

DISABLING AND ENABLING GEOGRAPHIES

Celebrating 20 years of research in *Social and Cultural Geography*

Abstract

The geographies of disability have been an important and enduring part of *Social and Cultural Geography* since its inception. The journal has featured more than 100 research papers on different dimensions of disability, illness, impairment, ableism and (in)accessibility. In this virtual special issue, we selected ten of these papers to highlight key theoretical and empirical contributions made within the journal. These include the careful spatial theorisation of lived experiences of disabilities, and critical analyses of shifting landscapes and politics of care and support that shape the lives of many disabled people. Collectively, these papers also signpost avenues for future research such as engaging with relational and more-than-human geographies, and the development of a more global politics of disability.

Introduction

Twenty years on from the inaugural issue of *Social and Cultural Geography* we want to celebrate the journal's importance in fostering a rich array of research exploring diverse disabling and enabling geographies. Since Carolyn Anderson's (2001) early call for readers of the journal to recognise and engage geographies of disability, *Social and Cultural Geography* has featured more than 100 research papers which discuss some aspect of disability, illness, impairment, ableism, or (in)accessibility. Looking back over two decades of back issues, we are heartened – indeed, pleasantly surprised – to note how one can trace a more-or-less continuing strand of publication on disabling and enabling geographies through the journal to date.

To celebrate twenty years of research on disabling and enabling geographies in *Social and Cultural Geography* we have closely re-read, and re-reflected upon, ten important papers from the journal. Selecting the ten papers (which will form a Virtual Special Issue during the Journal's anniversary year) was no easy task. We aimed to select papers of different vintages (and thus from different moments from Geographers' engagements with disability, amongst other theoretical and subdisciplinary developments). We also aimed to highlight papers which feature a diverse range of groups, experiences and disabilities in and from globally located settings. This necessitated some hard decisions and omissions, but we hope the following discussion at least gives a flavor of the major role of *Social and Cultural Geography* in fostering a sustained body of new work on disabling and enabling geographies.

The following essay has developed through our reading of the resulting ten papers. Our discussion is loosely grouped around three key themes, each representing a major area of theoretical-empirical innovation fostered within the journal. First, we highlight an important strand of work dedicated – across diverse contexts – to the careful spatial theorisation of lived experiences of disabilities. Second, we foreground work that has explored and critiqued the shifting landscapes and politics of care and support that shape the lives of many disabled people. Third, we celebrate work in the journal that signposts future directions, particularly by suggesting how research on disabling and enabling geographies might be extended and critically invigorated through engagements with scholarship on relational and more-than-human geographies, coupled with a more global, and critical/decolonised politics of disability.

Lived experiences

Over the last two decades, *Social and Cultural Geography* has featured an important, ongoing strand of work exploring everyday lived experiences of diverse disabling and enabling geographies. Reviewing twenty years of back issues, we are struck by the journal's achievement in opening a supportive space for rich empirical-theoretical consideration of diverse, lived disabling and enabling geographies. For example, the journal has featured moving qualitative or autoethnographic accounts of experiences of deafness (Valentine and Skelton, 2008; Kusters, 2017; O'Brien et al, 2017), epilepsy (Smith, 2012), learning/intellectual disability (Wiesel 2009; von Benzon, 2017; Wilton et al., 2018), cancer (Madge, 2016), Ménière's disease (Bell, 2017), dwarfism (Kruse, 2002), obsessive-compulsive disorder (Segrott and Doel, 2004), visual impairment (Worth, 2013; Sakaja, 2018), attempted suicide (Stevenson, 2016), emotional distress and PTSD (Atherton 2009), playing with disabled children (Horton, 2017), everyday (im)mobilities (Bissell, 2009), being a recipient of care (Wiles, 2011), and caregiving for family members with multiple chronic conditions (Giesbrecht et al, 2017). To celebrate at least some of this diverse work, in this virtual issue we have selected four papers that are centrally concerned with the theorisation of lived experiences of disabling and enabling geographies. The first of these is Inge Komardjaja's (2001) work on experiences of disabled middle class professionals in Bandung, Indonesia, which questions the appropriateness of normative western ideals of 'accessibility' and 'independence' for Asian and other global contexts. The second is Gill Valentine and Tracey Skelton's (2008) landmark work with D/deaf communities in the UK. The third is Joyce Davidson and Victoria Henderson's (2010) moving reflections upon 'coming out' on the autistic spectrum. Finally, we include Nancy Worth's (2013) careful theorisation of the complex social-relationalities of visually impaired (VI) young people in school settings.

Although diverse in focus, location and methods, these four papers share a number of themes and critical interventions. First, each paper contributes to a challenging, *spatial* critique of normative, medicalised and universalising understandings of disability. This is perhaps most explicit in Komardjaja's (2001) research in Indonesia. Komardjaja explores how lived experiences of

disability are always already geographically patterned and spatially unequal. In Bandung, for example, she notes that neighbouring families may have profoundly different experiences of disability depending on their class, caste and social-economic status, with professional middle classes typically having 24 hour access to domiciliary careworkers in the form of maids, servants and chauffeurs. Komardjaja also highlights regionally distinctive experiences of disability. Her research suggests that mobility impairments are especially exclusionary and stigmatised in Indonesia because they often preclude participation in a wide range of customary “habitual body traditions” (p.82) such as removing shoes, bowing to elders, and sitting or squatting during meals, household chores, market shopping, family gatherings, and religious ceremonies. Noting that these kinds of customary bodily practices have rarely been acknowledged within Disability Studies, Komardjaja argues that the theorisation of disability has been tacitly Eurocentric. She argues that apparently ‘universal’ concepts such as ‘accessibility’ – and policies, architectures and public spaces predicate upon them – have too often been “absorbed uncritically, with scant reference to local habits and resources” (p.78), neglecting “different nations,... different groups... distinct cultural traditions, economic bases, demographic distributions and resources” (p.84). Her implicit call for more research about diverse disabling and enabling geographies in the majority world and global south still resonates nearly two decades on.

Second, each paper provides rich insights into the identities, politics, communities and cultures constituted by diversely disabled people. Valentine and Skelton’s (2008) paper has been particularly important in this respect. Their work takes care to articulate the plural identities of D/deafness, noting from the outset a distinction between people who self-identify as Deaf (“a cultural and linguistic minority...with its own unique language – sign language – which has syntax and grammar...distinct from spoken language”) or deaf (those “who identify as disabled...[and] communicate orally (e.g. lip-reading and speech)”) (p.470). The paper explores diverse experiences of specialist UK support groups *for*, and more autonomous and politicised identities constituted *by*, D/deaf people. Valentine and Skelton were prescient in considering the potentially transformative impact of online and digital media for D/deaf communities, but end by critically reflecting upon the capacity of online communities to impact upon discriminatory ‘offline’ geographies.

Third, the papers recognise everyday experiences of coping with, and staying safe within, disabling everyday geographies. Davidson and Henderson’s (2010) paper is particularly useful and challenging in this regard. The authors highlight the ‘repertoires’ of exhausting everyday tactics commonly used to conceal or manage ‘hidden disabilities’. Analysing autobiographical texts by authors on the autistic spectrum, they identify different kinds of tactics: from rigid concealment (e.g. by suppressing or mimicking behaviours), to ‘qualified deception’ (diffusing awkwardness through partial or somewhat deceptive disclosures, e.g. explaining away AS behaviours as caused by migraines or allergies), to different forms of ‘coming out’ on the spectrum, to more activist dispositions of seeking to education others. Davidson and Henderson

are deeply critical of medicalised discourses and extant research in which “the loudest voices in debates over autism have tended to be (non-autistic) parents and professionals” (p.157). They also critique disabling environments – including the neoliberal academy – which continue to constitute ableist and ‘neurotypical’ norms of non-disclosure and concealment. However, they draw strength from work on ‘passing’ and ‘coming out’ from LGBTQ+ and D/deaf authors, which “offer personal and political lessons about the practicalities, tactics and strategies of disclosure” (p.156).

Fourth, these papers advance understandings of the complexly social-relational nature of disabling and enabling geographies. Worth’s (2013) paper is particularly important in theorising this complex social-relationality by exploring how lived experiences of visual impairment intersect with social geographies of age and institutional geographies of mainstream and specialist education in the UK. By exploring VI young people’s narratives of everyday friendship, bullying and relationships with care and support workers, Worth makes a number of important, nuanced contributions to understandings of “how disability operates through social relations” (p.106). Building upon Thomas’s work (2004), Worth argues that understandings of the social-relational in the ‘social model of disability’ must be attuned to the subtleties of individual lived experiences, the structural-institutional geographies of education and care, and the complex dynamics of “social spaces that are created by all of the differently positioned actors within” (p.119). The narratives of young people represented in Worth’s paper are, by turns, deeply moving, funny and urgent and demonstrate the necessity of exploring social-relationalities of disabling and enabling geographies through people’s own subtle, everyday narratives of lived experience.

Shifting landscapes of Care/Support

Another important area of work within the journal has been to critically examine the shifting landscapes of care and support that shape the lives of disabled people.¹ Here we draw attention to three papers that make important contributions to this topic. The first is Hester Parr and Chris Philo’s (2003) work on the landscapes of care confronting people with mental health problems in rural Scotland. The second is Edward Hall’s (2011) research on the personalisation agenda in the UK, and what this means for the spaces and scales of care/support available to people with learning (intellectual) disabilities. Finally, we feature Högström’s (2018) work on the post-asylum landscape in Sweden.

While focused on different contexts, the papers exhibit several common themes. First, all are broadly concerned with theorizing the shifting geographies of care and support. Thus, Parr and

¹ Work advancing the social and cultural geographies of care and caring has been an enduring presence within the journal (see the 2003 special issue (4:4) edited by David Conradson, the 2018 special issue (19:3) edited by Edward Hall and Andrew Power, as well as Hall and McGarrol, 2013; Cloutier-Fisher et al. 2015; Giesbrecht et al, 2017).

Philo's (2003, 472) aim is to "explore further the idea that care and caring are thoroughly social activities and always constituted by aspects of the places in which they occur". At a broad level, the papers note the spatial and scalar shifts over the past half-century from more centralized, institutional geographies of care, to more local, community-based geographies (also Kearns et al. 2010; Singer and Gillad, 2017). Hall and Högström are both concerned with more recent restructuring that shifts the focus from collective, community-based forms and spaces of support to a focus on individuals as the locus of care policy and practice (also Juhila et al., 2016). Each of the papers is interested in how these spatial and scalar shifts impact how care/support is provided, who provides it (formal paid support versus informal help), in what settings, and how it is enacted and experienced. In all three papers, we see the power of geography to shape the nature of care and caring relations. Parr and Philo, for example, describe a rural landscape in which formal mental health services are sparsely distributed and where people rely primarily on a small number of psychiatric nurses and local GPs for mental health care. GPs noted that because their time is scarce they tended to rely on medication as a way of dealing with emotional problems that might be dealt with by 'talking treatments' in other geographical settings.

Second, the papers draw attention to the multiple processes that structure these landscapes in many western countries. These include economic retrenchment, welfare state restructuring, the rise of disability rights movements that highlighted the oppressive nature of segregated and institutional forms of care and support, as well as enduring cultural norms of 'disabling' difference. Hall and Högström also highlight shifting care ideologies informed by a neoliberal emphasis on individual 'freedom of choice' to consume care/support. Both authors argue that the success of this neoliberal agenda can be attributed in part to the way in which it was able to draw legitimacy from (physically) disabled activists' calls for independent living and individual control over supports. This emphasis on self-determination and choice has since been extended to other groups in ways that ignore the diverse needs and capacities of the larger disabled population. For Hall in particular, the shift to the individual as the appropriate locus of caring has contributed to a de-legitimation of communal spaces of care even though these can "afford opportunities to be together, share experiences, gain support, build confidence and relationships of care and support" (2011, p.592). For Parr and Philo, attention to rural landscapes raises concerns about individualization of care but for quite different reasons. In their research, physical distances separating people combined with the socio-cultural climate of stigma and gossip worked against the creation of collective spaces of care/support in rural Scotland. This had implications for people living with mental health problems, but also for informal carers who remained isolated from alternative sources of information and support. The findings pose broader questions about the extent to which rural communities, where lives may be physically distant but socially proximate, are settings in which community care, and in particular *collective* experiences of care in the form of drop-in spaces, group therapy, can be realized.

Third, the papers are concerned with the potential to create and sustain what Högström (drawing from Tonkiss (2013)) terms ‘material spaces of hope’ in broader landscapes characterized by fragmentation, underfunding, isolation and hostility. For Parr and Philo, the rural setting offers few opportunities to foster such spaces of hope beyond the support and companionship offered to people in the privacy of their homes. For Högström, the fragmentation of contemporary mental health services creates opportunities to carve out spaces that embody “many of the positive features that deinstitutionalization was intended to entail but seldom did”. She uses the example of *The 197th*, a supported living facility that through its location, design and operation “evades a clear institutional framing” and offers residents opportunities to navigate recovery in public and private spaces within and around the facility. For Hall, the push for personalisation is grounded in a spatial imaginary of care delivered in the private space of the home, and public spaces of ‘open’ employment and ‘the street’ (2011, p.590), with a concurrent reduction in sheltered options and spaces. Yet this shift is not necessarily reflective of the realities or preferences of people with learning/ intellectual disabilities who continue to confront exclusion in mainstream spaces. In response, Hall notes that many people continue to value, use and defend these collective spaces of care. Recent work by Power and Bartlett (2018) also documents the efforts of people with learning/intellectual to create new ‘safe havens’ in the face of day centre closures.

Emerging/Future Directions

Finally, we draw attention to two evolving/emerging areas of scholarship. Notwithstanding the richness of scholarship on disability over the last two decades this work has often suffered from a narrow geographical focus, concerned principally with issues and experiences in Europe, North America, and others part of the global North. This is despite the fact that the majority of disabled persons live in the global South. Komardjaja’s (2001) paper in this journal offered an important early exception to this trend. Encouragingly, recent work in the journal has continued to expand understandings of impairment/ disability beyond the global North. Kusters’ (2017) paper considers how deaf and disabled people negotiate space in the ‘handicapped carriages’ of Mumbai’s suburban commuter trains. While officially designated for the exclusive use of disabled people, intense pressure for space means carriages must be actively defended from non-disabled commuters. This ‘grassroots’ struggle for control draws upon and reproduces hierarchies among and between deaf and disabled populations based on several factors, including the visibility of a condition and moral judgments about deservingness. Concurrently, hierarchies reflect other inequalities (particularly on the basis of class and poverty) that intersect with disability. Embedded within the specific socio-cultural setting of Mumbai, Kusters’ ethnography deftly illustrates how meanings and experiences of impairment/ disability emerge through shifting relationships with other people, objects and material surroundings. Embodied identities are contingent; “who is accepted in the compartment and who will get a seat is contextual, decided on the spot and not a fixed given reality” (2017, 220).

In recent years, there have also been concerted efforts to decolonize disability studies. Helen Meekosha (2011) has been at the forefront of these efforts, arguing that disability scholarship has failed to confront the reality in the global South that large numbers of “impaired people are ‘produced’ in the violence and war that is constantly provoked by the North, either directly or indirectly, in the struggle over the control of minerals, oil and other economic resources” (668). Max Counter’s (2018) paper offers an excellent example of research that engages directly with these colonial/neo-colonial contexts and relations. Counter documents the ways in which disablement and displacement intersect in the lives of landmine victims in Colombia’s Magdalena Medio region. Decades of conflict in the region have produced massive rural displacement and dispossession of rural land for the sake of agribusiness and mining expansion. The use of mines by all sides in the conflict has produced a landscape that is generative of both bodily impairment and a disabling rural geography of fear. For landmine victims, injury and impairment often force rural-urban relocation and a loss of daily rhythms. At the same time, victims confront structural violence as they fight for government assistance and reparations. While documenting the embodied experience of impairment/ disability, Counter is clear that these experiences must be understood in relation to “much larger processes of conflicts over land, territorial control and transnational flows of capital” and to Colombia’s position “within uneven and violent geopolitical contexts” (466).

Second, the issue features a paper by Franklin and Schuurman (2017) on ‘animal retirement’, particularly as this term is used to capture the treatment of horses as a companion species. This paper raises the possibility of a dialogue between critical scholarship on impairment/ disability and animal/more than human geographies. There may be reluctance to consider the conceptual and political implications of a more-than-human geography for populations who have too often been positioned as less than human. Yet as Sunaura Taylor (2017) demonstrates in her book ‘Beasts of Burden’ there is value in thinking through the ways in which human ableism is integral to, and reproduced through, the oppression of nonhuman animals. In their research, Franklin and Schuurman show how a series of social and institutional changes have rendered increasing numbers of horses ‘unable’ to meet the leisure needs of amateur riders. In part, these are changes within the equestrian industry (e.g., more stringent assessment of the soundness of limb and gait), but they also reflect an increasing intolerance of unsound bodies in equestrian communities and the ease with which horses can be replaced. The net effect is that growing numbers of horses are rendered impaired/disabled and subject to ‘retirement’. At the same time, we see in the research how the relationships that flow through retirement yards as spaces of care (proximate relations with retirement yard staff and other horses; more distant relations with owners) shape the daily and seasonal experiences of individual horses. Drawing from Cutchin’s work on human care homes, Franklin and Schuurman note that the space-time structures that characterize retirement yards, underlain by a particular ethics of care, are key to the pursuit of specific therapeutic aims. Under these conditions, retirement yards can become ‘places of meaning, attachment and association in which situated horse-human relationships have meaning’

(2017, 16). At the same time, horses' access to private retirement care remains contingent upon owners' willingness and ability to pay for such services.

In closing, the work of assembling this virtual issue has provided us with a rewarding opportunity to revisit the rich scholarship on disability that has appeared within the pages of the journal over the past two decades. The breadth and depth of this work, and the ongoing commitment to innovative scholarship in this area of research, leaves us optimistic that *Social and Cultural Geography* will serve as an important venue for critical disability scholarship in the years to come.

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