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# On Disability

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Edited by Dr Lars Cornelissen



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# On Disability

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# EDITORIAL

Dr Lars Cornelissen

ISRF Academic Editor

The global pandemic that began in 2020 and that is still with us today should have placed questions of ability and disability at the very heart of public debate. As was clear from the start of the pandemic, and was repeated tirelessly by disability campaigners, care and support institutions, and advocacy groups, many people with disabilities were at increased risk of harm not only from the coronavirus itself but also from its impact on social life. Disabled people, as Frances Ryan put it in retrospect, 'simultaneously found themselves at greater risk of coronavirus while least likely to be able to access food and medicine as many were forced to shield at home for months'.<sup>1</sup>

Likewise, as our scientific understanding of the novel coronavirus has improved, it has become clear that one of its distinguishing features is that it can cause new disabilities or interact with pre-existing ones. Indeed, what is colloquially known as 'long Covid' is formally understood as a disability by such organisations as Disability Rights UK, which in 2021 estimated that roughly 1.1 million people were affected by the condition.<sup>2</sup>

In spite of the evident centrality of these issues, no broad public conversation about disability took place. Instead, the demand for society to 'go back to normal' was placed at the heart of official policy. The space that, in the early phase of the pandemic, seemed to have opened up to begin to think differently about such things as care, community, climate, and indeed disability swiftly closed down.

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1. Frances Ryan, *Crippled: Austerity and the Demonization of Disabled People*, 2nd edition with a special afterword on Covid-19 (London 2020 [2019]: London), 204.

2. Disability Rights UK, 'Covid causing huge rise in Disability', 7 April 2021, <https://www.disabilityrightsuk.org/news/2021/april/covid-causing-huge-rise-disability>.

This ongoing absence of public reflection on disability is not for lack of social-scientific knowledge or sophisticated theoretical models. On the contrary, the field of Disability Studies is structured precisely around these questions. Having, over the past few decades, developed into a comprehensive body of theoretical, sociological, historical, and critical scholarship, today Disability Studies is flourishing.<sup>3</sup>

That Disability Studies is flourishing has also been noticeable within the ISRF. Even over the past few years, we have noticed a marked increase in the amount of project proposals we receive that work within or speak to Disability Studies. And, as a result, the Foundation has been able to fund a number of brilliant projects that, each in its own way, has contributed to that field. The aim behind this issue of the ISRF Bulletin is to bring some of these projects together and celebrate the contributions they have made.

In the opening article, Alison Wilde directly addresses the way the Covid-19 pandemic had a differential impact on disabled people. Focussing on official government communication about lockdowns and other public health measures, she discusses the difficulties created for many autistic people and people with learning disabilities by the confused, unclear and often contradictory messaging adopted by the British government. As Wilde concludes, important lessons are to be learned here about official communication and accessibility.

In her contribution, Elizabeth Evans also explores disability in British politics, looking at the historical record of Members of Parliament who publicly identified as disabled. Only 30 such MPs can be found in the public record and this, Evans argues, presents us with difficult questions about the barriers disabled people face when seeking to run for political office. Not only does this situation leave a representational deficit, since the specific needs and perspectives of disabled people are more likely to be understood by MPs with lived experience of disability, but it is also a matter of equality and justice.

Moving us from the parliamentary domain into the legal one, in her piece Beverley Clough argues that Disability Legal Studies could benefit

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3. For a potted overview of the history of this field, see Tom Shakespeare, *Disability: The Basics* (Abingdon 2018: Routledge), 157–159.



from a more robust conceptualisation of the spatial dimension of both law and disability. By paying attention to spatial categories, she holds out, we can arrive at a more subtle account of the always shifting boundaries between state and institutional responsibility, public and private, disabled and non-disabled identities. This, in turn, might help us move away from problematic conceptions of the law itself as an altogether static and immovable structure rather than as a living, dynamic, ever-changing one.

In their contribution, Steve Graby reports on their ongoing research into disabled people's involvement in co-operatives in Britain. They have found that there exist notable synergies between the values and priorities of disabled people's movements and co-ops, such as a focus on inclusion, egalitarian ideals, and collective ownership and self-management. As Graby takes care to note, however, there are also points of tension or friction, arising for instance from problems of accessibility or the presence of an internal culture that fails to acknowledge uneven availability or capacity amongst members. Taking a measured view, Graby invites us to see co-ops neither as a dead end nor as a panacea but as one valuable if limited element in broader strategy for disabled people's liberation.

Alice Baderin, in her contribution, reflects on the questions of justice that are raised by the specific efforts disabled people undertake to anticipate future risks, insecurities, or discrimination. When a disabled person has to spend time, money, and energy to prepare themselves to navigate inaccessible spaces or avoids certain interactions to ward off prejudice, they experience what Baderin calls anticipatory injustice. This is a form of injustice that arises from having to expend resources, material or mental, to mitigate risks and that becomes morally loaded when those risks are the result of vulnerabilities specific to identity factors like gender, race, class, and, indeed, disability. By naming this form of injustice, Baderin opens it up to political-theoretical reflection.

In the final piece of this Bulletin, Craig Jones similarly engages in theory work, focussing on the role mass wounding plays in warfare in general and structural violence in settler-colonial contexts in particular. Drawing on his research into the destruction of health care infrastructures in the Gaza strip and the resilient 'geographies of hope'

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that unfailingly follow in its wake, Jones observes that large-scale injury and maiming are defining features of war and occupation. In an effort to theorise this relation, he brings a number of distinct theoretical traditions into conversation and concludes that our understanding of situations like that facing Gaza remains incomplete unless we more fully consider the complex relation between war and disability.

As the Covid-19 pandemic continues to wreak havoc on our health care system, and with further, overlapping crises on the horizon, timely and careful research like that done by ISRF Fellows is well placed to make an important difference.

# MEDIA, COMMUNICATIONS, AND PEOPLE WITH LEARNING DISABILITIES AND AUTISM

## *Lessons from the Pandemic*

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Dr Alison Wilde

ISRF Independent Scholar Fellow 2022

Two weeks into the first pandemic lockdown, I became concerned about the confusion facing a friend with learning disabilities who had suddenly found themselves to be far more popular in their local community. People who rarely spoke to them began asking for favours such as shopping and collecting trips. In the face of the common experience of disinterest, scorn, and bullying<sup>1</sup> the opportunity to gain the approval of others can be enticing, a quick route to gaining the acceptance so often withheld. I realised that the pandemic had ushered in ample opportunities for new forms of ‘mate crime’, or exploitative familiarity, already a common problem for people with learning disabilities.<sup>2</sup> Within the same week, I spoke to another person with learning disabilities who was facing almost unbearable anxieties about every aspect of their lives, with no clear way forward, and with no clear information to guide them.

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1. D. Devine, ‘The bullying of people with autism and learning disabilities’, *Learning Disabilities Today*, March 2017, <https://www.learningdisabilitytoday.co.uk/the-bullying-of-people-with-autism-and-learning-disabilities>.

2. G. Doherty, ‘Prejudice, friendship and the abuse of disabled people: an exploration into the concept of exploitative familiarity (“mate crime”)’, *Disability and Society* 35, no. 9 (2020): 1457–1482.

With the onset of COVID-19, many disabled people found themselves in a situation where services struggled to provide even basic support. But people with learning disabilities and autistic people were exceptionally high-risk groups in multiple ways—socially, economically, ideologically, and communicatively. Moreover, there are clear health disparities between people with learning disabilities and autism and the general population.<sup>3</sup> Against a background of austerity-related cuts the lives of people with learning disabilities and autism have become even more precarious,<sup>4</sup> and their high levels of risk are borne out in a Care Quality Commission estimated increase in deaths of over 134%.<sup>5</sup>

In the early days of the pandemic, it had already become clear that most people felt overwhelmed with the massive and often contradictory information on COVID-19.<sup>6</sup> Despite considerable efforts by many organisations who assisted disabled people to find ways of meeting people's needs online, or in other safe areas, it was clear that autistic people and people with learning disabilities were often left behind.<sup>7</sup> The lack of access to technology, a lack of digital skills, unmet impairment-based needs, underfunding for services, the impact of COVID-19 infections on staffing, and the decline of face-to-face interactions often meant that autistic people and people with learning disabilities had major, yet often invisible, barriers to meaningful support and information.<sup>8</sup> This raised multiple concerns among service providers about the ways information is provided, received, and acted upon during the pandemic.<sup>9</sup>

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3. K.-M. Lodge, 'Covid-19 shows that the lives of people with a learning disability are still not treated as equal', *theBMJopinion* 1 September 2020, available at: <https://blogs.bmj.com/bmj/2020/09/01/covid-19-shows-that-the-lives-of-people-with-a-learning-disability-are-still-not-treated-as-equal>

4. K. Bates, D. Goodley, and K. Runswick-Cole, 'Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity', *Disability & Society* 32, no. 2 (2017): 160–175.

5. Lodge, 'Covid-19 shows'.

6. S. Rowe and N. Alexander, 'Pandemic Health Science Communications: Lessons Learned (or Not Learned)', *Nutrition Today* 57, no. 2 (2022): 70–73.

7. A. Rosken, A. Wilde, and L. Angelova, 'Report on Promising Practices in technology use during the pandemic', Report for European Association of Service providers for Persons with Disabilities (2021).

8. Ibid.

9. Ibid.

Simultaneously, there was a cultural tendency throughout 2020 and 2021 to write the deaths of disabled and ill people off as understandable, as they were identified as people with 'underlying conditions'. The use of this term seems to signify that those with underlying conditions are an accepted form of collateral damage for a society committed to neoliberal forms of governance, and reduced, semi-privatised, and underfunded forms of health and social care. Rather than questioning the political conditions which impose restrictions on the resources and budgets sustaining the lives and wellbeing of its citizens, the language of 'underlying conditions' perpetuated and extended the discourse of disabled people as 'bare life', making disabled people an exception to the rule of citizenship rights. As Reeve has suggested in general, such positioning places disabled people as external to the 'meaningful deaths' of non-disabled (and younger) people, abandons them, locating them in a 'zone of indistinction' which 'represents a state of exception' beyond 'political significance'.<sup>10</sup>

Language such as this has meant that disabled people have received the message loud and clear that they do not matter to the general public, the media, or politicians and policymakers. Simultaneously, the support and security provided by health and social care agencies diminished significantly in the early throes of the pandemic, reducing the availability of much-needed help and advice.<sup>11</sup> All of this has generated greater uncertainty, anxiety, panic, and the potential to exacerbate risks to self and others. Although this is likely to be true for many, these difficulties were especially marked for disabled people and others who have unmet communication needs. The failure to meet such requirements is a fundamental contradiction of the first principles of pandemic communications and preparedness, especially the prioritisation of inclusive forms of communication which build trust and 'dispel rumors'.<sup>12</sup> Instead, the vast range of commentaries on health, risk, care, science, and wellbeing have been frustrating,

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10. D. Reeve, 'Biopolitics and bare life: Does the impaired body provide contemporary examples of homo sacer?' in: K. Kristiansen, S. Vehmas and T. Shakespeare (eds.), *Arguing about Disability: Philosophical Perspectives* (London 2009: Routledge): 203–217.

11. Rosken et al., 'Report on Promising Practices'.

12. A. Vaughn, and T. Tinker, 'Effective Health Risk Communication About Pandemic Influenza for Vulnerable Populations', *American Journal of Public Health* 99 (2009): 324–332.

confusing, and overwhelming for us all<sup>13</sup> and have posed multiple and (largely) unknown problems for people with learning disabilities and autism, especially in choosing which information to trust and follow. From all sides, autistic people and people with learning disabilities have faced new significant difficulties in wellbeing and communications.

As groups of people whose support has often been reliant on face-to-face involvement from and with others to maximise work, social, and personal opportunities, research undertaken in the pandemic has shown that the new conditions of the (post-)pandemic world are likely to lead to exacerbations of disadvantage for people with learning disabilities and autistic people.<sup>14</sup> In the face of many pressing difficulties, including the capacity to meet health, care, social, and food needs, it would be tempting to see the provision of more inclusive communications as a less urgent task, but the early conditions of the pandemic swiftly reminded us that access to meaningful communications is crucial. As key members of the 'digital underclass',<sup>15</sup> the sudden move to online service delivery, communications, and many forms of socialisation has increased risks of social isolation and exploitation for autistic people and people with learning disabilities, and often blocked access to services. The danger that new communication needs will remain unmet was always high, especially as there is a marked absence of knowledge and understanding on how autistic people and people with learning disabilities understand and interpret media, and on how they are affected by new forms of communication.

### **Common themes in pandemic communications for autistic people and people with learning disabilities**

Even where health guidance and resources are provided to people, this tends to be instructional rather than explanatory, meaning people

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13. Rowe and Alexander, 'Pandemic Health Science Communications'.

14. S. Flynn, C. Hatton, D.W.F. Abbott, and P. Heslop, 'Health and social care access for adults with learning disabilities across the UK during the COVID-19 pandemic in 2020', *Tizard Learning Disability Review* 26, no. 3 (2021): 174–179; Rosken et al., 'Report on Promising Practices'.

15. M. Sourbati, 'Disabling communications? A capabilities perspective on media access, social inclusion and communication policy', *Media, Culture, and Society* 34, 5 (2012): 571–587.

with learning disabilities and autistic people are being told what to do rather than why they need to act, a strategy which is usually counterproductive in public health campaigns.<sup>16</sup> In our own research,<sup>17</sup> there was almost unanimous frustration, anger, and disapproval of slogans such as this, for example:



Condensing the many complaints and comments made on this particular government slogan to a few main points, common objections included those about the vagueness of its fully instructional character, with no direction as to how staying home and contributing to the common good was possible when access to shops, transport, work, and other crucial places were needed to meet basic survival needs. Whilst some noted that images such as this were written in a way which might be described as 'easy read' (but often without images), many commented that these worked best when they served to remind everyone of what they already knew, e.g., the 'hands, face,

16. E.C. Green and K. Witte, 'Can fear arousal in public health campaigns contribute to the decline of HIV prevalence?', *Journal of Health Communication* 11, no. 3 (2006): 245–259.

17. I am grateful to Robyn Steward, who has worked with me as a Research Assistant.

space' motto (accompanied by images). There was some appreciation of the way in which medical experts presented in the government briefings, but many participants explained that they stopped listening to daily briefings due the confusing messages delivered by key politicians, remarking on the anxiety which these sessions created for them. Similarly, many people limited themselves to key experts on the pandemic; Dr John Campbell (on YouTube) was seen as the most valuable source of information by several autistic people, for example, marked by scientific and medical credibility, honesty, and trust. Seeking consistency in messaging, or practicing avoidance, soon became key strategies for many who had decided to place severe limits on any communications about the pandemic.

Many of the people with learning disabilities had made clear decisions to trust only the members of their household, or the organisations which supported them. Commonly, these were mothers, and occasionally partners or friends. Although it seems that some of these communications were usually instructional rather than explanatory, there was a widespread acknowledgement that the ever-changing circumstances of the pandemic meant that changes in instructions were inevitable and wise. It seemed to be easier, and more reassuring, to pass the stressful activity of pandemic knowledge to significant others. Indeed, there was a high degree of understanding where people had been supported with this. The need to trust key people was crucial. In turn, the support and resources given to those in supporting roles can be seen as a necessity in such crises. Conversations with participants, staff members, and organisations and family members showed that this placed a heavy responsibility on those in supporting roles, often in situations where information and solutions to everyday dilemmas were hard or impossible to find. It was also common that these responsibilities had increased, with some people losing key support from people and organisations who had assisted them pre-pandemic.

As the pandemic went on, it was clear that a range of organisations grasped the opportunity to harness their (albeit limited) resources to benefit themselves and others from easy-read information services. Those who were supported well by local organisations spoke with pride about their involvement in newly formed co-productive



services such as this. Almost all the people who were involved in such organisations seemed secure in using them for advice and information on the pandemic. Again, the need for resources to fulfil these roles is crucial.

Ideally then, people with learning disabilities and autistic people who live with family and are embedded in local organisations have been in better positions to get through the pandemic, but the fragility of such arrangements highlights many outstanding issues. Some of those who lived alone, have experienced increasingly pressured or troubled relationships with family, and those with no organisations to support them were often placed in untenable situations. Although some found creative ways of dealing with pandemic-related communication difficulties, including two people who began to create (popular) resources to support other people, other shared experiences featuring extreme hardship. This included common experiences of fear and anxiety, going without everyday basics, extreme loneliness, suicidal ideation, withdrawal of support for essential health and social care, and pressures on, and even breakdowns in, close relationships. The reduction in social interactions also led to personal communication problems for some. While some autistic people felt some relief being able to escape social situations, many experienced much anxiety in the new restrictions placed on them, including the lack of opportunities to interact with others and the outside world. The withdrawal of social experiences caused some people with learning disabilities to develop reduced abilities to express themselves, with more than one person's desire or ability to speak reduced to minimal utterances.

The lack of interactions was compounded for many people with learning disabilities, as the majority either do not like using computers, the internet and smartphones, or could not use them. Despite the surge in new online meeting applications and efforts made to create inclusive and accessible online spaces, many autistic people and people with learning disabilities continued to face considerable barriers to inclusion.

So far, our discussions with over thirty people with learning disabilities and autistic people have demonstrated that it is a necessity to engage with these (and other) unmet communication needs, though a wider

survey on the extent of these experiences and their effects may provide additional insights. Although many presume that we are 'back to normal', this is not the case for many disabled people. Final discussions with participants revealed considerable fear of going out too often, or to potentially crowded spaces, such as public transport (used by the majority). Most people were ambivalent about the lifting of restrictions, and were angry about feeling unsafe around others, as they had begun to feel secure in the knowledge that people were expected to keep their distance and wear a mask. Some people said they would not go back to places such as cinemas and theatres, which they deemed exceptionally high risk. Many had adopted, or were renegotiating, new ways of arranging their lives, with more limited and structured ways of navigating the world, e.g., making a limited number of visits outside their homes in a week. Although some were grateful that they no longer had the onslaught of pandemic communications, most people believed that there was a strong case for providing up-to-date information on COVID-19 to allay fears of infection and unpredictable (and potentially risky) forms of social interaction.

Overall, it was unanimous that communications with autistic people and people with learning disabilities should be taken seriously by politicians, policy-makers and the media, if we are to improve social communications, support, and wellbeing in the future. All agreed that that this would necessitate an approach which places the views and/or and needs of people with learning disabilities and autistic people at the centre.

# DISABILITY AND POLITICAL REPRESENTATION

Professor Elizabeth Evans

ISRF Mid-Career Fellow 2021

In 1866 Arthur MacMurrough Kavanagh was elected to Parliament to represent the seat of County Wexford. His election is notable insofar as he is the first openly disabled MP for whom we have a record;<sup>1</sup> and yet, few have ever heard his name. Indeed, the political representation of disabled people has attracted little by way of academic analysis or political attention. In July 2021, over 150 years after Kavanagh's election, two disabled councillors were told that they could not participate in a debate regarding accessibility in York city centre because they were disabled—and would therefore be biased.<sup>2</sup> Although the decision to bar the two councillors from participating in the debate was eventually overturned, the incident raises questions about how the link between lived experience and representation is, and should be, understood and valued. More broadly, the incident also calls attention to the barriers disabled people often face when they seek to participate in politics. Questions that my research explores.

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1. Sarah Steele, *The Right Honourable Arthur MacMurrough Kavanagh, a Biography* (2010 [1891]: General Books).

2. See <https://yorkmix.com/u-turn-by-officers-who-tried-to-stop-two-york-councillors-with-disabilities-speaking-in-debate/>



*Figure 1: Arthur MacMurrough Kavanagh (1831–1889)  
(image in public domain).*

Beginning with Kavanagh's election, I compiled a database of all those MPs who publicly identified as disabled. This data was then used for two purposes: first, in order to understand the number of disabled politicians who have served, and are currently serving, at Westminster; and second, to examine the extent to which disabled MPs sought, or seek, to represent the issues and interests of disabled people, through analysis of Parliamentary activity. Only 30 disabled MPs are to be found in the database, which suggests that disabled people have been under-represented, because according to official statistics, around 20% of the

UK population is disabled.<sup>3</sup> That figure is likely to be higher given the various issues that pertain to collecting accurate data, not least the stigma associated with identifying as disabled.<sup>4</sup> Definitions of disability vary. Following UK activists, my research defines disability according to the social model, which interprets disability as a phenomenon produced by society. Disability is here understood as a system in which people with impairments (whether physical, mental, cognitive, developmental or intellectual) experience discrimination and stigma.<sup>5</sup> Importantly, disability is also produced in relation to its intersections with other structural forms of oppression such as gender, race and class.<sup>6</sup>

Since 2019 I have been interviewing disabled politicians, disabled activists and disabled party members in the UK.<sup>7</sup> Interviewees have described the number of barriers which they face, both during their campaigns to become a political candidate and then afterwards once they are elected. These barriers can be broadly grouped into 3 areas: 1) issues of accessibility—both in terms of buildings but also material which is not produced in accessible formats; 2) negative attitudes and stigma—especially related to capability; and 3) lack of resourcing to enable disabled people to participate.<sup>8</sup> That disabled people face barriers to political participation matters in and of itself—as a matter of justice and equality—however, the fact that disabled people are numerically under-represented at Westminster also matters, because analysis of the parliamentary activity of disabled MPs has revealed that

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3. Office for National Statistics, 'Outcomes for disabled people in the UK: 2020', 18 February 2021, available online: [www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020](http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020)

4. Lisa Schur, Douglas Kruse, and Peter Blanck, *People with Disabilities: Sidelined or Mainstreamed?* (Cambridge 2013: Cambridge University Press).

5. Mike Oliver, *Social work with Disabled People* (Basingstoke 1983: Macmillan); Mike Oliver, 'The social model of disability: Thirty years on', *Disability & Society* 28, no. 7 (2013): 1024–1026.

6. Nirmala Erelles, *Disability and Difference in Global Contexts* (New York 2011: Palgrave).

7. This is part of a wider project which I am working on with Stefanie Reher.

8. Elizabeth Evans and Stefanie Reher, 'Disability and Political Representation: Analysing Barriers to Elected Office', *International Political Science Review* (2020), DOI:10.1080/09687599.2022.2045191.

many of those MPs have actively sought to represent disabled people and to pursue disability-related policy. Of course, this is not to say that non-disabled people cannot represent the issues and interests of concern to disabled people, but that disabled people are likely to be the best advocates for disabled people because of their lived experience of disability.

The slogan at the heart of the disability rights movement, 'nothing about us without us',<sup>9</sup> is instructive when thinking about why the good representation of disabled people requires disabled politicians. In creating this slogan, activists sought to reject the paternalistic approach to decision-making that was often undertaken by non-disabled people on behalf of disabled people, without the latter's involvement or consent. This demand for political inclusion therefore centres upon the claim that *lived experience* of disability is necessary when it comes to decision-making that affects disabled people. Lived experience is a source of expertise that is distinct from expertise acquired otherwise. Non-disabled political representatives may have relevant knowledge about the lives of disabled people and the effects of policies on their lives, for example through caring for a disabled person, through working with disability rights organisations, or through doing research on disability. However, if they have never been disabled, they will not have the personal experience of living through the challenges that disabled people face. Knowledge from lived experience can be powerful: it gives individuals insight into issues which they may not necessarily have explicitly studied but have experienced; it means that they are likely to have tested and developed various potential solutions to challenges; and because recounting lived experience can bestow credibility and legitimacy in the eyes of other group members as well as non-members.<sup>10</sup>

Interviews with disabled politicians and activists revealed that having elected representatives with lived experience of disability was considered vital when it came to representing disabled people,

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9. James Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment* (Berkeley, CA 2000: University of California Press).

10. Ian McIntosh and Sharon Wright, 'Exploring what the Notion of "Lived Experience" Offers for Social Policy Analysis', *Journal of Social Policy* 48, no. 3 (2019): 449–467.

developing disability-related policy, and for tackling discrimination and stigma directed at disabled people. Interviewees noted that even though the disability community is diverse, having someone in the room who understood accessibility, ableist stigma and living as disabled in twenty-first century Britain was critical in order to create policies that had a positive impact on disabled people's lives. Given the impact of over a decade of austerity politics which have hit disabled people particularly hard,<sup>11</sup> many interviewees drew attention to the absence of disabled politicians in developing the welfare reforms which were so disastrous for disabled people. Similarly, research I have conducted on the manifestos produced by the two main parties revealed that it is only when the Labour Party began to create policy by collaborating with disabled people—through their disability equality roadshows ahead of the 2017 general election—that there was a significant increase in the number of disability-related policies.<sup>12</sup>

Analysis of the parliamentary activity of those self-declared disabled MPs revealed examples of politicians who pushed for key pieces of legislation. For example, Labour MP Jack Ashley (1966–1992), played a key role in initiating and developing the Chronically Sick and Disabled Person's Act 1970 - a landmark piece of legislation which included the key provision to require local authorities to collect data on the number of disabled people in order to make them and their policy needs 'visible'; in addition, the Act dealt with accessible housing, transport and education. During a speech delivered during the second reading of the bill, Ashley made representations on behalf of the D/deaf community, of which he was a part. Noting his 'particular interest in deafness' and observing that 'deaf people have been ignored' constituting the 'Cinderella of the disabled', during his speech he drew not only on his own personal experience of deafness but also his active involvement with the wider D/deaf community. Similarly, Anne Begg MP (1997–2015), frequently spoke on disability issues, often grounding her questions and speeches within her own lived experiences. For example, speaking in 1999 in favour of the establishment of the

11. Ellen Clifford, *The War on Disabled People: Capitalism, Welfare and the Making of a Human Catastrophe* (London 2020: Bloomsbury Publishing).

12. Elizabeth Evans, 'Disability Policy and UK Political Parties: Absent, present or absent-present citizens?', *Disability & Society* (2022), DOI:10.1080/09687599.2022.2045191.

Disability Rights Commission to tackle discrimination in the workplace, she noted, 'I speak as one of those who have faced discrimination.'

In response to COVID-19, changes were made to the established political process, for instance through the introduction of remote voting, as well as online debates and committee meetings. All these changes made politics appear accessible to many disabled people, and yet despite the potential transformative impact of these changes there was a quick return to business as usual. At the local level this has had a devastating impact on disabled councillors. For example, Green Councillor Blossom Gottlieb is no longer able to fully participate in the work of East Hampshire District Council as English local councils are not legally permitted to conduct their meetings online (the situation is different in Wales and Scotland).<sup>13</sup> While the changes wrought by COVID provided a moment to rethink how we do politics—and especially how we can make politics more accessible for all—this has not resulted in long-term change.

Research into disability and political representation revealed that having politicians with lived experience is important for disabled people, and that it is also important to have more disabled politicians—with a wide range of impairments—as a matter of equality and justice. It is important because disabled politicians are more likely to think about disability when it comes to policy-making—no matter how sympathetic a non-disabled person is, research has found that stigma and discrimination against disabled people remains.<sup>14</sup> Finally, it is important to have more disabled people in positions of power in order to counter negative stereotypes surrounding disability, especially the idea that disabled people are not capable of serving as elected representatives.

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13. See Disability News Service reporting on the issue <https://www.disabilitynewsservice.com/greens-call-for-end-to-discriminatory-ban-on-online-council-meetings/>.

14. Stacy Clifford Simpican, *The Capacity Contract* (Minneapolis, MN 2015: University of Minnesota Press).



# SPATIALISING DISABILITY LEGAL STUDIES

Dr Beverley Clough

ISRF Early Career Fellow 2018

There has been increasing engagement with spatial approaches across the social sciences and humanities. At the core of this is the recognition of how space is organised; how this impacts on subjectivity and experience; how spatial interactions create meaning; and how meaning is assigned, inscribed upon and produced through spatial imaginaries. The focus is not simply on the materiality of spatial organisation, but on the (material-discursive) processes through which the boundaries around particular spaces and spatial relations are drawn and reproduced. A spatial approach to disability is now well represented in the disability studies literature.<sup>1</sup> Similarly, law and legal studies have engaged productively with spatial approaches, particularly through legal geography.<sup>2</sup> Through this piece, I want to bring these

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1. See, for example, E. Hall and R. Wilton, 'Towards a Relational Geography of Disability', *Progress in Human Geography* 41, no. 6 (2016): 727–744; A. Power and R. Bartlett, "I shouldn't be living there because I am a sponger": negotiating everyday geographies by people with learning disabilities', *Disability & Society* 33, no. 4 (2018): 562–578.

2. D. Delaney, *Nomospheric Investigations: The Spatial, the Legal and the Pragmatics of World-making* (Abingdon 2010: Routledge); N. Blomley, D. Delaney, and R. Ford (eds.), *The Legal Geographies Reader: Law, Power, Space* (Toronto, ON 2000: Wiley); I. Braverman, N. Blomley, D. Delaney, and A. Kedar (eds.), *The Expanding Spaces of Law: A Timely Legal Geography* (Stanford, CA 2004: Stanford Law Books); M. Valverde, 'Jurisdiction and Scale: Legal "Tech-

spatial understandings of law and disability into conversation, to explore what productive insights are gained from doing so for thinking through disability justice.

Spatial approaches to disability studies have enabled a critical, complex interrogation of the interaction between individuals and their social world, and the construction of disability within this. They have responded to and built upon critiques of the social model of disability that have been bubbling away in the literature. The social model of disability—the idea that it is societal barriers, rather than impairments, that cause disability—has been heavily influential in disability activism and scholarship. It has, importantly, had an enduring influence in disability politics and law, being central to a range of arguments for recognition, rights and legal change. At the same time, and as with any central theory in a given field, it has not been without criticism.<sup>3</sup>

It has been recognised for some time now by some critical disability scholars that rethinking ontology through theories of vulnerability, new materialisms and post-humanism can disrupt current entrenched ideas of subjectivity as well as moving us beyond a strictly polarised view of materialism and more discursive or constructivist approaches.<sup>4</sup> Scholars such as Erevelles were particularly keen to challenge the humanist norm that the social model may be seen as reinforcing through the focus on barrier removal.<sup>5</sup> The subject of the social model, or the norm to be actualised, was critiqued as reinforcing liberal ideals such as autonomy, self-determination, rationality and independence. Such ideals are seen as problematic in creating and maintaining a disabled 'other', with Campbell frequently drawing attention to the

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nicalities" As Resources For Theory', *Social and Legal Studies* 18, no. 2 (2009): 139–157; M. Valverde, *Chronotopes of Law: Jurisdiction, Scale and Governance* (Abingdon 2015: Routledge).

3. L. Crow, 'Including All Our Lives: Renewing the Social Model of Disability', in: C. Barnes and G. Mercer (eds.), *Exploring the Divide: Illness and Disability* (Leeds 1996: The Disability Press); T. Shakespeare and N. Watson, 'The Social Model of Disability: An Outdated Ideology?' *Research in Social Science and Disability* 2 (2002): 9–28; N. Erevelles, 'Disability and the Dialectics of Difference' *Disability & Society* 11, no. 4 (1996): 519–538.

4. D. Goodley, R. Lawthorn, and K. Runswick Cole, 'Posthuman Disability Studies', *Subjectivity* 7, no. 4 (2014): 342–361.

5. Erevelles, 'Disability and the Dialectics of Difference'.

ableism which is foundational to such liberal approaches and which has the effect of excluding difference from the very outset.<sup>6</sup> In essence, if the social model is simply focused on removing barriers to achieve this (ableist) norm then this norm becomes reinforced without question of its foundation presuppositions. As Shakespeare suggested in his earlier work, “perhaps the maintenance of a non-disabled identity...is a more useful problem with which to be concerned; rather than interrogating the other, let us deconstruct the normality-which-is-to-be-assumed”.<sup>7</sup> The humanist logics thus structuring the social model have gradually become seen by critical disability scholars as an important target for critique. Erevelles has questioned this tendency, asking “[w]hat happens when the very essence of the liberal humanist self is necessarily predicated on the construction of the disabled Other as the embodiment of inalienable difference?”.<sup>8</sup> Spatial approaches have been instrumental in exploring the construction and (re)production of boundaries that entrench difference and the problematic norms that shape these, avoiding a static and linear account of disability and instead focusing on the processes and relations creating it.

Hall and Wilton, writing from a critical geography perspective, have drawn on new materialist theorists such as Barad and Braidotti, and the notion of assemblage, to advance an understanding of “complex and emergent geographies of disability, but also to unsettle broader assumptions about the nature of the ‘able-body’”.<sup>9</sup> Unseating the norm of the autonomous, rational, individual subject and rethinking subjectivity through and with impairment, interdependence, difference and relationality enables us to then see the “sheer diversity of embodied experiences that overwhelm any binary opposition between a normative ‘able-body’ and its disabled other”.<sup>10</sup> Difference is seen as an emergent and contingent state which is implicated in various webs of material and discursive relations. As such, differential embodied

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6. F.K. Campbell, *Contours of Ableism: The Production of Disability and Aabledness* (Basingstoke 2009: Palgrave Macmillan).

7. T. Shakespeare, ‘What is a Disabled Person?’, in: M. Jones and L. Bassar Marks (eds.), *Disability, Divers-Ability and Legal Change* (The Hague 1999: Martinus Nijhoff): 25–34, 28.

8. N. Erevelles, ‘Cognitive Disability, Race and the Politics of Citizenship’, *Disability, Culture and Education* 1, no. 1 (2002): 5–25, 11.

9. Hall and Wilton, ‘Towards a Relational Geography of Disability’, 727.

10. *Ibid.*, 741.

experiences are not erased or ignored—instead the question shifts to *how such experiences and embodied forms come to matter*.

Whilst there has been longstanding recognition of the need to bring disability studies and law into conversation<sup>11</sup> narrow understandings of law have impeded progress. Despite the important developments in critical disability studies, some of which have been outlined above, there has been surprisingly little engagement with law as a part of the assemblages which have otherwise warranted critical analysis. We see reflected in some of the disability studies debates the idea that law is a positivist phenomenon. For example, Oliver and Barnes in their later work advocated essentially for a turn away from law in a paper which argued that legislation and rights were being captured by certain powerful professions and interest groups.<sup>12</sup> Whilst this is undoubtedly true and resonates with a long standing argument against relying upon rights or law to solve issues of social justice, what is missing here is a more critical analysis of how law itself could be changed. Moreover, this betrays a view that law is something which can somehow be escaped in activism, a position which Lobel has critiqued in her argument that the legal and the social are not separate but instead permeate each other.<sup>13</sup> This turn away from law, as Munro suggests, still allows these power relations and norms to persist, albeit unchecked.<sup>14</sup> A static, ordered and positivist approach to law is taken without recognition of the ways in which law itself is a dynamic, ongoing process with shifting boundaries.

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11. A. Lawson, 'Disability Law as an Academic Discipline: Towards Cohesion and Mainstreaming?', *Journal of Law and Society* 47, no. 4 (2020): 558–587; A. Kanter, 'The Law: What's Disability Studies Got to Do with It or An Introduction to Disability Legal Studies', *Columbia Human Rights Law Review*, 42, no. 2 (2011): 403–479; S. Mor, 'Between Charity, Welfare, and Warfare: A Disability Legal Studies Analysis of Privilege and Neglect in Israeli Disability Policy' *Yale Journal of Law and the Humanities* 18, no. 2 (2005): 63–137.

12. M. Oliver and C. Barnes, 'Disability politics and disability movement in Britain: Where did it all go wrong?', *Magazine of Greater Manchester Coalition of Disabled People* (2006): 1–13.

13. O. Lobel, 'The Paradox of Extralegal Activism: Critical Legal Consciousness and Transformative Politics' *Harvard Law Review* 120, no. 4 (2007): 937–988.

14. V. Munro, *Law and Politics at the Perimeter: Re-evaluating Key Debates in Feminist Theory* (Oxford 2007: Hart), 68.

This is not necessarily a criticism of these scholars as it is an approach echoed across many fields, including in some more mainstream legal analysis. As Philippopolous-Mihalopolous suggests, “law presents itself as immaterial, abstract, universal, non-geographical. This is of course one of law’s greatest tricks”.<sup>15</sup> There is real scope for productive engagements between critical disability studies and socio-legal theorists in order to more carefully expose the intra-actions between legal processes and the problematic concepts which critical disability studies has grappled with and to challenge their given-ness. It is suggested here that law and legal processes occupy an important role within the spatial dynamics of disability: they help to define and solidify difference; they help to create, cement or dismantle roles and relations; and they define the boundaries of responsibility and appropriate response.

David Delaney has written about the importance of the spatial imaginary engaging not just with the material but also the social, discursive and performative aspects of space.<sup>16</sup> Indeed, the very distinction between the material and discursive here would be questioned. Delaney suggests the need to consider that “social space is continuously reproduced and transformed through how it is performed”<sup>17</sup> and that this encompasses the performative aspects of material-discursive spaces. It is crucial for socio-legal scholarship to rethink both the legal and the spatial. In terms of the spatial, this rethinking entails a concern with discursive organising and performance, but also “spatialisation of difference and the pragmatic effacement, denial or recalibration of difference”.<sup>18</sup> As well as reconceptualising space,

the legal must also be treated as consisting of and implicating the dynamic, reciprocal intertwinements of social imaginaries, with performative and material aspects of sociality... The legal is continuously performed, re-enacted.

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15. A. Philippopoulos-Mihalopoulos, ‘Critical Autopoiesis and the Materiality of Law’, *International Journal of the Semiotics of Law* 27 (2014): 389–418, 410.

16. Delaney, *Nomospheric Investigations*, 17.

17. *Ibid.*, 15.

18. *Ibid.*, 18.

The legal is continuously and creatively done and redone.  
The legal is always happening.<sup>19</sup>

This provides a useful framework for challenging the static and 'given' boundaries of law. A recent attempt to fundamentally rethink law, and in turn to expose the processes of boundary formation in law, is evident in the work of Margaret Davies. In *Law Unlimited*, Davies seeks to ask the *what, where, how* and *when* of law and the *who* and *why* in order to 'unlimit' it—"to suspend the conceptual, doctrinal and institutional boundaries to imagine different modalities for understanding law".<sup>20</sup> In doing so, she challenges the theoretical, political, doctrinal and geographical boundaries which are drawn, and which are perceived by both mainstream legal scholars and those 'outside' of this, as static and fixed. As she goes on to suggest, this vision sees law not as a static entity, but as a "material-social dialogue in process" whose "boundaries and limits do not work in isolation, but create a web of insides and outsides, together with all of the exclusory and identity-forming characteristics of such spaces".<sup>21</sup> Through this reconceptualisation, then, we see a challenge to positivist ideas of law as a closed system or structure with predefined boundaries, and an effort to understand law instead as an ongoing process through which boundaries are created, reproduced and negotiated. The institutional relations, and particular domains of law including the public and the private, become seen as more porous, and subject to constant maintenance (and potential disruption). Law is seen as much more diffuse, with the '*where?*' of law becoming more complex and as sited at a number of scales and locations including in the shaping of (as opposed to a reaction to) everyday interactions. Moreover, law becomes a more pluralistic force, not limited to law in the books or as practiced by legal professions, or even as various legal forces acting within a particular space, but as various, multiple, interacting forces having legal impacts. This important shift in approaches to law enabled by engaging with the spatial imaginary shifts attention to how meaning is produced in and through law, and how the boundaries of the legal subject, the state, institutions and society are drawn.

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19. Ibid., 19.

20. M. Davies, *Law Unlimited* (Abingdon 2014: Routledge), i.

21. Ibid., 2, 137.

One way in which this interaction is evident is in the structuring of disabled and non-disabled identity, or the creation of the 'Other'. In mental capacity law, for example, this occurs through the designation of individuals as capacitous or incapacitous, with incapacity being inextricably linked to the existence of an impairment or disorder of the mind or brain. As I discuss in my book *The Spaces of Mental Capacity Law*,<sup>22</sup> this legal framework has lent legitimacy (and with it, perceived objectivity and political neutrality) to a system of 'othering' disabled people, positioning them as different to those who are rational and autonomous and embodying the liberal legal subject. Engaging with this interaction between law and the norms that critical disability studies scholarship has critiqued through a spatial lens helps to understand the processes through which these norms come to be entrenched and reproduced. This enables us to be attentive to how such space is performed, as well as to the "social spatialisation of difference and the pragmatic effacement, denial or recalibration of difference".<sup>23</sup> Importantly, this spatialisation of difference has material and discursive effects which include the drawing of boundaries of state and institutional responsibility, of delineating the public/private, and bounding the self/other. Recognising their contingency and reliance upon a range of legal, political, societal and historical processes for affirmation opens up the space to reimagine alternative processes and to map out sites for change.

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22. B. Clough, *The Spaces of Mental Capacity Law* (Abingdon 2021: Routledge).

23. Delaney, *Nomospheric Investigations*, 18.





# CO-OPERATION FOR LIBERATION?

## *Disabled People and Co-ops in the UK*

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Dr Steve Graby

ISRF Independent Scholar Fellow 2021–22

The social model of disability, as originated by disabled activists and ‘organic intellectuals’ in Britain in the 1970s and 80s, and further developed since then through the growth of the academic field of Disability Studies, has at its core the claim that ‘to be disabled’ is not merely to have a body and/or mind that does not function in normative ways, but to be oppressed by modern society—and more specifically by the capitalist economy and wage labour system—in historically and geographically specific ways.<sup>1</sup> These include denial of access to social spaces (both literally through physical barriers such as stairs or narrow doorways, and symbolically through exclusionary attitudes), material deprivation through systems such as out-of-work benefits and social care charging which keep disabled people in poverty, and denial of autonomy in daily living through either

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1. B. Gleeson, *Geographies of disability* (London 1999: Routledge); C. Thomas, *Female forms: Experiencing and understanding disability* (Buckingham 1999: Open University Press); C. Thomas, *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology* (London 2007: Red Globe Press).

the lack or the inappropriately paternalistic provision of assistance services.

Disabled people's movements and organisations have over the last half-century adopted a variety of strategies, from lobbying politicians and campaigning for legislative changes to public-facing direct action and consciousness-raising through arts and cultural visibility, and have advanced analyses of what is needed to achieve disabled people's liberation ranging from the reformist to the revolutionary, in response to these social and material conditions.<sup>2</sup> These have often drawn on, but arguably have not managed to have much of an inverse influence on, movements in the broader British 'left' with more general membership.

One such broader movement, which I argue has largely untapped potential for disabled people in the UK, is the co-operative movement, whose origins can be traced to the 'Rochdale pioneers', who started a movement of consumer-owned food retail societies in the mid-19th century,<sup>3</sup> and which itself contains greatly varied positions and analyses ranging from the conservatively communitarian to the radically anti-capitalist. Co-operatives are not precisely defined in the UK, but in broad terms are businesses that are collectively owned and controlled by their members for their mutual benefit, and run according to co-operative values and principles.<sup>4</sup>

Workers' co-operatives (businesses, such as a shop or factory, collectively owned by workers) and housing co-operatives (housing collectively owned by residents, ranging in scale from single shared houses to larger co-ops with dozens or even hundreds of separate properties) are arguably the commonest and best-known types of

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2. M. Berghs, T. Chataika, Y. El-Lahib, and K. Dube (eds.), *The Routledge handbook of disability activism* (Abingdon 2019: Routledge).

3. J. Birchall, *People-centred businesses: Co-operatives, mutuals and the idea of membership* (Basingstoke 2011: Palgrave Macmillan).

4. S. Gradin, 'Radical Routes and Alternative Avenues: How Cooperatives Can Be Non-capitalist', *Review of Radical Political Economics* 47, no. 2 (2015): 141–158; International Co-operative Alliance, *Guidance Notes to the Co-operative Principles* (Brussels 2016: International Co-operative Alliance), <https://www.ica.coop/en/media/library/research-and-reviews/the-guidance-notes-on-the-co-operative-principles>.

co-ops in the UK. Other forms of co-ops include consumer co-ops, community benefit societies, and multi-stakeholder co-ops. The latter, which have two or more member/owner groups (for example, workers and consumers of services) are a relatively new development in the UK, but much more established in countries like Italy.<sup>5</sup>

Disabled people have been involved more or less incidentally in most if not all of these types of co-ops since their inception. However, a relatively small number of co-ops have been founded with the central purpose of meeting the needs and/or advancing the empowerment of disabled people. Some examples include:

- workers' co-ops made up largely or wholly of disabled workers which emerged from the closure of government-subsidised 'sheltered' workplaces for disabled workers run by organisations such as Remploy;
- multi-stakeholder co-ops providing social services for disabled people, jointly owned by service users and workers providing those services, such as personal assistance and sign language interpretation;
- housing co-ops focused on meeting disabled people's housing access needs.

While some connections have previously been made between co-ops and progressive tendencies in welfare policy that aligned with disabled people's movements (see for example Beresford<sup>6</sup> on UK social policy and Warren<sup>7</sup> on the influence of Franco Basaglia's de-institutionalisation movement on co-ops in Italy), and researchers in Disability Studies have examined specific types of co-ops and their potential to improve services for disabled people,<sup>8</sup> my present ISRF-funded research is, to

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5. P. Conaty, *Social Co-operatives: A Democratic Co-production Agenda for Care Services in the UK* (Manchester 2014: Co-operatives UK).

6. P. Beresford, *All our welfare: Towards participatory social policy* (Bristol 2016: Policy Press).

7. J. Warren, *The Cooperative Economy: Toward a Stakeholder-led Democracy* (unpublished PhD Thesis, Universität zu Köln 2022), <https://kups.ub.uni-koeln.de/62196/>.

8. E.g. A. Roulstone and S.K. Hwang, 'Disabled people, choices and collective organisation: Examining the potential of cooperatives in future social support', *Disability & Society* 30, no. 6 (2015): 849–864.

my knowledge, the first attempt to comprehensively look at disabled people's involvement in co-operatives of all types in the UK.

My research includes both case studies of some co-ops with disabled people and their needs at the core of their purpose, and interviews with disabled people who are or have been members of co-ops of any kind (in practice, the great majority of these were members of housing and/or workers' co-ops). Its initial findings include notable synergies between the principles and practices of co-ops and disabled people's movements, and many highly positive experiences of co-ops being powerful enabling tools in disabled participants' lives, but also some significant experiences of exclusionary attitudes and disabling barriers within both individual co-ops and wider co-operative movement circles.

Some participants were or had been involved in disabled people's organisations (DPOs) as well as co-ops, while others had had little or no contact with DPOs and knew relatively little about them. However, there was general consensus that the values of co-ops 'fitted' with those of the Disabled People's Movement. Interestingly, for some participants who had been involved in both DPOs and co-ops, shared values and connections between the two did not seem evident until prompted by me as interviewer, while for others there was a clear and obvious connection.

Shared values identified by participants included: inclusivity, egalitarianism and, as one participant said, "considering everyone's contribution to be important"; an organising principle of collective self-interest and ownership/leadership by those directly involved in an experience or activity (as the classic Disabled People's Movement slogan puts it: 'nothing about us without us'); and 'bottom-up' mutual aid as opposed to the 'top-down' paternalistic practices of government and charities. Co-ops were also seen, by those participants who had positive experiences of them, as exemplifying the social model by enabling living and/or working environments to be changed to fit people, rather than people being forced to fit into whatever inflexible environments were available.

A few participants reported examples of direct connection or collaboration between co-ops and DPOs (such as a DPO using the services of a media workers' co-op for publicity materials), but most felt that there was relatively little communication or interaction between the co-operative and disabled people's movements in their experience, though there was general agreement that there should be more.

Some, but not all, participants already had a well-developed anti-capitalist analysis, informed by their experiences as people disabled by capitalist society, which directly led to their choice to join (or to start)—this was predictably more common among founder members) co-ops. Others had come to be involved in co-ops coincidentally, through circumstances such as being in need of accessible housing and happening to hear about a vacancy in a housing co-op, but had become enthusiastic about co-ops and co-operative values through their experience.

Participants compared co-operative housing favourably to both privately rented and more 'mainstream' (e.g. local authority) social housing. Co-operative housing, while sometimes more expensive than mainstream social housing, was for most participants significantly cheaper than private market rents—a major issue with regard to housing security for disabled people given that most have substantially lower incomes than non-disabled people. Co-operative housing was also more secure in terms of not being at risk of eviction, and a significant benefit for many disabled people was the ability to make changes to their homes that private landlords would not permit—ranging from choosing colours to paint the walls in a student housing co-op to accommodate an autistic member's sensory access needs, to building a ramp to the front door of a shared-house co-op to give a member who used a mobility scooter full access.

Compared to mainstream social housing, participants described their experience of housing co-ops as more understanding of members' access needs and willing to make adaptations to housing to meet them, more responsive to requests for repairs or adaptations, and in some (though not all) cases quicker to find people appropriate housing, with less time on waiting lists. However, not all participants had similarly positive experiences.

Rosie, a neurodivergent single parent, eventually transferred from a flat within a co-op to local authority social housing after repeated experiences of exclusion from decision-making structures within the co-op, which she attributed to disablist attitudes and internal culture. This particular co-op placed a high emphasis on all members actively participating and putting in hours of unpaid work, with penalties for not doing so, something which came from a culture of 'do-it-yourself' activism and direct democracy, but which failed to acknowledge limits on individuals' capacity (whether caused directly by their impairments or coming from the added burden of negotiating barriers and social oppression on a daily basis), and inadvertently replicated capitalist norms of work as conferring the only valid membership of community (for a disabled critique of this, see Abberley).<sup>9</sup>

Other aspects of co-op culture that several participants found problematic, particularly in smaller housing co-ops, included a focus on environmentalism and 'ethical' consumption practices that could disregard disabled people's access needs, for example for easier-to-prepare food, higher indoor temperatures in winter, or simply for more living space per person.<sup>10</sup>

Several participants talked about the Radical Routes network—a secondary co-op of (primarily smaller housing) co-ops committed to working for radical social change, which provides funding and practical support to groups setting up co-ops which share its radically anti-capitalist and environmentalist principles<sup>11</sup>—as inaccessible in its organisational practices and problematic to negotiate for many disabled people.

Radical Routes organises itself through, and requires attendance from member co-ops at, large quarterly in-person gatherings, involving camping in summer and use of large indoor spaces with communal sleeping space in winter, which present significant access difficulties to

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9. P. Abberley, 'Work, Disability and European Social Theory', in: C. Barnes, L. Barton and M. Oliver (eds.), *Disability Studies Today* (Cambridge 2002: Polity Press): 120–138.

10. See also D. Fenney, 'Ableism and Disablism in the UK Environmental Movement', *Environmental Values* 26, no. 4 (2017): 503–522.

11. Gradin, 'Radical Routes and Alternative Avenues'.

many disabled people for many different reasons. Another problematic aspect of the network for many disabled co-operators is the '15-hour rule'—a requirement for all members of Radical Routes co-ops to commit themselves to at least 15 hours per week of unpaid work for radical social change. While this has arguably never really been enforced, it can be seen as exclusionary towards disabled people who may not (always or ever) have capacity for this level of contribution.

The communal style of living in small housing co-ops like those typically found in the Radical Routes network could be a double-edged sword for disabled and/or neurodivergent people. Some struggled with the intensity of constant interaction (such as eating communal meals every day), expectations of capacity to contribute 'equally' to household chores, and potential for interpersonal conflicts. However, for some the informal support with access and assistance needs from other co-op members was a major positive. For some participants this aspect of shared social reproduction, including meeting of emotional needs for company and human interaction (particularly in the context of the Covid-19 pandemic) was more important to them than co-operative ownership of the housing, and was a major (sometimes the primary) factor in their choice to join a housing co-op.

Disabled members of workers' co-ops reported that the ability to collectively set their own working practices was a major factor in making work within co-ops far more accessible for them than working for other employers. In some co-ops, for example, members could choose to work from home rather than in a sensorily overloading office environment, to set their own hours at times that could accommodate fluctuating fatigue or unconventional sleeping patterns, or to divide up work tasks in ways that fit with individual workers' strengths and limitations, all of which might not have been allowed within the hierarchical structures of other businesses. Some participants had founded workers' co-ops specifically in response to barriers (often largely attitudinal) to getting other forms of paid work.

However, as with housing co-ops, some participants found disabling barriers and lack of understanding of their access needs within workers' co-ops. Erica, a member of a large warehouse-based workers' co-op, found that an ideology of 'every member being able to do every

job' resulted in an unwillingness to provide adjustments for her and an expectation of being capable of heavy physical work, despite this not being required for her particular role within the co-op. Erica thought this may have been an unintended consequence of consciously opposing the typical workplace hierarchy of 'office' jobs being privileged over 'manual labour' jobs.

With an ongoing pandemic, a rapidly escalating cost-of-living crisis, and the looming threat of devastating climate change—all of which disproportionately harm disabled people, among other groups marginalised by capitalist society—co-ops are a potential tool (among many) for local-scale mitigation of the worst of these conditions, from which disabled people can benefit in real and concrete ways. Co-ops can also point towards different ways of structuring society, based on principles of equity, solidarity and inclusion, in which people who are born with or acquire impairments could be far less disabled than they are today.

However, all tools have their limitations, and it is necessary to recognise that co-ops cannot provide complete solutions to disablement. Personal assistance co-ops like those which exist in countries like Sweden, which I have elsewhere argued have potential for implementation in the UK,<sup>12</sup> cannot directly change the overall underfunding of social services, for example. As experiences of participants like Rosie and Erica show, changes in awareness and attitudes, and sometimes deeper ideological change, may be needed for some co-ops to be fully inclusive of disabled members.

The potential of co-ops to provide radical, prefigurative alternatives to capitalist (and disablist) ways of working and living is open to debate, with some on the left characterising them as inevitably co-opted into capitalist ideologies of entrepreneurship and self-exploitation.<sup>13</sup> This parallels arguments about the role of disabled people's organisations.<sup>14</sup>

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12. S. Graby, 'Personal assistance Co-operatives: Possibilities and pitfalls of alternative models of independent living', *Journal of Co-Operative Studies* 54, no. 3 (2021): 33–44.

13. M. Sandoval, 'What would Rosa do? Co-operatives and radical politics', *Soundings* 63 (2016): 98–111.

14. See for example C. Barnes, 'The Disabled Peoples' Movement and its



However, in workers' co-ops in particular, the micro-political elements of workplace democracy and collective self-management, particularly with regard to hiring practices, may make all the difference to whether some disabled people have access to paid work at all.

While the scale or level at which co-ops can affect the disabling conditions of present-day society is therefore debatable, it is undeniable that they can be concretely useful for disabled (and otherwise marginalised) people in achieving liveable day-to-day conditions, and therefore providing a foundation on which to build strategies for deeper transformations. They can, and I argue should, therefore be viewed as one important element in a broader, multi-faceted strategy of struggle for disabled people's liberation. Further research can play a role in determining this, but only if combined with and directed towards practical action, such as establishing new co-ops that directly meet disabled people's needs, and/or finding ways to overcome disabling barriers that still remain within existing co-ops.



# LIVING IN ANTICIPATION

## Dr Alice Baderin

ISRF Early Career Fellow 2019–20

*Curtis travels with a guide dog. He has well developed strategies to challenge potential access denials in public places, including memorizing state and federal accommodation laws, a legal hotline number and website URLs.<sup>1</sup>*

*Jason is an athletic young man with hemiplegic cerebral palsy. He has decided not to participate in Paralympic sport, for fear of being exposed to condescending views: “look at how hard those poor people to work”... it’s that kind of attitude that you’re trying to avoid’.<sup>2</sup>*

*Scott hides his visual impairment from most people he meets. He refuses adaptive equipment and avoids large gatherings where he would have difficulty identifying people. He sometimes encourages others to assume he is poorly prepared or uninterested, rather than acknowledging the effects of his disability.<sup>3</sup>*

Disabled people use a wide range of strategies to protect themselves against discrimination, exclusion, and misrecognition. These defensive

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1. Annika Konrad, ‘Access Fatigue: The Rhetorical Work of Disability in Everyday Life’, *College English* 83, no. 3 (2021), 194.

2. Michelle Spirtos and Robbie Gilligan, ‘In Your Own Head Everyone is Staring’: The Disability Related Identity Experiences of Young People with Hemiplegic Cerebral Palsy’, *Journal of Youth Studies* 25, no. 1 (2022), 57.

3. Adam Cureton, ‘Hiding a Disability and Passing as Non-Disabled’, in A. Cureton and T.E. Hill Jr (eds.), *Disability in Practice: Attitudes, Politics and Relationships* (Oxford 2018: Oxford University Press): 15–32. Cureton’s vignette about Scott is based on his own experiences of concealing his blindness.

practices may often be necessary, and sometimes empowering. But they can also exact significant costs. Curtis devotes time and cognitive resources to arming himself with the information he may need, at any moment, to secure his rights. Jason and Scott forgo valuable opportunities in their efforts to ward off prejudice. Scott also experiences the psychological strain of continually monitoring and controlling the presentation of his impairment in social interactions: work that Jackie Scully has described as the 'hidden labor' of encounters between disabled and non-disabled individuals.<sup>4</sup>

The practices described above are shaped by specific features of the individuals' circumstances and identity. For example, the fact that Scott's disability is not immediately apparent to others shapes his decisions to 'pass' as non-disabled. In other contexts, disabled individuals might choose instead to exaggerate or deliberately display a disability in order to protect themselves.<sup>5</sup> The kinds of defensive strategies adopted by Curtis, a white male, may not work in the same way for disabled women or ethnic minorities. However, these particular experiences are also illustrative of a much broader phenomenon, whereby risk exerts anticipatory pressure. When we are subject to threats of injustice, loss or hardship, we tend to contemplate, plan and sometimes execute protective steps. These anticipatory thoughts and actions often have profound effects on our present lives. For example, consider the undocumented migrant who restricts his day-to-day movements and forgoes access to public services to avert potential encounters with immigration authorities.<sup>6</sup> The women engaged in 'safety work' in public spaces: adjusting their body language, planning their walking route, and carefully choosing their seat on public transport to pre-empt harassment and violence.<sup>7</sup> The insecure

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4. Jackie Leach Scully, 'Hidden Labor: Disabled/Nondisabled Encounters, Agency, and Autonomy', *International Journal of Feminist Approaches to Bioethics* 3, no. 2 (2010), 25.

5. See, for example, Tobin Siebers, 'Disability as Masquerade', *Literature and Medicine* 23, no. 1 (2004): 1–22.

6. See, for example, Angela Stuesse and Mathew Coleman, 'Automobility, Immobility, Altermobility: Surviving and Resisting the Intensification of Immigrant Policing', *City & Society* 26, no. 1 (2014), 60.

7. For the concept of safety work, Fiona Vera-Gray and Liz Kelly, 'Contested gendered space: Public sexual harassment and women's safety work', in Vania Ceccato and Mahesh Nalla (eds.), *Crime and Fear in Public Places:*

workers devoting hours to preparing CVs and researching alternative openings, in case their current position is terminated. And the racialised minorities who, like those subject to threats of disability discrimination, are engaged in complex public identity management strategies to deflect prejudice. We can begin to trace a common set of anticipatory dynamics across these otherwise diverse contexts of insecurity. Some of these strategies are designed to reduce the probability of risk ripening into harm, others to mitigate or buffer against the damage if it does occur.

In my research, I explore the moral significance of vulnerable individuals' anticipatory responses to insecurity: What are the characteristic strategies that individuals use to mitigate risk? Which of these practices are specific to particular situations of risk, and which cut across diverse contexts of insecurity? When and why do these anticipatory dynamics matter from the perspective of social justice? I have argued that there is a distinct injustice that stems from the imperative to ward off threats to one's future wellbeing. I call this problem 'anticipatory injustice'. An account of anticipatory injustice can help us to answer a puzzle about why, if we care about social justice, we should be concerned about individuals' exposure to risk. Of course, risk matters when it ripens into harm, and people's lives go badly as a result: the disabled individual is subject to unequal treatment, the insecure worker loses her job, or the undocumented migrant is detained and deported. But what about the threat itself? Why should we care about risk independently of whether it materialises? An important part of the answer to this question lies in the anticipatory pressures that insecurity generates, and the profound consequences this has for individuals' present lives.

There are two aspects of the problem of anticipatory injustice. The first is distributive. Living with persistent insecurity often means paying an unfair price now in order to secure one's future wellbeing. Sometimes these costs are economic. Insecure individuals may forgo earnings opportunities in order to protect themselves, or pay more to obtain goods and services in less risky ways: for example, the undocumented migrant who uses expensive taxis rather than driving

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*Towards Safe, Inclusive and Sustainable Cities* (Abingdon 2020: Routledge): 217–231.

to avoid police checkpoints. But risk mitigation practices very often also bring significant non-material burdens. Persistently contemplating, planning, and enacting anticipatory strategies consumes time and energy. These less tangible anticipatory costs are captured in a number of powerful and interrelated concepts: the ‘access fatigue’ experienced by disabled people; the ‘battle fatigue’ of living with the persistent threat of racism; and the burdens of ‘deportability’ for undocumented migrants.<sup>8</sup> Consider, for example, parenting in anticipation of discrimination against a disabled child. Parents describe a range of protective practices such as ensuring that their child is always immaculately dressed, camouflaging assistive equipment, and restricting social activities to avoid stigmatising treatment.<sup>9</sup> These strategies are time consuming and emotionally and cognitively taxing. They can also intrude on the enjoyment of family life. Philosophers have described the values we realize through particular connections with special others as ‘personal relationship goods’: goods such as love, care, and emotional support that are only available within certain kinds of relationships, and that help to make those relationships what they are. In the context of parent-child relationships, these goods include a sense of intimacy, spontaneity and sharing together in the child’s enjoyment of the special goods of childhood.<sup>10</sup> Some of these family

8. See, respectively, Konrad, ‘Access Fatigue’; William Smith, Man Hung, and Jeremy D. Franklin, ‘Racial Battle Fatigue and the MisEducation of Black Men: Racial Microaggressions, Societal Problems, and Environmental Stress’, *The Journal of Negro Education* 80, no. 1 (2011): 63–82; Nicholas De Genova, ‘Migrant “Illegality” and Deportability in Everyday Life’, *Annual Review of Anthropology* 31 (2002): 419–447.

9. Patricia McKeever and Karen-Lee Miller, ‘Mothering children who have disabilities: a Bourdieusian interpretation of maternal practices’, *Social Science & Medicine* 59, no. 6 (2004): 1187–1188; David Gray, “Everybody Just Freezes. Everybody is Just Embarrassed”: Felt and Enacted Stigma Among Parents of Children with High Functioning Autism’, *Sociology of Health and Illness* 24, no. 6 (2002), 741.

10. Anca Gheaus, ‘Personal Relationship Goods’, *Stanford Encyclopedia of Philosophy*, September 2018, <https://plato.stanford.edu/entries/personal-relationship-goods/>. For the concept of ‘familial relationship goods’, see Harry Brighouse and Adam Swift, *Family Values: The Ethics of Parent-Child Relationships* (Princeton, NJ 2014: Princeton University Press). I discuss the tension between risk mitigation and relationship goods in more detail in the context of parenting against threats of racial discrimination—see Alice Baderin, “The Talk”: Risk, Racism and Family Relationships’, *Political Studies* (2022 online first), <https://doi.org/10.1177/00323217221074894>.

relationship goods may be crowded out when parents are persistently working to ward off discrimination against their children.

The second element of the problem of anticipatory injustice involves the loss of a distinctive and valuable kind of freedom. Persistent insecurity has powerful deliberative effects, when individuals come to approach a wide range of decisions through the lens of managing risk. For example, the imperative to mitigate the threat of deportation can frame many big and small choices: from where to live, what job to take, and how to interact with one's children, to how to travel and what times to leave the house. In extreme cases, it means that 'all your plans have to revolve around the same thing'.<sup>11</sup> What is lost here is one valuable component of individual agency: the capacity to engage in a direct and pure way with the reasons and values at stake in particular choices.<sup>12</sup> This freedom—I have termed it 'insulated agency'—matters when it comes to fundamental questions about values and the ways of life we adopt. For example, we should have the opportunity to consider decisions about religious affiliation as decisions *about religion*, rather than about avoiding social isolation or destitution. But it is also important that we can, at least on occasion, confront some of the trivial choices of life in an insulated way. We should sometimes be able to choose a meal on grounds of taste, or make a pure decision about how to spend some leisure time. This is a freedom that is compromised for many individuals living in persistent poverty, for whom economic considerations consistently loom large even in decisions that, to others, might seem to lack any economic dimension.<sup>13</sup> Similar deliberative effects arise in many contexts of ongoing insecurity. For example, the imperative to ward off racial or disability discrimination can frame diverse decisions over what to wear and what body language to adopt; where to work, to shop, and to take holidays; and what values to impart to one's children. In this way,

11. Paloma Villegas, "I can't even buy a bed because I don't know if I'll have to leave tomorrow": temporal orientations among Mexican precarious status migrants in Toronto', *Citizenship Studies* 18, no. 3–4 (2014), 287.

12. Seana Shiffrin, 'Egalitarianism, Choice-Sensitivity, and Accommodation', in R. Jay Wallace, Philip Pettit, Samuel Scheffler, and Michael Smith (eds.), *Reason and Value: Themes from the Work of Joseph Raz* (Oxford 2004: Oxford University Press), 289.

13. Anuj K. Shah, Jiaying Zhao, Sendhil Mullainathan and Eldar Shafir, 'Money in the Mental Lives of the Poor', *Social Cognition* 36, no. 1 (2018), 4.

persistent anticipatory pressures can pollute fundamental decisions about how to lead one's life, as well as preventing us from confronting quotidian choices as the trivial choices that they are.

Of course, almost all of us live our lives partly in anticipation of somewhat uncertain futures. We manage our public identities to mitigate risks of misrecognition and exclusion. We may take pre-emptive steps to cushion ourselves against potential economic hardship. Moreover, identifying and responding to risks is an important part of what it means to lead an autonomous life: to exercise agency over the course of one's future, rather than to be carried forward by events. However, the imperative to ward off risk should not be dismissed as simply a pervasive, even welcome, part of everyday life. Some people, much more than others, are avoidably burdened with the work of risk mitigation. Where these anticipatory pressures are contingent, unequal and persistent, they raise deep concerns of justice. What then should be done about the problem of anticipatory injustice? One important feature of anticipatory pressures is that they are often invisible to those who do not experience them directly. Thus a first step is simply to recognise the hidden efforts that some people are expending to secure their future wellbeing. Second, the anticipatory implications of insecurity should be a distinct consideration for policymakers. In many cases, we should already be working collectively to eliminate the risks that generate the protective responses. Individuals should not be subject to threats of discrimination or violence, regardless of the anticipatory burdens that accompany these risks. However, where progress on risk-mitigation is slow, policymakers should also identify tools that specifically target the anticipatory dynamics, to separate risk from its unjust anticipatory effects. For example, can we alleviate the additional time burdens of insecure work by capping hours for temporary workers without loss of pay? Can we collectivise some of the anticipatory labour undertaken by insecure individuals and families? For example, could schools and youth services share more of the work of preparing minority children to cope with discrimination?

Our ability to live well in the present depends on the pressures we face to protect ourselves against future injustice, loss, or hardship. If we care about social justice, we should seek to understand and to reshape



the anticipatory environments that burden people's lives and limit their freedom.



# WAR MACHINES, SETTLER COLONIALISM, AND THE PRODUCTION OF DISABILITY

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ISRF Early Career Fellow, 2019–20

In this essay I explore the relationship between war, settler-colonialism, and disability in relation to the besieged and occupied territory of the Gaza Strip. Specifically, I want to argue that war and certain forms of what we might call late settler-colonialism are oriented toward the incapacitation of bodies (and not only human bodies),<sup>1</sup> relationships (kin, community, family), and infrastructures. The suggestion, following work in critical disabilities studies, is that we attend to disability not as a category for the labelling of some innate or biological 'crip' quality but instead as a process or outcome of what gets articulated as the 'norm'. But to say that war and settler-colonialism produce disability is to suggest more than the mere social construction of disability; it is also to suggest, or rather evoke, the machinic-like qualities of the vast, terrifying, and world-altering power of war upon bodies and those physical and social infrastructures that make them thrive.

These arguments form a kind of self-critique of my slow realisation that war is about more than death and death-making, and that the

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1. See Joseph Pugliese, *Biopolitics of the More-Than-Human: Forensic Ecologies of Violence* (Durham, NC 2020: Duke University Press).

geographies of war are not reducible to what I have called 'spaces of killing'.<sup>2</sup> The arguments are inspired, in the first instance, by the figure of the wounded civilian (rather than the heroic wounded soldier that dominates frames of war both contemporaneously and historically), and by the fact that so little space in scholarship, even today, has been devoted to asking who these civilians are and what happens to them after they are injured. They are also indebted to a series of provocations made by Elaine Scarry, Omar Dewachi, Nirmala Erelles, Patrick Wolfe, and Danya M. Qato and this essay is something of an attempt to put them in very brief conversation together and with Gaza.

In her well-known essay 'Injury and the Structure of War', Elaine Scarry stripped war down to its essential bodily characteristics, arguing forcefully that the 'main purpose and outcome of war is injuring'.<sup>3</sup> There are, of course, other purposes and outcomes of war, but here I read Scarry as offering injury as the key analytic for understanding something fundamental about what war is and, importantly, what war does. The context in which Scarry wrote was full of Cold War euphemism, an era that sharpened warmakers' refusal to acknowledge that for all its technological prowess and brinkmanship, war is still about breaking things and killing people (and getting others to do the dirty work for you if you can). Scarry's injunction was first and foremost a refusal to sanitise war, a reminder not to be lulled by language,<sup>4</sup> by speed,<sup>5</sup> and by the mediatisation of war's awe<sup>6</sup>—because beneath those bombs and under those fragile barricades that some call homes are lives that are constitutively vulnerable to injury.<sup>7</sup> Scarry understood that this was perhaps a painfully obvious point, but her argument

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2. Craig Jones, *The War Lawyers: United States, Israel, and Juridical Warfare* (Oxford 2020: Oxford University Press).

3. Elaine Scarry, 'Injury and the Structure of War', *Representations* 10 (1985): 1–51, 1.

4. George Orwell, 'George Orwell: Politics and the English Language' (1946), [http://www.orwell.ru/library/essays/politics/english/e\\_polit](http://www.orwell.ru/library/essays/politics/english/e_polit).

5. Paul Virilio, *Speed and Politics: An Essay on Dromology* (New York 1986: Semiotext(e)).

6. Jean Baudrillard, *The Gulf War Did Not Take Place*, transl. Paul Patton (Sydney 2012: Power Publications).

7. On the vulnerability of life to violence, see Mikko Joronen and Mitch Rose 'Vulnerability and Its Politics: Precarity and the Woundedness of Power', *Progress in Human Geography* 45, no. 6 (2021): 1402–1418.

was precisely that injury seemed so self-evidently a part of war that warmakers had erased it while publics had forgotten it—a sleight of hand made easier by transferring risk onto racialised populations and away from what Wendy Brown memorably called the ‘injurious state’.<sup>8</sup> Nevertheless, we now understand war to be socially, economically and otherwise generative<sup>9</sup>—as opposed to merely being destructive—so while war certainly is about injury, it is also productive of bodily agency and identities that cannot be reduced to injury,<sup>10</sup> a point we will return to.

There is a literature on war and disability, even if it does not self-identify as such.<sup>11</sup> Broadly, the literature approaches war and disability from one of two disciplines—History and Anthropology—and they have not had a great deal to say to each other. Both remain resolutely focused on the experience of soldiers, which is understandable enough given the primacy of the wounded veteran in national cultural imaginaries and their importance on the battlefields of the twentieth and twenty-first centuries. Yet, the focus on soldiers occludes not only the civilians I have already mentioned; it also leaves precious little space for irregular fighters and those injured while participating in liberation struggles

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8. Wendy Brown, *States of Injury: Power and Freedom in Late Modernity* (Princeton, NJ 1995: Princeton University Press).

9. Tarak Barkawi and Shane Brighton, ‘Powers of War: Fighting, Knowledge, and Critique’, *International Political Sociology* 5, no. 2 (2011): 126–143.

10. Tanya Narozhna, ‘The Lived Body, Everyday and Generative Powers of War: Toward an Embodied Ontology of War as Experience’. *International Theory* 14, no. 2 (2022): 210–232, 213: “[T]he generative force of war is born out of the dialectical relationship between the power of the politics of injury to disrupt individual and collective being-in-the-world and the potential of embodied everyday practices to undo pernicious effects of the politics of war injury, restoring to the lived bodies their sense-making capacities, personhood, and agency.”

11. E.g. Julie Anderson, *War, Disability and Rehabilitation in Britain: ‘Soul of a Nation’*, illustrated edition (Manchester 2016: Manchester University Press); Ana Carden-Coyne, *The Politics of Wounds: Military Patients and Medical Power in the First World War* (Oxford, 2014: Oxford University Press); Emily Mayhew, *Wounded: The Long Journey Home From the Great War* (London 2014: Vintage); Emily Mayhew, *A Heavy Reckoning: War, Medicine and Survival in Afghanistan and Beyond*, main edition (London 2017: Wellcome Collection); Richard J. McNally and B. Christopher Frueh, ‘Why Are Iraq and Afghanistan War Veterans Seeking PTSD Disability Compensation at Unprecedented Rates?’, *Journal of Anxiety Disorders* 27, no. 5 (2013): 520–522.

and wars for independence. This has a particular salience for Gaza and for other places and peoples under regimes of settler colonialism, occupation, and siege and so far work on war and disability has largely reflected rather than challenged ideas around who constitutes a legitimate fighter and therefore who and what counts as a legitimate wound or wounded person. (This is not just a political question; it is also a serious ethical concern, for researching the enemies of the state risks exposing their identities to the state.) Work in medical anthropology has done much to challenge theories of disability among veterans, borrowing ideas from critical disabilities studies around capacities, debilitation and the formation of 'after-war' identities and bionic extensions of the more-than-human soldier,<sup>12</sup> but it is the work of Iraqi anthropologists and former medical doctor Omar Dewachi that gets us closer if not to a theory of disability and war beyond the soldier, then at least a geographical account of how such a theory might emerge.

In response to the ongoing wars in Iraq and Syria, and borrowing from work in health-geography, Dewachi coined the term 'therapeutic geographies' to describe the regional reorganisation of healthcare under conditions of war.<sup>13</sup> The concept was at once a recognition that war and its consequences cannot be contained by national borders, but also, and more important for our present purposes, that therapeutic geographies cast new light on the scale of the problem of the intimate yet deadly relationship between war and health, and by extension war and disability.<sup>14</sup> Disabilities studies scholar Nirmala

12. Kenneth T. MacLeish, *Making War at Fort Hood: Life and Uncertainty in a Military Community* (Princeton, NJ 2013: Princeton University Press); Jennifer Terry, *Attachments to War: Biomedical Logics and Violence in Twenty-First-Century America* (Durham, NC 2017: Duke University Press); Zoë H. Wool, *After War: The Weight of Life at Walter Reed* (Durham, NC 2015: Duke University Press); Zoë H. Wool and Julie Livingston, 'Collateral Afterworlds: An Introduction'. *Social Text* 35, no. 1 (130) (2017): 1–15.

13. Omar Dewachi, Mac Skelton, Vinh-Kim Nguyen, Fouad M Fouad, Ghassan Abu Sitta, Zeina Maasri, and Rita Giacaman, 'Changing Therapeutic Geographies of the Iraqi and Syrian Wars'. *The Lancet* 383 (9915) (2014): 449–457; Omar Dewachi, Anthony Rizk, and Neil V. Singh, '(Dis)Connectivities in Wartime: The Therapeutic Geographies of Iraqi Healthcare–Seeking in Lebanon', *Global Public Health* 13, no 3 (2018): 288–297.

14. See also Merrill Singer and G. Derrick Hodge (eds.), *The War Machine and Global Health* (Lanham, MD 2010: AltaMira Press); Craig Jones, 'War and

Erevelles identifies this in a way that I find immensely useful: 'War is one of the largest producers of disability in a world still inhospitable to disabled people and their predominantly female caregivers'.<sup>15</sup> There is so much to unpack here, but worth emphasising across Dewachi and Erevelles is the difficult-to-apprehend scale of the problem—one that leaves its mark not only on individuals but crucially also on entire populations. Statistics in war are notoriously contested, and casualty-counts (or what are sometimes called body-counts) often fail to mention the numbers of persons injured, subsuming the place of the injured beneath the dead in our calculus of war, and perhaps even suggesting that as long as one survives, one is going to be okay.

Between the First Intifada in 1987 and March 2017, some 250,000 Palestinians were injured by Israeli forces, including 110,000 in the Gaza Strip,<sup>16</sup> and in 2018–19 further tens of thousands of protestors were injured, and over 8,000 shot with live ammunition while claiming their right of return.<sup>17</sup> These are scales of injury that are difficult to comprehend, let alone to triage, treat, and rehabilitate and yet we know that such mass maiming is not unique to Gaza even while the healthcare system there operates under carefully calculated and especially punishing conditions of duress. Not all injury amounts to disability, and not all disability is permanent, but maiming on the scale that war so often entails constitutes a significant and long-term burden across intersecting scales of life from individual to family, from surgical intervention to public health, and from acute emergencies to enduring regimes of rehabilitation that pay no heed to the Cartesian mind/body dualism. Just as there are patterns and geographies of injury (bullet

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Health: The Medical Consequences of the Wars in Iraq and Afghanistan. Edited by: Catherine Lutz and Andrea Mazzarino (Book Review)', *Medical Anthropology Quarterly* 34, no. 3 (2020): 73–75; Catherine Lutz and Andrea Mazzarino (eds.), *War and Health: The Medical Consequences of the Wars in Iraq and Afghanistan* (New York 2019: NYU Press).

15. Nirmala Erevelles, 'The Colour of Violence: Reflecting on Gender, Race and Disability in Wartime', in: K.Q. Hall (ed.), *Feminist Disability Studies* (Bloomington, IN 2011: Indiana University Press): 117–135, 117.

16. Middle East Monitor, '250,000 Palestinians Injured since First Intifada', 14 March 2017, <https://www.middleeastmonitor.com/20170314-250000-palestinians-injured-since-first-intifada/>.

17. Craig Jones, 'Gaza and the Great March of Return: Enduring Violence and Spaces of Wounding', *Transactions of the Institute of British Geographers* (2022, Online First), <https://doi.org/10.1111/tran.12567>.

wounds, explosive blast injuries, burns, legs, torsos, heads, open fields, dense cities, collapsed buildings, targeted vehicles—all correlating with different military tactics and objectives, maiming is anything but incidental), there are therapeutic geographies too. While Dewachi is less attentive to the gendered dimensions of care, he is surely right that in the Middle East (and perhaps elsewhere) ‘wounds constitute the interstitial tissue of the social’,<sup>18</sup> and they do precisely because being wounded and having trauma is the norm rather than the exception.

Gaza and indeed the entire occupied Palestinian territories are subject not only to the force of war machines, but also the ongoing violence of settler colonialism. The late Patrick Wolfe once memorably argued that settler colonialism is a structure rather than an event, and referred to what he called ‘the elimination of the native’.<sup>19</sup> I had previously read Wolfe as claiming that the structure of settler colonialism’s violence was reducible to a strictly necropolitical logic, one that gave too little space for injury in its reading of settler-colonial power. But Wolfe is quite clear: ‘The logic of elimination’, he writes, ‘not only refers to the summary liquidation of Indigenous people, though it includes that.’ In its positive aspect, Wolfe shows that ‘the native repressed continues to structure settler-colonial society’,<sup>20</sup> and I would add that it does so in ways that are both detrimental to and also productive of new injured and injurious subjectivities, including the possibilities of care.

Disability, like war and like settler colonialism, is a structure rather than an event and it requires modes of social scientific inquiry that explain and remediate the conditions that produce and sustain it. In Palestine, then, it is simply impossible to understand what injury and woundedness mean and what human and social capacities have been foreclosed and enabled without understanding the material and ongoing conditions of war and settler colonialism. But it would also be a mistake to think about the wounded and disabled as (only) victims rather than vectors of power and political progress in and beyond Palestine. For as Danya M. Qato has recently argued:

18. Omar Dewachi, ‘When Wounds Travel’, *Medicine Anthropology Theory* 2, no. 3 (2015): 61, 61.

19. Patrick Wolfe, ‘Settler Colonialism and the Elimination of the Native’, *Journal of Genocide Research* 8, no. 4 (2006): 387–409, 387.

20. *Ibid.*, 390.



If we are to imagine public health as continuously transforming and evolving with the needs of our people, we need to imagine anew what it would mean for the science of public health in Palestine to challenge epidemiological approaches that focus on calculating rather than restoring health, and on reifying power rather than dismantling it.<sup>21</sup>

It is in this spirit, and along with these forms of decolonial scholarship, where I locate my own work on wounding and disability in Gaza. Aid and foreign humanitarianism drip into the besieged territory of Gaza, and it is no accident that at precisely the most acute periods of need, Israel ratchets up the pain by letting fewer people and goods across the border. This means that a sovereign healthcare infrastructure has been incapacitated, but it has by no means extinguished the improvisational strategies and tactics used by healthcare workers, families, women, and children to 'get by' as they navigate enduring violence and wounded life. During periods of mass violence and maiming, and under conditions of ongoing violence, hope emerges in the form of bodies in alliance and defiance, in the creation of new trauma and rehabilitative pathways, trauma stabilisation points that save lives and limbs, the rebuilding of bombed-out hospitals, services provided to the disabled, and the quiet and caring love of a family as it adjusts to the presence of another wound. These 'geographies of hope'<sup>22</sup> and spaces of care that inexorably follow the wounded are the subject of ongoing work that grew out of my ISRF-funded research, and they provide ample opportunities for social sciences, health sciences and the humanities to think through the dialectics of war-care, wounding, and enduring violence in and beyond Palestine.

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21. Danya M. Qato, 'Introduction: Public Health and the Promise of Palestine', *Journal of Palestine Studies* 49, no. 4 (2020): 8–26, 10.

22. Mikko Joronen and Mark Griffiths, 'The Moment to Come: Geographies of Hope in the Hyperprecarious Sites of Occupied Palestine' *Geografiska Annaler: Series B, Human Geography* 101, no. 2 (2019): 69–83.





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