Review article

Health-related stigma
Graham Scambler

Centre for Sociological Theory and Research on Health, UCL, London

Abstract

The concept of stigma, denoting relations of shame, has a long ancestry and has from the earliest times been associated with deviations from the ‘normal’, including, in various times and places, deviations from normative prescriptions of acceptable states of being for self and others. This paper dwells on modern social formations and offers conceptual and theoretical pointers towards a more convincing contemporary sociology of health-related stigma. It starts with an appreciation and critique of Goffman’s benchmark sensitisation and traces his influence on the personal tragedy or deviance paradigm dominant in the medical sociology from the 1970s. To allow for the development of an argument, the focus here is on specific types of disorder – principally, epilepsy and HIV – rather than the research literature as a whole. Brief and critical consideration is given to attempts to operationalise or otherwise ‘measure’ health-related stigma. The advocacy of a rival oppression paradigm by disability theorists from the 1980s, notably through re-workings of the social model of disability, is addressed. It is suggested that we are now in a position to learn and move on from this paradigm ‘clash’. A re-framing of notions of relations of stigma, signalling shame, and relations of deviance, signalling blame, is proposed. This framework, and the positing of a variable and changing dynamic between cultural norms of shame and blame – always embedded in social structures of class, command, gender, ethnicity and so on – is utilised to explore recent approaches to health stigma reduction programmes.

Keywords: health-related stigma; deviance; chronic illness; deviance versus oppression paradigms; enacted, felt and project stigma and deviance; stigma reduction

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group. This judgement is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgement is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgement may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgements about enduring features of identity
apart from health-related conditions (e.g. race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma (Weiss et al. 2006: 280).

Introduction

Cultural norms proscribing attributes, traits or conditions regarded as shameful stretch far back into history. Both philosophical and sociological arguments have been invoked to assert the omnipresence of such norms. According to Wittgenstein (1953), honourable upright behaviour, a staple of enduring sociability, is only possible if the breach of such norms is a realistic and publicly marked possibility. One of the core premises of Durkheim’s proto-functionalism is that all social formations have discriminated between the normal and abnormal, insiders and outsiders. There can be no ‘normal/acceptable’ in the absence of tangible exemplars of the ‘abnormal/unacceptable’. As Goffman (1968) puts it, there is a ‘self-other, normal-stigmatized unity’: stigmatised and non-stigmatised alike are products of the same norms.

There is a good deal of published data about shame and insider/outsider dynamics in ancient, traditional or pre-modern societies, and brief mention is made of this literature. It is to Goffman, however, that mainstream sociologists and specialists in health and healing still most readily turn for illumination on stigma. For a generation or so his dramaturgical sensitisation of the concept in Stigma: the Management of Spoiled Identity provided almost unquestioned paradigm and exemplar. A critical summary of his approach is offered. It is argued that while Goffman’s contribution retains its insight, subtlety and theoretical acuity, it is time to move on, or rather beyond: it is not so much that Goffman was wrong as that there were questions he did not ask. Some of these questions have been put with increasing impatience by disability theorists and, latterly, sociologists approaching stigma with a primary interest in social structure or political economy.

A deliberately selective review of analyses of stigma concentrates for the most part on studies of epilepsy and HIV. This selective approach reflects the main thrust of the paper, namely, to ‘represent’ existing work and suggest conceptual and theoretical ways ahead rather than systematically to review the literature as a whole. This is succeeded by the positing of an alternative framework which aims to build on the work of Goffman and his primary critics. It is a framework hinging on an analytic distinction between stigma and deviance, which goes on to attribute to social structures something of the external force of Durkheimian social facts. The concluding paragraphs assess the policy potential of this framework in light of the increasing recognition of the significance of stigma as an obstacle to good health and barrier to health care for those shamed or blamed in developing as well as developed societies.

The mark of the outcast

Historians provided the raw material, Goffman an interpretation of abiding salience, spokesperson for a modern discipline with pre-modern antecedents. With hindsight, it is always possible to anticipate the future that was. The mark of the outsider in the pre-modern world was often literal and painful, scarring the flesh and branding its victims. In ancient Greece it is estimated that only 43,000 residents of Attica and Athens out of a total population of 315,000 were citizens. Of the non-citizens, 115,000 were slaves, the remainder comprising manual workers deemed too lowly to qualify for citizenship. Slaves were valuable
property and to prevent their escape and ensure the return of runaways the Greeks ‘tattooed’ them: the sharp pointed instrument used for the purpose made a mark called a ‘stigma’ (the Greek for ‘to prick’ is stig). Today, usage of the word ‘stigma’ connotes a mark of disapproval, as likely to be invisible as visible, which allows ‘insiders’ to identify and dissociate from ‘outsiders’. It is the disgrace itself which is marked. In this way is the solidarity of ‘normals’ affirmed and underwritten (Falk 2001).

Goffman (1968: 13) suggests that stigma refers to ‘an attribute that is deeply discrediting’, but insists that it is a ‘language of relationships’ not attributes that is really required. ‘An attribute that stigmatizes one type of possessor’, he writes, ‘can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself’. Few sociologists since have disputed this ‘relational’ anchorage for a concept often deployed outside the discipline with more abandon.

While Goffman’s treatise on stigma is routinely – and understandably – mined for its perspicacity on the often poignant day-to-day dealings of the ‘discredited’ (possessors of visible marks of unacceptable difference, whose challenge is to ‘manage impressions’) and the ‘discreditable’ (possessors of invisible marks of unacceptable difference, whose challenge is to ‘manage information’), it is the symbolic interactionist/dramaturgical basis of his work that invites attention here. His principal sociological interest was in the structure of interaction: ‘to describe the rules regulating a social interaction is to describe its structure’ (Goffman 1967: 144). For him the structure of face-to-face interaction in the lifeworld is what steadies and sustains the social order. In many respects, he suggests, people conduct themselves in the lifeworld much as actors play scripted parts in theatre productions. A number of ‘ground rules’ specify the means available to individuals to realise their goals; they afford normative regulation. One of these ground rules has to do with ‘maintenance of face’, requiring individuals, like actors on a stage, to present and sustain consistent and positive images of the self, and to acknowledge the same process in those with whom they interact. This is accomplished by acting out ‘lines’: participants in interaction typically act to prevent lines from being discredited, thus avoiding loss of face for all parties. Social life proceeds as smoothly as it tends to because individuals finding themselves together arrive at a working definition of the situation. While individuals perform to maintain face through lines in ‘front regions’ (e.g. hospital clinics), in the absence of an audience they can stop performing, behaving in a manner that contradicts their performance, in ‘back regions’ (e.g. in the hospital canteen or at home).

Goffman was under no illusion that social life was always co-operative and egalitarian. Definitions of situations can reflect imbalances of power, as is the case in ‘total institutions’ (Goffman 1961). In mental hospitals, for example, a person’s performed self is discredited and challenged by others positing an alternative definition. The self, in other words, ‘is not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connection with the person by himself and those around him’ (Goffman 1961: 168). The self is the product of an institutional nexus of performances, although rarely in the extreme form found in total institutions.

In people’s ordinary everyday lives social order is maintained not only by rule-following but by rule-breaking, or ‘remedial interchanges’ (Goffman 1971). In fact rule-breaking is pervasive: this is because social interaction is structured primarily to afford individuals opportunities to ‘adjust’ in pursuit of their own private goals with minimal fuss or stress. Rule-breaking in face-to-face interaction, typically articulated by means of ‘accounts’, ‘apologies’ and ‘requests’, gets the traffic moving again (Goffman 1971: 108). In other words, it may be more felicitous to overlook someone’s rule infraction than to insist on rule-following behaviour. ‘Deviance’ of this kind is unlikely to be punished.
It has been argued that what is missing from Goffman’s account of the structure of interaction is the causal input of social structures like class, command, gender, ethnicity and so on, more often theorised from outside the symbolic interactionist/dramaturgical fold (Scambler 2006). These have something of the external and constraining character of Durkheimian ‘social facts’. That a synthesis of micro-analyses of the kind favoured by Goffman and familiar in interactionist and phenomenological studies with macro-analyses was more often associated with structural-functional or conflict sociology is evident in the contributions of theorists like Habermas (1984, 1987). This issue features later, but it is to Goffman’s immediate legacy that we turn now.

The ‘personal tragedy’ of chronic illness

What is described as the ‘personal tragedy’ or ‘deviance’ orientation to chronic and sometimes stigmatising disorder is not just down to Goffman. It reflects a much broader interactionist perspective. In the USA a considerable literature emerged on mental illness. Scheff (1966) claimed that ‘labelling’ is the single most important cause of mental illness. He argued that a residue of unusual and incongruous behaviour exists for which culture provides no explicit labels: such forms of behaviour constitute ‘residual rule-breaking or deviance’. Most psychiatric symptoms can be categorised as instances of residual deviance. There is a cultural stereotype of mental illness, blunted by sins of omission and commission. When for whatever reason residual deviance comes to public attention, this cultural stereotype becomes the guiding imagery for action. Contact with a physician is established, a psychiatric diagnosis made, and procedures for hospitalisation may follow. Problems of secondary deviance are predictable consequences of authoritative medical labelling.

Notwithstanding Gove’s (1970) prompt and compelling insistence that Scheff had exaggerated every facet of his case, the indirect influence of labelling theory – from the nuances of truth and falsity in cultural stereotypes to the ideologies and praxis of professional labellers to differentiated individual coping styles – continues to inform the American study of mental illness as stigma. Indeed, mental illness remains the primary focus of much research and theory generation on stigma in the US (Pescosolido et al. 2008), with some contributors conflating North American and global sociologies of stigma. Moreover, current programmes of intervention to reduce psychiatric stigma across developed and developing countries alike typically adopt the premise that better informed publics and sensitised professionals are barriers against virulent cultural stereotypes, likely to reduce both rates of discrimination and the prospects for secondary deviance when psychiatric diagnoses are made (see, for example, Putman 2008). We return to programmes of stigma reduction later.

This general orientation not only informed American medical sociology but helped define its British progeny, with Freidson’s (1970) Profession of Medicine being an important catalyst. The reputation of the journal Sociology of Health and Illness was arguably built on individualistic explorations of the day-to-day accommodation of medically labelled chronic and/or stigmatising illness (Armstrong 2003). Significant contributions alluded to the ‘biographical disruption’ and ‘loss of self’ occasioned by the onset and diagnosis of chronic disorder (Bury 1982, Charmaz 1983), as well as to the common need for ‘narrative reconstruction’ (Williams 1984). The issue was typically held to be a new and unwelcome deviant – or, for Goffman, ‘moral’ – career, calling for wholesale re-adjustment to lives threatened to varying degrees by ‘impairment’ (body deficit), ‘disability’ (functional loss) and, at the time of special concern to sociologists, ‘handicap’ (social cost) (Bury 1990). It was largely within this framework that studies of the stigma attaching to some but not all medically defined chronic disorders blossomed.
Many conditions and symptoms from nervous ticks and stuttering to tuberculosis and leprosy carry stigmatising connotations. It is more expedient to focus here on one or two chronic illnesses in some detail than to attempt to cover too much ground: since mental illness has received considerable attention elsewhere, epilepsy and HIV/AIDS have been selected. In relation to epilepsy Schneider and Conrad’s (1983) pioneering American research with people with epilepsy was followed by Scambler and Hopkins’ (1986) London-based study of adults with epilepsy. Schneider and Conrad (1983) produced a typology of modes of adaptation to epilepsy. This built on an underlying distinction between ‘adjusted’ and ‘unadjusted’ adaptations. Individuals defined as adjusted were those able to effectively neutralise the negative impact of epilepsy on their lives. They fell into three categories. The ‘pragmatic type’ downplayed their epilepsy by attempting to pass or cover, only disclosing when strictly necessary and then to a select few. The ‘secret type’ opted for elaborate tactics to conceal their epilepsy, which they regarded as ‘a stigmatizing, negative and “bad” quality of self’ (Schneider and Conrad 1981: 215). The ‘quasi-liberated type’ went beyond pragmatism by publicly proclaiming their epilepsy in an attempt to sidestep any antagonism and to educate others. Jobling (1977: 83) captured this kind of initiative to ‘de-stigmatise’ in his study of psoriasis: ‘deviance is shown to be no more than difference and discredit is denied’. Schneider and Conrad’s identification of quasi-liberated individuals importantly prefigures later rebuttals of the personal tragedy or deviance paradigm, a paradigm epitomised in their remaining category of the unadjusted, comprising people entirely overwhelmed by their epilepsy, for whom it had become a ‘master status’ or identity, effectively subsuming all others.

Scambler and Hopkins’ (1986) British study was similarly conceived. It led to a ‘hidden distress model of epilepsy’, a key distinction being that between ‘enacted’ and ‘felt stigma’ (Scambler 1989). The former refers to overt discrimination against those with epilepsy on the sole grounds of their social unacceptability, while the latter denotes both a sense of shame and a companion fear of encountering enacted stigma. The hidden distress model can be articulated in terms of three propositions. The first asserts that when confronted with a medical diagnosis of epilepsy, state-sanctioned, culturally authoritative and carrying legal weight, individuals develop a ‘special view of the world’ – or, after Bourdieu (1977), ‘epilepsy habitus’ – characterised by a strong sense of felt stigma and predisposing them to secrecy and concealment. Schneider and Conrad (1980) show how this sense of felt stigma can have its origins in the ‘stigma coaching’ of others, like over-protective parents and well-intentioned doctors. Secondly, this first-choice tactic of non-disclosure has the consequence that few others tend to know of a person’s epilepsy (four out of five of whom have their seizures well controlled by antiepileptic medication). The result, thirdly, is that felt stigma is typically more disruptive of the lives of adults with epilepsy than enacted stigma: it is the discredited not the discreditable whose biographies are skewed by enacted stigma.

Scambler and Hopkins, like Schneider and Conrad, recognised among minorities of their interviewees a capacity to fight back. While these two studies reflect the personal tragedy orientation of the time, ‘infecting’ also significant others through what Goffman (1963) called ‘courtesy stigma’, a nascent politics of identity can also be discerned. We shall return to this. That courtesy stigma can be a significant phenomenon in its own right is vividly shown in Gray’s (2002) study of the parents of children with high functioning autism. He found that most parents experienced both felt and enacted stigma, although these ‘types’ of stigma were rarely distinguished in their accounts.

While these studies of epilepsy are broadly representative of 1970s and 1980s research into chronic stigmatising conditions, specific mention might also be made of HIV/AIDS. Since its recognition in 1981 the human immunodeficiency virus (HIV) has elicited strong
reactions. In the USA, where the epidemic emerged among gay men and intravenous drug users, a persistently negative social response has played a crucial role in the experiences of individuals with the virus. Allowing for the fact that disease progression varies widely between individuals, Alonzo and Reynolds (1995) outlined a – now fatalistic and dated – four-phase ‘biophysical disease trajectory’ for HIV/AIDS: a transient flu-like syndrome associated with seroconversion, developing within weeks or months of infection; an asymptomatic period of more than four years’ average duration; symptomatic HIV infection of more than five years’ average duration; and, finally, AIDS characterised by opportunistic illness, HIV wasting syndrome, HIV dementia, lymphomas, and other neoplasms, averaging 9–13 months for treated and untreated individuals combined, and 21 months for those receiving antiviral medical treatments. This provides an essential background, they claimed, for any assessment of individual adjustment.

They went on to identify four phases of an ‘HIV stigma trajectory’, which is linked to but can vary independently of the biophysical disease trajectory:

- **At risk – pre-stigma and the worried well**: this does not correspond to a stage of the disease trajectory; it denotes a time of uncertainty when an individual thinks behaviours might have put him at risk of HIV. Much depends on the support available. The phase can end with testing for HIV.
- **Diagnosis – confronting an altered identity**: an individual can be diagnosed early or late in the disease trajectory. A typical stress response involves disbelief, numbness and denial, followed by anger, acute turmoil, disruptive anxiety and depressive symptoms. Identity and self-esteem can be threatened, stigma becomes salient, and decisions on disclosure have to be negotiated.
- **Latent – living between health and illness**: this is when the disease is asymptomatic and perhaps at its least disruptive. Individuals can normalise, conceal and even deny their positivity. They might choose to pass as normal, thereby avoiding enacted stigma, but felt stigma can exact a heavy price.
- **Manifest – passage to social and physical death**: there is often no fixed disease course because of widespread individual variation. However, there are fewer symptom-free periods, and opportunistic infections accumulate. Stigma tends to be less salient as matters surrounding social and biological death become paramount. Intensely felt stigma may nevertheless be associated with isolation and withdrawal as a means of concealing ‘abominations of the body’. Courtesy stigma may extend to carers who hesitate to reveal cause of death.

Once again emphasising the scope for individual variation, they note that stigma can be controlled and contained but also occasionally ‘expansive’, invading all aspects of a person’s biography and identity.

A more recent study of HIV-related stigma in India builds explicitly on the hidden distress model of epilepsy (Steward et al. 2008). The authors deploy the concept of enacted stigma, but they then distinguish between what they term ‘felt normative stigma’ and ‘internalized stigma’. Felt normative stigma refers to a subjective awareness of stigma which it is expected will motivate individuals to take action to avoid enacted stigma. This is distinguished from internalised stigma. When stigma is internalised by those Goffman designates ‘normals’ it results in prejudice and may lead to enacted stigma; when it is internalised by putative possessors of stigma the consequence is ‘self-stigma’. ‘In the latter case, people’s self-concept is congruent with the stigmatizing responses of others; they accept the discredited status as valid’ (Steward et al. 2008: 3). This distinction between
internalised stigma and felt normative echoes Scambler and Hopkins’ discernment of two dimensions to felt stigma, a sense of shame and a fear of enacted stigma. The general conclusion offered by Steward and associates suggests a kind of ‘hidden distress model of HIV’, although they usefully point to the salience for internalised and felt normative stigma of ‘vicarious stigma’, that is, learned stories of enacted stigma against others with HIV.

The recognition of coping strategies and styles as well as the lurking hazard of enacted and felt stigma remains salient for the empirical study of accommodating chronic illnesses with culturally negative connotations. Nevertheless new paradigms have emerged, most conspicuously in the arena of disability theory/politics. Before these theoretical innovations are reviewed, however, attention should be given to the ‘measurement’ of stigma conceived as a personal affront.

Measuring stigma as personal tragedy

The notion of ‘measurement’ is itself a controversial one in sociology: one person’s operationalisation is another’s subversion of a complex phenomenon; and stigma relations are complex indeed. Yet as Link and his colleagues (2004) maintain in relation to mental illness, crucial to the scientific understanding of stigma is our capacity to observe and measure it. In his review of the measurement of health-related stigma in 63 published papers, only some of which were specifically sociological, van Brakel (2006: 309) distinguishes between five foci or approaches to measurement. These are annotated in Box 1.

Box 1 Measuring health-related stigma

1. Surveys of attitudes towards those with certain health conditions conducted with samples of the public or of sub-populations like carers.
2. Assessments or audits of discriminatory and stigmatizing practices:
   • in the community, home or workplace;
   • in healthcare;
   • in legal statutes or practice;
   • in the media;
   • in educational materials in schools.
3. Interviews with those affected by certain health conditions about their actual experience of discrimination and stigmatization.
4. Interviews with those affected by certain health conditions about perceived or felt stigma.
5. Interviews with those affected by certain health conditions about self- or internalized stigma, incorporating feelings of loss of self-esteem and dignity, fear, shame, guilt and so on.

Adapted from van Brakel (2006)

Van Brakel recognises the relevance of a plurality of methods, ranging from the kind of qualitative investigations of epilepsy and HIV/AIDS already cited to quantitative studies oriented to operationalisation via scales or pre-defined sets of indicators. He considers generic scales/indicators as well as a wide range of instruments addressing particular health
conditions, most notably leprosy, HIV/AIDS, tuberculosis, mental illness, epilepsy and physical disability. His conclusions are threefold. First, cross-cultural studies, qualitative and quantitative, suggest that the consequences of stigma are ‘remarkably similar in different health conditions, cultures and public health programmes’ (van Brakel 2006: 329). Secondly, most instruments of measurement are condition-specific rather than generic. And thirdly, the degree of similarity in the consequences of stigma in different cultural milieu and the ‘cross-cutting applicability of many items from stigma instruments’ suggest that it might be feasible to develop a ‘generic set of stigma assessment instruments’ (van Brakel 2006: 329).

There is a distinction to be drawn between the credibility of, on the one hand, a generic measurement of the consequences of health-related stigma and, on the other hand, a generic or cross-cultural theory of health-related stigma. There is a risk indeed of conflating these two proximal but independent projects. The shame associated with, say, HIV/AIDS can have similar sequelae cross-culturally, as captured by a ‘generic set of stigma assessment instruments’, but be a product of entirely different structural and cultural relations. Another risk associated with measurement per se is a reification of the concept of stigma: concepts as subtle and dynamic as these do not readily lend themselves to transmutation into the likes of variables. Certainly, as yet it is appropriate to remain sceptical about the possibility of a cross-cultural or ‘transfigurational’ theory of health-related stigma (Scambler 2004).

What medical sociology missed

A divide opened up in the 1980s and 1990s between the sociology of chronic illness and disability and an experientially-endowed and hard-headed ‘rival’, disability theory/politics. Medical sociology’s ‘deviance paradigm’ was confronted by an ‘oppression paradigm’ (Thomas 2007). The accent was no longer on the labelled but the labellers. The message implicit in sociology’s 1950s and 60s labelling theory of deviance and applied to health and healing by Scheff and others, bore further fruit in the work of disability theorists like Oliver (1990). Why do those licensed and empowered to label act as they do? What else is at stake?

Disability research has as its basic premise the idea that disability involves the social oppression of people whose impairments mark them out, or are discursively constructed as marking them out, as different. ‘Disablism’ is thus added to the likes of sexism, racism, ageism and homophobia as a form of exclusionary and oppressive practice (Thomas 2007). This premise has often been articulated with reference to the ‘social model of disability’. An important catalyst in Britain was Hunt’s (1966) collection of 12 essays contributed by people with disabilities. Hunt, and later Finkelstein (1980), did the spadework for a social and materialist analysis of disability. As explicated by Oliver (1983), the resultant model was to displace ‘individual’ models of disability hinging on the notion of personal tragedy; moreover, this displacement was conceived as an urgent political as well as a warranted theoretical project. Disability, it was argued, was not the consequence of impairment but of the social restrictions imposed upon people with impairment, ‘ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on’ (Oliver 1996: 33). To acknowledge the salience of such oppressive ‘social barriers’ was to be challenged to politic for change.

Many disability study scholars subsequently left the materialist fold, turning in particular to non-material or post-structural understandings of culture. Adherence to the pioneering version of the social model of disability is no longer obligatory. Many critics reject the
distinction between impairment (characteristics of the body) and disability (social restrictions placed on people with impairments) utilised by Oliver. They dismissed this as another version of biomedical binary and reductionist thinking. Hughes and Paterson (1997: 334–5) advocated a phenomenology of the impaired body drawing on Merleau-Ponty:

‘The impaired body is a “lived body”. Disabled people experience impairment, as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction. The body is the stuff of human affliction and affectivity as well as the subject/object of oppression. The value of a phenomenological sociology of the body to the development of a sociology of impairment is that it embodies the addition of sentience and sensibility to notions of oppression and exclusion. Disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning’.

There is no space here to trace the nuances of the last decade’s re-theorising of the oppression paradigm, a task in any case scrupulously undertaken by Thomas (2007).

It is relevant, however, to close this section with an outline of Young’s (1990) belatedly influential discernment of five faces of oppression, each one according to Thomas having resonance with ongoing attempts to explicate disablism:

• **Exploitation** draws on Marx and refers to the process by which the products of the labour of one group benefit another;
• **Marginalisation** captures the expulsion of people for whom the system of labour has no use and their dispatch to society’s margins;
• **Powerlessness** occurs in employment and other settings in which the power and authority of some undermine the autonomy and capabilities of others;
• **Cultural imperialism** arises when the dominant group’s beliefs and attitudes are universalised, leaving others – feeling invisible or different – as deviant;
• **Violence** is reflected in systematic attempts to hurt, humiliate or eliminate groups considered beyond the pale.

Young’s breakdown of modes of oppression suggests the need for and contributes to a more refined conceptual framework for understanding estrangement and outsider status. Disability theory itself demands a sociology of chronic illness and disability beyond Goffman-like, personal tragedy-oriented exegeses. The paragraphs that follow offer one candidate for a post-Goffman research programme on health-related stigma.

**Health-related stigma and contemporary sociology**

If sociology was slow to position biographical accounts of ‘shameful’ personal tragedies in wider social and structural contexts, there are indications that this hole is being slowly filled in. Link and Phelan (2001: 363) draw on disability as well as sociological studies to define stigma ‘as the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination’, critically adding that for stigmatisation to occur ‘power must be exercised’. Discrimination here does not simply refer to one individual’s treatment of another, but to structural (or institutional) discrimination (*i.e.* a ‘disabling environment’) and to discrimination one or more steps removed from labelling and stereotyping, as when
a loss of status occasioned by stigmatisation leads to a spiralling of disadvantage. Link and Phelan (2001: 375) make power central: ‘stigma is entirely dependent on social, economic, and political power – it takes power to stigmatisate’. This raises a number of pivotal questions:

- Do those who might stigmatisate have sufficient power to ensure the human difference they recognise and label resonates in the public culture?
- Do those who might confer stigma have the power to ensure that the culture ‘deeply accepts’ the stereotypes they connect to labelled differences?
- Do those who might stigmatisate possess power enough to underwrite and maintain a separation of ‘us’ from ‘them’?
- Do those who might confer stigma have the power to control access to core institutions like schooling, job markets, housing and healthcare in order to ‘put really consequential teeth into the distinctions they draw’?

Positive answers to these questions, Link and Phelan argue, would lead us to expect stigma, while negative answers would seem to preclude stigma.

With specific reference to HIV/AIDS, Parker and Aggleton (2003: 5–6) also insist on the salience of concepts like discrimination and power for understanding stigma. They call for a post-individualist analysis of the stigma associated with HIV/AIDS that acknowledges its functioning ‘at the point of intersection between culture, power and difference’. Relations of stigma, they contend, are pivotal for the constitution of social order; and the social order ‘promotes the interests of dominant groups as well as distinctions and hierarchies of ranking between them, while legitimating that ranking by convincing the dominated to accept existing hierarchies through processes of hegemony’. In similar vein, Rhodes and colleagues (2005) emphasise that “much of the most needed “structural HIV prevention” is unavoidably political in that it calls for community actions and structural change within a broad framework concerned to alleviate inequity in health, welfare and human rights.”

One revisiting of the concepts of enacted and felt stigma that emerged initially in an individualistic, personal tragedy-oriented study of adults with epilepsy is indicative of this shift of emphasis in medical sociology (Scambler 2004). A post-individualist and post-Goffman sociology of stigma relations must accept that they are part of a nexus of social structures; and, relatedly, that stigmatisation (enacted stigma) is rarely the sole ingredient of disadvantage. Elucidation of this argument requires further conceptual clarification.

Stigma in the study of epilepsy was designated an ontological deficit. Picking up on Goffman’s (1963) observation that stigma implies an unwitting, non-culpable falling foul of cultural norms, it was suggested that people with epilepsy felt different and experienced shame out of a sense of ‘being imperfect’ (Scambler and Hopkins, 1986)). This led to an analytic distinction between two words with different ancestries – stigma and deviance – which have nevertheless often been treated as synonymous. While stigma denotes an ontological deficit, deviance refers to a moral deficit. Stigma invokes ‘shame’ and deviance ‘blame’. This distinction invites empirical consideration of enacted and felt deviance as well as enacted and felt stigma in the health arena (Scambler, 2004).

The point was made earlier that both the London-based and the American study of epilepsy by Schneider and Conrad identified minorities who rejected any sense of ‘victimhood’. Charges of stigma and deviance, even when levelled, are not always internalised or accommodated. This led Scambler and Paoli (2008), with reference to HIV/AIDS, to introduce the notions of ‘project’ stigma and deviance. Project stigma and deviance refer to the conscious rejection of attributions of shame and blame respectively. They signify resistance and/or defiance. These distinctions are outlined in Box 2.
The deployment of this conceptual apparatus took place within a frame insisting that the forms of interaction that provided take-off points for Goffman and the labelling theorists can only be explained sociologically if social structures, interpreted as necessary if rarely sufficient conditions of interaction, are empirically exposed. Cultural norms of shame and blame and the labelling processes with which they are bound up never exist in a structural vacuum but invariably arise within a structural nexus. In fact, as Deacon and Stephney (2007) have shown, such norms tend to follow the structural ‘fault-lines’ of society.

This embeddedness of norms of shame and blame in social structures has been illustrated with reference to the British government’s ‘welfare-to-work’ programmes directed at those with chronic disorders or disabilities (Scambler, 2006: 293–4). Rooted in the premise that the relatively low employment rates amongst these groups contribute to the evils of poverty and social exclusion, these programmes were designed to facilitate the transition from out-of-work benefit receipt to paid employment. The strategies on offer were: education, training and work placements; vocational counselling and support services; in-work benefits; incentives for employers; and the improvement of physical accessibility. Underpinning these strategies was an insistence on the exercise of ‘demonstrable’ personal responsibility. Monitoring these initiatives through the 1990s, Bambra and colleagues (2005) conclude that they have ‘helped’ some with chronic disorders and disabilities to get off benefits and into work.

The contention here is that welfare-to-work schemes, like the philosophy of personal responsibility imported from the USA, can only be explained sociologically in terms of the reinvigoration of relations of class relative to those of command during the era of the Washington Consensus and neo-liberalism. Increasingly, global corporate executives and their financiers now possess an (even) greater capacity to shape power. The ‘benefits’ of new work opportunities for chronically ill or disabled ‘clients’ have to be set against the partial transmutation of their stigma into deviance under pressures to contain labour costs and social transfers. In other words, any putative gain, or reduction in stigmatisation, has to be set against costs in terms of the requirement to actively avoid culpable deviance and

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**Box 2 Conceptual distinctions for stigma and deviance**

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<th><strong>Stigma</strong></th>
<th><strong>Deviance</strong></th>
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<td>an ontological deficit, reflecting infringements against norms of shame</td>
<td>a moral deficit, reflecting infringements against norms of blame</td>
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<tr>
<td><em>Enacted</em>: discrimination by others on grounds of ‘being imperfect’</td>
<td><em>Enacted</em>: discrimination by others on grounds of immoral behaviour</td>
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<td><em>Felt</em>: internalised sense of shame and immobilising anticipation of enacted stigma</td>
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<td><em>Project</em>: strategies and tactics devised to avoid or combat enacted stigma without falling prey to felt stigma</td>
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From Scambler and Paoli (2008)
in the currencies of (class-induced) exploitation and (command-induced) oppression. What is being maintained here is not that the stigma associated with chronic illness and disability is never decisive in its own right, nor that stigmatisation is now always transmuted into deviance and part and parcel of processes of exploitation and/or oppression. It does seem apparent, however, that stigmatisation is rarely the sole ingredient of disadvantage, other notable companions in Britain, more conspicuously since the 1970s, being exploitation and oppression. This analysis of an intervention to ‘reduce health-related stigma’ leads on to a brief consideration of stigma reduction.

Preconditions, ‘ifs’ and ‘buts’ of stigma reduction

Accounts of the impact of stigmatising conditions or labels on individuals’ lives and coping styles, the personal tragedy approach, should not be condemned out of hand. It is not so much that they were flawed, more that they were limited and, with hindsight, sociologically unambitious: they overlooked social structure. Many current interventions to reduce stigma, however, remain obdurately biomedical and individualistic (Heijnders and van der Meij 2006). In as far as they purport to empower, they do so on a ‘top-down’ basis, emphasising either information-giving/prevention or self-empowerment (Rhodes, Holland and Hartnoll 1991). Again, programmes constructed on this basis are not without value (they may be pragmatic best options); but they are likely to be exercises in damage limitation. This is not a simple plea for more ‘bottom-up’ (radical-political or ‘social transformatory’ (Rhodes et al. 1991)) initiatives, more an exhortation to the community of sociologists to attend to explanatory adequacy.

Consider stigma reduction programmes targeting people with HIV/AIDS. These tend to be top-down and aspire to empower individuals to behave in ways pre-judged to be in their interests (an odd but recurring perversion of the concept of empowerment). The research literature demands a more reflexive tack, cognisant of context as well as social structure. Accounts of living with HIV/AIDS within the personal tragedy convention, like that of Alonzo and Reynolds (1995) cited earlier, need to be complimented by others emphasising the structuring of agency and culture around issues of shame and blame (Scambler and Paoli 2008). There may be little overlap between options presented and taken by (a) a university professor with HIV in Los Angeles (able to access retroviral therapy), and (b) a 15-year-old seropositive girl trafficked out of Burma into a brothel in Bangkok (for whom HIV positivity may not be that salient). No more equivalent are interventions to reduce health-related stigma or deviance or to empower.

No cross-cultural or ‘universal’ theory of stigma or deviance is just around the corner, but adequacy at the level of theory might lead to a worthwhile contextualisation, even refinement, of predictions of efficacious stigma reduction programmes of the kind sought by epidemiologically-informed public health advocates. In this sense policy sociology cannot be estranged, not only from professional but also from critical and public sociologies (Burawoy 2005). Findings around the notion of co-stigmas support this judgement. Surveying attitudes to sex workers in China, Chan (2007) challenged the assumption that it is the stigma associated with HIV/AIDS that is of most significance for interventions to reduce HIV/AIDS-related stigma (and to minimise risks of transmission). She reports that both drug use and commercial sex work can summon a more negative response than HIV seropositivity, for which there is some compassion. Optimal interventions might focus on ‘risk behaviours’ rather than their putative product. But there is a further twist to the debate around health-related stigma.
A recent paper by Bayer (2008) questions the assumption that ‘stigmatization always represents a threat to public health?’ Is health-related stigma always a bad thing? Are shame, and blame, invariably to be contested? Bayer suggests that there are occasions when mobilising stigma – around smoking for example – might reduce the prevalence of risk behaviours linked to disease and premature death. One riposte is that stigma is a ‘barbaric form of social control’ (Burris 2008: 3). There is further evidence in this debate that sociological studies of health-related stigma can no longer afford – Goffman-like – to neglect the social structural underpinnings of cultural norms and individual choice. If Foucault too readily discarded the sociology of domination, his genius was demonstrated in laying bare the seductive properties of power. Enacted stigma and deviance can elide into government, and felt stigma and deviance into governmentality.

It was argued earlier that work done under the rubric of what was later termed the personal tragedy/deviance paradigm needs to be re-framed and deepened sociologically. Stigma and deviance can be inscribed on persons as well as embodied; but they are also – and this is where lessons can be learned from disability theorists and activists promoting an oppression paradigm – ‘structured’ social relations. Goffman was clear on this but was only a little ahead of his time. Health-related stigma, and deviance, can be examined from macro- and meso- as well as micro-perspectives, from the vantage point of conflict as well as interactionist sociology. As the welfare-to-work example illustrates, stigmatisation can be infused with exploitation and oppression. Recalling Young’s (1990) modes of oppression – not only exploitation but marginalisation, powerlessness, cultural imperialism and violence – there exists a ready conceptual apparatus for the empirical investigation of why as well as how the dynamic dyad of shame and blame impact on the lives of some individuals and not others.

Address for correspondence: Graham Scambler, Centre for Sociological Theory and Research on Health, Research Department of Infection and Population Health, University College London, Mortimer Market Centre, London WC1E 6JB

e-mail: g.scambler@ucl.ac.uk

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