People with disabilities
Hall, Edward

Published in:
COVID-19 and Similar Futures: Geographical perspectives, issues and agendas

DOI:
10.1007/978-3-030-70179-6

Publication date:
2021

Citation for published version (APA):
Abstract
The COVID-19 pandemic has had a series of significant and complex impacts on the lives of people with disabilities. A disproportionate number of people with disabilities have become ill and died; established inequalities in health and social care provision have been highlighted and exacerbated. The periods of ‘lockdown’ and ongoing restrictions have meant fewer social contacts and reduced care provision for many people with disabilities living independently, with impacts on physical and mental wellbeing. Telephone and online communication has been very effective for many, opening up new opportunities for social activities and receipt of care; for some, availability of and accessibility to technology have been challenging. Many community-based activities used by people with disabilities have been suspended, with concerns for provision in the longer-term. People with disabilities will be significantly affected by the economic and employment fallout of COVID-19; for some, the switch to working from home has meant more opportunities. COVID-19 has transformed social environments; mask wearing and social distancing, and one-way systems and restricted parking, present challenges for some people with disabilities. Geographers can make a significant contribution to the study of the impact of COVID-19 on people with disabilities, and the building of an equal and inclusive post-pandemic future.

Bio
Edward Hall is Reader in Human Geography at the University of Dundee, UK. His research interests are in disability, learning disability, and social care and support. He has completed projects on social exclusion/inclusion and belonging, creative arts, and employment; he has recently completed studies of ‘self-build’ social care and support with the University of Southampton, and disability hate crime. The projects adopt a co-productive and inclusive approach to research and involve collaborations with non-academic partners. He publishes widely, in academic journals in geography and disability and learning disability studies and is co-editor of Towards Enabling Geographies: ‘Disabled’ bodies and minds in society and space (Routledge, 2010) with Vera Chouinard and Robert Wilton.
Geographies of disabilities is now an established sub-discipline, offering particular insights into the experiences of people with disabilities (Chouinard et al., 2010). From a small number of studies in the 1980s focused on the incidence of chronic conditions and health and social care services, geography shifted and broadened its analytical focus to the societal and structural discrimination and exclusion of people with disabilities, following the lead of the disability political movement and academics with disabilities (Gleeson, 1999). At the same time, relations of research were increasingly challenged, with people with disabilities demanding involvement in the setting of the research agenda. While structural analyses remain important, as social and spatial exclusion persists, geographies of disabilities have contributed to significant theoretical developments, critiquing the ‘social model’ of disability by emphasising embodied experiences of impairment (Hall, 2000), and more recently drawing on notions of relationality and non-representational theory to conceptualize ‘dis/ability’ as the outcome of an emergent set of relations between bodies, places and objects (Hall & Wilton, 2017). Geography has also continued to contribute to the study of the ongoing transformation of the landscape of care and support for people with disabilities, in the context of broader changes in policy and discourse related to disability (Power & Hall, 2018).

The COVID-19 pandemic has had a series of significant and complex impacts on the lives of people with disabilities, which continue to unfold; a fuller assessment of the nature and scale of the impacts will have to take place at a later stage. For now, some initial reflections on the challenges and opportunities for geographical insights and contributions, can be proposed.

Of immediate importance is the disproportionate illness and death rates amongst people with disabilities. The UK Office for National Statistics reports that between March 2 and July 14 2020, 27,534 people with disabilities died having tested positive for COVID-19, 59% of all deaths recorded (although constituted 16% of the study population); women with disabilities were 2.4 times, and men 2 times, more likely to die than those without disabilities, once demographic factors had been taken into account (ONS, 2020). Further, a complex epidemiology of incidence of COVID-19 cases, hospital admissions, and deaths has emerged, with clear and dynamic demographic and geographical patterns: people with higher level of impairment, older people, those with co-morbidities, those from ethnic minorities, and people living in deprived housing and in poor areas, are all more likely to be impacted. As such, the pandemic is a timely reminder of the (commonly neglected) complex intersectionality of people with disabilities. Geographical analyses of the type first undertaken by (medical) geographers, as noted above, could make a significant contribution here (Li, 2020). That the majority of COVID-19 deaths (as of July 14 2020) were people with disabilities, has led to calls for an inquiry (Disability News Service, 2020a); accounts from people with disabilities and disability organizations have highlighted how the pandemic has reflected and exacerbated long-standing inequalities and inadequacies in healthcare and social care and support, including lack of access to Personal Protective Equipment (PPE) for care staff, insufficient testing, and restrictions on care and support provision in people’s homes and, in some cases, hospitals (with some reports of discrimination in provision of intensive care and other hospital treatments for people with existing health issues) (Disability News Service, 2020b; Dickinson et al., 2020). Illness and death rates, and inequalities in healthcare provision, have highlighted the significance of who ‘counts’ as a ‘person with a disability’ (Reed et al, 2020). Further, being identified as a person with a disability (or not) determines access to assistance and support, instructions to ‘shield’, and to receive a vaccine when one becomes available. As geographical studies have demonstrated, there are multiple ways of defining ‘disability’; the centrality of biomedical data in the surveillance, assessment and management of the pandemic, has reinforced the equating of disability with impairment and illness. Geographers, who have long contested this ‘medical model’ of disability, can contribute to the study of
COVID-19 by demonstrating how social contexts and relations shape the impact of the pandemic on the lives of people with disabilities.

For many people with disabilities, whose impairments or conditions mean that they are particularly vulnerable if they contract COVID-19, the UK government has instructed ‘shielding’ for an extended period, i.e., remaining at home with very limited contact with other people (only essential care staff). Whilst there are medical reasons for this, there has been evidence of a lack of guidance and support (including inability to access food home delivery services and reduced at-home practical care provision). For many people with disabilities, the loss of everyday social contacts, within and outside their homes, especially if they live on their own, has had significant, and as yet not fully understood, impacts on mental and physical health, with some speaking of social isolation and ‘being abandoned’ (Webster, 2020). COVID-19 has also exposed deeper health and social inequalities; for example, people with intellectual disabilities are more likely to be obese, have diabetes, and asthma, and to be on a low income and live in low-quality housing, all of which make someone more vulnerable to the effects of COVID-19, and also face discrimination in access to and quality of care from healthcare services before and during COVID-19 (Hatton, 2020).

For all the population, COVID-19 has meant (and will mean for the foreseeable future) a constrained social world, with more time spent at home and restricted movement outside the home. For many people with disabilities, this has meant further constraints on already limited access to and presence within local community and public spaces. The major policy shift over the last 20-30 years towards personalization and independent living for people with disabilities, and the related closures of institutional and collective care provision, has meant that many more people are now living on their own or with a partner, friends or family. Of course, no-one lives a truly independent life; geographical studies have shown how people with disabilities living on their own are in almost all cases interacting (to varying degrees) with a network of others – family, friends, formal care, or support staff (private and public sector), voluntary organizations, community groups, etc. – in the course of their everyday lives, and it is these interrelations and interdependencies that make independent living both possible and meaningful. COVID-19 is a major disruption to these complex and in some instances fragile networks of relations and supports, and hence the ability to live independently and sustain wellbeing. As political attention and policy action focused on healthcare provision, at least in the early months of the COVID-19 pandemic in the UK, social care services were neglected. When social care did reach the news agenda, it was chiefly in relation to the high case numbers and death rates in collective environments of (older people’s) care homes; people living on their own largely disappeared from view. For people living independently, visits by paid care staff, including personal assistants, and from local voluntary support organizations, were reduced and in some cases stopped; contact with family and friends was also significantly reduced. It was reported that in many cases local authorities have focused their resources on those in most ‘critical need’, with home support stopped for many (and challenging to ensure consistency as personalised care and support commonly involves a multitude of care staff and agencies) (Dickinson et al., 2020); UK Government legislation has permitted this to happen (BBC Disclosure, 2020; Disability Law Service, 2020). Whilst this was understandable and in line with UK Government guidance, it can also be seen as an acceleration of the withdrawal of financial, practical and social support for people with disabilities during the decade of austerity in the UK (from 2010) (Power and Hall, 2018). Many people with disabilities are now seeing few people beyond some care staff (as noted above), with family and friends unable to visit, and movement outside their homes severely restricted; for many children with disabilities, families are taking on more responsibility for care and home education, as care sites and schools in the UK for those with Special Educational Needs and Disabilities remain closed or with restricted opening. For the care visits that remain, these have focused on essential support, and
involved the increased use of PPE, as well as social distancing. For some people with disabilities, in particular people on the autism spectrum, and with intellectual disabilities, such measures have been distressing. More broadly, the use of PPE, whilst necessary to prevent infection, has further emphasized how for many people with disabilities, whilst they live in ‘their’ homes, institutional/clinical practices and objects enter these spaces and in doing so subtly or more obviously transform them. Concerns have been raised that, whilst crucial, measures to protect people with disabilities, as noted above, have meant that public health regulations are increasingly ‘in tension’ with the established norms of a rights-based person-centred approach to decision-making about delivery of care and support (Doyle and O’Brien, 2020).

Telephone and online have been very effective means for many people with disabilities to maintain communication and social contact. Indeed, wider society’s increasing presence in virtual space has meant greater opportunities for many people with disabilities to participate in employment, arts and leisure, and social activities (Ryan, 2020); and some have welcomed what have rapidly become the ‘norm’ of online medical consultations and care contacts. However, there have been challenges of availability of technology and accessibility. For many, online formats cannot adequately replace face-to-face and physical contact, with significant impacts on mental wellbeing. As more people with disabilities have been encouraged to live independently, mainstream community spaces and organizations (including libraries, leisure centres, and arts venues, as well as cafés and shopping centres) have been presented as ‘appropriate’ places for people to be ‘cared for’ by their communities (Power & Hall, 2018); alongside this, many voluntary sector organizations have been set up to provide opportunities for people with disabilities to develop interests and skills in arts, employability, and leisure. All of these have come to a grinding halt in the ‘lockdown’ period, and even as restrictions are eased in many areas, many of these organizations are finding it very hard – practically and financially – to restart their activities. There is a widespread concern that a whole swathe of this new emergent ‘landscape’ of care and support, that has been rapidly replacing formal care provision, will not survive the COVID-19 pandemic, with a significant long-lasting impact on the lives of people with disabilities. More hopefully, many small community organizations, and new networks of volunteers, have been practicing ‘personal and collective acts of care’, providing practical and emotional support for people with disabilities in local areas in the midst of the pandemic (Sparke & Anguelov, 2020; Yarker et al., 2020). As the current crisis eases, there will need to be a comprehensive review of social care and support, in particular its financial and logistical sustainability, the role of technology in provision of care, and further, the necessity to involve people with disabilities in this process (Disability Rights UK, 2020a).

As geographical studies have demonstrated, there is long-standing, persistent, and deeply-embedded discrimination and social and spatial exclusion experienced by people with disabilities. COVID-19, as with any crisis, has exposed and exacerbated these exclusions (Inclusion London, 2020). For example, people with disabilities are less likely than those without disabilities to be in paid employment (and even more so for people with intellectual disabilities), and when in work, are more likely to be on temporary and/or part-time contracts, and further are over-represented in the retail and hospitality sectors (Disability Rights UK, 2020b). The economic and employment fallout from COVID-19 is such that these jobs are the ones most likely to be lost. The forthcoming severe recession will undoubtedly significantly reduce the opportunities for inclusion of people with disabilities in paid employment; in addition, many of the volunteering positions occupied by many people with disabilities have been suspended, and will be slow to recover as organisations struggle in the post-COVID world (as noted above). For those people with disabilities employed in service sector jobs, where home working has become the ‘new normal’ in response to COVID-19, increased flexibility – and perhaps more importantly heightened awareness of the need for flexibility in working hours, caring responsibilities, people’s broader/complex needs to
sustain their wellbeing in their jobs, and employers realizing how many employees they have with a range of needs, and their responsibilities, legally and otherwise, to support them – has provided opportunities for people with disabilities who face challenges with commuting and access to and within office spaces. Long-standing discussions about the need for flexible, home-based, working, have been accelerated by COVID-19 and enabled by enhanced communication technologies. However, this assumes that employers are adequately responding to the needs of employees in relation to equipment and accessible technology; further, it can strengthen assumptions about who ‘should’ be working where, and with people with disabilities absent, could postpone efforts to make workplaces accessible.

COVID-19 has transformed social environments, with communities, streets, and public spaces emptied of people during the lockdown period; as restrictions ease, rules regarding social distancing, social gatherings and wearing of masks, will almost certainly remain in place. Geographical studies have highlighted the relative absence of people with disabilities in public spaces, and the physical inaccessibility and social attitudes that drive this (Hall, 2019a); lock downs and shielding has further removed people with disabilities from these spaces, with the potential that the often hard-won access and inclusion will be lost when ‘normal’ life resumes. Redesigning public spaces to facilitate social distancing has enhanced accessibility for some people with disabilities. For others, including those with visual impairments, and some with intellectual disabilities, one-way systems and restricted parking, rules on social distancing and restrictions on ‘tactile contact’, can be challenging (Senjam, 2020); for D/deaf people who use lip-reading, compulsory mask wearing has been exclusionary. Further, people with disabilities experience significant levels of hate crime (Hall, 2019b); there is evidence that COVID-19 has led to some people with disabilities in public spaces being labelled as ‘virus spreaders’, including some incidences of those not wearing masks for health reasons being subject to harassment (PA Media, 2020). For people with disabilities who are subject to ‘interpersonal violence’ in their homes, there is evidence that lockdown has increased the risk (Lund, 2020).

The participation of people with disabilities in both research to understand the impacts of COVID-19 on health and society, and in devising responses to the pandemic, is crucial for building an equal and inclusive post-COVID-19 future, for people with and without disabilities. Geographers of disability are well placed to make a significant contribution: in the analysis of incidence of the disease; mapping the dynamic landscape of health and social care provision; listening to and interpreting the experiences of people with disabilities in transformed social and physical environments; recognising both people’s vulnerability and their skills of resilience; highlighting accounts from people with disabilities internationally, in particular in countries in the Global South where the pandemic is having a major impact; designing new arrangements for employment, and accessible community and public spaces; and developing innovative and accessible online research methods in co-production with people with disabilities.
References


