

The double bind of social legitimacy: On disability, the sick role, and invisible work

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Abstract

During the last few decades, the human rights paradigm has shifted the normative status of disabled people, providing, in principle, the right to full and equal participation. Particularly in neoliberal economies, however, participation in work life is a major constraint on social legitimacy, creating a predicament for people who cannot adhere to the ideal of the 'productive member of society'. In this article, I explore this predicament at the intersection of disability studies and the sociology of health and illness, reviewing literature and discussing key concepts. I argue that in neoliberal societies, two distinct and largely incompatible pathways to social legitimacy depend, respectively, on (a) a version of the classical sick role and (b) a more recently constituted able-disabled role. Of these, the first pathway has mainly been explored and critiqued in the sociology of health and illness, while the second features mainly in disability studies. However, both pathways can be understood (1) as ableist mechanisms for maintaining adherence to values of productivity and by (2) imposing on disabled people an unequal burden of invisible work—a key feature of ableism, driving inequality both within the group of disabled people and for the group as a whole.

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INTRODUCTION: SOCIAL LEGITIMACY AND WORK IN THE AGE OF HUMAN RIGHTS

For people with disabilities, the first 2 decades of the 21st century was a time of unprecedented symbolic victories. Following decades of political struggle, various pieces of national anti-discrimination legislation and the United Nations' Convention on the Rights of Persons with Disabilities (United Nations, 2007), which explicitly includes people with 'long-term' conditions, enshrined the right to 'full and equal' participation in all areas of society. Particularly in the Global North, the discourse of disability inclusion and equal participation has become thoroughly pervasive in the public sphere as well as a great many fields of policy.

In this article, which is part of a larger project on the contemporary politics of disability identity, I critique the presuppositions and consequences of this discourse, explore the contingencies that circumscribe the right to participation in neoliberal societies and discuss the ways in which disability rights may coexist with ableist structures. Specifically, I examine the relationship between disability, social legitimacy and work that is respective paid/unpaid, recognised/unrecognised and visible/invisible. This relationship speaks to the persistent ontological discrepancy between medical sociology and disability studies (Cooper et al., 2023; Porter et al., 2022; Remnant et al., 2022), though also to the 'intersection, boundaries, and collaborative opportunities' (McLaughlin et al., 2023) between the disciplines—serving as an exemplar of how an interdisciplinary approach can help explain the way in which the discourse of rights and inclusion may legitimise ableist expectations.

I will use the term 'disability' to include what is alternately called 'long-term illness', 'long-term health conditions' and 'chronic illness' (Dowrick et al., 2005; Walker, 2001), acknowledging that the group of people covered by this term is vast and heterogeneous and that the degree to which they are protected by disability rights varies considerably. Nearly all of its members are united in that they experience some degree of exclusion from society and an ongoing struggle for social legitimacy, which is arguably now available to a higher degree than at any historical moment. Legitimacy is unequally available, however, and as in other considerations of marginalisation, intersectionality (Crenshaw, 1989) is an important tool for considering the way in which disadvantage is compounded. In effect, resources of class, gender, ethnicity (and, of course, health) determine much of what it is possible to *do* with the right to participation.

This article begins with the assumption that participation in the work force is an important index of citizenship—understood broadly as a sense of belonging in society as a whole (Gordon & Lenhardt, 2007). In modern states and in the Global North in particular, being in work is not only a way to earn money. It is also a status that is accompanied by multiple formal privileges, and, almost as important, one that provides the social legitimacy of being a productive citizen, that is, of demonstrating adherence to what Varul (2010) has termed 'universalistic achievement values'. In what follows, I aim to better understand how, in neoliberal societies, this dynamic perpetuates inequality amongst disabled people as well as between disabled people and the non-disabled population.

This project has an interdisciplinary slant to it. The relationship between work, illness, disability and norms of productivity has chiefly been studied in the sociology of health and illness

and in disability studies. In a slight twist on the words of Oscar Wilde, these disciplines have everything in common except for a set of core concepts. Certainly, one thing they have in common is the people in which they are interested. The World Health Organisation's *World Report on Disability* (2011) includes one seventh of humanity in the categories of people with disabilities and people with chronic illnesses and notes that the dividing line between the two is often blurred. Referencing the work of Carol Thomas (2007), Mauldin and Brown (2021, p. 478) note that various laws, government programmes and organisations on the international as well as national levels define disability in 'relation to both physical and mental bodily functions, which would clearly include chronic illness'. Thus an inclusive use of the term 'disabled' seems warranted and the common ground between disability studies and sociology ample.

However, studying people necessitates concepts, which tend to be specific to disciplines. And as Mauldin and Brown go on to note, for a long time mainstream sociology more or less ignored the concept as well as the category of disability, thinking of it as a 'niche "area" study rather than an axis of inequality core to the discipline's commitment to understanding stratification and power' (2021, p. 480). A consequence of this is that a fair amount of sociological work, some of it canonised, has taken a reductionist view of disability, treating it as purely medical problems that are in equal measure social, economic, cultural, and political.

The concept of disability does of course have a longstanding history in sociology, with its origins in, amongst others, the work of Irving Zola (1972) and the UK activist tradition that is best known through its refinement in the work of Mike Oliver (1990) and what came to be known as the British Social Model of disability. And, particularly from the 1990s onwards, the growth of the interdisciplinary field of disability studies has shifted the disciplinary conversation in several sociological subfields towards an appreciation of disability as a complex and theoretically productive concept—that troubles many foundational assumptions about what it means to be human and how human lives are valued (Goodley et al., 2019; Liddiard et al., 2019).

As disability studies have shifted towards the study of structural and systemic ableism, its perspectives can productively be integrated with various established sociological topics that centre on norms and values (Hughes, 2019). Conversely, many concepts of classical sociology may turn out be useful in identifying specific ableist mechanisms in different societal spheres; developing such an interdisciplinary connection is a key aim of this article. In the following section, I will discuss in more detail how the sociological concept of the sick role can and should be supplemented with a disability studies-inflected analysis of neoliberal or 'soft' ableism, particularly with a view to understanding what Talcott Parsons termed *problems of legitimation* and how the paths to social legitimacy for disabled people are structured by ableist norms and values related to work.

THE CLASSICAL SICK ROLE, ITS NORMATIVE FUNCTION AND SYSTEMIC ABLEISM

In modern societies, the seminal role of paid work as a fount of social status (Hollingshead, 1975) creates a foundational problem for people with disabilities and chronic illnesses. I will return to the issue of how 'disability' is partly a category defined by a formally sanctioned exclusion from the regular labour market. Parsons, as is well known, introduced the concept of the sick role as a way to capture problems of legitimation 'in terms of [a] wider value-system' (1951, p. 291), but the structural functionalist account tended to focus on the successful accommodation of a narrow range of cases of individual deviance. The 'safety valve' metaphor of the classical sick role

explained how social legitimacy could be temporarily preserved in cases of acute illness but did not account for long-term illness or permanent disability.

That the Parsonian concept of the sick role derived from a narrow range of qualitative observations and thus could not account for the full range of illness experience (Burnham, 2012, 2014, p. 78; Charmaz, 2020) was acknowledged inside sociology's disciplinary boundaries. By contrast, disability studies advances a more fundamental critique, which is also directed at sociology's longstanding tendency towards medicalisation. For disability studies, the classical sick is conceptually flawed because it relies both on the assumption of an (eventual) return to normality and on the assumption that social role failure is caused primarily, if not singularly, by individual pathology. Both of these assumption are part of a medical model that, though it does not accurately describe disability, has had considerable influence in the sociology of health and illness (Barnartt, 2017b; Thomas, 2004, 2007)—and in society at large.

Within a medical model framework, social legitimacy was not on the table for disabled people. In his landmark study of the politics of disablement and from a neo-Marxist point of view, Oliver (1990) suggested that 'disability' primarily denoted a category of oppression and exclusion rather than a functional social mechanism. Crucially, the primary cause of exclusion was not individual pathology but lack of accessibility and, crucially, a binary devaluation of certain levels of labour power. Particularly since the dawn of the industrial age, people who were unable to work standardised shifts under standardised labour conditions were forced into the ranks of the unemployable, with no pathway to social legitimacy.

On this count, disability studies diverged strongly from sociology's view of disability as a form of social deviance from given norms (Mauldin, 2021; Mauldin & Brown, 2021; Thomas, 2007), centring its critique on the norms themselves—and a narrow conception of *normality* (Davis, 1997; Garland-Thomson, 1997). This critique developed along many axes, in the United States, the UK, Scandinavia and elsewhere (Goodley, 2010; Shakespeare, 2013; Tøssebro, 2004). Approaches were grounded in the humanities as well as the social sciences, but a recurring feature was that disability was viewed as an ontologically autonomous mode of being, and that the pressing issue was to explore the structural factors that shaped not only pathways to inclusion for disabled people but the category of disability itself.

On an assumption of biophysical normality, and given acute illness as an occasional exception to the rule of health, the classical sick role is a reasonably functional concept. Should either or both of those assumptions be faulty, as has shown to be the case, the sick role loses much of its descriptive power. It remains, however, interesting as a normative force, providing a picture of how society wishes its members to be ill, and thus into the 'wider value-system', which much recent work in disability studies has been characterised as *ableist*, that is, 'a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human' (Campbell, 2001, p. 44).

The argument that most societies are to some degree ableist has been extensively developed (Campbell, 2009; Goodley, 2014; Wolbring, 2008). Social norms that assume average physical and mental functioning may ultimately be rooted in evolutionary mechanisms (Nario-Redmond, 2019) but have become embedded in complex societal structures and ideological justifications. Ability is *valued*; thus, social legitimacy comes to depend on people's ability to demonstrate it, not least through work.

Another key function of the concept of ableism is to point out how binary conceptual oppositions may be created out of continuous qualities, devaluing anything that falls outside the boundary value. The forms of embodied experience collectively referred to as disability are, on

one reading, simply parts of the spectrum of human embodiment. But through social, political, economic and cultural mechanisms—not least the growth of statistics (Davis, 1997)—‘disability’ has become reified as subaltern to the *normate* (Garland-Thomson, 1997).

In other words, ableism centres a statistically average level of physical and mental capability, but also construes as abnormal or deviant those levels of capability that fall below a particular, historically contingent threshold. In the neoliberal economy, a key facet of ableism is the assumption that illness is a short-term phenomenon and that full-time work is the norm; thus, the inability to work full-time under given conditions is, historically, closely aligned with disability (Stone, 1984). These are normative assumptions that legitimise a circumscribed, temporally delimited sick role. They naturalise the exclusion of non-normate embodiment from work life.

Thus, the legitimacy promised by the extension of human rights to the group of disabled people is undermined by socioeconomic structures, though also by cultural history. And empirically, disabled people and people with chronic illnesses lag on most indicators of social wellbeing; they are poorer, have lower levels of education and are more isolated than the population in general (WHO, 2011). Even so, when seeking access, they are routinely stigmatised on suspicion of requesting ‘special privileges’ rather than equality (Dorfman, 2019).

In the following, I pursue the matter of how the classical sick role functions on a normative basis, how it interacts with the ableist ‘wider value-system’ of neoliberal society, and how it relates to role expectations for disabled people. I argue that, absent a stint in the classical sick role, disabled people incur an obligation to perform various unacknowledged tasks in order to secure social legitimacy and minimise stigma. I further argue that these tasks and activities amount to a burden of *invisible work* (Daniels, 1987) that becomes, in itself, a hindrance to full and equal participation.

In sociology, the classical sick role was acknowledged from the beginning to be, in part, a mechanism for minimising the disruptive potential of disease/illness—but through the *balanced* imposition of privileges and burdens. With long-term illness, an imbalance arises that could only be defended on normative terms if chronic illness were an exceptional case. In sociology, this problem became difficult to ignore, partly as a result of the post-war increase in rates of chronic illness, but it took a surprisingly long time for the Goffman-derived study of long-term illness and disability as a form for deviance (Barnartt, 2017a; Brune et al., 2014) to be supplanted by investigations that assumed a more pluralistic set of social roles.

By contrast, the enduring prescriptive force of the classical sick role may have been underestimated. One vector where it continues to exert influence may be through *disease prestige*. *Ceteris paribus*, acute diseases are routinely ascribed higher prestige by doctors, nurses and patients (Album et al., 2017; Album & Westin, 2008), while long-term illnesses and the medical subfields that treat them are viewed as having lower prestige. In other words, to be acutely ill is more legitimate than to be chronically ill. This fact will be reflected in the experience of patients of how others perceive them—and provide standards for their behaviour.

From the beginning, it was clear that the ‘wider value-system’ and the sick role jointly impose moral standards for illness behaviour that may be at odds with physiological reality. For Parsons, the sick role was accompanied by privileges that could only be legitimised in a state of exception. In order to claim these privileges, the sick person had to *enact an intention* to return to normal life and to act as if this return would in fact take place—following prescribed medical treatment, for example. The sick role provides social legitimacy through the absence of moral blame and so depends on a perception of moral rectitude in the person claiming it. Disease prestige, too, relies on this logic—conditions that imply moral failure (e.g. lung cancer and cirrhosis of the liver) are accorded lower prestige than comparable conditions. Seen in this perspective, the normative

expectations accompanying the Parsonian sick role represent an ableist trap for people with long-term illnesses. A failure to improve, even when it is the consequence of biophysical factors beyond individual control, becomes a moral failure.

This dimension has not always been recognised in sociology; Freidson (1970) argued that chronic illness provided access to the sick role with unconditional legitimacy. Much work in disability studies has been dedicated to showing that disability as well as chronic illness has primarily been socioculturally *disavowed* (Shakespeare, 1994; Snyder & Mitchell, 2006) rather than legitimised and that accusations of malingering, faking or otherwise attempting to improperly assume the privileges of the sick role have been more common than its legitimate occupancy (Schweik, 2009; Siebers, 2008). A well-known case in which this dynamic has played out over the last few decades is that of ME/CFS. The details of the clinical and socio-political controversy over the 'contested condition' or conditions in question lie beyond the scope of this article; I have discussed these elsewhere (Grue, 2013). In this context, the salient issue is that, absent a clear consensus over aetiologies, treatment strategies and hope of cure, patients who have been diagnosed with ME or CFS often experience unmanageable and incommensurable expectations of progress. Consequently, the sick role, first perceived as a temporary reprieve, soon becomes an impossible set of expectations.

In this limbo, the normative expectation of health-promoting behaviour is particularly problematic. ME/CFS patients and patient organisations often disagree with medical professionals not only about treatment regimens but about these regimens' epistemological foundations. Some patient NGOs expressly endorse only 'pure' biomedical aetiologies, eschewing, for example, psychosomatic factors and consequently cognitive-behavioural interventions. Given a Parsonian sick role and the logic of disease prestige, this makes perfect sense—under social conditions where the perception of 'not wanting to get better' imply role failure, it is better to avoid anything that might further this perception. The question is what other means are available for achieving social legitimacy.

ESCAPING MORAL BLAME: THE 'ABLE-DISABLED ROLE'

Some people with long-term illnesses may credibly signal a narrative trajectory that will at some point lead them to a return to health and to working life. But others may not, and impairments, whether congenital or acquired, are usually understood as permanent. This does not mean that disability should be dichotomously opposed to illness, as scholars from disability studies as well as sociology, and indeed the World Health Organization, have pointed out. Long-term health conditions and disability are closely entwined, both on a conceptual and an empirical level. But permanent disability may productively be juxtaposed with acute illness, not only because it so clearly represents a 'baseline' or normal state of being but because of the subtly different obligations associated with a socially legitimate 'disabled role'. Illness and disability throw light on different aspects of ableism in neoliberal societies not only because of the way they represent exclusion but because of their different paths to inclusion.

Earlier epistemological regimes may have framed disability in mythical or theological terms, and social legitimacy may have derived from religious precepts or kinship relation. In their cultural-historical study, Snyder and Mitchell (2006) suggest that there have been many 'cultural locations', such as (in a chiefly Western/Global North context) charity systems and state institutions, that have rendered disabled people culturally legible. In the late modern world, the disabled role is all but inextricable from the relationship between medicine and work, with disability

defined through an exemption from work that is also an exclusion. Stone's (1984) analysis of the 19th-century emergence of state-sanctioned work exemptions of disabled people foregrounds the gatekeeping function of medicine. Here, the 'disabled role', though it is characterised by permanence and by a much lower degree of social legitimacy, is joined to the sick role in that both reflect the moral economy of universalistic achievement values. Current measures of quality of life 'often associate functionality with economic productivity, valuation, and cost' (Atkin et al., 2023, p. 48).

Of course, disability does not imply a total inability to work—no more than illness does. Absent a hard, binary distinction between a work-based and a needs-based economy, disability becomes a matter of bricolage and improvisation, as suggested by the rapidly growing study of disability in the Global South (Grech & Soldatic, 2016). And even in OECD countries, disability was never a matter of either/or. Employment rates for disabled people in these countries currently range from 29% to 58%, a function of societal context, historical circumstance, and political choice (OECD, 2022). As was the case for women, employment rates for disabled people skyrocketed during the Second World War (Barnes & Mercer, 2005).

The question, then, is how and to what extent a *contemporary* disabled role functions as a path to social legitimacy. What obligations does it impose? Sutherland (1981) presents the 'disabled role' not in contrast to the sick role, but to the 'feminine role' (p. 7). Discussing it primarily in terms of power, he suggests that the disabled role consists in part of normative expectations and obligations that impose performative requirements on people with disabilities. The important thing is not to be in or out of work, per se, but to 'act disabled' in a socially acceptable way.

This understanding of the disabled role was later taken up by French (1994), who also emphasised its function in imposing norms for what constituted 'properly disabled' behaviour. Some studies stress the similarities to the sick role and its relationship to the medical professions (Scullion, 2000), with others (Porter, 2000) defining it entirely in terms of the expectations of welfare bureaucracies, following in the research tradition after Stone (1984). This latter direction can be related, albeit uncomfortably, to earlier research that seeks to resolve the 'problem of disability' (Larson & Spreitzer, 1970; Ludwig, 1981), understood in terms of moral hazard, in affluent societies.

In this framing, medical gate-keeping of economic resources remains critically important. As Stone pointed out, in welfare states, disability defined (and continues to define) the moral as well as political boundary of the larger sector of the economy that was structured around wage labour, a boundary that has to be heavily policed. Under these circumstances, achieving the 'disabled role' is a matter of being medically legitimised as such, though unlike the sick role, the disabled role is also permanently discrediting. Here, the moral economy of the disabled role overlapped with what was described in the 'personal tragedy theory' (Oliver, 1990) of disability. Closely linked to the medical model, personal tragedy theory implied that disability equated marginalisation and incompleteness, setting out expectations of gratitude and an upbeat demeanour, but no implication of a need for societal change.

Both the medical model and personal tragedy theory were constructs of disability studies, developed as objects of critique. Part of the point for disability activists, as for many academics working in disability studies, has been to show that other 'disability roles' are possible and that they are compatible with full societal participation. These efforts have met with considerable success—as only one example, disabled people are routinely included among the minority groups whose inclusion in various societal arenas constitute 'diversity'. Representations of disabled people and public understanding of what it is to be disabled has changed dramatically in many countries, and stigma has lessened considerably. Arguably, however, the new, socially

legitimised disabled role that has emerged in recent decades regularly represented in global discourse by multinational companies' diversity campaigns and in quadrennial advertisements for the Paralympic Games, derives from the requirements of neoliberal capitalism and is just as tightly bound to ableist values as the older disabled role.

This new role can be understood, in keeping with Tanya Titchkosky's definition of the 'able-disabled' (Titchkosky, 2003, 2007) as centred on the subset of disabled people who are most likely to be able to adapt to existing social structures, particularly in terms of productivity—those who can survive employer's tendencies to compare disabled job seekers with 'ideal', non-disabled workers in terms of productivity (Østerud, 2022). This is the group whose combination of resources (embodied, social and economic) is sufficient for them to *compete* in work life and other societal fields. This minority within the minority may benefit disproportionately from the lowering of formal barriers to participation, for example, from anti-discrimination policies in hiring and from broader implementation of universal design. But it requires them to fit narrowly into the ideals of 'productive citizen', that is, someone who is unburdened by familial or care obligations and who can adapt to existing structures in most respects.

It should be remembered, of course, that the able-disabled role may be problematic even for disabled people with a relatively greater amount of resources. Mitchell and Snyder (2015) discuss the way in which ableist norms remain in force through mechanism of inclusion. Playing the able-disabled role is partly a matter of acting as a guarantor of the goodwill of the existing social system—of performatively demonstrating that the 'full and equal participation' envisioned by the UN Convention on the Rights of Persons with Disabilities is eminently achievable.

The performative aspect of the able-disabled role is particularly striking in working life and sports, where disabled people are regularly represented as inspirational figures or super-crips (Grue, 2015; Howe, 2011). Where the older disabled role was predicated on enacting debility in order to stave off accusations of malingering and the classical sick role predicated on demonstrating health-seeking behaviour, the able-disabled role requires a direct demonstration of universalistic achievement values, aimed at undercutting suspicions of diminished productivity. Again, ableism imposes a binary. The traditional disabled role confers the 'privilege' of a permanent exemption from the obligation to work, but at the cost of full citizenship. The able-disabled role provides a greater degree of social legitimacy, but on ableist terms, and with the added requirement of performative concealment of structural deficits. In particular, it imposes a burden of invisible work.

INVISIBLE WORK AS A CONCEPT AND METAPHOR

Both the classical sick role, predicated on acute, temporary illness followed by a return to work and the able-disabled role, framed by the ideal of full participation and productivity regardless of embodied disadvantage, depend on and reinforce universalistic achievement values while eliding the socioeconomic conditions that systematically exclude disabled people. For the sick role as well as for the able-disabled role, performative effort is required in order to live up to the normative constraints of these universalistic achievement values. For the sick role, health-seeking behaviour must be balanced against proper illness behaviour, that is, a demonstration that the illness is sufficiently serious to merit privileges of exemption. The same applies to disability privileges, that is, rights-based access to compensatory accommodation. In each case, the role becomes a balancing act, and a double bind is created, one that can be framed in terms of unacknowledged or invisible work.

Understanding the tasks associated with disability illness as work is not in itself a new approach. Corbin and Strauss (1985, p. 224) addressed ‘some of the problems of managing chronic illness at home [...] in terms of the concept of “work”’ and established a tripartite typology of illness work, everyday life work and biographical work. From this analysis arose a considerable literature dealing with the unpaid work that goes into the management of chronic illness, exploring, for example, the importance of social capital and social networks (Vassilev et al., 2011, 2013) in condition management. Another direction of inquiry has focused on how *labour* (here understood as paid work) carried out by disabled people is often rendered invisible, taking place largely out of sight, as in sheltered workshops (Hatton, 2017).

A seminal article by Daniels (1987) discusses the complex relationship between work and labour. Drawing on earlier feminist research, Daniels used the concept of invisible work to analyse domestic work as unpaid labour. What was conventionally understood as ‘women’s work’, including the ‘emotion work’ of managing the feelings and expectations of others, and the effort required for performing a social role in a particular way, were here understood as a necessary precondition for the ability of married men to perform formally recognised work, that is, paid labour. Invisible work was important both because it helped explicate the social obligations associated with gendered roles and because it was unacknowledged but essential part of the labour economy.

I will here take some time to discuss in conceptual and linguistic terms what it means to pursue Daniels’ direction of inquiry. First, I will note that it is clearly established that disabled people and people with long-term illness are required to carry out a number of unpaid and unacknowledged tasks in order to live up to socially constructed role expectations. In linguistic terms, this framing can be viewed either as a *polysemic* intervention that stresses the broad concept of work or as a *metaphorical* intervention that stresses the narrower concept of paid labour. Polysemy refers to the fact that words have multiple meanings, often related to different domains, and the word ‘work’ can mean both salaried labour and sustained, but unpaid effort (and, more esoterically, to sail windward). Many researchers, and certainly many disabled people, have adopted the polysemic approach. For them, the everyday tasks required by disability and long-term illness fall under the wider meaning of work, though they remain socially unacknowledged and therefore invisible.

However, Daniel’s understanding of invisible work as inextricably linked to salaried labour, that is, as those activities that makes salaried labour possible, suggests a more radical, metaphorical intervention. In metaphor theory, the use of concepts from one domain to understand phenomena in another is viewed as a key element both in cognition and in social structure (Kövecses & Csábi, 2002; Lakoff, 1987, 2002; Lakoff & Johnson, 1980). To metaphorically suggest that ‘love is a fire’ is to highlight certain aspects of what love can feel like, without claiming that it requires high temperatures or combustible materials. Similarly, the everyday tasks associated with disability and long-term illness are not, literally, labour. But as both Daniels’ analysis and earlier feminist critiques of the invisible work imposed upon women pointed out, compulsory unpaid tasks *can* be analysed as unpaid labour—and productively so (Federici, 1975).

Metaphors can be dismissed as extraneous to real understanding and insight, as so much literary ornamentation or as rhetorical flourishes. But metaphor theory emphasises their centrality to cognition, as well as to policymaking and institutional praxis. Moreover, it stresses the culturally dominant dynamic in which abstract domains are usually understood in terms of more concrete domains and how very broad domains are usually understood by way of narrower domains. We say that ‘life is a road’, not that ‘this road is a life’.

Against this background, it should be noted that illness and disability, culturally speaking, have long been suffused by the metaphor—but not metaphors of work or labour. Metaphors of passivity are common, but as pointed out by Susan Sontag (1991), one of the most culturally salient active metaphors related to illness is that of *conflict* or *battle*. A disease is framed as an antagonist, whether in a semi-abstract form or by way of another figure of language, usually metonymy so that the struggle is carried out against the virus or bacterium causing the disease, against the embodied symptoms etc. For disability, the battle metaphor is also common, though here, the antagonist may be the body itself, with the mind or soul playing the role of protagonist (Norden, 1994; Snyder & Mitchell, 2006). It is unclear to which extent the metaphorical framing of illness experience as an antagonistic struggle is embedded in classical notions of the sick role. But many problematic consequences of the cultural prevalence of the ‘battle’ metaphor have been documented and explored (Ehrenreich, 2010). This metaphor is often coupled to a warrior ethos and a logic of heroism, which is less accepting of the limitations and constraints of everyday life.

To use the domains of work and labour as tools for understanding the efforts associated with illness and disability is, by contrast, an act that both stresses their ongoing and ultimately unresolvable nature, and one that illuminates the way in which these efforts are structured by the neoliberal economy. This operation develops both a political-economic and a cultural analysis. To speak of the invisible work of illness and disability is both to point out the literal requirements made of disabled people and to reconceive their experiences—to make them, in Snyder and Mitchell’s terms, culturally legible—in a more precise way than is possible through the battle/warrior metaphor.

Following Daniels’ role-centred definition, it is clear that performative tasks aimed at cultural legibility form a crucial part of the invisible work required both by the sick role and the able-disabled role. While the exact tasks involved will vary greatly in situations of acute illness as opposed to permanent disability, an underlying principle is that this work serves to reinforce universalistic achievement values through the imposition of a social burden, much as gendered invisible work perpetuates gender inequality.

At the intersection of disability studies, the sociology of health and illness and feminist theory, illness work has already been directly related to the efforts of maintaining valued (and gendered) social roles only recently. In a study of women living with cancer, Pritlove et al. (2019) notes that the work of maintaining everyday life with a serious health condition cuts across multiple social fields and includes paid as well as unpaid tasks, with a salient aspect of role maintenance; this, of course, holds true for disability and long-term illness in general.

As the authors point out, ‘life doesn’t stop when you’re sick’ (Pritlove et al., 2019, p. 766). Nor does it when you are disabled. Here, the detailing of embodied invisible work can counter inaccurate but deeply embedded cognitive metaphors wherein illness and disability is conflated with passivity. People are described as being *wheelchair-bound* or *confined to wheelchairs*; deafness and blindness are routinely used to signify an absence of active interest or attention. Bruno Bettelheim’s (1967) infamous ‘empty fortress’ metaphor for autism suggests defensiveness and isolation. Correspondingly, the word ‘disabled’ has among its literal meanings ‘rendered inoperative’ (Merriam-Webster.com, 2022), ‘made incapable of use or action’ (en.wiktionary.org, 2022), and ‘incapable of functioning’ (thefreedictionary.com, 2022).

To explore the ubiquity of invisible work is therefore an analytical strategy for clarifying the Catch-22 that structures the predicament of disability and long-term illness under ableist conditions. On the one hand, disabled people and people who are ill may face a cultural expectation of passivity, withdrawal and debility. On the other, they may face expectations of proper health

behaviour and optimisation for productivity, of being warriors and of being totems of inclusion. The resultant double bind creates a burden for individuals that can only be shifted onto institutions if it is first made visible and anatomised.

ANATOMISING EMBODIED INVISIBLE WORK

In Daniels' original definition, invisible work functioned as a support system for paid labour; I will largely adhere to this approach. It further consists of tasks that, morally speaking, have to be carried out by particular groups of people—but would require remuneration if done voluntarily by others. Using the concept of invisible work to analyse the various tasks routinely associated with the sick role and the disabled role must therefore take into account how these roles intersect with other roles of everyday life (e.g. parent, caregiver, spouse or partner) that may come with their own ableist norms. Furthermore, the disabled role itself is entangled with other identity categories. Emens (2020, p. 2331) refers to 'disability admin', that is, 'all of the office-type work that it takes to run a life and a household' and the resultant drain on mental energy, a type of work may be gendered in formally structured ways; for example, as when gender-role expectations impact degree to which personal assistance and other forms of state support (von Granitz et al., 2017).

Daniels analysed invisible work along physical, emotional and logistical dimensions; these too are entangled, for example, in the form of 'access work' (Hamraie, 2017). To take an ostensibly trivial but important example, access to bathrooms is a perennial problem for people with mobility impairments and many chronic illnesses. Across countries that nominally adhere to universal accessibility and principles of universal design, accessible bathrooms are often few and far between, with varying levels of actual accessibility. Simply finding them requires logistical work, and making use of them may require considerable physical effort—if there is insufficient space for a wheelchair, for example. The use of such bathrooms is frequently restricted, meaning that one has to contact staff and request a key. Such interactions may involve emotional work, particularly for people with hidden illnesses or impairments, who may also be subjected to stigma by people who believe that 'disability privilege' is being improperly assumed; much the same dynamic plays out in the use of accessible parking spaces.

In anatomising this work, intersectional analyses must come into play. Contrary to the stereotype of disability as a 'master status' (Hughes, 1945) or a 'metanarrative' (Bolt, 2021) that obscures every other facet of identity, it interacts with race, class, gender, sexuality and other key dimensions of the social experience (Naples et al., 2019)—in complex, non-linear ways (Watermeyer & Swartz, 2023). As Collins (2015) points out, intersectional analysis must begin with the acknowledgement that the phenomena in question are mutually constitutive. For disabled mothers, for example, the risk of demonstrating debility, that is, of deviating from the able-disabled role seems particularly high; their experience of disability is constituted in part by the role expectations of motherhood (Grue & Lærum, 2002; Malacrida, 2009).

Achieving the able-disabled role is therefore partly a matter of 'passing, in which an individual hides his identity, or covering, in which an individual acknowledges her identity but suppresses outward signs or aspects of the identity' (Pendo, 2016)—it amounts to performing disability in a way constituted by the (ableist) expectations made of 'normal' workers. The role may well allow for the foregrounding one's illness or disability in a particular way but heavily constrained (in Goffman's terms) by the need for impression management that conveys competence, productivity

and mastery. A disability ‘success story’ (Lundberg, 2022) must conform to ableist norms—which may coexist perfectly with other discriminatory practices (Bergths et al., 2021).

If social legitimacy is achieved, either by way of the sick role or the able-disabled role, it is largely by avoiding those implications of moral badness that are expressed through embodiment. This requires complex social negotiations. With employers, even when these are supportive (Bramwell et al., 2016), a balancing act is required; it is important to come across as ‘deserving’ rather than ‘demanding’ (Remnant, 2019). The onus remains on the marginalised person to project a particular image that is aligned either with a (mostly) non-stigmatised role or with role with lessened stigma. Passing may be attempted by those who are able to do so, while covering will be employed by those who have no other options. In either case, considerable effort is required.

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How we understand disability and long-term illness matters a great deal. Historically, understanding them as forms of deviance suggested that the imposition of moral order was necessary, while understanding them as forms of heroic struggle has reinforced the significance of personal responsibility. Understanding them in terms of their relationship to work, too, suggests a moral economy, but the work frame is potentially both more open and more productive in terms of its implications.

Investigations of disability-as-work can, as investigations of ‘women’s work’ have done, trouble both the dividing line between acknowledged and unacknowledged work and the way in which values are linked to and enforced through socially constructed roles. For the sociology of health and illness, it seems important to pay greater attention to (to draw on Arlene Kaplan Daniels’ words) the innumerable things that one ‘has to do’ when one has an illness or is disabled. Those tasks are the precondition of being socially recognised as an acceptably sick or disabled person and the way in which they continue to rely on role expectations defined by paid employment amount to an ableist trap. In neoliberal economies, disability and long-term illness do not represent withdrawal or passivity but the exchange of one set of tasks for another, a much more thankless set.

The analysis of the invisible work of disability and illness is therefore a matter of anatomising society’s imposition of a complex regime of social control in which marginalised positions may acquire some degree of social legitimacy, but at the cost of directing everyday life entirely towards the support of paid labour—and to performing a socially legitimate role. The burden of invisible work becomes a strong teleological constraint on the behaviour of disabled people, one that, paradoxically, may lead both to the neglect of self-care (Dyson et al., 2021)—and to the detriment of work as a source of meaning (Carmichael & Clarke, 2022).

Is there a way out of the ableist trap? On an individual level, it seems apt to quote Sunaura Taylor’s (2004) essay on the right not to work: ‘I have very little work value (if any), and I am a drain on our country’s welfare system. I have another confession to make: I do not think this is wrong, and to be honest, I am very happy not working. Instead I spend the majority of my time doing the activity I find the most rewarding and valuable, painting’. There are times and circumstances in which the ideal of full participation may be rejected—and while much of the invisible work of disability is inescapable, some of the tasks that are most closely associated with living up to the able-disabled role may be rejected too.

Of course, this is not a structural solution. In the same essay, Taylor notes that '[t]he same rule that often excludes the impaired from the traditional workplace also exploits the able-bodied', raising the possibility of solidarity. But to note that the implications of the issues discussed here are ultimately systemic in nature is also to invite the observation, variously attributed to Fredric Jameson and Slavoj Žižek, that it is easier to imagine the end of the world than the end of capitalism.

On the more modest, interdisciplinary scale of this article, I suggest that, for sociology, a more critical consideration is in order of two issues. First, of the way in which even an ostensibly inclusive society's approach to disability and long-term illness remains informed by a moral economy of work that is distinctly ableist. And second, of how this moral economy perpetuates itself as the arbiter of value and meaning for the lives of non-disabled as well as disabled people.

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Jan Grue: Conceptualization and writing.

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DATA AVAILABILITY STATEMENT

The article is a conceptual/theoretical essay, drawing only on previously published research.

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