied citizenship we are able to critique everyday ableist practices and structures that articulate who is welcome and in what spaces. It also allows us to challenge dominant able-bodied, heteronormative, white, male assumptions about what citizenship is and how it should be enacted or lived. Injustice, discrimination and inequality are embodied events; they are felt, perceived and they have profound impacts on sense of self and personhood. Here I will position body-management at the very centre of citizenship.

Critical Neurodiversity Stream

The Participatory Autism Research Collective (PARC) was initially developed at London South Bank University (LSBU) by Dr Damian Milton and Professor Nicola Martin, with the first meeting being held in April 2015. PARC was set up with the purpose of bringing together autistic people, including scholars and activists (but not exclusively), together with early career researchers and practitioners who work with autistic people, with the aim being to build a community where those who wished to see more significant involvement of autistic people in autism research could share knowledge and expertise. This presentation explores the development of the PARC network and its work to date as an introduction to the Neurodiversity stream that the PARC network is hosting.

Visit our website at www.PARCAutism.co.uk

Damian Milton

Stream Convenor

Craftivism Workshop

How we 'do' disability studies and to what effect is the underpinning discussion of the Lancaster conferences. Simply providing a space to present work and ideas about disability is an inadequate response to the challenges of disablism and ableism in the academy and beyond. Instead the conference has sought to provide opportunities to practice disability studies by broadening its scope, hearing marginalised and excluded voices, and by seeking to be inclusive in our 'doing' of the conference.

Art and protest been at the heart of the Disabled People's movement in the UK (and beyond), frequently intertwined to promote affirming and celebratory understandings of disability and disabled lives and to chart outrage, dissent, claims for justice and rights and challenges for change.

This year at #CeDR18 George Julian is running an ongoing workshop/breakout space that provides an opportunity to take time out from conference presentations, to reflect on what we hear and consider how to start conversations with the help of craftivism.

The true essence of craftivism is that people create something that speaks to their own interest and skills. By its nature craftivism is very personal and is very slow. There will be an opportunity to pimp your conference bag, contribute to a key note collage, provide mini protest banners, craft an alternative conference poster or access a range of materials and resources and spend time in the breakout space to have a go at crafting what ever takes your fancy.

Disability & Society: Meet the Editors

Disability & Society: Meet the Editors

As in previous years, members of the Disability & Society Executive Editorial Board will be available throughout the conference to talk about the journal, including new innovations and ideas on how to get published or involved with our work. We will be holding a 'Meet the Eds' session on Tuesday at 5.15pm and warmly invite everyone to come along.

I'd like to take a moment to thank everyone who is involved in making Disability & Society the world leading journal that it is, a unique resource for Disability Studies academics, activists, personal and professional stakeholders across the world to share ideas and drive change. Through its consistent focus on such issues as human rights, discrimination, definitions, policy and practices and interrogation of the way disability is viewed and responded to, Disability & Society has earned its standing as 'the leading journal in Disability Studies'. We are extremely grateful to the support offered by the journal's publishers and conference sponsors Taylor & Francis, which is key to maintaining and developing the journal's strength. Helen Oliver, our Journal Administrator, keeps production of the journal in ship-shape and we couldn't do without her. Our Executive Editors, including Overseas Executive Editors, Reviewing Editors and Occasional Editors all make a huge contribution to our body of work as well as every book reviewer, author, video performer and reader to whom we extend countless thanks.

We would love to hear your reflections on a paper from the journal that had a particular influence on you. We've been asking for reflections, feelings and thoughts about papers in the journal on Twitter, so please dig into your memories and share your thoughts with us in the session if you'd like to.

We've been working hard on making the journal more accessible over the last few years so we will also be showing three films made by people with learning difficulties about papers they have found important in the journal. These will also be available to view during the lunch breaks.

As well as reminiscing, we are looking forward to talking with you about what Disability & Society offers, to encourage your ideas for

papers and urge your involvement with the journal's work. 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 a drinks reception immediately following this session - come and say hello!

Professor Michele Moore
Editor, Disability & Society

Twitter: @JDisSoc

Website: <https://www.tandfonline.com/toc/cdso20/current>

Book Launch

Disability Studies scholars and activists produce a wide range of new books each year. Many of them are available at the conference book stall run by Blackwell, to whom we are grateful for providing such a useful resource for delegates.

A number of authors will be introducing their new publications at the reception on Tuesday evening or in paper sessions including:

Karen Soldatic *Disability and Neoliberal State Formations* (Routledge)

Brian Watermeyer, Judith McKenzie and Leslie Swartz (Editors) *The Palgrave Handbook of Disability and Citizenship in the Global South* (Palgrave)

If you are interesting in reviewing a new book for *Disability & Society* or you have a new book you would like the journal to review, please contact Hannah Morgan, Book Reviews Editor,
h.morgan@lancaster.ac.uk

**Abstracts:
Papers, Panel and Poster Presentations**

Listed in alphabetical order by first author

David Abbott
University of Bristol (UK)

Main Conference
Paper

LGBTQ Disabled Men and Women using Self-Directed Social Care Support in England

LGBTQI+ Disabled People* who use self-directed support reported many positives from having more choice, control and power over who supports them and the kind of support they get. However, several things also worked against support being as good as it could be. This paper reports on research carried out by a partnership of the University of Bristol, Regard (the Disabled People's organisation of/for LGBTQI+ Disabled People), the Social Care Institute for Excellence (SCIE) and Stonewall. In a 2016-17 survey of 56 LGBTQI+ Disabled People who use self-directed social care support in England and 20 follow-up face-to-face interviews, we found: concerns that coming out about sexual orientation or gender identity to Personal Assistants (PAs) or other social care staff (including assessors) could jeopardise that support; an overall lack of attention to equality issues relating to sexual orientation and gender identity when social care needs were being assessed and reviewed; difficulties in recruiting and retaining good PAs; difficulties in securing or cuts in support for so-called 'social hours' leading to social isolation; experiences of discrimination and a sometimes lack of inclusion in the wider LGBTQI+ community. The research suggests that austerity and discriminatory attitudes are responsible for some LGBTQI+ Disabled People making "bad bargains" with themselves and others. They do not always feel able to be open about their sexual/gender identity for fear of losing essential support.

Liz Adams Lyngbäck

Department of Special Education, Stockholm University (Sweden)

Main Conference

Paper

**The role of uncertainty in the development of disability literacy:
drawing on examples of processes of becoming in parenting a deaf
child**

This paper will explore the role of uncertainty in parenting in spaces of sensorial differentness which envelopes the relationship between a hearing parent and a deaf child. This process of transformation, a becoming process in an adult life builds on coming to know about life conditions of another individual. Lived, in-depth experiences of disability and uncertainty are what seem to enable parents to adopt alternative attitudes going against societal norms and values about what it means to have a disability. They make choices based on how they imagine their adult child's future belonging and identity. The analysis builds on the findings from the ethnographic material in a study on parenting children who use cochlear implants. Qualities certain parents exhibited and others were in the process of developing are the examples used to show how uncertainty is involved in 'unlearning', an orientation which allows new insights about disability and being deaf to guide decisions and actions.

It will be argued that this social learning process does not end in complete knowledge but rather as a way of becoming disability literate which can increase and recede because of how it involves the minds and lives of others. Parents continue arriving as they continue 'reading their child', continuous arrivals which imbue their interactions with groups like their child.

The frameworks of disability studies in education and social justice in education drawing on care ethics will serve to employ the term allyship to present how following the paths others formed can be studied to develop one's own disability literacy. The presentation will include an example of an online program being developed to facilitate communication and understanding between hearing people and people who are deaf or hard of hearing in order to increase awareness, actions and commitment to goals of more inclusive and equal conditions.

Charmaine Agius Ferrante
Northumbria University (UK)

Main Conference
Paper

Continuity and Change in the Support of Learning for Children with Down Syndrome: A case study of the Influence of early learning experiences within an intervention programme on the educational experience of one child with Down Syndrome

This paper presents some of the outcomes from the experiences and the story of one child with Down Syndrome, and his family, following a Flashcard Language Programme using a Case Study Methodology. This is a qualitative study based on interviews and observations. A thematic analysis was used within an interpretative approach of hermeneutic phenomenology.

Research regarding flashcard use has been carried out with children with children with Down Syndrome (Buckley, 1996; Oelwien,1995). I have been using this system as the backbone of an intervention programme with children from infancy to school age, originally as a vehicle to augment language and communication development. However, noting the impact this has had on the holistic development of the children using this method, I extended the Flashcard Language programme to support the ongoing learning of children both at home and within the classroom. The purpose of this paper is to look at flashcards as a teaching strategy that underpins a dynamic learning process which supports the learning, teaching and inclusion of learners with additional needs, whilst supporting whole class teaching and universal design for learning.

This individual learning journey is explored through a qualitative lens. Overall this paper offers examples of intervention and inclusive practices in the areas of language and communication, meaning making, play, reading, learning experiences and parental partnership across and throughout the eight-year journey of this one child, his family and school.

Overall, this paper offers examples of inclusive practice in the areas of supporting language and communication, teaching and learning, parental partnership, transition between educational phases for one child with Down Syndrome, within a journey of becoming a community of learners.

Niklas Altermark
Lund University (Sweden)

Hampus Nilsson
Lund University (Sweden)

Main Conference
Paper

Symposium: Questioning the 'generosity' of the Swedish welfare state - investigating austerity measures against disabled people

Legitimising austerity - the rhetorics of disability cutbacks

This paper presents an analysis of how cutbacks on personal assistance are justified by the current Swedish government. For the last four years, the Social democrats in power have more or less exclusively described this service as haunted by "rising costs" - primarily as a result of welfare frauds and greedy private assistance enterprises. Following the work of Carol Bacchi, I argue that personal assistance in this way is constructed as a "cost problem", akin to how austerity measures have been legitimised in the UK and elsewhere. This way of framing disability services are in turn picked up and reinforced by public agencies, most notably the Swedish Social Insurance Agency, whilst the devastating effects of the cutbacks for disabled people are brushed off as "individual cases". Overall, the sole focus on costs and fraudsters means that the needs and rights of disabled people are being replaced in the public debate with questions concerning whether their independent living is too costly, which are underpinned by the impression that this is a group full of fraudsters. Nevertheless, I show that the actual actions of the government are not designed to meet the problems described. Rather than fighting welfare crimes or hampering profits of private enterprises, what we see in Sweden are general cutbacks, targeting all personal assistance users - whether one is cheating or not. Hence, rather than a starting point of policy, I argue that the "cost problem" serve as an ad hoc discursive construction, designed to justify general cutbacks.

Joana Alves
Centre for Social Studies (Portugal)

Main Conference
Paper

Disability and models of care: characteristics, trends and underlying ideologies

This paper results from my Phd research (SFRH/BD/77839/2011) and intends to contribute to the debate on the care production in the field of disability in Portugal. Specifically exploring the models and care relationships amongst people with disabilities in need of permanent and long-term care assistance. With the aim of examining the role of different parts - care receivers and caregivers. Specifically trying to address the following questions: how do the cared for and their carers envision and deal with care in their lives? What practices, representations and knowledges are called upon by its different actors and how do they articulate amongst themselves? What role do they play in defining the models of care? What is the influence of its contexts of production in defining the models of care? Are care models suited to the needs and individual desires of people with disabilities?

To answer these questions a qualitative approach was adopted. Ethnographic work played a decisive role in the study outcomes that resulted from an extended work of direct observation in two settings: at home and the institution.

This is followed by a critical review of models of care produced in these two settings, identifying characteristics, trends and underlying ideologies. The final aim is to outline the characteristics of actions in this area and dialogue the research results with recent changes in disability policy in Portugal (Independent Living Support Model).

Petra Anders
TU Dortmund (Germany)

Main Conference
Paper

Disability Studies and Film Studies: Activist Influences on Teaching about Cinematic Narratives of Normalcy and Diversity

Thomas Hoeksema and Christopher Smit first argued for ‘The Fusion of Film Studies and Disability Studies’ in 2001. They say: ‘Students of disability and film need to be concerned with portrayals of disability not solely because of their inadequacies, but because they are emotional, relational and artistic offerings as well. [...] Dismissing films because of alleged inaccuracies denies their teaching and learning value.’ (Hoeksema/Smit 2001: 42) Their approach can, for example, benefit teaching. More recently, I have extended it by combining queer theory with disability studies, drawing, for example, on Robert McRuer.

My paper discusses the benefits of those approaches for analysing cinematic representations of disability. I illustrate how such activist interdisciplinary approaches can enhance teaching: film studies students can discuss disability and students of disability or queer theory can find new ways of looking at these subjects through film. I also investigate how editing, camera and music perpetuate or challenge, emphasize or contrast with certain narratives of normalcy and diversity. In Michael Akers’s film *Morgan*, for example, while Morgan gets ready for his first date after the accident that paralysed him, Akers uses the song ‘Get up and Dance’ to symbolize both a personal tragedy and the confidence Morgan feels in this moment.

Alan Armstrong

Barod Community Interest Company (UK)

Anne Collis

Barod Community Interest Company (UK)

Main Conference

Paper

Yes I have a learning difficulty, no I don't do inclusive research

Barod was set up in 2013 as a workers' cooperative. Two founders were leaders in the People First movement Wales; one was a support worker; one was an ally. 'Barod' is Welsh for 'ready'; we were fed up with being told we weren't ready and had to do yet more unpaid work placements.

In 2013, Alan (a People First leader) had no research experience. Anne (an ally) had been research assistant to Dr Gordon Grant in the mid 90s, and had recently completed a taught Masters.

Fast forward to 2018. Alan has gone from no research experience to designing and managing research, conducting field research, analysing data and reporting findings. Anne has been seconded by Barod to a part-time sociology PhD (funded through KESS, a European programme) to develop an alternative approach to public consultation.

In Barod, Alan and Anne are equal colleagues - same hourly pay, same power and responsibility to make day-to-day and strategic decisions, same voting rights, same respect for what each of us says. This is not a level of equality we have observed within the world of inclusive research, although we value and respect the determined efforts of many inclusive researchers to achieve this kind of equality.

Our paper critiques power within research relationships. We describe the research relationship Alan and Anne have with each other within Barod, head-hunting academic partners, and the research relationships Alan has had with two universities and with an independent academic researcher. We discuss tools we have developed or discovered that make it easier for academic and non-academic researchers to work together on an equal basis. We question whether research conceptualised as 'inclusive' can ever be a relationship of equals, and we offer our own conceptualisation of 'coproduced research' as an alternative.

Victoria Armstrong
Disability North (UK)

Neil Armstrong
55 Creatives/Independent Artist (UK)

Main Conference
Paper

The Dog Ate My Wheelchair

The project entitled, 'the dog ate my wheelchair' is a collaboration between Disability North (a user-led charity), established video artist Neil Armstrong, and disabled people living in both urban and rural environments in the North of England. The final piece is a series of four looped videos sited at four locations along the route of the Great Exhibition of the North (GEO N) and an online participant led multimedia blog which will be exhibited and 'live' during Summer 2018. The video pieces are aimed at the general public, and will be placed in art and cultural venues, transport and retail spaces in Newcastle upon Tyne. The video content will be shaped by workshops facilitated by Disability North with focus on disability access in all its forms with particular reference to universal concepts of inclusion/exclusion and sameness/difference. Our project takes 'Urban' and 'Rural' as its framework, drawing in participants from around Newcastle, Yorkshire and from rural parts of Northumberland. It is important to emphasise that the aim of this process is to allow the conceptual input of the participants to show through in the making and a crucial element of the piece is that we intentionally leave open to development the final participant led content. This paper showcases, critically examines, reviews and evaluates the project and its associated activity.

Larry Arnold
Independent Scholar (UK)

Critical Dialogues in Neurodiversity Stream
Paper

Context and subtext, a part of the world or apart from it?

Working through Identity and beyond, how can one work around an identity disputed between factions?

Identity, as a means of achieving selfhood, and combatting shared prejudices, oppressions and micro aggressions has a long history.

However, should it be the ultimate aim of an egalitarian and equitable society? Can we foresee a stage when it has “withered away” as a transition stage in universal emancipation.

This paper will examine the way we are represented and how we represent ourselves; how much are we influenced by the context of the times we live in and how much are we free spirits to reconstruct our own destinies?

Amongst the problems are intergenerationality and intersection in the autism world, how atomised identities mesh into wider societal constructs of nationhood and ethnicity. Is strong individual identity useful as a political tool, or part of Marxian false consciousness or internalised oppression, proving ultimately divisive from the standpoint of shared subjugation to global capitalism and the neo liberal agenda.

Identity is also a problematic concept in terms of ownership. The central idea of the existence of a unitary selfhood in competing arenas of field and habitus is open to question. Is it an enlightenment outgrowth that is contingent on moments in history or the universal neuro-cognitive reality many believe it to be.

Much like the zen paradox “first there is a mountain”, I have transitioned through engagement, from, having moved from no strong identity, to the espousal of and inseparable autistic I and now I see the “mountain” from on top, contextualised in a way it would not have been without experiencing the climb and watching others come to grips with the rock face, so close to them that the mountain is obscured.

Julia Bahner

Centre for Disability Studies, University of Leeds (UK)

Main Conference

Paper

Symposium: Questioning the 'generosity' of the Swedish welfare state - investigating austerity measures against disabled people

'Living a (sexual) life like others' - a luxury in times of austerity?

The Swedish personal assistance scheme aims to make it possible for assistance users to 'live a life like others' under good living conditions and, furthermore, to make possible equal participation in society. Although sexuality is not mentioned in the law or in any other national disability policy, having a sex life can indeed be considered leading 'a life like others'. However, such an interpretation is not the case among most service providers, who feel insecure as to whether supporting assistance users' sexual activities should be included in service provision - precisely because of the lack of mention in the law and the non-existence of relevant policies. Besides this insecurity over the legitimacy of supporting assistance users' sexual lives, there is also the context of austerity measures, leading the disability movement and individual assistance users to focus their advocacy and efforts upon fighting for their basic rights and keeping the assistance they currently have. In such a climate, it is not surprising that sexual rights advocacy is not high on the agenda. It is almost as if sexuality becomes a luxury, something that people who do not rely on the welfare state's support can enjoy, and not an important part of being human, and a citizen. Essentially, such a discourse is built upon an ableist structure where non-disabled people in power positions define disabled people's (sexual) lives.

Julia Bahner

Centre for Disability Studies, University of Leeds (UK)

Main Conference

Paper

Sexual rights - not(thing) about us?

Disability movements are important stakeholders in influencing policy. So what happens when they do not advocate on certain issues or do so in a non-coherent way? This paper analyses sexual rights as a policy issue - albeit one that is not often prioritised.

In an ongoing research project, policy analysis and interviews with disability rights organisations were conducted in three countries. This paper reports on a case study from England, focusing on sexual rights advocacy for people with mobility impairments.

The results show that neither disability policies nor sexual health policies engage in any depth with disabled people's sexual rights, such as the right to sexual pleasure and being supported to express one's sexuality. Instead, their primary focus lies in safeguarding and risk management. Looking at the major disability rights organisations, sexual rights are not on their agenda. There are few organisations that prioritise sexual rights advocacy, including charity organisations, smaller organisations led by disabled people's or peer support groups, and professional organisations. Disability activism needs to take into account the ways in which their policies on sexual rights are shaped by ideology, organisational structure, and disabled people's participation.

Although sexual rights are often framed as human rights, they are seldom dealt with in a more detailed way than merely stating the rights. For people in need of support to express their sexuality and/or to engage in sexual activity, there is a need for more meaningful ways of framing policy - and advocacy. By using a participatory approach, it is hoped that this research will be able to further disabled people's sexual rights in ways relevant to the research participants, and the people they represent more broadly, for example in developing stronger alliances for policy advocacy, and creating guidelines or other types of best practices for disability services.

Maria Berghs

De Montford University (UK)

Simon Dyson

De Montford University (UK)

Mamaddie Keibe

De Montford University (UK)

Main Conference

Paper

Rethinking activism around work, employment and welfare

Sickle cell is a complex long-term genetic condition, which in the United Kingdom (UK) mainly affects people of black and minority ethnic descent although this is changing. This DRILL project, overseen by a project management group led by people with sickle cell, investigates the employment experiences of forty adults living with sickle cell in England. A preliminary analysis suggests differences with discourses around independent living and six major areas for consideration when thinking about barriers to employment and activism for social change. First, contrary to (dis)abling discourses we found that there was an aspirational class of socially mobile and (self) employed professionals. Secondly, we noted how employment trajectories were affected by disabling and racist barriers at work and even professionals could be unfairly dismissed. Thirdly, we noted informal economies and alternative social security structures within (enclave) communities (i.e. church saving clubs). Fourthly, those with the condition are also intergenerational care-givers as well as care receivers, for example, keeping children which is not always gendered. Fifthly, we found evidence of extensive unpaid societal, community and voluntary work. Finally, one support group stressed to us that some people with sickle cell were so challenged by their condition that they do not feel they could reasonably be expected to undertake paid work and that aspirational exemplars of successful professionals living with the condition undermined their sense of self. We argue that the reality is more heterogeneous and nuanced than is popularised (even within communities) and this has implications for policy work and activism around employment and welfare. We also noted how people with sickle cell become embedded and mobilised in their communities and this has a different trajectory from neoliberal values around independence.

Arndis Bergsdóttir
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Disability before Disability

Museums apparatuses and absent dis-/abilities

This paper focuses on the matter of absence and museum registration as it investigates how museum processes involve interventions that render the lived lives and experiences of dis-/abled people absent from historical narratives in exhibitions. It is part of the project Disability-before-Disability at the University of Iceland and grounded in ongoing research on the material collections and cataloguing system of the National Museum of Iceland that aims to identify and collect information about artefacts related to disability and investigate the histories and narratives involving dis-/abled bodies. As presented in museums, history and heritage emerge through exhibitions that subtly, yet strongly, privilege able bodied narratives. Such observations are underpinned by research, engaging with representations of disabled people in museums which indicate, that attempts to counter the under- and misrepresentation of disabled bodies have been rare. Thus, significant absences are entrenched in historical narratives and delicately woven into the portrayal of heritage in museums. This paper applies new-materialist and STS approaches and argues that the absence of disabled bodies in museum narratives is not nothing - a non-being - but matters that emerge through material-discursive relations that always already involve accountabilities and ethics. This provides opportunities to approach museums as apparatuses that involve exclusions - the making of absence. Here, apparatuses do not render an uncontaminated outcome but rather, they are capable of transforming entities into narratives intricately woven to convey specific meanings. Through this lens museum practices are interventions that foreground relationships privileging able bodies at the cost of dis-/abled 'others'. As part of the museum apparatus the registration of objects offer clues to how absences come to matter - not as gaps that wait to be filled - but as a relevant matter that is dynamically entangled with technologies and presence and deserves to be trusted.

Melisanda Berkowitz
Chukyo University (Japan)

Main Conference
Paper

A relational study of transition to adulthood in Japan for people with severe learning dis/abilities

The experience of becoming an adult with severe learning disabilities is shaped by sociocultural and policy constructions of adulthood/personhood, and by how those policies are implemented.

In the UK, transition to adulthood has fore-fronted individual choice and self-determination. However, government austerity in the UK since 2008 has excluded more people with learning disabilities by reducing the range of choices practically available to them. Conversely, in Japan while self-determination features heavily in policy literature, in practice mothers (or other guardians) are expected to make informed choices on behalf of learning disabled youth. Meanwhile, following disability rights legislation in effect since 2016, Japan's government has increased budget support for both mainstream and sheltered employment, broadening the range of off-the-rack choices, albeit marginalized ones.

Comparing transition from school to adult life in different contexts may elucidate how societies construct learning disability and able personhood, or in Goodley's term, dis/ability, and point to more fulfilling and inclusive alternatives. As a western mother of a learning-disabled youth in Japan, it means grappling with how to raise my child.

In this qualitative longitudinal study I follow up on my prior research regarding social relations of learning-disabled Japanese youth. Using eco-maps and other graphic organizers to facilitate participatory interviews, I trace the youths' paths from finishing school in 2016 to formal coming of age at twenty in 2018, and elicit the parents' reflections on actors and processes involved in decision-making. The youths' social networks changed little over the period, they were still residing with their parents, and the mothers remained major decision makers in their lives. In Japan, learning dis/abled adulthood is constructed as interdependent, with workplaces valued for sense of belonging and achievement, and segregated according to level of productivity. Predictably, I call for more support to enable learning-disabled youth to make their own decisions.

Hanna Bertilsdotter Rosqvist
Umeå University (Sweden)

David Jackson-Perry
Queen's University Belfast, Northern Ireland (UK)

Critical Dialogues in Neurodiversity Stream
Paper

Not doing it properly? Tracking assumptions of healthy couple intimacy through an exploration of narratives of “non-sociable” autistic sexualities

Asexuality and sexualities that prioritize objects or imaginary partners rather than ‘real’ human partners, are largely pathologised. People (not) practising sex in these ways may find themselves stigmatised and subject to educative interventions intended to bring them to a ‘healthy’, that is to say human partner-oriented, sexuality. Here, we use Gayle Rubin’s ‘charmed circle’ as a theoretical base to explore ways in which research into autistic accounts of sexuality may serve to confirm and perpetuate the hierarchies and definitions of ‘good, real and healthy’ sex. We consider this more particularly in relation to narratives of non-sociable sexualities (sexual expressions that do not involve a human partner or where another human is not the primary sexual object) and asexuality among autistic people on two online discussion forums, one based in the United States of America, the other in Sweden. In analysing these forums, we do not ultimately seek to better understand autistic sexual experience, but rather to explore how different meanings of non-sociable sexualities and asexuality are being used by autistic people to (re)negotiate meanings of autistic sexualities. We use our analyses of those narratives to deconstruct (NT) normative assumptions of couple (hetero)sexuality which dominate meanings of sociable sex. In doing so we challenge how sociable sex is taken for granted, naturalized, and used to exclude alternative sexual expressions from domains of “healthy”, “good” and “real” sexuality.

Hanna Bertilsdotter Rosqvist
Umeå University (Sweden)

Lindsay O'dell
The Open University (UK)

Critical Dialogues in Neurodiversity Stream
Paper

Conversations in different languages: exploring and connecting knowledges of autism in different epistemic communities

In the Editorial in first issue of *Autonomy*, the Critical Journal of Interdisciplinary Autism Studies, the editor Larry Arnold makes a state of the art for the journal. It will be working toward bringing in autistic voices from outside academia, into academia as subjects and authors, rather than as more or less voluntary subjects of research (Arnold, 2012). It will also bridge disciplines otherwise existing “within silos, failing to understand the contributions that other disciplines have to make on each other” (Arnold, 2012). In this paper we use the concept of ‘epistemic communities’ to think through Arnold’s challenge to work across what he sees as silos. Epistemological communities, ‘structure knowledge through: shared language and concepts; collective ‘public conceptual schemes’ which structure and make intelligible narratives of experience; and legitimate particular sets of theories, concepts and standards’ (O’Dell et al, 2016; Wheelan, 2007). The concept enables us to trace how some knowledges become shared and powerful whilst others remain within a particular community. For example, ‘brain based’ explanations and also clinical knowledge is seen to unproblematically transcend cultural contexts; whereas autistic knowledge remains often within autistic spaces. In this paper we use the conceptual tools of epistemic communities and epistemic authority to examine how ideas about autism gain legitimacy and are played out across contexts. We draw on a series of conversations with autistic activists, academics and charity groups in the UK and Sweden to illustrate how meanings shifts across contexts- both geographical and neurodiverse. Further we argue that particular, familiar, discursive tropes are drawn on to perpetuate the need to autistic people, rather than NTs, to bridge the silos in contrast to ‘brain based’ and deficit models of autism which are assumed to transcend silos.

Hanna Bertilsdotter Rosqvist
Umeå University (Sweden)

Lindsay O'Dell
The Open University (UK)

Alison Davies
The Open University (UK)

Paul Stenner
The Open University (UK)

Critical Dialogues in Neurodiversity Stream
Paper

‘Being one of the weird kids’: exploring spatiality, temporality and friendships of women with ADHD

Friendships are commonly viewed as important in gendered socialization into adulthood. However for many who are assumed to have impairments in social communication and therefore have difficulties with friendships and being social. Traditional developmental theorizing about friendships does not account for friendships in neurodiverse ways. The women in our study were recruited from an online website for adults with ADHD and from community support groups in the UK. 16 women were interviewed, of whom 1 had a diagnosis of ADHD as a teenager; 8 had a diagnosis in adulthood, and 7 self-identified as having ADHD. The women in the study talked about a range of experiences of friendships in childhood and in adulthood. From our analysis we discuss the women’s experiences of the (supposed) ‘right’ intensity of interaction (not being too intense) or misreading social cues of pace including being aware of when to give your opinions and when not, and women’s experiences of friendships that accord, and that are different to normative expectations. The analysis seeks to show how women with ADHD negotiate their identity through narratives about their current and past friendships in relation to both normative and alternative forms of friendships, focusing on temporality, spatiality and power dimensions of female friendships.

Lara Bezzina
Independent Scholar (Malta)

Main Conference
Paper

Participatory Video with People with Disabilities: Narrowing the Gap between Social Research and Action

One of the main goals of action research is to “produce practical knowledge that is useful to people in the everyday conduct of their lives” (Reason and Bradbury, 2008: 4). The ultimate aims of this knowledge are to enable vulnerable groups in acquiring sufficient leverage to transform their situation (Fals-Borda, 1991). This is one of the reasons why participatory action research (PAR) is so significant in working with people who are oppressed: it narrows the gap between social research and action. Rather than waiting for research results to be discovered, the research itself sets the ball rolling (Foote Whyte, 1991). Participatory video is one method which embodies this. It is “a set of techniques to involve a group or community in shaping and creating their own film” (Lunch and Lunch, 2006: 10) which gives a glimpse of “the ‘inside view’ in a... way that is accessible to people at all levels” (ibid: 12). This is vital for the purpose of the research presented in this paper, which sought to create spaces in which people with disabilities, who are usually ‘invisible’ and unheard, can be ‘visible’ and express their views (ibid: 13). This paper is based on participatory research facilitated in Burkina Faso, where a group of disabled people came together to design, film and partially edit a film in which they share their lived experiences, including their successes and the challenges they encounter. They also speak out to the state authorities and international organisations who work with disabled people, asking them to engage with the reality on the ground before intervening. In this way, the participatory video process brings disabled people as co-producers of knowledge and lays the ground for a process of change and analysis based on local knowledge and experiences.

Kathy Boxall
Edith Cowan University (Australia)

Main Conference
Paper

Mad Studies Moment(um): Activism, epistemology and the power of numbers

This paper will explore the recent development of Mad Studies - cooperative study of mental health service users' and survivors' experiential knowledges - and respond to the conference question: In what ways can the relationship between the academy and activism develop praxis? In Australia, antidepressant prescriptions doubled between 2000 and 2011 (OECD, 2013) and prescriptions for neuroleptic medication trebled between 1992 and 2016 (ABS 2017). The paper will suggest that this rapid increase in prescription of psychiatric drugs has resulted in a diminution of stigma associated with seeking, or being seen to seek, treatment for mental health difficulties. As more people are open about taking psychiatric medication, it becomes more acceptable to seek such treatment. It could also be argued that this increase in medication (albeit medication which may have been prescribed by general practitioners rather than psychiatrists) is indicative of the increasing power of psychiatry and big pharma. However, at the same time, increasing numbers of people are voicing concerns about their experiences of psychiatry and psychoactive medication (eg. www.theinnercompass.org) and critical psychiatrists are questioning the efficacy of psychiatric drugs (eg Gøtzsche et al 2015). Drawing on the author's experience of psychiatric treatment in the 1970s and 1980s and comparing this with recent developments, this paper will suggest that a critical mass of dissatisfaction with psychiatry's deficit-focussed epistemology is coalescing and the current historical moment offers an important opportunity for Mad Studies. It will also argue that, in order to capitalise on the momentum of recent developments, it will be important for activists, academics, and critical professionals to come together to develop cooperative epistemologies of mental and emotional distress (which do not locate problems in individuals, but in the systems and structures that fuel hegemonic discourses of mental illness), with which to underpin Mad Studies activism, praxis and research.

Kathy Boxall
Edith Cowan University (Australia)

Main Conference
Paper

No room at Airbnb? Disability, holiday accommodation and the new sharing economy

When disability is understood as socially imposed restriction, it is amenable to change and improvement through the removal of barriers to disabled people's inclusion in the mainstream. Conversely, disability can be created or exacerbated by the development of new socially or societally imposed restrictions. Shared economy approaches (international peer-to-peer platforms such as Airbnb, Uber etc.) are changing the ways in which our society is organised. It appears that the sharing economy is further disabling people with impairments who wish to take holidays in Margaret River, a key tourist destination in the southwest of Western Australia. The Australian Disability (Access to Premises - Buildings) Standards 2010 require hotels, motels and hostels to make a specified number of bedrooms accessible. But these standards DO NOT apply to private residential dwellings, where much peer-to-peer holiday accommodation, such as Airbnb, is situated. This paper will present findings from research which identified the expansion of Airbnb in Margaret River. It will also discuss a project which employed Levitas's (2013) Utopia as Method to develop hypothetical future scenarios in order to explore the wider social, economic and political implications of peer-to-peer holiday accommodation. When developing these scenarios, we found it impossible to see a way of regulating people's spare bedrooms, or to imagine a utopian version of Airbnb - fully inclusive of disabled people - which exists within a society that does not itself endorse full social inclusion. We conclude that the role of the state lies in creating the wider social and economic conditions for full social inclusion, within which the sharing economy can operate. And that the role of the academy is to support activism for inclusion by highlighting the potential implications of the widespread adoption of shared economy approaches for disabled people's social in/exclusion.

Toby Brandon
Northumbria University (UK)

Victoria Armstrong
Disability North (UK)

Main Conference
Paper

Where does Mad Studies belong and where is it going?

Both Mad Studies and Disability Studies provide strong critiques of the medical model. Both are based on interdisciplinary, or perhaps transdisciplinary, status and are fundamentally concerned with personal experiences of people and how they are interpreted by powerful others. For example, Mad Studies challenges attempts at biological reductionism, replacing it with an examination of social, holistic and humanitarian approaches. This paper explores some questions arising as a result of positioning Mad Studies in a UK context. Should Mad Studies align itself with Disability Studies where it is so often placed? If 'yes', where within Disability studies should it be situated? If 'no', where might it be better located? To explore answers to our questions there will be emphasis on the theoretical and practical intersections of Mad Studies and Critical Disability Studies, drawing on our experience of delivering one of the first UK Mad Studies module convened as part of the existing Disability Studies program delivered by Northumbria University. Key to our discussion is considering whether Madness is synonymous with disability. Whilst both share protection from discrimination under the law (Equality Act 2010), some characteristics of Madness are not overtly protected characteristics, Madness can become subsumed in disability and Mad people often contest notions of disability, resisting identifying themselves as being disabled or 'Mad'. This disjuncture, underlined by our teaching experiences, leads us to critically explore the social model of disability in relation to Mad Studies, considering Disablism in relation to Sanism and what 'Mad' means in relation to the social creation of both Disability and Madness through oppression. Perhaps we raise more questions than we answer but in doing so we present a number of avenues for consideration, contemplating that it may not be where Mad Studies belongs that is important for the time being, but where it is going.

David Brehme
Humboldt University of Berlin (Germany)

Main Conference
Paper

Smashing normalcy? On the (f)utility of normalcy for disabled people

In this paper, I will explore the notion of normalcy and argue its utility for disabled people. While other disciplines reflect little on what it means to be 'normal', within Disability Studies normalcy is key to understanding disability as a socio-cultural phenomenon (Davis, 2016, Waldschmidt, 2017). However, the term 'normalcy' remains vague. This premise has led to various responses within the discipline: from the frequent call to arms to smash, destroy and do away with normalcy altogether (e.g. Köbsell, 2012; Mallett, Ogden & Slater, 2016) to more moderate visions of new normalcies (Boxall, 2016; Oliver, 1996). In this talk I will provide a cursory overview of the various positions on the question of normalcy within Disability Studies in order to argue for a discursive understanding of 'normalcy'. Taking Normalism Theory (Link, 2004) as a starting point, this talk will argue that while it may seem a theoretically attractive proposition to do away with normalcy altogether, it may be counterproductive because of its consequences for disabled people. This talk aims to stimulate a debate around the question: (how) can we put normalcy to productive use as Disability Studies scholars and activists?

Leah Burch
University of Leeds (UK)

Main Conference
Paper

What is disablist hate speech? Storytelling as a tool of engagement

Research suggests that disabled people experience disablist hate speech and verbal abuse on a regular basis. Yet current legislation in England and Wales is limited in its ability to challenge this. This paper considers the limitations of policy, and provides the grounding for developing a broader and more inclusive approach to hate crime legislation. This paper seeks to explore conceptual debates surrounding hate speech by positioning the experiential accounts of disabled people at the forefront. By considering this debate through the stories of disabled people, I suggest a more nuanced and reflective policy framework can be developed, which would be more inclusive of the diversity and complexity of everyday experiences.

Drawing upon research findings, this paper attempts to forge links between conceptual debates and everyday realities in order to generate a more nuanced understanding of disablist hate speech that is informed by and through experience. I discuss some of the ways that disablist hate speech is understood and experienced. Doing so, I bring to light the complex ways that hate speech ‘harms’ through the internalisation of hateful attitudes. In addition, I recognise the everyday practices of resistance that people employ to challenge hate speech and provide more affirmative counter narratives.

Emmeline Burdett
University College London (UK)

Main Conference
Paper

'Poster-Children for Redefining 'Normal' '? Do Disabled Cats on Social Media Transform or Reflect Societal Reviews of Disability?

This proposal was inspired by a comment made Jackson Galaxy, a well-known US cat behaviourist who has made his name advising cat-owners on such television shows as Animal Planet's 'My Cat from Hell'. As part of his YouTube show 'Cat Mojo', Galaxy interviewed Mike Bridavsky, whose cat, Lil Bub, has multiple impairments and, rather because of this, has become extremely famous on both social media and the internet in general. During the course of the interview, Galaxy described Bub as 'a poster-child for redefining 'normal' '. In this paper, I will investigate Jackson's assertion, and ask whether Bub, and the increasing number of other famous disabled cats do indeed have a transformative effect on societal attitudes to disability. Though this is an unusual lens through which to view disability studies, it is important for a number of reasons. Firstly, there is an increasing awareness amongst disability studies academics that cultural representations of disability matter, and that they influence those who see them. For example, in her review of Katie Ellis's 2015 book 'Disability and Popular Culture', Hilary Martin of York University wrote that 'from a disability studies perspective, popular culture is a forum where the societal representation and response of disability can be examined'.

The image of disability which the cats put across will, of necessity, owe something to their owners' own ideas about disability. This, and the huge audiences which the cats are able to command thanks to their internet and social media presence, makes this an important, if somewhat unusual, instance of the importance of considering societal representations of, and responses to, disability.

Emma Q Burns

Centre for Disability Law and Policy, NUI Galway (Ireland)

Main Conference

Paper

Participation in public and political life: learning from the National Platform of Self-Advocates

This paper explores how self-advocacy organisations promote participation in political and public life among people with intellectual disabilities in Ireland. People with intellectual disabilities have historically been marginalised in public life due to disregard for human rights. Exclusion from positions of power at both public and personal level is the norm. As Ireland ratifies the UN Convention on the Rights of Persons with Disabilities, efforts are underway to assert the rights of people with intellectual disabilities in law; however, institutional practices and people's everyday experiences demonstrate that these rights are not guaranteed.

Article 29 of the Convention affirms the right of persons with disabilities to participate in public and political life. Meaningful participation requires more than people having a voice; it aims to empower them to contribute to the decision-making process about issues that affect their lives. The emerging self-advocacy movement has promoted the establishment of peer-led organisations in which people with intellectual disabilities hold leadership roles and direct activities.

This paper presents findings from a qualitative case study of the National Platform of Self-Advocates in Ireland. It follows the experiences of 11 members of the Platform steering committee as they negotiate the work of collective advocacy. Through semi-structured interviews and a variety of ethnographic and participatory research methods we explore the policies, practices and interactions that empower people with intellectual disabilities to participate meaningfully in public and political life. The barriers that remain demonstrate the need for expanded theories of participation to address the continuing battle that people with intellectual disabilities face in gaining access to the higher levels of decision-making.

Angharad Butler-Rees
University of Southampton (UK)

Main Conference
Paper

Adapting to Changing Times: Spaces of Disability Activism at a time of Austerity

Austerity cuts have brought a new era of oppression for disabled people, which is having a very direct impact on their lives. This has become increasingly evident in the UK, with the re-assessment of the Personal Independent Payment and Employment and Support Allowance; the controversial bedroom tax, and breakdowns in service provision as social care budgets are squeezed to a 'tipping point'. Unsurprisingly, such changes have been accompanied by a recent growth in disability activism, as individuals have sought ways of resisting and coping under increasingly difficult conditions.

This paper is based on the preliminary findings of a study of anti-austerity disability activists in the UK, with data collated through twenty-five biographical interviews and participant observation of their various networks. Recent austerity measures have motivated more urgent and visible resistant strategies. Disabled people have had to adopt innovative and creative approaches to challenge government policy and garner public attention and support. Recent anti-austerity activism has consequentially taken various forms, including the visual and performing arts, online networking, blogging, advocacy networks and more conventional forms of direct action protest such as 'ATOS Kills' and 'Save the ILF'.

Through the use of individual case studies, this paper gives voice to the various experiences of disability activists and highlights the different ways that they are resisting current austerity measures. By drawing attention to the rise of new spaces of activism, this paper advances scholarship in both disability history and political geography, through expanding existing research on political space and the geographies of disabled people's resistance.

Colin Cameron

Northumbria University / Shaping Our Lives (UK)

Ann Nutt

Shaping Our Lives (UK)

Michele Moore

Shaping Our Lives (UK)

Main Conference

Paper

Improving Understanding of Service User Involvement and Identity

We are a group of disabled people involved with Shaping Our Lives, a Disabled People's Organisation, who have recently conducted research which arose directly out of one of our member's own concerns. Our work responded to our observation that, while many disabled people are involved as service user representatives in social work, health, education and other human services, little attention is paid to the impact of this involvement on disabled people who give their time and energy to the role. Our research explored ways in which disabled service user representatives say inclusion can be improved so that disabled people's input to service development, policy and practice is not marginalised or under-utilised but fully acknowledged, productive and personally rewarding.

Our paper will report our research findings with the aim of improving understanding of good and bad experiences of service user involvement in the commissioning, design, delivery and evaluation of public sector services. We consider the challenges faced by service users in negotiating their dual role of being both service user representatives and recipients of services.

We have found that when arrangements for user involvement do not pay sufficient attention to dismantling of barriers to participation, service user representatives experience organisational exclusion; they feel their contribution is neither adequately respected nor properly valued and is left in the half-shadows. When service user involvement is respectful and inclusive this has a positive and mutually beneficial impact for professionals and service users alike. We will conclude by offering clear practice pointers on how to enable the process of service user representation so that that it is a beneficial experience with positive outcomes for all.

Fiona Kumari Campbell
University of Dundee (UK)

Main Conference
Paper

Epistemic Justice: Open Access Course “Introducing Studies in Ableism”

“Epistemic oppression refers to persistent epistemic exclusion that hinders one’s contribution to knowledge production. Epistemic exclusion, here, will be understood as an unwarranted infringement on the epistemic agency of knowers” (Dotson, 2014, 115). These exclusions manifest in a variety of way; significantly in the form of lack of access to contemporary scholarly debates (due to journal paywalls and the high cost of university program admissions), but also extend to limited opportunities to dialogue around the complexities of academic language resulting in epistemic exclusion, simplification and anti-intellectualism. A denial of dialogical encounters can diminish the voices and deliberative capacity of disabled people. This paper examines these challenges within the context of a six session free webinar course, “Introducing Studies in Ableism” run by the author, as an activist contribution during February - June 2018. By using open access software, Padlet an online bulletin board and Zoom webinar technologies, brought together in a closed Facebook group, the course attracted 40 participants from 16 nations. Not only were students able to be exposed to new materials they were able to collectively engage and unpack core concepts in disability studies and Studies in Ableism (SiA) within the context of transcultural knowledge exchange. Whilst there were limitations to the course (there was no live captioning) due to an absence of funding or sponsorship, the experience of running a course in SiA demonstrates the possibilities for academic activism via independent open access courses in contributing to epistemic justice for disabled people.

Fiona Kumari Campbell
University of Dundee (UK)

Main Conference
Paper

Symposium: On Ableness: Using Studies in Ableism to explore cultures of ablement

On Why Ableism and Compulsory Abledment is not just a Disability Issue

We are witnessing a particular moment in history where there are great movements and flows of people across the globe struggling to cross nation-state borders to flee persecution and live safe lives. Simultaneously, there is reterritorialization by governments bent on securing borders (for example, Trump's Mexican wall, European fences, the inclinations of Brexit, Australian border control) as well as the reterritorialization of access to benefits and safety nets (PiP (re)assessments, the narrowing of the ADA, Australia's robodebt, to name a few) within nations. The theorisation of ableism points to processes that involve "differentiation, ranking, negation, notification and prioritization of sentient life" (Campbell, 2017: 287 - 288). These five prong aspects have a bearing on ways that ableist processes are implicated in dividing practices based on the productivity of the multitude (Hardt and Negri, 2005) and the intersectionalities of gender, race, class, disability; aligned to subject-positions and bodies deemed as normative benchmarks for the building a nations-states and the delineation of 'who' is a productive, unencumbered citizen. This paper will argue that in understanding ablement as an emergent and expansive force, through utilising Studies in Ableism; it is possible to identify points of interest convergence amongst the struggles of peripheral populations, beyond being confined to disability alone. Compulsory abledment is a measure that promotes privilege and a sense of entitlement for certain bodies/citizens and invalidates remnants populations and induces daily microaggressions. These experiences are differential as well as overlap precarious communities. Studies in Ableism as a conceptual tool and methodology has the capacity to reinvigorate coalition building and consciousness between peripheral communities.

Murad Canbulut
Altinbas University (Turkey)

Main Conference
Paper

Who defines the norms? Is marketing the new norm setter?

Throughout the history, disabled people (labeled as disabled - LAD) have been discriminated, oppressed and labeled in society. Disability has been the focus of medicine for a very long time, from the earliest asylums, then hospitals and modern rehabilitation centers. Medicine has been the primary actor which has been used to control the human body. Then, the emergence of the social approach had a crucial impact on the interpretation of disability. Instead of controlling individual bodies, it was aimed to control perceptions of the masses through media, advertisement, products, and services. The market system began to take a role alongside medicine. The initial focus was individuals and their bodies in the context of disability studies. Considering the deficiencies, medicine was the mechanism to discipline those bodies as much as possible. When populations grew, the role of medicine evolved throughout history. The focus was communal bodies through perceptions of people. In order to control those bodies, medicine and market mechanism collaborated with each other.

Today, the market system enforces these labels, and the individuals, as consumers, experience the imprisonment “consumer imprisonment”. This study investigates the impact of consumer culture among other factors on the lives of LAD people and makes theoretical contributions to the relatively silent literature in marketing about the needs of this vulnerable group.

Taking a consumer-centric approach, with a qualitative perspective, 30 in-depth interviews were conducted, aiming to achieve a deeper understanding of the feelings, thoughts, and perceptions of those who experience disability and those who are able-bodied and contributes label creation process. The findings lay out the inclusion and exclusion process of LAD people in society. With this study, I also aim to shed light on marketing’s role as the norm setter.

Lieve Carette

Ghent University, Department of Special Needs Education (Belgium)

Main Conference

Paper

Sowing little seeds in the minds of people as a quiet activist

Looking for a good title which could cover what I wanted to talk about, I saw it was already taken: “Planting the seeds of a quiet activism” (Pottinger 2016). Are you an activist if you try to contribute to change, slowly by planting seeds, not knowing if they will grow in that kind of soil, without making a big fuss about it? Who is allowed to select the seeds and places to sow them? And how can you give the seeds the power to survive?

Starting from my own journey, I will discuss why I think there is an important intertwining between disability activism and academia, even starting with little acts of activism within this context. My collection of seeds began with listening to students in distress, talking about special needs and their personal conditions that made it harder to be(come) a ‘normal’ student. As they told their stories in confidence, the seeds were only planted in my head, where they began to grow and rankle. Trying to find a way to spread them in a position where you have to maximize negotiation possibilities for students and staff reluctant to look at things differently, you can’t force things, otherwise you cultivate resistance. You keep giving it chances, over and over again, but you go back to document the growing process. When you keep track and start using precedents to create new opportunities on behalf of students with special needs, you become an advocate. You cross the line and become an activist when it’s your intention to create a mind shift, contest the system and try to influence people to make permanent changes for the benefit of all. As a quiet activist, you plant seeds by participating at different levels in the education system and by empowering students. Quietly something’s growing.

Marie Caslin
Liverpool Hope University (UK)

Main Conference
Paper

The will to punish - the impact of recent government policy initiatives on the educational experiences of 'difficult' young people

There is a group of young people who continue to be pushed to the outskirts of the current English education system due to the behaviours they display in the classroom not conforming to our expectations of how pupils should be within this setting. This group of young people have had a wide variety of labels attached to them including Maladjusted; Emotional and Behavioural Difficulties (EBD) and most recently Social, Emotional and Mental Health (SEMH). They are the most likely group of young people to be excluded from school and rather worryingly this year we have seen an increase in the numbers of such children being removed from mainstream education. It is of concern that this is seen as an appropriate and in some cases a justified way of dealing with this group of pupils. Especially when evidence suggests that having extended periods of time out of the education system has a detrimental impact on an individual's future prospects.

This paper seeks to critically explore the impact of recent government policies such as 'Behaviour and Discipline in Schools' (DfE, 2016) on educational experiences. It has been widely noted how such legislation continues to reinforce the medical model of disability. I am interested in how disability evokes emotion and how for this group of young people they will be reduced to their label within legislation as they are framed as difficult, disruptive and disturbed which leads to them being punished. They are said to be the least liked group of pupils amongst both staff and their peers. The fact is we are failing these young people and I believe disability studies can be used as a powerful tool to help highlight their position as it calls us to look beyond the so-called 'problem child' and instead address the problem society.

Nurten Çelik
Ankara University (Turkey)

Main Conference
Paper

The Disabled Body and Humour

Jacob Levine asserted: “The humorous attitude is a state of mind. In that state, man re-asserts his invulnerability and refuses to submit to threat or fear”. This attitude, despite its seemingly cathartic element, reduces certain physical images that are outside of the accepted social norms into laughable objects. The question how the tragedy of the disabled becomes a source of comedy for the non-disabled is still debatable. There has been, among the disability theorists, a consensus that comedy surrounding the disabled body is one way to stigmatize the disabled. Yet, considering the complex nature of humour and disability studies in tandem, this common view remains inadequate to explain the fundamental reason underneath this stigma. This study, therefore, aims to problematize the contradictory relation between disability and humour and opens up a discussion concerning how humour is considered a source of power within the dynamics of social relations between the disabled and the non-disabled.

“Humour”, as Freud argued, “is not resigned; it is rebellious. It signifies not only the triumph of the ego but also of the pleasure principle, which is able here to assert itself against the unkindness of the real circumstances.” Drawing upon Freud’s view, this study argues that if humour is seen as a reaction against the disturbing realities and undesirable situations, humour directed at the disabled body can be considered as a veil to cover up the feelings of fear, disgust and threat that the abject disabled bodies evoke within the non-disabled - the gazer. It also proposes that humour directed against the disabled becomes a source to exercise power over the abled individuals. In developing this argument, Julia Kristeva’s theory of abjection and Freud’s ideas will be utilized so that they present a further insight into the relations between disability and humour.

Anna Chalachanova
VID Specialized University (Norway)

Main Conference
Poster

Participatory action research - research circle with people with learning disabilities

Ph.D. project with the focus on inclusive research with people with learning (intellectual) disabilities.

The goal of this project is to visualize citizenship in everyday life of people with learning disabilities through inclusive research.

Research questions:

1. How are citizenship practices expressed in everyday life in the stories of people with disabilities?
2. What barriers to citizenship are shown in these stories?
3. How do people with learning disabilities communicate their citizenship?

Design and methodic approach:

1. Review - systematic literature review with the focus on inclusive research with people with intellectual disabilities and active citizenship in everyday life.
2. Inclusive research circle inspired method with people with learning disabilities - in Slovakia
3. Inclusive research circle inspired approach with people with learning disabilities - in Norway

The theoretical framework for this Ph.D. project is theories about citizenship and inclusive research. Inclusive research is essential within the field of health and social services where we often operate with concepts of professional supreme power. Principles of the study are to invite people with learning disabilities to take an active place in research and become a subject of research, not the object. We would like to do that through dialog-based research including people with learning disabilities in research circle inspired method. The topics of the meetings are everyday life of people with learning disabilities. Participants take an active role in research. They choose the themes for research and participate in every step of the way; from the question through the preparation of interview guide, data collection, analysis, and dissemination. In this presentation, the first results of

data analysis will be presented with the focus on both methodology and citizenship and how it is expressed in everyday life of people with learning disabilities.

Helene Combrinck
North-West University (South Africa)

Philip Bothma
North-West University (South Africa)

Main Conference
Paper

“Let’s Shake on That”: Consumer Protection and Supported Decision-Making for Persons with Intellectual Disabilities

The adoption of the UN Convention on the Rights of Persons with Disabilities [CRPD] in 2006 brought about a radical shift regarding the acknowledgment of various disability rights. Notably, the CRPD recognises universal legal capacity with support, which stands in stark contrast with the traditional approach in most countries, which entailed a denial of legal capacity on the basis of actual or perceived limitations in mental capacity (decision-making skills). The CRPD however states that all persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life, and States are required not only to provide persons with disabilities with access to support to exercise their right to legal capacity, but also to ensure the rights of persons with disabilities with respect to financial and economic affairs. This implies a move away from the imposition of substituted decision-making regimes (usually in some form of guardianship) to supported decision-making mechanisms.

These provisions therefore envisage a situation where persons with disabilities may exercise their right to legal capacity in a far more independent and autonomous way than is currently the case - with appropriate support, where required. This includes entering into contracts as consumers of commercial goods and services, which in turn indicates that consumer protection measures (such as the principle that contracts should be framed in “plain language”) come into play. Founded in the paradigm of human rights and social justice, this paper explores the application of consumer protection measures, such as the move away from obfuscating legalese and illegible small print, and aims to propose practical measures that may support decision-making by persons with intellectual disabilities.

Stephanie Cork

University of Maryland (US)

Beth Douthirt-Cohen

Frederick Community College (US)

Kelly Hoffman

University of Maryland (US)

Paul Jaeger

University of Maryland (US)

Amanda Strausser

University of Maryland (US)

Main Conference

Paper

Beyond Random Acts of Diversity: Ableism, Academia & Institutional Sites of Resistance

The ableist infrastructure of post-secondary education in the United States often precludes disability as a full part of the university community; rarely recognized as more than a compliance requirement under the Americans with Disability Act. This medicalized approach supports disability as a subject of research and compliance at universities, but precludes the topics of disability culture, activism and advocacy as core to the work of the institution. The University of Maryland College Park boasts numerous offices that centralize the advocacy of race, ethnic, LGBT+, religious and other minority voices, but does not have a formalized office or space for disability advocacy and activism. In this way, full inclusion remains elusive, seen not only in the lack of administrative support but also in the physical structure of the university itself. Any attention given to such issues occurs in short bursts, with seemingly “random” events, projects and initiatives that rarely live past the tenure of a few dedicated individuals.

However, over the past two years, a small group of academics and community members have come together to form a contingent of rights-focused scholars who want to make disability advocacy a priority on this campus. Their efforts have culminated in an annual UMD Disability Summit and the financial support of the Moving Maryland Forward (MMF) Grants. These two sites will be used to form a case study to explore how disability is seen and supported at the University of Maryland, College Park. The data and analysis from this paper will

help identify strategies and practices for better integrating disability advocacy on campus, making it less “random” for students, staff and faculty alike. This will help foster “inclusive excellence,” creating best practices for the University of Maryland and other public institutions that face similar issues.

Grainne Collins
National Disability Authority (Ireland)

Caroline O’Nolan
National Disability Authority (Ireland)

Main Conference
Paper

The problems of research consent: dispatches from the front line

Although consent is often viewed simplistically as dichotomous- agreed or not agreed- in reality it is a dynamic process negotiated from question to question and minute to minute. Obtaining the informed consent of social research participants is understood to be standard best practice. Departures from this practice are red flags in applications to research ethics committees (REC) which have to be justified. Problematizing research with participants who lack the capacity to provide informed consent is likely to discourage researchers from focusing on this group of vulnerable people. Yet, research may provide insights and information which assists in the vindication of the rights of these people, rights which might otherwise not be upheld. Conversely, an overly protective stance on the part of researchers and /or RECs could result in the exclusion of participants who cannot consent and a failure to recognise their needs and uphold their rights.

This paper explores some of the ethical dilemmas we as researchers have faced when research participants have had cognitive and/or communication issues. It presents examples of research participants that have required the researchers to carefully weigh the risks, burdens and benefits of their participation in the research. The examples include, people whom: are non-verbal, have short-term memory loss, are on the autistic spectrum, are heavily medicated or have a moderate or profound intellectual disability.

The paper argues that lack of informed consent is not necessarily indicative of ethically poor research but does require researchers to engage in reflexive practice. Similarly obtaining consent is not sufficient to ensure ethical research. There should not be an a priori presumption that research which does not obtain the informed consent of participants is ethically compromised but rather that it is research which presents ethical challenges.

Lisa Davies

University of Central Lancashire (UK)

Main Conference

Paper

The Assessed Self: Exploring the Complexities of Disability Assessment Through Lived Experience

This paper is based on a chapter of my PhD thesis entitled: Writing the Disabled Self: Using the Autobiographical, Personal Narratives of Disabled People to Make a Case for Socio-political change. The chapter I am drawing on here is entitled 'The Assessed Self'. The key aspects of 'The Assessed Self' are the deficit-based character of assessment (Grover and Piggott 2007), the way in which I am compelled to represent myself because of the deficit basis, how this makes me feel, the resulting practical and psychological implications of this for myself and other disabled people (McGrath 2015). In this chapter I discuss my own and other disabled people's experience of assessment under the British Government's policy of austerity. The chapter itself includes my experiences of a range of assessments, DLA, DSA, and NHS wheelchair assessment. For brevity, I shall confine my analysis in this paper to discussion of Employment and Support Allowance (ESA) and The Work Capability Assessment. A brief extract from my chapter which highlights the challenges of representation in the context of ESA assessment is below:

The ESA assessment process produces a paradox in terms of representation in the context of the assessed self, because although I don't consider my disabled self-incapable of work, and indeed I do work, this is the assessed self-representation I am forced to make in order to get support, because being found 'fit for work' does not mean I will obtain employment, but it does mean I would have been denied much needed financial support.

I use my lived experience of assessment under austerity, alongside that of other disabled people, to highlight the damaging impact of deficit-based assessments, and call for an end to their implementation and use.

Runa Dawood
Psychological Therapist & Researcher (UK)

Main Conference
Paper

Disability and Formulation in Psychological Practice

The Disability Rights Movement addresses the limitations of the way in which the Welfare and Medical systems construct the definition of disability. The introduction of the “Social Model of Disability” (Oliver, 1983) facilitated the disunion between the term ‘disability’ and its associated notion of impairment. This broadens disability issues out from the remit of physical and mental impairment, to socio-political oppression. Psychological studies reveal the significance of this on the individual, families and carers. However the limitations of the individualistic model in psychological practice and research may play a role in the over-simplification of disability issues.

This talk examines the role of the socio-political in individual formulation in psychology and questions the potential for bias towards normalcy in research, guidelines and implementation. This is discussed with reference to the application of the disability studies literature to therapeutic practice and models in reflexivity. It is the author’s viewpoint that insight and reflective practice specific to marginalised identities can enable psychologists when working with individuals who identify as disabled.

Alise de Bie
McMaster University (Canada)

Main Conference
Paper

Finding ways (and words) to move: Mad student politics and practices of loneliness

In this paper, I blend the conceptual frameworks epistemic injustice (Fricker, 2007) and ethical loneliness (Stauffer, 2015) and apply them to a variety of campus-based examples of “referral” - from the literature and my own experiences as a Mad doctoral student - to describe the epistemic injustices that contribute to the abandonment of Mad students as knowers/learners. I then dwell in and politicize the condition of (ethical) loneliness these harms produce by seeking to “practice” it as a form of Mad knowing, being, and framework for visioning justice. Describing Mad student experiences in this way opens up several possibilities for epistemic justice:

-- First, it offers additional language and interpretive resources (like abandonment, loneliness) for naming and protesting our experiences of violence. These interpretive tools can help us disentangle ourselves from pathologizing perspectives to further politicize (and collectivize) our experiences and develop them as a source of knowing/knowledge.

-- Second, it compels us to understand and attend to Mad student experiences of harm beyond a procedural (policy, compliance, training, human rights) approach to accessibility and inclusion or clinical/social welfare (mental health service provision) approaches to distress. When we do this - when we reframe the harms experienced by Mad students as epistemic and dwell in those harms - we invite new ways of understanding and responding to them and restoring Mad students’ capacity to expect just treatment. Dwelling in these harms and allowing ourselves to be moved by them, we can also begin to recognize how Mad forms of knowing/knowledge are routinely generated in their wake.

This work contributes to the broader political projects of recovering the university as a place where Mad students and scholars can be supported as knowers and learners, and politicizing Mad student distress through the development and articulation of Mad Studies approaches to loneliness.

Gemma Díaz-Garolera
University of Girona (Spain)

Maria Pallisera
University of Girona (Spain)

Judit Fullana
University of Girona (Spain)

Main Conference

Paper

A university-social service collaboration: design, development and evaluation of a training program to enhance friendships

Introduction: Despite people with intellectual disability (ID) positively value having friendships, research suggests that they usually have reduced social networks, and these are often composed of family members and/or professionals. We present the collaborative experience between the University of Girona and a social service oriented to the ordinary job inclusion of people with ID. We designed, developed and evaluated a Training Program (TP) aimed at enhancing the construction of social networks and friendships among young people with ID. This experience attempts to link the university students' learning with the real needs of their work field, incorporating dynamics of collaboration between the academic and professional fields.

Method: Some Social Education students and some service users with ID identified -through focus groups- the skills needed to establish and maintain friendships. The first ones developed, with guidance from university professors and service professionals, some of the 12 sessions of the TP. A master student and a service professional developed the program at the university twice and evaluated its outcomes.

Results: The participants agree on the usefulness of the TP through expressing their desire to put into practice many of the worked aspects. They positively value using videos related to the different worked topics. The themes that most value working are: taking care of the relationship and maintaining it, friendship values, and conflict solving strategies.

Conclusions: It is a collaborative experience that benefits all the participants. University students design contextualised proposals,

favouring their motivation. They approach their professional field in a practical way. The youth with ID increases their probability of having greater success in their present and future friendships. Service professionals learn new and different work dynamics and methodologies. However, we should consider increasing the participation of university students, allowing them to collaborate as trainers in the different sessions of the TP.

Harriet Dunn

Liverpool Hope University (UK)

Main Conference

Paper

Applying the Tripartite Model of Disability to Art Education and Blindness

This interdisciplinary research employs Bolt's (2015) Tripartite Model of Disability as a method of ensuring engagement in art education for individuals identified as having visual impairment (VI). The model asserts that there is 'a complex understanding of disability that recognises assumptions and discrimination but not at the cost of valued identity' (Bolt, 2016, p.1). This theoretical framework, which underpins the research, explores practices and experiences of art educators at the beginning of their careers, working with young people identified as having VI. Application of the Tripartite Model of Disability can transform art practice for those with disabilities, specifically VI, so that educators can break down barriers and utilise the most appropriate skills to ensure the engagement of such individuals. It is necessary that this research identifies and challenges ableist and disablist policy and practices, since this denies individuals with VI the opportunity to engage in art education. As a result, recognition can be given to the third aspect of the Tripartite Model of Disability, non-normative positivisms, where individuals with VI can be appreciated and valued for their contributions and capabilities within art education. Consequently, this model, which advocates for the engagement of such individuals, provides the opportunity to enable each individual with VI to practise art education and develop their creative practice to the best of their ability. Furthermore, the research will create outputs - a framework which can inform educators working with individuals identified as having VI, on how engagement can be recognised and practised. The findings of this research may also be applied to any aspect of education, since it may be possible that not just art educators at the beginning of their career, but all those working with individuals with VI, in any aspect of the curriculum, can ensure that engagement is recognised and practised.

Hanna Egard
Malmö University (Sweden)

Main Conference
Paper

Accessibility and its Resistance

If we look upon today's laws, policies and regulations there is no doubt that principles of human rights, inclusion, participation and accessibility for people with disabilities have conquered many areas in society, and seized the attention of several authorities. In Sweden the Swedish Agency for Participation monitors the implementation of the national disability policy and "works to ensure that the policy will have an impact in all corners of society". According to the national disability policy the implementation of the policy shall target accessibility, universal design, individual support and on combating discrimination, four areas that are perceived as central for achieving equality and full participation for persons with disabilities.

This paper will focus on accessibility, more precisely on the different definitions and meanings of the concept that are used and described in documents such as international conventions, Swedish laws and regulations, policies and governmental reports. The purpose of the paper is twofold. The first purpose is to describe and analyse accessibility as a concept and norm and the arguments for an accessible society. The second purpose is to describe and analyse what is considered as "accessible enough", highlight the norms that conquer the accessibility norm and neutralizes the arguments for accessibility and which arguments that serves as explanations for not achieving the goal of an accessible society.

Snaefrídur Egilson
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Life quality and participation of disabled children and youth (LIFE-DCY)

Life quality and participation of disabled children and youth living in Iceland

This presentation introduces the background, objectives and implementation of the LIFE-DCY research project that aims to explore life quality and participation of disabled children and youth, using social, cultural, and human rights perspectives. A sequential mixed-methods design is applied within a transformative framework. The perspectives of disabled children and youth are in focus although the perspectives of parents and other key-stakeholders are also included in order to better understand important aspects of the children's daily lives. By comparing and contrasting different views and experiences, we aim to locate commonalities, differences, and conflicting issues in the processes that facilitate or restrict the disabled children's life quality and participation - and an understanding of why they persist. A theoretical lens will be used to integrate the findings, drawing mainly from critical disability and childhood studies. The theoretical understandings from this research will serve to unpack childhood disability in terms of knowledge and power and promote further understandings of how ideas about normality and childhood disability are constructed. The research will also clarify important aspects of the constructs of life quality and participation as well as how they intersect within different contexts.

Liz Ellis

University of the Highlands and Islands (UK)

Main Conference

Paper

Is there a ‘second wave’ of inclusive research? New futures or a return to old ground?

This presentation will explore the idea that there has been a shift in the way in which inclusive research with people with the label of learning difficulties is conducted. Drawing on the history of inclusive research, I will explore how changes in policy over time, often underpinned by inclusive research, and austerity measures introduced since the 2010 coalition government in the UK, have fundamentally changed the landscape of inclusive research.

I suggest that many of these historical policy changes have been positive signs of progress for people labelled with learning difficulties. However, I problematize the way in which these emancipatory notions of independence and autonomy in policy have been hijacked in the name of neoliberal economic policies. This process is designed to both shrink the publically funded welfare state and shift remaining resources into the private sector. This, I argue, has made people, and especially disabled people, vulnerable to poverty, ill health and higher levels of mortality as support is withdrawn. For those still seen as ‘deserving’ of support, the process facilitates the hyper-monetising of (re-)institutionalisation and the attendant horrors of neglect and abuse.

I will conclude by returning to the potential for Inclusive Research to uncover disempowering practices and illuminate pathways of resistance and emancipatory approaches that will promote human flourishing.

Silvia Favalli
University of Pavia (Italy)

Main Conference
Paper

Social Media and Disability Rights: A Human Rights Perspective

In the last decade, the untapped potential of social media has fast become the privileged arena for research and development studies to create new social media tools, generating at the same time new challenges for the existing legal framework which proved its inability to stay at pace. Within a few years, social media tools - such as social networking platforms, blogs, microblogs, wikis, media-sharing sites, virtual reality and gaming environments - acquired a primary role worldwide. In particular, for vulnerable groups at risk of social exclusion they represent an unprecedented opportunity to actively participate and be fully included in society. Persons with disabilities are increasingly turning to popular social media, taking advantage of interacting with social network platforms and benefitting from targeted mobile apps.

However, these tools also generate new challenges for the existing policy and legal framework, related to the unequal balance between social media use and human rights protection (i.e. privacy, data protection and cybersecurity, freedom of expression and opinion, access to information, participation in political and public life). Insofar as new technologies develop faster than the existing juridical context protecting the fundamental rights of persons with disabilities, new concerns addressing core disability rights emerge. However, the general protection provided by the human rights international treaties fails to provide an effective legal protection to disabled persons on equal basis to the mainstream 'digital society'.

Against this background, this paper seeks to determine the possible negative implications of social media use for the fundamental rights of persons with disabilities. The final purpose is to suggest critical legal and policy responses and to identify best practices to be disseminated to all the relevant private and public stakeholders, including activists, policymakers and practitioners.

Sam Fellowes
Lancaster University (UK)

Critical Dialogues in Neurodiversity Stream
Paper

Broadening the voice of neurodiversity through subtyping autism

The way in which the diagnosis of autism is formulated can influence the neurodiversity movement. I describe alternative ways of formulating autism by using the history of autism and then relate these to neurodiversity.

The DSM-5 in 2013 reformulated autism to become a non-subtyped spectrum, a single diagnosis (ASD) without further subcategories. This contrasts with DSM-IV which was a subtyped spectrum, containing subtypes such as Asperger's syndrome. Earlier decades, roughly from the 1950s to the 1970s, saw a much greater range of subtypes employed, ones with more significant differences than was the case with the subtypes of DSM-IV. I discuss those subtypes then outline what impact they could have for the neurodiversity movement.

Within a non-subtyped spectrum which covers all autistic people some strengths and weaknesses of autistic individuals are relative common whereas others are relatively rare. Those rarer strengths and weaknesses would occur more commonly within meaningful subtypes, each covering only some autistic people. Neurodiversity needs to speak for all autistic people. A non-subtyped spectrum emphasises more common strengths and weaknesses but de-emphasises rarer strengths and weaknesses, meaning those rarer strengths and weaknesses are less likely to feature significantly within neurodiversity. In contrast, they would be emphasised by meaningful subtypes. Consequently, a neurodiversity centered around meaningful subtypes would help raise public awareness of those less common autistic individuals, help build a more diverse autistic culture and help ensure their voice is heard within both scientific research and support services.

I contrast my account with Steve Silberman's Neurotribes which solely favours non-subtyped spectrums and unfairly dismisses subtyped spectrums. I show how this limits his notion of neurodiversity.

To conclude, I argue that the way in which various formulations of autism can enhance or hinder neurodiversity should be a factor in discussions about reformulating autism for future editions of the DSM.

Rebecca Fish
Lancaster University (UK)

Hannah Morgan
Lancaster University (UK)

Main Conference
Paper

Challenging the discourse of challenging behaviour

‘Challenging behaviour’, as defined by Emerson in 1995, is generally used to describe particular actions of people with learning disabilities. The term was coined to describe actions that services find challenging to respond to. Used in practice, however, the term often individualises the behaviour, removing the context in which it occurs, and referring to challenging behaviour as something a person ‘displays’ (Wilcox et al, 2011).

Haydon-Laurelut (2015) highlights this individualisation by describing his conversation with ‘Amy’, after she used the word “appropriate” when discussing her actions:

Mark: "So (manager) wants you to be more appropriate?" Amy: "Yes" Mark: "Amy, what words come to mind when you think about appropriate?" Amy: "Sensible" Mark: "What word comes to mind when you think about the word sensible" Amy: "Normal"

NICE guidance (2015) acknowledges context in terms of environments, including:

'those [environments] with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It also includes care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed'

Context and relational aspects can therefore combine and accumulate, to bring about ‘challenging behaviour’. The extent to which a person has resilience to such contexts is related to relationships and their associated resources, and thinking about challenging behaviour in this way opposes a culture that valorises independence and autonomy over connection and relationality.

In this presentation, we offer a sociological and gendered analysis of the use of the term 'challenging behaviour', asking why the term is used in particular with learning disabled people, and analysing the available knowledge base. We also present findings from a recent study where staff who work with men with learning disabilities who self-harm were interviewed about their experiences.

Fernando Fontes

Universidade de Coimbra (Portugal)

Joana Alves

Universidade de Coimbra (Portugal)

Mónica Lopes

Universidade de Coimbra (Portugal)

Bruno Sena Martins

Universidade de Coimbra (Portugal)

Paula Campos Pinto

Universidade de Lisboa (Portugal)

Sílvia Portugal

Universidade de Coimbra (Portugal)

Ema Loja

Universidade Porto (Portugal)

Main Conference

Paper

Disabled People and self-determination in Portugal: the promise of Independent Living

Disability policies in Portugal have been unable to guarantee disabled people the exercise of citizenship rights, thus contributing to the maintenance and reproduction of the barriers that create disabled people's social and economic vulnerability. Their lives, thus remain constrained by phenomena of social exclusion, discrimination and oppression by a society structured around supposed bodily normality. In the case of disabled people, however, this inequality is not only an inequality in access to resources but, above all, a structural inequality, which has in its genesis preconceived ideas about disability and about disabled people.

The launching of the Lisbon Independent Living pilot-project by Lisbon City Council in December 2015, the introduction of the Inclusion Social Benefit in October 2017 and the creation of the Independent Living Support Model (MAVI) that will allow the formation of Centres for the Support of Independent Living (CAVIs) across the country before the end of 2018, mark an undeniable shift in Portuguese Disability Policies. As our analysis reveals, these policy changes are still far from producing a substantial change in the reality of people with disabilities in Portugal.

Based on an ongoing research project "DECIDE - Disability and self-determination: the challenge of Independent living in Portugal"

(PTDC/IVC-SOC/6484/2014 - POCI-01-0145-FEDER-016803), and drawing on documentary analysis, semi-structured interviews with disabled people across the country and focus-groups with disability NGO representatives and stakeholders we will examine the progress, impact and efficiency of these local and central government initiatives in disabled people's lives, comparing and contrasting the lives of those people included and not included in the Lisbon Independent Living pilot-project. This analysis will allow us to assess the depth and extent of the announced changes in disability policies in Portugal.

Frederic Fovet
UPEI (Canada)

Main Conference
Paper

Academia, the Social Model and Mental Health: Say it like you mean it!

There is an increasing discourse on North American campuses around the Social Model of Disability. Campuses have come to realize over the last decade the limitation of the medical model in relation to accessibility issues, the issues this raises in terms of capacity and sustainability; as a result models like Universal Design for Learning are gaining momentum. Yet there remains one area where the institutional discourse will not shift from a medical model approach: mental health. This presentation will seek to examine the academy's unshakable adherence to the medical model when it comes to mental health issues. It will examine in particular:

- How the medical model is embedded in the current flurry of policy documents appearing across North American campuses around the management of mental health in the student population;
- How student services are focusing on growth of psychiatric and bio-medical services rather than on examining the systemic causes and triggers of mental health issues within Academia;
- How inclusive models such as Universal Design for Learning are being routinely framed in ways that fail to consider students with mental health issues;
- How these hurdles are characteristic of a mindset, rather than represent a genuine, tangible effort to address mental health in Academia through the lens of the Social Model.
- How activism is required in order to shift this mindset and advocate the adoption of a design thinking approach to mental health in the classroom.

Frederic Fovet
UPEI (Canada)

Main Conference
Paper

Examining the (lack of) impact of the #disabilitytoowhite movement on North American campuses

There is much talk of Intersectionality within Critical Studies in Academia, and yet there continues to be a disconnect between discourse and practice in this respect. In 2016, the #Disabilitytoowhite movement brought attention, within North America, to the pressing lack of focus on Intersectionality within the Disability movement. It created debate, gave rise to emotion and offered hope that the Disability movement, and more particularly Disability service provision, advocacy and scholarship within Academia, might take notice and address this gap. Almost two years on, the sad observation has to be that little has changed.

The presentation will:

- Examine the media overage surrounding the #disabilitytoowhite movement;
- Unpack the agenda of this activist movement;
- Survey and gauge the current state of play around Intersectionality within Disability services, advocacy and scholarship in Academia within the North American landscape;
- Attempt to examine and analyze the resistance to change in this area.
- Examine possible sustainable solutions for campuses attempting to address the lack of Intersectionality within Disability service provision.

Judit Fullana

University of Girona (Spain)

Maria Pallisera

University of Girona (Spain)

Gemma Díaz-Garolera

University of Girona (Spain)

Ivan De Castro

University of Girona (Spain)

Main Conference

Paper

Guardianship from the perspective of people with learning disabilities in Catalonia: An inclusive research study

The Spanish government signed the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006), yet the legal capacity of people with learning disabilities is often questioned and their freedom to make decisions is curtailed. Thus, an inclusive research team at University of Girona, the Research Group on Diversity, selected guardianship as the research topic for 2017-18. This research group, active since 2012, is comprised of 12 people with learning disabilities and three academic researchers and one master's student. This study aimed to (1) document what guardianship means in the lives of people with learning disabilities in Catalonia (Spain), (2) compare and contrast these experiences with the principles of the CRPD, and (3) provide an evidence-base for implementing changes to policy and practice among Spanish service providers that better align with CRPD. This participatory action project involved the research team co-designing this qualitative study. People with learning disabilities, supported by academic researchers completed interviews with 10 participants. Participants were experts with academic/professional background and experts by experience, that is, people with learning disabilities with first-hand experience of having their legal capacity questioned. Their stories were integral to thematic analysis. This presentation contains four key elements. First, the process of co-designing and completing the study will be critically reviewed. Secondly, the support strategies used to create an inclusive research process will be discussed. The findings and implications will be presented. Preliminary data analysis indicates that people with learning disabilities have very little knowledge and awareness about what impact guardianship has in their

lives, how guardianship can limit their choices in particular life domains such as money management, housing and even personal relationships and how to demand their rights. Finally, actions organized by this inclusive research team to catalyse political change in guardianship practices will be highlighted.

Peter Fuzei
Lancaster University (UK)

Main Conference
Paper

A walk on the wild side?

My presentation draws on material from my PhD that focuses on how assistive technologies are commissioned, designed and delivered for “clients with complex needs”. I conducted ethnographic fieldwork among clinical and technical professionals, an excursion that might be seen as a “walk on the dark side” from a disability studies perspective. Here, I focus on how the notions of medical diagnosis, impairment, and normate (Garland-Thomson, 1997) were reconfigured in clinicians discussions and practices.

I found that in the practical work of delivering systems client’s medical diagnosis took less than central significance. It was considered in each case but only as one among other important factors such as clients’ preferences and skills, social and material environments and emotional wellbeing. Personalising systems was recognised among my informants as the only possible way to deliver these assistive systems.

The development, design and delivery of assistive systems progressed through an ongoing inquiry and trials into what how particular clients can (and cannot) operate specific devices. But rather than solidifying into a static and definite impairment categories or labels, client’s dis/abilities were primarily relevant for an open, specific and empirical inquiry to adapt systems for the client’s changing preferences and needs.

The image of “normal” human development play an important role in both rehabilitative and assistive technologies. I found that in the latter normate figures served primarily as a background against which individual cases are specified; achieving or approaching normal states was not articulated as the objective, rather clinicians’ efforts went into finding out what clients want to achieve by using technology. Clients’ participation as co-developers was crucial not only to negotiate the purpose and functionality of these personalised systems but also whether someone wants to use technology at all.

Ingunn Fylkesnes
Nord University (Norway)

Main Conference
Paper

The everyday life of severe disabled children living in small group-homes and the possibility for getting a bottom-up perspectives

There is an increasing body of research on and with disabled children. Still, the amount of research in social sciences concerning severe or profound intellectually disabled children are scarce. It is, however, a growing literature on the topic (e.g. Simmons & Watson, 2014; Evensen, 2017, 2018), which focuses on the children's perspectives more than professionals and parents' point of view. Much of it belongs to the discipline of education and communication (AAC). Just few concern residential settings, and then frequently connected to residential schools.

My PhD-project "Children and young persons living in small group-homes - meaning, participation, lifeworld" intends to shed light upon the life of severe intellectual disabled children living away from home. The small group-home is in Norway an institution providing 100% respite service. This service might be controversial in light of the closedown of the big institutions in the 1990s. There is, however, a slight increase in the number of children inhabiting this type of care in Norway.

My aim is to gain deeper insight in children's life in group-homes. obtained as far as possible from their own perspectives through observations. The children and their life constitute the units of analysis, while the group-home and cooperation between carers and parents represent the close context. In a wider context the analysis also relates to more superior frames as the policy of care and rights of the child, as well as childhood studies and disability studies.

In this session I will discuss theoretical possibility of generating sound empirical evidence by observing some of these children: their meanings expressions, participation and empowerment in their everyday life in the group-home. To guide analysis of empirical data and theoretical discussion of findings, I will draw on several methodologies and perspectives including ethnomethodology (Goode,

1994), phenomenology (Merleau-Ponty, 1994) and symbolic interactionism (Blumer, 1969).

Catriona Galbraith
University of Stirling (UK)

Main Conference
Paper

Cane and Able - Illness Visibility and Assumptions of an Able Body

This presentation explores preliminary findings of PhD research with families where a member has fibromyalgia, and the usefulness of Campbell's (2009) concept of ableism in conceptualising peoples' experiences. Fibromyalgia is a chronic, remissible, non-terminal illness causing fatigue, chronic pain, brain fog, anxiety and depression, whose symptoms vary from day to day and person to person. The illness is invisible, with no known aetiological markers of its existence making it medically contested, stigmatised, and invisible in social interactions (providing assistive devices, for example walking sticks, are not used). Semi-structured interviews with those with fibromyalgia and their families were conducted and focused on daily routines and people and places who are/are not supportive of fibromyalgia. Findings from this suggest that people's lack of understanding of their illness came from fibromyalgia's invisibility causing scepticism and a 'you don't look ill to me' attitude. This could lead to assumptions of ability which created stress for participants and impacted their personal lives. It is argued that ableism is an important conceptual tool to explore people's experiences of fibromyalgia. Campbell (2009) defines ableism as a blend of culturally and historically formulated actions, systems and ideas which constitute a silently accepted standard of an able body. Assumptions of ability directed to participants by themselves and others due to fibromyalgia's invisible, unpredictable and chronic nature encompass the conflicting and fluid ontologies experienced by participants in their daily life. The able/disabled Other dichotomy supports norms of the able body, however, fibromyalgia poses a challenge to this norm by occupying the spaces in between. It is argued knowledge of ablest practices could serve as a means to raise awareness in this group where disablement and impairment effects can be a variable ontology in daily life and not readily identified with, despite being a real source of social and material oppression.

Rasa Genienė
Vilnius University (Lithuania)

Main Conference
Paper

Independent living of persons with disabilities in post-Soviet countries: between imitation and practice

In today's Europe, persons with disabilities live in two parallel worlds. On the one hand, with the advent of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), much attention was paid to the responsibility of States to take action to protect and promote the rights of disabled people. On the other hand, in some countries, the Soviet mentality is still alive and the widespread rooted flawed culture of service provision makes it hard to give a way to new, modern, assuring human rights services. Therefore, such a significant development of CRPD has a little meaning for those people with disabilities (PWD) who are segregated in institutions, often for life, unless the governments take concrete action to end this practice.

The subject of this study is the implementation of article 19, "Living independently and being included in the community," of CRPD in the post-Soviet countries. This article provides that all PWD have the right to live and participate in the community. So this research will try analyse the factual implementation of this goal in the countries of Central and Eastern Europe. In this region PWD were massively closed to remote institutions and violations of their human rights eventually became a normal practice of the service system. This is a significant legacy of the communist regime, which is still in existence today.

The methods of this study include quantitative analysis of countries reports on the implementation of the Convention as well as alternative reports prepared by non-governmental organizations for the Committee on the Rights of PWD. The research will focus on countries: existing legislation; national strategies of transferring the provision of care from institutions to the community; holistic approach and identifying all the barriers; etc.

Hege Gjertsen

Institute of Social Education, The Arctic University of Norway (Norway)

Main Conference

Paper

Can we talk about inclusive research in quantitative studies?

Inclusive research is mainly associated with qualitative studies. We want to discuss challenges and advantages of trying to do quantitative research inclusively. The Arctic Centre of Welfare- and Disability Research at The Arctic University of Norway (UiT) conducted a study of living conditions of Sami people with intellectual disabilities in October 2017. The Norwegian Directorate for Children, Youth and Family Affairs and the Nordic Centre for Welfare and Social Issues funded the project. The main purpose of the study was decided in advance; to examine living conditions of people with intellectual disabilities from 16 years old, living in Sami areas. According to the assignment we were imposed to examining central living condition variables such as housing, social networks, participation, quality of life etc., and to use a structured questionnaire schemes with mainly fixed response categories. As a condition for signing the project agreement, we insisted that people with intellectual disabilities must get opportunity to answer the questionnaire themselves, even though it had never been done before in Norway. Instead of having a reference group of experts following the project, we also established a research group consisting of researchers employed at the University and persons with intellectual disabilities and Sami people, defined as co-researchers. The co-researchers participated in the research process by discussing the questionnaire (what questions to ask and how), taking part in the analyzing process (how to understand or interpret the findings) and participate in the dissemination of the results. The main question for this paper is; can we talk about inclusive research in a quantitative study, or to what extent can we do quantitative research inclusively? Another question that is being discussed; how can co-researchers develop an ownership to the research project when the sponsors already have identified and initiated the research questions to be asked?

Hege Gjertsen

Institute of Social Education, The Arctic University of Norway (Norway)

Main Conference

Paper

Innovative service providers as promoters for work inclusion for people with intellectual disability

The paper present preliminary results and analysis from an ongoing study of work inclusion for people with intellectual disability. People with intellectual disability are mainly excluded from ordinary work in Norway, despite strong political endorsement. Only approximately 25 percent of people with a known intellectual disability in working age is in employment. Almost all those employed have jobs with adapted measures, of which 90 percent in sheltered workshops. During a period of three years (2018-2020) the Institute of Social Education at The Arctic University of Norway (UiT) will conduct a research project where the primary objective is to develop research-based knowledge relevant to strengthen competencies in work inclusion for people with intellectual disability. The project “Rethinking work inclusion for people with intellectual disability” is funded by the Norwegian Research council. Collaboration partners are NTNU, HINN (Inland Norway University of Applied Sciences), HSN (The university college of Southeast-Norway) and the University of Iceland. The project consist of four work packages using different methods and exploring work inclusion from different perspectives. In one of the work packages, we will study what kind of skills, knowledge and competence increase social educators’ ability to be promoters of innovation in work inclusion within sheltered workshops. This will give us knowledge about how service providers can succeed in the difficult transition to ordinary work for people with intellectual disability. Interviews with service providers and people with intellectual disability working in sheltered workshops or having work training at ordinary work places, emphasizes the importance of several factors for succeeding with work inclusion. These are among others related to the extent and content of support, both for the employee with the intellectual disability and for the employer.

Charlotte Glintborg
Aalborg University (Denmark)

Dorthe Birkmose
Self-Employed (Denmark)

Main Conference
Paper

If only they had seen me as a human being. Inside perspectives from adults with acquired brain injuries.

The aim of this study was to explore how Danish adults with an acquired brain injury (ABI) experience encounters with professionals during their rehabilitation process. The study draws on empirical data from 82 adults with moderate to severe ABI collected as part of a Ph.D. project (Glintborg, 2015) and a 5-year follow up study. Discourse analysis drawing on the concepts of self and other positioning (Harré & van Langenhove, 1999) was applied to investigate participants' construction of identity through self-narratives. Analysis reveal that once diagnosed with ABI, this label can take a master status in encounters with professionals. Professionals' reification of the diagnosis of brain injury can be oppressive because it subjugates humanity such that everything a person does can be interpreted as part of the neurological disability. We conclude that there is a need for a new kind of professionalism that balance the diagnostic lens with a lens on the person as a human being.

Steve Graby
University of Leeds (UK)

Main Conference
Paper

Personal assistance co-operatives: possibilities and pitfalls of alternative models of 'independent living' in the age of austerity

The employment of personal assistants (PAs) by disabled people has long been considered by disabled people's movements in the UK and elsewhere as one of the fundamental pillars of 'independent living'. Its proponents argue that making disabled people employers with the right to 'hire and fire' PAs is necessary for a shift in power from 'care providers' towards disabled people, replacing paternalistic power structures with individual choice and control over day-to-day provision of support. However, taking on the role of 'employer' also forces many disabled people to take on legal and bureaucratic responsibilities that they may not want or be equipped to deal with, and may also be relationally uncomfortable or undesirable for some personal assistance users.

The situation in the UK where disabled people are expected to be direct employers of PAs as individuals can be contrasted with that in the Nordic countries, where there is an established tradition of co-operatives run and controlled by disabled people providing personal assistance services. These and other alternative employment structures arguably call into question the role of 'employer', in particular suggesting a potential separation between the legal or financial definition of employment and the relational authority of the disabled person as 'boss' or manager of PAs.

Drawing on my qualitative interview research with disabled employers and PAs in the UK and on recent activist conversations within the Disabled People's Movement (which have highlighted both a synergy between the values of the DPM and co-operatives and an urgent need for activist attention to social support provision at local and national levels), this paper will examine the possibilities and pitfalls of co-operative employment strategies for personal assistance in the context of austerity and the threat of reinstitutionalisation.

Elizabeth-Anne Graham
University of Stirling (UK)

Critical Dialogues in Neurodiversity Stream
Poster

“He’s just not autistic enough for the autism support base”

This presentation will discuss the complex issues relating to defining and diagnosing autism and the impact that this has had on some pupils from mainstream schools within Central Scotland. It will also highlight how these issues can impact on the parents of autistic pupils and influence the ways in which autistic pupils are supported in school. This discussion is based on my current PhD research which explores the experiences of receiving and implementing support for autistic pupils in mainstream secondary schools across the central belt of Scotland. The study consists of multiple task-based interviews with autistic pupils aged between 12 and 18 as well as semi-structured interviews and informal discussions with their parents, therefore the study has an ethnographic element to it. It also involves face-to-face and email interviews with support and teaching staff in Scottish mainstream secondary schools. Initial findings have shown that some pupils do not receive additional support in school provided to other autistic pupils because they are “not autistic enough” “too high-functioning” or because they “pass as normal”. Often this comes from judgements from school staff who deem them to be “just shy” or “being a typical teenager” but can also be directed by some of the pupils themselves who do not wish others to know about their diagnosis and, for some, feeling like they have “autism” stamped on their forehead. Interestingly, parents have also conveyed feeling that they have lost the child that they thought they had, which for some happens immediately following a diagnosis, demonstrating the impact that a diagnosis has in the lives of autistic people and their families. Most pupils in this study expressed that an assembly to educate others in the school about autism would be beneficial to their school experience.

Emmanouli Gratsias
Northumbria University (UK)

Toby Brandon
Northumbria University (UK)

Su McAnelly
Northumbria University (UK)

Main Conference
Paper

Advocacy, what difference does it make, exploring the theoretical and practice impact of advocacy work

Given austerity and the rise of disablist hate crime, the role of advocacy for disabled people would appear to be more important than ever. Advocacy in its basic form is “speaking up” for oneself or others however, it is very rarely that simple (Atkinson, 1999). It can be seen as producing two main types of outcomes. Firstly “Hard” or “end point” outcomes which involve reaching a practical target, such as a house move, and are relatively easy to measure. Secondly “Soft” or “process” outcomes, such as increased confidence and assertiveness. These tend to be associated with the advocacy journey and are more difficult to explore and quantify. Advocacy encourages partners to pursue the issues they see as important.

This paper presents an empirical doctoral study into the meaning of different advocacy outcomes for a group of people with learning difficulties. The work, within the limits of a PhD, adopted principles that encouraged the active participation of advocacy partners in the study. Participatory research principles were used to promote the involvement of people with learning difficulties that have been under-represented in research (Walmsley et al, 2014). Five self-advocacy group members took part in a focus group that developed case vignettes to be used in later in depth interviews. Thirteen people with learning difficulties who had direct experience of advocacy took part in the interviews. The study used elements of narrative research approaches in relation to data collection and analysis which encouraged participants to express themselves more freely (Nind, 2008).

Social constructivism underpinned this study (Holstein and Gubrium, 2008). The findings showed that participants placed a stronger

emphasis on the process outcomes compared to end point outcomes. Participants consistently brought up themes around working together, empowerment, feelings and mutual earning. This paper concludes with a potential model of advocacy outcomes.

Dominic Griffiths
Manchester Metropolitan University (UK)

Critical Dialogues in Neurodiversity Stream
Paper

“He’s suffering from Neurodiversity”: How do teachers understand this term and how does this affect their practice?

This paper explores findings from an evaluation of a recent training initiative for inclusive teaching with English schools and further education colleges, which was entitled ‘Teaching for Neurodiversity’.

Data from this study, from observation of one such training event and from semi-structured interviews with teachers in six case study schools, selected on the basis of their reporting of high impact of this training, reveals a wide range of understandings of this term: a range which might influence their approaches to teaching.

These teachers’ understandings of the notion of ‘neurodiversity’ are also discussed in the context of the dominant discourse of ‘special educational needs’ in the English education system.

Chris Grover

Centre for Disability Research, Lancaster University (UK)

Main Conference

Paper

Employment and Support Allowance: a decade of the social murder of disabled people

There can be no doubt that Employment and Support Allowance (ESA) is having a devastating impact upon income poor disabled people. Quantitative research, for example, demonstrates the detrimental impact of ESA on suicide and suicidal thoughts, mental health and distress, and the prescribing of anti-depressant items (Barr et al., 2015; McManus et al., 2016). Such findings are reinforced by information gathered by disabled people's organisations (Spartacus Network, 2013, 2015) and even the House of Commons Work and Pensions Committee (2018) about the impacts of ESA on the lives and deaths of disabled people.

Drawing upon heterodox political economy, the paper will argue that these impacts of ESA can be understood as a form of social murder. In this context, social murder relates to the consequences of state action that results in the early death of some of the poorest disabled people. The point is that those deaths are foreseeable and avoidable. From the early days of its operation ESA was known to be problematic. Governments of various political persuasions though, choose to continue with its introduction, its extension to existing Incapacity Benefit recipients and to make little more than superficial changes to it.

It will be argued that social murder via ESA is the consequence of the violence of contemporary forms of capital accumulation, to which the receipt of income replacement benefits is held to be deeply problematic on a number of economic levels.

Carolyn Gutman
Tel Hai College (Israel)

Ayala Cohen
Tel Hai College (Israel)

Main Conference
Paper

Advocacy to activism: transforming policy through collaborative action research

As social work educators grounded in community social work and disability studies, we argue that the contemporary neoliberal context demands that social work practice must, of necessity, involve political activism. This activism needs to strengthen and redefine the relationship between legislative policy and social work practice. However, this form of social work intervention has remained on the sidelines of social work practice and education in most welfare states, including Israel, and remains a practice method adopted by a minority of members of the profession. Furthermore, we believe that all social workers, not only those with formal policy positions, should engage in policy practice activities aimed at influencing policy, and that this should be an integral part of social work education.

Here we present a unique policy practice track which we developed in the undergraduate social work program at Tel Hai College located in the northern periphery of Israel. We focus on the track's defining research seminar in the final year of study. In this seminar, which is grounded in a participatory action research framework, social work students collaborate with service users with disabilities to develop a research methodology for learning from the knowledge and experiences of the service users and create a practice agenda to further policy change in their specific fields of interest.

The presentation, builds on a vision of expanding social work practice to encompass policy practice, and articulates key issues raised by both students and service users as they learn to work in partnership. We address the numerous challenges and dilemmas that are raised during the seminar, including examples of working with the socio-political model of disability, and the assumptions about service users' knowledge.

Mèlani Halacre
Spokz People (UK)

Main Conference
Paper

Symposium: Disability, psychotherapy and the politics of the personal

Providing Disability Affirmative Therapy in the UK - a challenge?

This paper explores the challenges a non-profit Disability Affirmative Therapy (DAT) service has been experiencing delivering this service UK-wide during the last 9 years. This paper will consider:

- Challenges in the therapeutic work: many disabled people have experienced childhood adversity, abuse, medical trauma, poverty, and experience ongoing negative situations (small traumas or disability hassles) in society, with government bodies and medical establishments. In addition, due to isolation and impairment effects such as pain and fatigue, clients sometimes have fewer internal and external resources. Positive change can be challenging in this environment and stigma can prevent clients from seeking out this specialised support.
- Structural challenges, there is: little awareness of the need for this service; a major issue around funding as many clients are unable to self-fund; a lack of resources, referral routes and support from government organisations; an issue with therapist recruitment, training and turnover. All are affecting an expansion of DAT.

The aim of this paper is to use practical examples to build on these points, to provoke discussion and gain ideas on how these challenges could be addressed, both within the UK and further afield. Please do join us: we welcome your contributions.

Mel is an experienced psychological therapist who has worked with many disabled people and has personal experience of disability.

Rune Halvorsen

University of Leeds and Oslo Metropolitan University (Norway)

Main Conference

Paper

Collective identity and self-representation among disabled people - a life-course perspective on social movement mobilisation

This paper compares the construction of collective identity among disabled people. The paper identifies mechanisms and processes that influence whether disabled people believe they have a common cause and associate with other disabled people. Drawing on life-course interviews with persons with mobility, visual and mental health disabilities in Norway, the paper compares how cultural classifications and interpretations of disabilities, the attribution of meaning and perception of disabilities influence their capabilities to act collectively together with others in a similar situation. The life-course data provide insights on how disabled people have positioned themselves and how they have related to other disabled people over the life-course. The paper compares how dominant cultural narratives influence whether disabled people identify with, interact with or avoid contact with other disabled people, and asks whether we find more country specific differences in the narratives. More specifically the paper compares whether persons with mobility, visual and mental health disabilities believe they have anything in common with other disabled people, whether they believe they are entitled to demand rights and advocate their own opinions and needs, and whether they consider their disability or impairment to be temporary or permanent. The paper concludes by discussing the implications for collective self-representations among disabled people.

Kristofer Hansson
Lund University (Sweden)

Main Conference
Paper

Critical Places

This is a conceptual paper trying to present and develop the concept of “Critical places” and how it can be used when studying the everyday experience of living with long-term sickness or/and disability. I developed the concept a couple of years ago in a chapter about young men living with asthma and allergy (2007). The concept analyse the duality of both physical risk and social benefit and how they can collide in one specific place and create a bodily situation were the individual need to act. “Critical places” focus on the phenomenological thought about doing and what happens in the specific situation, in this way the concept can also be seen as an ethnographic method. As a more theoretical concept “critical places” can be used for a hermeneutic analyse of risk-taking, hiding from stigma, identity formation, power relations in a specific place, highlight limitations of accessibility and so on. I have also used the concept in a couple of chapters concerning disability (Hansson 2009, Hansson 2013, Alftberg, Apelmo & Hansson 2016). The concept have also been used by Cridland (2017) in here ethnographic study of eating communities and by Hagen (2012) in his study about people living with Huntington’s disease. In this paper I will develop the concept with my new research project about limitations of accessibility for people living with disability in Sweden.

Kristofer Hansson
Lund University (Sweden)

Ellen Suneson
Lund University (Sweden)

Critical Dialogues in Neurodiversity Stream
Paper

Vulnerable Normality: Popular Neuroimaging and the discursive logic of the (dis)able(d) brain

The aim of this paper is to analyse popular neuroimaging of the (dis)able(d) brain as a cultural phenomenon, as well as to explore how there has been, during the last decades, a subtle but important change in the way the “normal” brain is depicted in popular science. Popular neuroimaging is introduced and used as an empirical basis to analyse what Fiona Kumari Campbell sees as a critic against ableism. The empirical material consists of two British popular science documentaries (both produced by the BBC) on the topic of the brain: Human Brain (1983), and Brain Story (2004). The article argues that the position of normality and able-bodiedness have changed as the development of brain scanning techniques has emerged. Specially, there seem to have been a change in how the discursive logic of the brain is visualised and talked about. New frameworks for understanding normality, disability and vulnerability have appeared. Furthermore, we claim that this shift needs to be studied from a theoretical perspective that analyses the discursive logic of the (dis)able(d) brain where an indistinction transpires and creates a form of vulnerable normality.

Freyja Haladsdottir
University of Iceland (Iceland)

Anna Sigrun Ingimarsdottir
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Life quality and participation of disabled children and youth (LIFE-DCY)

Justice as quality of life: young disabled people look back and beyond

As a part of the LIFE-DCY research attention has been directed at how young disabled people reflect on their childhood and teenage years in relation to quality of life and participation. What constitutes life quality has been explored through focus groups with young disabled people who look back and beyond at their childhoods, aiming to reflect on their own assumptions regarding their definitions and discourses. Central to this part of the research is illuminating their notions on matters regarding the two concepts. Further the question is asked whether those notions are in line with ideas of non disabled people regarding how they emerge or how they should emerge in the lives of disabled youth. The focus is on what it means to participate in society and how participation, or lack of it, influences opportunities to lead a good life. Also, taken in account, how other factors such as gender, class and sexuality, intersect with disability in young disabled people's experiences.

In this presentation Anna and Freyja will share some of the findings from the focus groups with young disabled people. Freedom from ableist stigma and shame seems to be essential in developing a sense of self and pride in disability. Also, access to justice, not only legally but emotionally, plays a big part for disabled youth in claiming control over their bodies and lives. Participants also agreed on the fundamental value of having their own voice in all circumstances concerning their affairs, specially in relations to others. Those are among the many qualities that young disabled people identify as important and contributing to their life quality when growing up as disabled children.

Bjørn Hamre

University of Copenhagen (Denmark)

Main Conference

Paper

Inclusion and the management of diversity in the Danish welfare state

The purpose of the presentation is to analyze inclusion as a historical concept in the Danish welfare state. A concept that features ambiguous and contradictory meanings. The analytical optics of the presentation draws on a conception of education as a phenomenon and practice that includes both norming and normalizing functions in relation to the state and the school system. The analysis itself consists of three different sections analysing the school system's way of dealing with diversity. The first sections addresses the emergence of special education such as the school's handling of diversity in the mid-20th century. The second section analyses the emergence of the vision of inclusion as a historical concept that problematized special needs education as a way to address diversity. The third section deals with the impact of the marketization, accountability and testing in the new Danish school system, representing a challenge to the vision of inclusion. Inclusion risk to be absorbed by the political will to optimize the academic qualifications of the students. In conclusion, the contradictory concept of inclusion is discussed in relation to the welfare state's contradictory interests.

Haraldgur Thor Hammer Haraldsson
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Disability before Disability

The Disabled Dead

This contribution will present preliminary findings from the osteoarchaeological perspective from the interdisciplinary project Disability before Disability in Iceland. These findings will be interpreted in conjunction with a critical disability studies perspective in order to understand how the physical evidence of impairment from skeletal remains may shed light upon how contemporary society at the time viewed certain individuals with impairments. I will also attempt to provide analytically driven interpretations for the evidence of possible social exclusions, inclusions or even reverence of these individuals. One of the primary objectives of this research is to take methodologically derived observations of skeletal remains of individuals with impairments and put them into contemporary social context and vice versa. The subjects within this project are only from Icelandic skeletal records and will therefore only be representative for Icelandic contemporary societies in the country's past.

The individuals in this project will be examined in chronological order, and their remains date from the Settlement period of Iceland (8th to 10th centuries AD) to the 18th to 19th centuries AD. The pathological conditions which have been identified are as follows: Kleinfelder's syndrome, which causes unusually tall physical stature, infertility and in some cases mental disorders, such as autism or schizophrenia; paralysis on entire left side of the body; Paget's disease which is a condition where new bone formation coincides with bone destruction; hydatid disease (Echinococcus) which is a parasite that forms infectious bladders within the host body and can cause multiple problems for the individual involved; and lastly a case of severe scoliosis.

As stated above, it will be the purpose of this presentation to demonstrate how osteoarchaeology/ bioarchaeology can possibly further our modern understanding of impairment and disability in the

past, and how skeletal material can be indicative of societies perspective regarding individuals with impairments.

Freyja Haraldsdottir
University of Iceland (Iceland)

Anna Sigrun Ingimarsdottir
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Life quality and participation of disabled children and youth (LIFE-DCY)

Justice as quality of life: young disabled people look back and beyond

As a part of the LIFE-DCY research attention has been directed at how young disabled people reflect on their childhood and teenage years in relation to quality of life and participation. What constitutes life quality has been explored through focus groups with young disabled people who look back and beyond at their childhoods, aiming to reflect on their own assumptions regarding their definitions and discourses. Central to this part of the research is illuminating their notions on matters regarding the two concepts. Further the question is asked whether those notions are in line with ideas of non disabled people regarding how the emerge or how they should emerge in the lives of disabled youth. The focus is on what it means to participate in society and how participation, or lack of it, influences opportunities to lead a good life. Also, taken in account, how other factors such as gender, class and sexuality, intersect with disability in young disabled people's experiences.

In this presentation Anna and Freyja will share some of the findings from the focus groups with young disabled people. Freedom from ableist stigma and shame seems to be essential in developing a sense of self and pride in disability. Also, access to justice, not only legally but emotionally, plays a big part for disabled youth in claiming control over their bodies and lives. Participants also agreed on the fundamental value of having their own voice in all circumstances concerning their affairs, specially in relations to others. Those are among the many qualities that young disabled people identify as important and contributing to their life quality when growing up as disabled children.

Stefan Hardonk
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Life quality and participation of disabled children and youth (LIFE-DCY)

Deafness, quality of life and participation: a critical approach

The concepts of quality of life and participation in relation to the experiences of disabled children are at the centre of the Icelandic LIFE-DCY research project. In this lecture I will look particularly at the meaning of these concepts in relation to children who are born deaf or hard-of-hearing. Ever since cochlear implantation (CI) has become available as a means to improve children's hearing capacity quality of life and participation have been key concepts in the debate that ensued. Advocates and opponents of the technology have argued to the benefit of their case that CI is either beneficial or a threat to the quality of life and participation of children who are born deaf or hard-of-hearing. Departing from quality of life and participation, some studies have taken specifically the perspective of young persons to discuss the issues that CI raises in terms of deaf identity, a key issue in studies of deafness, which shows the centrality of these concepts. In this lecture I will combine critical literature on quality of life and participation with literature from deaf studies to explore the different ways in which quality of life and participation have been defined and used in theoretical papers and empirical studies. I will argue that there is an opportunity in research about children who are deaf or hard-of-hearing to critically redevelop these concepts using two fundamental principles: (a) quality of life and participation should be defined by listening to the voices of the children themselves; (b) a critical approach to these concepts should be aimed at placing them in context and uncovering the power relations that surround their definitions and related experiences of children who are deaf or hard-of-hearing. I will conclude by outlining how I will apply this approach in the empirical case studies of the LIFE-DCY research project.

Per-Olof Hedvall

Lund University (Sweden)

Jan McArthur

Lancaster University (UK)

Sue Cranmer

Lancaster University (UK)

Main Conference

Paper

**Recognizing diversity within everyone's lived experience:
Strengthening the theoretical foundations of Universal Design**

This paper situates Universal Design (UD) within the framework of social justice theory, drawing Honneth's conceptualisation of social justice as mutual recognition. It takes as a starting point the perspective that UD requires a robust theorisation and rationale to support implementation in practice. For Honneth, social injustice occurs when mutual recognition believed to be legitimate is withheld. He offers a tripartite understanding of social justice with three different spheres of recognition needed to realise a fulfilled life: love (focused on affective care; emotional support); respect (focused on equal treatment in law); esteem (focused on the traits and abilities that people have through which they contribute to the social whole). Connecting Honneth's fundamental set of social justice concerns to UD can potentially stimulate debate; engage new audiences. It can demonstrate that to treat others as anything less than full members of society, as in the case of discrimination or a lack of care, diminishes ourselves. UD has been around for more than thirty years, and stands for an ambition to design with people of all ages and abilities in mind. It marks a shift from working towards accessibility to primarily support disabled people to inclusive design, targeting all people. We argue that while UD remains strongly associated with the disability community, its chances of being universally accepted and realised remain remote. We use Honneth's work to demonstrate the need to understand UD as relating to all members of society, not just those with impairments and to highlight how everyone can potentially experience disablement due to the environment. This can occur when there is a misrecognition of social needs that would benefit from a commitment to UD, such as creating inclusive public spaces for families with children, stimulating

inclusive workplaces, or making life a little bit easier when someone breaks a leg.

Anna Katharina Heiniger
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Disability before Disability

The Silence of the Limbs

This contribution will present some initial findings from the ‘Disability before Disability’ project based at the University of Iceland. These specific findings have emerged from the strand of the project dealing with Icelandic medieval narrative sources and disability. At the moment, the main focus of interest lies on the depiction of impairments within the corpus of the Icelandic Family Sagas (Íslendingasögur), which were written down between the mid-13th century and the early 15th century.

In the course of many of the fights, duels and skirmishes that are depicted in the Íslendingasögur, many saga figures experience serious physical traumata such as deep flesh wounds or even chopped off limbs. Interestingly, however, it seems that these incidents are considered collateral damages, which are not thematised or revisited later on. The presentation’s title - the silence of the limbs - thus points to the fact that the sagas keep silent about the process of healing and recuperation as well as living with a missing limb.

For a modern audience this observation is puzzling to the extent that in modern daily life, physical impairments often tend to trigger empathy and are repeatedly thematised. It thus remains to be pondered what relationship the saga world had towards physical harm and what importance was attributed to an (un-)blemished body.

Kevin Hickman
Wheels for Wellbeing (UK)

Main Conference
Paper

Cycling, Disability and Activism

Two minority groups (in the context of the UK) with organised campaigns of activists which tend to be in opposition. What, if anything, do they have in common?

If the first ever cyclist was a disabled person who invented a cycle as a mobility aid in the seventeenth century, would that event be recorded in the history of disability, in the history of cycling, or both?

Do the various forms of cycling receive equal attention and how is the participation of disabled people characterised in 'the media'?

Is cycling an enabler or a threat to disability?

Nick Hodge

Sheffield Institute of Education, Sheffield Hallam University (UK)

Emma Rice

Sheffield Institute of Education, Sheffield Hallam University (UK)

Main Conference

Paper

Developing a framework of autism activism engagement in schools

The high levels of anxiety and depression experienced by autistic people and the effects of these on well-being are of international concern. Research has predominantly located the causes for these within the defining characteristics of what has been constructed as a disordered autistic self. In doing so, researchers have neglected the role of school as a site of critical importance in the development of the self. Educators are centrally positioned to support autistic pupils with development of an empowered sense of self but little is known about how they conceptualise and respond to the autistic self. This presentation reports on a study with staff in 4 different types of schools in England that focused on identifying how these educators understand and respond to the autistic self. The findings reveal that they have established empathetic relationships with their autistic pupils and analyse the experience of school from a pupil perspective. The educators conceptualise autistic pupils as different from non-autistic peers and as individuals but with a shared experience of disabling attitudes and practices within school. They identified potential benefits for pupils in embracing an autistic identity and finding belonging through connection to the autistic community. However currently there appear to be no established mechanisms for enabling this process. This is a concern as many autistic young people and adults remain unaware of, and isolated from, the autistic community (Coleman-Fountain 2017). In response we propose here a framework of activism engagement to enact Levitt's (2017) active model of disability within schools. We will then ask those attending this presentation whether they perceive potential value in such a framework and, if so, how its introduction into schools might be achieved.

Roni Holler

Hebrew University of Jerusalem (Israel)

Yael Ohayon

Hebrew University of Jerusalem (Israel)

Main Conference

Paper

Disability Policy Formation: Some Theoretical Remarks

A noticeable lacuna in the disability studies literature is the lack of systematic inquiry into the development of disability policies and the factors that underlie them. Furthermore, the relatively few attempts to understand the development of disability policies have largely provided over-reaching explanations, ones that emphasize, for example, the importance of capital accumulation or the professionalization, bureaucratization and rationalization processes that arise from the modern era. While these explanations surely point to crucial factors, being too reductive of the complexities of the disability policies arena, they found it difficult to open the black box of disability policy development and to specify the theoretical mechanisms that underlie these factors. Relatedly, this a-theorization tendency also makes it hard to provide empirical support for these explanations. Following these drawbacks, some important questions remain unsolved, such as: How can we explain cross countries differences? Why is it that in some countries some radical changes have occurred? And why is it that in others maintaining the status quo has been the norm? And lastly, are the "usual suspects" (trade unions, parties, etc.) relevant to disability policy formation?

It is these gaps that the present presentation seeks to address. Specifically, the aim is to review some of the influential theoretical perspectives in the social policy discipline. This presentation attempts to translate these perspectives into the realm of disability, that is to show how these analytic tools are useful in understanding disability policy formation. No less important, by doing so we also seek to show how these welfare state theories themselves could benefit much both from the insights of disability studies and from the unique experience of disability.

Lill Hultman

Karolinska Institutet, Division of Social Work (Sweden)

Main Conference

Paper

Symposium: Questioning the 'generosity' of the Swedish welfare state - investigating austerity measures against disabled people

The construction of disability in personal assistance assessments

For Swedish social workers responsible for the provision of personal assistance (PA) directed towards disabled children, professional conduct is defined by the ability to make correct and 'objective' assessments. Nevertheless, the outcomes based on these structured assessments amounts in adverse consequences for the assistance users and their families. This paper is based on the results from two separate studies; one from the perspective of young disabled teenage girls and boys applying for personal assistance, the other one from municipal social workers who administer such support. These contrasting perspectives underline the different strategies utilized by both parts in order to handle the assessment meetings. Through their different roles and positions the construction of disability is enacted in a double-bind process where young people have to display a certain kind of disability in order to gain access to PA, in which social workers have to legitimize and justify their behavior by invocation of professionalism. When claims for social justice is abandoned by the professionals, it contributes to raise questions about the impact of discourses of new public management and evidence-based practice. Furthermore the results emphasize the need for professionals to strive for an increased awareness of social work ethics in which assistance users and their families should be considered as knowledgeable allies.

Sekwang Hwang
Northumbria University (UK)

Philip Heslop
Northumbria University (UK)

Main Conference
Paper

"We are parents": A Pilot Study on the Lived Experiences of Parents with Autism

A large body of scientific literature on autism deals with autistic children and their normal parents, but tends to avoid the topic of parents diagnosed with autism. In the UK, many parents are diagnosed or are not formally diagnosed with autism as adults. Autistic parents are known to be over-represented in child care proceedings but their different parenting style and capacity have been generally misunderstood, and seldom respected. To address this gap, this pilot study, adopting a participatory approach with two parents with autism, explored how autistic parents understand and interpret their roles, responsibilities and the positioning of care. This study found that pathologising assumption on parental capacity labelled autistic parents as disqualified parents. The parents argued that practitioners and clinicians have categorised autism as disorders or problems and their different parenting have been generally misunderstood, and seldom respected. But they claim to recategorise autism and their parenting as 'diffability' (Lawson, 2011) associated with a unique profile of strengths and challenge that non-autistic parents also have. The parents argued that they may succeed in raising their children, especially their autistic child, well if provided with appropriate support services. However, this study found that we still do not know how far parents with ASD are not thought reasonable and provided with any adjustment to carry out their parenting role based on child protection. This study concludes that the lack of comprehensive information on the hidden needs of autistic parents leads to their exclusion from health and social care planning and commissioning processes.

Kay Inckle
University of Liverpool)

Main Conference
Paper

Disabled cyclists and the emotional burden of everyday activism

This presentation is drawn from a wider, qualitative research project in which I am working with a user-led organisation, Wheels for Wellbeing (<https://wheelsforwellbeing.org.uk/>), to explore the health, identity and social impacts of cycling for people with physical disabilities. In this paper I highlight the emotional impacts of the everyday activism, emotional labour and resilience that is required of people with (relatively invisible) physical disabilities who use a bicycle as a mobility aid. This emotional impact is most heightened when people are challenged for using their bikes and ordered to walk, even when walking is very difficult or virtually impossible for them. Cycling therefore enables immense physical freedom and pleasure for people whose mobility is otherwise very limited, but it is also tinged with the threat of social (and sometimes legal) approbation and demands for self-justification. This tension has emotional impacts for disabled cyclists which I present in multi-voice I-poems. I first utilised I-poems as a means to unlock my creative and intuitive engagement with the transcripts as I attempted to analyse them, and initially I viewed the poems as a process rather than an end or an “output” in themselves. However, as I worked with them, I found the I-poems to be a powerful and evocative method of representing the often conflicting emotions, agency and experiences that the participants recounted.

Paula Jacobs
University of Edinburgh

Kenneth MacMahon
University of Edinburgh

Ethel Quayle
University of Edinburgh

Main Conference
Poster

Transition from school to adult services for and with young people with severe or profound intellectual disability: a systematic review utilizing framework synthesis

Background: The transition to adulthood has been described as the “black hole” in the lives of individuals with intellectual disability and their families. In relation to those with profound or severe intellectual disability, the transition process poses questions about capacity and how others can make a decision in place of the individual themselves. There has been little emphasis on young people with severe or profound intellectual disability in previous research, even though their pathways may differ, due to greater support needs across the life course.

Methods: A systematic review was conducted utilising Bronfenbrenner’s ecological model to inform framework analysis to synthesise qualitative findings.

Results: Taking an ecological perspective proved valuable. However, relationships between systems were only tentatively sketched and studies did not provide detailed information on how different systems interrelate. The transition process was described as stressful and barriers were identified across the ecological levels. The review found that families and service users seem to have very little involvement in ‘wider’ decision-making such as service commissioning. The question is raised if all ecological levels need to be given equal importance to achieve true participatory practice.

Parents accounted for the majority of participants in studies, and the needs of young people and their parents emerged as highly interdependent. Concerns about the long-term future dominated the narratives of parents.

Conclusion: This review found that pathways and needs for young people with severe or profound intellectual disability differ. Themes reflect the complexity of the question how adulthood should look like for young people. There is a lack of involvement of multiple stakeholders and young people themselves within research studies. The exclusion of young people from the research process requires attention.

Elaine James
Lancaster University (UK)

Rob Mitchell
Lancaster University (UK)

Nina Riddlesden
Health and Wellbeing Bradford Council (UK)

Ryan Cowley
Health and Wellbeing Bradford Council (UK)

Shvonne Nakonecznyl
Health and Wellbeing Bradford Council (UK)

Hannah Morgan
Lancaster University (UK)

Main Conference
Paper

Reflections on the Named Social Worker for Adults with Learning Disabilities Pilot in the UK

The role of a Named Social Worker to support people with learning disabilities has been muted in UK policy since the early 1970s. During 2017 and 2018 the UK Government has piloted the role across nine Local Authority social work services in England. We were involved with two of the pilot sites. Setting out the evolution of the policy framework and the emerging findings from the pilot sites we were involved with, we are seeking to stimulate debate over the role of a Named Social Worker role. The empirical evidence from the pilots remains emergent and as such is problematic, however the evidence for the emancipatory nature of involving self-advocates in the co-design and delivery of the pilots we were involved with is more firmly established. With our self-advocacy partners Bradford Talking Media, we shall examine emerging findings from the pilots and three social work approaches to practice: relational basis for interactions between social workers and people with learning disabilities; legal literacy in case-based reasoning; and Post Qualifying Professional Development in Advanced Practice for social workers. Drawing on theories from both the leadership and management and the disability studies literature, the paper is situated within the changing context in the UK of the Transforming Care for adults with learning disabilities national policy agenda. We argue that social workers practicing with adults with

learning disabilities need to uphold the person's voice at the heart of decision making and recognise learning disabled adults as human with human rights. To do so requires legal literacy, an appreciation of the implications of the UN Convention on the Rights of Persons with Disabilities and an understanding of the social model of disability.

Ásta Jóhannsdóttir
University of Iceland (Iceland)

Main Conference
Paper

Symposium: Life quality and participation of disabled children and youth (LIFE-DCY)

**Exploring affect as a useful research tool in disability studies:
Shame and the use of assistive technology devices**

This paper focuses on theories of affect and how they can be used as a research tool in disability studies. Affect theories have become widespread in feminist research and other critical social science but are just now entering critical disability studies. This paper is an attempt to connect the two.

Research among young disabled people shows that the use of assistive technology (ATD) such as mobility devices often diminishes at least temporarily when adolescence hits, even though it might mean decreased independence or opportunities to participate in their communities. This paper attempts to investigate the possible forces behind these actions and argues that shame, as a strong affect, may be influential.

The use of ATD as affective practice becomes apparent when looking at the affective pull of shame. It has been pointed out how affect makes clear the transmission of cultural values. Shame, influenced by the ableist benchmark of norms, can therefore impact the experience of ATD. A case study is used to validate the theoretical arguments - the importance of affect as research tool in critical disability studies.

Nicola Jones
University of East Anglia (UK)

Main Conference
Paper

Parenting with personal assistance

Growing numbers of disabled adults have active roles and responsibilities in raising children, however they continue to experience significant disadvantage and a wide range of barriers to parenting. Existing literature about disabled parents reflects concerns about their capacity to parent and reveals a presumption that their children may become 'young carers'. Research suggests that personal assistance may be particularly suited to disabled parents; it may also prevent children from becoming carers, however, no studies have explored the lived experience and ongoing impact of PA support in family life.

Qualitative methods are being used within this doctorate study to examine the relationships between disabled parents and their children, exploring the significance, influence and meaning of the PA role. 29 participants were recruited across three sample groups: disabled parents, children, and PAs. Views were gathered by means of semi-structured interviews; discussions with children were based around age-appropriate activities.

Thematic analysis is ongoing. Early findings highlight the complexity, intensity and fluidity of relationships within families using PA support, and reveal the dichotomies and tensions embedded within these. Data suggests that parenting with personal assistance can enhance a loving and stable home environment, enabling disabled people to express their parenting choices, and enriching the lives of their children. Many support relationships are positive and helpful; however, parents and children can worry about the long-term sustainability of these, and disruption to their lives when PAs leave their employment. Negative relationships can also develop; these have the potential to be disempowering and create a barrier to parenting.

Findings from this study will inform best practice, by providing the basis for open discussions about the meaning and management of personal assistance within families; this will better prepare parents,

children and PAs for their encounters, leading to more positive and enduring support relationships.

Anthon Sand Jørgensen
Aalborg University (Denmark)

Main Conference
Paper

Experiences of inclusion and exclusion - A presentation of a qualitative interview study of adults with intellectual disabilities

Inclusion has been a dominant theme for more than two decades among activists, policy makers, social workers and researchers in Denmark. While the positive ideals of inclusion are often highlighted, there tends to be less focus on the risk of exclusion. In 2011, a research review pointed out a general lack of disability research in Denmark and particularly research focused on the risk of exclusion. Some mechanisms of social exclusion can be described in terms of how we categorize and institutionalize e.g. people with intellectual disabilities (ID), and Goffman has pointed out how categorization can cause stigma and ruptures in social identity.

This abstract is based on my Ph.D. research project that focuses on processes of in-and exclusion related to adults with ID. The methodological approach is a qualitative case study and, in order to identify the informants' own experiences, I have been doing nine semi-structured interviews.

The preliminary analysis of the interview study:

- Job and residence are situated in daycare centers and group homes because, as some informants explained, it is difficult to handle daily life without support.
- The informants see themselves as having difficulties that make them different compared to so-called 'normal' people.
- The informants describe how communities for people with ID have a significant impact preventing loneliness.

A conclusion that can be drawn is that some adults with ID, in Denmark, still live most of their daily life in institutionalized settings. On the one hand, this provides security and a clear sense of social identity. On the other hand, this social identity can because it is primarily institutionally determined, contribute to the risk of being stigmatized and excluded.

Alexandra Kaley

Lancaster University / Dundee University (UK)

Main Conference

Paper

Therapeutic spaces of care farming: transformative or ameliorating?

Since Wil Gesler's earliest articulation (Gesler, 1992; Gesler, 1996) key thinkers in the field of therapeutic landscapes have sought to emphasise the embodied, contextual and wholly relational nature of the relationship that exists between people and place. However, the extant research has tended to focus on the relational healing experience as this occurs 'in the moment' and with reference to a specific location or site of healing, with less attention being paid to what happens to people when they return to their ordinary or everyday places. In this paper, I reflect on findings from visual ethnographic work (including photography and film) that explored the therapeutic landscape experiences of people with intellectual disabilities engaged in community farming interventions for health and wellbeing. Having identified a gap in our understanding, consideration is given to wider impact that engaging in these sorts of activities had on the everyday lives of the participants in this study. I argue that this study has identified two types of therapeutic journey that broadly fit the experiences of study participants. The first type of journey denotes landscape experiences that are transformative. Here the therapeutic power of the care farm landscape resides in the ability of activities conducted on care farms to influence other aspects of participants' lives in ways that promote wellbeing. By contrast, there is another type of journey where the therapeutic power of the care farm resides in its ability to ameliorate challenging or harmful life situations, thus offering people a temporary site of respite or refuge. I conclude that these findings denote an important development for this sub-field of health geography, not only because they draw attention to the transformative power of the therapeutic encounter, but also the broader socio-spatial environments in which people live and ways in which these can limit that power.

Müjde Koca-Atabey
Istinye University (Turkey)

Bahar Öz
Middle East Technical University (Turkey)

Burcu Tekeş
Middle East Technical University; Işık University (Turkey)

Main Conference
Paper

The Traffic Experiences of Blind Road Users: An Interpretative Phenomenological Analysis

One of the key features of independent living is a fully accessible transport system, however, traffic experience finds relatively limited place within the whole disability literature. Traffic experience of disabled people in Turkey is also an under-researched area. Accessibility is the major problem in Turkey where disability has never been taken into account in relation to urban planning, architecture, infrastructure, and public transportation. This study explored the traffic experiences of 11 blind road users; there were eight males and three females. Semi-structured interviews were conducted at the places that the participants choose. The interviews lasted for 60-65 minutes, were recorded and transcribed verbatim. Participants were asked questions regarding their traffic experiences. Interpretative Phenomenological Analysis (IPA) was used for analysis. IPA deals with participants' personal lived experience and how participants make sense of that personal experience. There were four superordinate themes: Accessibility problems: 'They park on pavements'; It is a very subjective experience; It is sometimes amazing: 'Don't you have a family?'; Positive experiences: Rare but remarkable. The superordinate theme accessibility problems were divided into three subthemes: Road, vehicles and climate related problems. The superordinate theme 'Don't you have a family?' has a further subtheme titled 'People insist on...!' It is concluded that being a blind road user is a challenging experience in Turkey where the environment is chaotic, coercive and unfriendly.

Antonios Ktenidis

School of Education, University of Sheffield (UK)

Main Conference

Paper

Height(ism) As The Elephant In The (Class)Room: Biopedagogies Of Pathologisation & Students With Dwarfism In The Secondary School Class

While the medicalisation and pathologisation of (the lack of) height (and dwarfism) through m/educational (medical and educational) discourses occurred since the 1970s by referring to it as a ‘handicap’ and to its ‘adverse implications for child development’ (de Onis and Yip, 1996:74), heightism is still a form of discrimination that is still to be taken seriously (Osensky, 2018), especially during schooling. Moreover, only little research has looked into the educational experiences of people with dwarfism (e.g. Shakespeare et al., 2007).

Engaging with a critical participatory narrative approach, which conceives storytelling as a communal praxis, the embodied stories of performativity of 14 British young people with dwarfism (aged 11 to 30 years old) were collected in the first half of 2018 and were analysed through thematic analysis.

In particular, the (bio)pedagogies of pathologisation (Subini Annamma, 2018) that the students with dwarfism dealt with during their secondary education are looked at. More specifically, the technologies of hyperlabelling (the politics of being ‘statemented’ and the hidden assumptions behind labels), hypersurveillance (the role of teaching assistants and of the special equipment, the institution of schooling as a panopticon) and hyperpunishment (being punished both due to one’s body not fitting to the ‘corporeal standard’ (Kumari-Campbell, 2009) as well as for resisting to be casted as a ‘misfit’ (Garland-Thomson, 2011) and their negotiation/resistance from the young people are discussed.

While a range of terms is used to label people of a certain stature (4 feet and 8 inches), such as restricted growth, dwarf, little people etc), for this presentation dwarfism is the preferred one because a) this is the term used by various scholars who identify as ‘dwarfs’ (Pritchard, 2016, 2017; Ellis, 2017, Shakespeare, 2015) b) the word dwarfism

draws the attention to both the cultural representations as well as the medical construction of people-labelled so.

Maria Larsson
Begripsam (Sweden)

Stefan Johansson
Department of Human-Computer Interaction, Royal Institute of
Technology, KTH, Stockholm (Sweden)

Main Conference
Paper

"We're not waiting to be invited", Begripsam - a pragmatic take on participatory action research

Begripsam is a group of mainly disabled people, with a diverse range of cognitive impairments, based in Sweden, which works to make society, products and services more accessible and usable. Our main area of interest is knowledge production and societal change, based on lived experiences of disablement and disabling structures. Our core aims and values are that we prefer to discuss 'participation' rather than 'inclusion', that (without waiting for an invitation) we identify and target social or technological structures, practices, products or services that disable us, and that we actively seek co-operation with key organisations, to initiate and influence social change.

The group is now starting to have influence on how governmental agencies and companies handle cognitive accessibility matters. Reports with results from our survey 'Swedes with impairments, and usability of Internet' have been cited by the Swedish minister of Digitalization and several politicians in the Swedish Parliament. Begripsam is also a main contributor of content to an upcoming ISO standard on Cognitive Accessibility.

In this paper we will describe how Begripsam started as a traditional 'top-down' project and how a pragmatic approach to participation and collaboration led to a friendly 'take-over', initiated by disabled participants, inspired by action research, that changed and re-arranged the group. We will illustrate how the group handles different accessibility needs, and our potential impact on society, by presenting two cases: Our survey 'Swedes with impairments, and usability of Internet' and the ISO standard 'General Guidelines on cognitive accessibility'. We will present and discuss how, in partial co-operation with the Royal Institute of Technology (KTH) in Stockholm, we are

gradually developing a pragmatic, experience-based participatory method to involve all members in all parts of the research process.

Subodha Laththuwa Handhi
University of the West of Scotland (UK)

Main Conference
Poster

Entrepreneurship and Self-employment for people with disabilities in Sri Lanka

There are more than billion people, about 15% of the world population are estimated to live with some form of disability both socially and economically. Interestingly, four of every five disabled people are living in poverty in economically deprived rural areas of developing countries. Disabled people are often met with harsh conditions such as peer prejudice and social stigmatic attached to their capacity to carry out workplace duties. In addition, the lack of opportunities, unfair treatment, discrimination, bullying and harassment at work and other legal environmental barriers also prompt more disabled people to choose entrepreneurship and self-employment. Over the last few years' significant amount of research has been done in developed countries regarding entrepreneurship and disability. However, entrepreneurship and disability remain as an under researched as well as largely neglected topic in developing countries compared to developed countries.

Therefore, it is vital to better understand self-employment options available for disabled people in developing countries, their motivations, and challenges confronted in their pursuits of becoming self-employed. Further research on to this topic could shed light onto existing literature by demonstrating what sort of strategies and processes are adopted by disabled individuals and how such strategies contribute to their personal well being in comparison to people who are not disabled.

This research will carry out a longitudinal qualitative study, based on semi structured, in-depth interviews with several disabled entrepreneurs in Sri Lanka. They will be recruited within the personal network of the researcher by adopting a snowballing process of sampling. This research area will aim to provide an insight into the entrepreneurship and disability in developing countries. The study will also have some implications to researchers, policy makers, health care workers and business support agencies will immensely benefit from an

increased understanding of challenges, opportunities and experiences of different aspirant disabled entrepreneurs.

Gyeonghwa Lee
University of Leeds (UK)

Vanessa Walker
University of Leeds (UK)

Main Conference
Paper

Creating accessible transport information for people with vision and colour-vision impairment: A focus group interview

Barriers faced by disabled people using public transport have been well-investigated, yet there is little information that shows visually impaired users' difficulties regarding readability of information at bus stops or shelters. Although current guidelines do provide the standard to help visually impaired people read information, there is a significant gap between guidelines and practice. Also current guidelines are not sufficiently detailed.

This research aims to articulate visually impaired people's views with a view to creating an accessible route map, and to document a range of opinions about transport information. Four visually impaired people and one with colour and vision impairment were involved in a consultation in Leeds. Two focus groups were held, to develop a design solution with visually and colour-vision impaired people in mind. Before the first focus group interview, a proposal for an accessible route map was created.

In the first focus group, participants were asked how they used bus information at bus stops and on the bus itself, frequency of use, and barriers faced. Next, they were questioned about their ability to read existing maps. Lastly, the newly-designed accessible route map was tested - for font size, background colour, colour-coded zone system, and overall size. In the second focus group, redesigned route maps were evaluated by participants to establish their preferred design. During the session, it was suggested that white lines between route colour and background would create strong contrast. Lines made from thin strips of paper were added and evaluated. All participants agreed that this final route map would be useful in reality.

This study provides qualitative support for the insight that people with vision impairment and colour vision impairment require more accessible transport information, and a large printed colour-coded map

would work effectively. These findings could be applied to current guidelines to improve them.

Jonathan M Levitt
University of Wolverhampton (UK)

Main Conference
Poster

The potential for people associated with disability to learn from gerontology research

This poster focuses on some findings in gerontology research that could be of interest ways people associated with disability. For example:

- Physical exercise, increased resilience and greater social interaction are each associated with a reduction in levels of disability in older people.
- Elderly disabled people deploy a wide range of techniques for adjusting to, or coping with, disability and that the same disabled person could use different adaptation techniques for different types of activity.
- Low level disability is very common amongst older people and visual, hearing, mobility and cognitive impairments in elderly people are classified as 'normal aging'.
- Elderly disabled visually impaired people were found to have a 40% greater risk of death than non-disabled people.
- Gerontology research tended to focus more on the effects of social support on elderly disability people than on the barriers they met.

Jonathan M Levitt
University of Wolverhampton (UK)

Mike Thelwall
University of Wolverhampton (UK)

Main Conference
Paper

Barriers to obtaining academic employment and conducting research

This presentation describes my research project on obstacles to people with disabilities obtaining academic employment or conducting academic research. My presentation relates to the panel instigated by Naomi Lawson Jacobs at the 2016 Disability Studies conference, called ‘Normalcy in Academia: The exclusion and oppression of disabled academics today.’

Disabled people are under-represented both in academic employment and in research. For April-June 2017 the number of UK people classified as disabled under the Equality Act of working age was 17.12% of the number of UK people of working age (Office for National Statistics). In contrast, only 4.0% of academics in 2015 were classified as disabled (HESA) and disabled researchers are more under-represented: only 1.84% of staff included in the UK’s 2014 research assessment were classified as having complex circumstances. Here, ‘complex circumstances’ includes not only disability but also other extenuating circumstances, such as caring responsibilities (HEFCE).

My research aims to understand barriers to disabled people becoming academics or conducting academic research and how these could potentially be reduced. Its research questions are:

- 1) What are the barriers due to disability, to UK-based people with disabilities becoming academics or researchers?
- 2) What measures can be taken to alleviate these impediments?

I plan to address these questions by surveying samples that seem likely to contain substantial numbers of people who have experienced barriers, due to disability, to academic research and employment.

In this presentation, in addition to discussing the way I envisage implementing my project, I plan to discuss the following extracts related to this project:

- a) Mike Oligomer and Colin Barnes (1997, Disability & Society,) wrote “All we are saying is give disabled researchers a chance.”
- b) Fiona Kumari Campbell (2009, International Journal of Inclusive Education) asked “Does it matter who teaches disability studies, whether that teacher has a disability or not?”

Kirsty Liddiard
The University of Sheffield (UK)

Main Conference
Paper

For Your Pleasure: Rethinking Disabled Sexualities

In this talk I consider the politics of pleasure both inside and outside of disability. I argue that through being denied access to their bodies and to pleasure, disabled people have been rendered on the margins of what it means to be human. In response, I centre disabled people's own experiences of and engagements with pleasure, to affirm the ways in which disability opens up new ontologies of pleasure and prisms open alternative economies of desire. Utilising Goodley and Runswick-Cole's (2014: 5) 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 (Liddiard 2018). To do so, I locate the very dis/human moments in disabled people's own sexual stories, sketching out the dis/sexual as a transformative space through which disabled subjects can claim their humanness through conventional modes of sex/uality and gender, yet simultaneously defy, crip and exceed such boundaries.

Sources

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Kirsty Liddiard

The University of Sheffield (UK)

Co-Researcher Collective

The University of Sheffield (UK)

Main Conference

Paper

Symposium: Living Life to the Fullest: Arts, Activism and Youth

The Co-Researcher Collective

In this paper, we explain how the co-researcher collective has developed, what our role is and the expertise we bring as young disabled people contributing to research about our lives. We describe our innovative use of on-line methods and the ways in which our contribution as researchers is shaping the wider research project.

Kirsty Liddiard

The University of Sheffield (UK)

Dan Goodley

The University of Sheffield (UK)

Katherine Runswick-Cole

The University of Sheffield (UK)

Main Conference

Paper

Symposium: Living Life to the Fullest: Arts, Activism and Youth

Feeling Disability: Theories of Affect and Critical Disability Studies

This paper explores connections between affect studies and critical disability studies. Our interest in affect is sparked by the beginnings of our new research project. There is something instantly emotive around the idea of a child or young person living a short life. People are affected, often deeply, by the idea that a young person's lifecourse is reduced through the presence of impairment. We know that cultural and individual responses to young people with LL/LTIs are significantly shaped through a plethora of dominant ideas and practices linked to idealisations associated with quality of life, human productivity and lives lived well and long. Young people with LL/LTIs appear to be at odds with the neoliberal imperatives of self-sufficiency, autonomy and independence. Cultural responses to these young people are shaped by dominant discourses associated with lives lived well and long. We use this paper to think through how we might conceptualise affect and disability. We present three themes; ontological invalidation in neoliberal-able times; affect aliens and crip killjoys; disability and resistant assemblages.

Kirsty Liddiard

The University of Sheffield (UK)

Katherine Runswick-Cole

The University of Sheffield (UK)

Dan Goodley

The University of Sheffield (UK)

Main Conference

Paper

Symposium: Living Life to the Fullest: Arts, Activism and Youth

An Arts Retreat: Methodological Opportunities and Challenges

In this paper we detail some of the methodological opportunities and challenges experienced thus far in hosting a residential Arts Retreat for young disabled people with LL/LTI and their families. As well as interviewing parents, families and young people, the Arts Retreats were designed to make space for young artists (participants) to explore and immerse themselves in a range of creative practices in order to tell their own stories of their lives. We make use of the arts in our project because of the ways in which they offer the tools to resist the well-known ‘single story’ of disability (see Rice et al. 2014; Adichie 2009; Liddiard 2014) by creating and centring, without normalizing, representations of disability that have previously been relegated to the margins. This politicised artistic practice contests the typical therapisation of disabled young people and their art making practices, whereby the arts are only made available for assessment, therapy and/or treatment. Instead, we view disability art as ‘educative, transformative, expressive, emotionally exploratory, and participative’ (Barnes 2003: 9). We conclude by asking some critical questions of our journey so far and, perhaps more importantly, how the answers to these questions will inform the remainder of our empirical inquiry in this project.

Heidi Lourens

University of Johannesburg (South Africa)

Leslie Swartz

Stellenbosch University (South Africa)

Main Conference

Paper

‘Every now and then you slip up and then you are in trouble’: The responsibility on visually impaired university students to access reasonable accommodations in South Africa

Within the last two decades, the South African government drafted impressive policies to fully include and accommodate visually impaired students within higher education. And, previous studies suggest that, at least in terms of equal participation, these inclusive policies partly succeeded in infiltrating universities. The establishment of disability units, for example, currently facilitate the equal participation of disabled students on tertiary campuses. Yet, literature suggests that disabled students are still experiencing disability-related barriers during their university years. Challenges include, amongst others, social isolation, difficulties navigating around campus, late and inaccessible course material and, in severe instances, physical abuse.

With this paper we will discuss the experiences of visually impaired students regarding reasonable accommodations at two historically different universities.

Method

Data was collected through semi-structured interviews with 23 visually impaired students from two historically different universities.

Interview transcripts were analysed according to the interpretative phenomenological approach.

Findings

The narratives of the students revealed that, (a) despite stringent policies, lecturers still had the power to decide whether they wanted to accommodate students with reasonable requests; (b) the students still took the largest portion of the responsibility to ensure that they had their lecture notes and textbooks, and (c) economic background and the legacy of Apartheid still disadvantage some Black students. We suggest that students and lecturers might benefit from clear guidelines

regarding their roles and responsibilities. Students should also receive information regarding their legal rights

Laufey Löve

University of Iceland (Iceland)

Rannveig Traustadóttir

University of Iceland (Iceland)

Main Conference

Paper

Lived experience of disability as core component of disability policy and legislation

In response to the proposed question on the role that academia can play in supporting disability activism, this paper draws upon ongoing research initiated in 2017 that focuses on the right of disabled people and their representative organizations to be actively involved in the development and implementation of policies and legislation that concern them. This right is firmly stated in article 4.3 of the United Nations Convention on the Rights of Disabled Persons (CRPD) and further defined by the CRPD Committee in its Guidelines on the Participation of Disabled People's Organizations, which states that such organizations should be governed, led and directed by persons with disabilities, thus providing recognition of the need to embed the lived experience of disability in policy and legislative processes. By taking this step, the Convention aims to ensure that the voices heard and the opinions given in these processes include disabled people themselves, a call long echoed in the disability community's mantra "nothing about us without us". The research, drawing on qualitative data gathered among leaders of disability organizations in Iceland, finds that there has been a shift toward disabled people and their representative organizations taking more of a lead role in legislative and policy negotiations with the authorities and increasingly rooting their claims to rights on their lived experience of disability. This movement has in large part been led by activist organizations as a response to what they perceive to be a stalled negotiating process, as defined and directed by the authorities at both the local and national levels. The final data of this ongoing research, to be collected in June and July 2018, will be analysed to further evaluate this trend and disability leaders' assessment of its usefulness.

Laura Lundy

Queen's University Belfast (UK)

Bronagh Byrne

Queen's University Belfast (UK)

Michelle Templeton

Queen's University Belfast (UK)

Gerison Lansdown

Queen's University Belfast (UK)

Main Conference

Paper

Rights in the Digital Environment: The Views of Disabled Children and Young People

The online environment has been recognised as a huge benefit to many people, including disabled children and young people, enabling them to participate in a world from which they can otherwise be excluded. However, there are concerns that the ease of communication online can result in the unintended consequence of further isolating disabled children and young people from participation within the physical world. Although the issues facing disabled children and young people generally may vary significantly from their non-disabled peers, little remains known specifically about the views and experiences of disabled children themselves in the digital environment, particularly since most of the information currently available has been generated from the non-disabled adults in their lives.

This paper will examine disabled children and young people's views and experiences of their rights in the digital environment. It draws on a project commissioned by the Council of Europe in 2017-18. The project itself adopts a rights-based approach, guided by the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child; both in substantive content and the research process. As such, we worked with four advisory groups representing a range of disabilities, to advise the research team on the research questions and design, and data analysis. The substantive research was carried out with disabled children and young people in four European countries; Germany, Portugal, Belgium and Moldova. This paper has two aims: firstly, it will illustrate the advantages of

working with children's rights advisory groups in developing a more nuanced and co-produced research process, and secondly, it will provide an overview of findings to date. In so doing it will identify both the benefits and barriers to accessibility in the online environment and consider young people's perspectives on ways in which barriers may be addressed.

Nina Mackert
Universität Erfurt (Germany)

Main Conference
Paper

Symposium: On Ableness: Using Studies in Ableism to explore cultures of ablement

The Calorie and the Production of Metabolic Abledness in late 19th and early 20th Century US

The paper discusses early calorimetric research around 1900 as an example of how the life sciences fundamentally contributed to ableism by creating blueprints of efficiently functioning human bodies as well as corresponding abilities that an individual had to have in order to be acknowledged as a subject and citizen. In the late 19th century, nutritional science introduced the calorie to an American audience. Calorimetric research was part of broader efforts by physicists, physicians, chemists, and nutritionists to measure and maximize the workings and efficiency of human bodies. While the first laboratory experiments sought to quantify how much energy bodies needed to do work, calorimetric studies in the early 20th century focused on defining the basal metabolism of human bodies. By thereby naturalizing metabolic regularities of working and resting bodies, I argue, calorimetric science spawned metabolic able-bodiedness. Moreover, the calorie's suggestion that metabolic processes could be measured, regulated, and, thus, governed, created ways of eating 'right.' A short foray into early weight-loss dieting shows how calorimetric science shaped understandings of able citizens as those capable of properly budgeting their caloric intake in accordance with the needs of their bodies.

Nicki Martin

London South Bank University (UK)

Critical Dialogues in Neurodiversity Stream
Paper

Disabled Leaders in HE. What do we want? Universal Design. When do we want it? 2010

This research, commissioned by The Leadership Foundation for Higher Education (LFHE) focuses on UK universities . 100+ HE leaders highlighted various workplace barriers they have encountered, strategies they have employed in order to progress and ideas about good institutional practice in relation to promoting disability equality.

Numerous examples were collected of participants effective use of workbased problem solving strategies gained through navigating disabling barriers in life. Unsurprisingly, disabled leaders knew exactly what they needed from the workplace in order to thrive and contribute at a high level. Principles of universal design and inclusive practice which would benefit everyone were strongly advocated.

Usually universal design coupled with some minor cheap reliable adjustments and supportive colleagues was all that was required. Achieving this was often frustratingly complex and hard to sustain therefore people often stayed put rather than progressing after attaining a workable situation because there was no guarantee that this could be replicated. This feels like a massive (preventable) waste of talent.

Participants frequently expressed irritation about identity being boiled down to impairment labels. Those with unseen impairments described frustration about being challenged to prove they were disabled. Understanding of Barriers identified included limitations of the UK Equality Act 2010, stereotyping, invisibility of role models, limited senior buy in to strategic change, ableist assumptions, and disorganised infrastructure which simply makes life more difficult for everybody. The Social Model of Disability and identity politics was perceived to be annoyingly limited within HE.

A striking degree of congruence emerged between participants' descriptions of their own values and approaches as leaders and the principles of distributed leadership including supporting and

encouraging all the talents, collaboration and building functional teams and productive alliances.

The value of diversity in leadership cannot be overstated and this paper brings excellent ideas of disabled leaders to the table.

Sarah Manns

University of the West of England (UK)

Tillie Curran

University of the West of England (UK)

Mat Jones

University of the West of England (UK)

Main Conference

Paper

How does peer research promote disabled young people's voice, hopes and dreams in a rapidly changing society? A critical reflection

This paper is based on Imagining Young Disabled People's Transitions in a time of major societal change, a DRILL funded, UK-based project in which young disabled people act as peer researchers exploring ideas for their contemporaries' futures.

Run by a User Led Organisation (ULO) and partnered with a University and social services, the project aimed to place lives of young disabled people, aged 14 - 25 years of age, at the centre of knowledge generated. The project sought to move beyond cataloguing problems, assessments of need, deficit-based constructions of identity, and narrow narratives of services transition. Instead, the research started with an aspiration to create a platform for young disabled people's hopes, dreams and ideas for the future. In principle, this form of peer research respects, values and honours young people's experience and is concerned with social change from the outset. The extent of respect, voice and change is the focus of this critical reflection.

We share the peer research approaches used in the knowledge cafes that involved over 50 participants. Three aspects of preparation are presented: relationship building with a disability equality framework around 'what we can do'; getting to know each young person and their interests; and flexible use of creative methods throughout the research process.

The asset and social model of disability framework modelled and advanced by two disability equality advocates from the ULO, is identified as key to respect. However we question our expectations regarding peer research and voice showing how space and support can be compromised through our failure to resist institutional normalcy. We critique the ethics involved in exploring hopes and dreams in an

ablest context without the visibility of dialogue linking academia, service provision and activism throughout the project. We call upon funders, ethics committees, and steering groups to share in that aspiration.

Nicola Maxwell
University College Cork (Ireland)

Claire Edwards
University College Cork (Ireland)

Main Conference
Paper

Spatial legalities of disablist violence and hostility: exploring the case of hate crime in Ireland

This paper employs the intellectual landscape of critical legal geography, which recognises the co-constitution of spatial, legal and social worlds, to explore debates around, and responses to, hostility, hate and violence experienced by people with disabilities in Ireland. Whilst discussion of hate crime, including disablist hate crime, has received attention in the EU and internationally, Ireland remains one of the only countries in Western Europe that does not legislate for such crime. Drawing on a study examining the impact of fear and experience of crime and hostility on disabled people's everyday geographies in Ireland, this paper seeks to make sense of this jurisdictional anomaly. Based on analysis of policy documents, and in-depth interviews with policymakers, Gardaí, disability organisations and people with disabilities, the paper considers the specificities of the Irish context in explaining this legislative vacuum, and how the mutually constitutive elements of social context, space and law coalesce to imagine prospective hate crime legislation, its performance and effect with regard to disability in Ireland. This involves not just recognising the scalar dynamics which intertwine local, national and transnational discourses and legal norms surrounding hate crime, but also the potential for law to create particular subjectivities which can have a diverse range of socio-spatial consequences. In our research, for example, support for the introduction of hate crime legislation in Ireland with regard to disability emerged as mixed; whilst a number of participants expressed support for any legislation that deals with the effects of crime perpetrated against people with disabilities, others raised concerns about the potential of hate crime legislation to further stigmatise disabled people and construct them as legal 'others'. We suggest that socio-spatial-legal analyses of disablist violence and hate crime are well placed to explain some of these complexities and ambivalences.

Aless McCann
University of Cambridge (UK)

Main Conference
Paper

Thoughts on the Mentoring Scheme at Cambridge University

This paper will explore the impact the mentoring scheme at Cambridge University has on the lives of disabled students who engage with it. Mentoring aims to enable students' participation in all aspects of university life. Mentors support students to find strategies to live independently at university and beyond. One method of doing this is setting goals for students' academic and social progress which can be reviewed and refined as time goes on. The paper will look at training offered to Mentors at Cambridge to support their work with students and enhance both their soft and hard mentoring skills. Students can take up mentoring at any point whilst at university and having lived with impairments for different time periods; the paper will look at the differences these factors have on the mentoring relationship and outcomes of the partnership.

Emma McKinney
University of Western Cape (South Africa)

Main Conference
Paper

Our normal family: a visual exploration of a family with disabilities

Using visual media, I share how I, as a person with a hearing disability married to a partner with quadriplegia paralyzed from the shoulders down, with a son with Tourettes Syndrome, experiences life as a wife and mother in South Africa. There is existing literature relating to families with disabilities including disability and marriage (Parker, 1992), sexuality and social beliefs (Mall & Swartz, 2012; Shakespeare & Richardson, 2018); mothers and fathers with disabilities (Kilkey & Clarke, 2010; Mitra, Lezzoni, Zhang, Long-Bellil, Smeltzer & Barton, 2015); parents of children with disabilities (Hodge & Runswick-Cole, 2013); and the impact of carers/personal assistants on partners with disabilities (Kelly, 2011; McKinney, 2018). I have selected photographs and videoclips from our family and have aligned to each of the above-mentioned themes to encourage interactive discussion during the session. My presentation also explores the unique challenges of living with these disabilities in a developing country, and in particular how we cope with reactions and interactions of others towards us individually, as a couple and as parents. The presentation covers our lived experiences, as well as the broader challenge facing South Africans with disabilities on the following topics: families and friends' reactions to choosing to get married, undergoing fertility treatments as a result of disability, dealing with full-time carers/personal assistants, accessing appropriate assistive devices and technology, lack of accessible public transport, perceived differences between having visible and invisible, acquired and congenital disabilities, coping with having a child with a disability as parents with disabilities, as well as the routine aspects of our day-to-day family life, such as lip-reading a seven-year old who has lost his front teeth, and not being able to blow your own nose.

Wendy Merchant

Norah Fry Centre for Disability, University of Bristol (UK)

Stephen D'Evelyn

Norah Fry Centre for Disability, University of Bristol (UK)

Victoria Mason-Angelow

National Development Team for Inclusion, Bath (UK)

Main Conference

Paper

Excellence, Rigor and Resilience- how the deficit model of Disability is embedded in Higher Education?

The academy should sustain a culture in which intellectual freedom and creativity brings to light deeper knowledge about people and the world. This should mean greater value being placed on people in all their variety and an assumed vision of equality. Our research into disabled staff members' and disabled students' experiences, however, shows that higher education assumes a view of disability as deficiency. This is both counter-productive for the university and harmful for individuals.

Using vignettes gathered from disabled staff and disabled students, within the wider ESRC funded "Getting Things Changed" research project, this paper addresses the deficit model of disability within the academy. We consider three related terms, 'excellence', 'rigor', and 'resilience' which appear to express unquestionable and positive qualities which are uniquely embodied in higher education. Through the consideration of three case studies of disabled staff, we see how autoethnographic accounts show how these terms can express and create a culture of disregard instead of collegiality, positivism at the expense of narrative experience and individualism which creates and enlarges barriers to participation.

Justifications to maintain the status quo are accomplished through talk. It is a primary way in which social actors not only understand the world but consciously and unconsciously create and reinforce marginalization. We consider the activism required by disabled staff and students within the academy to challenge this status quo. We offer an alternative vision for individuals, groups and institutions to adopt this activism in order to Get Things Changed.

Wendy Merchant
University of Bristol (UK)

Jamie Merchant
Child (UK)

Main Conference
Paper

What can I say? The activism of a mother who tries to access play activities for her child, who happens to be disabled

This paper is based upon our recently published chapter “What can I say” from *The Palgrave Handbook of Disabled Children’s Childhood Studies* (Runswick-Cole, Curran and Liddiard 2018). We use an animated film, a play and audience discussion to consider the activism of a mother trying to arrange play activities for her disabled child in the summer holidays. Writing from disabled children and their family’s experiences and the ethics involved are key principles of disabled children’s childhood studies, a relatively new area of study (Curran and Runswick-Cole 2013). This means asking disabled children’s permission to talk about their experience of childhood and listening to their voice and not an adult’s interpretation of it.

The stories of mother and child are not a large study or even a small one, but using film and drama art forms we present an exemplar that illustrates the layer upon layer of disabling practices that require deep change. Within our story we try to make links to research and policy that shows that our situation, like many others, is unlawful, commonly experienced and difficult to change. The strengthened mandate from both children’s and equality legislation (Equality Act 2010, Children and Families Act 2014) in England offers opportunities for successful challenges but given the level of change needed, we end with a number of strategies and “solutions” that might be effective at the deeper level and one of these is about our own strength.

Our aim in sharing our experience is to draw attention to the shared activism that is part of the shared experience of mother and disabled child.

Victor Benno Meyer-Rochow

Hachijo Institute, and Oulu University (Finland)

Helinä Hakko

Oulu University Hospital (Finland)

Matti Ojamo

Finnish Federation of the Visually Impaired (Finland)

Hannu Uusitalo

University of Tampere (Finland)

Markku Timonen

University of Oulu (Finland)

Main Conference

Paper

Suicides in Visually Impaired Persons in Finland

A cohort-based study of suicides, focusing exclusively on the visually-impaired, both on those with low vision and those who are blind, has neither been undertaken in Finland, nor anywhere else in the world.

In Finland out of a population of 5.4 million (2012) roughly 60,000 were considered visually handicapped.

In the Finnish Register of Vis.Imp. there are some 50,000 entries, out of which over 30,000 are deceased. Causes of deaths were obtained from the National Cause-of-Death Register. In linking the data we used unique personal identification codes given to each Finnish citizen.

Mortality after a suicide was significantly increased in the vis.imp. persons (SMR = 1.3), but in gender-stratified analyses the increase only affected males (SMR = 1.34) and not females (SMR = 1.24). Age-stratified analyses identified blind males of working age and, surprisingly, women with low vision 90years or older as high risk groups, which requires particular attention. The spring suicide peak (seasonality) was more noticeable in the blind than in persons with low vision.

Reasons for increased suicides of the visually impaired might be feelings of depression, loneliness, helplessness and hopelessness.

Reetta Mietola

University of Helsinki (Finland)

Simo Vehmas

Stockholm University (Sweden)

Main Conference

Paper

Life-long opportunity for change: Claiming ordinary lives for young adults with profound intellectual disabilities

Our paper examines cultural conceptions concerning youth, and how these are discussed in relation to young adults with profound intellectual disabilities. The paper is based on an ongoing project studying lives of adults with profound intellectual disabilities. During ethnographic fieldwork we noted that while our research participants were of different ages, their chronological age seemed to have only little, if any, significance in their lives. At the same time as the service system did not appear as being sensitive to age, our data was however filled with comments and thinking related to chronological age. This contradiction seemed most poignant when looking at the youngest participants of our study. Our data seemed to be suggesting that when thinking about good life in relation to a young person, age and more specifically youth was an important aspect to be considered. This has led us to think about the relationship between youth and normativity: if we had to provide a normative account concerning youth, what would this include. What kind of life should every young person be entitled to (in a specific cultural context)? In our paper, we are approaching this question by analysing data produced with 'Hugo', a young man with a profound intellectual disability. Our analysis focuses on meanings given to youth, but it also extends to discuss the purpose this 'youth talk', by asking what makes these arguments plausible or even necessary in this specific historical and cultural context. Our paper suggests that by talking about youth, the professionals are tactically drawing from the principle of age-appropriateness in order to challenge the stagnated intellectual disability service system, and to make concrete claims concerning 'ordinary lives' for young adults with profound intellectual disabilities. These claims are often stressing the right to learn, develop, or even just to change.

Damian Milton

Tizard Centre, University of Kent, Participatory Autism Research Collective (UK)

Main Conference

Paper

Disability and diversity: the challenges faced by autistic people'

Symposium: Diverse ways of addressing the challenges of disability: understanding contrasting types of disability

Autism has been variously described as everything from an evil spirit that robs parents of their children, to a differing cognitive style, or even a fundamental asset to human evolution. The spectrum of ways in which autistic people can present is so myriad, that it may be little wonder that the 'enigma' (Frith, 1989) still evades simplistic descriptions, as scientists search in vain for what exactly autism is. Although various attempts have been made to categorise differing subgroups of the autism spectrum, e.g. 'Asperger Syndrome', 'low-functioning autism', 'atypical autism'; it is highly questionable as to how accurately such distinctions can be made and how useful they are in practice. This presentation looks at the challenges of understanding and addressing the needs of such a diverse array of people in relation to both traditional models of disability and that of more recent proposals. This presentation will also comment on the work of the Participatory Autism Research Collective (PARC) in relation to meeting such needs.

Teodor Mladenov

European Network on Independent Living (Bulgaria)

Main Conference

Paper

What is good personal assistance made of?

In this presentation, I will reflect on the initial results of a two-year research on personal assistance in Europe, conducted in the framework of a Marie Curie Individual Fellowship and hosted by the European Network on Independent Living (ENIL). The project seeks to involve personal assistance users and their allies in co-creating a tool to enable the assessment of personal assistance schemes from the perspective of independent living ('choice and control').

As part of this project, I conducted a survey in the period 19 January - 4 March 2018. I used ENIL's membership network and newsletter subscriptions to invite assistance users, their organisations and allies to evaluate a series of statements about personal assistance, elaborated through literature review. The statements described possible characteristics of personal assistance schemes, including details about guiding principles, funding mechanisms, needs assessment procedures, organisation of provision, working conditions of assistants, and so forth. 54 people from 21 European and one Asian countries responded, with (self-identified) assistance users constituting a majority (65%) among the respondents.

Reviewing the responses to this survey, I will address the following questions: What characteristics of personal assistance are perceived by the respondents as enablers and what characteristics - as barriers to choice and control? To what degree is there a consensus? Is there a difference between the answers of users and non-users? How do the results relate to my previous research (e.g., Mladenov, 2012) and to recent debates on personal assistance within disability studies (e.g., Shakespeare et al, 2017)?

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Teodor Mladenov

European Network on Independent Living (Bulgaria)

Gabor Petri

University of Kent, The Tizard Centre (UK)

Main Conference

Paper

Deinstitutionalisation in Postsocialist Europe

A report published in 2007 estimated that nearly 1.2 million people, including children and adults, live in residential institutions for disabled people in 25 European countries (Mansell et al, 2007: 25). This data also showed that the rate of institutionalisation in large institutions was higher in the postsocialist region compared to the rest of European sample, with ten of the fifteen top-ranked countries being former socialist states (Mladenov, 2018: 38). Since then, deinstitutionalisation reform has progressed, but with uneven and sometimes re-institutionalising results (Parker et al, 2016).

In this paper, we look critically at deinstitutionalisation in postsocialist Central and Eastern Europe, paying specific attention to recent developments in Bulgaria and Hungary. We contextualise the reform with reference to state socialist legacy and processes of postsocialist neoliberalisation (Mladenov, 2018). We argue that EU-driven deinstitutionalisation programming that draws heavily on human rights discourses, and particularly on the CRPD, has been mediated by these historical forces and that the results have been different and sometimes antithetical to the ones anticipated in official documents such as the EU Disability Strategy 2010-2020. More specifically, many efforts at deinstitutionalisation have eventually ended up with 're-institutionalising' policies, cultures and practices (Deneva and Petrov, 2016; Kozma et al., 2016).

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Karen Mogendorff
Independent Scholar (Netherlands)

Critical Dialogues in Neurodiversity Stream
Paper

Neurodiverse ways of being in the world and what we can learn from it

Cerebral palsy (CP) - the most common physical condition in children in the West - is primarily seen as a movement disorder that may affect cognitive functioning. Treatment generally focuses on normalization of body structures and movement. Little attention is paid to how citizens with CP are differently wired neurologically and how this may affect their sense of self, their well-being and their responses to and interactions with others and the environment. Moreover, disregard of the neurodiverse nature of CP has contributed to adverse medical treatment outcomes and may exacerbate disablement in encounters with others.

In this paper, the lived embodied experiences of people with CP - including the author's lived experiences are investigated based on (auto)ethnographic research. Lived multisensory experiences of neurodiversity are deployed to argue how a recognition and better understanding of the lived neurodiverse body may contribute to a better understanding and management of impairment and disability effects and how knowledge production through neurodiverse bodies may increase insight into the body-identity and the body-society relationship. Last but not least, the merits of knowledge production through and with people with lived neurodiverse bodies are discussed vis-à-vis more traditional forms of research.

Sarah-Anne Muñoz

University of the Highlands and Islands (UK)

Liz Ellis

University of the Highlands and Islands (UK)

Main Conference

Paper

The brave new world of digital homes for independent living

This paper presents early findings into an evaluation of a ‘smart home’ pilot project. The project provides disabled people living in a rural area with a range of impairments and from different age groups, with smart, sustainably produced, co-designed, future-proofed homes, built to adapt as they age and their impairments change. The idea is that the in-built technology will monitor residents and, with the help of Artificial Intelligence, use the data gathered to help predict events like falls and changes in health. The aims are to reduce hospital admissions, maintain the ability for residents to live in their own homes for longer and promote community support, thus increasing the residents’ privacy, independence and social connections. It is hoped that this will provide a model for lifetime homes built along the principles of universal design.

We report on the emergent outcomes from the project and explore some of the ethical and political issues arising from the use of technologies such as digital surveillance aimed at promoting independent living.

Kirthy Nair

Tata Institute of Social Science (India)

Srilatha Juvva

Centre for Disability Studies and Action; Tata Institute of Social Science (India)

Main Conference

Paper

The liminal experience of disability: An existential & psychoanalytic understanding

Having an impairment and being disabled creates a position of living in the margins, or rather in a suspended zone of indistinction. Victor Turner's (1969) conceptualisation of liminal entities who are betwixt and in between therefore applies to people with disabilities who are forced to live a reality of being visible yet rendered invisible. The person with disability is hastily 'othered' and driven to the margins by both the members and stakeholders of the society. This creates vulnerability and threat in both the person who others and the person who is being othered. While the former, experiences threat in the way s/he perceives body image which makes him or her vulnerable in subsequent interactions with both the impairment and the person with disability, the latter feels threatened and made vulnerable as s/he is marginalized and denied access to equitable resources and opportunities. These contribute to questioning the very existence of a person and his or her personhood leading to the paradoxical experience of "I exist, but I am still invisible". Liminality in this context is thus juxtaposed between 'disembodied body' and 'disability pride'. This paper attempts to examine the state of liminality experienced by persons with disability in the Indian socio-political context wherein policy guidelines are still driven by ableist assumptions and cultural impediments, and essentially explore the factors within the individual and the society that compounds this state of intentional suspension, using existential, social psychoanalytic and critical psychology perspectives to deconstruct the psyche of a disabling society.

Isa Norberg
The University of Glasgow (UK)

Main Conference
Paper

Symposium: Questioning the 'generosity' of the Swedish welfare state - investigating austerity measures against disabled people

Challenging austerity and 'cost'

This paper is based upon my ongoing doctoral thesis, which looks at how austerity has impacted disabled people in Sweden. Austerity policies targeting disability policies have a long history in Sweden but, especially, since 2005 onwards, efforts have intensified - attempting to initially combat supposed 'welfare fraud' and more recently, to curb 'costs'. The consequences of austerity on disabled people in Sweden has been significant and contributed to increased economic insecurity, fear, and precarity. The way that austerity has been implemented and its accompanying discourse, this paper argues, opens up important considerations for academics regarding the role of academia and its role in relation to the state. In Sweden, disability research was developed alongside the welfare state and, politically, the relationship between disability organisations and the government is based on 'consensus' and consultation. Through the presentation of empirical data, I argue that these relationships become increasingly problematic and suggest that this symbiosis can be challenged by engaging with normative assertions and suggested alternatives. The paper is based on 40 qualitative interviews carried out between 2014-2015 with Swedish disabled people, disability organisations, and welfare professionals. The discourse points to significant structural disablism within the Swedish welfare system and this paper hopes to contribute to a critical discussion on how we challenge that structural inequality going forward.

Joseph Ocran
Central University, Tema (Ghana)

Main Conference
Paper

Confronting the Beast in Disability Stigma and Oppression with Mass Media

This paper examines how disability stigma and oppression can be confronted with mass media in Ghana. 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, radio 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 in the representation of disability in movies and music videos made in Ghana as well as discussions on radio. This paper examines one Ghanaian music video, one radio programme and a television chat-show, all of which break away from the tradition of representing disability with negative imagery. They do this by their portrayal of disability with a more progressive imagery. These mass media representations of disability challenge the usual disability stereotypes and negative imagery. The nature and form of these mass media events and how they may influence people's attitudes are examined, considering the ways in which mass media influences and shapes people's attitudes within society. An understanding of the dynamics of disabling imagery and a counter movement that emphasises progressive imagery of disability and reform will lead to better management of disability issues in Ghana and beyond.

Kehinde Olowookere
Coventry University (UK)

Main Conference
Paper

Subjectivity and Organisational Discourse: Experiences of employees with Mental Health Conditions in the workplace

This paper investigates the role played by discursive work contexts in shaping the subjectivities of employees with mental health conditions in the workplace. The paper locates disability within the social context of the workplace and investigates the perceptions of disabled people as 'different' relative to the 'norm'. The notion of 'difference' itself is conceptualized as a social construct discursively produced within social relations.

The paper is informed by qualitative semi-structured interviews with individuals who have bipolar disorder, allowing for a detailed exploration of how participants interpret their work experiences. Participants' narratives were taken to be subjective accounts, influenced by the discursive contexts of the workplace. These narratives offered insight on the particular social rules participants follow, for instance, with regards to how they should react or relate with colleagues at work.

The findings provide a nuanced and in-depth perspective of the experiences of a concealed, yet marginalized identity in the workplace. The insights gained point to how the discursive context of work may be shaped by the delineations of disability as a 'deviation' from the norm. Specific discursive connotations have been attached to the label of 'disability' which, when allotted to disabled employees, constructs such individuals as 'less capable'. It allows for the dissemination of meaning to participants' experiences, and opens up positions of subjectivity for these individuals.

These findings have implications for our understanding of the correlation between disabled employees' subjectivities and discursive practices in the workplace. The analysis of the resistance of subjective positions in the paper adds to knowledge of how the 'disadvantaged' position of disabled employees can be confronted and altered. Essentially, the findings call for the modification of work to comprise

inclusive strategies, which are suited to the individualities of 'different' employees.

Ruchi Palan
Independent Scholar (Ireland)

Main Conference
Paper

Hearing Disabled Students' Voice from the Global South: Teaching and Learning Experiences in Higher Education in India

In the Global North, research on inclusion of disabled students in higher education has increasingly focused on hearing their voice to better understand their issues and needs. Consequently, much is known about the barriers encountered by disabled students pursuing higher education in the UK, USA and Europe and the strategies that could be adopted to improve their academic and non-academic experiences. Contrary to this, very little information is available on how their counterparts in the Global South experience higher education.

The paper attempts to reduce this lacuna by highlighting the teaching, learning and assessment experiences of students with physical and/or sensory impairment in higher education in India. The findings presented here are from the author's doctoral study for which data was collected in 2013-14. Through semi-structured interviews, forty-six disabled students enrolled in nineteen higher education institutions (HEIs) in Mumbai and Thane shared their experiences and aspirations. The findings highlight that formal support for teaching, learning and assessment is usually limited or not available. Where support is available, it is often inconsistent or delayed, leading to an adverse impact on disabled students' academic performance and personal well-being. In this scenario, the coping strategies used by them are discussed. While the positive measures adopted by teachers and HEIs are acknowledged, the ways forward to provide sustained and relevant support to facilitate disabled students' access to learning are suggested.

Emma Partlow
University of Birmingham (UK)

Main Conference
Paper

Unreasonable Adjustments? The impacts of equalities legislation on disabled people in the workplace

Drawing on planned fieldwork research, this paper foregrounds the importance of researching disabled people's experiences in order to critically scrutinise the issues which can be masked rather than surfaced by the implementation of equalities legislation within the workplace.

This is timely research given that the government propose within their recent paper: 'Improving Lives: the future of work, health and disability' that one million more disabled people should be in work by 2020. The rationale for this study is that it is hazardous for the government to continue to make bold statements about wishing to create inclusive workplaces, encourage flexible working models and coining work as a health outcome without first beginning to understand the experiences of disabled people currently employed and experiencing equalities legislation.

The impacts of policy and legislation are both a contemporary and a long-standing historical issue; literature in the field outlines a historical background of disabled people being ill-treated within the workplace in Britain. An interrogation of the implications of and potential gaps that exist within equalities legislation is to be undertaken whilst recognising the value of taking such a historical perspective.

There are many potential emotional, financial, physical and psychological implications that disabled people may experience when securing and retaining paid employment. Equalities legislation does not often take account of 'whole person' well-being and this is problematic for the future of work, amongst other areas of society.

Disabled and non-disabled people are complex individuals with a range of physical, social, psychological and emotional needs: it is envisaged that this research will uncover that disabled people's employment rights are not being protected, supported or met under current equalities legislation implemented within the British workplace.

Further it will seek to offer learning on method and research practice to support the development of future disability and work focused research.

Beth Pickard

University of South Wales (UK)

Main Conference

Paper

Construction of Normalcy and Diversity in Music Therapy Theory and Practice

This paper will explore the potential harmony and dissonance in the music therapy discipline about the conceptualisation and communication of the dichotomies of ability and disability. As is recognised widely in critical disability studies, social construction of disability suggests that interactions, language and attitudes have significant impact on lived experience of disability (Rapley, 2010; Bolt, 2016). It is proposed that music therapy contributes to both neurodiversity and deficiency-based narratives in the construction of disability, through contrasting contributions in practice and in theory. Music therapy practice is widely recognised to be inclusive, affirmative and nurturing; celebrating non-normative ways of being and supporting clients to express their authentic self (Bunt and Stige, 2014). Conversely, as an allied health profession, music therapy engages with medical diagnostic criteria and often medical referrals, contexts and perceptions (Wigram, 2006; Aigen, 2015). The language of therapist and client has been discussed in talking therapies as generating a hierarchy of knowledge and experience (Rogers, 1980; cited in Mearns, Thorne and McLeod, 2013), and this hierarchy may be perpetuated in the transfer of this vocabulary to music therapy, despite the aforementioned potential harmony of partnership working in practice. Many theorists have explored the junctures between music therapy and other disciplines, including: music psychology (Cross, 2014; Ansdell, 2014); music education (Ockelford, 2008; Mitchell, 2016); music sociology (Procter, 2011; DeNora, 2015) and psychotherapy (Bruscia, 1998; Mössler, 2011). Each of these disciplines have their own conception and interpretation of disability, articulated in the professional language they engage with. It is proposed that the translation of affirmative, non-verbal practice into clinical, verbal narrative, as well as the related professions with which music therapy shares vocabulary and professional recognition, can blur the constructs of normalcy and diversity in the discipline (Ansdell, 2001; Gross, 2018; Pickard, In Press).

Monika Piecek

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Main Conference

Paper

The ‘compliant’, the ‘pacified’ and the ‘rebel’: experiences with Swiss disability insurance

Swiss Disability Insurance (DI) has undergone three major revisions since 2004. In line with active social policies, these reforms were aimed at reducing the number of pensions awarded by restricting the definition of ‘disability’ and increasing the recourse to rehabilitation measures. The implementation of this new agenda has expanded the range of measures designed to maintain or (re)integrate disabled persons into the labour market and it has redefined both the target population and the nature of rehabilitation.

This paper explores how persons experience their interactions with DI within this context of rapid transformations of disability policies. What stance do they adopt? What trials (Boltanski and Chiapello 1999) are they confronted with?

Drawing on 33 interviews conducted with individuals who have recently been involved in programmes set up by Swiss disability insurance, we highlight how our interviewees perceive, interpret and/or critique their identity (re)assignments and new status. Three ideal-typical discourses were identified: the first characterised by an agreement with DI status classification, the second by a conflictual reaction having given way to a pacified attitude, and the third by rebellion. Our findings show that despite the great variety of situations experienced,

in almost all cases DI has challenged the interviewees' position in a society hierarchically organized on the basis of capacities (Davis 2013; Goodley 2014; Campbell 2009). We argue that experiences with DI thus take the form of an ableist trial: after a health problem, the uncertainty about one's worth and that of others wanes - or grows - in the confrontation with the universe of DI.

Our analysis relies on data collected in a research project entitled "Living under the new paradigm of Swiss Disability Insurance" (2015-2017) funded by the Swiss National Research Foundation.

Andrew Power
University of Southampton (UK)

Ruth Bartlett
University of Southampton (UK)

Main Conference
Paper

Ageing with a learning disability: Care and support in the context of austerity

Recent work on caregiving has begun to look at the opportunities for support from siblings, friends and neighbours alongside parents and spouses. This paper examines the daily relationships that middle to older age adults with a learning disability have with remaining kin members, friends, and neighbours, within the context of declining formal day services. Adults with learning disabilities are likely to have different life course experiences and be living on low incomes and in poor housing than the rest of the population as they have had less opportunity to work and save money through their lives. We draw on two qualitative studies with adults with learning disabilities. Findings suggest that friend and kin networks are anything but certain, as opportunities to meet and socialise shrink, and connections with siblings do not necessarily lend themselves to support. The findings raise the possibility of ‘care deserts’, understood as spaces of attenuated care to convey the increasingly limited fronts from which support can be derived.

Donna Reeve
Independent Scholar (UK)

Main Conference
Paper

Symposium: Disability, psychotherapy and the politics of the personal

A personal exploration of the intersections between psycho-emotional disablism and trauma

(TW: childhood abuse, medical trauma)

Kafer (2016) suggests that disability studies needs to consider the traumatic effects of disability and calls for the development of 'disability theories of trauma, mourning, and loss, theories that recognize the traumatic histories many of us bring to the field' (Kafer, 2016: 4). Hence a theoretical space is imagined where the trauma associated with becoming impaired and acknowledgement of loss can be explored in an anti-ableist way. Experience of trauma can lead to flashbacks, depression and anxiety, further complicating the 'disability experience'.

It is well documented that experiences of trauma, especially in childhood, change the wiring of the brain. Hence PTSD, depression and anxiety can manifest in later life, along with higher rates of chronic pain. Childhood trauma can therefore lead to impairment and disability. Survivors of childhood abuse - a common source of trauma - often experience deep feelings of shame, low self-esteem and self-worth.

Psycho-emotional disablism - the experience of everyday 'acts of invalidation' (Reeve, 2008) - similarly undermines a positive sense of self and self-esteem. If one considers psycho-emotional disablism to be a form of 'small-t trauma' then it is likely that the emotional pathways of psycho-emotional disablism and trauma/abuse have the potential to reinforce each other.

Drawing on my own personal history of trauma and psycho-emotional disablism I will consider:

- How might past experiences of trauma - childhood and/or impairment related - impact on the experience of current psycho-emotional disablism?

- How might disablism in childhood change how trauma/abuse is experienced and the forms it takes?

I suggest that this intersection is potentially a significant part of the experience of disability for many people and is one which disability studies (and many therapists) have failed to consider fully

Emma Rice
Sheffield Hallam University (UK)

Critical Dialogues in Neurodiversity Stream
Paper

Employing participatory methods: autistic pupils' sense of self and the influence of mainstream schooling

Autism advocates critique autism research for the exclusion of autistic voice, its predominant focus on identifying deficit development, and its subsequent focus on 'normalising' through treatment (Chown et al., 2017; Milton, 2014; Milton & Bracher, 2013). Autism and sense of self research regularly employs autistic young people in comparison with their 'normative' counterparts, exploring autistic sense of self in terms of what is lacking in comparison with others. Responding to the call for more participatory and inclusive research methods, the research project reported on in this paper, draws on participatory paradigms to enable autistic young people to articulate their sense of self- to tell the story of 'who am I?' with their own voice (Chown et al., 2017; Milton, Mills & Pellicano, 2012). Alongside this, the mainstream secondary school environment and its influence on autistic young people's positive or negative self-views is explored. In focusing on an inclusive research approach, the project is engaging with a plurality of research methods, as advised by Stone and Priestley (1996) with the autistic young people involved employing individualised modes of expression. Consequently, this research project draws together visual, verbal and written methods to consider how autistic young people conceptualise their sense of self, including the impact of mainstream schooling on this. Within this presentation, I will explore how drawing on a participatory paradigm and providing a range of choices, including in methods of expression, has enabled autistic pupils to share their views and experiences. This evaluation will include autistic pupils' own appraisal of the participatory methods employed together with their experiences, thoughts and opinions in relation to sense of self and mainstream schooling.

Begoña Rodríguez Díaz
Universidad Francisco de Vitoria (Spain)

Main Conference
Paper

Monitoring the NIPT are not used to discriminate on grounds of disability in Spain

Disability activism has achieved remarkable milestones, being one of them the adoption of the UN Convention on the Right of Persons with Disabilities (CRPD). Since then, the main task has been to monitor the implementation of the CRPD and raise awareness of the pending. Though, not enough attention has been given to the threat posed by the new non-invasive prenatal testing (NIPT) and its use with eugenic purpose.

Being the abortion legal and free (no grounds required) up to week 14 of the pregnancy, and being the NIPT able to detect chromosomal abnormalities in the first 12 weeks, this paper focuses on the existence of regulations and practices that encourage terminations on the grounds of disability and thus breach the CRPD main purpose: avoid discrimination based on disability.

We shall analyse the effect of the NIPT and other routine screening tests on the terminations of foetuses with certain chromosomal abnormalities, mainly Down syndrome. The role the disability activists may play in this scenario and its consequences is the object of this study.

Jessica Saffer
University of Hertfordshire (UK)

Main Conference
Paper

Living on a knife edge: How People with Physical Health Conditions Respond to Changes in Disability Benefits

This talk will present research on the experiences of people with physical health conditions who make disability benefit claims and live as a benefit claimant. This is an increasingly important area since the recent and ongoing changes to the benefits system in the UK. The research aimed to explore the social processes that impact on people with a physical health condition who have experienced a loss of or change in disability benefits, particularly in relation to their identity and their relationships with society. Results from interviews with fifteen people with physical health conditions or disabilities will be presented. The research found that participants experienced the benefits system as dehumanising, and felt that they lived in a judgemental society, where they were perceived as ‘scroungers’ and faced discrimination, and sometimes hate crime, from others. These experiences seemed to negatively affect their mental and physical health and wellbeing. Participants often internalised the stigma surrounding disability benefit claimants and they attempted to resist this in order to maintain a preferred sense of self. The presenter will share her conclusions on how the findings demonstrate the significant negative impact of benefit changes on wellbeing and identity. The speaker will invite conversations about the actions we could take to influence changes in the benefits system and change attitudes in society to improve standards of living for people with physical health conditions.

Alice Scavarda
University of Turin (Italy)

Main Conference
Paper

Normal, disabled or something in between. The identity of people with learning difficulties from the point of view of their siblings

The paper deals with the identity representation of adolescents and adults with learning difficulties produced by their siblings. Results are derived from a qualitative study about the brotherly bond when one of the siblings has intellectual problems and the mutual process of identity construction between them. The sample is made up of 32 siblings (aged 14 to 20 and 40 to 60 years) and data collection methods are semi structured interviews and two focus groups. The identity construction of the person with learning difficulties is variable, seldom multiple, being always referred to the concept of normalcy, by denying or emphasizing it, or admitting that their brother/sister is nor normal nor disabled, is simply himself/herself. Moreover, siblings are often unable to specify the moment when they acknowledged the diversity of their brother/sister, because they grew up with his/her peculiar characteristics.

Marie S epulchre
Uppsala University (Sweden)

Main Conference
Paper

Disability rights activists engage in the public sphere: a content analysis of debate articles in Swedish newspapers

Although states have adopted laws and strategies to enhance the rights of disabled people, their effective participation in society is jeopardised because of welfare cuts. This situation is not quietly accepted but indignant citizens engage in the public sphere to struggle against these injustices. Yet, how does one proceed to struggle for the rights of disabled people in a context where rights are formally granted but not fully implemented because they are deemed ‘too costly’?

Previous studies have analysed the organisation and the history of the disability rights movements in various countries and underlined the challenges related to their internal diversity as well as the new possibilities created by digital media. However, the content of the claims of the disability rights activists engaging in the public sphere today has received less attention.

This paper focuses on the case of Sweden and analyses the debate articles about disability that were published in the major Swedish newspapers - which are distributed both in print and in digital format - between 2008 and 2018. A quantitative and qualitative content analysis of the newspaper articles was performed and was guided by the following questions: What are these debate articles about? Who are the writers? What emotions do they convey? What do the activists react against and what do they propose? What debate articles are most often shared on social media?

The paper interprets the results of the content analysis through the lens of citizenship and in light of the Swedish context. As such, the paper focuses on the case of Sweden but it invites a comparison with disability rights activism taking place in other socio-political contexts.

Alison Sheldon
University of Leeds (UK)

Main Conference
Paper

Teaching Disability Studies in the Neoliberal University: Has anyone seen the academic road to critical consciousness?

Despite ongoing tensions between the goals of activism and academia, disability studies has enjoyed a meteoric rise, apparently transforming the ‘intellectual scene’ and establishing a ‘new paradigm around disability’ (Roulstone et al. 2012: 4). In order to maintain its relevance to the disabled people’s movement, it has been argued that a key challenge for academics within disability studies is ‘to try to provide the political education that might serve to raise levels of social awareness and increase the urge to collectively self-organise and demand change’ (Sheldon 2014: 331). Reflecting on over 15 years’ experience of teaching disability studies in higher education, this paper will examine if, and how, the field offers such a route to ‘critical consciousness’ (Freire 1972, 1974). It will further argue that in today’s neoliberal university (Rustin 2016) disability studies’ transformative potential for both students and staff is being eroded. If it is to continue as a radical field, we need to resist and reimagine the neoliberal university. With this year seeing staff and students uniting on the picket lines for the biggest strike of HE workers in British history, it seems that these reimaginings are beginning to emerge. Disability studies could usefully engage with, and inform, these hopeful conversations.

Carla Silva
Nottingham Trent University (UK)

P. David Howe
Loughborough University (UK)

Main Conference
Paper

Is the 'Last Leg' a good idea? The critical pedagogy potential of the marriage between disability sport and humour

While people experiencing disabilities are widely acknowledged as one of the social groups enduring systemic discrimination, it has been also recognised that sport, in particular, the Paralympics, can help disrupt some of the harmful cultural stereotypes grounding inequality.

This paper explores the social-cultural significance of Channel 4's innovative approach to the Paralympic Games coverage. It focuses upon the current affairs' comedy vehicle the "The Last Leg" in which sport and humour can be seen as tools to disrupt and (re)construct traditional ableist (Campbell, 2009) narratives on lives touched by impairment and disability. Discussing the potential of the show to enact a critical public pedagogy (Rossing, 2015), the question is: is this programming format a tool that empowers the impaired or does it further stigmatise disability? The answer is complex. In this presentation, we will explore some possible ways of articulating the empowerment potential of the marriage between sport and humour, as materialised in "the Last Leg."

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This work is part of a wider AHRC funded project "Re- presenting Para-Sport bodies. Disability and the cultural legacy of the Paralympics", a collaboration between Bournemouth University, Loughborough University, University of Bath, Nottingham Trent University and the University of Western Ontario.

Karen Soldatic
Western Sydney University (Australia)

Main Conference
Paper

Disability, Poverty and Ageing in Regional Australia

Australian disability policy has undergone considerable reform since the early 2000s. While recent research and scholarship has largely focused on the new National Disability Insurance Scheme, there is a dearth of research that examines the impact of reform to the Disability Support Pension, and even less so the effects on Indigenous Australians living with disability. This is surprising as a higher proportion of Indigenous Australians live with disability than the non-Indigenous population. This article pays particular attention to the experiences of Aboriginal Australians who have acquired a disability after extensive years of working (25-40 years), yet are still of workforce age (less than 65 years of age). Because of tightened eligibility criteria for the Disability Support Pension, people in this group are placed onto the lower paid Newstart Allowance (general unemployment benefit). The article illustrates the high levels of poverty that Aboriginal Australians with disabilities experience daily, and the ongoing costs they incur in managing Newstart conditionality to maintain continued access to the general unemployment benefit.

Kathryn Stamp
Centre for Dance Research (C-DaRE) (UK)

Main Conference
Paper

Shifting the Lens: Exploring spectatorship through dance, disability and photography interventions

In 1980, the French literary theorist and philosopher Roland Barthes described photography as an “uncertain art...a science of desirable and detestable bodies” (18). Not only does Barthes acknowledge here the complex relationship between object and spectator in photography, but also the impact of judgement by said spectator. Emerging from a mixed-methods evaluation, audience questionnaires, semi-structured interviews and researcher observations, of People Dancing’s ‘11 Million Reasons to Dance’ (11MRTD) project, this paper will examine the impact of employing photography as a medium for changing perceptions of dancers who are disabled. As a multifaceted project, 11MRTD included a touring, curated exhibition of photographs, which demonstrated disabled dance artists recreating famous dance scenes from popular films. Not only might this project raise questions concerning comparative ableist ideals, it could also prompt questions regarding spectatorship and the engagement between audiences and the disabled dance performers who appear in the photographs. How (or why) might using photography affect our interaction with a moving art form? In a project focused on changing perceptions of disability, how significant is it that the disability is recognised and/or acknowledged in a photographic image? Also, how could photography be used as a medium within an activism intervention, promoting dance and disability performers and activities?

Research reconnoitring dance, disability and photography is sparse but through exploring discourse on dance photography, as well as dance, disability and film, this paper aims to draw out key considerations regarding the intersection of dance, disability and photography. Additionally, this paper will present the scoping of designs for a public intervention that aims to utilise photography in presenting disabled dance artists and exploring the complexities of curation, outsider research and spectatorship. The intervention will focus on activism and quiet protest, and how the researcher, and the academy, can initiate discussions around perception change.

Astridur Stefansdottir
University of Iceland (Iceland)

Main Conference
Paper

What is wrong with the Down syndrome fetus?

A diagnostic test (NIPT) able to reveal from a simple blood test whether a pregnant woman is carrying a Down syndrome fetus has been put on the market. This new test deepens the difference between how the disability movement on the one hand approaches and values disability and the medical profession on the other. The medical profession is constantly working towards more sensitive and more specific tests to detect Down syndrome fetuses early in pregnancy so it can easily be terminated. The underlying view being that a Down syndrome fetus in itself is a disease that should be prevented from being born. At least it should be a choice whether to give birth to a baby with Down syndrome. Within disability studies and those who speak publicly on behalf of people with Down syndrome and their families claim on the other hand that to seek out Down syndrome fetuses to terminate them on account of them being with Down syndrome can never be justified. Their voices are characterized by constantly showing how good their lives are and how they contribute to society. They are refuting the medical dialogue and put in the position of having to justify their existence. In my talk I will draw attention to these different voices and to the underlying values that drive them. These values have not been directly addressed and are usually hidden in public discourse.

Allan Sutherland
Edward Lear Foundation (UK)

Main Conference
Paper

Adventures in the Sitcom Trade: The Story of ‘Inmates’

‘Inmates’, written by me and my co-writer Stuart Morris in the early 1990s, was the first situation comedy commissioned by BBC Television to feature a group of disabled lead characters and be written for a cast of disabled actors. A pilot episode was made in 1992. A later version, commissioned by BBC Radio Drama as a series pilot and recommissioned as a 90' single play, was broadcast in November 1997.

This paper charts the progress of this groundbreaking project, contextualises it in relation to developments in such fields as the Disability Movement, Disability Arts and discussions about representation, and considers the obstacles it faced. It links the project to other advances of the same time such as the first Telethon demonstration and the publication of David Hevey’s ‘The Creatures that Time Forgot’.

It also considers some of the practical issues involved in creating such a work. How to write comedy about disabled characters without ridiculing disabled people? How to write disabled characters that will be castable using disabled actors without writing for specific actors? Is it acceptable for a disabled actor to play a character with another impairment? Is it acceptable for an actor to play a character with a more extreme version of their own impairment? Questions such as these had never been addressed before within British television.

A particularly interesting area of discussion concerns how radio provided extra creative possibilities for developing disabled characters, especially in relation to the use of interior monologue. (Gobbo, a character who communicates only through an alphabet board, became narrator of the radio version.)

‘Inmates’ was far from perfect, particularly in its first incarnation. But it was undoubtedly pioneering, and some things it achieved have never been repeated. Its story deserves telling.

Matilda Svensson Chowdhury
Linnaeus University (Sweden)

Main Conference
Paper

The value of activism

Since 2015, the Swedish government has geared up their work to promote austerity measures, whilst at the same time aggressively encouraging an understanding of personal assistance as “too expensive” due to benefit frauds and “overuse”. This paper draws on an interview study with circa 40 parents that are legal representatives of children with combined cognitive and motor disabilities, focused on how they see and respond to these political developments.

In the Swedish debate about disability service provision, family members are regularly portrayed as biased and unreliable speaking out of self-interest. To the contrary, I will argue that we need to view the advocacy of family members of people with extensive disabilities as human rights activism. This means that people that are fighting on behalf of their disabled relatives are Human Rights Defenders (in accordance with the UN definition). This re-conceptualisation offers a more adequate understanding of the situation and struggle of parents of disabled people about to lose their personal assistance.

Leslie Swartz

University of Stellenbosch (South Africa)

Xanthe Hunt

University of Stellenbosch (South Africa)

Brian Watermeyer

University of Cape Town (South Africa)

Mark Carew

University College London (UK)

Stine Hellum Braathen

SINTEF (Norway)

Poul Rohleder

University of East London (UK)

Main Conference

Paper

Symbolic violence and the invisibility of disability

Disability as a social justice issue is not part of mainstream talk. This is despite the fact that approximately 15% of the world's population has a disability, making disabled people the largest single minority group. Symbolic violence as a concept depends on an understanding of the violence of representation. Included in the question of the violence of representation is the violence of lack of representation, the violence of hiding issues away and making them into non-issues, a factor well recognized in terms of the history of lack of representation of and talk about gender-based violence. Amongst minoritised groups, exclusion is a potent form of symbolic violence. One group of minoritised subjects for whom such exclusion is chronically entrenched, is disabled people.

In the lives of disabled people, the symbolic violence of the public domain involves either no representation, or misrepresentation. The latter takes a host of cultural forms. This talk explores a few examples of the symbolic violence to which disabled people are subjected, forms which are both institutional and social. We explore the idea of internalisation of negative social value as a form of symbolic violence experienced by disabled people. We argue that disabled people must constantly act against subtle and blatant acts of symbolic violence - including exclusion - and that the 'necessity of constant resistance' characterises the lives of disabled people. We argue that it is

necessary not only to recognise the exhaustion of constantly having to gird oneself as a disabled person against the symbolic violence of a society which is structured for the benefit of those not like you, it is also necessary to frame this social violence as something which leads to very real and very dangerous exclusions.

Liz Tilly
University of Wolverhampton (UK)

Main Conference
Paper

Transfer of DLA to PIP in the UK; implications for people with a mild learning disability

As part of the ongoing UK Government's welfare reform programme, the Department for Work and Pensions (DWP) is changing disability benefits. Starting in 2013 PIP (Personal Independence Payment) is replacing DLA (Disability Living Allowance). The transfer was originally planned for completion in 2017, however this transition period is now extending into 2018.

This research project, grounded in disability rights and the social model of disability, explored whether people with a mild learning disability lost or gained disability welfare benefit income following their reassessment. This is due to there being no replacement for the DLA 'low rate' care component in PIP. The research project also explored whether access to and type of support received during the reassessment process affected the assessment outcome, and what impact, for those affected by a change of income have on independent living and the ability to live a full life in the local community. This hidden population already face financial hardship due to the combined effect of not being eligible for learning disability services, living long-term on welfare benefits and having poor budgeting skills.

In the first stage of the project 20 people with a learning disability were recruited, they completed a questionnaire about their welfare benefits including DLA and PIP rates, and the level and type of support they receive, and later shared their PIP assessment results and scores.

In the second stage, 6 people from this group were interviewed after the outcome of their PIP assessment was known. The interviews provided qualitative data in the form of case studies, and in-depth accounts of the personal impact, to highlight the findings of the questionnaires. An analysis of the points scored in the independent assessments was also undertaken.

This presentation will share findings from the research project and discuss implications for policy and practice.

Steve Tyler

Main Conference

Paper

A strategy to bring game changing technologies to people with mobility disabilities.

Symposium: Diverse ways of addressing the challenges of disability: understanding contrasting types of disability

This presentation focusses on the promises that technology brings to the disability community and the challenges that remain in delivering on these. Today, in 2018 in the UK and Europe, many would argue correctly that there has never been more access to products, goods and services for people with disabilities. With the advent of Artificial Intelligence, 3D printing technologies, home automation, accessible information options, and much more, real engagement in education and employment opportunities, as well as leisure and social interaction, have never been easier. But there are significant dependencies. To avail ourselves of the latest and greatest opportunities, much needs to be in place - the knowledge of what to purchase, the money to purchase it with, training and support, access to assessments delivered through vehicles that offer comprehensive knowledge, and a means of developing technologies that cater to individualised needs.

The most obvious challenge is that of our existing access to work system and similar support within education - without a job, there is no technology leading to large groups of people with mobility disabilities that have no access to basic on-line services. As a person with a mobility disability, assuming there is motivation, knowledge of possibilities, a willingness to embrace what there is and commit to it, there is a chance of success; but for people with more complex disabilities and/or without those prerequisites, choices are extremely limited. I propose a strategy that addresses these issues as well as more fundamental challenges in the world of work for the future.

Jennifer Van Aswegen
Disability Federation of Ireland (Ireland)

Main Conference
Paper

‘Neoliberal-ableism’: A Critical Discourse Analysis of Comprehensive Employment Strategy for People with Disabilities 2015-2024 Ireland

Comprehensive Employment Strategy for People with Disabilities (CES) 2015-2024 was launched into Irish policy in October 2015. Representing a significant policy event in Irish disability policy-making, this paper aims to subject CES to an interrogation through the lens of critical dis/ability studies (Goodley, 2014), using methods developed from Critical Discourse Analysis (CDA) and Poststructuralist analysis. As the globalization of ‘neoliberal workfare’ becomes a hegemonic discourse and practice for disability policy restructuring (Soldatic, 2011), the rationale for undertaking such an approach to disability policy analysis becomes increasingly urgent.

Drawing on theories of discourse, ableism and normativity the study presents a series of snapshots, representing a critical reading of the policy text from CES. What emerges from this reading is a deeply troubling portrait of disabled people rendered abject, invisible and less than human, constructed on normative assumptions where ableism is forefronted as natural, necessary and rational for the normal functioning of society (Dolmage, 2014).

Irish disability activism is increasingly showing an interest in the potential contributions of Disability Studies to their political struggles. Following Mladenov (2015: 445) the paper argues that neoliberalism challenges the disabled people’s movement with two difficult tasks: ‘to defend self-determination while criticising market-based individualism, and to defend the welfare state while criticising expert-based paternalism’. This study contributes to the growing body of literature highlighting the importance and value of CDA and problematisations in critical disability policy research to support the cause of disability activism. Against the new tyranny of measurement and scientific competence that is transforming the academy (Pinto, 2018) this study highlights the importance of critical disability policy analysis in the pursuit of social justice for disabled people as well as ‘re-modelat[ing] the ways in which we relate to one another as neo-

liberal subjects, individual, responsible, striving, competitive, enterprising' (Ball, 2015: 258).

Eva Lill Fossli Vassend
University College of Southeast (Norway)

Ketil Eide
University College of Southeast (Norway)

Anna M. Kittelsaa
Norwegian University of Science and Technology (Norway)

Hans Abraham Hauge
University College of Southeast (Norway)

Main Conference
Paper

Agency among young people with intellectual and developmental disabilities seeking intimate relationships and independent family lives

Formal rights to independent family life have been strengthened over the past few decades, especially following the UN's Convention of Rights for People with Disabilities (CRPD). Such rights have traditionally been restricted for people with intellectual and developmental disabilities (IDD). They have been stereotyped as "eternal children" incapable of becoming autonomous citizens, and exposed to repressive measures including sterilization, institutionalization, and social and legal discrimination. Current policies prescribe equal opportunities to people with IDD, but there is scarce knowledge about the social processes and practices influencing realization of such rights.

This presentation explores how young people with IDD reflect on intimate relationships and independent family life, and what they experience as enabling or inhibiting their aspirations. Data used consists of a combination of individual interviews with, and observations of, people 16-30 years of age in Norway. The observations were conducted in classrooms in secondary school or in consultations with professionals in specialist health services. Interviews and observations were documented in and analyzed as texts.

The results indicate that interviewees compare themselves with peers without IDD. They want to be recognized as independent adults, yet also seek recognition from parents by looking for partners they think will be appreciated. They acknowledge own needs for assistance from professionals, but also experience such assistance as barriers to

independent family life. Many are willing to take risks to establish intimate relationships, making them vulnerable to violence, sexual abuse and sexual exploitation.

An important implication is that young people develop and exert their agency despite misrecognition from peers, parents and professionals. Honneth's theory of recognition does not seem adequate for explaining this phenomenon, which is probably better understood using Gustavsson's theory of dynamic and diverse identities. People with IDD's agency in seeking independent family lives should be explored further in research and professional education.

Simo Vehmas
Stockholm University (Sweden)

Main Conference
Paper

The animalised lives of persons with profound intellectual and multiple disabilities

History of intellectual disability is a history of segregation, subjection, cruelty and downright brutality. People with limited cognitive capacities have been seen as animal-like, subhuman, and thus of lesser value than other humans. Understandably, the mere comparison between non-human animals and humans with intellectual disability has been seen empirically and ethically inappropriate; to say that a human is psychologically like a pig, is seen to suggest that he or she should be in the same moral category with pigs as well. Only relatively recently, there have been calls in disability studies for a positive engagement with the animality of persons with various impairments. I will discuss the meaning and significance of animality in the lives of persons with profound intellectual and multiple disabilities (PIMD) in the light of ethnographic observation and interview data of an ongoing research project. I will specifically analyse how animality is manifested in their everyday lives regarding housing arrangements, sexuality, and daily routine in general. I will also reflect upon the possibility of animality being something affirmative in the lives of this group of people.

Walter Rafael Villanueva
Western University (Canada)

Main Conference
Paper

Queering Madness: Critiquing Mad Studies Through the Lens of Queer Theory

Mad Studies is a political endeavour that has been influenced by the sociopolitical projects that preceded it, including the gay rights movement. Mad Studies shares the spirit of queer theory in that an articulation of selfhood is at the core of both these fields. I intend to interrogate 'Mad' as an identity category. I will explain how Foucault's concept of 'the confession' has informed the writings of Sedgwick, a prominent queer theorist. *Epistemology of the Closet* was a turning point for queer theory because, within it, Sedgwick universalizes 'queerness' by exposing how even heterosexuality is in itself an unstable—and hence queer—classification of identity. In the same vein, Mad Studies should work to 'madden' the sane and 'normalize' the mad. As with any theoretical school, language is important to Mad Studies. The Mad movement attempts to reclaim the word 'mad' for political purposes, ostensibly rescuing the term from its pejorative connotations. However, having only those who have had negative experiences with the mental health industry declare themselves 'Mad' is not productive. Essentializing Mad identity like this precludes a more nuanced understanding of how madness is constructed and ignores the differing experiences of 'Mad' people. Mad Studies is so concerned with identity politics that it has begun to reproduce the same psychiatric rhetoric of its oppressors, and therefore risks relaying a tautology of madness. Its definition of madness is narrow and results in the exclusion of those who may have had positive experiences within the psychiatric system. People have a right to identify as they wish, but if the Mad movement were to repudiate all labels (even those it has created), perhaps then can it become more inclusive and recognize the multiplicity of experiences it claims to represent.

Mitzi Waltz

Athena Institute, Vrije Universiteit Amsterdam (Netherlands)

Critical Dialogues in Neurodiversity Stream
Paper

Getting from "you can't speak for my child" to "nothing about us without us": A brief history of diagnostic denial, misuse and misunderstanding in autism

During the modern history of autism, a common thread throughout has been the use of diagnosis, lack of diagnosis, or diagnosis-based stereotypes or misunderstandings to bar, discredit or promote individuals with particular views on autism. In cases like that of researcher Michelle Dawson, the presence of a diagnosis has often been used to discredit the bearer of unwelcome truths. In cases like that of self-advocacy pioneer Ari Ne'Emen, it has been used to accuse the bearer of a privileged state that makes him or her unable to represent the needs of 'less able' individuals. In many cases, diagnostic information has been weaponized: used to discredit or demean, or conversely, to claim (sometimes questionably) lived expertise. And when an individual lacks a formal diagnosis but self-identifies as autistic or neurodiverse, what then? In this presentation I will discuss the history of diagnostic denial, misuse and misunderstanding, and suggest some ways that researchers, rights campaigners and self-advocates can manage the risks and pitfalls.

Mitzi Waltz

Athena Institute, Vrije Universiteit Amsterdam (Netherlands)

Main Conference

Paper

Included in Training and Work: Transforming Policies and Practices for People with Disabilities

During People with disabilities experience disadvantage and discrimination in the job market, and are often unemployed. This impacts their lives financially and may have additional impacts in terms of self-esteem, social inclusion, and subjective feelings of belonging. They may be also penalised for being workless. Adult vocational (special or inclusive) education and specialist support exist to remedy this situation, but we know that these are not as accessible or effective as they could be. All too often, adults with disabilities, and especially those with intellectual or developmental disabilities or significant physical disabilities, find that they cannot access vocational education, or that they have not had adequate preparation in vocational education for real-world work. Outcomes of vocational education are significantly less positive for people with disabilities. In addition, a parallel world of disability-specific vocational education and work has emerged where disabled people may be required to attend endless rounds of vocational education courses and temporary trainee placements that can be costly in financial and personal terms, but still do not lead to viable employment.

In 2017, Disability Studies in Nederland led an eight-month research process involving people with disabilities, service providers, policymakers and Disability Studies academics. The project started with international teams working online to focus on barriers to and facilitators of inclusion in vocational training and work that had been identified in previous research. These groups presented their findings at a Lorentz Centre workshop, during which the full team heard guest speakers and worked together with additional contributors for a full week to further develop their recommendations and consider emerging topics. The result is a clear, research-based set of recommendations for policymakers, practitioners and DPOs (see <https://disabilitystudies.nl/lorentz-workshop>).

In this presentation I will present our key findings, with an eye towards further dissemination and real-world use.

Hannah Ware

University of Cambridge (UK)

Main Conference

Paper

“You tell secrets and then I tell secrets”: methodological reflections from inclusive research with children identified as having SEND in England

Young people identified as having special educational needs and disabilities (SEND) remain some of the most marginalised learners in the English education system and face multiple barriers to quality education. Their voices are seldom reported in educational and academic contexts. This paper, based on an empirical study undertaken in England, focuses on exploring the ways in which young people identified as having SEND describe themselves and their experience of “belonging” in different types of schools. Making space to understand the heterogeneity of all young people’s educational experience is key to furthering human and educational rights within school settings.

This research is innovative in using a methodology designed to be both inclusive and participatory, empowering the young people to share their stories on their own terms, in the way that best works for them. The methods used, including video voice and self-portraits, have been constructed without the presumption of literacy, rather, designed as accessible tools capturing multi-sensory data. For those with severe learning disabilities, videovoice can offer an opportunity to collect data which is representative of the full human sensory experience. Participatory member checking and authentic pseudonym selection are presented as ways young people can mediate their voices within the research.

The inclusive nature of the research methodology is examined in order to reflect on the ways in which the process facilitated the young people to present themselves on their own terms and if relevant, articulate a resistance to othering discourses in society.

Brian Watermeyer
University of Dundee (UK)

Main Conference
Paper

Symposium: Disability, psychotherapy and the politics of the personal

The place of psychotherapy in disability emancipation: Frameworks, contexts and identities

The place of psychotherapy in disability emancipation is controversial. For materialists, emotional inquiry is anathema. For others, a variety of theoretical stances are argued to have different relevance to political mobilisation. Feminist critiques contrast ‘domesticating’ therapy with work which highlights political contradictions in private and public life. Disabled people in various contexts face a complex, diverse range of barriers to participation in community life, as well as a range of forms of culturally condensed prejudice. As psychotherapy trainer, practitioner and supervisor, as well as disabled person, the author draws on clinical material to map a proposed research engagement with these three levels of concern in this increasingly important area; viz. theoretical frameworks, social contexts, and issues of identity politics. Conclusions surround the need for both research and advocacy initiatives to create therapeutic services which are subversive and emancipatory in nature, and firmly grounded in the lived experience of the disability community.

Yvonne Wechuli
University of Cologne (Germany)

Main Conference
Paper

Disability Studies & Ableism. What's emotion got to do with it?

The proposed paper seeks to explore the role of emotion in shaping disability as a negatively perceived difference in an ableist society.

In a sociological perspective emotions are perceived as socially shaped and culturally as well as historically specific - not only regarding their expression but also regarding the actual feeling. What do emotional responses towards disability thus tell us about underlying societal norms and trends as well as concepts of normalcy?

In the sense of “doing emotions” (Ahmed 2014) the effects of emotion take centre stage as they for instance evoke emotional labour that is delegated to those individuals who are perceived as not fitting in. Or, according to Bill Hughes (2012): as disability confronts able-bodied people with their own vulnerability it evokes aversive emotional responses (like disgust, pity and fear) that lead to two major societal reactions: kill or cure.

Naming feeling as a specific emotion (e.g. “fear”) always fixes (and shapes) elusive and contextual phenomena (Illouz 2006). How can the fixing of aversive emotions towards disability (as disgust, fear, hate or pity) be interpreted against this background? How is it related to the disguise of social components of emotion that Thomas Scheff (1990) has described for the emotion of shame?

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Shirli Werner

Hebrew University of Jerusalem (Israel)

Main Conference

Paper

The role of university lecturers in meeting accessibility needs of 'non-traditional' students in higher- education

Aim: In line with current legislation and policies, more and more children and youth with disabilities have moved from segregated schools to the general education system. However, in many countries, including Israel, fewer opportunities exist for inclusion of persons with disabilities within colleges and universities. In Israel, a recent project entitled "Academic Friending" allows individuals with disabilities who do not meet university eligibility criteria ('non-traditional students') to study within academic courses side-by-side to students without disabilities. Based on an evaluation study of these courses, this presentation will focus on the means by which universities and lecturers can adapt to meet the learning needs of these students.

Methods: Participants in this study are 31 'non-traditional' university students with disabilities who studied within these courses during the 2016-2017 school year, 25 university students without disabilities and 20 lecturers. Data includes qualitative interviews, focus groups and observations.

Results: The following recommendations were made to successfully include 'non-traditional' students within higher education: (1) Conduct a separate orientation meeting for students with and without disabilities before the beginning of the course; (2) Teaching should be conducted by the lecturer, while 'non-traditional' students are supported by a coordinator; (3) Balance between theoretical teachings and active tasks with hands-on experience conducted within small study groups; (4) Topics in which students without disabilities have no prior knowledge are of better fit for such courses; (5) Input will be provided on cognitive accessibility methods; (6) Lecturers should be highly aware of their use of language and their behaviors which greatly influence the learning experience.

Conclusions: Results will be discussed in light of recent laws advocating for greater inclusion within higher education. We will discuss insight

gained from the current experience and how this experience can be extended to additional settings.

Alison Wilde
Leeds Beckett University (UK)

Main Conference
Paper

Cinema, disability, desire and subjectivity: An exploration of disabled people's criticisms of 'The Shape of Water'

Recent arguments about the film *The Shape of Water* have revealed significant difficulties and contradictions in our expectations of disability representations, the roles of people with impairments cast within screen media, and the participation of disabled people in the creation of portrayals of disability. Not least, some of the criticisms circulating in the media speak of the desire for 'impairment-matching', while making assumptions of static impairments, and the need to declare a 'disabled identity'. I will argue that such calls are counterproductive, especially in an industry where people with impairments are woefully under-employed, and I will show how following some of the demands for 'better' representations to their logical conclusions will marginalise disabled people further. Moreover, the tendency to look for 'positive' imagery tends to result in an unhelpfully reductive approach to 'affirmative identities' which overlooks the nuances of genre and storytelling. Focusing on disabled people's critiques of *The Shape of Water* and a comparison with alternative readings of the film's portrayal of impairment and disability as ground-breaking, I will illustrate how disabled people can adopt and perpetuate the process of disability as masquerade (Siebers, 2004), reinforcing the epistemology of the closet (Sedgwick, 1990) and its binary classifications. In so doing, I will argue for a rethinking of a representational politics, one which avoids the danger of presenting the need to treat disabled characters as a 'special' case; this is seen as a matter of importance and urgency at a time when the desire for the inclusion of 'others' is a high priority on the film and television industry's agendas.

Cara Williams
Lancaster University (UK)

Main Conference
Paper

Employment and Support Allowance: State Crafting the “Disability Category”

The aim of this study was to uncover and then interpret the ideologies which are implicit in two government Green Paper documents relating to the introduction and development of Employment and Support Allowance (ESA) policy over a ten-year period. The paper is particularly concerned with the language of politics as a discourse, and the ways in which successive governments have used discourse and concepts to strategically manufacture doubt with respect to the causes of the “disability employment gap” and the implementation of social security reform.

By analysing changing discourses of policy texts over time, we can identify ideological change in policy constructs to explain how ESA was and continues to be justified. By looking at the discourse more critically one begins to question whether a rhetorical shift away from a primary concern with the associated costs linked to benefit levels and the disability employment gap is a deliberate political strategy linked to a wider ideology of the “disability category”; which serves to obscure the contradictions of capitalism and thus sustain it (in the very specific Marxist sense of ideology). This paper broadens the analysis by examining the situational contextual factors shaping the introduction and development of ESA, providing a timely contribution to ongoing contemporary debates about the meaning and “problem” of social security dependency.

Val Williams

Norah Fry Research Centre, University of Bristol (UK)

Caroline Miles

Norah Fry Research Centre, University of Bristol (UK)

Main Conference

Paper

Disability justice in practice: how ‘activist’ research can make changes to social practices

Human Rights conventions and local UK laws are notoriously slippery when it comes to practice, and disabled people are still facing huge problems in achieving their rights across many areas of life, including domestic life, family, health, social life, and creative arts. ‘Getting Things Changed’ was a three year programme of research (2015-18) in which a large team of researchers, activists, disabled people and organisations worked together. We argued that this is the time to include disabled people, not just as recipients of care, but as change makers. Our aim was to look at the barriers faced by disabled people through the lens of ‘social practice theories’ (Shove, Pantzar et al., 2012; Author et al., 2017) and to explore whether those ideas might help us to understand the way in which practices become disabling or exclusionary.

This presentation will look back at some of our key findings, to pose questions about the reach and impact of disability rights and the Equality Act 2010 in changing practices, taking a critical look at the concept of ‘reasonable adjustments’ and their impact on disabled people’s experiences. We are mindful of the fact that research should make a difference to disabled people’s lives, on their terms, and we will discuss how our ideas about social practices and the drivers for change were shared with disabled people and their organisations. Our argument is that change can never happen without the insider perspective of disabled people. We will conclude with some insights from our team about fundamental changes to practices which have gone further than simply adjusting access, but have instead created new ways of doing things.

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Phillippa Wiseman
University of Glasgow (UK)

Patrick Kermit
Norwegian University of Science and Technology (Norway)

Nick Watson
University of Glasgow (UK)

Main Conference
Paper

Revisiting Recognition and Personhood in the context of Disablism

The affirmation of disabled people's equal human value and treatment has been a central element of disability studies since its founding. Paul Hunt and his co-writers in their ground-breaking collection, *Stigma*, all sought to make the point that disabled people are 'fully human in all that is ultimately necessary'. They wanted to counter prevailing attitudes that denied disabled people full recognition as humans and acted as a force for their exclusion, denying personhood and participation as full and active citizens. In this paper we look to the work of Honneth, Hegel, Fraser and Goffman to examine concepts of recognition, citizenship and interdependence to explore and unpack how personhood is afforded or denied to identities that are devalued and negated in contemporary society. By bringing together these concepts we will move beyond the tendency toward the instrumental application of recognition, where it becomes a heuristic tool to tolerate difference and celebrate diversity, to develop an approach that allows us to talk about misrecognition and redistribution. We will employ Honneth's work to show how, whilst rights based approaches are important, they require inter-subjective recognition if they are to be realised. Here reciprocity is key to the actualisation of personhood. We will draw on the work of Fraser to argue that capitalism serves to alienate us and to deny opportunities for reciprocity and inter-subjectivity. We will critically examine these ideas to explore how they can be used to understand, address and tackle disablement. Implicitly, we suggest that debates about the importance of redistribution versus recognition is not necessarily a discussion where one concept must be given priority over the other. Rather, struggles for redistribution and recognition can be seen as complementary elements in a social ontology where barriers to being are both material as well as of a moral kind.

Phillippa Wiseman

University of Glasgow (UK)

Nick Watson

University of Glasgow (UK)

Main Conference

Paper

Hate Crime, Violence and (mis)Recognition in the Community; Understanding Place, Impact and Wellbeing

Despite the fact that hate crime and bullying are everyday occurrences for people with learning disabilities there has been very little research into the impact these have on their wellbeing. That people with learning disabilities are subject to exclusion and stigma and that their lives within communities are punctuated by discrimination and harassment is now well established. What effect this has on health and wellbeing is less well understood. Given how extensive this is it is unsurprising, then, that people with a learning disability in Scotland experience as many health conditions at age 20 as the rest of the population at age 50 and live 20 years less than their nondisabled peers. In this paper we draw on qualitative research with people with a learning disability to explore the impact of hate crime on their sense of self and wellbeing. The interviews sought to locate their everyday experiences of hate crime and violence, socio-spatially, within a framework that allowed us to unpack the subsequent health outcomes that result from being targeted. We use the work of Bauman and his concept of 'strangers' with Honneth's model of (mis)recognition to shed light on the complex relationship between hate crime and wellbeing. Our data show how hate crime and targeted violence represent the destruction and negation of personhood; it symbolically and physically removes people with learning disabilities from the communities in which they live. Recognition of personhood and belonging are critically linked to wellbeing and so essential to what it means to have a good, flourishing and non-humiliating life. Our aim is to be able to evidence the complex relationship between hate crime and the poor health outcomes experienced by people with a learning disability in order to make the case for hate crime to be understood as a public health issue.

Sarah Woodin
University of Leeds (UK)

Main Conference
Paper

Civil Society Monitoring and the Potential for Change

Despite the impetus towards Independent Living, residential institutions persist in most countries. There are well - documented dangers for residents living in them, especially where contact with the public is limited. This paper will discuss findings from an international project that aimed to improve monitoring by civil society of violence and abuse against disabled children living in institutions in four European countries. The project had three components: development of monitoring tools, training of monitoring teams and the reporting of findings from visits. Overall leadership was provided by an international human rights NGO, working with civil society participants in each country. This paper will describe what was accomplished and the issues that arose from the work.

The training of monitoring teams involved many interesting challenges, including the need to deal with the vested interests of professionals and organisations. Problems of access and the question of how abuse should be dealt with also presented the participants with decisions to be made. The paper will analyse the various dilemmas raised in terms of the potential of various courses of action for leveraging organisational and societal change and discuss how they were dealt with. Comparisons will be drawn with some other similar initiatives and the potential for future developments will be discussed.

Rebecca Yeo
University of Bath (UK)

Main Conference
Paper

The discursive logics dividing disabled citizens from asylum seekers and refugees

This paper explores possible reasons and solutions to the divide between issues of disability and forced migration. Multiple forms of legislation reduced the rights of disabled asylum seekers over recent years, with little if any response from the disability movement. Drawing on post-structural discourse theory, I explore key policy documents shaping current entitlement, focussing on the logics underpinning different representations of ‘the problem’ and the consequent policy solutions.

Distinctions between the ‘deserving’ and the ‘undeserving’ feature heavily in the policy discourse which restricted the rights of some, while upholding that of others. I argue that the Asylum and Immigration Act (1999) withdrew the rights of asylum seekers to access mainstream benefits including Disability Living Allowance, paving the way for the targeting of disabled citizens more than a decade later. In apparent contrast, the Vulnerable Person’s Relocation Scheme, introduced in 2013 in response to the Syrian conflict, includes disability among the criteria of eligibility for increased entitlement. Meanwhile, I consider the discursive shifts taking place with regard to provision of services and support for disabled citizens.

It appears that a shift in hegemonic logics was required before the policies imposed on asylum seekers could be extended to a broader population of disabled citizens. I suggest this example highlights the contingency of political practice. The discursive logics of Tony Blair’s (1999) welfare reform speech paved the way for a shift from the language of rights inherent in the social model, to the language of individual responsibility and the primacy of work which became core to the biopsychosocial model. I suggest that the assault on the rights of disabled citizens which is currently taking place, would not have been

Abstracts: Symposia

Listed alphabetically by title. Constituent paper abstracts are listed in the previous section.

Disability before Disability

Hanna Björg Sigurjónsdóttir
University of Iceland (Iceland)

Main Conference

The interdisciplinary project ‘Disability before disability’ (DbD) brings together researchers representing various fields of the social sciences and humanities into a dialogue about the embodied experience of disabled people existing in Iceland from the settlement in 9th century to the first disability legislation in 1936 which encompasses 30 generations of the Icelandic nation. The disciplines involved are; history, archaeology, medieval Icelandic literature, folklore and ethnography, museum studies, anthropology, informational science and disability studies. The project sets out to open up new and understudied perspectives and unheard voices from the past by investigating ‘disability’ (as a concept and embodied experience) in variety of sources from the medieval Icelandic prose literature through history to the personal narratives in the 20st century, artefacts and archaeological evidences. The aim is to shed light on the hidden history of disabled people during this time period as evident through colourful collection of sources available to the project. In the proposed symposium two post-doctoral researchers and (dl. Two) ONE doctoral student (dl. S) in the field of archaeology, medieval literature, (dl. Folklore) and museology will give insight into their first year of data collection. The proposed symposium wants to raise question concerning how literature and material culture can possibly further our modern understanding of impairment and disability in the past. The project is funded by the Icelandic Research Fund, Grant of excellence nr. 173655-051.

Disability, psychotherapy and the politics of the personal

Donna Reeve

Independent Scholar (UK)

Mèlani Halacre

Spokz People (UK)

Brian Watermeyer

University of Cape Town (South Africa)

Main Conference

The aim of this symposium is to present a starting point for a discussion about the intersections between disability, psychotherapy and the politics of the personal. Disability studies is still somewhat reluctant to engage with matters of the psyche, preferring to concentrate on material barriers which are amenable to social change. However, as will be shown, the emotional difficulties experienced by disabled people can be intricately tied up with the disabling world in which they live.

The three presenters will draw on their experiences - personal, academic and professional - to present a snapshot of the challenges facing disabled people who access therapeutic services. The papers will reveal the highly complex emotional histories which disabled clients can bring to therapy as well as the difficulties this can cause practitioners working within systems which fail to take account of the needs of this particular client group.

The papers will be short to enable time for discussion about the issues raised and to start the process of identifying future directions for research and interventions in this neglected area of disabled people's lives.

Diverse ways of addressing the challenges of disability: understanding contrasting types of disability

Jonathan M Levitt

University of Wolverhampton (UK)

Damian Milton

Participatory Autism Research Collective Network and University of Kent (UK)

Glen Sheader

Galloway's Society for the Blind (UK)

Steve Tyler

Leonard Cheshire Disability (UK)

Main Conference

This symposium focusses on effective ways of dealing with the challenges of disability. It aims to increase awareness, amongst people associated with disability, of the diverse ways of addressing these challenges. It seeks to identify similarities and differences between different types of disability. It also seeks to explore how the comparison of different disability types could contribute to the understanding of disability: Disability researchers and writers have not often compared different types of disability.

Some of the difficulties faced by disabled people can be understood through models of disability. For example, the social model of disability focuses on societal barriers to disability and, its use can focus attention on reducing barriers. In addition, the medical model focuses on the effects of the disabling condition on disability, and can focus attention on addressing the effects of disabling conditions. Moreover, the active model (introduced in “Developing a model of disability that focuses on the actions of disabled people”, Levitt, 2017) focusses on the effects of the actions of disabled people on disability, and may focus attention on encouraging disabled people to take actions to reduce the effects of their own disabilities.

Other difficulties faced by disabled people are not closely associated with models of disability. For example, people who become newly disabled need to find effective ways of adjusting to disability. In addition, disabled people need to have lifestyles that are compatible with their disabilities.

The speakers describe the practical ways of addressing the challenges of the type of disability in which they specialize. Damian Milton will focus on autism, Glen Sheader focus on visual impairment and Steve Tyler focus on mobility impairment.

Life quality and participation of disabled children and youth (LIFE-DCY)

Snaefrídur Egilson

University of Iceland (UK)

Stefan Hardonk

University of Iceland (UK)

Ásta Jóhannsdóttir

University of Iceland (UK)

Main Conference

This symposium focuses on the LIFE-DCY research project that is directed at life quality and participation of disabled children and youth living in Iceland. The perspectives of disabled children and youth are in centre although the perspectives of parents and other key-stakeholders are also included.

The first phase of the study (quantitative) focuses on child and parent perspectives of life quality of disabled children compared with a group of non-disabled children. Parent perspectives on child participation at home, in school and in the community will also be included as well as on how environmental features affect the children's participation. The second phase (qualitative) will provide in-depth understanding of how and why positive or negative experiences in terms of life quality and participation come into being. Close attention will be paid to the social and material environment of the children in different fields such as the home, school, the community, health care and social services. We will also take into account when, how, and how often disabled children get to be involved in decisions regarding important aspects of their lives. We depart from a critical disability studies approach which enables us to critically analyse how the children's social environment influences their life quality and participation.

The results from the study will reflect how the concepts of quality of life and participation interact and what they mean to disabled children and their families. Improved ways of addressing and measuring quality of life and participation will be recommended, taking into account the role of the children's environment in creating opportunities for their well-being and inclusion.

Altogether five presentations will be given during this symposium, focusing on different parts of the LIFE-DCY project. The project was funded by the Icelandic Research Fund (nr. 174299-051).

Living Life to the Fullest: Arts, Activism and Youth

Kirsty Liddiard

The University of Sheffield (UK)

Katherine Runswick-Cole

The University of Sheffield (UK)

Dan Goodley

The University of Sheffield (UK)

Co-Researcher Collective

The University of Sheffield (UK)

Main Conference

In this panel we share our methodological and theoretical journey so far in our narrative and arts-informed ESRC-funded research project, *Life, Death, Disability and the Human: Living Life to the Fullest*. Our research seeks to forge new understandings of the lives, hopes, desires and contributions of disabled young people with what are classified as having, according to medical language, ‘life-limiting and life-threatening impairments’ (hereby LL/LTIs). We can gauge the values of any society by considering how it treats those people who are the most marginalised and too often disabled young people find themselves on the outskirts of society. This is especially the case for young people with LL/LTIs. And, while we know much about the deaths of young people with LL/LTI, we know relatively little about their everyday lives, ambitions and desires. This invisibility is detrimental to their social and emotional wellbeing, and that of their families, carers and allies. Working alongside our Research Management Team of community research partners, disabled people, parents of disabled children living with LL/LTI, academics, researchers, activists and other supporters, and the Co-Researcher Collective, a core group of young co-researchers living with LL/LTI, we are in the process of co-producing knowledge that seeks to value short lives and respect death as part of the human condition.

Major work ahead, the post psychiatric landscape of Autism

Larry Arnold

Independent Scholar (UK)

Gillian Loomes

University of York (UK)

Stephen Kapp

University of Exeter (UK)

Claire Evan-Williams

The Autism Academy (UK)

Dinah Murray

National Autistic Taskforce (UK)

Critical Dialogues in Neurodiversity Stream

The publication of DSM5 in 2013 was merely the latest change to the societal map of autism. Given the history, first of autism's appearance in 1980, it's change from an infantile disorder in 1987, the entry of Aspergers Syndrome and various subtypes in 1994, and the latest collapse into Autism Spectrum disorder, it can easily be conceived that the landscape of autism has anything but a clear roadmap and communal understanding. It is more like a set of roadworks attempting to cross an indistinct landscape, not so much certain knowledge, as constant flux. Diagnoses come and go, not necessarily because of the state of medical knowledge at the time so much as because of societal changes, the elimination of homosexuality in 1973, before autism was ever an official thing being one of them. The removal did not mean that the category disappeared from the world as either a natural kind, or a focus for securing human rights for those negatively nuanced by societies reactions to it.

Autism can likewise be categorised as a discourse about a presumed category more than it can described in any way as a Kantian "noumenon". Whither Autism when it is no longer a catalogued disorder? How should society deal with a divergent constellation of what is currently psychologically described difference? What is to be the landscape of the ideal future, and how do we start making our roads to the future destination now? I propose a symposium whereby activists and researchers can publicly debate these issues."

On Ableness: Using Studies in Ableism to explore cultures of Ablement

Fiona Kumari Campbell

School of Education and Social Work, University of Dundee

Nina Mackert

Department of North American History, Universität Erfurt

Main Conference

Ableism is beginning to be used with frequency in research and on the web, often without clarification about the way the concept is understood. As a summary, ableism is a process that promotes a certain kind of valued, productive, aesthetically pleasing body/mind. As a result, many people who are deemed non-normative and sometimes regarded as ‘disabled’ are excluded from being considered ‘abled’. Ablement is also seductive and promoted as the right way of being human, the gold standard for being a full citizen. Ableism is in effect an instrument for the government of populations (nationally and globally) and is an aspect in our daily lives we all have to negotiate. Sometimes abledment is obvious, often though it is hidden and unacknowledged. Instead of a typical focus on ‘disability’, the panellists will present their research on ways that Studies in Ableism can be engaged to foreground the production of the idea of ablement including inducements towards ablebodiedness, which we theorise as abledment, i.e. actions towards be/coming ‘abled’ and the impacts that ablement may have on peripheral peoples. Panellists will draw upon their research from the disciplines of sociology, history, education and philosophy.

Questioning the ‘generosity’ of the Swedish welfare state - investigating austerity measures against disabled people

Julia Bahner

Centre for Disability Studies, University of Leeds (UK)

Niklas Altermark

Lund University (Sweden)

Hampus Nilsson

Lund University (Sweden)

Ida Norberg

University of Glasgow (UK)

Lill Hultman

Karolinska Institutet (Sweden)

Matilda Svensson Chowdhury

Lund University (Sweden)

Main Conference

Sweden is often regarded as the gold standard when it comes to disability rights, de-institutionalisation and a personal assistance as a means to achieve independent living. More broadly, Sweden is well known for its generous welfare state. However, in light of recent attempts by the current Social Democratic-Green government to ‘decrease expenditure’, not least on personal assistance, the view of Swedish welfare and disability policy needs to change.

There are empirical as well as theoretical reasons to look into these developments. First, as it stands, the literature on austerity and disability politics has a heavy focus on the UK and the US. Examining the specificities of the Swedish case thus adds empirical breadth to the literature. It is our hope that the Swedish case here can function as a point of comparison. Secondly, from a theoretical perspective, we believe that it is central to understand how austerity plays out in the context of the expanded welfare state - not least since the cutbacks are being accelerated under a social democratic government. Thus, any theoretical understanding of how austerity strikes against disabled people need to incorporate cutbacks in the developed Scandinavian welfare states into the explanation.

This symposium aims to give examples from different research projects examining the discourse, as well as the effects, of austerity measures and other types of service provision limitations on disabled people's lives.

Showcasing: The new disability activism

Maria Berghs

De Montford University (UK)

Tsiti Chataika

Institutional University of Zimbabwe (Zimbabwe)

Miro Griffiths

Miro Consultancy (UK)

Damien Haslett

University of Birmingham (UK)

Liz Crow

Roaring Girl Productions (UK)

Armineh Soorenian

Multiple Organisations (UK)

Wendy Merchant

Independent Scholar (UK)

Main Conference

Against the onslaught of neoliberalism and austerity cuts, disabled people are fighting back and we urgently need to understand how, where and what they are doing, what they feel their challenges are and what their future needs will be. This symposium will provide a platform and showcase some of the activist work of contributors to the Routledge Handbook of Disability Activism. The contributors from the United Kingdom will be elucidating the role of youth activism (Miro Griffiths), sports activism (Damian Haslett), parental activism for children (Liz Crow and Wendy Merchant) and activism as an independent academic outside of the violence of neoliberal academia (Armineh Soorenian). We also wanted to ensure accessibility of our platform and have been sent in videos about toilet activism in the United Kingdom, legal activism in Zimbabwe and global dementia activism from Australia.