

Forgotten People, Forgotten Places – Volume 2, Issue 2 Editorial

Angharad E. Beckett

Professor of Political Sociology and Social Inclusion, University of Leeds

Anna Lawson

Professor of Law, University of Leeds

I. Forgotten People, Forgotten Places

In our last editorial we promised that we would invite submissions focused on the rights of disabled people in the context of armed conflict to be published in future issues of this journal. Whilst acknowledging that an academic journal can only achieve so much – in such situations words alone can *never* be enough – we hope that the *IJDSJ* can make at least *some* positive contribution by helping to bring attention to the lives of disabled people living in conflict zones and the challenges that they face.

Disabled people are disproportionately impacted by war, yet are all-too-often ‘invisible’ within peace and security agendas and forgotten within and by humanitarian efforts. Time and again, the story repeats: disabled people’s pre-existing isolation and exclusion is a contributing factor in the failure to meet their needs at times of conflict; and their isolation and exclusion is significantly exacerbated by that conflict. This is a story of how ‘slow’ and ‘fast’ forms of violence operate, together. Slow violence, as Nixon (2011) defined it, occurs gradually and out of sight. It is often not considered to be violence because it is not spectacular and explosive, as is the violence of war. Yet there is a violence to processes of exclusion, to the manufactured marginalisation and isolation of people, to the denial of human rights and stripping away of human dignity – however gradually these things happen. What we are learning is that to understand the situation that disabled people face in armed conflicts around the world, we need to understand how ‘slow’ and ‘fast’ forms of violence are part of one single complex. They cannot and should not be decoupled. The slow forms of violence against disabled people that take place pre-conflict are imbricated with fast forms that occur during times of war.

This issue opens with two short bulletins about the war in Ukraine and the devastating impact that this conflict is having on disabled people. Readers may well find content in the two bulletins distressing. We certainly did. There is no easy way to avoid this – and to avoid it would be to erase the truth. Nevertheless, we believe neither bulletin describes experiences/situations in gratuitous detail. Both highlight, starkly,

the ‘single complex’ of violence that we describe above. Whilst in no way denying the critical factor that is the invasion of Ukraine by the Russian Federation, they articulate the relationship between pre-existing inequalities and exclusions faced by disabled people in Ukraine and the horrific situation that they are now facing.

The first is written by Jonas Ruškus, at the time of writing Vice Chair of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee). Jonas reflects upon what he learnt from relevant bodies, including the Ukrainian government, Ukrainian disabled people’s organisations and other non-governmental organisations, during hearings of the CRPD Committee that sought to investigate the situation for disabled people in Ukraine. The hearings took place in August 2022. The second has been submitted by Disability Rights International and focuses on the situation in Ukraine for disabled children living in congregate care.

These are powerful pieces. Testimonies written by passionate advocates for disabled people’s human rights. We want the *IJDSJ* to be a publication that provides an outlet for this type of important contribution and welcome similar submissions. It is our hope that this journal will be and become a space for knowledge exchange between experts inside and outside academia; prompting collaboration and solidarity amongst all parties striving to achieve social justice for disabled people.

2. Introducing the Remainder of this Issue

Like earlier volumes, this issue brings together thought-provoking pieces on a wide range of subjects. We are delighted that our authors continue to include people based in different parts of the world, at a range of career stages, with diverse disciplinary backgrounds and specialisms. Following the two short pieces about the situation in Ukraine, there are four further research articles and one book review. While the articles were selected independently of one another, and without regard to any connections between them, there is a common thread: they are all qualitative studies that take a deep-dive into persistent, seemingly fathomless aspects of disability and social justice. As with most small-scale, qualitative explorations, the questions that emerge from the studies are as interesting as the answers that they provide. Whilst the findings of these studies can only be fully understood in relation to their particular contexts, they nevertheless have broader, practical relevance, since the types of social justice challenge considered by each article occur across the globe. We hope that these articles will prompt fresh thinking and new, positive interventions.

The first of the four articles, by Ciara Brennan, Niamh Lally, Patricia O’Brien and Catherine O’Leary grapples with a pressing, and one of the most fundamental of disability rights challenges: how to effect a shift from institutional to community-based living. In this article, entitled ‘Abandoning a “Lifetime of Habits” to Avoid the “Sins of the Past”. De-Congregating Institutions with Deeply Ingrained Traditions’, the authors investigate the reasons behind the all-too-familiar tendency for institutionalised practices to persist within community-based settings despite the closure of large congregate living facilities. While this article draws upon a study carried out in Ireland, its insights and reflections will be of interest to independent living scholars

and activists, internationally. The authors highlight the complexity involved in reforming systems that are well-established and deeply embedded in socio-political life, having traditions and legacies that shape the sense of identity and purpose of relevant staff. We believe readers will find it interesting to consider this article alongside the DRI piece on the situation in Ukraine.

The second article is by Julia Bahner. Julia tackles another hugely important cluster of issues for disability scholars and activists – collaborative and inclusive governance, representation and the meaning of ‘disability’. Her article, “‘Nothing About Us Without ... Who?’ Disability Rights Organisations, Representation and Collaborative Governance”, presents a case study of the participation of local Swedish disability organisations in a regional consultative citizens’ council. Her article might be understood as a critical intervention into debates about citizenship, disability and identity politics. Julia draws our attention to how different conceptualisations of ‘disability’, as well as determining eligibility to take part in relevant policy debates and deliberations, also affect the way that disability organisations present themselves and the types of issue for which they advocate. Such conceptualisations, she argues, can themselves generate unproductive and unhelpful tensions and divisions between advocacy organisations.

The third of the articles, ‘Does Policy Impact Equitable Access to Services? A Critical Discourse Analysis of Discharge Policies in Paediatric Rehabilitation’, is concerned with access to habilitation and rehabilitation services – services addressed by Article 26 of the CRPD. Here, Meaghan Reitzel, Briano Di Rezze, Lori Letts and Michelle Phoenix present a study, carried out in Ontario, of the impact on disabled children (and their access to rehabilitation services) of the missed appointments policies of Children’s Treatment Centres (CTC). They conclude that the language of CTC discharge policies results in dominant practices that infringe upon a disabled child and their family’s right to choose whether to access rehabilitation. They present this as a social justice issue, exploring reasons why families might choose not to use rehabilitation services, including that such services are situated in a traditional rehabilitative discourse that privileges notions of ‘normal’ development and service provider expertise over lived experience.

The final article, by Noa Tal-Alon, Nitsan Almog and Michal Tenne Rinde is ‘That Sinking Feeling: People with Disabilities in Hospital Wards’. It presents a national, qualitative study of the experiences of disabled patients during periods of hospitalisation. The authors identify three main types of problem or barrier – inaccessibility, lack of relevant medical expertise amongst practitioners, and negative stereotypes. They argue for a whole-service approach to accessibility (embracing issues such as communication and assistance) rather than an approach that focuses only on the accessibility of physical infrastructure.

Completing this issue, Greg Hollin reviews the book *Disability and Other Human Questions* by Dan Goodley. Greg notes that this text is structured around six fundamental questions about humanity, community and desire. Disability features explicitly in only the first of these questions but, as Dan explains, disability remains

key because it provides a perspective or lens through which to consider the remaining issues. Despite the evident weightiness of the subject-matter, Greg describes the book as ‘an enlightening and enjoyable read’. The book is published as part of the new *Society Now* series, which aims to make ‘the best academic expertise accessible to a wider audience, to help readers untangle the complexities of each topic and make sense of the world the way it is, now’. Greg, whilst rightly highlighting the fact that this ambition is shared by the *IJDSJ*, acknowledges how important it is that Disability Studies features amongst the titles in this series. Greg’s reflections on what it takes to make academic work ‘accessible’ to a non-academic audience, particularly in relation to issues of cost, are insightful and prompt reflection. One aspect of accessibility is writing style and, on this point, he observes that ‘Goodley turns out to be a lucid, engaging, and thought-provoking tour guide’.

To continue Greg’s metaphor, we now bring our tour of this issue to a close. We hope you will find the journey through its content as stimulating and thought-provoking as we have. As ever, we welcome the thoughts of readers and look forward to new contributions from authors.

ACKNOWLEDGEMENTS

Thank you, as always, to the contributing authors for selecting this journal as an outlet for your important work. Many thanks to all the reviewers for your helpful feedback, so carefully articulated. We are very grateful to you all. Particular thanks are due to Simon T.M. Ng, for his work as book reviews editor; and Rachael Thomas for vital editorial and publication assistance.

REFERENCE

Nixon 2011. *Slow Violence and the Environmentalism of the Poor*. London: Harvard University Press.