
Social Theory and Health Annual Lecture

Theorising disability and chronic illness: Where next for perspectives in medical sociology?

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Abstract The proposal in this article is that the time is ripe for a distinct *sociology of disability* to come into being as a new sub-discipline within *mainstream* sociology. This sociology of disability would be a variant of *equality and diversity studies* in the discipline – located alongside the now familiar engagements with gender, ‘race’, sexuality, age and social class. The sociology of disability would encompass the study of disablism and impairment effects, with the former taking centre stage. This means that disability would cease to be located almost exclusively in a specialized sub-field of interpretative medical sociology – known for several decades as *the sociology of chronic illness and disability*. Rather, disability – like gender – would become a key dimension of global social divisions and inequity that can be approached from a multiplicity of analytical directions, using a rich mix of theoretical perspectives, methodologies and research techniques. This article will unpack some of the arguments in favour of such a move – dividing these into three argumentative threads for presentational purposes. Of course, no one can determine the direction taken by a discipline – it is a matter of argument, debate and initiative. *Social Theory & Health* (2012) **10**, 209–228. doi:10.1057/sth.2012.7; published online 27 June 2012

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Introduction

It was an honour to be invited to give the *Social Theory & Health Annual Lecture* in February 2010 in London.¹ This article builds on the ideas presented there, and moves my argument on with regard to the *disability question* in medical and mainstream sociology.



The 2010 lecture marked a telling moment in a personal intellectual and political quest that began about 10 years earlier. In short, my quest was to win some academics and research students in the heartland of medical sociology over to the view that sociologists and other social scientists in *another* discipline known as disability studies were pursuing novel and important ideas in their study of disability and impairment effects.² Moreover, I proposed that the sociological perspectives generated in disability studies were of relevance and value to the future of medical sociology in the twenty-first century. This case was first articulated in my book *Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology* (Thomas, 2007).

Now, in early 2012, my views have crystallized on what I would like to see happen on the disability question in medical and mainstream sociology – and this makes up the topic in this article. My proposition is that the time is ripe for a distinct *sociology of disability* to come into being as a new sub-discipline within *mainstream* sociology – on the global stage. This sociology of disability would be a variant of *equality and diversity studies* in the discipline – located alongside the now familiar engagements with gender, ‘race’, sexuality, age and social class.³ In the spirit of making disciplinary pronouncements, like Michael Burawoy (2005) or Ulrich Beck (2012), this means that a reconfiguration of sociology is called for. In this case, *disability* would cease to be located almost exclusively in a specialized sub-field of interpretative medical sociology – known for several decades as *the sociology of chronic illness and disability* (but increasingly referred to as simply *the sociology of chronic illness*) (Bury, 1991). Rather, disability – like gender – would become a key dimension of global social divisions and inequity that can be approached from a multiplicity of analytical directions, using a rich mix of theoretical perspectives, methodologies and research techniques. This article will unpack some of the arguments in favour of such a move – dividing these into three argumentative threads for presentational purposes. Of course, no one can determine the direction taken by a discipline – it is a matter of argument, debate and initiative.

My suggestion for a disciplinary shake-up may be timely because significant changes are already underway *within* medical sociology in the United Kingdom.⁴ For example, Graham Scambler and Sasha Scambler (2010, p. 1) have recently referred to research on chronic illness as being in a ‘transitional phase’, partly as a result of the flurry of debates between medical sociologists and writers in disability studies in recent years. Simon Williams (2010, p. 205) exemplifies changing times by arguing that ‘... the sociology of chronic illness would benefit not simply from a more avowedly political but a more explicitly biopolitical form of analysis and engagement’. Also of note is B.S. Turner’s (2004) more generalized call for a new medical sociology that incorporates a *universal theory of human rights* – reflecting human vulnerability and social instability.



Of relevance too is Turner's earlier observation that a *sociology of disability* is effectively missing in sociology: 'Apart from the influential works by Erving Goffman [...] and Irving Zola [...] sociology has contributed surprisingly little in terms of systematic theory and research to the study of disability' (Turner, 2001, p. 252). Such in-house developments will be returned to later in the third argument.

Key to my arguments in favour of a new sociology of disability in the equality and diversity genre is the importance of the study of *disablism* – defined, in brief, as follows:

Disablism: refers to 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'. Disablism is *social-relational* in character and constitutes a form of *social oppression* in contemporary society – alongside sexism, racism, ageism, and homophobia. As well as enacted in person-to-person interactions, disablism may manifest itself in institutionalised and other socio-structural forms. (Thomas, 2010, p. 37)

A second concept of use in what follows is *impairment effects*:

Impairment effects: the *direct and unavoidable* impacts that 'impairments' (physical, sensory, intellectual, emotional) have on individuals' embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course. (Thomas, 2010, p. 37)

These are familiar concepts in disability studies, but not in sociology. The new sociology of disability that I propose for mainstream sociology would import, utilize and develop both of these concepts, with disablism taking centre stage. Currently, the longstanding interests of medical sociologists specializing in chronic illness are actually bound up with the sociology of impairment effects, especially: coping with disease and chronic illness symptoms; the changing body and self-identity; becoming a patient, medical practices and interrelationships with doctors and care workers; and the nature of health services and systems matters. These impairment effects are, of course, crucially important in people's lives – but they generally become of secondary or irregular significance to disabled people as time moves on. Preoccupations with meeting *basic* social needs usually come to the fore, and disablism invariably makes its presence felt either subtly or explicitly – for example, when: accessing education, trying to hold down a job, paying the bills, accessing health care, bringing up a child, looking after an ill parent, finding suitable



housing, getting a car adapted, getting to the shops or cinema and so on (Thomas, 1999; Oliver, 2009).

It must be appreciated from the start that this article's focus on sociology is not at all to undervalue the importance of other disciplines in the study of disability,⁵ and is certainly not to propose a displacement of the multidisciplinary *disability studies* that exists today in the academy. Rather, it is to encourage academics in sociology departments and members of the *British Sociological Association* to think about disability as an essential thematic arena within equality and diversity studies – alongside gender, 'race', sexuality and age. The following arguments seek to build up my case in a step-wise fashion, starting with a brief review of the contemporary policy landscape.

Argument 1: Staying Connected with the Policy Landscape

The first argument follows from broader social and cultural change. In short, British sociology is currently behind the times with regard to seismic ideological shifts in civil society on the disability question. Dislodging the study of disability from its almost exclusive home in medical sociology and adding it to equality and diversity studies in the mainstream would be entirely consistent with social changes captured in policy shifts and government legislation in recent years. In my view, the discipline needs to catch up and look ahead in substantive terms if it is to retain its relevance and linkage to the social landscape on disability matters. In the same way that sociology had to transform its thinking on gender in the wake of the twentieth century women's liberation movement and its effects, so sociology must transform its thinking in the wake of the impact of the disabled people's movement (DPM) over the last 40 years (Campbell and Oliver, 1996).

Of particular note in this connection are the Disability Discrimination Acts (1995, 2005), the report by the last Labour Government on *Improving the Life Chances of Disabled People* (Cabinet Office, 2004), and the introduction from the 1990s of financial arrangements designed to facilitate *independent living* – namely, direct payments and personal budgets (Pearson, 2012). Evidence of the significance of these developments is clearly articulated in pronouncements by the *Equality and Human Rights Commission* (EHRC) – the body formed in 2007 that laid innovative conceptual foundations for the *Equality Act 2010* and the follow-up *Equality Duty*, now in force in England, Scotland and Wales. The Equality Act brought disability anti-discrimination law into alignment and interconnection with equality legislation targeted at other sectional interests – notably on the grounds of 'race', gender and sexuality. This legislation required: the rethinking of the meaning of *social diversity*; the recognition that disadvantaged social groups have many socio-structural disadvantages in common;



and an appreciation that *multiple disadvantage* stalks the social landscape. In political terms, this policy agenda demanded joined-up thinking and equality monitoring across government departments:⁶

The Equality and Human Rights Commission will work with the government as it moves towards single equality legislation. The Commission will seek to help government to create effective legislation that protects people's rights and helps to bring about a Britain confident in its diversity The Commission will also seek to influence the development and amending of all government policy making such that policy takes into consideration the importance of equality, diversity and human rights. (EHRC, 2011a)

Interestingly, the EHRC has also expanded the inclusion criteria for social groups in need of *protection*. The EHRC tells us that:

We have a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the nine 'protected' grounds – age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment. (EHRC, 2011b)

However, the foregoing overview is not at all to claim that disabled people have actually *achieved* greater social equality with their non-disabled counterparts in daily life. Rather, it is to highlight the fundamental rhetorical and discursive shifts that have occurred in policy-making and official circles in the United Kingdom. The degree and extent of *real* beneficial social change is a matter of fierce debate and dispute in disability politics and disability studies, especially in these times of economic austerity (Roulestone and Barnes, 2005; Thomas, 2011; Barnes, 2012). Indeed, large sections of the disabled population have reported worsening living standards in recent years, as well as diminished opportunities for social participation; these are outcomes found in both the global north and south (Soldatic and Meekosha, 2012). In disability studies, it is argued that the language of *empowerment*, *inclusion* and *individual rights* has been appropriated by politicians and state officials because it has served their shared neoliberal political and economic agendas in the last three decades (Roulestone, 2012). That is, the freeing-up of market mechanisms and the curtailment of state welfare provision have been hastened by encouraging disabled people to *self-manage*, deepen their *individual responsibility* and join the ranks of the employed.

International policy shifts

On the global stage, policy and legislative developments on the disability question have similarly moved disability away from medicine's jurisdiction and



towards matters of social *equality and diversity*. Two brief illustrations are noted that, in my view, add weight to the argument that medical sociology must rethink its approach to disability in the light of social change.

The first illustration concerns the formulation of the *United Nations Convention on the Rights of People with Disabilities* (CRPD, 2006) – an international agreement designed to protect and promote the social rights of disabled people throughout the world (the UK Government signed up in 2007). In the words of England's Commissioner and Chair of the Disability Committee at the EHRC in 2010:

The Convention is not just a paper 'declaration' without any teeth. It requires government to take action to remove barriers and give disabled people real freedom, dignity and equality. We can use it in lots of different ways to make sure our rights are respected and to get a better deal. (EHRC, 2010, p. 2)

Surely sociological research connected to the CRPD would *not* be served by hanging on to the disability perspective nested in medical sociologists' *sociology of chronic illness*?

The second illustration involves the World Health Organization's (WHO) formal replacement of the *International Classification of Impairment, Disability and Handicap* (ICIDH; Wood, 1980) with the *International Classification of Functioning, Disability and Health* (ICF) in 2001. This change marks a purposive attempt to build in social model thinking on the disability question, not least by consulting disabled people's organizations during the scheme's development and testing (see Bickenbach, 2012). So, will medical sociologists stick with the ICIDH or make use of the ICF?⁷ Once again, movement towards the ICF would require a rethink on the disability question by medical sociologists.

The ICF retains the ICIDH's imperative to collect, collate and standardise data on human health and disability across the globe, but the ICF's detailed classification framework has evolved wherein human functioning is assessed by the body's (impaired or non-impaired) interrelationship with, and freedom to participate in, given contextual environments. Environmental 'factors' in this schema are both physical and social, and embrace: (a) features of the physical environment (for example, climate and population density), (b) features of the human-built world (for example, streets, homes, public buildings), (c) people's attitudes, values and beliefs, and (d) the prevailing social, cultural and political institutions and systems (Bickenbach, 2012).⁸ As well as offering a means of classification, the ICF is to be used to provide regional statistical evidence on the prevalence of disability, and for mandatory CRPD monitoring purposes (*ibid.*).



Argument 2: Reject the Social Deviance Paradigm

In my book *Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology* (Thomas, 2007), I attempted to demonstrate that medical sociology has a *social deviance paradigm* at its conceptual core. This deviance paradigm has been deployed in the study disability and chronic illness in *all* theoretical perspectives used by medical sociologists since the 1950s: structural-functionalism, interpretative approaches, conflict perspectives and poststructuralism. Expressed another way, it has been sociologically normative to approach the ill and disabled as ‘socially deviant individuals’ (Turner, 1987, p. 2).

Argument 2 flows from this observation, and can be briefly stated as follows: it is no longer politically or morally appropriate to analyse disability, or disabled people, using the social deviance paradigm. That is, in the same way that it would be antipathetic for contemporary sociologists engaged in critical race studies, gender studies or queer studies to consider these groups as *socially deviant*, so it should be unacceptable to use the normal/deviant dualism to study disability or disabled people. Like feminists and others studying power relations and the social construction of subalterns, writers in disability studies have consistently rejected the social deviance paradigm, turning instead to a *social oppression* paradigm. If a *sociology of disability* is to be developed in mainstream sociology, as proposed in this article, then the medical sociologists’ social deviance paradigm must be rejected in favour of the social oppression paradigm – or variants of it. In other words, perspectives are required that are suited to theorising and researching social life in a new branch of equality and diversity studies.

The distinction between the social deviance and social oppression paradigms in medical sociology and disability studies, respectively, can be summarised as follows:

... two overarching and contrasting sociological paradigms are in play. Sociologists in disability studies use a *social oppression* paradigm: to be disabled, or to be discursively constructed as ‘disabled’, is to be subject to social oppression. *Disablism* functions alongside sexism, racism, ageism, and homophobia in society. Medical sociologists, I argue, theorise chronic illness and disability through the *social deviance* lens, and have done so in different theoretical guises for many years. Ideas about social deviance have infused medical sociologists’ analyses of two main themes: societal responses to people designated chronically ill or disabled, and the social experience of living with stigmatised bodily states. Theoretical diversity is evident in both the oppression and social deviance paradigms. (Thomas, 2007, p. 4)



In the next section the focus will be on providing a brief summary of the evidence for my claim that the social deviance paradigm is at the core of medical sociologists' study of *chronic illness and disability*. Finally, consideration is given to whether the *potential* existed for a distinct *sociology of disability* to come into being in mainstream sociology in the twentieth century.

Medical sociology and social deviance

Ever since the foundations of sociology were laid in the nineteenth century, *social deviance* has persisted as a core and robust conceptual theme in the discipline, helping to cement its scientific credentials. Durkheim played a formative role in this regard – distinguishing between the socially *normal* and *abnormal* (Durkheim, 1895 (1964 edn.)). Subspecialties like twentieth century medical sociology and criminology thrived on this normal/deviant dualism, not least because medical sociology mirrored the enlightenment inspired *normal/pathological* bifurcation in medicine (Turner, 1987; Cockerham, 2004). Despite this basic commonality, sociologists aligned to different theoretical perspectives have made use of the social deviance paradigm in contrasting ways – arriving at moral and political stances that varied markedly on the disability question.

In the mid-twentieth century in the United States, Talcott Parson's seminal writing on illness and medicine in *The Social System* (1951) laid the foundations for medical sociology as a distinct sociological sub-discipline (Gerhardt, 1989). Parsons' *structural functionalist* perspective focused on the social deviance represented by *the ill* – sections of the population who abandoned social roles (for example, employees, mothers, soldiers) so essential to the maintenance and longevity of the social organism. He proposed that medicine's social function was to contain this threat by regulating access to the *sick role*. Thus, doctors ensured that legitimate holders of the *patient* status observed the two rights and two obligations invested in the sick role:

Rights: (i) To suspend social roles whilst ill. (ii) To avoid blame for dropping duties due to illness.

Obligations: (i) To strive to get well. (ii) To seek out medical assistance, then to comply with doctors' orders.

Parsons' analysis referred initially to acute rather than chronic illness, but he made it clear in follow-up publications that chronic illness posed parallel threats to sustaining societal equilibrium, and thus required the same degree of medical containment (Gerhardt, 1989). Moreover, in Parsonian thinking, the purported unconscious motivations of people to opt out of their social responsibilities by claiming to be seriously ill had to be kept in check continually – if not by individuals' own superegos then by stronger external social forces such as the



medical profession or, if necessary, the criminal justice system (Gerhardt, 1989). It is clear, therefore, that Parsons saw the chronically ill and disabled, like the acutely ill, as people who had a social duty to seek to overcome their limitations by complying with medical dictates. In this way, his moral and political stance on the disability question was to side unequivocally with the social interests of *the normal*, especially those who occupied positions of power.

Parsons' ideas have been extremely influential in medical sociology, and continue to be critically reviewed, re-evaluated and utilised (Turner, 1987; Williams, 2005). However, when structural functionalism was challenged and rejected by interpretative sociologists from the 1960s in the United States, the sociological status of chronically ill and disabled people seemed to change for the better (Gerhardt, 1989; Thomas, 2007). That is, interpretative sociologists in the second half of the twentieth century often appeared to be highly sympathetic to – even on the side of – those disadvantaged by illness or trauma (physical or mental). For example, Erving Goffman (1963 (1968 edn.)) explored the social stigma that disabled people had to shoulder and manage because *the normal* could not cope with the feelings of discomfort engendered by their interaction with visibly disabled individuals. Did this mean that Goffman had abandoned the social deviance paradigm? Certainly not; like other interactionist and interpretative thinkers in the Chicago tradition, Goffman engaged in a form of micro-sociology that located the normal/deviant dualism at its interactional core; in particular, he examined the ways in which deviance was bestowed by social actors invested with power in social engagements. What was reversed was the Parsonian moral and political stance; now it was the ill and disabled who were identified as disadvantaged, and *siding with the other* was in evidence (see Goffman, 1961, 1968; Scott, 1969).

Turning to the interpretative tradition that subsequently developed in medical sociology in the United Kingdom, the 1980s witnessed the flourishing of qualitative research studies examining the day-to-day experiences of people living with chronic illnesses such as rheumatoid arthritis, diabetes, epilepsy and respiratory conditions (Anderson and Bury, 1988; Kelleher and Leavey, 2004; Kelly and Field, 2004). The social deviance paradigm remained in command, but was used sympathetically to highlight the difficulties and challenges faced by chronically ill and disabled people. Lifeworld assaults wrought by such illnesses on *self-identity* were of particular interest (Charmaz, 1983). Moreover, Michael Bury's seminal writings on *biographical disruption* and *illness management* were intended to assist people with chronically illness by influencing medical practices and health-care policy (see Bury, 1991).

The *conflict theory* tradition – composed of a loose mix of Marxists, political economists, critical social epidemiologists, socialist feminists and critical realists – also employed the *illness as deviance* paradigm but this time for



macro-sociological purposes (see Thomas, 2007). From the 1970s, the *social deviance* lens was swivelled from the ill individual towards the structural, especially: the health-damaging and exploitative effects of capitalist economics; the bourgeois state; and powerful social institutions such as medicine. The chronically ill and disabled were now theorised as socially disadvantaged and socio-economically excluded by these socio-structural forces. In this way, it is possible to see that some conflict theorists came very close to an equity perspective on the disability question, most notably Peter Townsend (1979; see Thomas, 2011). However, many conflict theorists were/are not strong on matters of social *diversity* among the socially oppressed and excluded.

It was in the poststructuralist tradition – marking a ‘cultural turn’ in sociology in the 1980s – that the *illness as social deviance* paradigm was given a fresh intensity. Now of interest was the *social construction* of deviance and abnormality by the representatives of institutions invested with bio-power. Michael Foucault’s (1965, 1973) name reigns supreme in this connection. Bio-power was identified as rooted in systems of scientific knowledge spawned by Enlightenment thinkers and articulated with vigour in the discursive practices employed by medical professionals. Doctors spearheaded the regulation and governance of bodies – singly and collectively – by diagnosing *the pathological* and distinguishing it from *the normal*. Indeed, subjects could be discursively cajoled into behavioural *self-regulation* by doctors and media moguls. Given this emphasis in Foucauldian medical sociology, the *absence* of interest in chronic illness and disability is both evident and rather surprising: surely the classification of bodies as *disabled* served to epitomise bio-power? Contrary to such expectations, it has been left to scholars in disability studies to take up the poststructuralist challenge on the disabled body (Tremain, 2002; Shildrick, 2012). Moreover, equality and diversity matters have only figured minimally in the work of poststructuralists in medical sociology – not least because Foucault’s early work ruled out subjectivity and the possibility of social *resistance* to bio-power.

Thus, I rest my case that sociologists aligned to different theoretical perspectives in medical sociology have all made use of the social deviance paradigm – but in contrasting ways, resulting in moral and political stances that varied markedly on the disability question.

Past fragments of a sociology of disability

Was there a possibility that sociologists could have ploughed a different furrow on the disability question in the twentieth century? Background research for *Sociologies of Disability and Illness* (Thomas, 2007) revealed an interesting fact about both mainstream and medical sociology. This was that a number of mid-twentieth century texts exhibited work that concentrated on disability *per se* and demonstrated that a critical *sociology of disability* had the potential to



emerge – an approach that foregrounded matters of socio-structural exclusion and inequality. That is, there are fragments of a nascent sociology of disability to be found in literature published in North America and the United Kingdom, fragments that share of ideas with analyses that were later to develop in the disability studies arena. It is certainly interesting that the first instincts of *some* sociologists in the mainstream on the disability question were to recognize that structurally engendered inequality and unfair social treatment were fundamental.

Notable examples include the following publications: Marvin Sussman's edited collection *Sociology of Disability and Rehabilitation* (1966); Erving Goffman's *Stigma. Notes on the Management of a Spoiled Identity* (1968); Robert Scott's *The Making of Blind Men* (1969); Mildred Blaxter's *The Meaning of Disability: A Sociological Study of Impairment* (1976), Peter Townsend's section on disability in *Poverty in the United Kingdom* (1979); Gary Albrecht's edited collection *The Sociology of Physical Disability and Rehabilitation* (1992); and Wolf Wolfensberger's *Social Role Valorisation* (1983). Some might include in this list the name of the well-known American medical sociologist: Irving Zola. However, I view Zola's writings on disability as belonging to the disability studies tradition because his personal journey with impairment and minority group activism led him to use the language of social oppression rather than social deviance (Zola, 1982a, 1982b, 1989, 1991, 1994; see also Williams, 1996).

I have suggested that these fragments of a nascent sociology of disability did not cohere for four reasons (Thomas, 2007, p. 40). First, as the names in the list above indicate, the few sociologists who did turn their attention to disability *per se* were aligned to different theoretical camps and academic communities, circumstances that often militate against the formation of generic research groupings. Second, the development of the interpretative *sociology of chronic illness and disability* in the United Kingdom in the 1980s dampened down medical sociologists' interest in structural approaches in the study of disability and long-term illness. Third, sociological research on disability in the United States was subsumed by the influential Gary Albrecht under the generic heading *disability studies* in the 1990s – an all-inclusive and *multidisciplinary* field concerned with the social scientific study of disability (see Albrecht *et al*'s *Handbook of Disability Studies*, 2001). Fourth, sociological studies of disability became the core business of a radical new discipline in the United Kingdom from the 1980s – disability studies, a discipline that was hostile to medical sociology and its social deviance approach. But perhaps a fifth factor to draw attention to here is that *disability studies* in the United Kingdom was fashioned by disabled writers and their close supporters (non-disabled and disabled); it was they whose personal experiences and political orientation demanded the rejection of ideas about disability as *social deviance*. They turned instead to



ideas about disability and *social oppression* – taking inspiration from preceding social movements on ‘race’ and gender (see Hunt, 1966; UPIAS, 1976; Oliver, 1990; Thomas, 2007).

Argument 3: Accelerate Changes in Medical Sociology on the Disability Question

As noted in the Introduction, significant changes are already underway within British medical sociology on the disability question – changes that appear to mark some movement away from the social deviance paradigm. These developments are bound up, in part, with a flurry of debates between medical sociologists and writers in disability studies in recent years (Scambler and Scambler 2010a). But do these changes go far enough? My third argument is that it would be beneficial to sociology as a discipline if these changes were consolidated and accelerated. One welcome consequence might be that medical sociologists let go of their effective ownership of the disability topic, thus assisting in the birth the *sociology of disability* in the mainstream – a new and multidimensional branch of *equality and diversity studies*. Another welcome consequence might be that medical sociologists consolidate their expertise in the study of what they do excel in: *impairment effects* (see my earlier definition). Indeed, perhaps the interpretative sociology of chronic illness could morph into *the sociology of impairment effects* – feeding into an overarching sociology of disability. However, such speculations about the future are fanciful. The point here is to look at the changes that are underway in medical sociology and to argue that these should be consolidated and accelerated.

Of course, at a basic level, *change* in academic disciplines is inevitable and necessary: vibrant disciplines cannot stay fixed or unresponsive to alterations in the social landscape. In medical sociology, there is evidence that recent years have witnessed both a broadening of focus and a politicization of stances adopted on the disability question. For example, as reported in the Introduction, Simon Williams (2010, p. 205) has argued that ‘... the sociology of chronic illness would benefit not simply from a more avowedly political but a more explicitly biopolitical form of analysis and engagement’.

Let us examine these changes more closely. In *Sociologies of Disability and Illness* (2007), I explored the way in which one influential British medical sociologist, Graham Scambler, set out his new thinking on the chronic illness and disability question in a paper entitled: *Re-framing Stigma: Felt and Enacted Stigma and Challenges to the Sociology of Chronic and Disabling Conditions* (2004). Looking back on his own use of the concept *stigma* in influential research on epilepsy (see Scambler, 1984, 1989), Scambler reported that his old approach had



three problematic features: first, it took as given the epistemic authority of the biomedical perspective; second, it presumed that a diagnosis of epilepsy is a 'personal tragedy'; and, third, it intimated a form of fateful passivity on the part of the person with epilepsy – one conventionally associated with 'victimhood'. This critical self-assessment led Scambler to pose questions that, I suggest, point towards the need for a *social oppression* rather than *social deviance* paradigm; to put it another way, answers to these questions will best be found by using a variant of *equality and diversity studies*. Here are the questions:

How and why did the institutional order and symbolic framework emergent in modernity in nation-states like Britain come to incorporate cultural norms of identity or being that denounced and oppressed people with epilepsy as *imperfect*? To what extent were these norms the intended or unintended consequences of the system imperatives of the economy and state? Do they bear the taint of ideology? When people with epilepsy were interred in 'epileptic colonies', a practice not long abandoned, did this process represent also a 'colonization of the lifeworld'? What social relations other than the class relations of the economy and the command relations of the state have had a significant impact on the definition and control of those with epilepsy And, of course, how paradigmatic of stigma is epilepsy in these respects? The posing of questions such as these provides a number of pointers towards a long overdue re-framing of *stigma* ... (Scambler, 2004, p. 37)

In subsequent work, Graham Scambler has pursued this changed direction, and has encouraged other medical sociologists to challenge past orthodoxies in their work on chronic illness and disability. Of most relevance here is his book, co-edited with Sasha Scambler, entitled *New Directions in the Sociology of Chronic and Disabling Conditions* (2010a). The chapters therein leave no doubt that sociologists known for their seminal work in the sociology of chronic illness in the 1980s and 1990s have taken up the challenge. For example, the chapter by Michael Bury (2010) involves both an acknowledgement of the correctness of some of his critics concerning his influential concept *biographical disruption* (Williams, 2000) and, of more significance here, a broadening of his perspective on living with chronic illnesses in the twenty-first century. The latter theme is illustrated in his examination of state initiated health-care policies and practices within the health and social care sectors. Bury uses politico-structural and discursive frameworks to explore how contemporary medical treatment and care is managed and delivered. The so-called *self-management* and *expert-patient programmes* advanced in the National Health Service are critically analysed. He concludes that these *apparently* empowering initiatives are actually means of cost-cutting, of



securing patient control, and of limiting patients' and doctors' expectations. In short, these policies and practices are actually ways to enhance the power of the managerial strata:

Much of the emphasis on self-management and a more active role for patients can be seen as part of a long-term managerial battle to control the resources in health care that were once under the near complete control of the medical profession Thus, the rhetoric of self-management forms part – an important part – of a wider project: the transformation of health care into a managed and controlled system of production and consumption. (Bury, 2010, p. 175)

The examples above of the changing foci and emphasis in medical sociology are not isolated aberrations. As Scambler and Scambler (2010b) note, these developments mark meaningful changes bound up with the further enrichment of theoretical perspectives and empirical applications in medical sociology. In my view, the nature of these changes and developments are such that *in sum* they suggest more: that a welcome move away from the social deviance paradigm on the disability question is well underway. It will be interesting to observe whether medical sociologists new to the discipline will opt to consolidate and speed up such changes.

Disability studies

Changes are also underway *within* disability studies in all global regions, and the discipline has witnessed rapid theoretical and empirical enrichment and diversification in the academy since the 1980s (see Watson *et al.*, 2012). For example, there is regular talk of bifurcations such as *Feminist Disability Studies* (Garland-Thomson, 2005) and *Critical Disability Studies* (Shildrick, 2012). However, the *social oppression* paradigm remains at the core of disability studies and its off-shoots, and linkage to the promotion of the social interests of the world's disabled people continues to be a defining feature. Such developments do not mean that the study of living with *impairment effects* is absent from disability studies, as is often supposed by medical sociologists and other commentators outside the discipline. On the contrary, there is growing interest in using a disability studies framework to encompass studies of the lived experience and impairment effects of having medically defined chronic illnesses, mental distress, intellectual impairment, dementia, speech impairment – and many other human *conditions*.

In the United Kingdom, the *social model of disability* retains its banner headline status in both the DPM and disability studies, although fierce debates about the utility and sustainability of this model persist (Shakespeare, 2006; Barnes, 2012). The writer who formulated this model, Mike Oliver, is



obliged to regularly remind critics that the social model of disability is *only a model* (not a theory) – but one that has demonstrated, repeatedly, its power to politically mobilize people in campaigns to either advance or defend of disability rights:

In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television, and newspapers. (Oliver, 2004, p. 21)

This is not the place to review recent scholarship within disability studies, nor to elaborate upon new ideas found therein (see Thomas, 2007; Watson *et al*, 2012). But – as a final gesture – it may assist thinking on the disability question in medical and mainstream sociology to draw attention to the increasing use of the concept *intersectionality*. This concept has proven to be useful in efforts to theorise the intersection of social diversity, and thus to consider the complexity of social identity.

Intersectionality is a concept originally developed within feminist scholarship in an attempt to better understand intersecting social locations and multiple inequalities (McCall, 2005; Walby, 2007; Bilge, 2010). The concept reminds us, first, that homogenized categories like *women*, *gay people* or *disabled people* must be unpacked and disassembled because they conflate and disguise huge social *differences* and variations in status and power among and between social groups. Second, we are reminded that individuals' identities (ascribed or self-defined) are constituted by multiples of such reference categories – and that any attempt to define a person singularly (by gender, 'race' and so on) inevitably results in crude reductionism. Third, these ascribed categorical qualities interact in complex ways, and have differential weighting and salience in the day-to-day lives of individuals and communities.

Given these observations on intersectionality, it is not surprising that writers move in contrasting directions when attempting to conceptualise and knit together different dimensions of individuals' identities and experiences of oppression (Bilge, 2010). Different theoretical schools of thought offer contrasting solutions to intersectionality puzzles. In disability studies, writers are currently grappling with these matters when thinking through the relationship between *disability and gender* (Bê, 2012) and *disability and ethnicity* (Stienstra, 2012). If mainstream



sociologists do embrace the idea of addressing the disability question by developing a new branch of *equality and diversity studies*, then it will not be long before matters of intersectionality demand attention.

Summary

This article has built on the *Social Theory & Health Annual Lecture* that I was invited to give in London in February 2010. The lecture was based on the analysis outlined in my book: *Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology* (Thomas, 2007). Revisiting this lecture has provided the opportunity to move my thinking on, especially on the treatment of the disability question in medical sociology.

I have proposed that the time is ripe for a distinct *sociology of disability* to come into being as a new sub-discipline within *mainstream* sociology – on the global stage. This proposal has revolved around the idea that this sociology of disability would be a variant of *equality and diversity studies* – located alongside the now familiar engagements with gender, ‘race’, sexuality, age and social class. The sociology of disability would encompass studies of disablism and impairment effects, with the former taking centre stage. This means that in medical sociology, disability would cease to be located almost exclusively in a specialized sub-field of interpretative medical sociology – known for several decades as *the sociology of chronic illness and disability*. I have set out three linked arguments to support the overall proposition.

The article’s focus on sociology is not at all to undervalue the importance of other disciplines in the study of disability, and is certainly not to suggest the displacement of the multidisciplinary *disability studies* that exists today in the academy. Rather, the article paper concentrates on contested *sociologies* surrounding the disability question.

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Notes

- 1 The full title of the lecture was: Theorising Disability and Chronic Illness: Where Next for Perspectives in Medical Sociology and Disability Studies?
- 2 For the purpose of both convenience and clarity in this article (as in my book: Thomas, 2007), I shall refer to both medical sociology and disability studies as ‘disciplines’ – although medical



- sociology is, of course, a sub-specialty within sociology, and disability studies is multi-disciplinary in character, with sociology as its core.
- 3 Symbolic progress was made in this regard when the Research Assessment Exercise (RAE) 2008 Sociology sub-panel, of which I was a member, changed the previous panels' statement of the discipline's Unit of Assessment (UOA) boundaries. The 2008 statement added disability into the following list so that it read as follows: 'The sub-panel expects to receive submissions from all fields of sociological enquiry including, but not restricted to, research on ... class, ethnicity, gender, sexuality, disability, and age;' (HEFCE, 2006, p. 45).
 - 4 Of course, disciplines are continuously changing and evolving, but sometimes quantitative turns into qualitative change.
 - 5 Alongside sociology and feminism, there are currently strong contributions to disability studies from writers and researchers in social policy, social geography, literary and cultural studies, history, and political science and law – see, for example, Watson *et al* (2012).
 - 6 Of course, initiatives such as these in the United Kingdom and elsewhere – and related celebrations of a *diversity culture* – have, in turn, generated critique in feminist and queer studies quarters because they can also be seen as official ways to *dilute* the rights and interests of particular groups and communities with investments in identity politics (Bilge, 2010).
 - 7 This is a sensitive area because medical sociologists, for example Michael Bury, were very much involved in, and committed to, the development of the ICIDH in the 1970s (see Wood, 1980).
 - 8 Thus, in the ICF: 'Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors' (Leonardi *et al*, 2006).

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