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Introduction to Special Issue

New Dialogues Between Medical Sociology and Disability Studies

Introduction

This special issue explores the intersections, boundaries, and collaborative opportunities between the disciplines of medical sociology and disability studies. Both disciplines co-exist, yet, outside of important exceptions (Barnes & Mercer, 1996; Scambler & Scambler, 2010; Thomas, 2004a; Thomas, 2007; Thomas, 2010), and especially in the UK, there is a long legacy of disconnection and territory-protection with little recognition of, and attempt to find, points of convergence and divergence.

Medical sociology has developed well-established and well-used concepts and sentiments on chronic illness and disability: the sick role (Parsons, 1951), biographical disruption (Bury, 1982), loss of self (Charmaz, 1983), narrative reconstruction (Williams, 1999), and illness narratives (Frank, 1995), to name a few. However, scholars such as Carol Thomas (2004b; 2010) argue that the use of these concepts aligns with a 'social deviance paradigm', that is, a personal tragedy bias that understands disability as living with a personal failing and a source of pity, shame, stigma, and abjection. This critique is informed by a 'social model of disability' (Oliver, 1990; UPIAS, 1975) that distinguishes between bodily 'impairment' and the disabling conditions that people encounter in their everyday lives. Medical sociology, it is said by some, is often apolitical and frames disability simply as impairment, without a substantive and critical analysis of the influential role of structures and oppression in the lives of disabled people. Yet, others contend that setting up a disciplinary 'divide' in this way is both naïve and overstated. Shakespeare and Watson (2001, 2010) claim that impairment can play an integral role in the life-worlds of disabled people, and that a sole focus on a 'social oppression' paradigm risks silencing the embodied pain and physical suffering that disabled people can face. They advocate, instead, for a sociology of disability that recognises and analyses impairment, yet places power and structure at the core of the analysis.

This is not the space to rehearse the entirety of these arguments, nor will we speculate as to why this tension remains. Instead, we contend that the framing of the supposed differences and disagreements between both disciplines – e.g. engagement with medicine, structure and agency, politics, embodiment and impairment, research practice, the distinction between 'illness' and 'disability', and so on – is largely unfair and unproductive. Work in disability studies has examined lived and embodied experiences of what might be called 'impairment effects' (Thomas 2010), and contributions in medical sociology have attended to matters of power, structure, and inequality. In the 1970s, Ivan Illich (1974) and Irving Zola (1972) recognised medicine as an institution of social control, especially so for chronically ill and disabled people. More recently, scholars like Laura Mauldin (2016), Emma Sheppard (2020), and Ned Coleman-Fountain (2020) provide productive approaches for intermeshing approaches, tropes, and outlooks from medical sociology and disability studies.

It is worth noting, too, the wealth of scholarship across other disciplines – including social policy and ageing studies/critical gerontology (e.g. Garthwaite, 2015; Johnson 2022; Moffatt & Noble, 2015) – and drawing upon different theoretical paradigms – including feminist theory, critical race theory, sexuality studies, and queer theory (e.g. Goodley, 2011; Schalk & Kim, 2020) – which have significant potential to inform both medical sociology and disability studies (indeed, some is published in Sociology of Health and Illness). Here, we recognise the importance of feminist writers, particularly, in seeking new ways to incorporate ideas of intersectionality and embodiment into discussions of disability and chronic illness (Kafer, 2013; Morris, 1993; Morris, 1996). This special issue recognises past disagreements, whilst also working across current fields of inquiry, to engage with the challenges faced by chronically ill and disabled people. Given the multiple challenges many face across different global contexts, collaboration and working across previous boundaries is a contemporary necessity.

We also believe that disability continues to be marginalised in academic circles. Given the relevance that disability holds for conceptual, methodological, and empirical debates across the social sciences, and particularly in sociology, this is frustrating and, arguably, a form of 'epistemic injustice' (Fricker, 2007) – a concept drawn upon in the special issue. This is not to say that sociologists and related others have always ignored disability (Barnes, 1998; Barnes, 2012; Hughes, 2009; Hughes & Paterson, 1997; Meekosha, 2011; Shakespeare, 2006; Shildrick, 2005). Rather, disability is frequently cast aside, or at least overlooked, as a serious sociological topic. Maintaining boundaries between medical sociology and disability studies risks wasting time and fostering insular scholarship. Scholars located in both fields mostly seem fuelled by similar aspirations. By pursuing a critical yet open and collegial dialogue with one another, we can explore the complexity of living with disability from multiple vantage points. This special issue is a step in this direction. At the same time, the marginalisation of disability as a topic also generates experiences of marginalisation for those working in the field – particularly disabled scholars who remain extremely underrepresented in academia. Working across these boundaries, thus, also requires working across power differences and inequalities. This one special issue cannot resolve all these issues, nor can we say that we have been fully successful in confronting this lack of representation.

We are excited to introduce a collection of insightful, eclectic, and thought-provoking contributions from authors located in nine countries (Bulgaria, Canada, Chile, Czech Republic, England, Malawi, Scotland, Spain, Wales), at multiple career stages, and from within and outside of academia. These contributions introduce new contexts, ideas, and possibilities for collaboration between scholars in medical sociology and disability studies (and possibly beyond). This special issue is organised into five primary, albeit intersecting, themes: 1) theorising disability; 2) embodied experiences; 3) diagnosis and diagnostic categories; 4) care and care practices, and; 5) expanding perspectives and methods.

Theorising Disability

Medical sociology and disability studies introduce concepts, ideas, and theoretical paradigms for making sense of people's experiences, perceptions, and practices when living with chronic illness and disability. Each acknowledges the significance of institutional and material factors in shaping such experiences, but draw upon different conceptual tools to do so. Authors in this special issue recognise the contemporary points for convergence in theorising disability and, in so doing, dismantle the notion that medical sociologists and disability studies scholars are unwaveringly interested in different matters. Their contributions represent efforts to enable greater possibilities for working together rather than apart. Whilst all contributors work with and add to theoretical concerns, we focus here on three who draw from wider shifts in theoretical thinking to conceptualise how we can use alternative tools to the social model to conceptualise the wrongs directed at chronically ill and disabled people.

Both Teodor Mladenov and Ina Dimitrova (2022), and Tom Porter, Nick Watson and Charlotte Pearson (2022), use Fricker's (2007) concept of 'epistemic injustice' to explore how systems and processes supposedly designed to support disabled people and those who are chronically ill, instead leave them marginalised and oppressed. Mladenov and Dimitrova discuss 'hierarchies of epistemic power' that inform the interactional exchanges between patients and health care professionals (2022 3). With reference to a qualitative study of how parents seek a diagnosis of, and treatment for, disabled children in Bulgaria, Mladenov and Dimitrova outline three modes of epistemic injustice: testimonial injustice, hermeneutical injustice, and contributory injustice. The intersectionality of disabled people's experiences is also observed through how gender, class, and race mediate parents' experiences, whereby their accounts are refuted (testimonial injustice), knowledge and resources are not provided (hermenutical injustice), and their alternative configurations of their child and what they require is denied (contributory injustice). As with Rojas-Navarro and colleagues (2022) later in the issue, Mladenov and Dimitrova contend that diagnosis can in some cases be a form of justice, where testimonies are validated in a way that enables the child and their needs to gain recognition. Yet, parents continually confront 'epistemic wrongs', namely 'political acts ensuing from structural inequalities and painful assaults' on them and their children (our emphasis, 2022 15).

Porter et al. (2022) concentrate their analyses on the knowledge (mis)production that occurs when people apply for disability benefits within the British welfare system, an area acknowledged to be interest to both disability studies and medical sociology. The authors undertook qualitative interviews with people who had applied for two key disability benefits in the UK – Employment and Support Allowance (ESA) and Personal Independent Payments (PIP) – and detailed discursive analysis of the 'rule books' that assessors follow when reviewing applications. Within these processes, disability is reified 'as an administrative category' (2022 2) devoid of the social realities of trying to live or work in a disablist society. Like Mladenov and Dimitrova, Porter et al. find testimonial injustice and hermeneutical injustice occurring through the kind of evidence accepted and rejected in the assessment process, and through the ways that guidance to assessors directs them to be suspicious of claimants as their default starting point. The result is 'epistemic sabotage', whereby the disabled mind/body 'exists only administratively as the interaction between contested impairments with unreal tasks and environs, all of which are framed by the latest legal ruling as to what is (un)permissible at a given moment in time' (2022 19). In both articles, then, epistemic injustice is proposed as a concept to politicise medical sociology, whilst preserving its occupation with the everyday experiences and perspectives of ill and disabled people.

In the article by Dan Goodley, Rebecca Lawthom, Kirsty Liddiard, and Katherine Runswick-Cole (2022), drawing from Sara Ahmed (2004) and new materialist theory, the authors ask what are the social and cultural foundations of 'affect' that locate the production of suffering, particularly those in enforced marginalised locations. They draw upon an analysis of public blogs produced by disabled people across the world during the COVID-19 pandemic. Whilst acknowledging the material impact of COVID-19 for disabled people (e.g. death rates, socio-economic deprivation), their focus – by theorising affect – is to consider the emotional impacts of the pandemic, and what this can tell us about bridging approaches and interests in medical sociology and disability studies. Disabled people's affective realities, for Goodley and colleagues, were observable in how their everyday lives were made 'fragile' via the marginalisation cultivated by State responses that privileged the treatment and rights of apparently abled-bodied people. 'Feeling fragile', they profess, is 'exacerbated by a dis/ability complex that values (assumed) ability over (prescribed) disability' (original emphasis, 2022 8). At the same time, the authors recognise, disabled people and others enacted interdependence in online and offline spaces. This offered both material and emotional, in the absence of State, support – along with the affirmation that disabled people's lives are valuable and they have the right to live and be protected from infection. Goodley and colleagues contend that 'affect' works as a conceptual tool for developing a 'frictional relationship' between medical sociology and disability studies, where disability becomes a 'driving subject' and where modes of dis/ableism are at the centre of analysis (2022 6).

Diagnosis and Diagnostic Categories

One way in which bodies may become recognised as 'valid' or 'deserving' of care, treatment, and access, is by having a diagnosis (though, as medical sociology analyses often highlight, it is rarely this simple). Diagnosis is an area across medical sociology and disability studies where there is shared criticality, if not always collaboration. Both disciplines fully recognise the political and social constructed nature of diagnostic processes and categories, together with the power inequalities that remain in who or what can be a/the authoritative voice.

Nevertheless, we argue, there are differences in how medical sociology has seemed more interested in those with experiences of a range of health and illness 'problems' campaigning to acquire a diagnosis (sometimes to validate, sometimes as a necessitated gateway to services), while disability studies has been arguably more wary of the problems created by embodied differences falling under the jurisdiction and (paternalistic) power of medicine through diagnostic categorisation. Recent work examining the practices and agents involved in diagnosis offers ways to bring these different interests together – for example, work examining the role of diagnostic categories in welfare entitlement decisions (Hansen et al., 2014) and the social complexities of genetic diagnosis (Dimond, 2014; Latimer, 2013). Two articles in this issue offer templates of how working across medical sociology and disability studies enables understandings of the dynamics involved.

Sarah Redikopp and Sarah Smith (2022) argue that non-suicidal self-injury disorder (NNSID) – proposed by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) to distinguish patterns of self-injury from other diagnostic categories – is a fruitful area of enquiry for medical sociology and disability studies. Taking NSSID as an entry point, and drawing upon feminist psychiatric disability theory, the authors claim that NSSID illuminates the limits of a fully 'de-medicalised' engagement with self-injury, whilst 'locating the socially and historically specific nature of the production of "disability" and madness itself' (2022 2). Medicalisation has historically been a vital conceptual tool for questioning modes of labelling behaviours and ways of being, together with highlighting power hierarchies permitting labelling and misidentification of social/political failures as personal failures requiring cure and treatment. Nonetheless, Redikopp and Smith set out to recognise that 'conditions of oppression can be themselves maddening' and require response, including medical treatment (Redikopp & Smith, 2022 4). Here, both medical sociology (with its focus on diagnostic processes and labelling) and disability studies (emphasising embodied and affective dimensions of pain) have something to offer for their analysis. They show how some people can engage with the diagnosis of NSSID with awareness of the scope for such a classification to stigmatise and de-emphasise the social and material conditions that lie behind their issues, whilst making use of it to alleviate the pain – through medical treatment – that their self-injury practices produce. Nonetheless, focusing on everyday embodiments, for Redikopp and Smith, shows us how self-injury practices can be a way to 'cope with, survive or respond to structural and social forms of gendered, racialised, ableist and classed violence' (2022 10).

The politics of diagnostic categorisation is also explored by Felicity Boardman and Gareth Thomas (2022) in their article on the 'expressivist objection'. The expressivist objection – in the context of reproduction – refers to the idea that preventing the lives of would-be disabled people (i.e. via prenatal testing and termination, genetic selection, genetic modification) is objectionable, as selecting against disabling traits 'sends a 'hurtful message' to those in society who share those traits' (2022 2). Boardman and Thomas combine separate qualitative studies with disabled people and their families to examine attitudes towards prenatal screening and how their views align with, or sit against, the expressivist objection. They found that disabled people and their families bring experiences of what it is like to live with different impairments/disabilities into considerations of prenatal screening, what is a liveable disability, and what is it like to give birth to a baby who will die. They claim, among other things, that the perceived stigma of a condition influences the degree to which people identify with it as part of who they are, along with their level of support for screening a condition 'out'. In contrast, others who envisaged themselves or their relative as a member of a 'community', now and in the future, were more likely to have expressive objections to screening. Here, Boardman and Thomas argue that stigma can become a barrier to people developing a political (and positive) identity around disability which is often disvalued by others. Through their analysis, the authors identify how blending the conceptual architecture of medical sociology and disability studies allows us to think critically about disability, impairment, and illness – and their various intersections with identities.

Embodied Experiences

A common criticism of disability studies, at least from the perspective of those with some affiliation with medical sociology, is that it frequently abstracts the lived, embodied experiences of disabled people – and, in so doing, risks undermining, if not negating, impairment effects (i.e. bodily suffering and pain). Medical sociology may be reasonably seen as the home of such analyses. Taking the example of pain, such scholarship dismantles dominant physiological and psychological understandings of pain, and analyses how pain is moulded and comprehended by people in diverse socio-cultural contexts (Bendelow, 1993; De Souza & Oliver Frank, 2011). Here, pain is seen as an everyday and embodied experience; the body, which often remains in the background but 'dys-appears' (Leder, 1990) when it becomes 'ill', is a source of feelings, sensations, and perceptions that demands attention and, possibly, disturbs familiar scripts of what it means to live with a (gendered/racialised) body (e.g. Bendelow, 1993; Chandler, 2016; Pryma, 2017). The continued suspicion of such analyses, for some in disability studies, is: (a) it appears to become interested in pain when it fractures the lives of 'normal' bodies, and; (b) it loses sight of the location of such embodiments in wider socio-economic contexts. The four contributions below avoid such problems by locating fleshy, painful, and sometimes leaky bodies in their wider socio-economic localities.

Drawing on ethnographic research in the Czech Republic, Kateřina Kolářová, Tereza Stöckelová, and Lukáš Senft (2022) explore the eating practices (e.g. eating, making, tasting, knowing) of people with irritable bowel disease (IBD) to challenge normative notions of metabolism. Medical sociology approaches to illness experiences, they argue, focus upon the changes that people make to a diet rather than on eating practices themselves, whilst disability studies largely overlooks eating practices altogether. Examining 'crip guts', Kolářová and colleagues extend research into how ill/disabled people reflect upon the pleasures and restrictions attached to food and eating. People with IBD expend considerable time and financial resources, for example, learning how to identify and categorise 'good' and 'bad' foods, challenging the idea of 'eating well' and characterisations of 'good food'. The crip body, within this context, becomes a 'food sensing and calibrating community/multiplicity' (2022 13). For Kolářová and colleagues, attending to modes of (not)knowing and sensing provides the grounds for a conversation between medical sociology and disability studies. They claim that this must start from an understanding of disability as contextual, political and relational, that is, how illness/disability involves a web of complex entanglements beyond the human.

The contribution of Kolářová et al. further recognises how illnesses, such as IBD, set embodiment and metabolism in complex relation to time – as something uncertain, fluctuating and ongoing. In a separate contribution which complements this article, Lauren White (2022) reports upon her qualitative study with people living with irritable bowel syndrome (IBS). In so doing, White – whose article was awarded the Mildred Blaxter New Writer's Prize 2022 – shifts the focus away from medical diagnosis and treatment (as the wheelhouse of medical sociologists), and toward the lived realities of having IBS. Her analysis is guided by the concept of 'crip time', a staple of disability studies rarely utilised in medical sociology, to 'acknowledge the ways in which social clocks bend to meet bodies and minds' (2022 2). Asking how we might recognise change within the body along with an attentiveness to its embeddedness within social structures and time, White explores her participants' everyday management strategies to work around the problems created by unresponsive public places, including workplaces. Here, bodies are 'bounded' (2022 9); mundane everyday tasks, such as waking up and walking a dog, are 'anticipated, (re)structured, and (re)imagined in line with inaccessible public landscapes and (un)predictable bowels' (2022 14). White argues that bringing crip time to the table, where the body and the social are forced into direct entanglement (and in ways that can be challenging to a person), means dialogues between medical sociology and disability can illuminate temporality.

White's analysis shows, among other things, how individuals take on being a bounded body in workplaces and feel prohibited from their social desires with respect to their working lives. Relatedly, the article by Jen Remnant, Katherine Sang, Katriona Myhill, Thomas Calvard, Sushila Chowdhry, and James Richards (2022) examines how different embodiments are managed within workplaces, emphasising the efforts required to manage 'leaky bodies' in settings that deny such bodies exist. Drawing upon three separate qualitative studies with disabled University workers in the UK, Remnant et al. explore the mismanagement of bodies at work. Interviews with participants show how they undertake serious labour to produce an acceptable body in difference spaces. This is informed by workers' corporeal realities not being recognised or validated; those who were menstruating, who had IBS, or had particular toilet needs, were frequently disregarded and silenced. Focusing upon toilets, for example, their data identifies how, while available, toilets were made inaccessible by organisations that did not recognise 'leakiness, unruliness and/or disability' (2022 14). Yet, whilst this had a negative impact upon people's (particularly women's) working lives, such conditions were rarely addressed. Instead, the 'internalisation of disability oppression' was observed in how people focused on 'self-managing their condition and needs rather than challenging the work environment' (2022 16). Remnant and colleagues, then, draw from medical sociology to hold onto a corporeal approach, but combine this with a social relational model of disability (Thomas, 2004c) to understand the challenges of living with impairment effects and institutionalised barriers to equality.

In the final article in this theme, Harriet Cooper, Fiona Poland, and Tom Shakespeare (2022) sketch out the 'adjustment work' that people do within rehabilitation practices. The idea of rehabilitation as adjustment work, they argue, is largely absent in medical sociology, disability studies, and rehabilitation science. Cooper and colleagues' research is informed by scholarship in medical sociology (on the 'illness work' that patients do) and disability studies (on the value placed on paid work). If disabled people's adjustment work is considered as socio-political and positioned more fully in its socio-material context, they contend, adjustment can subsequently be understood as a site of tension between medical sociology and disability studies. This is because 'it exposes seemingly irreconcilable ontological differences' and offers, instead, a 'potent site from which to explore a possible rapprochement' (2022 3). Cooper and colleagues report upon how people talked about the time, energy, and expectation that they had to invest into rehabilitation to maintain their quality of life. This included the 'administrative work' that they performed to make rehabilitation happen, and the 'adjustment work' that assisted in coming to terms with the impairment. Analysing the socio-material context for narrative reconstructive work makes a difference, the authors claim, to how impairment is processed, and to how adjustment activity is valued. They conclude that reworking the concept of 'adjustment', that finds its home in medical sociology, sets the groundwork for disputing how patient responsibility and illness work is thought about – often in ways that act to normalise, and so render invisible, the adjustment labour that disabled people engage in.

Care Practices

Discussions about care are a site of significant contestation between disability studies and a number of disciplines, including medical sociology. Disability studies has produced a necessary critique of care due to the way it as been used to describe institutionalised practices and interpersonal interactions which have been anything but caring (Hughes, 1999; Morris, 1997; Oliver & Barnes, 1998). Disabled people have experienced great harm through the power inequalities embedded in the paternalism of charity, the enforced dependency of State-provided support, and a fixation in much social science, including feminism, on the 'burden' of care experienced by the carer. This led, as part of campaigns for independent living, to a move away from the language of care to focus instead upon personal assistance and support. Moves to the personalisation of welfare have been hugely important for providing some level of say and control for disabled people (although the impacts of welfare austerity in the UK and elsewhere have undermined some of the promise such reform implied (Rummery, 2002)). More recently, encouraged by the desire to critique the self-sufficiency narrative embedded in neoliberal welfare reform (as discussed in the article by Porter and colleagues (2022)), feminist medical sociologists and others have sought to bring back the language of care. This emerges out of a concern that the focus on support has instrumentalised the personal interactions involved in providing support, and that one way to challenge the current hegemony of neoliberalism – in which 'independence' is valorised – is to shift the focus towards the a recognition of interdependency where care is integral (McLaughlin, 2020b; Ward, 2015; Williams, 2001). Two articles in this issue, by examining the possibility of producing 'care' in different settings, seek to show how practices can be caring in both institutional spaces and embodied intimate interactions.

Sebastián Rojas-Navarro's, Samanta Alarcón-Arcos', and Ismael Tabilo-Prieto's (2022) contribution is based upon research in Chile, involving interviews with educational psychologists, ethnographic fieldwork at a school, and analysing guidelines of an education programme which provides schools with funds for students diagnosed with special education needs. Disability studies work on such programmes regularly highlight the risk of medicalisation and labelling of children, particularly where schools receive additional funding for children who are afforded a medical categorisation. The authors acknowledge that the programme they are researching risks producing 'technologies of normalisation… oriented by neoliberal principles' (2022 3) through its diagnostic processes. Taking inspiration from conceptualisations of care in feminist theory and science and technology studies, though, Rojas-Navarro et al. argue that clinicians and teachers respond and work with diagnostic processes to develop practices of care which avoid the potential for normalisation. Diagnosis, for clinicians, may be considered as an 'ambivalent way of caring', whilst teachers work with pupils to foster their capacity whilst upholding differences (2022 6). Diagnosis, then, can be an ethical action oriented by a caring purpose. Through this, the authors claim, a diagnosis becomes 'a non-human actant' able to put in place 'relationships and responses that care for the child' (2022: 12). Equally, however, there are negative implications of diagnostic processes for some, including children without a diagnosis and support, and there may be moments were non-care emerges (e.g. when professionals are not supportive of difference).

The other article drawing care back into consideration is by Andrea García-Santesmases, Daniel López Gómez, and Asun Pié Balaguer (2022). The authors utilise Julia Twigg's (2000) concept of 'body work' to examine the embodied care practices of personal assistants in Spain. Here, the authors use body work to situate care within both complex embodied practices and the socio-economic contexts within which the personal assistants 'do' their labour (i.e. independent living welfare policies in Spain). It is in such arrangements, the authors claim, that 'the employer and the PA's bodies are mutually configured' (2022 3). They argue that performing the roles of 'body-tool' and 'body-prosthesis' requires a specific type of personal assistance bodywork – what they call 'performing body-absence', where the personal assistants must contort their bodies to be physically present yet symbolically and emotionally absent (2022 9). At other times, personal assistants must perform a mode of 'body-presence', where they recognise their own discomfort when asked to perform particular tasks (2022 12). As with the study by Goodley et al. (2022), there is an affective element shaped by the social position and context of the personal assistant-employer relationship. Here, García-Santesmases and colleagues contend, both 'the carer' and 'the cared for' might be in a position of vulnerability; the former risks becoming exploited if demands for availability and flexibility are too high or if working conditions are poor, whilst the latter risks being dependent on the personal assistant to perform everyday activities of daily living for them (2022 16). It is by showing these tensions that García-Santesmases and colleagues point out the need for both disability studies and medical sociology to develop a more relational and materialist conceptualisation of disabled people and their bodies.

Expanding Perspectives and Methods

Both medical sociology and disability studies face rightful scrutiny for absences relating to both what they examine and who is involved in shaping their ideas. Some of the most interesting work highlighting those absences and seeking to respond to them are, uncoincidentally, also arguing that distinguishing between disability and chronic illness makes little sense. A key contribution to this work is being made by Global South scholars, often embedded within activist collaboration. Meekosha (2011 668) argues that disability studies, due to its location in the Global North, must acknowledge that it practices a form of 'scholarly colonialism'. This process of reflection, we would add, is also required in medical sociology too, perhaps more so, given the legacies of eugenics in early medical sociology work (Oakley, 1991). Underpinning theorising is an approach to embodiment, which connects the discursive production of marginalised embodiments to the very real making of impaired and ill bodies, made so by their location within the epicentres of oppression systems (Puar, 2017).

Demands for greater diversity bring with them advocacy of different methodologies that can trouble existing power dynamics within research to recognise research participants as experts and theorists. One area where researchers are developing inclusive methodological practices is around disabled childhoods (Runswick-Cole & Curran, 2013). Here, there is a deliberate move away from debating children's capacity to be involved in research (McLaughlin, 2020a), towards a focus on methods that can bring disabled children's perspectives and knowledge to the fore (Powell & Smith, 2009). Disability studies' roots in the disability movement mean that calls for 'nothing about us, without us' are more embedded in practice than in medical sociology. However, both can work together to expand who has an active presence in research and how methodological tools – and values – can be expanded. Our final two articles provide evidence of the importance of different kinds of collaboration with marginalised actors, and the kinds of methods that can help such collaboration.

Lena Wånggren, Jen Remnant, Sara Huque, Limbani Kachali, Katherine Sang, and Jenipher Ngwira (2022) confront the gap between policy and practice in Malawi, by looking at disability discrimination in a qualitative project co-designed, co-researched, and co-written with trade unionists, disability activists, and researchers in Malawi and the UK. In so doing, they examine the extent to which employment policies are shaped by colonialism and neo-colonialism in the form of development and international aid. The authors found a discord between government-level rhetoric about supporting disabled people, and practices at the local level. Deeper than this, they identified a significant gap between the rhetoric which is shaped by the Global North, and local realities where campaigning is on behalf of disabled people rather than led by them. Here, Wånggren and colleagues recognise, and put to task, the gap between the social model of disability and medical sociology models of illness. Both disciplines, they argue, are dominated by Global North contributors, which limits their value and applicability in other economic, cultural and social settings. As other scholarship in the Global South has shown (Grech and Soldatic 2016; Ingstad and Whyte 2007) disability is not self-explanatory; in Malawi, for instance, long-term illness is not seen to overlap with disability unless there is a permanent or visible injury. Moreover, disability is not conceptualised in relation to work, or the exclusion from it – especially as formalised employment is relatively rare in Malawi, and individuals engaged in the informal economy are often not considered workers or employees. Where analyses of disability define disability alongside work, they risk neglecting contexts where formal employment is not commonplace. Wånggren and colleagues' article provides an opportunity for localised theory and practice – one which incorporates the rejection of the term disabled as stigmatising and recognises the experiences of people in the non-formalised economy. Understanding disability in this (non-universal) way will allow scholars to address theoretical flaws in both medical sociology (which has largely neglected experiences of illness in the Global South) and disability studies (which has neglected local, regional, and inter/national economies and labour markets).

The final article in our special issue is by Geraldine Brady, Anita Franklin and a disabled young research collective called RIP: STARS (which stands for: Research into Practice/Policy: Skilled Team with Ambition, Rights and Strength). The social location of disabled children and young people highlight many of the issues which medical sociology and disability studies examine, yet it is only recently that disability studies (with sociology of childhood an influence on this) has started to take seriously the need to study disabled children's lives and to recognise their capacity to have research agency. This move is at the heart of Brady and her colleagues' work together. RIP: STARS have been working with Brady and Franklin for five years, including the upheaval created by the COVID-19 pandemic. Starting with an agenda to look at inclusive education, they have expanded their remit to cover a variety of areas around disability rights, including in healthcare. Drawing from the work of Berry Mayall (1998), they argue for the 'need to look beyond disability studies more generally and focus on children's lived experience of being defined as disabled or impaired' (2022 X). Brady et al. argue that greater understanding of disabled children's lives requires understanding them as 'active participants in the management of both their bodies and their minds, rather than being regarded as passive recipients of processes which are imposed upon them in the form of 'civilisation', 'regulation' and 'surveillance' (2022 X). The RIP: STARS discuss the recognition they have developed of the presence of medicalisation in their lives, and the way educational and health processes of establishing their needs can produce a deficit understanding of who they are that disturbs their sense of identity and desire to shape their worlds. The authors conclude, whilst RIP: STARS think differently about their rights and identity due to being introduced to medical sociology and disability studies, they and other disabled children and young people can help both disciplines work together by 'providing alternatives ways of knowing and contributions to knowledge production' (2022 X).

Conclusion

This special issue highlights the potential intersections and collaborative opportunities between medical sociology and disability studies. In so doing, it – we believe – dismantles the notion that contributors to both disciplines are fundamentally and staunchly interested in separate matters. Indeed, the special issue is testament to the reality that many scholars are already working productively across the boundaries of both disciplines. The contributions in this issue point to the virtues of a disciplinary pluralism and of partial, or at least fluid, alliances (Thomas 2022). We recognise this theoretical elasticity as appropriate, if not necessary, for understanding the lives of ill and disabled people, which do not always cleave at neat and linear points. In making these claims, we have built upon the work of predecessors in attempting to unite concepts, ideas, and sentiments from medical sociology and disability studies to study individual experiences and the broader canvass of complex structural practices and relations. Yet, we also identify that this is an ongoing conversation. This special issue represents the editors' and authors' contribution to such a dialogue, where we urge scholars within both disciplines to, in turn, expand their alliances and broaden their scope.

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