

Approaching Rest, Work, and Activism through the Lens of Disability Politics: Relationships and Contradictions

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*A British Sociological Association PGR Event (Symposium) - hosted by the University of
Birmingham*

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Panel One

1.1 Moving beyond the Rest-Work Dichotomy Through the Lens of Disability

Politics: Rest as a Collective Necessity - Ioana Cerasella Chis

Abstract: In capitalist societies that venerate productivism (such as the UK), 'working' (especially for a wage) is deemed to be an active, productive process through which one 'contributes' to society. On the other hand, the activities associated with the realm of 'rest' (not least idling, recuperating, slacking, rejuvenating, 'dolce far niente', and sleeping) are, in mainstream thought, mostly conceptualised in terms of passivity, unproductivity, and the private sphere. Rest, then, is reduced to an individual form of self-indulgence underpinned by not doing, not working, and a scarce luxury that has to be 'earned'. As evidenced in a recent national UK YouGov poll, people subjected to processes of disablement and proletarianisation are generally considered unworthy of having access to such luxury.

In this presentation, I critique and reject productivist portrayals of rest as an individualised and passive non-activity. In response, I consider rest(ing) as a collective necessity that requires structural, social transformation, and I call for its prioritisation as part of anti-disabling capitalist struggles over waged and unwaged work – including those of trade unions. The presentation is structured as follows.

First, I posit that collective, anti-disabling capitalist struggles ought to move beyond the conceptualisation of work, activism, and rest strictly as part of a zero-sum game. Instead, an expansive, materialist understanding of these three forms of activities is necessary, in relation to oppression and exploitation. Resting, then, is an active process produced through activities whose meanings and roles ought to be analysed in their historical and socio-political specificity.

Second, I argue that no activity, on its own, is inherently or universally 'good', 'bad', restful, or non-restful – instead, we ought to consider whether and how certain activities fully reproduce, resist, or move beyond disabling capitalist social relations and infrastructures. To illustrate this point, I will draw on three concrete examples – namely, sleeping, returning home from a work shift, and sitting in a café-, and their socio-political meaning, positioning, and manifestations in different contexts.

Third, I propose that a fundamental social transformation of society towards centring the collective necessity of rest entails critiquing and changing the overall disabling capitalist institution of work. Thus, time-based demands for 'less work and more rest' or increasing free time in one's everyday life are an important starting point – however, on their own and devoid of a perspective that takes the structural processes of disabling capitalism into account, they are incomplete. In short, activism through the lens of Disability Politics ought to build and make space for infrastructures and social relations that move against-and-beyond disabling capitalism's productivism and its failed version of 'rest'.

Author bio: Ioana Cerasella Chis (she/her) is a doctoral researcher at the University of Birmingham, in the Political Science and International Studies Department. She is a member of Marxism and Disability Network's steering group, co-convener of British Sociological Association's Theory Study Group, and the Anti-Disablement Officer of her trade union branch, Birmingham UCU. Ioana's current research project (@DisPrecWork) explores the politics of disablement and precarious work in the UK, through which she aims to make theoretical and empirical contributions to Critical Political Economy, Disability Studies, Sociology, and to the thought and praxis of activist circles. Ioana's website can be found at <https://ioanachis.com>.

1.2 Rest, Disability and Work: Applying Diffractive Analysis to Counter Disabling Hermeneutical Injustice in the Justice System - Becca Jiggins

Abstract: My PhD research employs a new materialist agentic ontoepistemological framework to consider case law on reasonable adjustments in the employment context to inform critical rewriting of disability judgment, following the Feminist Legal Judgments project approach. My research models the value of a new materialist agentic framework for understanding judicial decision-making in a minority rights context to mitigate the risk of epistemic injustice owing to a lack of hermeneutical resources available to the court for understanding the experiences of Claimants.

This paper uses this model of socio-legal analysis developed in my PhD to explore rest and disabled working lives. The legal framework of working time, health & safety, and adjustments for disability are diffractively 'read through' (Barad 2014) disabled people's activist theorising via Spoon Theory (Miserandino 2003), Crip Time (Kafer 2013; Samuels 2017), and Rest as Resistance (Hersey 2022). This diffractive reading of legal frameworks through activist theorising is used to expose areas that create risk of hermeneutical injustice in the operation of judicial decision-making. Legal questions of reasonableness, proportionality, and balance of probabilities civil standards of proof are resituated in embodied disabled realities, as the construction and operation of legal tests relevant to workplace stress, working time, and disability discrimination civil claims, are 'read back' diffractively through activist theorising.

The diffractive reading is put to work in considering litigation strategies for the presenting of claims and early case management stages of the Employment Tribunal. The very low number of ET cases that proceed to final merits hearings reveals that the impact of hermeneutical injustice influencing judicial decision-making in the ET will be predominantly experienced at case management stages, where litigation realities heavily restrict the opportunities to identify, much less directly challenge, such injustice. The paper concludes with strategies for practitioners and activists drawn from the diffractive reading for positioning rest as central to disability justice, in the language of the courts and the interests of the overriding objective.

Author bio: I'm a part-time PhD candidate at the University of Leeds, researching critical jurisprudence of reasonable adjustments in employment. After a 20-yr career in the charity sector beset with experiences of disability discrimination, I got my LLM in Employment Law & Practice and founded Just Reasonable Ltd, a

non-profit organisation providing full litigation representation in the Employment Tribunal. My day job is co-leading The Work Inclusion Project Ltd, supplying specialist in-work support to disabled academics, professionals & entrepreneurs. (she / her)

1.3 Rethinking the Spatial Exclusion and Disability Politics: A Case Study Based on Rest Infrastructures in Beijing Museums - Yishuai DING, Xuan YI, Yiqi Hu

Abstract: Museums, as public cultural institutions, should take the responsibility of providing equal access and barrier-free facilities for all visitors, including those with disabilities. Although many museums in Beijing seem to invest and equip with good infrastructure, they suffer from various detailed problems, such as the inconveniently placed rest areas or the absence of rest areas in large exhibition spaces, significantly impacting access, perception, experience and enjoyment for disabled individuals in reality. This study focuses on a project initiated by a Beijing social organization for the disabled, the Disabled Sisters Best. The project's primary objective is to assess and enhance the accessibility of major and significant museums in Beijing, the capital of China. Through comprehensive and meticulous evaluations, incorporating the perspectives of diverse disabled individuals, this research sheds light on the implications of the lack of adequate resting facilities for disabled visitors. By conducting on-site investigations and gathering authentic feedback from disabled participants, this study pursues two main goals. Firstly, it seeks to create a comprehensive report on the practicality and effectiveness of museum infrastructure. Secondly, it aims to highlight the impact of non-functional or poorly designed facilities on the museums' role in public cultural engagement. This research's main aim is to underscore the adverse effects of neglect and misguided assumptions concerning the rest needs of disabled individuals. Beyond merely hindering their access to museums, these issues obstruct their opportunities for knowledge acquisition and social inclusion. Such findings expose the presence of disregard, scrutiny, and negligence to the disabled inherent in certain aspects of capitalist societies. This study endeavors to raise awareness and promote the necessary improvements in museum accessibility and infrastructures of rest for disabled individuals, fostering a more inclusive environment, policies and practices.

Author bios:

Yishuai DING, Intern in the Disabled Sisters Best (Beijing Tongzhou Leyirong Social Work Organization), Undergraduate in the Department of Sociology and Anthropology, China Agricultural University. she/her

Xuan YI, Intern in the Disabled Sisters Best (Beijing Tongzhou Leyirong Social Work Organization), Undergraduate in the Department of Sociology and Anthropology, China Agricultural University. she/her

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1.4 Exploring Experiences of Disabled Volunteers: An Interpretative Phenomenological Pilot Study - Natalie Jarvis

Abstract: This paper presents insights into the experiences of disabled volunteers, utilising an interpretative phenomenological approach (Smith et al., 2022). The study aimed to examine both positive and negative experiences faced by disabled individuals during volunteering activities. This paper focuses on a single case study used as a pilot study for the testing of an appropriate approach for a larger PhD project. The participant, named as Faith, identifies with physical and mental disabilities, and has extensive volunteering experience, including involvement with a reducing discrimination charity that resembles activism. The study investigates Faith's experiences, which included fatigue, the need for breaks and rest, flexibility and contingency planning and addressing the guilt that is associated with missed participation due to health-related reasons.

This study employs an interpretative phenomenological approach, allowing for in-depth interviews that explore Faith's experiences as a disabled volunteer. The researcher adopts a hands-off approach during interviews to highlight Faith's experiences. This single case study, part of a larger PhD project, examining participants' experiences who identify as disabled and have engaged in volunteering activities in the UK. The themes developed from this data involved the need for breaks, flexibility, and proactive support, aligns with the conference's focus on rest, work, and activism within the context of disability.

This (IPA) study delves into Faith's experiences as a physically and mentally disabled volunteer. The in-depth interview, lasting 1 hour and 37 minutes, provides valuable insights into Faith's journey in volunteering and the interplay between rest, work, and societal assumptions of ableism. The study identifies twelve main personal experiential themes, including the transformative impact of volunteering on employability, challenges faced by disabled volunteers, personal growth, positive outcomes, setting boundaries, the influence of mental health, photo elicitation, addressing mental health stigma, the importance of inclusive volunteering with proactive support, accessibility concerns, cultural perspectives shaping disability perceptions, and navigating assumptions and ableism.

The study's findings highlight the prevalence of fatigue, guilt, and the need for disabled volunteers to manage their energy and well-being while engaging in volunteer work. The identified themes emphasise the significance of embracing diverse productivity abilities and understanding the complex relationship between rest, work, and activism for disabled individuals. The study also underscores the importance of proactive support, contingency planning, and addressing accessibility concerns to create inclusive volunteering environments that promote well-being and meaningful engagement. This pilot study offers valuable insights into the experiences of Faith, a disabled volunteer, within the broader context of rest, work, and activism in disability politics. The themes identified in this research hold implications for fostering inclusive and supportive volunteering practices, encouraging further exploration of the relationships and contradictions between rest, work, and activism for disabled individuals. This study contributes to a richer understanding of

the challenges and achievements faced by disabled volunteers and offers potential pathways for enhancing their engagement and well-being.

References:

Smith, J., Flowers, P., & Larkin, M. (2022). *Interpretative Phenomenological Analysis: Theory, Method and Research* (2nd ed.). SAGE Publications.

Author bio: Natalie is a PhD candidate at Swansea University, specialising in the exploration of disabled volunteers' experiences. With over a decade of volunteering experience, she currently serves as a director at Age Connects Cardiff & The Vale, Trustee Secretary for Discovery SVS, and works part-time as a Volunteer Manager at Matthew's House. Her research examines the intersectionality of disability, volunteerism, and the voluntary sector. As a cancer survivor with ADHD, Natalie possesses a unique lived experience that fuels her commitment to advancing academic insights in this specific field.

Panel Two

2.1 Rest Against the Machine: Using the Perspective of Disability to Develop Radical Minor Politics - Anat Greenstein

Abstract: In this paper I will use autoethnography to argue that activism based on love, care and solidarity, is as radical, crucial, life sustaining and timely as those tactics based on rage, disruption and conflict. Starting from the perspective of disability, and in particular energy limiting impairments, and drawing on the idea of “minor politics” (Deleuze & Guattari, 1987), I will explore how low energy and the need for rest bring into focus previously neglected avenues of activism, that may open up new ways of resisting hegemonic and oppressive power.

I will be looking at my experiences as a feminist, anti-Zionist and anti-militarist, disabled activist (though not necessarily a “disability activist”) in this particular time in Israel/Palestine. Life as a Jewish citizen of Israel is characterized by an ongoing cycle of crisis, followed by periods of “almost -war” and “almost peace” (Givoni, 2021). On an affective level, this routinization of emergency brings about a heightened sense of preparedness, alertness and anxiety. This ‘crisis orderiness’ (Berlant, 2011) brings about a sense of “stuckness”, and the notion that (anti-apartheid) activism can at best delay some atrocities, with little hope of radical change. Yet, since the election of Israel’s most right-wing, Jewish -supremacist and messianic government, a huge wave of rage and resistance has swept a large portion of the Israeli public, bringing with it sustained mass demonstrations and mainstream approval for tactics of confrontational civil disobedience.

When these confrontational tactics, previously reserved for a radical milieu, became mainstream, I found myself struggling with shame and guilt over my broken body, that is too fragile to stand up against fascism. The urgent call for “everybody” to take to the streets can become excluding and even ableist when chronic pain and fatigue greatly limit the ability to part take in demonstrations and direct actions. The need for rest, recuperation and support, not as a “nice to have”, but as a basic need, necessitates the development of other, less confrontational and less intensive forms of activism. The concept of “minor politics” refers to tactics that do not seek to gain major power, but rather to minimize the level of oppressive power that is operated on and operates through the activist (Zehavi, 2010). The development of such minor activism requires the slow pace, close attention to nuance and micro changes, and the prominence of interdependent webs of relations, that are often part of living with energy limiting conditions. This presentation will explore how starting from the position of disability can help us develop such minor tactics, which, alongside more major politics, have the potential to allow movement and change within a perpetual state of crisis.

Works cited:

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Deleuze, G. & Guattari, F. (1987). *A Thousand Plateaus: Capitalism and Schizophrenia*. University of Minnesota Press.

Givoni, M. (2021). Hope on the move: Israeli humanitarians between resilience and utopianism, *History and Anthropology*, DOI: 10.1080/02757206.2021.1954633

Zehavi, O. (2010). Minority. *Mafte'akh: Lexical Review of Political Thought*, 1: 91-103.

Author bio: Anat Greenstein (she/her) is a disability studies scholar, and a feminist, anti-militarist activist in Israel/Palestine. She is the author of *Radical Inclusive Education: Disability, teaching and struggles for liberation*, which examines what education would look like if built from the perspective of dis-ability. Her work often explores what a dis-ability perspective can reveal about implicit, underlying norms and social structures.

2.2 Approaching Rest, Work, and Activism as Sites of Struggle - Bob Williams-Findlay

Abstract: Shortly after this BSA Event has taken place, Pluto Press publishes *Disability Praxis*. A core argument within the book, and offered presentation, is that over the last twenty five years the lens of disability politics have become increasingly obscured. British activism from the early 1990s began to cut corners and instead of reflecting upon what theories and frameworks would be the most insightful for exploring the distorted social relationships differing groups of disabled people with capitalist societies and contradictions these throw up, the focus switched away from the original 'transformative' emancipatory approaches towards adopting a less radical 'rights based' approach which sought accommodation within the status quo. This has stunted our analytical ability to address disablement, disablism, and emancipation.

In my presentation, I would argue disability politics ought to be about changing the relations various groups of people have with given societies. I would be suggesting that the four cornerstones:

- the fundamental principles of disability;
- the self-organisation of disabled people;
- the advocating deinstitutionalisation and the promotion of self-directed living;
- and the development of a counter-hegemonic culture and political collective identity

are interconnected and formed the basis of disability politics in Britain and were influential worldwide. The interconnectedness stems from the understanding that capitalist societies created disablement which resulted in social marginalisation and exclusion. Thus disabled people's lifestyles become sites of struggle. To fully understand and address disabled people's social oppression, I want to suggest it is necessary to consider the argument Paul Abberley makes which is that there are significant dimensions which place disabled people in an inferior position to other members of society. He speaks of how the disadvantages experienced by disabled people dialectically relates to what I refer to as the individual tragedy approach towards disability which justifies and perpetuates their situation. The historical materialist approach, which he and I favour, must therefore go beyond just viewing disability as being simply caused by the economic

interests within capitalist societies, and incorporate other dimensions which have led to disabled people's social exclusion.

This has implications for how to approach rest, work, and, indeed, activism. The dialectics of disability are contradictions, antagonisms and conflicts arising from existing social relations between disabled and nondisabled people. A central feature of these dialectics sees disabled people wanting to create a path towards inclusion or integration into a society/system that by its very nature has both rejected and included them.

The absence of a social model of impairment has had a profound impact upon disability politics. Its absence provides areas of ambiguity regarding relations between impairment realities and encountered social environments. Having bodies and minds that are judged to be non-conforming, the nature of impairment 'production', and the material realities associated, need to be factored into understanding disabled people's oppression.

By introducing these often absent concepts I would contribute to reflecting upon existing and/or future theories and frameworks.

Author bio: Bob Williams-Findlay has been a leading disability activist for over thirty years appearing on TV and delivering keynote speeches at numerous conferences. He has written numerous articles and book chapters on Disability Politics and Social Oppression. His publications include: 'The Disabled People's Movement in the Age of Austerity: Rights, Resistance and Reclamation', in *Resist the Punitive State, Grassroots Struggles Across Welfare, Housing, Education and Prisons*, Emily Luise Hart, Joe Greener and Rich Moth, eds (London: Pluto Press, 2019), *More Than a Left Foot* (London: Resistance Books, 2020), *Disability Praxis: The Body as a Site of Struggle* (London: Pluto Press, 2023).

2.3 The Concept of Rest and Work through the Disabled Bodyminds in Select Indian Science Fictions: Technological Advancements and their Effects - Samriddhi Singh

Abstract: Rest and work remain explored in the mainstream disability texts, but have an underrepresentation in the genre of science fiction. In imaginative alternate worlds of science fiction, the lives of disabled bodyminds are formed and shaped at the hands of technology. There are bodyminds which get help via technology to do their work and there are bodyminds which result in disablement in the course of working with technology. The concepts of work and rest functioning on disabled bodyminds in the worlds of science fiction open for us a plethora of theories and ideas to be analyzed.

In the short story "Upgrade" by Manjula Padmanabhan, Mrs. Ganpathy, an eighty-seven-year-old lady who in the beginning led a lonely life, later experiences a complete makeover of her lifestyle and daily engagements when introduced to a humanoid robot as a house-help by her granddaughter. Bodyminds

transformed into fully functioning or high functioning entities through technological interventions experience a different level of quality jump in their existence. They become productive, contributing bodies of the society, almost immediately. Such embodiments and the various complexities which come with this shift find detailed involvements in science fiction texts. The short stories, “Little Begum” by Indra Das and “Interface” by Manjula Padmanabhan have their premises set on such ideas.

The paper tries to take a fresh perspective on the idea of rest and work in the works of Indian Science Fiction. Bodies, be they vulnerable or all-powerful that form part of the alternate worlds, experience the dynamics of everyday life which put before us different dimensions of living, existing, resting or working. Science fiction texts, where action seems inexhaustible, just like our present-day workaholic world, find direct references and parallels to the latter. The paper will analyze how rest and work, when theorized via the genre of science fiction, deal with disability and the everyday world.

Author bio: I am Samriddhi (she) and I have done my post graduation in English from Banaras Hindu University, India. Currently, I am working on my doctoral proposal. My research interests include Critical Disability Studies, Posthumanism, Science and Speculative Fiction.

2.4 “Pull Yourself Together” – The Need for a Collective Awareness of Rest and Crip Time in Political Activism Using the Example of a Community Radio Station in Germany – Barbara Neukirchinger

Abstract: Urban community activism has often dealt with the struggle for or the preservation of open spaces. The aim was to have a material as well as an immaterial space that was not determined by commercialisation or criteria of usefulness and exploitability and that was open to the community.

Politically motivated community radio in urban spaces followed a similar motivation. On the hand it aimed to provide a counter-public to mass media information, on the other hand – in the sense of taking back control of the means of production – it was also about involving all radio broadcasters in decision-making and in all areas of organising and running the radio station.

In the context of disability activism this had several implications. Activist community radio had the opportunity to open up spaces for forms of radio broadcasting that would have not been possible on formalised radio broadcasting. It allowed for experimentation, “deviant” or less streamlined forms of radio design and the inclusion of contributors who would otherwise have been excluded from making radio. At the same time community radio was not detached from the society in which it was active and could also reproduce exclusionary mechanisms and structures despite the often noble political demands. Community radio had also been affected by internalised ableism and the encounter with external barriers that fully or partially excluded disabled or chronically ill people from participation in radio broadcasting. The accommodation of rest or of the needs of impairment or chronic illness could also pose a challenge in this context.

From the perspective of a former activist and current academic researcher, who was active in German community radio in Hamburg, this presentation wants to critically discuss the potential of community radio for disability activism, but also take a look at its downsides and shortcomings. Important theoretical points of reference for the presentation will be the critique of capitalist exploitability logic, subjectivation, disability studies and radio theory.

Author bio: Preferred pronouns she/they. Barbara Neukirchinger is originally from South Germany. She was a member of a community radio station in Hamburg for 10 years where she was involved as a media activist and editor for several information and educational radio programmes. Barbara moved from Hamburg to the UK in 2013 and carried out a PhD in Sociology at Bangor University. She has just been awarded a PhD this year and her thesis is on the intersection of disability and gender from a social theory perspective.

Panel Three

3.1 Sometimes You Just Want to Lie in Bed and Eat Crisps... How We Struggle to Relax and Rest as Disabled & Neurodivergent Activists – Heather Davidson

Abstract: The UK Disabled People’s Movement’s commitment to self-organisation, under the principle of ‘nothing about us without us’ has been crucial for resisting co-optation and maintaining political principles, but it also leads to some dilemmas for disabled activists. As disabled people, activists in the DPM cannot separate our activism from our personal identity and our day-to-day material survival – in contrast to activists in other movements, such as environmentalist or anti-war activists, who are more able to set aside their activism from their everyday life, and ‘take a holiday’ from it if they want or feel the need to. However, for disabled activists whose activism focuses on disabling barriers we face every day, this is often not possible – even if we go on a literal holiday, activism is often necessary to deal with barriers such as inaccessible transport and accommodation. Activists are often advised to regularly rest and step away from activist work to avoid burnout, but this is impossible if there is no boundary between ‘activism’ and simply struggling to access basic needs for everyday life.

Our movement is often sustained by acts of mutual aid between disabled activists as friends and comrades that necessarily blur the distinction between ‘activist work’ and personal life. Activism can thus feel like it is inescapably one’s whole identity. For some disabled people, impairment effects [Thomas 1999] may also contribute to this – for example, autistic and otherwise neurodivergent people are often driven to become activists by a strong internal sense of fairness or justice, and may find it harder to resist a sense of moral obligation to commit to activism beyond sustainable capacity.

In a society that glorifies productivity, and in an activist movement that has arguably lost more than it has won in recent decades, it is easy for disabled activists to be drawn into a ‘hustle culture’ in which it is easy to feel that however much we do, it is never ‘enough’ – despite the ironic fact that the activism of the DPM originates in an analysis of people with impairments being oppressed precisely by this capitalist construction of ‘productive work’ as an obligation and a marker of ‘valid’ membership in society [Abberley 2002; UPIAS 1976]. This ‘activist treadmill’ that we end up reproducing, can affect our relationships with friends and comrades. Some might believe that we’re prioritising activism over spending time with them, while others may think that we’re not dedicated enough to activism. And yet, when we rest, we feel guilty about it.

Drawing on my experience as a chair of a Disabled People’s Organisation, I will explore some of these contradictions and argue that unlike some other fields of activism, disabled people’s activism is intrinsic to our being, health and safety. I will pose ways that we can work together across all levels of society to both give space for disabled people to rest while still being recognised for the contributions. My aim is to open a dialog for those who have the research and methods of effective rest to share those with those who are often struggling under the workload of activism.

Author bio: I have always been an activist, even before I knew what that word meant; as a young person I was always asking questions and challenging inequalities where I saw them. It was when I moved to Manchester I found a place to do this alongside others, campaigning with and now co-chairing the Greater Manchester Coalition of Disabled People. I am also community researcher, working with the People's History Museum and other local organisations on exhibitions and events related to topics I identify with and feel passionate about. My pronouns are she/her.

3.2 The Experience of Black Activists with Disabilities in Fighting Violence and the Importance of Rest As an Activism Strategy - Cátia Brito dos Santos and Luciana Viegas Caetano

Abstract: In disability studies, people refer to ableism as the oppression that people with disabilities suffer. However, Black disabled people are also crossed by racism, which, because it is structural, is involved in all sectors, including the political construction of activism.

The purpose of this text is to discuss how ableism together with racism and the fact of being a Black person with a disability can constitute as axes of intersectional oppressions in the construction of activism and rest for Black people with disabilities.

It is clear that the leaders of intersectional movements that debate race and disability in international debates are largely Black women with disabilities, however there is a reflection that needs to be taken into account: How have these leaders created strategies to face violence that take into account their well-being and mental health?

Activism has become increasingly complex and with a dynamic that requires hypervigilance and almost daily confrontation of violations of the black population with disabilities that suffer from double discrimination and/or intersectional discrimination. In addition to the violence, rest is necessary and urgent, however, the complexities of realities that these leaders face make rest a lesser priority.

However, we think it is possible to create a community of local and international activists and academics who understand the importance of creating networks of support and collective exercise of leadership. Networks that not only help activists facing violence and double discrimination in all spaces but that take into consideration the importance of the well-being and mental health of each Black leader with a disability.

Author bio:

Luciana: Autistic activist and ADHD Educator; Creator of the Black Lives with Disabilities Matter Movement; Elected D-30 Disability Impact List

* * *

A vivência de ativistas negros com deficiência no enfrentamento da violência e a importância do descanso como estratégia de luta - Catia Brito dos Santos and Luciana Viegas Caetano – Vidas Negras com Deficiência Importam (VNDI)

Nos estudos da deficiência as pessoas referenciam ao capacitismo como a opressão que pessoas com deficiência sofrem, entretanto, quando a pessoa negra e com deficiência ela é atravessada pelo racismo, que por ser estrutural está envolvido em todos os setores inclusive na construção política do ativismo.

O objetivo deste texto é discutir como o capacitismo juntamente com o racismo e o fato de ser uma pessoa negra com deficiência podem se constituir como eixos de opressões interseccionais na construção do ativismo e descanso para pessoas negras com deficiência.

É notório que as lideranças dos movimentos interseccionais que debatem e raça e deficiência nos debates internacionais são de mulheres negras com deficiência, entretanto há uma reflexão que precisa ser levada em consideração: Como essas lideranças têm criado estratégias de enfrentamento à violência que levem em consideração o bem estar e a saúde mental das lideranças?

O ativismo tem cada vez mais se tornado complexo e com uma dinâmica que requer hipervigilância e enfrentamento quase que diário das violações que sofrem da dupla discriminação e/ou discriminação interseccional da população negra com deficiência. Além das violências, o descanso se faz necessário e urgente, entretanto há complexidade de realidades que essas lideranças surgem faz com que o descanso não seja uma prioridade.

Toda via pensamos ser possível criar uma comunidade de ativistas, acadêmicos locais e internacionais que entendem a importância de se criar redes de suporte apoio e de exercício coletivo das lideranças que não só ajudam no enfrentamento da violência e da dupla discriminação em todos espaços mas que levem em consideração a importância do bem estar e saúde mental de cada liderança negra com deficiência.

Biografia do autor: Luciana: Ativista autista e TDAH Educadora || Idealizadora do Movimento Vidas Negras com Deficiência importam Eleita D-30 Disability Impact List.

3.3 Sleep - Richard Downes

[Sleep](#) is based on a collection of monokus I wrote on the theme of Sleep.

Monokus based on titles from Max Richter's Sleep album; still images, words and breaths by myself; music and atmospherics by Ivan Riches; film editing by Ivan Riches and Richard Downes.

Author bio: Richard is founder member of Disabled People's Direct Action Network, experience of coordinating pan advocacy services at Brent Advocacy Concerns, engagement work at Merton Centre for Independent Living, currently practicing as an emerging socially engaged artist and spoken word artist with Disability Arts Online where he was in the first cohort of Associate Artists and Artist/Ambassador with Outside In. Life time experience of disability which is where is interest in social engagement as an artist mainly resides. (he/him)

3.4 Rest and Prefiguration through Disabled People's Co-operatives - Steve Graby

Abstract: Workers' co-operatives are businesses owned and collectively controlled by their workers, typically according to egalitarian and anti-hierarchical principles. While the broader politics of individual workers' co-operatives varies, they have been constructed both as prefigurative means for working towards a post-capitalist future society and as pragmatic means of survival for precaritised workers within capitalism.

My recent research about disabled people's involvement in co-operatives in the UK (see <http://www.disabledcoops.uk>), involving semi-structured interviews with disabled people who were or had formerly been members of co-operatives (including but not limited to workers' co-ops), found many points of similarity and potential for connection between co-ops and the Disabled People's Movement, in particular shared values of collective self-determination, subsidiarity (control by those with most stake in an issue, or 'nothing about us without us') and seeking to change environments to fit people rather than vice versa.

Interviewees who were members of workers' co-ops frequently reported that co-operative workplaces were significantly more accessible for them than other workplaces in the same fields, often to the extent that it made the difference between paid employment being possible or impossible. Several interviewees had co-founded – as, previous to this research, I did myself – workers' co-ops precisely as a means to create accessible working environments for themselves and/or because of their experiences of exclusion from other workplaces due to disabling norms and practices.

In particular, workers' control over work patterns and conditions was frequently what made the difference between work being accessible and inaccessible for disabled workers, with co-op members citing examples such as flexible working hours, freedom to work from home, recognition of the need for rest, and unconventional divisions of labour according to individual workers' capacities, as well as the intentional creation by co-ops of forgiving and comradely workplace cultures which avoid many of the unnecessary, punitive and wasteful practices which are typical of hierarchical work environments, and which disproportionately oppress disabled workers.

Co-operatives are not a panacea, nor can they in themselves end capitalism; but I argue that disabled co-op members' experiences show that they can prefigure, and help us make concrete moves towards, ways of living that deconstruct 'work' as commonly understood, distinguishing the genuinely necessary from that which is only considered to be so because of capitalist disciplinary ideologies. Additionally I argue for active alliance between co-operatives and disabled people's organisations to find concrete ways to resist capitalist disablement.

Author bio: please visit Steve's 'About me' page on their [Disabled Coops' website](#).

Panel Four

4.1 Disability as Refusal of Work in the COVID-19 Pandemic – Raia Small

Abstract: ‘Refusal is the shorthand for what can’t be named within the conceptual field of the enclosure. It expresses our unwillingness to be conscripted to man’s project or world. It is easier to index than to describe. All of the gestures bent on eluding the imposed terms of order and value— the me and the mine, the propertied earth. The vision of us in the clearing best conveys it’ — Saidiya Hartman.

The COVID-19 pandemic revealed multiple threats to capitalists’ demand for continuous growth: grief, disability, care, and organized refusal of work as we know it. As a result, capitalists and their handmaidens in government and media have launched an attack against these features of contemporary life. At the moment, the COVID-19 pandemic has been declared over by the CDC and the WHO because these institutions have identified their primary concern as getting the workforce “back” to work. What are we going back from?

In 2020 and 2021, record numbers of people in the U.S. lived on unemployment, many earning more than they had in low-wage jobs. People all over the country stopped commuting, traveling, going to events, and consuming goods outside the home. Meanwhile, “essential” workers continued to labor and commute to their workplaces in hazardous conditions.

In May 2020, millions of people protested the Minneapolis police’s murder of George Floyd. State-facilitated rest (for many) enabled this outpouring of public grief, rage, and love in the form of the riot. There was a relationship between the logic of care in the early pandemic (wear a mask to protect others, flatten the curve, mourn the dead) and widespread refusal to accept the business-as-usual of police killing Black people in the ordinary places of public life. Give people money to live on, an eviction moratorium, and a rupture in the ordinary pattern of accumulation, and watch a police station go up in flames.

While the mainstream disability rights movement that brought us the ADA lauded inclusion in the workplace, the school, and the body politic, disability also holds radical potential as a site of refusal of work. I’m interested in exploring the relationship between disability, grief, and rest in a pandemic that’s disrupted our relationship to work, death, care, and being in public together. I’m interested in asking how disabled ways of being, caring, organizing, and surviving can challenge capitalist norms of work and health. During this forced return to the office, when the corporate media decries that “no one wants to work anymore,” how does disability, debilitation, and a renewed embrace of rest challenge capitalist production in the genealogy of the slowdown, the sickout, and the wildcat strike? How can the affect of refusing work, refusing productivity, and failing to be a healthy worker be mined as a site of disabled resistance?

Author bio: Raia Small is a writer and community organizer living in Oakland, California. She has organized with disabled people and seniors for mask mandates on transit and in healthcare since early 2022. Her work has recently been published in *Midnight Sun*, *Peste*, *Copwatch.Media*, *Kaleidoscoped*, and *Make/shift*. Her writing engages affective labor, illness and disability, Marxism, feminism, aesthetics, and feelings.

4.2 Hidden Labour and Tourette Syndrome: The Restless Cycle of Misinformation, Stigma, and Pressured Awareness-Raising - Daniel P. Jones

Abstract: The topic of hidden labor has been explored extensively across disciplines (cf. Scully, 2010), and it is generally agreed upon that disabled people are subject to additional and hidden labour. However, this is something that has not been explored specifically in the case of activism and facilitation work happening within the context of the Tourette Syndrome community. Tourette Syndrome is a neurological disorder characterized by the presence of multiple vocal and motor tics. Tourette Syndrome is an incredibly stigmatized disability (Malli et al., 2016; Bervoets et al., 2022) and has received a significant amount of public attention over the last few years. Currently there are debates happening amongst community members and Tourette Syndrome researchers over the reinforcing of misinformation and stigma happening within academic and medical spaces (cf. Conelea et al, 2022). I argue that this misinformation is further perpetuated by popular media outputs (Jones, 2022), which feeds further into the continued stigmatization of the Tourettic population.

Drawing upon in-depth interview data from current doctoral research project 'Geographies of Impulse' this paper explores the ways in which members of the Tourette Syndrome community are pressured into facilitation and activism work particularly in online spaces, and the cycles of additional hidden labor being carried out by these individuals. By taking an empirical approach, and drawing heavily from first-person accounts of community and awareness-raising from adults with a diagnosis of Tourette Syndrome, this paper will highlight the sources of cycles of misinformation as rest-less cycles, and seeks to illustrate the ways in which these cycles work to further increase stigma about Tourette Syndrome and therefore also pressure to engage in activist and awareness-raising activities.

Tourette Syndrome cycle of inadequate support (Jones, forthcoming)

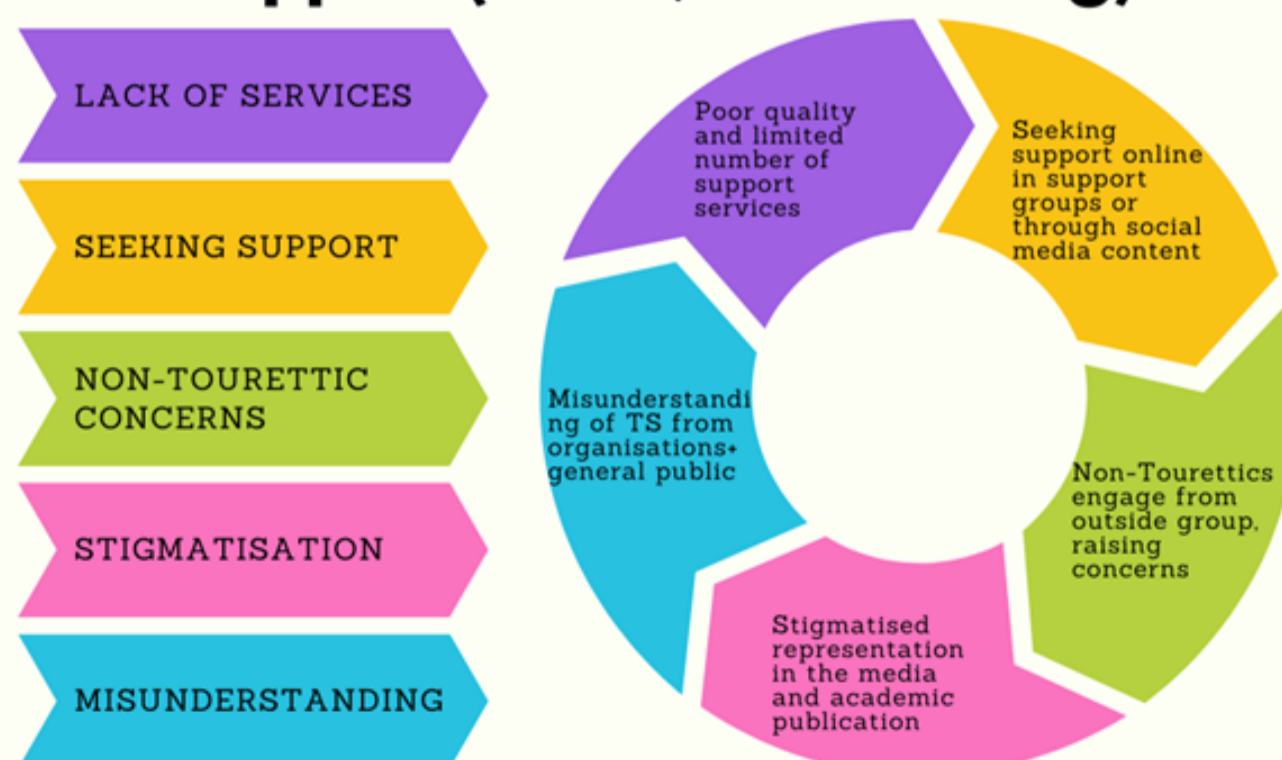


Image description: Tourette Syndrome cycle of inadequate support (Jones, forthcoming):

- Lack of services
- Seeking support
- Non-Tourettic concerns
- Stigmatisation
- Misunderstanding

These factors influence the elements of a cycle:

- poor quality and limited number of support services
- seeking support online in support groups or through social media content
- non-Tourettics engage from outside group, raising concerns
- stigmatised representation in the media and academic publication
- * misunderstanding of TS from organisations + general public.

Considering the pressures of involvement in activism and awareness-raising both internal and external to the Tourette Syndrome community, the paper carefully considers the implications of this cycle on Tourettic people when it comes to rest, recovery and personal well-being.

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Scully, J. (2010) 'Hidden labor: disabled/nondisabled encounters, agency, and autonomy'. *International Journal of Feminist Approaches to Bioethics*, 3(2), pp. 25-42.

Author bio: Daniel P. Jones (he/him) is a PhD candidate based at Newcastle University, researching the embodied experiences of Tourette Syndrome in and around public spaces. He does so through multi-modal and creative methodological approaches, notably zines, and through taking an interdisciplinary approach to research. Aside from this, Daniel is also a freelance creative practitioner, working across fine art and theatre.

4.3 'Let Nothing Perish': Can a Conservative Heritage Site Present Radical Opportunities for Engaging Neurodivergent Audiences? – Fiona Crouch

Abstract: Snowhill Manor is a National Trust property in the Cotswolds. The author's doctoral research is based at the site and considers the concepts of neurodiversity, identity, connection, and enchantment. She has extensive professional and volunteer experience, in the arts and education sectors, working with individuals who are neurodiverse. The organisations she works with invest significant resources in improving the experiences of neurodivergent audiences, but what if sites exist that have innate appeal to visitors who perceive the world differently? The author has identified Snowhill as being somewhere that may appeal to neurodivergent individuals. Based on her research, this paper will explore features that the author believes are particularly engaging for neurodiverse visitors and assess whether they are unique to Snowhill or can be reproduced at other cultural sites.



Charles Paget Wade

unconventional or neurodifferent?

Artist, architect, poet, crafter, businessman, performer, and reluctant soldier

- He was seen as eccentric at a time when neurodiversity didn't exist as a concept
- He was hyperfocused on some tasks
- He kept irregular hours
- He liked plain food and had a limited diet
- He was very tidy
- He was creative and curious
- He saw the world differently, preferring to live in the past
- He didn't form friendships with other children at school
- He daydreamed at school - doodling in his workbooks
- Did he find learning academic subjects difficult? He preferred art lessons
- Struggled with authority figures
- Collected specific objects



Snowhill Manor and Garden
Wade's great achievement

Image description: Charles Paget Wade – unconventional or neurodifferent?

Artist, architect, poet, crafter businessman, performer, and reluctant soldier.

- he was seen as eccentric at a time when neurodiversity didn't exist as a concept
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- struggled with authority figures
- collected specific objects.

In the corner a photo of Snowhill Manor and Garden Wade is featured.

The author believes that it is probable that Wade was neurodiverse. She developed a document that can be shared with her research activity participants. In conversations with the site team, the author has discussed the value of Wade's potential neurodiversity as a narrative strand that could be inspirational to neurodivergent visitors. Might they be drawn to the site due to a sense of affinity with Wade, particularly if they share his interests and/or dislikes?

Collection: Individuals with autism often have an interest in collecting and might also develop an attachment to specific objects (National Autistic Society, 2023). Wade's dedication to his collection – the processes of selection, design/restoration, and display – entrances many visitors. Among a collection of over 22,000 objects and costumes, there will be something that appeals to every visitor. Indeed, throughout the house, Wade curated and organised his objects into groups, unlike in a museum, but in a way to provoke curiosity and fire up a visitor's imagination. This is further enhanced by a lack of labelling across the site which empowers all visitors to access in a similar way and make their own meaning.

Atmosphere: The lighting of a site significantly impacts its atmosphere. The effect of light is potentially relevant to Snowhill as individuals with autism and ADHD are often sensitive to bright light. During Wade's ownership of Snowhill there was no electricity in the manor house; it was lit by candles. While this is not possible today, the site's modern day artificial lighting is designed to replicate this gentle effect.

Rural Setting: Snowhill's garden rooms and rural setting are key to Wade's vision for the site. Wade advocated 'A Garden is an extension of the House, a series of outdoor Rooms' (Wade, no date p.7). He also commented 'Far estranged from mad-denning riot and the busy haunts of man. A garden is a lovesome thing.' (Wade, no date; p?). He believed that gardens celebrate the property's connection with nature. This preference for the natural world is shared by many neurodifferent people. In his account of living with autism, Higashida (2014) notes that 'Nature calms me down when I'm furious, and laughs with me when I'm happy' (p.124).

The author will coalesce these strands to explain the specialness of Snowhill and how it is a place of rest and leisure for neurodivergent individuals, as well as their friends/families.

Author bio: Fiona is a PhD candidate at Northumbria University. After serving as an Army officer, she now enjoys a portfolio career in the Performing Arts and education sectors. In 2019 she completed her MA in Creative and Cultural Industries Management, also at Northumbria University. Her research considers the concepts of neurodiversity, identity, connection, and sensory interaction. She is passionate about empowering inclusion and democratising participation in creative/cultural activities. Fiona is a volunteer trustee at Cheltenham Festival of Performing Arts. She regularly contributes to the Culture Project, a web magazine, and her first play was recently performed at Cheltenham's Everyman Theatre. (She/Her)

4.4 A Dismodernist Reading of Paul Lafargue's 'The Right to Be Lazy': For Monstrous Anti-Capitalist Modes of Resistance and Solidarity - Arianna Introna

Abstract: As Compagna and Steinhart suggest, 'Monsters simultaneously cross borders and demarcate them' according to exclusionary paradigms entangled with conceptions of good and evil, normal and abnormal entertained vis-à-vis a specific community (2020, p.ix). My paper will develop a dismodernist reading of Paul Lafargue's refutation of the Right to Work, contained in 'The Right to Be Lazy' and other essays, to explore how disability politics can be generative of 'monstrous' modes of anti-capitalist resistance and solidarity. In order to do so, it will put into conversation Lafargue's theorization of the ways in which capitalist morality 'anathematizes the flesh of the worker', in an attempt to sentence him to fulfil 'the role of a machine, turning out work without respite or thanks', with the concept of 'dismodernism' developed by disability theorist Lennard Davis. The latter, I will argue, supports Lafargue's refutation of the Right to Work in a two-fold manner: first, by highlighting the multitudinous ways in which non-normative bodyminds materially frustrate capital's ability to control workers' bodyminds; secondly, by providing a standpoint from which to challenge the anathematization of the 'flesh of the worker' and the normative framework it produces. This framework positions subjects which entertain a non-relation to the sphere of production as 'monstrous others' of the capital – labour relation and, most importantly, of the working class itself. A dismodernist engagement with Lafargue's 'right to be lazy' expands to the whole of the working class the condition of material and symbolic marginalization vis-à-vis capitalist relations of production that disabled people embody. It does so, I will contend, by demonstrating how life at 'the edges of capitalism' materialises collective survival through 'relations of mutual aid instead of market competition' (O'Hearn and Grubačić 2016, p.147). My paper will conclude by proposing that disability politics can be entangled with, and contribute to, a 'monstrous' anti-capitalist politics of resistance and solidarity grounded in the fight for the 'right to be lazy' through a double process: by originating from outside the working class, and by working to 'dismodernize' the working class itself through the symbolic universalization of disability.

Author bio: Arianna Introna (she/they/none) got her Mlit and PhD in Scottish Literature from the University of Stirling and is now Associate Lecturer with the Open University (Scotland). Arianna researches and writes

about Scottish literature, Marxist theory and disability studies. Their first book, *Autonomist Narratives of Disability in Scottish Writing: Crip Enchantments*, engages the intersection between representations of disability and class in Scottish literature from the start of the twentieth century to the present.