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Understanding Disability in the Sociology of Health and Illness

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<a>Abstract<a>

In this chapter, I provide an overview of disability as a category of analysis in the sociology of health and illness. I begin by discussing the lack of dialogue between medical sociology and disability studies. Both disciplines co-exist, yet there are few interdisciplinary exchanges that recognise their associated intersections and inconsistencies. From here, I outline three topics that offer opportunities for merging concepts, ideas, and sentiments from both disciplines. First, I capture how attending to the *individual* and *structural* properties of stigma unites concerns of both medical sociologists and disability studies scholars. Second, I show how we can further ponder this disciplinary relationship by considering matters of care, both inside and outside of health and social care services. Third, I recognise the value of medical sociology and disability studies for understanding the COVID-19 pandemic, both in terms of its disproportionate impact on disabled people and its illumination of a troubling history of hostility and indifference to disability. In so doing, I contend that disability aligns with central and longstanding points of interest within sociology, in ways which merit more theoretical and empirical attention.

<a>Keywords<a>

Care; COVID-19; Disability; disability studies; medical sociology; stigma

<a>Introduction<a>

Disability is reported to impact 15% of the world's population (WHO 2021). Yet, disability frequently remains on the margins of sociology. This is not to say, however, that sociologists have never attended to matters of disability (see: Barnes 2000; Hughes 2019; Hughes and Paterson 1997; Oliver 1990, 1996; Thomas 2004, 2007, 2010; Zola 1982a, 1982b, 1991). Sociologists have also drawn on tropes and ideas from other disciplines, such as disability studies, to gain it insights relating to living with disability (Blum 2015; Mauldin 2016; McLaughlin 2017; Thomas 2021; White 2022). Nonetheless, disability is persistently relegated to the periphery of the sociological imagination. This is not the space for speculating as to why this has happened, although I suspect one reason is the difficulty of defining what is meant by disability. Disability is not a universal classification (Davis 1995; Grue 2016); what is seen as disability in one context may not transfer to others, as researchers in the Global South make clear (Ingstad and Whyte 2007). Similar to Mauldin and Brown (2021), I use the term disability here to refer to chronic illness *and* typically-defined disability categories that correspond to self-definitions of disability status. Moreover, whether one should refer to 'disabled people' or 'people with a disability' has been widely contested. In this chapter, I opt for 'disabled people', because it recognises disability's political character and it as a product of a social context, rather than being *exclusively* an attribute of an individual. That said, I recognise the position that 'people with a disability' is preferred by some since it aligns with a person-first approach. I also appreciate how individuals with different impairments (and even the same impairment) will have their own preferences, and my own use – like Irving Zola's (1993) – is not static, nor is my aim here to argue for any 'politically correct' usage. Regardless of the complex, and possibly irresolvable, debates surrounding language use, it seems that disability remains largely side-lined in mainstream sociological thought. This is despite holding relevance for conceptual, methodological, and empirical debates within sociology (e.g. ageing; reproduction; inequality; familial relationships; stigma; citizenship and welfare; work).

Two fields where analyses of disability have emerged are in medical sociology and disability studies. However, both disciplines, for the most part, passively co-exist, and there has been a history of silence about the possible intersections of and inconsistencies between the two fields (Mauldin and Brown 2021; Thomas 2021). This is where I begin my chapter: outlining the broad ideas and sensibilities of each discipline, as well as identifying literature that confronts this disciplinary divide. From here, I outline three topics that offer opportunities for merging concepts, ideas, and sentiments from both disciplines. First, I capture how attending to the *individual* and *structural* properties of stigma unites concerns of both medical sociologists and disability studies scholars. Second, I show how we can further ponder this disciplinary relationship by considering matters of care, both inside and outside of health and social care services. Third, I recognise the value of medical sociology and disability studies for understanding the COVID-19 pandemic, both in terms of its disproportionate impact on disabled people and its illumination of a troubling history of hostility and indifference to disability. In so doing, I contend that disability aligns with central and longstanding points of interest within sociology, in ways which merit more theoretical and empirical attention. My analysis largely draws on statistics, examples, and research in the United Kingdom (UK), but the analysis is applicable to other international contexts.

<a>Disability Studies and Medical Sociology<a>

Following the seminal contribution of Talcott Parsons (1951) on the 'sick role', generations of medical sociologists continue to study the impacts of chronic illness and disability. This research often asks what it means to be 'ill' or 'well', to have symptoms, and to be un/diagnosed. The intention is to move beyond reductive biomedical explanations of health and illness that perceive health as freedom from pain, disease, or defect, and illness as the breakdown of 'normal' functioning which can be repaired via biomedical intervention. Medical sociologists have critiqued this limited perspective and urged for an empirical comprehension of the lived experience/narrative of health and illness.

Several concepts and ideas concerning chronic illness and disability are well established and highly influential in the field. For example, Mike Bury (1982) contends that illness is interwoven into people's own biographies and that serious, persisting symptoms disrupt their everyday lives. He refers to the destabilisation, questioning, and reorganisation of identity following the onset of chronic illness as 'biographical disruption'. Experiencing pain and suffering ordinarily viewed as a distant possibility or the plight of others, such people may experience a loss of networks and subsequent social isolation. Similarly, Kathy Charmaz (1983) introduces the notion of 'loss of self' to convey how the onset of illness or disability can ignite social suffering. Indeed, individuals see their 'former self-images crumbling away without the simultaneous development of equally valued new ones' (1983: 168). This can cause isolation, stress, restrictive living, and self-perceptions of being a burden to friends and family. Likewise, Gareth Williams (1984) identifies how people use narratives to explain the cause of illness/disability. In their 'narrative reconstruction', people are able to 'reconstruct a sense of order from the fragmentation produced by chronic illness' (1984: 177) and 'reaffirm the impression that life has a course and the self has a purpose' (194: 179). Later, Arthur Frank (1995) published his seminal book on 'wounded storytellers'. When people tell stories about an illness or disability, Frank tells us, they can make sense of their suffering and, ultimately, find some redemption. He identifies three basic illness narratives: 1) ‘restitution’ (anticipate recovery and cure); 2) ‘chaos’ (sense of despair and loss of hope), and; 3) ‘quest’ (illness/disability provides an insight that provides an opportunity for growth).

Despite the longevity of such concepts, they have been subject to debate and revision, both from the scholars themselves and others. In the context of disability, Carol Thomas (2007, 2010) argues that medical sociology, particularly when influenced by the ideas outlined above, operates as part of a ‘social deviance paradigm’; that is, medical sociologists (influenced by symbolic interactionism) regularly align with a personal tragedy bias which equates disability to living with a personal failing and as a pitiful, catastrophic bodily state. This critique relates to how disability is defined. It is a contested category, particularly ‘in terms of what it signifies, what its origins are said to be, how it is produced and what its boundaries are’ (Coleman-Fountain and McLaughlin 2013: 134). For Coleman-Fountain and McLaughlin, disability studies was founded in the ‘social model of disability’ (UPIAS 1975; Oliver 1990), that makes a distinction between an *impairment* a person has and the *social disability* an individual may face as a result of ‘disablism’ (i.e. the ‘social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as “impaired” by those deemed “normal”’ (Thomas 2010: 37)). Simply put, the social model frames disability as a *social* rather than a *biological* ‘problem’; it is society which disables people through attitudinal, architectural, and structural barriers. The model is regularly contrasted with a biomedical model, which depicts disability as a *biological problem* belonging to a person that requires a fix or cure. As Oliver (1996: 35) contends, disability ‘has nothing to do with the body’ and, instead, is ‘a consequence of social oppression’, namely, a prolonged, cruel, and unjust treatment of persons on the basis of biological *difference*. This corresponds to Hughes’ (2020) historical sociology of disability, that examines how disability has been distinguished from infirmity and which, ultimately, allowed for the modern disability movement to become a social movement. Moreover, to understand disability, for Hughes, we must consider how disabled people have historically been devalued via a lens not just of pity, tragedy, and vulnerability, but of abjection, disgust, and inferiority. He claims this is central to the ‘ontological and moral invalidation’ of disabled people, whereby they are perceived in the non-disabled imaginary as ‘good to mistreat’ (2019: 830) – and have been so throughout Antiquity, the Middle Ages and Early Modernity (Hughes 2020).

In sum, for the likes of Thomas (2004, 2007, 2010), medical sociology conventionally operates in a biomedical paradigm that defines disability *as impairment* and examines what she calls ‘impairment effects’ (i.e. (the direct, unavoidable impacts biological impairments have on an individual’s embodied functioning), whilst disability studies attends to the influential role of structures and oppression in the lives of disabled people. As such, Thomas argues, medical sociologists must demonstrate a stronger affiliation with a ‘social oppression paradigm’ that accounts for how disabled people are subject to oppressive and unjust practices.

However, this is not easy or straightforward. The social model has been critiqued for erecting a crude distinction between disability and impairment, downplaying and ignoring impairment, not appreciating the full *spectrum* of what ‘counts’ as disability (and the neglect of people with invisible conditions), and failing to account for difference and intersectionality by presenting disabled people as a unified group. Indeed, the distinction between disability and impairment has caused polarisation in the disability movement, which has been built on ideas related to the social model. In academic circles, the likes of Charmaz (2020) and Tom Shakespeare and Nick Watson (2001, 2010) argue that setting up the disciplinary divide between disability studies and medical sociology as a debate between a personal tragedy versus social/political model of disability is simplistic, overstated, and overlooks lived realities. For Shakespeare and Watson, impairment *is* central to the life-worlds of disabled people, yet, by aligning purely with a *social oppression paradigm*, sociologists risk discounting experiences of pain, limitation, embodiment, and suffering (see also: Coleman-Fountain and McLaughlin 2013). Moreover, Shakespeare and Watson highlight the futility of classifying people with different forms of impairment in the same way because it homogenises diverse experiences. Instead, they suggest disabled people are disabled both by their bodies and by societal barriers, and each of these are difficult to disentangle from one another. They recommend that scholars from medical sociology and disability studies come together to offer a sociology of disability analysing impairment yet placing inequality, powerlessness, and structure at the centre of analysis.

I suggest that, together with Shakespeare and Watson (2001, 2010) and Charmaz (2020), there are other examples that show the value of uniting concerns and driving tenets from medical sociology with disability studies – or, at least, present an analysis which espouses similar ideas, even if not in name. In the 1980s, whilst both disciplines were still budding, Ivan Illich (1974) highlighted the iatrogenic tendencies of Western biomedicine, leading to an over-medicalisation and pathologisation of everyday life for chronically ill and disabled persons. More obviously located in a disability studies sensibility, Irving Zola – who, similar to Illich, recognised medicine as 'an institution of social control' (Zola 1972) – pushed back against common understandings of disability as a tragedy that an individual 'suffers'. Furthermore, he highlighted not only the bleak realities of deprivation, oppression, and marginalisation faced by disabled people, but also the need for research in clinical rehabilitation and to understand the embodied, personal lives of people living with impairment (Zola 1982a, 1982b; 1988). Since this work, various scholars have 'explored the divide' (Barnes and Mercer 1996) between medical sociology and disability studies (Mauldin and Brown 2021; Scambler and Scambler 2010; Williams 1991, 2001, 2010) or, at least, draw on empirical material which suggests points of convergence are observable (Harper 2019; Mauldin 2016; Sheppard 2020; White 2022). This includes recent scholarship drawing on ideas from both disciplines along with principles and concepts from feminist theory, gender studies, sexuality studies, critical race theory, and queer theory (e.g. Bailey and Mobley 2019; Campbell 2008; Coleman-Fountain 2020; Goodley 2014; Jones et al. 2019; Kafer 2013; Schalk and Kim 2020; Shildrick 2009; Slater et al. 2019).

For the remainder of this chapter, I suggest three topics of analysis where a new dialogue can emerge and resolutions may be found between both disciplines: 1) stigma; 2) care; 3) the COVID-19 pandemic.

<a>Disability and Stigma<a>

It is often assumed – no doubt perpetuated through cultural representations and historical stereotypes (Garland Thomson 1997) – that living with disability is defined by pity, disaster, and stigma. Indeed, disabled people are said to experience stigma as their 'embodied presence in the world does not fit with how others interact and use their bodies' (McLaughlin 2017: 244). Disabled people are regularly excluded from social life and rendered 'abnormal' and powerless, with their practical and ideological marginalisation pushing them into poorer conditions than their non-disabled counterparts. This subsequently leads to attempts to avoid the penalty of stigma by managing embodied differences to soothe, and possibly repair, the interaction order (Garland-Thomson 2009; Nijhof 1995; Scully 2010). Analyses that attend to the matter of stigma frequently do so with reference to symbolic interactionist literature and, specifically, Erving Goffman (1963). As conceived by Goffman (1963), stigma refers to a mark of infamy, disgrace, or reproach which causes embarrassment and shame. He suggests that, rather than stigma being a matter of attributes – where certain characteristics, such as one's gender, race, or disability, are automatically *stigmatised* – it is a 'language of relationships'. That is, stigma is rooted and acquired in interaction; for example, through stares, comments, glances, and name-calling.

Stigma is a concept that has been widely applied in medical sociology, especially in research on mental health, HIV/AIDS, addiction, obesity, chronic illness, and disability – the latter, perhaps, since disability commonly connotes marginality and stigma (Grue 2016). This work addresses similar experiences: un/certainty offered by a diagnosis (or lack of); the personal/social impact of a diagnosis; negative effects on personal relationships (e.g. friends, family) and interactions; techniques for 'managing' and 'coping with' stigma, and; the 'outcomes' of stigma, such as discrimination, stress, isolation, and poor job prospects. Medical sociology analyses of disability have used Goffman's ideas and concepts, such as 'courtesy stigma' (how stigma extends to the close affiliations of the stigmatised), in research on a range of topics, including parenting a disabled child (e.g. Gray 2002; Green 2003; Koro-Ljungberg and Bussing 2009). However, such work, I argue, frequently does not sufficiently engage with Goffman's ideas (and, sometimes, misuses them), nor does it reflect on its limitations. Disability studies has been more vocal in this respect (Barnartt 2017; Brune et al. 2014; Fine and Asch 1988; Gleeson 1999), lamenting Goffman's detached and othering tone, his shortcutting of stigma's origins and operations, his assumption of disability *as* deviance, his oversight of what counts as 'normal', and his disregard of power, resistance, and the structural forces that shape disability and how personal interactions are the outcome of social, economic, and political forces. Furthermore, work which aligns with Goffman's conception of disability as deviance can be charged with promoting a tragedy model and intimating a form of passivity often associated with 'victimhood' (Scambler 2004; Thomas 2010).

It is worth noting that some disability studies scholars have reflected upon Goffman's ideas with more sympathy and appreciation (e.g. Healey and Titchkosky 2022; Love 2021). Nevertheless, we can note how some medical sociologists have acknowledged the influential role that disability studies can play in helping us to appreciate the *structural forces* which erect and maintain disabling conditions. This involves conceiving of stigma not as an attribute owned by the stigmatised individual, but rather as an 'experience imposed on individuals by prevailing socio/cultural conditions' (Green et al. 2005: 211). It also involves moving away from analyses located in the 'individual/medical model' of disability that, as identified above, marks the disability experience as one of negativity and misfortune. Most illustratively, for me, is Graham Scambler's reflections on his own comprehension and, in turn, (re)conceptualisation of stigma (Scambler 2018). In a canonical text on epilepsy and stigma, Scambler and Hopkins (1986) proposed a distinction between 'felt' and 'enacted' stigma; felt stigma refers to shame and *expectation* of stigma and discrimination, whilst enacted stigma refers to the *actual experience* of stigma and mistreatment by others. Later, Scambler (2004, 2018) accepted that his own concept of disability and illness gave epistemic authority to the biomedical perspective, presumed epilepsy to be a tragedy, and assumed a passive tone associated with victimhood. Influenced by disability studies, Scambler now suggests moving beyond individualistic/Goffmanian understandings of stigma and considering the structures of power in classifying/treating 'epileptics' and the possibility that people can resist stigma. Returning to an earlier example – parenting a disabled child – several analyses have shown how an appreciation of power, structure, and inequality can elevate Goffman's analysis. For example, Farrugia (2009: 1012) argues that whilst Goffman's paradigm has remained a/the dominant theoretical foundation for studies of stigma in medical sociology, this work – as well as being apolitical – rarely considers the origins of negative stereotypes, positions the stigmatised as powerless victims, and fails to consider 'structural power relationships'. Equally, research by Francis (2012) and Thomas (2021) examines how stigma encountered by parents stems not from their child's attributes, but from dominant (and problematic) ideas around disability and parenthood.

The value of an approach that brings a *structural* dimension to stigma (i.e. not just focusing on matters of *impairment*, as is often the case in medical sociology) is compellingly illustrated when focusing on matters of disability, illness, and the welfare state, particularly within a UK/global context of austerity (e.g. Hansen et al. 2014). For Charmaz (2020), neoliberal policies and practices affect experiences of stigma and exclusion along with the temporality of diagnosis, disclosing illness/disability, and dealing with unpredictable bodies. This includes the shrinking of welfare services and, for disabled women in her study, subsequent calls to *prove* they deserve access to services. The retrenchment of resources and widespread promotion of individualist ideals is coupled with a demonisation of disability welfare claimants (Briant et al. 2013; McLaughlin 2017; Runswick-Cole and Goodley 2015). This creates social and financial costs for disabled people, and is so powerful that recipients of welfare, or those eligible for them, have been reported to define themselves according to stigmatising labels ('scrounger', ‘skiver’, ‘sponger’; ‘faking/fakers’) and, in some cases, to refuse help on this basis (Garthwaite 2011, 2015; see also: Mauldin 2022; McLaughlin 2017).

Here, we can think of stigma as being exercised through State power, with disabled people being asked to solve structural problems as part of the weight of oppression, with the physical, cultural, political, and attitudinal barriers they face largely erased and undermined. Because of this, as Charmaz (2020) argues, sociologists must analyse how disabled people’s lives play out in everyday interactions and structural arrangements; the latter referring to how they face obstacles and destitution in a neoliberal context that both accelerates and deepens stigma and injustice. The joining of subjective experiences with structural forces is key to Janice McLaughlin’s (2017) analysis of the lives of disabled young people and how they perceive medical intervention. They talk of ‘independence’ as a core life-goal, reflecting political imperatives to be self-sufficient as welfare services are depleted. Moreover, their agency in these debates – of remaking their bodies in consultation with medicine, which allows them to reimagine their futures and everyday activities – suggest resistance to stories *only* of stigma. By considering ‘the wider structures informing everyday experiences of stigma’ (McLaughlin 2017), medical sociologists can emulate the structural appreciation evident in disability studies scholarship. This involves examining the political economy of stigma (see: Day 2021; Hansen et al. 2014; Link and Phelan 2001; Scambler 2018; Tyler 2020) and modes of ableism/disablism that shows how certain people are valued or not valued (Mauldin and Brown 2021; Campbell 2012).

<a>Disability and Care<a>

In this section, I consider how ‘care’ intersects with matters of disability. Most obviously, we can think about disabled people’s access to health/social care as a global issue. It is reported that over 1 billion people live with disability, with numbers dramatically increasing (WHO 2020). This increase is due to a number of factors, including demographic trends (such as increased longevity) and a rise in chronic health conditions. Importantly, though, the ‘social determinants of health’ (see, for example, Marmot 2005) have an enormous, devastating impact on the lives of disabled people – that is, the conditions in which people are born and live, and the preventable structural and political forces that impact their lives (e.g. income, food security, healthcare, employment, housing, education).

In the context of health care and services, it is recognised that these are invariably of poor quality or under resourced at a global level (Kuper et al. 2018; WHO 2020). Few countries (and particularly low-income countries) adequately offer services for general health services. Barriers include financial costs (e.g. healthcare, transport), limited availability of services (e.g. remote areas; rehabilitation services), physical (e.g. inaccessible buildings) and information (e.g. braille and easy-to-read document access) barriers, poor attitudes (e.g. from healthcare professionals toward disabled people), and insufficient training of, and equipment for, health care workers. According to Shakespeare (2017), critiques also apply to high-income countries, with reports in the UK of poor attitudes of healthcare workers, little-to-no consent for procedures, and a dismissal of disabled people’s expertise in managing their needs. As he reminds us, if we view access to care as a human rights issue, we can observe how disabled people face many barriers and prejudice worsened not simply by their underlying impairments, but by the failures of general health and social care. Small interventions and changes, for Shakespeare, can make a big difference, such as targeted health checks and more imaginative social support, to allow disabled people to live and thrive (see also: McLaughlin 2020b). Yet, as Mauldin (2022) contends, this is challenging not only when the care infrastructure is inadequate, but when there is a fundamental disregard for disability more broadly. Caregiving and paid care work, according to Mauldin, is devalued ‘because we devalue the people who need it… We tell people we don’t care about them when we refuse to provide the means for them and those who care for them to live well’. Disability, in turn, becomes a stand-in for disaster, suspicion, and contempt.

With respect to learning disabilities (LD), statistics of health inequalities and avoidable deaths are stark. The Learning Disabilities Mortality Review (LeDeR) reported, between April 2017 and December 2018, that the median age of death was 60 for men with learning disabilities (LD) and 59 for women with LD, 23 years lower for men without LD and 27 years lower for women without LD. Furthermore, the Confidential Inquiry into the premature deaths of learning-disabled people found 38% of people died from an avoidable cause, compared to 9% in a comparison population of people without a LD (Heslop et al. 2013). Moreover, studies consistently show that learning-disabled people are much less likely than those without LD to be in employment, have friendships and/or sexual relationships, and are more likely to be marginalised and living in residential settings with low levels of support. There is also a 'steady drip of heart-breaking stories about the unspeakable treatment of [learning disabled] people that has led to death or serious harm' (Ryan 2021: 15). In the UK, the public scandals at Winterbourne View in 2013 and Whorlton Hall in 2019 uncovered a pattern of serious abuse at homes for adults with LD. Such incidents demonstrate how disabled people experience repeated failures of health and social care systems and are subjected to inhumane treatment and little political interest (Ryan 2021). This is also true for parents, certainly mothers, of learning-disabled children (Blum 2015). Together with navigating discourses of burden and limitations, parents lament 'fights and battles' (Thomas 2021) with inhumane and bureaucratic systems (e.g. health and social care, education) that leave them feeling bruised, beleaguered, and hidden. Grassroot organisations and movements – for example, #JusticeforLB, #RightfulLives, and #FliptheNarrative – lead the way for showing learning-disabled children as human and valued, and for confronting limitations cultivated by oppressive regimes that dehumanise and disregard them. Yet, there is more that needs to be done outside of Governmental lip service and empty rhetoric of rights, choice, and independence (Goodley 2014; Ryan 2021).

When considering matters of care, it is crucial to note that care *for/with* disabled people exists both inside *and* outside of health and social care settings. Care itself has a troubling presence in medical sociology and disability studies. Scholars in disability studies, for instance, have sometimes suggested that care connects problematically with ideas of passivity and charity, not least as it does not allow for disabled people's greater independence and since institutionalised models of care have been argued to result in oppression (McLaughlin 2020b). Medical sociologists, in contrast, have sometimes focused on the purported burden of care, especially for the carer.

More recent work has, though, considered the relationships, practices, and inter-dependence of caring for, and with, others. I understand care here as a relational, intersubjective process emerging between people, with the intention of enabling a 'good life' (Errington et al. 2018; Thomas and Sakellariou 2018). This form of care – from talking with people to helping them use the toilet, from assistance with mobility to building relationships with people – can transform relations and intimacies in ways that are not always exploitative or demeaning (Sakellariou 2015). Care can be enacted by family members, spouses, paid workers, friends, and children, among others. It 'implies reaching out to something other than the self' (Tronto 1993: 102). Disability studies can offer an important observation here, namely, that notions of inter-dependence, community, and support must be emphasised not as indicators of deficiency, but as extensions of what it means to dwell and exist *with* and *alongside* others (Goodley et al. 2014, 2019). Moreover, it shows how documenting the embodied practices of everyday life illuminate the ways in which disability can enable the emergence of inclusive forms of citizenship and belonging (Errington et al. 2018). Disabled people are active agents in negotiating how their desires and needs can be met to produce an optimal outcome, and practices of care are central to this. For example, in their case study with Jay, a young woman living with cerebral palsy, Wedgwood et al. (2018) convey Jay's creative self-management of support workers. In telling Jay's story, Wedgewood et al. consider how disabled people requiring daily personal assistance negotiate their support in a disablist society which treasures and rewards specific forms of autonomy associated with normative bodies. Instead of aligning with a neoliberal regime privileging self-sufficiency, independence, and able-bodied-ness, Jay shows how the complexities of care are traversed, how this support is infused by an 'ethic of care' (Tronto 1993), and how she imaginatively navigates her transition to adult life. In her words (Wedgwood et al. 2018: 139): 'I employ a crew that can do life with me'.

Focusing on 'care' offers another opportunity for bringing together approaches from medical sociology and disability studies. We can utilise the empirical thrust of the former, for example, to think about the experiences of disabled people within health and social care settings. This means uncovering not only the bleak health inequalities that plague the lives of disabled people (especially people with LD), but how they understand and navigate health and social care practices. Furthermore, we can use the political impetus of disability studies to locate such matters as a product of disablism that impede the possibility of living a good life, whilst also considering moments in which the humanity and worth of disabled people can be realised. A fruitful area of cross-pollination would be with analyses from critical gerontology. Indeed, many of the issues outlined here are similarly faced by older people (and, often, *disabled older people*). Differences remain, of course; there is a long history and social policy trajectory of disability being a site of political action, whereas this is not necessarily the case for older people. Nonetheless, whilst some authors have written about the relationship between ageing and disability (see Irving Zola's corpus, for example), this remains largely under-explored in medical sociology and disability studies, despite an ageing population and relations of care for disabled people frequently being established with older age in focus. A recent collection by Albrecht et al. (2020) addresses this absence, analysing the distinction between ageing *with* disability and ageing *into* disability and, in turn, showing how multiple identities, socio-economic forces, culture, and communities shape people's experiences. However, research that examines ageing *and* disability together remains underbaked.

<a>Disability and COVID-19<a>

In this final section, I discuss what medical sociology and disability studies – with a particular focus on disability – can tell us about the COVID-19 pandemic. The pandemic caused rapid and radical transformations across all areas of our daily lives (Schillmeier 2020), yet there were arguably few groups more impacted than disabled people. Remote working (where possible) and the increased use of digital technologies for communication purposes opened up possibilities for inclusion. Yet, the pandemic equally exacerbated a systemic exclusion of disabled people. For example, we can consider the popular public discourse of 'underlying health conditions' (UHC) and 'herd immunity' in the UK, particularly in early responses to/accounts of the pandemic. This, seemingly, type-casted certain kinds of bodies as disposable and their demise as inevitable. Similar to Rijul Kochhar (2020: 73), who highlighted how discourses of risk, safety, and wellbeing during the pandemic have been 'able-bodied', Kirsty Liddiard (2020) referred to such phrases and slogans (herd immunity, UHC) as 'ontologically violent messages', as a form of reassurance for non-disabled others. This, for Liddiard, shores up everyday ableism, that is, the 'material, cultural and political privileging of ability, sanity, rationality, physicality and cognition'. We can also consider how disabled people were: disregarded in public health messaging (e.g. no ASL interpreters at Government policy briefings in England); overlooked for vaccine and PPE provisions; abandoned with respect to face covering mandates (Thomas and White 2022); designated as 'non-entitled bodies' (McLaughlin 2020a) via implementing blanket 'do not resuscitate orders', and; devalued through the early adoption (and later abandonment) of the Clinical Frailty Scale (that devalues dependence) to determine admission to critical care and/or ventilator access. Notably, these same discourses and policies also impacted older people, suggesting further possible research crossovers between critical gerontology, medical sociology, and disability studies.

Such disparate effects were not felt exclusively in the UK. Nonetheless, in the UK, a Government report published in November 2020 suggested that disabled people made up 6 in 10 (59.5%) of all deaths involving COVID-19 for the period to 20 November 2020, despite making up only 17.2% of the study population (Gov 2020). People with LD are also at least four times more likely to die from COVID-19 than those without LD. During the UK's first 'lockdown', the death rate for people with LD aged 18-30 was reported as thirty times higher than non-learning-disabled peers, and the disability charity Mencap (2020) reported that 80% of all deaths of people with LD in 2020 were related to COVID-19. The reasons for this extend beyond biological functioning and, I argue, are located in a haunting legacy of disturbing inequalities for disabled people. The pandemic highlighted and exacerbated a longstanding indifference to the lives of disabled people and, particularly, people with LD (Goodley et al. 2022)[i].

Medical sociology, which has provided a home for analyses of the everyday experiences of people living with chronic illness and disability, has something to offer here. The concepts of biographical disruption (Bury 1982), loss of self (Charmaz 1983), and narrative reconstruction (Williams 1984), for example, seemingly fit with the onset of the long-term effects of COVID-19 ('Long COVID'). The uncertain length of time for full recovery could be a source of anxiety for people, and the greater risk of contracting the virus for disabled people may elevate unease. Moreover, prompts to 'shield' ignited concerns about isolation and exclusion. Medical sociology has the appropriate vocabulary to make sense of such experiences. I argue, though, it is by bringing in ideas and tropes from disability studies that we can understand the structural inequalities and disenfranchisement that disabled people faced (and which, I suggest, has a long history). During the pandemic, we have observed how disabled people face barriers and discrimination worsened not simply by their underlying impairments, but by the actions, failures, and limited interest of Government and institutional actors (Shakespeare et al. 2021). Disablism and ableism defined COVID-19; ableist imperatives deemed impaired bodies/minds as of lesser value and subject to different priorities than 'the abled' (Liddiard 2020). Whilst almost all lives were radically transformed, disabled people were disproportionally impacted, not least in encountering dis/ablist assumptions about their overall health, quality of life, and social utility (Scully 2020). In her account of how her reactions to disability-imposed lockdown 'remain unrecognised, invalidated, and unseen', Heidi Lourens (Lourens and Watermeyer 2021: 1) claimed that 'my experiences of lockdown during the Coronavirus pandemic are not altogether different from my everyday experiences as a visually impaired person'. Bringing together medical sociology and disability studies to make sense of the experiences of disabled people in the pandemic, McLaughlin (2020a) argues that certain bodies became perceived as 'entitled' and 'non-entitled'. For McLaughlin, disabled people's entitlement to being present in society was further threatened during the pandemic, a position which has historically been precarious. Researchers in medical sociology and disability studies must continue to examine and evaluate the material and emotional impacts of events, like the pandemic, for disabled people – and how this highlights and aggravates longstanding modes of dis/ableism (see: Goodley et al. 2022).

<a>Conclusion<a>

In this chapter, I have outlined the historical divide, and legacy of silence, between medical sociology and disability studies. In what followed, I discussed how combining ideas and concepts from medical sociology and disability studies allows us to appreciate both the interactional and structural properties of 'stigma'. From here, I examined the notion of 'care' – both inside and outside of health and social care services – and how medical sociology and disability studies can help us to make sense of the situations/plights of disabled people with respect to matters of care. Finally, I captured how the COVID19 pandemic provides an opportune moment for thinking about the disproportionate impacts of the pandemic on disabled people, and how it exemplifies and energises a troubling legacy of hostility and indifference to disability. If the reader is to take away one argument from this chapter, it is to urge for more interdisciplinary conversations between medical sociology and disability studies. Each has much to learn from the another, and whilst this risks caricaturing disciplines which inevitably contain factions and fractures, it is my belief that a willingness to explore disability from different vantage points, and accept the contributions of others, will only benefit us. I do not stake my own disciplinary allegiance here, nor do I entertain the prospect of being embroiled in stake-claiming which is, frankly, futile and mutually harmful. Instead, returning to Shakespeare and Watson (2001, 2010), I contend that scholars should work towards a sociology of disability that acknowledges the impacts of impairment, but which attends primarily to matters of inequity, power, and structure.

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<a>Notes<a>

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[i] For a more comprehensive overview of the impact of COVID-19 on the lives of disabled people, see Goodley et al. (2022) and Shakespeare et al. (2021).