Centre for Disability Studies Postgraduate Conference 2019

Disability Studies: Past, Present and Future

Book of abstracts

CDS Leeds

#CDSPGConf19

Keynote Presentation by Professor Roger Slee

Title: Writing fiction – the case of inclusive education and students with disabilities.

Notwithstanding espoused commitment to UNCRPD (2006) by education jurisdictions around the world, the educational experiences of children and young people with disabilities do not live up to the promise of inclusive education. Recent reviews of education for students with disabilities in Australia collectively build a narrative of exclusion. Educational exclusion is a stubborn foe. This address will attempt to move beyond critique to identify levers for building the capacity of schools to build inclusive educational cultures.

Biography:

Roger Slee is the Vice-Chancellor's appointment to Chair of Education at the University of South Australia. He has previously held research chairs at The University of Western Australia, Goldsmiths College University of London, Victoria University and the Institute of Education UCL where he was the Chair of Inclusive Education. Roger is the former Dean of Education at Goldsmiths, The University of Western Australia and Magill. He holds an honorary chair in critical studies in education at The University of Auckland in New Zealand. He is currently working on major inclusive education projects in Ethiopia and Queensland.

Roger is the Founding Editor of the *International Journal of Inclusive Education* and is on the Editorial Boards of many other journals. He is also the Editor of an important book series published by Sense Publishers. This Series 'Studies in Inclusive Education' focuses on the ways in which schools contribute to the failure of different student identities on the basis of gender, race, language, sexuality, disability, socio-economic status and geographic isolation. Reflecting Roger's own perspective on Inclusive Education, books in this series are innovative in that they expand the focus from a narrow consideration of what has been traditionally referred to as 'special educational needs' to understand school failure and exclusion in all its forms. The series considers exclusion and inclusion across all sectors of education: early years, elementary and secondary schooling, and higher education.

Roger is the author of many books and articles including the well-known and respected 'The Irregular School. Exclusion, Schooling and Inclusive Education' (Routledge) and most recently, the book 'Inclusive Education isn't Dead Yet, It Just Smells Funny' (Routledge) in which he delves deep into the architecture of modern-day schooling to show how inclusive education has been misappropriated and subverted, manifesting itself in a culture of ableism, an ethic of competitive individualism and the illusion of *special educational needs.*

Beyond academia, Roger has advised governments and education authorities in Canada, Australia, New Zealand, Singapore, Kosovo, Montenegro, Greece, England, India, Iraq and Jordan. He was formerly a Deputy Director General of the Queensland Ministry of Education and has recently stepped down from being the Chair of the Board of Directors for Children and Young People with Disabilities Australia.

Plenary Presentation by Professor Colin Barnes

Title: 'Disability Studies at Leeds, 1982 - 2013: A personal journey'.

This presentation will cover the history of disability studies at Leeds from its origins in the 1980s through to my retirement in 2013. Emphasis will focus on the link between disability activism and research and the development of disability studies as an 'academic' discipline.

Biography:

Emeritus Professor & founder of the Centre for Disability Studies, Professor Colin Barnes is an important pioneer of Disability Studies. He is a disability activist, author and editor of several books and articles and a researcher with an international reputation in the field of disability studies and disability research. His research into the discrimination faced by disabled people in the UK influenced the development of the first major piece of civil rights legislation relating to disability in this country. His work has been proudly cited by the University of Leeds as one of the "10 ways the University has changed the world".

Professor Barnes work as committed advocate of disabled people's rights has not only transformed people's understanding of disability but inspired a generation of disability activists. Professor Barnes has conducted research on various disability issues, published widely, and spoken about the experience of living with impairment in a disabling society to various audiences in a variety of locations, both in Britain and across the world. These include the House of Commons, the European Parliament and the World Health Organisation.

Professor Barnes was a member of several local, national and international organisations controlled and run by disabled people including the National Centre for Independent Living (NCIL), the Disability Equality in Education Trust (DEE) and the European Network of Independent Living (ENIL).

Graduating from the University of Leeds with a PhD, Colin went on to become an influential and world-renowned professor in Disability Studies and campaigner for Disability Rights. His story is an inspiring example of persevering to achieve one's dreams in a disabling society.

Professor Barnes extensive publications on disability related topics include: Disabled People in Britain and Discrimination, 1991; Independent Futures: Creating User-led Disability Services in a Disabling Society, 2006, co-authored with Geof Mercer; and The New Politics of Disablement, 2012, co-authored with Michael Oliver. His other works include: Cabbage Syndrome: The Social Construction of Dependence, 1990; Equal Rights for Disabled People: The Case or a New Law, 1991; Exploring Disability: A Sociological Introduction, co-authored with Geof Mercer and Tom Shakespeare, 1999; Disability Studies Today, 2002, edited by Colin Barnes, Mike Oliver and Len Barton; and The New Politics of Disablement, 2012, co-authored with Michael Oliver.

Interactive Workshop with Dr Fiona Kumari Campbell

Title: 'Using Studies in Ableism as a research Methodology'

Fiona will deliver a short presentation on the above topic and then the floor will be opened up for questions. This is intended to be a very interactive questions and answer workshop.

Biography:

Fiona Kumari Campbell currently is a Senior Lecturer in the School of Education & Social Work, University of Dundee. Fiona is Co-Lead of the Peripheries Research & Academic Scholarship Theme at ESW, and Co-Chair of the University's Disabled Staff Network. In 2019, Fiona became a Fellow of the RSA (Royal Society for the Encouragement of Arts, Manufactures and Commerce). She was Deputy Head of School (Learning & Teaching Scholarship) at the Griffith Law School until July 2014. Previous to this she was Convenor of Disability Studies, School of Human Services & Social Work, Griffith University (2001 – 2010).

Fiona Kumari Campbell is an Adjunct Professor in Disability Studies at the Faculty of Medicine, University of Kelaniya, Sri Lanka, a person with disability and is associated with several minority groups (BAME, LGBTI).

Fiona has written extensively on issues related to disability – a philosophy & sociology of ableism, disability in Sri Lanka, biotechnology and is recognised as a world leader in scholarship around studies in ableism. After the successful publication of Contours of Ableism: The Production of Disability & Abledness (Palgrave) in 2009 Fiona is working on three book manuscripts: "Textures of Ableism: Disability, Voice and Marginality", "Kamma, Buddhism and Disability", "Ableism: The Plain Truth".

Her research interests include: Disability/Ableism studies (disability in law, social exclusion, epistemologies of ableism,); sociology of the body; sociological theory; interfaith/intercultural dialogue, health & wellbeing; disability jurisprudence; Buddhist Studies; decolonisating knowledges; systemic advocacy & human rights; capacity building; community development theory/practice and Sri Lankan studies.

Fiona is currently working on several funded projects including "Healthy Universities for Healthy Communities" with Professor Judith Sixsmith, Helen Ryall, (University of Edinburgh) and Dr Linda McSwiggan; Making "Masculine" Pettah (Sri Lanka) More Inclusive: Familiarisation of Spaces by Women and Gender-nonconforming Persons to Reduce Inequalities and Promote Good Health and Wellbeing, funded by the, Scottish Funding Council; and Social Care and Disabled Prisoners in Scotland.

Paper presentations

A Critical Analysis of Advance Directives in Mental Health; A Solution that Legitimatizes the Problem?

Alexius Kamangila, NUIG Student and Open Society Scholarship Fellow (CDLP NUIG)

'Article 25 of the CRPD calls for persons with disabilities to enjoy the highest attainable standard of health without discrimination on the basis of disability. It demands that this right should be rendered on the basis of free and informed consent. Determining whether the patient is competent to give consent has been seen as critical in balancing between respecting patient's autonomy for those capable of making informed decisions and protecting those deemed cognitively impaired. Advance Directives, which provide patient's preferences on treatment, have advanced among service users and protagonists of patient's rights in mental health. The coming into force of the CRPD with Article 12 propagating universal legal capacity, brings the theoretical basis of Advance Directives into question. This article examines whether Advance Directives have the ability to promote the will and preference of the persons with disability specifically in relation to decisions on treatment, to safeguard legal capacity as envisaged by Article 12. It proposes Advance directives as construeing cognitive disability as the basis of one's loss of ability to decide, thereby, albeit subliminally, thwarting the right to health. It argues that Advance Directives contextually and in practice, legitimizes concepts of lack of mental capacity (hence lack of legal capacity) for persons with psychosocial disabilities. To promote Advance Directive legislations in the absence of legal framework that recognizes legal capacity in the sense/standard of the CRPD, is a recipe for disaster. A solution that legitimizes the problem becomes the problem requiring a solution; the story of Advance Directives.'

Representing Down's syndrome in Documentary

Amy Redhead, Liverpool Hope University

This paper examines the documentary genre and questions to what extent this particular media form contributes towards, or challenges, traditional understandings of Down's syndrome within contemporary society. While all forms of textual representation have the potential to have a damaging impact on certain groups of people, this paper focuses specifically on documentaries, based on the argument that this particular genre is, potentially, more problematic than other forms of textual representation, in that filmmakers (and audiences alike) identify documentary-makers as purveyors of "truth". Uniting the fields of Disability Studies and Media Studies, this paper employs textual analysis as a means of exploring two short documentary films from the past: Educating Peter (1992) and Graduating Peter (2001), and a television documentary series from the present-day: The

Special Needs Hotel (2015). From the data analysis emerged two distinct themes: the documentaries analysed (both past and present) represent people with Down's syndrome as "different" and "dependent". Problematic narratives, displaying documentary subjects (people with Down's syndrome) as passive subjects and manipulating an illusion of inclusion within the texts meant that the documentaries, which had the potential to educate viewers, instead misrepresented the lives of people with Down's syndrome and reinforced many of the common tropes surrounding this condition.

Relational ethics, relational aesthetics: how can CDS contribute to theories of socially engaged, participatory and collaborative art practices?

Anne-Marie Atkinson, Manchester Metropolitan University

I propose to explore disability as "a moment of relational ethics" (Goodley et al, 2014) alongside the nascent theories of socially engaged, participatory, and collaborative art practice. The "social turn" (Bishop, 2006) has increasingly solidified its presence within contemporary art, so that it can now be spoken of as being 'normalised' (Matarasso, 2019). These new art forms often privilege dialogue, sensitivity to context, co-labouring, shared authorship, and engagement with lived experience. Bishop has criticised some modes of these art practices for placing an ethical process above an aesthetic outcome, but Kester (2011) responds that these practices frame 'exchange' in a way that sets it apart from everyday interaction, encouraging self-reflection and "calling attention to exchange itself as creative praxis" (p. 28). Traditional art criticism relies on ethico-epistemological oppositions, such as: individual vs. collective; pure vs. compromised etc., so we need new ways of understanding and critiquing art to make sense of these new practices. Disability could allow us to think in productive terms in the continuing theorising around these practices because it "demands mutuality, support and interdependence" (Goodley et al, 2014). By applying interdependence and assemblage theories borrowed from critical disability studies, a new art criticism could be developed that reconfigures the artist and the artwork into one of entangled, dispersed competencies and mutual becoming.

Attracting the wrong kind of attention: Boys, mothers and ADHD

Anna Miller, University of Leeds

Attention Deficit Hyperactivity Disorder is associated with 'abnormal' patterns of inattention, hyperactivity and impulsivity. In the UK, the diagnosis of ADHD is highly racialized, gendered and classed, with white boys living in deprived economic circumstances being the most likely to attract a diagnosis (Southall, 2007; Hart and Benassaya, 2009; Singh, 2018). NICE, who govern clinical practice for ADHD in the UK, advice against the prescription of stimulant medication, and instead, suggest group based parenting training (NICE, 2018). Despite the gender neutral terminology, research has demonstrated parenting intervention classes target mothers more.

This study suggests that in order to understand how ADHD operates as a diagnostic category we must therefore go beyond the practices of psychiatry, medicine and schooling to consider gender and class inequalities more widely. In doing so, it is possible to explore the workings of power that have allowed for parenting classes to be established as the first line of treatment for ADHD in the UK. I am concerned with mapping how the emergence of the figure of the 'bad mother' allows institutions to interpret ADHD-associated childhood behaviours as an issues of morality, and, significantly, as the result of ineffectual parenting. Of particular concern to me is how the diagnosis of ADHD maps onto the class and gender norms which are embedded within the culture of 'mother blame' which surrounds the diagnosis of ADHD.

The social model of disability and 4e cognition - a literary-critical analysis of what this tells us about how we can support autistic adults and those with other 'invisible' disabilities

Anna Stenning, Bath Spa University

Certain interpretations of the social model of disability, when it is seen to focus predominantly on social barriers to flourishing, struggle to account for some of the broader environmental experiences at the heart of autistic life writings of autism. What if, we try to understand autistic experience in terms of an experiential lifeworld within a neurotypical cultural world? How might this account for painful experiences by autistic adults in ways that are not accounted for by a social model, and which will also support the cultural flourishing of all disabled people? Finally, what if we include accounts by those who are experiencing 'eco-anxiety' (anxiety about ecological challenges and threats to the natural environment)?

While at a very early stage in my research, this paper argues that the social model of disability, focusing as it does on the built environment, is not as responsive to the full extent of the lifeworld that is differentially experienced by all human beings, including the disabled

and non-disabled human and our non-human companions. Focusing on a series of memoirs by autistic writers, this study looks at the breadth of possibility of drawing on '4e' (embodied, embedded, enactive, and extended) cognition and cross-species ethics to develop an account of disability as embodied difference within a dominant ableist and anthropocentric culture.

The social model and the construction of a disability rights movement: the case of Mozambique

Clodoaldo Castiano, National University of Galway

This presentation will focus on recent developments of the disabled persons' movement in Mozambique which led to the rejection of a Disability Bill proposed by the Government and the constitution of a civil society committee to draft and advance an alternative bill. The presentation will highlight the use of the social model as an instrument of policy analysis in this process to ground the allegations of the disabled persons' movement towards the rejection of the Disability Bill. Hence, it will sustain that the social model has provided a political discourse to unite the disabled persons' movement.

On the other hand, the presentation will also point to the challenges against the affirmation of the social model that arose in this process. In particular, it will indicate the lack of a mechanism to ensure genuine and ongoing participation of persons with disabilities in the drafting process of the new disability bill. It will also criticize the use of the Government bill as a basis to draft the new bill showing how it has negatively impacted the substance of the bill.

Finally, the presentation will put forward some suggestions to strengthen and complement the social model analysis in this process. It will particularly focus on the need to take into consideration comprehensive human rights and inclusive equality models as proposed in General Comment n. 6 of the United Nations Committee on the Rights of Persons with Disabilities.

Freedom to fail? Disabled people's employment opportunities in contemporary China.

Cunqiang Shi (Felix), Cardiff University

The Chinese economy has continued to boom over the past few decades, which has brought a significant number of employment opportunities. However, during this transition to marketisation, urbanisation and industrialization, Chinese disabled people's employment rights have been relatively neglected. China is famous for its strong state presence in terms of public life, but how much the government has done to support disabled people during this critical transition to a market economy is still unclear. Being employed is considered to be a crucial factor for disabled people to be included in mainstream society, yet the employment gap between disabled and non-disabled people in China is estimated to be

30%. Such a significant gap raises the questions of how the state promotes employment opportunities for disabled people, and what choices are available to disabled people in employment.

This paper will explore the four key means by which disabled people pursue access to employment, namely through social welfare enterprises, the quota system, self-employment and family/community work. By contrasting these different routes the aim is to identify how disabled people's employment experiences are affected by the interaction between the role of the state, family and labour market. Taking a historical materialist approach it will analyse how the concept of disability in Chinese society has evolved. Discussion is based on a literature review that will contribute to a PhD thesis, which will provide a contextual background to disability and employment in China.

Disability Language and the Development of Disability Policy in China

Dong Lin, University of Dundee

China has been criticised for the medical model of disability-related language, which focuses on physical defects inherent in disabled persons and prevents them from equally perform activities and rights as others. It has been argued by China that it is important to consider 'national conditions', especially at the level of economic development and thus China has been promoting an approach with 'Chinese characteristics' to improve the lives of disabled people. Consequently, China's application of the *Convention on the Rights of Persons with Disabilities* (CRPD) and domestic disability policy and law are significantly influenced by the current approach of 'Chinese characteristics'.

This presentation will first look at the Chinese language of disability, including its change and development over the years and the metaphor of the term 'disability' in Chinese characters, which reflects on what disability has been seen in the Chinese context. Then, it will move on to the international debate about the Chinese language of disability and China's argument and current approach against international criticism. The final section is the discussion about what China's argument and current approach mean for China's application of the (CRPD) and it's development of disability policy and law.

"I already had presumed I was going to go to uni so losing my sight didn't change that, I was just going to go differently". Visually Impaired students as activists within higher education.

Emma Croft, University of Northumbria

Taken from a recent doctoral research project (Croft, 2019) which examines the tensions experienced by visually impaired students within higher education, this paper explores how the experiences shared by the participants demonstrate a challenge to ableist norms they experience within the positioning of disability, and more specifically visual impairment, in higher education.

Where participants discuss their responses to the ableist notions often experienced through the responses of others to their participation in higher education, they show how, by giving voice to these experiences, these students promote subtle and overt forms of activism. Engaging with a critical disability studies (CDS) lens to explore disability and the neo-liberal notions of ideal personhood (Goodley, 2014), what is uncovered is how, through this approach to understanding what is experienced by visually impaired students, this allows us to uncover ways in which subtle forms of activism, alongside more overt examples, offer an alternative approach to understanding how activism and academia can create a challenge to the inherent disabling practices which position disability and particularly visual impairment on the fringes of participation.

Where a Freirean (2006, p.47) stance towards the purposes of education understands education as a key component of enacting social justice, higher education, as informed by the experiences of disabled students could offer a unique opportunity to explore the ways in which academia and activism can work together to offer a strong challenge to the inherent ableist attitudes which dominate our social worlds.

Disabled children, their voice and the power they hold.

Elvira Psaila, University of Malta

In current research practices, disabled children are increasingly being recognized as capable, active agents and/or co-directors in studies exploring their lives. But is this equal stance being transferred and recognized in the spaces they occupy in their everyday lives? This paper deconstructs four short narratives experienced by four disabled children I have worked with as a pediatric physiotherapist and as a mother. The stories of Leah, Gareth, Alexander and Max are then discussed using the philosophical thinking of Jacques Rancière to help understand better the notions of equality and power of voice at play in present day society. This paper thus attempts to identify the different mediums disabled children employ to project their voice, and possibly transgress the traditional passive space they are expected to occupy. Furthermore, using Rancière's concept of equality and distribution of the sensible, the paper discusses whether disabled children's voice is heard, acknowledged and valued by the adults (parents and professionals) present in their everyday lives. The paper concludes by inviting the reader to question current practices and attempt to present a clearer picture of whether disabled children can occupy a position of power in present day society.

What about my right to access justice? A Disability Studies Perspective on the Intersectional Discrimination experienced by disabled women under article 13 of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Esther Anato–Dumelo, University of Leeds

Access to justice has been described as an indispensable precondition for the defence and advancement of all other human rights in tackling economic and social exclusion and ensuring the rule of law and democratic governance. This right becomes even more significant for disabled women for two reasons: Firstly, the intersectional discrimination experienced by disabled women as a result of their gender and the disability imposed on them by cultural, legal, environmental, economic and other societal barriers; Secondly, the general lack of awareness of their human rights in international and national laws, policies, service provision and general feminist and disability discourse. Research suggests that disabled women are twice more likely to experience challenges to accessing justice than others.

This paper examines the progress and challenges experienced by disabled women in the implementation of the right to access to substantive, procedural, symbolic and participatory justice as articulated by Article 13 UNCRPD. The arguments advanced are positioned within an intersectional contextual analysis of the operation of these barriers within the justice system of Germany and Serbia. It is submitted that whilst there has been progress in certain

aspects of the implementation of Article 13, it has been canvased by the serious challenges that still remain ten years after its ratification by both states. These challenges can be overcome by a collaborative partnership between all interested stakeholders which prioritises the inclusive participation of disabled women as equal citizens and leading experts in realising transformative reform.

Rights Not Roses: direct action by disabled people in Leeds in the 1990s

Gill Crawshaw

Disabled people in Leeds carried out several significant protests using direct action during the 1990s. This paper will highlight some notable actions, illustrated with news cuttings, photographs and other documents, and invite discussion of the effectiveness of direct action in the fight for disabled people's rights.

The Disabled People's Direct Action Network (DAN) was a national network of disabled people who used tactics such as blocking roads, occupying buildings and handcuffing themselves to vehicles – or people – in the fight for equal rights and freedom (Greater Manchester Coalition of Disabled People, 2010). DAN's targets included public transport companies, charities, local authorities, government and politicians (Parker, 1995; Rose, 2015), reflecting the demands of the wider disabled people's movement (Campbell and Oliver, 1996).

DAN was created in 1993 following the huge Block Telethon protest outside ITV's Telethon fundraiser the year before. A busload of activists from Leeds attended this demonstration (Lisicki, 2018). DAN subsequently carried out actions across the country, including in Leeds (Disabled People's Direct Action Network, 1995-1999).

Disabled people in Leeds had been organising direct actions before DAN started (Zillessen, 1991). This activity ran alongside the early years of the Centre for Disability Studies (indeed, Colin Barnes was a member of the Leeds contingent at Block Telethon!). The paper will consider the Leeds context that enabled direct action by disabled people to take place.

Rethinking Advance Planning under the Convention on the Rights of Persons with Disabilities

Grace Carter, University of Nottingham

My research is focused on 'advance planning' (AP) which is a process by which an individual can create a written will or preference to become legally enforceable once a person has lost mental capacity. As a method of support it's advocated for by the Convention on the Rights of Persons with Disabilities (CRPD) Committee. However the CRPD also stipulate that an AP should be triggered *not* by a mental capacity based test, but should enter into force and cease to have effect according to conditions decided by the individual. Theoretically this has raised many challenges for the law, including how a person could stipulate the beginning and end of an AP without reference to a mental capacity test; and how the communication of wishes should be navigated. My research proposes an alternative to mental capacity based tests by turning to social and philosophical theories on 'self' (what makes us, us) to explore whether a loss of self may be a more effective and CRPD compatible trigger. This involves critiquing dominant conceptions of 'self' in social theory which either disclude disability, portray disability as 'deviant' or include disability as an afterthought. Disability inclusive elements of self are then analysed with reference to how different types of mental health conditions can create losses in different elements of self and how these losses could be navigated in an AP. The aim of this research is to provide both theoretical and practical suggests of how APs may be improved for those who use them.

Designers' responses to information accessibility needs

Gyeonghwa Lee, University of Leeds

The term disability is associated with impairments that can require obvious design interventions. Designers and communication professionals have increasingly been concerned with provision for disable people, and accessibility or awareness are central issues here. This paper deals with the issue of information accessibility. Information is often inaccessible for disabled people, particularly for visually impaired people. Most visually impaired people face a number of additional difficulties compared to other groups of disabled people when accessing information. Vision impairment can also relate to colour vision difficulties which impacts also on the quality of people's lives. The project involves in-depth focus group interview with information design experts to explore a huge gap between what information design experts predict about the needs of vision and colour vision impaired people, and what vision and colour vision impaired people actually do need as information users. Overall, it is argued that the findings provide support for new directions in how information needs to be offered to designers to change their attitude, behaviour,

and the value they place on providing accessible information for disabled, visually impaired and colour vision impaired people.

The Nominal Group Technique (NGT) as a tool for facilitating pan-disability focus groups & as a new method for quantifying changes in qualitative data

Jason Olsen, Ulster University

This article reaffirms the value and flexibility of the nominal group technique (NGT) when conducting qualitative focus groups (QFG). In the project that will be discussed the methods used expands the application of the NGT into the realm of pan-disability (i.e. individuals with differing impairments) research. It provides requirements and recommendations for the full inclusion and participation of disabled people into projects where the pertinent source of qualitative data is obtained from QFGs. However, this article also describes new innovative steps that are beneficial to researchers. This includes methods of evaluating the data that is often lost between the NGTs stages of initial and final rankings. These methods ensure pertinent data does not get overlooked.

Nothing about us without us? Yes, but not when applying for research ethics!

Presented by Jessica Mannion, University of Dublin
Authors: Mannion, Jessica and Sheerin, Fintan, Brady, Vivienne

Carrying out a meaningful co-operative inquiry, whilst also negotiating ethical approval in line with a university's academic requirements, can prove challenging (Northway et al., 2014). Drawing from the authors' experiences in developing an inclusive research project, this paper presents a theoretical discourse on the potentially disempowering role of research ethics. The study consists of a team of co-researchers with intellectual disabilities and a PhD student. The co-researchers will decide the questions that matter and the methods to explore this, undertake field work, analyse data and disseminate findings. Yet they are excluded from the ethics application process. Such exclusion assumes vulnerability and precludes capacity to engage from the outset, contrary to contemporary understanding of how, and in which contexts, people can and do make decisions. Exclusion enforces power imbalances between academic researchers and researchers with intellectual disabilities (Brydon-Miller and Greenwood, 2006). Inclusion provides a sense of ownership (Ham et al., 2004). Applications are not accessible; are time consuming; and potentially stressful to inexperienced researchers (Ham et al., 2004). Then there are concerns about informed consent (Nind, 2008; Gates & Waight, 2007). There is a lack of published work on people with disabilities views on research ethics (McDonald & Kidney, 2012; Ham et al., 2004). Our aim is not to resolve these issues but to initiate discussion and to describe how the use of an

informed consent procedure (Arscott et al., 1998), accessible documents (Change, 2018; Mencap, 2002) and creative methods (Edwards, 2019) to explain ethics were developed to support this study.

From violence to neglect: the mistreatment of disabled adults in residential care

Josephine Sirotkin, University of Leeds

Research shows that people with learning disabilities are dying premature and preventable deaths in the UK. Yet, there has been little government action to address this fact. This raises important questions about the values underpinning society, and the ways in which some lives are positioned as more precarious and less valuable than others. This paper considers these dis/ableist societal values and their potential implications for health and social care. Specifically, it examines the impact that these values may have on the (mis)treatment of disabled adults in residential care, in England. To do this, initial findings from the first phase of my PhD research will be shared. This phase of the research is currently ongoing and involves a documentary analysis of Safeguarding Adult Reviews. These reviews are commissioned by Local Authorities when a situation has occurred "in which harm to or death of a vulnerable adult has occurred, or where abuse or neglect was suspected and local agencies' responses were deemed in need of scrutiny" (Manthorpe and Martineau, 2017a, p.2086).

This paper, then, highlights the extent of the mistreatment of disabled adults within residential care in England, as well as how it is responded to by Local Authorities. In doing so, the paper demonstrates the broad range of practices encapsulated by the term 'mistreatment.' Here, mistreatment includes (but is not limited to): physical, psychological and sexual violence; neglect; theft; inappropriate restraints; and the inappropriate deprivation of liberties. By including such a broad range of practices, this paper aims to get us thinking about how one form of mistreatment could lead to another and how particular practices and logics, which may appear to be mundane and insignificant, may also do the same.

Participation of disabled children and young people in Education, Health and Care Plans and in research; moving in an emancipatory direction.

Louise Arnold, University of East London

My doctoral research seeks to find out whether/how disabled children and young people are included in the creation of an Education, Health and Care Plan (EHCP). The Children and Families Act (DfE, 2014), introduced the EHCP which replaced the old 'statement of Special Educational Needs'. The 'statement' was seen to be imposed on the child, with little to no input from the child in how to meet their needs, where the EHCP is supposed to be written in collaboration with the individual and their parents.

Moving towards an emancipatory paradigm, and using participatory approaches, I will be interviewing children and young people (using their preferred communication method) about their views on the creation of their EHCP. I will also be interviewing parents about how well they felt their child was included in the process. I have recruited a steering group, of disabled children and parents, who are guiding me on the research design and instruments. Drawing upon critical disability studies, early childhood studies and child rights perspectives, this presentation will focus on methodological and ethical issues in researching with disabled children and young people, who have historically been underrepresented in research.

Taking selfies and eating in the toilets: Disabled children resisting classroom surveillance and control

Katharine Terrell, Sheffield Hallam University

Gallagher (2010) argues that schools are sites of discontinuous surveillance open to resistance by those surveilled, the pupils. I use two examples from my fieldwork in a mainstream primary school to illustrate this in relation to disabled children. With regards to photography, I show how children take technology used by adults for surveillance of children and creatively subvert its intended use, sometimes literally turning the gaze onto adults. Teachers often take photos to demonstrate and track children's educational "progress" and "development", in ways that are often unscrutinised (Goodley & Runswick-Cole, 2011). My data suggests that taking photos allows children to challenge the ubiquitous use of tablet computers to photograph them. I then move on to discuss the ways in which certain children's bodies are more closely surveilled than others, and the embodied ways in which those children resist the control of adults. Specifically I talk about children's use of toilets in ways which clash with adults' expectations. Burton suggests that "What children choose to do in relation to school toilets – to comply or to protest – is political in that it is their embodied expression of everyday power struggles" (2013). Despite adults' concern

with hygiene, I argue that in fact a child taking their lunch into the toilet illustrates wider problems with education settings, rather than disabled children needing to be "trained" to behave appropriately. I use Slater, Jones & Procter (2018) to consider how school toilets are connected to ideas of civilisation and therefore to normative, and oppressive, ideas of development.

Marketing disability services for autistic people: A social model approach

Madiha Aslam, Heriot-Watt University

Despite significant legislative changes, people continue to be disabled in a wide-range of ways and across a range of contexts. The medical model has dominated historical approaches to disability, limiting the nature and scope of understanding the true accounts of disability and the potential value of the social model to society. More work is required using the social model of disability, as a valuable tool to shift the locus of the problem towards the discriminating practices of society, which is the focus of this research.

Whilst research concerning disability is gaining momentum, many areas remain under researched. In particular, studies using the social model of disability to analyse the lived experience of autistic people throughout the labour market has received relatively scarce attention. By applying a social model of understanding to contexts such as recruitment, the potential exists to offer applied understanding of society's engagement with disabled individuals and, in particular, to those diagnosed with ASD. This research begins by tracing the historical development of the disability movement, and the consequent social model of disability. It further explores how disability is conceptualised throughout contexts and will suggest approaches for marketing agencies to recruit and retain autistic people. This research takes a new direction, integrating the social model throughout interdisciplinary studies to account for lived experiences within the 21st century and contribute towards an enabling society.

Note: The research is at an early stage – early second year PhD, and as such, the paper will be based around progress so far and current ideas for researching autism in terms of recruitment/employment services and reflecting the social model of disability.

Self-organisation of Swedish disabled researchers/activists

Maria Larsdotter, Lund University

I am an autistic 'returning' student (just finished a Master in Disability studies, about to enter Phd studies) and a founding member of the Swedish action research collective Begripsam, which aims to combine academic and activist ambitions to promote change in academic and general practice. Our goal is societal change, through academically based work, within the area of cognitive accessibility, grounded in our lived experience.

The collective consists mainly of disabled people with cognitive impairments, not excluding allies with other / without disclosed impairment, who agree on its shared aim. Some of us are employed by the collective, but the majority take part on a volunteer basis, the aim being everyone taking part on terms possible and desired.

I will present how we formed the group and how we have been successful in introducing ourselves into the research scene of cognitive accessibility at a national /governmental level in Sweden. I will then discuss my own and other group members' experiences of difficulties and barriers, pursuing a quite new perspective in the Swedish disability research context (Sweden having a strong but rather traditional disability research history).

I aim to encourage peer-discussion with the audience on topics like:

- Shared responsibility for research outcomes
- Handling the risk of being co-opted
- Negotiations of access needs
- Cross-language issues (i.e. academic English in a non-English setting, AAC and conceptual differences)

The presentation builds on personal examples to discuss pragmatic academic activist self-organisation, in an international perspective.

Elective amputations: (elective) disability as a challenge to the 'normal' paradigm.

Mireia Garces De Marcilla Muste, University of Oxford

My MPhil thesis investigates the desire to acquire a disability, focusing on the desire to have one's limb amputated in particular, in order to understand how the medico-legal framework accommodates (elective) disability. Drawing on disability scholarship, I investigate what discursive formations about the body inform the legal treatment of disability and how they influence its reaction to elective amputations.

The term 'elective amputations' is used to make reference to the process of amputating a healthy limb at patient's request. This has been a widely debated issue in the ethical, legal and medical literature and it is contended that it provides a fruitful approach for the proposed endeavor of revisiting the legal view of disability: while disability is usually seen as a "negative" state that is acquired through happenstance, would-be amputees seek to abandon their able-bodied condition and move into a disabled body in order to feel "normal" and "whole". Analysing how —and why— law and medicine react to this bodily modification demand allows for an examination and critique of the understandings of the body (e.g. in relation to normal functioning, structure and ability, for instance) that underpin the medico-legal framework. Hence, the primary research question that my MPhil aims to answer is: How and why does healthcare law react to the desire of having one's limb amputated?

Revolution, Global development and Disability Politics in Egypt

Mostafa Attia, University of Leeds

The ongoing process of the Egyptian Revolution was a factor that influenced disabled peoples' self-organization and empowerment and their movement's activism as a whole. The UNCRPD, which Egypt ratified three years earlier, was also a motivating force. It increased disabled people's attention to the advocacy of their rights using rights based language and models to express their demands freely and independently. The third factor is the global move from the Millennium Development Goals (MDGs) towards the Sustainable Development Goals (SDGs). Having this 6 years after the revolution may have supported Egyptian policy makers in following the path of inclusive development. This thesis examines whether such global and national events influenced the self-organization and representation of disabled activists and, in turn, whether they affected the way in which the disabled people's movement were able to participate in the government's policy consultations e.g. the formulation of the Egyptian constitution and the ESDS (2016- 2030). Moreover, did this situation differ from that before the Revolution? Capturing the momentum of the UNCRPD additionally informed the other factors that were shaping the

liberality of disability activism. Moving on, the thesis seeks to further understand whether the disabled activists' involvement in the revolution has established a unique unity. It frames this possible shift in order to determine whether it was temporary, only lasting the 18 days of the Revolution – or whether it was more permanent. It also aims to understand whether disabled activists were satisfied with the level of their rights as included in the post-Revolutionary policies, such as the 2014 Constitution.

Although there is much literature on the Egyptian revolution, global disability discourses and inclusive development in their own contexts, combining these three influences underpins recommendations as to how Egypt can benefit from the application of an inclusive development approach to its Sustainable Development Strategy. It is the first piece of research to utilize the ongoing discussions about SDGs within the post- revolutionary era, with disability in mind.

The research question examines to what extent the United Nations Convention of the Rights of Disabled People (UNCRPD), the Egyptian Revolution and the newly emerged Sustainable Development Goals (SDGs) contributed towards paving the way for more sustainable and inclusive development for disabled people in Egypt. In answering the research question, this qualitative research relies on document analysis and semi-structured interviews along with participant observations as data generation methods. It is worth noting that the research participants include: Egyptian politicians, disabled MPs and Disabled People Organization (DPO) representatives, while observational methods were employed to conduct some field visits to four Egyptian development projects: two governmental projects and two DPOs.

Improvised Performances of Filipino Blind Buskers at LRT Stations: Will you stay or will you go?

Neslie Carol Tan, University of Melbourne

Street performance in Manila, Philippines is not as vibrant as in other cities. The most familiar figure is possibly the blind busker singing along sidewalks, church fronts, malls, and other public areas. This paper thus explores this recognisable figure in the urban landscape of Manila, specifically focusing on the performances of Filipino blind buskers at what may be considered as privileged liminal busking sites: the Light Railway Transit (LRT) stations. These performers are produced by wider, systemic conditions, but have in turn become productive agents within their performance sites. Despite the precarity of their performance situation, hinging on unpredictable busking periods and venues and the necessity of navigating operational relations with institutions, these performers *make do* with their creative and improvisational musical, spatio-temporal, material, and social practices. These tactics in turn help blind buskers negotiate their status as invisibilised vulnerable bodies by generating a certain sociality with their predominantly nondisabled audience—provoking transitory yet

iterative moments of potentially productive and affective encounters with commuters-turned-spectators.

Improving disability inclusion for disabled academics

Olugbenga Abraham Babajide, Heriot Watt University

In the UK, Disabled academics are unfairly and unequally treated in Higher education (HE) compared to disabled students, and this is problematic. Ableism and disablism are both jointly housed in HE (Dolmage, 2017). Hence, there is a need for disability inclusion (Fenney, 2017). Ableism negatively portrayed being disabled as less human and invisible but positively endorsed able-bodiedness and able-mindedness as an ideal or normal human (Dolmage, 2017). This contributes to why disability is not often disclosed and underrepresented in HE, especially for academics with hidden impartments (Brown & Leigh, 2018). Therefore, disablism then emerged and further nurtures the social and structural barriers that not only exclude/restricts disabled people (Goodley, 2016) but also put more pressure on their doubly living and working disabled experiences in an intensified and highly demanding working nature, such as academia (Sang et al., 2015). Ableism is an illusion (Wendell, 1989) and it is problematic. This research will employ Phenomenological Analysis (Smith, 1996) to understand the interpretative account of the lived experiences of disabled academics. Data collection will involve interviewing and visualising techniques from current and past academic employees across UK universities. Nvivo software programme will be used to analyse the emerging themes from the transcribed interviews of participants. Potential findings from this study would reveal the lived experience of disabled academics and will help shape policies and initiate action plans for disability inclusion for disabled academics in HE. The presentation will include talks about disabled academics, disability disclosure among disabled academics and the proposed research approach.

Cripping the politics of death(s): How might we use necropolitics to understand disabled people's oppression?

Rebecca Louise Porter, University of Leeds

This paper highlights the valuable contribution the theory of necropolitics could make to disability studies. A postcolonial theory that builds on Foucault's biopower (Foucault, 1975), Mbembe (2003) asserts that certain citizens are subjected to different forms of death. States operate three forms of being: living, dead, and in-between the living dead. The living dead group occupy a form of existence, where they are denied the privilege of living as full citizens: a social death (Bauman, 1997, in Mbembe, 2003). Previously applied to LGBT+ communities in different states (Azuira et al, 2007) and the European response refugee crisis (Davies et al, 2017), this paper will suggest that Necropolitical theory can be utilised to better understand how disabled people are oppressed by the state, through bureaucratic forms of political violence. This will be discussed using numerous studies on poverty (Joseph Rowntree Foundation, 2018, Scope, 2019) and United Nations investigations into human rights breeches. Moreover, the data will be illustrated with the stories of disabled people who have experienced the impact of austerity measures, causing poverty, poor quality of life, destitution, and in some cases, death (Ryan, 2019).

Disabled New Negroes? Disability and impairment in the literature of the Harlem Renaissance, 1919-1929

Samuel Brady, University of Leeds

Adapted from my Undergraduate dissertation submitted in May 2018, this paper explores the ways in which impairments and disabled people were represented in literature from the Harlem Renaissance period. In the early Twentieth Century, African Americans began to radically alter how they defined their own blackness as they examined their place within American society. This culminated in the Harlem Renaissance, a socio-cultural creative movement which produced a plethora of literature and art concerned with shifting conceptions of race and blackness. This paper aims to explore how disability was represented in examples of this literature, and how this may indicate how disabled African American were valued in the community. Two examples will be explored in detail; Mary P Burrill's *They that Sit in Darkness* (1919) and Wallace Thurman's *The Blacker the Berry* (1929). Using these pieces of literature, this paper will explore how disability was used as a metaphor for racial experience, and how disabled people fit into changing conceptions of race. Importantly, this research into disability and race presents a unique insight into the study of the Harlem Renaissance, as much of the existing intersectional research into the period has focused on matters of gender and sexuality. Furthermore, this research presentation makes consideration of the need for more historical consideration of

impairments and will include insights into issues faced in the historical study of disabled people.

Risk and the calculable future of disabled students

Sharon Smith, University College London

Since the 1990s, there has been an increased focus within education on both keeping pupils safe in school and minimising the risk of problems in the future, such as potential underachievement or dependency. This has resulted in some students, frequently those who have SEND, being labelled as 'at risk', with interventions subsequently being put in place to reduce the probability of undesirable outcomes occurring. Those with the most significant special educational needs or disabilities are issued with Education, Health and Care Plans, detailing additional provision to be put in place, which aims to ensure agreed life outcomes are achieved.

This presentation will argue that the move within the education of those with SEND towards pre-determined future outcomes, within a discourse of risk management and minimisation, results in the extension of disciplinary power over an individual's 'calculable' and knowable future. It will further argue that the future of the other is not something that can or should be comprehended in the present, nor should there be any attempt to contain it. Instead, there should be a relationship with the future, based on 'the temporal transcendence of the present toward the mystery of the future' (Levinas, 1987). This requires an encouragement of risk and uncertainty as a core aspect of the education of disabled students, rather than an education based on assessed needs and interventions to deliver pre-determined outcomes.

Independent Living Revisited: assistance, autonomy, and ambiguity in the age of austerity

Steve Graby, University of Leeds

The concept of 'independent living' has been central to disabled people's movements in the UK, the USA and elsewhere since the 1970s. However, the concept of 'independence' in a broader sense has also been consistently criticised by disabled scholars and activists (as well as feminists and others) as an impossible ideal which is based on ignoring the mutual dependence of all human beings (including non-disabled and disabled people) and which serves to maintain the oppressive power structures of patriarchy and capitalism (Fraser & Gordon 1994; Morris 1991; Taylor 2004). The term 'independent living' has thus been at times criticised by more radical voices within the DPM as playing into the hands of capitalist interests (Finkelstein 2004; Richter 2017). A potential response to this is that the DPM has redefined 'independence' to mean something more like autonomy or self-determination within an interdependent society, in accordance with some feminist literature on 'relational

autonomy' (Mackenzie & Stoljar 2000; Nedelsky 1989).

My doctoral research about personal assistance, involving qualitative interviews with both disabled people who employ PAs and PAs themselves, uncovered productive tensions around autonomy and independence within the relationship between PA and employer. In this paper I will explore the implications of some of these tensions in order to consider the ambiguities and usefulness (or otherwise) of the term and concept of 'independent living' in the context of the contending forces of 'marketisation' and 'social protection' identified by Dodd (2016) and the current political conditions of austerity and rising post-neoliberal authoritarianism.

Crip Killjoys, Emotion Work, Political Emotions: Concepts from the Sociology of Emotions and Affect Studies in Disability Studies

Yvonne Wechuli, University of Cologne

The proposed paper explores the inspiration that concepts from the Sociology of Emotion and (cultural) Affect Studies can bring to Disability Studies. It draws on a PhD project that seeks to map out how emotions are theorized in the field of Disability Studies. Some Disability Studies scholars employ theoretical concepts of emotion and/or affect in their work – for instance Martha Nussbaum's (2013) political emotions (e.g. Soldatic & Meekosha 2012) or Sara Ahmed's (2017) killjoy (e.g. Goodley, Liddiard & Runswick-Cole 2018). Other publications deal with emotional issues without theorizing emotions in a sociological or cultural studies fashion. Still, sociological or cultural studies theorizations on emotions and affect can be applied to such contributions, such as Arlie Hochschild's (2012 [1983]) notions of emotion work and feeling rules (e.g. to Berghs 2011). This paper argues for the need for shared theoretical concepts and terminology on affect and emotion for a comprehensive engagement around emotionality within the field of Disability Studies.

My interest in this topic sparked when noticing the common superficial labelling of societal reactions towards disability as distinct emotions, such as fear or hate. This is surprising assuming that the way emotions work between disabled and non-disabled people is key to ableism.