MSo — Medical Sociology online

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Editorial Foreword

University of Liverpool Editorial Team

We would like to welcome all readers to the second issue of volume 2 of Medical Sociology online (MSo). We are continuing to receive very positive feedback on what we have achieved so far with MSo, in particular the open-access format and our move to peer-review submitted articles. Now, a year after our launch, we are attracting a steady stream of academic articles, many of which we will publish in our editions next year.

If you would like to submit an article to Medical Sociology online, please use the link:

http://www.medicalsociologyonline.org/submissions.html

In this edition we are publishing a thought provoking article by Helen Spandler entitled: **From Social Exclusion to Inclusion? A Critique of the Inclusion Imperative in Mental Health,** which contributes to the debate as to whether policies and practices apparently designed to improve the lives of people with mental health difficulties may have the opposite effect.

Following the Opinion Pieces in our previous edition by Gareth Williams and David Morgan, Mary Dixon-Woods has written an Opinion Piece on the professionalization of medical sociology, and Mike Saks and Ivy Bourgeault have also made contributions to this highly topical debate**.**

After the successful British Sociological Association (BSA) Medical Sociology Group Conference (6th – 8th September 2007) held this year in Liverpool, we are delighted to include papers from the two invited plenary speakers. Gareth Williams discusses Incapacity and Jane Seymour's paper is entitled 'Windows on Suffering: Sociological Perspectives on End of Life Care'**.**

As next year will mark 40 years of the BSA Medical Sociology Group, MSo is currently discussing plans with the BSA MedSoc Committee to celebrate this anniversary in the 2008 editions of MSo. One idea we are exploring is a 'BSA MedSoc Conference Retrospective' in anticipation of the Medical Sociology Group Annual Conference 2008, to be held on 4th – 6th September at the University of Sussex, Brighton http://www.britsoc.co.uk/events/msconf.htm. If you have any reflections or stories to share with us from any time over the last 40 years, please contact Jude Robinson at MSo@liv.ac.uk.

Our Book Review section continues to be extremely successful, with contributors from the medical sociology community, both in the UK and North America. As usual there is a mix of titles to suit all areas of interest, but of note are Tom Shakespeare's book, *Disability Rights and Wrongs,* which Jane Seymour draws on in her plenary paper, and Palgrave's *Living with the Genome*, edited by Angus Clarke and Flo Ticehurst, which was advertised in the last edition of MSo. If you would like to review a book for MSo, books can be requested from the Book Review Editor Mona Killey, is a space where people can share their good news and achievements with the rest of the medical sociological community, whilst the Current Research section provides a space for the presentation of work which is currently ongoing, including postgraduate projects as well as studies being conducted by more established academics. It is hoped that these sections combined will help to stimulate discussion on various topics and possibly bring people with similar research interests together, forming partnerships for the future.

We also have reflections from attendees at recent conferences and seminars from the UK

and international events which provide an insight into the experiences of the participants. Two of the reviews reflect on conferences that extended beyond the conventional to include performances, readings and poetry, indicating perhaps changes not only in conference formats but also the methods now being used in research and dissemination. Other contributions to this section come from the Medical Sociology Group Sociology of Mental Health Study Group and symposia at the September 2007 Medical Sociology Conference. We welcome brief, insightful commentaries on conferences and seminars. If you are attending a conference and wish to write a review, please do get in touch with Clare Thetford at MSo@liv.ac.uk.

Our final feature is 'A day in the life of…', which is something we have revived from former issues of MSN. In this issue a contract researcher, Narelle Warren, who has recently completed her PhD, based at Monash University in Melbourne, Australia gives us an insight into her daily working life as she manages and balances her varied responsibilities.

We hope you enjoy reading this edition and look forward to receiving any comments or feedback sent to MSo@liv.ac.uk.

Best wishes,

Helen Bromley   Sara Edwards

Paul Harrison (Wed Editor)   Julia Hiscock

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From Social Exclusion to Inclusion? A Critique of the Inclusion Imperative in Mental Health

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ABSTRACT

This paper critically explores notions of social inclusion in mental health and considers some of the problems associated with its wide scale adoption as a policy driver and moral imperative. It draws out some of the assumptions underpinning strategies of inclusion and possible consequences of the move from a focus on exclusion to imperatives to 'include'. It argues that these assumptions may lead to individualised practices guided by judgments as to what constitutes a 'healthy' or 'normal' life. Rather than being seen as a necessary and unquestionable 'human right' *or* a top-down form of social engineering, social inclusion can be viewed as a paradoxical claim which both expresses a genuine demand to tackle the consequences of social inequality and yet at the same could become another way people with mental health problems are subject to moral and social regulation.

KEYWORDS Social exclusion, social inclusion, citizenship, inequality, critical social theory, mental health services, social policy, service users.

Introduction: From Exclusion to Inclusion?

Over the last few years there has been a significant shift in social policy discourse in the UK from a focus on tackling social 'exclusion' towards one of promoting 'inclusion'. Such a change in focus inevitably has consequences for how we understand, frame and potentially address the ways in which certain individuals and groups are marginalised and excluded. Whilst the concept of social *exclusion* has attracted much interest and debate, (Fairclough 2000; Humpage 2006; Levitas 2004; Burden and Hamm 2000; Gray 2000; Lister 2000) there has been less critical attention paid to social *inclusion* (Ratcliffe 2000). The notion of social inclusion is difficult to critique because, like other concepts in the Government's 'modernisation' agenda (such as 'choice', 'user involvement' and 'recovery'), it is presented as self evidently desirable and unquestionable. This has resulted in a growing consensus around the need for inclusion which is often framed as a human right or moral imperative. An interrogation of the notion of social inclusion is particularly urgent in the field of mental health because it is being used to reshape services and redesign delivery in ways that could have serious consequences for users of mental health services and the future of mental health provision. Without denying the progressive impetus behind the demand for inclusion, nor the ways the term has been creatively employed by campaigners, service providers and users, this article raises the question of whether it has been too readily embraced as a policy imperative and asks if this has obscured some potential negative consequences.

It is important to state at the outset some of the ideas which underpin this critique as I

make a number of assumptions about what might be considered a 'progressive' approach to policy and practice. It is possible to identify two key influences on the position I adopt here. First, I draw on a broadly 'Sedgwickian' approach to mental health practice which is explicitly socialist, humanist and libertarian and seeks to explore the conditions of political possibility for people with mental health problems and their allies to make demands on society for the organisation of appropriate collective welfare provision (Sedgwick 1982). Second, my approach takes into account the emergence of the organised service user/survivor movement and various 'critical' approaches to mental health and psychiatry, all of which demonstrate the coercive nature of policy and practice and the ways it can pathologise mental health service users and view them as passive objects of policy and treatment. Instead, by placing a concern with power at the centre of my analysis, highlighting the potential for coercion, and taking seriously individual diversity and difference, it is possible to prioritise strategies which increase self determination.

With this in mind, I explore whether the notion of social inclusion helps or hinders possibilities for wider social change which would enhance the ability of mental health service users to make collective demands *and* to develop strategies for self determination (a kind of 'collective individualism' which, following Sedgwick, avoids making artificial distinctions between the individual and the collective). By drawing on other critiques of modern social policies, this approach highlights the possible contradictions and consequences of polices of 'inclusion' implemented within the context of a free market capitalist society.

The notion of inclusion, like 'mental health' itself, is hard to define and has many possible meanings. Whilst 'mental health' is increasingly used as a euphemism for 'mental illness' in service provision, social inclusion and exclusion are increasingly used either interchangeably or, as we shall see, as unproblematic opposites. However, whilst 'mental health' cannot be seen merely as the absence of 'illness', social inclusion cannot be seen as necessarily the absence of exclusion as they have complex interrelated, contested, but independent meanings. Indeed it may be the very flexibility and elasticity of the term 'inclusion' which has allowed it to be used to progress a number of outward looking, non-medicalised and non-stigmatising initiatives inspired by a social model of disability (Bates 2002), However, notwithstanding its contested meanings, for the purposes of this article I view social inclusion as the policy drive towards 'bringing people with mental illness into mainstream society, enabling access to ordinary opportunities for employment, leisure, family and community life' (Rankin 2005:9-10).

Firstly, it is important to acknowledge that many mental health service users do experience profound social exclusion and this often has a number of negative consequences for individuals and communities (Rankin 2005; Dunn 1999; Social Exclusion Unit 2004b). Indeed, one important aspect of the notion of social exclusion was that it drew attention to the many ways that people with mental health difficulties can be excluded, marginalised and discriminated against in a variety of spheres of life (Sayce 2001; Sayce and Morris 1999; Social Exclusion Unit 2004a).   However, while exclusion refers to an act with an agent or agents (e.g. individuals, groups, institutions or markets) that have the power to exclude (Atkinson 1998; Kleinman 1998), inclusion tends to imply a benign effort on behalf of these exclusionary agents to 'include'. The policy shift to 'inclusion' can make invisible the social structures and divisions which generate and sustain exclusion and create an obsession with the choices and responsibilities of the individual rather than the constraining context in which they live.

As this shift occurred, the concepts of social inclusion and exclusion were also increasingly used as if they were polar opposites, as if one was the unproblematic negation of

the other (Levitas 2004). As this logic is followed to its conclusion, the solution to the problem of social exclusion becomes one of promoting a policy direction which stressed the inclusion of individuals. Whilst seemingly 'obvious' and 'logical', the assumptions involved in such conceptual slippage have not been explored or theorised. As a result the two concepts are used unproblematically as diametrically opposed poles within policy making. For example, although the Social Exclusion Unit report on mental health and social exclusion focused on some of the causes of exclusion, its recommendations and subsequent discussions have seamlessly moved towards endorsing inclusion as the way forward without a demonstrated awareness of the complexities of these twin concepts (Social Exclusion Unit 2004a). Such use of these concepts, as binary categories, is most obvious in policy documents but is also common in social science discourse where one might expect a more rigorous interrogation. For example, an Economic and Social Research Council (ESRC) seminar on 'mental health and social exclusion' in Manchester in 2007 opened with presentations regarding social inequalities and ended with a presentation from the National Social Inclusion Programme (NSIP), with little theoretical discussion about the conceptual nature or desirability of this shift in focus (http://www.mhseminars.info/)

Such analytical slippage is worthy of attention not only because it denies the complexity of the concepts and the ways in which they are used, but also because it increasingly contains a moral dimension. Inclusion is seen as a universal good and so any critique is constructed as resistance to change or a symptom of institutionalisation (Popperwell 2007). In this way, inclusion has been constructed as a 'moral imperative' by both the Government and leading mental health policy advisors. This is clearly laid out in recent policy reviews which emphasise the 'costs' of not pursuing an inclusion agenda:

> Without serious efforts to promote social inclusion, people with mental health problems are likely to remain marginalised at the edges of society. Mental health will continue to exact heavy costs on individual lives, and financial costs on government (Rankin 2005:20).

Indeed there is a growing consensus amongst government, policy makers and progressive practitioners that social inclusion should be a common goal for health and welfare services (and service users). Some have even argued that social inclusion is the key challenge and ultimate goal of mental health services (Sayce 2001; Rankin 2005) requiring leadership from psychiatry, mental health professionals and the service user/survivor movement (Sayce 2001). Additional weight is given to the social inclusion agenda because it was not developed simply as a 'top-down' policy priority, but rather it was developed from a complex interaction between policy makers, activists and theorists. Most notably, the demand for 'inclusion' has emerged from a liberal human rights based perspective which has drawn on the ideas and practices of the disability movement. For example,

> Social inclusion is an imperative both as a rights issue, in terms of changing a pattern of massive social and economic exclusion, and in relation to the goals of therapeutic practice (Sayce 2001: 121)

Critical social theorists have often argued that an exploration of how policy discourse contains 'slippages' between concepts, and the ways in which policies are constructed as necessary, can enable us to understand the underlying assumptions of particular polices (Fairclough 2000; Cooke and Kothari 2001). This paper argues that the notion of 'social inclusion' cannot be construed merely as either a progressive demand for human rights or just another form of top-down social engineering. However, it does highlight the potential ways

in which social inclusion policies might result in the subjugation of psychiatric survivors through new forms of expert knowledge and power at the expense of genuine collective empowerment and self determination.   In other words social inclusion could become the latest way in which society regulates people with mental health problems.

The next two sections explore some of the implicit assumptions and potential consequences of the move from exclusion to inclusion. Following this, I look at how social inclusion has become one of the ways in which contemporary western societies seek political legitimation.

Assumptions of 'Inclusion'

Just as the conceptual slippage from exclusion to inclusion has happened without much debate, the assumptions which underpin this shift have not been examined. Social inclusion initiatives which attempt to simultaneously fuse the identification of the socially excluded with attempts to incorporate them into the mainstream of society, confuse the identification and tackling of social exclusion with promoting inclusion. In doing so, such initiatives make a series of assumptions about the excluded, the society they are seen to be excluded from, and the solutions that are deemed necessary.

While it seems well evidenced that social exclusion has a negative impact on health and well-being, there is an accompanying widespread assumption that 'inclusion' in mainstream social settings is important for mental health and wellbeing. Thus social inclusion taps into common sense established ideas that 'everyone should be included in the one-nation Britain, that everyone should have a chance to contribute and be involved' (Sayce 1998:341). In other words, people with mental health problems should *want* to be involved and take part, as it is undeniably good. However, it is precisely this 'common sense' idea that is problematic. One of the problems with the move to 'promoting inclusion' is that inclusion in practice implicitly assumes that the quality of mainstream society is not only desirable, but unproblematic and legitimate (Levitas 2004; Fairclough 2000).

Equally, a fundamental, if implicit, premise of social inclusion is the existence of an 'ideal of common life' (Gray 2000: 22) which everyone should aspire to. In practice this assumes a general consensus on basic values around involvement in community, work, family and leisure (Burden and Hamm 2000; Gray 2000). To be included is to participate in this ideal, and to do so is both 'healthy' and desirable. Despite this shared and 'common sense' belief, the link between inclusion in mainstream social settings and increased mental well-being has not been clearly established (Angus 2002). Research has also questioned the assumption that inclusion is necessarily lacking or desirable for everyone with mental health difficulties (Secker et al. 2007).

In addition, social inclusion discourse implies that society is comprised of a comfortable and satisfied 'included majority' and a dissatisfied 'excluded minority'. This focuses attention on the excluded minority and fails to take seriously the difficulties, conflicts and inequalities apparent in the wider society which actually generate and sustain exclusion *and* mental health problems (Kleinman 1998; Levitas 2004; Fairclough 2000; Burden and Hamm 2000).   Indeed, it is often the pressures and expectations underpinning this ideal of common social life which contribute to mental health difficulties in the first place (Cornett 2007). This is evident in recent research in the UK which highlights the increasing levels of mental health problems within mainstream society (James 1997; Layard 2005a; 2005b; Bird 1999). Indeed it is not only people with diagnosed 'severe and enduring' mental health difficulties who do not necessarily 'feel at home in mainstream society' (Bates and Davis 2004: 199).

Recent research has suggested that affluent western societies are experiencing an epidemic of mental ill-health, particularly anxiety and depression, as well as alcohol and drug related mental health difficulties (WHO 2000; Layard 2005a; b). These difficulties are experienced across the spectrum of society, not just amongst the socially excluded. Researchers have also noted that societies which place more value on money related values and expectations have lower levels of mental well-being (Kasser and Ryan 1993) and that people who attach more importance to material possessions, and who judge personal success through them, experience lower levels of happiness (Dittmar 1992).

These concerns have led some commentators to argue that we need to move away from status based consumerism towards recognising other types of contribution in society, not just those dependent upon money, paid work and status (Faiers 2004). Yet these are precisely the qualities of mainstream society which people with mental health difficulties are increasingly being encouraged to aspire to, under the promise of social inclusion, primarily through paid work. Although social inclusion initiatives are intended to promote choice in living one's desired life in the community and emphasising involvement in all potential elements of social life, including sports and leisure (Bates 2002; Rankin 2005), the main route to inclusion is usually seen as paid work. For example, it is commonly argued that 'employment *must* become a fundamental part of *every* service user's care plan' (Evans and Repper 2000:20, emphasis added). The 'hard outcomes' measured to assess inclusion usually relate primarily to employment, or at least proximity to, and involvement in, the labour market (Rankin 2005). This often means that other (so-called 'softer') outcomes such as improving self esteem and participation - themselves not without criticism (see Furedi 2003; Cooke and Kothari 2001) - are merely viewed as 'distance travelled' towards these government defined outcomes, rather than ends in themselves (Kent 2002; Secker et al. 2005; Dewson et al 2000).

Whilst there are many good reasons for considering employment as an important agenda for mental health services (Secker et al. 2001), the relationship between work and health is complex (Sparks et al. 2001). A recent review concluded that the 'evidence is clear that, for working people, the design and management of work can be a major threat to their mental health' (Cox et al. 2004:184, see also Gabriel and Liimatainen 2000; Siegrist 1996). Modern employment is increasingly poorly paid, un-unionised, insecure and characterised by longer working hours, short term contracts, increasing workloads, stress and uncertainty (Stewart 2004). In addition, focusing on employment as the route to inclusion ignores the necessity, value and gendered nature of unpaid work and also undermines the legitimacy of non-employment' (Levitas 2004; Kleinman 1998).

Many argue that the promotion of social inclusion is about more than access to employment and conceptualise inclusion as involvement in a wide variety of social and community settings as well as paid work (Repper and Perkins 2003). However, this broad view of social inclusion makes a number of *additional* assumptions about the nature of society and the desirability (or undesirability) of the kinds of relationships that people form, especially with mental health services, the State and other mental health service users. For example, assessments of inclusion are based on an assumption that an individual's main contacts should not be mental health focused i.e. they are not 'dependent' on mental health services, the benefits system and/or other people with mental health difficulties. It also assumes that participation in a wide *variety* of mainstream and community settings is necessarily desirable and this becomes a further component of what is considered to constitute a good or healthy life (NIMHE/CSIP 2006).

Moreover, this implicitly assumes that the so-called 'normal' population are themselves 'socially included' in a variety of aspects of social and community life. Yet it is well-known

that people in full time work spend little time on non-work related activities and full time work negatively affects people's ability to socialise, volunteer or help others (Ruston 2000; Lader et al 2005). Similarly, research has noted how the inhabitants of middle class suburbs (the core of 'mainstream society') are often socially isolated and rarely mix with others outside their own socio-cultural group (Kleinman 1998; Baumgartner 1988). Furthermore, some people actually *choose* their own exclusion as exemplified through the phenomenon of 'gated communities' where the affluent develop enclave-style housing developments where they segregate themselves from the rest of society (Blandy et al. 2003; Hutton 1996) yet are rarely, if ever, a target of social inclusion initiatives.

Consequences of 'Inclusion'

The ways in which the socially excluded are constructed within policy and practice discourse can result in a number of potential consequences. In particular, it can lead to a focus on changing the individual's choices and aspirations, rather than the social context which constrains their choices. In assuming that the 'mainstream' is ideal and desirable, it is possible that discourses around mental health are increasingly constructed within a deficit model, which constructs the socially excluded as lacking in the skills and dispositions required for paid work and other mainstream activities. In this way, the problem which needs to be addressed is not social inequality, oppression or discrimination, but cultures of low aspiration and fatalism (Fairclough 2000). The moral imperative for service users to engage in a way which is defined as appropriate by government, policy makers and services can lead to those who do not co-operate being viewed as dysfunctional.

This is apparent with modern policy concerns about the issue of 'dependency'. Increasingly, service users are constructed as being 'dependent' on welfare services if they use services in particular ways. The notion of dependency is almost invariably constructed in negative terms and is opposed to the ideal of 'independence' (usually through employment). In this way, service users' reliance on benefit payments, services and/or other people with mental health difficulties becomes a 'moral hazard' (Levitas 2004:4) which encourages dependency, rather than a social good which prevents destitution or provides support, solidarity and care (Burden and Hamm 2000). It is interesting to note that some elements of the service user/survivor movement also place a lot of emphasis on independence from services as part of their aspiration for greater autonomy and may view 'getting back to work' (for example) as a particular individual mark of achievement (see for example, the new campaign group 'Stand to Reason' (www.standtoreason.org.uk).

If the socially excluded (or service users) are constructed as 'lacking' or 'dependent', the problem then becomes how to 'help, cajole or coerce' those perceived as outsiders back into mainstream society (Levitas 2004:7). Social inclusion strategies often target groups and individuals whose behaviour or choices are seen as problematic (single parents, teenage mothers and members of the 'underclass') and try to encourage or impose more appropriate or acceptable modes of behaviour, choices or lifestyles (Kleinman 1998; Levitas 2004). Although the mantra of 'individual choice' and 'person centeredness' often accompanies social inclusion initiatives, in effect the inclusion imperative inadvertently imposes certain choices as more desirable than others. In other words some choices are privileged and encouraged while others are problematised or pathologised.

This has the potential to introduce a two-tier welfare system based upon the relationships that service users have with welfare services (Lyons 2005). For example, the implementation of policies relating to 'day service modernisation' (NIMHE/CSIP 2006) and the increasing

push for 'direct payments' or individualised funding, where money is paid direct to the service user in lieu of social care services (Department of Health 2003), could result in services users who continue to 'choose' to use day services or to receive social care directly from social services being viewed as less responsible, more dependent and thereby pathologised (Spandler 2004). Thus the shift to inclusion endorses a particular view of the necessity and desirability of specific forms of behaviour, choices and relationships. For example, 'real jobs' and 'ordinary college classes' are preferable to 'segregated day centres' and 'special classes' (Bates 2002: 3).

As we have seen, the notion of 'social exclusion' as a dynamic term focusing attention on the power dynamics involved in social practices of exclusion and marginalisation has given way to notions of the 'socially excluded' as a particular set of individuals who require social inclusion. Thus 'exclusion' has been turned from a process (with identifiable causes) into an outcome, a 'condition people are in' (Fairclough 2000: 54) which can be measured, monitored and rectified by initiatives to change the behaviour of the excluded by influencing choices made about their lives and welfare services. Indeed, the priority placed on particular 'mainstream' opportunities such as paid work results in the promotion of particular individualised therapeutic and behavioural interventions, as evidenced by the trend of giving people Cognitive Behavioural Therapy for long term depression and anxiety to help them get back to work (Layard et al. 2006).

Many proponents of social inclusion are well-intentioned in their aim to liberate mental health services from a primary concern with 'care' and 'treatment' (Sayce 2001). However, because psychiatry is largely, and it might be argued, unavoidably, an individualistic and interventionist discipline characterised by management and social regulation, social inclusion could become another form of treatment or technique which is imposed on service users 'for their own good'. In this way, mental health services are given the task of social engineering/regulation by imposing and reinforcing particular dominant cultural values and practices. Paradoxically, such policy measures may actually reproduce exclusion by enforcing a moral conformism. For example, the more social inclusion is seen to relate to paid work, the more those *not* in paid work will feel excluded and marginalised (Lister 2000). In this way, the inclusion imperative could actually increase the gap between the supposed 'included majority' and the 'excluded minority'.

Moreover, social inclusion has a *conditional* element in which coercion can be used to ensure compliance (Burden and Hamm 2000; Humpage 2006). Thus, alongside seemingly progressive modernisation strategies which promote greater choice, control and independence for welfare service users, we are also witnessing a growth in the social control of people with mental health difficulties. Recent moves towards compulsory treatment in the community, supervision orders and assertive outreach services have often been viewed as mental health 'anti social behaviour orders' (ASBOs) which function to exclude certain undesirable people (and their behaviour) from the rest of society.[1] Such treatment of the issue bears similarity to

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[1] For discussions about the new reforms of the Mental Health Act see http://www.mentalhealthalliance.org.uk/ and www.criticalpsychiatry.co.uk

the way in which the tenants of social housing are compelled to behave 'properly' or have their tenancies revoked (Young et al. 2004). Mental health service users are being urged to exercise greater choice and control, but only if they make the 'right' decisions. Moreover, reforms of the benefits systems may result in the withdrawal of welfare benefits to people on long term sickness benefits.

If inclusion shifts attention to changing the individual's behaviours and choices, then a final consequence of the inclusion imperative is that the conditions of possibility for collectivist demands and solutions are undermined (Stewart 2000). In this way, initiatives such as individualised funding may actually encourage a minority of social care users to find individual solutions to the effects of social exclusion rather than address the fundamental divisions which cause exclusionary practices (Spandler 2004; Lyons 2005). In addition, a focus on inclusion tends to result in cutbacks in particular services which provide communal responses to mental distress and ill-health.

In summary, despite good intentions, there is a risk that a narrow social inclusion agenda may foster a disproportionate focus on 'slotting in, rather than transforming society' (Bates and Davis 2004: 202). Such concerns have led to some disquiet amongst service users about the social inclusion agenda:

> Survivors don't necessarily want to be part of a mainstream society which has rejected them and in which they will never easily fit until society itself redresses its prejudiced attitudes and tunnel vision. Where is the problem located, in the individual who has dropped out or been excluded, or in society, which tries to force people to fit its stereotypes? 'Social inclusion', if we are not careful, can sound rather like 'normalisation', which appeared to mean making people more normal so they would fit in (Wallcraft 2001, in Secker et al 2007: 11).

Inclusive Governance

In order to understand why social inclusion is increasingly promoted and accepted as a key driver for policies and services, we need to explore the ways modern western societies seek to achieve social and economic legitimation through 'inclusive governance' (Ryan 2007). Promoting inclusion, integration or cohesion has become a key part of the contemporary political agenda across contemporary Europe (Lister 2000; Ratcliffe 2000). Government policies are increasingly aimed at ensuring that users of welfare services play an 'active' part in mainstream society and contribute to the national economy rather than being dependent upon welfare services and benefits (Marinetto 2003; Social Exclusion Unit 2004a). Increasingly aware of the economic costs of mental illness (SCMH 2003), the UK Government has sought the advice of economists to try and solve the problem of the rising costs of social security benefits, mental health services and productive days lost through mental health problems. It is clear that paid work lies at the heart of many Western Governments' attempts to build inclusion and ensure cohesion (Lister 2000; Humpage 2006; Fairclough 2000). Attempts to pull a greater majority of the population into a 'productive' and 'responsible' role within society helps offset an impending economic crisis as well as a crisis of social legitimacy (Marinetto 2003).

A key feature of modern governance is to seek to legitimise the status quo through inclusion and consensus, rather than conflict and coercion. In this way, inclusion, involvement and participation become important ways of ensuring that the marginalised and excluded feel they have a stake in the modern social order. Modern government increasingly achieves this through what appear to be progressive social policies which galvanise our discontents and

appear to solve an agreed social problem. Yet, inclusive governance conventionalises and prioritises certain principles, values and behaviours such as competitiveness, efficiency, flexibility, employability and consumption (Ryan 2007). To enable these values to take root, Governments have increasingly formulated policies, established new programmes and promoted initiatives to regulate the conduct of citizens, not only by social control, but also through acting upon their choices and aspirations (Rose 1989). Inclusive governance does not necessarily reflect a deepening of the modern democratic ideals of liberty and equality, but ensures that we all sign up to a range of uncontested objectives which, by default, foreclose more radical alternatives to tackling social inequalities (Cooke and Kothari 2001; Ryan 2007).

In this context it is important to recognise the ways in which the 'socially excluded' themselves develop their own social networks and survival strategies to respond to exclusion. It is possible that the socially excluded might actually value their own 'strategic exclusion' from particular aspects of mainstream society which they may view as unacceptable or un-accepting (Humpage 2006). Such strategies might resist the worst excesses of exclusion through the formation of alliances with other similarly excluded people but may not necessarily involve 'inclusion' or 'integration' (Jordon 1996; Fairclough 2000; Merli 2002). However, under present policy objectives these activities can too readily be viewed as the 'problem' of voluntary exclusion, whereby those on the margins reinforce their marginalised status by seeking the support of those who are similarly marginalised (Rankin 2005; Percy-Smith 2000).

Similarly, others have suggested a dynamic approach which opens up spaces for those who are excluded to develop their own ways of tackling exclusion (Lister 2000). Although many people may want to participate in 'mainstream society' this is not the case for everyone and nor is it the *only* response to exclusion. In Ontario psychiatric service users have developed strategies of community economic development, not to try and integrate service users into the mainstream labour market, but to use the economy to develop survivor businesses (Church 1997; Church et al. 2000). Church sees the main aim of these initiatives not as one of promoting integration or inclusion but rather as promoting 'healthy segregation' because she argues that connections developed with the strengths and capacities of the self help and user/survivor movement are more valuable than mainstream society. In social inclusion discourse, the notion of 'bridging' social capital (developing connections between the individual and mainstream society) is favoured over 'bonding' social capital (connections fostered amongst the socially excluded themselves) (Putnam 1995). However, the kinds of enterprises described by Church serve to question these hierarchical distinctions and problematise any simplistic ideals of 'inclusion'. Attempts to prioritise 'bridging' social capital in order to promote inclusion may undermine the building of solidaristic social networks through which exclusion can be challenged through self defined networks of common experiences and interests. Notions of social inclusion do not explicitly take into account the positive identities that are often essential to groups and social movements who are able to collectively challenge oppression and discrimination (Shakespeare and Watson 2001). Indeed there is little sense of agency in the notion of social inclusion which tends to construct the individual as a passive recipient of necessary interventions (Ratcliffe (1999).

Conclusion

This article has highlighted a number of possible negative consequences of the move from exclusion to inclusion in the context of mental health. Despite its flaws, which have been much debated, social exclusion can be seen as a helpful term which highlights the

marginalisation of people with mental health difficulties because it sustains a focus on issues of power and the ways in which institutions and cultures operate exclusionary practices and it is easier to retain a sense of society as the locus of structural inequalities (Kleinman 1998 Merli 2002). However, because these dynamics captured by the concept of exclusion are lost in the move towards social inclusion, there may be a case for a re-focus on social exclusion as a critical concept.

Finally, the demand for social inclusion is paradoxical in that it both expresses a genuine desire to tackle the consequences of social inequality and yet at the same time could become co-opted as a modern form of moral and social governance which reproduces and legitimises the prevailing socio-economic order. On the one hand it offers the promise of emancipation through the resolution of social exclusion and yet it simultaneously becomes another way in which the 'mentally ill' are subject to social, moral and economic regulation. To ensure that social inclusion does not become a 'new tyranny' (Cooke and Kothari 2001), we need to be mindful of the context in which inclusion policies are implemented, the assumptions that become implicit within these policies, and the possible consequences of their adoption as a moral imperative.

Acknowledgements

References

Angus, J. (2002) *A Review of evaluation in community-based art for health activity in the UK*. London, Health Development Agency, http://www.dur.ac.uk/resources/cahhm/reports/CAHHM%20for%20HDA%20J%20Angus.pdf

Atkinson, A.B. (1998) Social Exclusion, Poverty and Unemployment. In A.B. Atkinson and J. Hills (eds) *Exclusion, Employment and Opportunity*. CASE paper no. 4. London: Centre for Analysis of Social Exclusion, London School of Economics.

Bates, P. (ed) (2002) Working for Inclusion: Making social inclusion a reality for people with severe mental health problems. London, Sainsbury Centre for Mental Health.

Bates, P. and Davis, F.A. (2004) Social Capital, Social Inclusion and Services for people with learning disabilities. *Disability and Society,* 19(3): 195-207.

Baumgartner, M. (1988), *The Moral Order of the Suburb*. New York: Oxford University Press

Bird, L. (1999) The Fundamental Facts: All the Latest Facts and Figures on Mental Illness. London, Mental health Foundation.

Blandy, S., Lister, D. Atkinson and R Flint, J. (2003) *Gated Communities: A Systematic Review of the Research Evidence* http://www.bristol.ac.uk/sps/cnrpapersword/cnr12sum.doc

Burden, T. and Hamm, T. (2000) Responding to Socially Included Groups. In J. Perry-Smith (ed) *Policy Responses to Social Inclusion*. Buckingham: Open University Press.

Church, K. (1997) Because of where we've been: the business behind the business of psychiatric survivor economic development. Toronto: Ontario Council of Alternative Businesses.

Church, K., Fontan, J-M., Lachance, E. and Shragge, E. (2000) Re-inventing the Trojan Horse: non-profit businesses attack the process of social exclusion. *Canadian Social Work Review,* special issue on "Work and the Changing Labour Market: Issues for Social Work," 17 (1): 131-143.

Cooke, B. and Kothari, U. (eds) (2001) *Participation: The New Tyranny?* London/New York: Zed Books.

Cornett, J. A. (2007) Becoming-Paranoid: Displacements of 'paranoia' in circulations of counter-knowledges. *Journal of Critical Psychology, Counselling and Psychotherapy* 7(1): 4-8.

Cox, T., Leka, S. Ivanov, I. and Kortum, E. (2004) Work, employment and mental health in Europe. *Work and Stress,* 18(2): 179-185.

Department of Health (2003) Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance England. London: Department of Health.

Dewson, S., Eccles, J., Tackey, N.D. and Jackson, A. (2000) *A Guide to Measuring Soft Outcomes and Distance travelled.* London: Institute for employment Studies for the DfEE.

Dittmar, H. (1992) *The Social Psychology of Material Possessions.* Hemel Hempstead: Harvester Wheatsheaf.

Dunn, S. (1999) Creating Accepting Communities - Report of the MIND Inquiry into Social Exclusion and Mental Health Problems. London, MIND.

Evans, J. and Repper, J. (2000) Employment, Social Inclusion and Mental Health. *Journal of Psychiatric and Mental Health Nursing,* 7(1): 15-24.

Faiers, A. (2004) Inclusion without cure will liberate us all. *Journal of Mental Health Promotion,* 3(1): 24-30.

Fairclough, N. (2000) *New Labour, New Language?* London: Routledge.

Furedi, F. (2003) Making people feel good about themselves, Inaugural Lecture: British social policy and the construction of the problem of self-esteem, University of Kent, 24 January 2003 http://www.frankfuredi.com/index.php/site/article/106/

Gabriel, P. and Liimatainen, M. R. (2000) *Mental Health in the Workplace.* Geneva: International Labour Office.

Gray, J. (2000) Inclusion: A Radical Critique. In P. Askonas and A. Stewart (eds) (2000) *Social Inclusion: Possibilities and Tensions.* Basingstoke: Macmillan.

Humpage, L. (2006) An Inclusive Society: a 'leap forward' for Maori in New Zealand? *Critical Social Policy,* 26(1): 220-242.

Hutton, W. (1996) *The State We're In.* London: Vintage.

James, O. (1997) *Britain on the Couch.* London: Century/Random House.

Jordon, B. (1996) *A Theory of Poverty and Social Exclusion.* Cambridge: Policy Press.

Kasser, T. and Ryan, T.M. (1993) A Dark Side of the American Dream: correlates of financial success as a central life aspiration. *Journal of Personality and Social Psychology,* 65: 410-422

Kent, P. (2002) *Quality of Life as Distance travelled: final report* prepared for Fairbridge and the Foyer Foundation December 2002.

Kleinman, M. (1998) *Include Me Out? The New Politics of Place and Poverty.* CASE paper No. 11 London: Centre for Analysis of Social Exclusion, London School of Economics, http://sticerd.lse.ac.uk/dps/case/cp/paper11.pdf.

Lader, D., Short, S. and Gershuny, J. (2005) *The Time Use Survey.* London: Office for National Statistics.

Layard, R. (2005a) *Happiness: Lessons from a New Science*. London: Penguin Books.

Layard, R. (2005b) Mental Health: Britain's Biggest Social Problem? Paper presented at the No.10 Strategy Unit Seminar on Mental Health, LSE 20th January 2005,
http://cep.lse.ac.uk/textonly/research/mentalhealth/RL414d.pdf

Layard, R., Clark, D., Knapp, M. and Mayraz, G. (2006) *Implementing the NICE Guidelines for depression and anxiety: a cost-benefit analysis.* Mental Health Policy Group, LSE, May 2006, http://cep.lse.ac.uk/textonly/research/mentalhealth/RL446g.pdf

Levitas, R. (2004) Let's Hear it for Humpty: Social Exclusion, the Third Way and Cultural Capital. *Cultural Trends,* 13(2): 41-56.

Lister, R. (2000) Strategies for Social Inclusion: Promoting Social Cohesion or Social Justice. In P. Askonas and A. Stewart (eds) (2000) *Social Inclusion: Possibilities and Tensions.* Basingstoke: Macmillan

Lyons, J. (2005) A systems approach to direct payments: a response to 'Friend or foe? Towards a critical assessment of direct payments. *Critical Social Policy,* 25(2): 240–252.

Marinetto, M. (2003) Who wants to be an active citizen? The politics and practice of community involvement. *Sociology,* 37(1): 103-120.

Merli, P. (2002) Evaluating the social impact of participation in arts activities. *International Journal of Cultural Policy*, 8(1): 107-118.

NIMHE/CSIP (2006) *From segregation to inclusion: Commissioning guidance on day services for people with mental health problems* National Inclusion Programme National Institute for Mental Health in England (NIMHE), Care Services Improvement Partnership (CSIP), London, Feb 2006.
http://www.socialinclusion.org.uk/publications/Day_Services_web.pdf

Percy-Smith, J. ed (2000) *Policy Responses to Social Exclusion: Towards Inclusion?* Buckingham: Open University Press

Popperwell, I. (2007) The Dynamics of Social Inclusion. *A Life in the Day,* 11,(2): 19-21.

Putnam R. (1995) Bowling Alone: America's declining social capital. *Journal of Democracy* 6(1): 65-78.

Rankin, J. (2005) *Mental Health in the Mainstream: Mental Health and Social Inclusion.* London: Institute for Public Policy Research
http://www.mentalhealthshop.org/document.rm?id=847

Ratcliffe, P. (1999) 'Race', Education and the Discourse of 'Exclusion': a critical research note. *Race Ethnicity and Education,* 2(1): 149-155

Ratcliffe, P. (2000) Is the Assertion of Minority Identity Compatible with the idea of a Socially Inclusive Society? In P. Askonas and A. Stewart (eds) (2000) *Social Inclusion: Possibilities and Tensions.* Basingstoke: Macmillan.

Repper, J. and Perkins, R. (2003) Social Inclusion and Recovery: a Model for Mental Health Practice. London: Bailliere Tindall

Rose, N. (1989) Governing the Soul: the shaping of the private self. London: Routledge.

Ruston, D. (2000) Volunteer, Helpers and Socialisers: Social Capital and Time Use. London: Office for National Statistics

Ryan, K. (2007) *Social Exclusion and the Politics of Order.* Manchester: Manchester University Press.

Sainsbury Centre for Mental Health (SCMH) (2003) *The economic and social costs of mental illness.* Policy Paper 3. London: SCMH.
http://www.scmh.org.uk/80256FBD004F6342/vWeb/pcPCHN6FRLCM

Sayce, L. (1998) Stigma, Discrimination and Social Exclusion: what's in a word? *Journal of Mental Health,* 7(4): 331-343.

Sayce, L. (2001) Editorial: Social Inclusion and Mental Health. *Psychiatric Bulletin,* 25: 121-123.

Sayce, L. and Morris, D. (1999) Outsiders Coming In? Achieving Social Inclusion for People with Mental Health Problems. London: Mind.

Secker, J., Grove, B. and Seebohm, P. (2001) Challenging barriers to employment, training and education for mental health service users: the service users' perspective. *Journal of Mental Health*, 10(4): 395-404.

Secker, J. Hacking, S, Spandler, H., Kent, L. and Shenton, J. (2005) *Mental health, social inclusion and arts: developing the evidence base.* London: National Social Inclusion Programme, Care Services Improvement Partnership
http://www.socialinclusion.org.uk/publications/MHSIArts.pdf

Secker, J. Hacking, S, Spandler, H., Kent, L. and Shenton, J. (2007) Mental health, social inclusion and arts: developing the evidence base: Final report from Phase 1: The state of the art in England. November 2005
http://www.socialinclusion.org.uk/publications/Phase%201%20report.pdf

Sedgwick, P. (1982) *Psychopolitics.* London: Pluto Press.

Shakespeare, T. and Watson, N. (2001) Making the Difference: Disability, Politics and Recognition. In G.L. Albrecht, K.D. Seelman and M. Bury (eds) *The Handbook of Disability Studies.* Thousand Oaks: Sage Publications, 546-564.

Siegrist, J. (1996). Adverse health effects of high effort-low reward conditions at work. *Journal of Occupational Health Psychology,* 1(1): 27-43.

Social Exclusion Unit (2004a) *Mental Health and Social Exclusion: Social Exclusion Unit Report.* London: Office of the Deputy Prime Minister.

Social Exclusion Unit (2004b) *Breaking the Cycle*. London: Office of the Deputy Prime Minister

Spandler, H. (2004) Friend or Foe: Towards a Critical Assessment of Direct Payments. *Critical Social Policy,* 24(2): 187-209.

Sparks, K., Faragher, B. Cooper, C.J. (2001) Well-being and occupational health in the 21st Century Workplace. *Journal of Occupational and Organizational Psychology,* 74: 489-509.

Stewart, A. (2000) Social Inclusion: A Radical Agenda. In P. Askonas and A. Stewart (eds) (2000) *Social Inclusion: Possibilities and Tensions.* Basingstoke: Macmillan.

Stewart, P. (ed.) (2004) *Employment, Trade Union Renewal and Future of Work*. Basingstoke: Palgrave

Wallcraft 2001, cited in Secker, J. Hacking, S, Spandler, H., Kent, L. and Shenton, J. (2007) *Mental health, social inclusion and arts: developing the evidence base.* London: National Social Inclusion Programme, Care Services Improvement Partnership
http://www.socialinclusion.org.uk/publications/MHSIArts.pdf

World Health Organisation (WHO) (2000) International Consortium in Psychiatric Epidemiology, Cross-national comparisons of the prevalence and correlates of mental disorders. *Bulletin of the World Health Organization*, 78: 413-26.

Young, F., Huntington, A., and. Foord, M. (2004) No room for nuisance. *Community Care,* 22 April 2004: 42-44.

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OPINION PIECE

Should medical sociology professionalise?

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The professionalisation of medicine has been one of the enduring topics of medical sociology. Recent years have seen the self-conscious professionalisation of other groups within health care, including, perhaps most prominently, nurses. An interesting but little noted development has also been the professionalisation of a particular type of social scientist - the health psychologist. The professionalising of health psychology involves familiar tactics: creation of a register (building on the existing framework for Chartered Psychologists); completion of postgraduate training accredited by the British Psychological Society (BPS); assessment of competences; a system of supervisors and continuous professional development; being bound by the BPS code of conduct; and the granting of the exclusive right to use the term 'Chartered Health Psychologist'.

Notwithstanding the ongoing elusiveness of the definition of a profession, there are many grounds on which medical sociology can consider itself to be a profession too. As Bloom's (2002) magisterial historical account illustrates, medical sociology (a term which dates back to 1894) is fully institutionalised as a field of study, with organised demand for its teaching and research; specific professional associations and scholarly journals; and a body of methods, theories, and practices that are distinctive. 'Doing' medical sociology properly requires the exercise of expertise, discretion and good judgement, as well as having the appropriate competence and commitments to ethical practice. But there is no professional registration of medical sociologists in the UK. Though certainly there is the option of joining the BSA Medical Sociology Group, this is entirely voluntary. Becoming a member of the group does not confer "chartered" status or any exclusivity over the claim to be a medical sociologist.

Why have medical sociologists not done like their health psychology counterparts, and staked a more forceful claim to their own professional standing? One important reason is that, although some chartered health psychologists are solely involved in research and teaching, many provide psychological interventions, in areas such as pain management, cardiac rehabilitation, smoking cessation, alcohol and other substance misuse, and so on. A system of

formal accreditation and registration of people involved in providing forms of therapy to patients is often a requirement of health service organisations. However, another important reason for the non-professionalisation of medical sociologists is likely to be found in sociology's own role in commenting on professionalisation.

Medical sociologists have often been rather unsympathetic - sometimes even hostile - in their accounts of the professionalisation of medicine. They have been attentive to the means by which doctors were able to engage in market monopolisation and occupational enhancement through a variety of tactics and strategies, including the use of educational and ethical credentials to secure claims to distinctiveness, autonomy, and status. One popular analysis of professionalisation characterises it as a process driven by the interests of the professional group and aimed at achieving dominance. On this view, claims to be benevolent moral agents who can be trusted both by individual patients and to serve the public good are little more than a (potentially corrupt and self-interested) legitimising strategy. This model sees the professions, especially medicine, as 'an elite set of occupations which have somehow obtained state powers to monopolise their domain of work, train their own members, dominate the boards of licensure that approve new members and related institutions (like hospitals), monitor the quality of their professional work, and run most of the institutions where their work takes place' (Light, 1988: 204). Other analyses, typified by the work of Larson (1977), have focused on the 'professional project', which describes the attempt to translate one order of scarce resources (special knowledge and skills) into another (social and economic rewards); professionalisation is thus seen as the corporate efforts of an occupation determined upon upward mobility. Dating back to Weber's (1979) analysis of the role of qualifications and certificates in the 'bureaucratisation of capitalism', sociologists have also been sceptical about what has latterly become known as credentialism; it is often seen, in the political economy of the professions, as a means of achieving occupational closure and excluding others.

However, there has been recent reappraisal of the possible benefits of professionalism. Thus Freidson, though one of the principal architects of the 'professional dominance' thesis, has recently (2001) offered a new emphasis on the virtues of professionalism or the 'third logic'. I use the term 'professionalism' here quite deliberately, to underline Evetts' (2006) stress on professionalism as a normative value. Evetts notes that in addition to protecting market position through controlling the licence to practice, professionalism might also represent a distinctive form of occupational control or, after Durkheim, a moral occupational community. What she terms 'occupational professionalism' (as distinct from 'organisational professionalism' used by managers in work organisations) involves a discourse constructed within professional groups that is operated and controlled by practitioners themselves and based on shared education and training, a strong socialisation process, work culture, occupational identity, and codes of ethics that are monitored and operationalised by professional institutes and associations.

Part of the argument in favour of professionalism as far as medical sociology goes concerns our responsibilities as research practitioners. We ask organisations, particularly within the NHS, to allow us access to data, settings, staff and patients. When we do interviews, observations, focus groups, and so on, we are relying on people to allow us into their lives and are asking them to trust us. Sometimes we ask them invasive questions; often they grant us the privilege of sharing deep confidences with us. But what can we offer as the 'front end' of our profession - what do we do to encourage confidence in our competence, ethical commitments, and motivations? At present, often very little other than our CVs and the fact that we are (usually) employed by a university or registered as a student. I am fully

aware that most medical sociologists are indeed competent and of good character, but should research participants and organisations who host research be able to rely on more formal assurances? Otherwise, our complaints about the research governance system may seem rather arrogant when we make the demand 'trust me, I'm a medical sociologist'.

Clearly, professionalism (which most of us would aspire to) can exist without professionalisation. But credentialism can have positive benefits, providing assurances of the competence of individuals to perform certain types of work and of expected standards of conduct. One way forward would be to follow the Health Psychologists down the route of formal professionalisation.

Some of the arguments in favour of professionalising are indeed self-interested. It is unlikely that having exclusive claim to a particular professional title would make many of us rich. But maintaining a register of practitioners whom we are satisfied are competent and of good character could offer us a more coherent professional identity and promote a sense of community; offer us certain protections; facilitate our interactions with research governance; assist in "marketing" our particular skills; attract new entrants to the field as well as research funding; encourage reflexivity; and help to clarify the nature of the contract between ourselves and society. Clearly, it would be naive to assume that there is a simple and direct relationship between any of these outcomes and professionalisation, but it is a start.

I realise that there would be many downsides to professionalisation. The transaction costs for any system of registration are always high, because it requires a process of bureaucratisation and formalised governance. The thought of the paperwork makes me sigh, as does the prospect of yet another annual fee. Setting up the process would be tedious, involving meetings, discussions, and negotiations. Some rigidity and unwelcome removal of useful discretion is likely to be inevitable. Conflict will be inescapable, especially when decisions are made about who is in and who is out, and anyone involved in either striking off or being struck off will have a horrible time. But I do wonder if we owe it to ourselves and to others to at least begin the debate.

References

Bloom S. (2002) The Word as Scalpel: a History of Medical Sociology. Oxford: Oxford University Press.

Evetts J. (2006) Short note: the sociology of professional groups: new directions. *Current Sociology,* 54: 133-143.

Freidson E. (2001) *Professionalism: the Third Logic.* London: Polity Press.

Larson, M.S. (1977) *The Rise of Professionalism.* Berkeley: University of California Press.

Light D.W. (1988) Turf battles and the theory of professional dominance. *Research in the Sociology of Health Care,* 7: 203-2.

Weber M. (1979) *Economy and Society: an Outline of Interpretive Sociology*. Ed. R. Ross and C. Wittich. Berkeley: University of California Press.

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Professionalisation to what ends?

A response to Mary Dixon-Woods

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Mary Dixon-Woods presents a very interesting argument for the professionalisation of medical sociology. As a medical sociologist and a sociological scholar of the professions these two frameworks are (perhaps surprisingly) not something that I had considered together before. Perhaps this is precisely because, as Mary noted, medical sociologists typically provide a commentary on professionalisation rather than apply this framework to our own profession. This has provided some interesting food for thought.

My initial response to Mary's piece was to ask, 'to what ends would professionalisation serve medical sociology?' In answering this question, it is important to present some further points for consideration. First, Mary has pointed out how we medical sociologists *qualify* to be treated as professionals. This point is difficult to contradict. As she has clearly pointed out we have a unique body of knowledge, methods, practices, etc. But how does this differ from our professionalism as academics and research scientists? Are we not already professionalised through our membership in the academic/scientific research profession? Indeed, couldn't the same argument presented here also apply to health economists and health policy analysts or equally to criminologists and a host of other disciplinary specialists?

As Mary highlighted in her comparative case analysis of health psychologists, in addition to being research scientists, they are also involved in the treatment of patients. This leads us naturally to a discussion of who are our clients? In a traditional academic sense these would be our students, in our pursuit of knowledge – other academic researchers, and in the spirit of knowledge transfer – health and health care decision makers at a variety of different levels. Typically, when a profession makes a case for controlling an area of practice (borrowing Johnson's (1972) definition of a profession) it is because the lack of regulation can cause harm. For example, when the Health Professions Legislation Review set out in the early 1980s to develop a decision making tool for inclusion in and exclusion from what ultimately became the Regulated Health Professions Act in the province of Ontario, one of their key criteria for inclusion was whether the profession, if left unregulated, could pose harm to clients (this being largely patients of health care services of some kind, from medicine to massage therapy). Other non-health professionals – such as engineers and accountants – are

also regulated primarily in the interests of safety of the public (e.g. structures and advice, respectively). Can we make the case that unregulated medical sociology is causing our various different client groups or the public at large potential harm? Perhaps. Although the issues of 'harm' and 'safety' may not necessarily be the criteria we must (or want to) use, they do beg the question as to whether the 'unregulated' system within which medical sociology presently exists poses a particular social problem that registration and regulation could solve.

Another perspective on this professionalisation issue is not just from a client perspective but from a management perspective. Is our professionalism being undermined by managers in a way similar to what is happening in the case of other professionals? It is here that I think there are some important data to support Mary's case. In a forthcoming article, Kevin Leicht and Mary Fennell provide a compelling argument for the increasing management of academic work/life and how recruitment to this managerial stratum is increasingly not from within the ranks of academia. This sounds like a déjà vu for what many of us have described as happening with doctors and nurses. I'm sure the RAE process that my British colleagues have to endure must cause them to feel that medical sociology (as other academic disciplines) is under the thumb of New Public Management (capitalised or not). But is this peculiar to medical sociology?

At the same time as I might disagree (at least upon initial inspection) with some parts of Mary's arguments, I fully agree with the need to foster medical sociology and to create a sense of community among like-minded (and some not so like-minded) scholars. Indeed, this is one of the primary purposes in my attempt to bring together Canadian medical sociologists at the upcoming International Sociological Association interim meeting of RC 15 to mirror the collegiality of the British Med Soc meetings that I have previously enjoyed. I agree with Mary that there may be some important benefits that may be gained by controlling our particular disciplinary specialty within the academic profession through registration and regulation (the typical means by which professionalisation occurs), but I am not yet convinced as to its necessity. Perhaps other aspects of the Canadian context for medical sociologists differ in a marked way from the U.K.

In all, I may remain somewhat sceptical of the need for the professionalisation of medical sociology, but nevertheless think that this is an intriguing question that Mary has set for us and think it is something which we should continue to consider and discuss.

References

Johnson, T. (1972) *Professions and Power*. London: Macmillan.
Leicht, K.T. & Fennell, M.L. (forthcoming 2008) Who staffs the US leaning tower?
    Organisational change and diversity. *Equal Opportunities International*.

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Should medical sociology professionalise?

A response to Mary Dixon-Woods

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The paper by Mary Dixon-Woods raises the intriguing possibility of medical sociologists following in the footsteps of health psychologists and professionalising – and will no doubt at least prompt renewed debate about how far the area should move in this direction in future. In so doing, it rightly maintains a sense of perspective by highlighting the dualistic nature of professionalisation, which can be seen to point in two directions. On the one hand, fully-fledged professionalisation carries the virtuous badge of statutorily underwritten integrity and expertise centred on a carefully policed register, codes of ethics and credentialism. On the other, leaving aside the bureaucratic transaction costs of formalising governance arrangements, it invokes a less rosy picture of professional tribalism, parochial self-interest and the defence of monopoly veiled by the ideology of serving the public interest (Saks 2003a).

This latter environment arguably contributed to recent health scandals in which, amongst other things, the notorious Dr Shipman was for so long able to murder many of his patients without detection and human organs were used for experimentation by doctors without consent at Alder Hey Hospital and elsewhere (Allsop and Saks 2002). Medical sociology itself is also not primarily an interventionist discipline involving the treatment of patients in the same way as other health occupations like medicine, physiotherapy and clinical psychology are. There may well be benefits from the viewpoint of ensuring that the responsibilities of medical sociologists as research practitioners are carried out appropriately in a field where research governance has become so significant (Saks and Allsop 2007) – and indeed from the possible longer-term effects of enhancing our status, income and power through upward collective social mobility based on exclusionary social closure (Witz 1991). Nonetheless, the formal need for the protection of the public in practice in patient-facing disciplines cannot so readily be invoked as a driver of professionalisation in medical sociology.

Moreover, despite the long history of medical sociology as a distinct field of study, it is odd that further professionalisation is being suggested for this sub-area of sociology, however popular it may be amongst sociologists. The proposal in fact perversely mirrors that encouraged by the sub-specialty identities of medicine itself and increasingly other health

professions such as nursing, which medical sociology is involved in studying (Saks 2003b). Why not also seek to professionalise the sociology of work, the sociology of deviance and the sociology of law for that matter – as well as the multitude of other sociological specialisms – to add to the ever burgeoning range of professions in modern society? This would surely be taking the application of the concept of professionalisation to extremely fragmented and unacceptable lengths. In some senses such a myopic approach subverts the identity of the sociological community as a whole, in an area which has no distinctive purchase on public protection.

It is interesting in this respect that the British Sociological Association has itself for long drawn back from a full-blown desire to professionalise. Whilst it has been concerned that sociologists behave ethically (British Sociological Association 2002), it has not sought the exclusivity of membership associated with the British Psychological Society. It has instead striven to keep sociology as a broad church without threshold entry criteria, not least to protect the discipline from the elitist ravages of an exclusionary approach that so many other occupations in the health field and elsewhere have sought to cultivate. This may be the most appropriate pitch in the diverse field of medical sociology, for – as Mary Dixon Woods herself indicates in her paper – it is possible to have your cake and eat it by playing on the distinction between professionalism and professionalisation. In this vein, it may indeed be wise for us to encourage evidence-based practice and to act with integrity in our discipline. However, this does not mean that medical sociology or sociology itself have to seek statutory self-regulation with all the negativity this has thrown up in recent years, not least in the health field – in an age where health-related occupations with too extensive professional powers have come under serious attack from government (Department of Health 2007).

References

Allsop, J. and Saks, M. (eds) (2002) *Regulating the health professions.* London: Sage.
British Sociological Association (2002) Statement of ethical practice for the British Sociological Association.
http://www.britsoc.co.uk/user_doc/Statement%20of%20Ethical%20Practice.pdf
Department of Health (2007) Trust, assurance and safety: the regulation of health professionals. London: HMSO.
Saks, M. (2003a) The limitations of the Anglo-American sociology of the professions: a critique of the current neo-Weberian orthodoxy. *Knowledge, Work and Society,* 1: 11-31.
Saks, M. (2003b) Orthodox and alternative medicine: politics, professionalisation and health care. London: Sage.
Saks, M. and Allsop, J. (eds) (2007) Researching health: qualitative, quantitative and mixed methods. London: Sage.
Witz, A. (1991) *Professions and patriarchy.* London: Routledge.

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BSA MEDICAL SOCIOLOGY CONFERENCE PLENARIES

Incapacity

Plenary Address to Annual BSA Medical Sociology Group Conference, Liverpool, 6th September 2007

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Introduction

It is a particular pleasure to be able to deliver this lecture in one of the grander hotels in a city, which the writer Jan Morris (1986) has called 'the capital of north Wales'. I don't think it is very well known that Welsh people – alongside those of Irish, Afro-Caribbean, Chinese and many other origins – made a vital contribution to the economy, society and culture of Liverpool. In each decade between 1851 and 1911 at least 20,000 Welsh people came to live in Liverpool – agricultural workers, slate quarrymen and many others, mostly monoglot Welsh speakers, in search of work and education (Merfyn Jones, 1981). A hundred years ago the streets of Everton and Anfield would have been noisy with Welsh speech, many of the streets had Welsh names, and there were fifty or more Welsh chapels. The historian, John Davies (1994), has gone so far as to suggest that out of this strong Protestant ethic Liverpool produced the only well-established bourgeoisie that Wales has ever possessed! 'Though young and usually poor', another historian D. Ben Rees (2007) has suggested, 'they were men and women who were determined to make a better world for themselves and their children'.

Now, desperately seeking a smooth segue to the subject of this lecture, I suppose I could say that what I want to do this afternoon is to explore some of the things which prevent people from making a better world for themselves and their children, how we construct a more satisfactory sociological understanding of that, and what implications there are for politics, policy and practice.

Living structures

When I started life as a medical sociologist in the 1980s, my interests were primarily in what Margaret Thatcher would have referred to at the time as 'individuals and their families' – if you remember her infamous 'no such thing as society' comment in *Woman's Own* magazine

in 1987. Now, it may be that I have been rendered helplessly nostalgic by 10 years of relentless New Labour spin, but I would like to remind people that later on, in her 1995 autobiography *The Downing Street Years*, Margaret Thatcher reflected on the notoriety achieved by that remark and wrote:

> My meaning, clear at the time but subsequently distorted beyond recognition, was that society was not an abstraction, separate from the men and women who composed it, but a living structure of individuals, families, neighbours and voluntary associations (quoted in Osborne, 2002)

I am sure there are few people in this audience who would disagree with the concept of society as a 'living structure'; although you might want to develop it in different directions and amplify it in ways that are distinct from those mentioned by Mrs Thatcher. We might suggest, for example, that Margaret Thatcher neglected wider aspects of the structure of economy, society and power, concentrating instead on what C. Wright Mills referred to as 'milieux', or what we might nowadays describe as social networks or social capital. But on the basis of her autobiographical reflection we could hardly concur with the dominant view of her ideological position as one of neo-liberal individualism. She sounds much more like Anthony, now Lord, Giddens, or some other harbinger of communitarianism or the Third Way. Indeed, we could argue that the Third Way is in fact Mrs Thatcher's outstanding contribution to modern political life!

Although my own work at the time, in the early 1980s, was small-scale and focussed on individual experience, like Margaret Thatcher my interest was in individual people within the living structure of society. Here is a middle-aged woman, whose account I have used in the past, talking to me about the impact of the 'living structure' upon her health:

> …I had had many years of very hard physical work, you know – washing and ironing and cooking and shopping and carting kids around and carrying babies and feeding babies and putting babies to bed and cleaning up their sick… Bringing up five children is hard work. That, and with the stress on top, I'm sure that I just cut out, I just blew a fuse.
>
> (quote taken from Williams 1984)

Someone totally unfamiliar with my work at that time would not jump to the conclusion from this extract that this was an interview with someone talking about her rheumatoid arthritis. The vividness of the remark is in its communication of the social realities of the 'living structure' and their impact in this particular situation. A middle-aged woman with five children and 'the stress on top', as she puts it, was trying to convey to the then young male interviewer with no children and few stresses how she had gone from a state of health to one of considerable incapacity in such a short space of time. This woman understood her rheumatoid arthritis, and who was I to contradict her, as the long-term outcome of a hard life – biographical disruption was woven through it in causes and consequences.

Incapacity

I have chosen to speak about incapacity partly because of my long-standing interest in chronic illness and disability. However, the immediate stimulus comes from the work I have done more recently on the determinants of health and inequalities in health, and on community-

based approaches to health development in the context of the post-industrial regions, in particular south Wales. My starting point is the poor health of specific places, and how we can better understand this and formulate some kind of solutions to the difficulties in which people find themselves.

There are very high rates of incapacity benefit claims in a number of Britain's classical post-industrial regions: areas dominated in the past by coal, steel, dock work, ship-building and various manufacturing industries. South Wales, the north east of England and the Glasgow conurbation have particularly high rates. There are a number of reasons why incapacity is a problem for public policy.   First, the number of people on incapacity benefits has more than trebled since 1979. Whilst what is known as the inflow onto incapacity benefit has stabilised over the last ten years or so, 7.6 per cent of the population of working age are in receipt of incapacity benefits. Moreover, the duration of time on incapacity benefit has increased, and there is evidence that duration is strongly linked to the likelihood of a return to work. Secondly, rates of incapacity claims are unequally distributed across social classes and regions. Although this may seem to be common sense, the discussion of what is to be done tends to be undertaken without any clear sociological analysis of either the cause or meaning of this inequality. Thirdly, incapacity is a 'wicked issue'. Therefore, although incapacity benefit has traditionally been the responsibility of the Department of Work and Pensions, it relates in complex ways, to patterns of ill-health and wider issues of economic development, poverty and social exclusion that are the responsibilities of other departments of government.

For those of you not familiar with the arcane world of benefits, a standard, official definition of incapacity is that it is the inability to work associated with sickness or disability (Waddell and Aylward 2005). Once an individual has passed through the complex process of assessment, initially by a GP and later by a Jobcentre Plus doctor, they may be approved for receipt of 'incapacity benefit' (IB) which gives working age people a replacement income when they become sick or disabled and stop working, or looking for work, as a result. Incapacity Benefit, is a contributions-based benefit paid to people who, whether for reasons of physical or mental health, are unable to obtain or hold on to formal employment. It is used to make decisions about the allocation of benefit to individuals on the basis of their unfitness for work, and is therefore an indicator of a breakdown in the capacity of someone to enter or remain in the labour market.

The interesting feature of incapacity, as understood in this way, is that it is both a health indicator and an economic indicator. Indeed, we could say that incapacity and its distribution tell us something important about the functional relationship between chronic ill-health, the labour market and forms of social and economic life in different groups and localities. Enduring political anxiety about the growth of a population of working age unable to work because of ill-health or impairment lies at the heart of the way in which States screen and process populations. Most of the discussion of incapacity benefit at the present time examines it in the context of what are referred to as New Labour's 'activation policies' (Walker and Wiseman 2003), their strategy to modernise the welfare state by encouraging movement from welfare benefits into work, and by making that movement worthwhile in financial terms: work for those who can, security for those who cannot, as the Government put it in an early Green Paper.

Much of the debate about incapacity is therefore focused in a rather narrow and instrumental way on the relationship between ill-health, disability and work. However, it seems to me that incapacity is something that can be seen within a number of different frames or fields of sociological activity: social inequalities in health, social exclusion and the 'underclass', disability and the welfare state, social regeneration and civic renewal. My

modest aim in this lecture is at least to begin to raise some questions to do with what we mean by incapacity, how it is constructed within different frames, and what relationship it has to long-term illness on the one hand and social and economic development on the other. In so doing I hope to make a contribution also to the wider analysis of the things which prevent people from making a better world for themselves and their children.

Inequalities in limiting-long term illness

Incapacity and limiting long-term illness(LLTI) are clearly closely related. However, whilst LLTI tells us what people feel about their health, incapacity represents the outcome of a long process of thought and action by individuals with health problems and a complex network of other actors and organisational structures. Nonetheless, LLTI clearly has an important role in determining incapacity claims.

Much of the literature on inequalities in health has focused on life-expectancy and mortality. However, it is well recognised that health status measures like 'limiting long-term illness' can reveal important things about the health of groups and populations, which are additional to what we learn from looking at mortality data. Quite a lot is known about rates of chronic or limiting long-term illness thanks to information gathered via Census since 1991 and the General Household Survey (GHS) intermittently over a number of years, as well as other *ad hoc* surveys or series of surveys, such as the Welsh Health Survey, and its equivalents. Unlike incapacity, the limiting nature of long-term illness is defined in relation to a broader range of activities than work alone. Indeed, the GHS definition of limiting long-*standing* illness does not specifically mention work. Data based on these questions tell us about people's perceptions of whether or not illness interferes with the conduct of their everyday lives.

The proportion of adults aged 45-64 who have a limiting long-standing illness in Wales, the north-east region of England and Northern Ireland is almost double that in south-east England. When we examine the different regions those with the lowest rates are uniformly in south-east England. Of the worst ten, five are in south Wales, two are in northern Ireland, one is in the west of Scotland (the city of Glasgow, of course), one in north-west England, and one – the worst of all – is in north-east England. Indeed, in most tabular representations of this issue, Easington, Merthyr Tydfil and Blaenau Gwent (which includes a number of former coal and steel towns like Ebbw Vale) appear to jostle for a position at the top. In reality of course, people living and working in these areas are often profoundly depressed by such public representations of what is increasingly discussed judgmentally as a matter of personal, professional and municipal failure.

The work of people like Mel Bartley and Heather Joshi over a number of years has shown that if county districts in England and Wales are organised into one of twelve groups in an area classification based on individual Census items, areas classified as 'coalfields' and 'ports and industry' have far and away the highest levels of LLTI. The key epidemiological question in trying to understand these area differences, of course, is whether they can be accounted for by the characteristics of the individuals living in them, or whether there is something about the areas themselves. This is the much discussed problem of disentangling compositional from contextual effects.

There are, of course, regional differences in mortality too, which have widened considerably over the last twenty years, and we now have the largest regional mortality differences in the post-war period. However, as Bartley and others have pointed out, LLTI is more concentrated geographically than mortality, suggesting that these subjective measures

are encapsulating something that cannot be fully explained in biomedical terms. There may be characteristics of the people or the places which make subjective experiences of illness that limits daily activities more prevalent in some regions and localities than others.

So, although data on LLTI and incapacity benefits are not capturing the same thing, they are clearly connected in important ways. Localities with high rates of LLTI are the same areas with the highest rates of incapacity benefit claimants. Though as some of the recent interesting work by Sarah Salway and her colleagues on ethnicity and long-term illness has indicated, some minority ethnic groups with relatively high levels of long-term ill-health have low levels of incapacity claims – for a number of complex reasons (Salway et al. 2007).

Much of the orthodox literature on incapacity is written as if it was not part of the wider historical process of socio-economic development and change. The local economies in the areas, shown to have rates of LLTI in excess of those that would be predicted on the basis of purely individual characteristics, and high rates of incapacity, underwent massive transformations during the 1980s and 1990s. The loss of traditional 'male' industrial employment was not matched by an equivalent creation of new jobs. Moreover, those jobs that were created were of a very different kind: light industry and services sectors, less well paid, contractually insecure, and with weak or non-existent trade unions. The Pot Noodle factory in Blackwood (home of the Manic Street Preachers) is a good example.

Loss and Change

The impact of this period of economic transformation on the living structure of these working class communities cannot be overstated:

> At East Moors they've closed the steelworks…
> … Demolition gangs erase skylines
> Whose hieroglyphs recorded all our stories…'

as the Welsh poet Gillian Clarke has articulated it.[1]

The emotional, visceral, immediate impact on the people who experienced this is powerfully expressed in an extract from the PhD thesis of Robert Cornwall, a recent graduate from the School of Social Sciences at Cardiff. Robert Cornwall has recently retired, but he worked all his life in south Wales, in the fields of employment, life-long learning and regeneration. Here he is recalling a day in his life as the Employment Service Area Manager responsible for the Gwent and Glamorgan Valleys:

> The closure of the Oakdale Colliery in 1992 provided an unforgettable insight into its effects on the state of mind of the 750 men employed there. The colliery had been adjudged a loss-making pit and there was speculation that one coal face would be abandoned with the loss of a third of the workforce. Union representatives were called to a meeting with management one Thursday and

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[1] Gillian Clarke, 'East Moors', in: *Collected Poems*, Manchester: Carcanet

[they] arranged a mass meeting of the workforce the next morning to inform them of the outcome. At 4.00 pm on the Thursday [I] was informed, in confidence, by the National Coal Board that a decision had been made to close the [entire] colliery forthwith and [I] requested a team of jobcentre staff to attend the colliery the next morning to deal with any queries concerning benefits. On entering the colliery at 9.00am the next morning [I] was greeted by the sight of hundreds of men wandering around the pit-head in a state of shock. All were carrying a single, black plastic bin-bag containing the contents of their lockers. Having attended the meeting expecting to be told that some of them would be losing their jobs they were dumfounded to learn that the colliery had actually closed. They had already worked their last shift and they needed to empty their lockers and leave the site as soon as possible. No-one was even allowed down the pit to collect their tools from their last shift for fear of sabotage. Perhaps we should not be too surprised that many of these men who had given the best years of their lives to the coal industry never worked again [and joined] the rapidly growing ranks of the economically inactive. (Cornwall 2005: 5)

The 750 men at Oakdale were indeed only a small fraction of the rapidly growing ranks of the economically inactive. Oakdale was one of the last south Wales pits to close, in the slow death by a thousand cuts, of an industry that was finally put out of its misery by the swift retribution of Mrs Thatcher's government following the miners' strike of 1984-85. As the important work of Christina Beatty and Steve Fothergill has shown, during the period between the early 1980s and the closure of Oakdale in 1992, over 160, 000 jobs were lost from the coal industry. The fact that official unemployment amongst these redundant men rose by only 500 during the same period suggested that something odd was going on. Indeed, as Beatty and her colleagues have demonstrated conclusively, most of these men did become economically inactive, but rather than going onto unemployment benefit they became recipients of invalidity and, later, incapacity benefit (Beatty et al. 1997; 2002).

In 1992, amongst those colliers at Oakdale, rendered surplus to requirements at the fag-end of the British coal industry, there were both moral and financial benefits to being unable to work, rather than unwilling to work or simply out of work. In the coal industry, there was of course a long history of people being unfit for work for all kinds of reasons: 'silicotics, arthritics, ripped flesh, smashed bones and damaged souls' as the Rhondda coal miner-turned-novelist Ron Berry so searingly states it in his autobiography (Berry 1998: 41).

It was also beneficial to the government at the time to be able to say that large numbers of people were not actually unemployed at all, but rather unable to work because of long-term illness or disability. Even if it cost the exchequer a little more, it allowed the government to present a much more successful picture of the economy than it would otherwise have been able to do. It was also encouraging for general practitioners to be able to sign people off, and act as a portal to what up until 1993 was called 'invalidity benefit'. This was what we might nowadays irritatingly refer to as a win-win situation. An individual can describe themselves as unable to work as a result of illness or impairment and gain access to higher rates of benefit; the government is able to redefine them as incapacitated and point to declining rates of unemployment; and doctors can feel some satisfaction in the positive role they are playing in the lives of people without work.

As part of a widespread review of spending in 1993, Peter Lilley, then Secretary of State for Social Security, reformed Sickness and Invalidity Benefits into the then new Incapacity Benefit. This reform introduced the 'all work' medical test, meaning that claimants had to be unfit to perform any work before being eligible to receive the benefit.

As Beatty and her colleagues argue in their most recent report on this issue:

In all, incapacity claimants account for 2.7 million non-employed adults of working age. This is three times more than the number of claimant unemployed. It is also nearly three times more than the number of lone parents claiming income support' (Beatty et al. 2007: 10).

As Bartley and colleagues have commented:

The perception of oneself as having a limiting illness… may be a combination of the effect of underlying ill-health and the availability or non-availability of central social roles such as employment as the "breadwinner". So the heavy concentration of LLTI in certain areas may be explainable in terms of the shifting availability of such roles to men who are also at high risk of disease (Gleave et al 1997: 21).

This analysis seems to me to begin to make sense of what we are looking at when we consider LLTI and incapacity. However, the autobiographical comment from Robert Cornwall seems to be saying something more than this. The power of the extract from Cornwall's research lies in the way in which it combines a simple, factual and precise narrative of events with a strong sense of what Max Weber called *verstehen*: that is, the meaning of action from the actor's point of view. Cornwall's account conveys what the events mean and what consequences they are likely to have. In reading this narrative fragment, you do indeed get the feeling of looking through a window opening onto the social reality of those '…rapidly growing ranks of the economically inactive'. However, what is seen through the window is not self-evident, and requires considerable interpretation. There is some subtlety to the point being made. You would of course expect economic inactivity to be higher following redundancy in areas in which there are fewer appropriate opportunities for work. However, Robert Cornwall is also conveying something else: that the *relationship* of these men to their work and the manner in which the work was taken away from them are also partly responsible for subsequent long-term economic inactivity. The sense of loss of meaning and respect, and impending hardship are palpable.

Let me give you another example of this sense of loss, and the way in which it affects more than the immediate workforce. Following a major strategic review in February 2001, Corus the steel makers announced that they were going to restructure their enterprise and activities in Wales. The company had 64,900 employees at the end of 2000, with approximately 33,000 of those employed in the UK, and almost 11,000 of them working in Wales. The main element of the restructuring was the announcement of the closure of the well-known Ebbw Vale steelworks. Most of the Corus jobs were those of full-time, relatively well-paid men (£26,000 per annum on average, at 2001 prices), occupying posts that encompass a wide range of skills. Contrary to popular impression, many – possibly most – of the job losses occurred amongst men aged between 30 and 50, with long-term domestic responsibilities and financial commitments. Most of these ex-steel workers would have found it very difficult to transfer to similar jobs with comparable levels of remuneration. Moreover, the loss of the wages of the steel workers was sharply felt throughout the local economy.

As part of a rapid analysis of the impact of the announcement of steelwork closure, during 2001 we interviewed a small number of people working in the towns and villages within the local authority area of Blaenau Gwent close to the Ebbw Vale steelworks. They comprised health professionals, church ministers, welfare officers, and other 'key informants', and were asked about what they thought was going to happen to the area. Here are two community psychiatric nurses:

> The deterioration in Blaenau Gwent has been on-going for many years… [But] this has been a big blow for the community because this has been a steel working community for years. This is just the final nail in the coffin…
>
> [Closure] has always been a threat. My father-in-law worked there in the 1930s. He said they always said that it was going to shut and it never has. And so they automatically think that it is never going to happen…it's always been said but it's never happened.   [Now] I think the community is a bit shocked.

These quotations illustrate the way in which, in one example of an area with high rates of poor health, the loss of the key driver of economic activity in the area was a shock not only to the largely male workforce, but also to the wider networks – both economic and social.

I have recently been re-reading the work of the late Peter Marris, particularly *Loss and Change*, which is one of my favourite sociology books, originally published in 1974, and his more recent 1996 book *The Politics of Uncertainty*. Peter Marris died in June this year, and on reading the newspaper obituaries I wrote a brief appreciation of him (Williams 2007). In *Loss and Change*, Marris writes about slum clearance as a kind of bereavement. He asks:

> What makes slum clearance a kind of bereavement? Even in the West End of Boston, some families were glad of the opportunity to move. Once the sickness for the old home has worn off, people may become equally attached to their new surroundings. The reactions to clearance run all the way from eagerness to escape through transient nostalgia to lasting grief.   If we can understand a change of home, like bereavement, as a potential disruption of the meaning of life, we may be able to see more clearly who will suffer grief, and what might help them to retrieve a sense of purpose. (Marris 1974:44)

The words seem to come from a much more gentle and hopeful time. However, it seems to me that the data to which I have referred above illustrate a very similar process, affecting not only the individuals losing their jobs, but the texture and living structure of entire communities.

The impact of the loss of employment in coal and steel, and the manner in which it was handled by both national governments and local agencies had a huge impact on the people who lost their jobs and on the wider networks, communities, societies and economies in which they lived. In research undertaken by Huw Beynon and his colleagues, comparing the impact of colliery closure in different coalfields, they make a number of important points, nicely encapsulated in the following Durkheimian proposition:

> [In South Wales] this was not just a case of localised economic decline but rather one of cultural crisis. The collapse of coalmining undermined a range of mechanisms of social regulation that were grounded in the politics of the workplace and the trades unions, but spread more widely into local society and politics. There was an acute sense of loss in places in which coalmines closed after decades of existence. This was typically accompanied by a period of grieving as people in these places tried to come to terms with the manifold implications of the precipitate ending of the economic raison d'être of their place. (Bennet et al. 2000: 12)

It is perhaps not surprising that according to data from the Department of Work and Pensions, by the mid-1990s the main underlying diagnostic reasons for incapacity claims had shifted. Up until that period it had been 'musculo-skeletal conditions'. Since then it has been 'mental health conditions'. By 2003, 44 percent of incapacity benefit recipients were diagnosed as having some kind of mental health problem.

If we take Marris' line of argument, the collapse of the communities in question has contained some kind of process that could be described in terms of bereavement. However, I prefer to think of this in what I am calling psycho-material terms. That is to say while psycho-social processes are *part* of the explanation, there is a material or economic base to it – if I can use some old Marxist language. For example, the loss of incomes in these post-industrial communities has had a real and direct effect on levels of poverty and on the possibility of economic renewal.

Labour Aristocracy and Lumpenproletariat

I now want to own up to the fact that although I was very proud of my short title for this lecture, there has been an absolutely brilliant long title just waiting to burst out: From 'Labour Aristocracy' to 'Lumpenproletariat': reflections on the social determinants and social construction of incapacity and what to do about it.

What we have seen over the last couple of decades is the creation of large areas of labour market disadvantage and social exclusion. Global economic restructuring has transformed many previously high-skilled, well organized aristocracies of labour into the disillusioned and disrespected communities of the 'New Poor', with little to do and even less reason for doing it. Karl Marx and Frederick Engels depicted the lumpenproletariat as 'the refuse of all classes'; they are, and I quote from a famous passage:

> …the scum of the depraved elements of all classes ... decayed roués, vagabonds, discharged soldiers, discharged jailbirds, escaped galley slaves, swindlers, mountebanks, lazzaroni, pickpockets, tricksters, gamblers, brothel keepers, tinkers, beggars, the dangerous class, the social scum, that passively rotting mass thrown off by the lowest layers of the old society. (Marx and Engels 1967: 92)

This savage litany contains many interesting terms of abuse, some of which are unfamiliar, while others like 'scum' are still in popular use. Indeed, the recently elected President of the French Republic, Nicolas Sarkozy used the French equivalent 'racaille' to describe the citizens of the Parisian banlieues just prior to the riots of 2005. Conspicuous by its absence from Marx's list however is any term of abuse to described disabled people, possibly because they only became visible as a distinctive group with the creation of the welfare state. More recent characterisations of 'the underclass' or the 'New Poor', which developed to an hysterical peak in the 1980s and 1990s, would probably include people on incapacity benefit as 'the passive poor', and the passive poor clearly have no place in the relentlessly and breathlessly active society being engineered by New Labour.

What I hope I have begun to illustrate in this lecture – and I realise that the hard work of research and scholarship has to be undertaken - is the close relationship between patterns of LLTI and incapacity, and changes in labour markets. These economic changes are important for many reasons: the personal loss and community disruption to which they give rise, the politically-driven movement of people on and off different kinds of benefit, the victim-blaming and individualised explanations of economic inactivity, the emphasis on flexibility rather than the virtuous continuity of a particular skill or trade, and the 'spectre of uselessness' which haunts this historical experience (Sennett 2006). It is interesting how quickly the massive contribution of these now stigmatised communities to Welsh, British and global capitalism can be forgotten, and how any attempt to understand their contemporary predicament in historical terms is pushed to one side by the false positivism of evidence-based

policy.

It seems to me that there are opportunities here for an historically-informed sociology of work and non-work related ill-health. The complex patterns of long-term illness and incapacity in localities of the kind I have described are the product of the interaction of a number of processes: a long-term legacy of working class hardship, the political destruction of the economic base in which those working class lives had been rooted, the impact of this on what is nowadays referred to as the 'resilience' of once robust communities and ways of life, the growth of poverty in those communities and inequality in relation to other communities nearby, and the modernisation of the welfare state into one which seeks to place people in work of any kind, however time-limited, insecure, low paid, disrespectful and purposeless it may be. Any research of this kind would need to move beyond the caricatures of 'hard' positivist epidemiology and 'soft' interpretivist sociology. More than ever these methodological dichotomies get in the way of our using the full range of intellectual resources available to us to broaden our understanding - including the intellectual resources of those people and places whose living structures have been turned upside down.

References

Beatty, C., Fothergill, S., Gore, T. and Green, A. (2002) *The Real Level of Unemployment 2002*, Centre for Regional Social and Economic Research, Sheffield Hallam University.

Beatty, C., Fothergill, S., Gore, T. and Herrington, A. (1997) *The Real Level of Unemployment*, Centre for Regional, Social and Economic Research, Sheffield Hallam University.

Beatty, C., Fothergill, S., Gore, T. and Powell, R. (2007) *The Real Level of Unemployment, 2007*, Centre for Regional Social and Economic Research, Sheffield Hallam University.

Bennet, K., Beynon, H. and Hudson, R. (2000) *Coalfields Regeneration*. York: Rowntree,

Berry, R. (1998) *History is What You Live*. Llandysul: Gomer.

Cornwall, R. (2007) *Learning, Soft Skills and Community Regeneration: a Case Study Analysis*, unpublished PhD Thesis, Cardiff University.

Davies, J. (1994) *A History of Wales*. Harmondsworth: Penguin, 1994

Gleave, S., Bartley, M. and Wiggins, R.D (1997) 'Limiting long term illness: a question of where you live or who you are? A multilevel analysis of the 1971-1991 ONS Longitudinal Study', paper presented at the APHA Conference, Indianapolis, November 9-13, 1997

Jones, R. Merfyn (1981) *The North Wales Quarrymen, 1874-1922*. University of Wales Press.

Marris, P. (1974) *Loss and Change*, London: RKP.

Marx, K. and Engels, F. (1967) *The Communist Manfesto,* trans. Samuel Moore and Engels. Harmondsworth: Penguin Books.

Morris, J. (1986) *The Matter of Wales*. Harmondsworth: Penguin, 1986

Osbourne, Peter (2002) 'Who inspired Thatcher's most damaging remark?', *The Spectator*, 24 August

Rees, D. Ben (2007) 'The Liverpool Welsh', BBC Homepage, March 2007 http://www.bbc.co.uk/wales/northeast/sites/history/pages/liverpool.shtml

Salway S., Platt, L., Chowbey, P., Harriss, K. and Bayliss, E. (2007) *Long-term ill-health, poverty and ethnicity: a mixed methods investigation into the experiences of living with a chronic health condition in the UK.* The Policy Press: Bristol

Sennett, R. (2006) *The Culture of the New Capitalism.* New Haven/London: Yale University Press.

Thatcher, M. (1995) *The Downing Street Years*. London: Harper Collins.

Waddell, G. and Aylward, M. (2005) *The Scientific and Conceptual Basis of Incapacity Benefits*, London: TSO.

Walker, R. and Wiseman, M. (2003) Making welfare work: UK activation policies under *New* Labour, *International Social Security Review*, 56(1): 3-29.

Williams, G. (1984) The genesis of chronic illness: narrative reconstruction, *Sociology of Health and Illness*, 6: 175-200.

Williams, G. (2007) 'Peter Marris: an appreciation', *Medical Sociology Online*, Spring 2007.

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Windows on suffering: sociological perspectives on end of life care

Plenary Address to Annual BSA Medical Sociology Group Conference, Liverpool, 8th September 2007

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ABSTRACT

Competing tensions towards and away from medicine underpin the complex phenomenology of living towards the end of life, shaping the 'co experience' of suffering among all those facing death. This paper explores three relatively neglected themes in the sociological study of death and dying: firstly, some insights relating to the shift that has occurred in relation to the cultural and social construction of suffering and death through the application of medical technologies. Secondly, picking up the theme of 'resistance' to medicine, attention turns to a trend in which the solution to suffering is increasingly seen as the exercise of rational autonomous control or 'choice' over the manner and timing of death. Thirdly, attention turns some critical questions relating to the organisation and delivery of care to older people who are reaching the end of their lives, who may be frail and disabled, but who are not clearly 'dying'. This has resulted not only in a general lack of awareness or concern about the needs of older people living towards the end of life but also paradoxically, a culturally nihilistic assumption that the last stages of life in late old age are a 'living death' devoid of dignity or value.

The experience of suffering is universal across time and cultures, and reminds us of our human vulnerability, and the fact that one day we all must face dissolution through death. There is a long tradition of philosophical and sociological perspectives on death and dying,

with many proposing that our shared awareness of our inevitable mortality, and by implication the possibility of suffering, is the key factor in how we construct the very fabric of society, how we understand what it means to be human and how we negotiate the business of living (Clark and Seymour, 1999). Since the Second World War, a rich field of scholarship in the sociology of death and dying has emerged (see for example, Howarth, 2007; Kellehear, 2007), which has been tightly related to the medicalisation critique (Illich, 1976). The 'wild death' depicted in the famous historiography of Phillipe Ariès (1974; 1981), in which the newly medicalised death is the icon of the unnatural death, is perhaps the most famous of these. I observed some years ago (Seymour, 1999) that within this and other similar analyses, there tends to be a taken for granted polarisation of technology and 'natural' death to the extent that 'naive romanticised notions' (Timmermans, 1998:162) of dying in pre-technological societies still hold considerable thrall over the representation of death. These have led to a lack of attention to the ways in which competing tensions towards and away from medicine have become a central aspect of all illness and death related experiences. As Frank has noted, drawing on Kleinman's notion of 'resistance' to suffering: 'high tech medicine offers real hopes, [but] resistance to 'dying on a machine' is itself resisted by wanting what that machine might offer' (Frank, 1995: 174). This dialectical relationship to medicine underpins the complex phenomenology of living towards the end of life, shaping the 'co experience' of suffering (Frank, 2004: 104) among all those facing death: whether these are persons likely to die or those charged with the responsibility to provide care and make decisions which may either hasten, arrest or reverse the dying process.

In his study of suffering, the physician Eric Cassell argues that suffering as experienced by persons, occurs when an impending destruction of the person is perceived and continues until the integrity of the person can be restored in some manner (Cassell, 2004: 32). Insights into how the suffering of persons is socially and culturally shaped are vividly portrayed in a book on living and dying with dementia by Neil Small and colleagues (Small et al, forthcoming), where they posit that the essential challenge of end of life care in the late modern world is to attend to the life world of suffering while working within an ever more complex systems world (Habermas, 1987)[1]. The latter threatens divergence from the concerns of the life word and understandings among not only those who face death and their companions but also the foot soldiers who care on a daily basis for dying people: health and social care staff. In this lecture, I explore the interaction between the phenomenology of suffering and three aspects of the systems world which constrain and shape the experiences of persons who suffer, and within which they, in their turn, work together to create an endless variety of meaning.

Firstly, I explore some sociological insights relating to what Margaret Lock (1996: 209) has referred to as the 'paradigm shift' that has occurred in relation to the cultural and social construction of suffering and death through the application of medical technologies. This shift is characterised by profound questions about the management of illness and of the body, the identity of the person who is dying and the procurement, timing and very definition of death.

Secondly, picking up the theme of 'resistance' to medicine, my attention turns to a trend

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[1] This is a point also made by Howarth (2007).

in mainstream policy and public debate relating to end of life care in the developed world, in which the solution to suffering is increasingly seen as the exercise of rational autonomous control or 'choice' over the manner and timing of death. Drawing on some of the debates surrounding the 'right to die' as one manifestation of this, I argue that the promotion of 'control' and 'choice' poorly represents the complexity of clinical actions at the end of life and has created a barrier to developing a more nuanced understanding of ethical and moral dilemmas in end of life decision making.

Thirdly, my attention turns to some critical questions that have arisen relating to the organisation and delivery of care to older people who are reaching the end of their lives, who may be frail and disabled, but who are not clearly 'dying'. Receiving a medical diagnosis of dying, one of the primary characteristics of the 'status passage' towards death (Field, 1996), as a result of chronic disease is perhaps less likely now than at any time hitherto, but remains the basis on which existing palliative and end of life care services are organised. This has resulted not only in a general lack of awareness or concern about the needs of older people living towards the end of life but also paradoxically, a culturally nihilistic assumption that the last stages of life in late old age are a 'living death' devoid of dignity or value (Kellehear, 2007).

Technology and death: a paradigm shift

In the developed world, even when it is recognized that death is a likely outcome of disease or injury, widespread access to life-support technologies, defined as those drugs, medical devices and medical and nursing procedures that keep individuals alive who would otherwise die within a foreseeable, but usually uncertain period of time (Office of Technology Assessment, 1987), may radically transform the life expectancy of some potentially dying people from the few days or weeks usually associated with a terminal disease to the several months or years more often associated with a chronic disease (Jennett, 1995).

With this shift has come an enduring uncertainty surrounding the status of persons as dying or not; with related questions about the application, withdrawal or withholding of life-supporting interventions, and arguments about the best and most morally 'correct' way in which to make end of life decisions and to break the news that dying may be inevitable, giving rise to intense debate and ethical conjecture. Available evidence suggests that there is much to do before we are in a position to manage the Pandora's Box of new medical technologies in a way that ensures that the last stage of life is of a better quality for those who die and those who are bereaved.

For example, a report[2] released in the UK a few months ago, which analysed 16, 000 complaints to the Healthcare Commission: the NHS watchdog in England, over a two year period, found that more than half of complaints from bereaved families about hospital treatment were about end of life care. Of these, most centred on failures perceived in relation to communication and degree of 'preparedness' for the death. Over the last decade or so, research evidence painting a similar picture has emerged from many other developed

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[2] http://www.healthcarecommission.org.uk/_db/_documents/spotlight_on_complaints.pdf accessed May 15th, 2007

countries. Amongst the largest and most frequently cited is the US SUPPORT study, which found that among a large sample of patients who were recognised to be at high risk of dying, 50% of DNR orders were written in the last two days of life and more than one third of patients spent their last days in ICU (SUPPORT Principal Investigators, 1995). A rich but comparatively small body of sociological research conducted since the early 1950s sheds light on how ill persons, their companions and clinical staff, encounter and negotiate these problems. I turn now to look at some examples of these.

In 1959 the young sociologist Renee Fox (Fox, 1959) published a book, which arguably is one of the first participant observation studies of a highly technological clinical environment. Fox takes us into the world of the eleven physicians turned researchers of a 'cutting edge' Metabolic Group and their patients, all of who had renal or adrenal insufficiency, on ward F Second in a North American hospital. This was at a time when the development of steroids and their clinical application, together with surgical techniques for renal and adrenal disease, were in their infancy. Fox explains how she was concerned to portray:

> ...the various problems these physicians and patients encountered in this setting; some of the stresses they experienced and some observed consequences of the ways of coming to terms they evolved (Fox, 1959: 14).

What were then entirely radical and experimental techniques, such as adrenalectomy, haemodialysis and renal transplant - were attempted only on patients who were *'acutely, seriously and often terminally ill'* (Fox 1959: 18). Fox describes how the patients and their physicians developed shared ways of coping with, and giving meaning to what for most patients was certain future death although at an uncertain time (Glaser and Strauss, 1965:16). This was achieved through the creation of companionship, intimacy and trust between them, by seeing each other as professional partners in a research process, and perhaps most of all by generating together what she calls 'grim' humour about the very thing that most troubled or disturbed them: the prospect of dying. Sometimes this was exchanged between patients and physicians, but most often it was expressed privately from one patient to another, or from one doctor to another:

> Dr D: Mr Goss is still alive.
> Dr S: Is he putting out urine?
> Dr D: No.
> Dr S: Is he having hemodialysis?
> Dr D: No.
> Dr S: Then how is he still alive? (Laughter)
> (Fox, 1959: 78).
>
> Mr M: On this ward we have what you might call a rotating population- the same guys coming in
>   and out all the time….
> Mr O: Yeah, but a lot of them never come back. They go to Heaven instead!
> (Fox, 1959: 174)

Fox's study, while not focused explicitly on death, was one of the first examining how the potentially disruptive threat of death and dying to persons is managed in daily social interaction in a clinical setting, and in the new context of the emergent innovative health technologies that were subsequently to change the face of disease management. Her monograph can be seen as study of how suffering is contained by the remaking of persons. In

her words:

> [the] F Seconders were proud of the ward community to which they belonged and which they had helped to create. Many of them felt that the kind of 'oneness' and 'concern for the welfare of others' that characterized their ward made it morally superior in some ways from the 'world of wellness' from which they had been removed. This conviction gave them some compensation for the enforced exemption and isolation from....the outside world. (Fox, 1959: 141).

Further insights into the transformation of persons followed in a series of seminal studies in the 60s, 70s and 80s (Glaser and Strauss, 1965; 1967; Sudnow, 1967; Quint, 1967; Field, 1989; Peräkylä, 1991), which were explicitly focused on the consequences of uncertainty produced by new medical technologies for probably dying patients and those that cared for them. The most famous of these was conducted by Barney Glaser and Anselm Strauss, who described the interactions between staff and patients in six hospitals in San Francisco. They introduced the concept of 'awareness': '*Who in the dying situation, knows what about the probabilities of death for the dying patient'* (1965: ix) and identified different "patterns" of dying - sudden death, lingering, certain to die on time, and the vacillating pattern. Their focus was on expectations of when a patient would die and communication among hospital staff, patients, and families regarding such expectations. Since the 1980s, the central problem associated with high technology care is not so much to transform the personhood of sentient patients through bringing them to awareness as they face the finality of death, but rather to understand how to remake persons in situations where the boundaries between life and death are blurred and uncertain (Kaufman, 2005) and the conscious self can play no part in proceedings. To this extent, the notion of awareness, far from being a central consideration in the negotiation of end of life care, becomes largely an irrelevance. In the UK, one of the most pivotal cases that led to a fundamental review of end of life decision-making was that of Tony Bland[3] who was fatally injured in the Hillsborough disaster of 1989. It is perhaps fitting, here in Liverpool, to briefly reflect on the significance of his tragic case. Bland was 19 years old when he was crushed at Hillsborough; he remained in a persistent vegetative state until 1994 when, at the request of his parents and following a prolonged legal battle, his feeding tube was withdrawn and he died.

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[3] Since April 15, 1989, Anthony Bland has been in persistent vegetative state. He lies in Airedale General Hospital in Keighley, fed liquid food by a pump through a tube passing through his nose and down the back of his throat into the stomach. His bladder is emptied through a catheter inserted through his penis, which from time to time has caused infections requiring dressing and antibiotic treatment. His stiffened joints have caused his limbs to be rigidly contracted so that his arms are tightly flexed across his chest and his legs unnaturally contorted. Reflex movements in the throat cause him to vomit and dribble. Of all this, and the presence of members of his family who take turns to visit him, Anthony Bland has no consciousness at all. The parts of his brain which provided him with consciousness have turned to fluid. The darkness and oblivion which descended at Hillsborough will never depart. His body is alive, but he has no life in the sense that even the most pitifully handicapped but conscious human being has a life. But the advances of modern medicine permit him to be kept in this state for years, even perhaps for decades.

Extract from Airedale NHS Trust v. Bland (C.A.), 19 February 1993, 2 Weekly Law Reports, p. 350, of Hoffman's description of Bland. Cited in Singer 1994: 58)

The case of Anthony Bland pushed forward the establishment of a House of Lords Select Committee on Medical Ethics, which reported in 1994. The committee ruled that Bland's death was a case of 'double-effect' in which death was an unintended, although not unforeseen, consequence of the removal of futile life-prolonging medical therapy (House of Lords, 1994). This judgement on the Bland case led to a clarification of the distinction between 'killing' and 'letting die', with the recommendation made that where death is inevitable, then life-prolonging treatments such as resuscitation, artificial ventilation, dialysis, artificial nutrition and hydration can be withdrawn or withheld, and the goal of medicine redirected to the palliation of symptoms and the provision of 'basic care' and comfort, which are mandatory (British Medical Association, 2007). In the media debates about Bland, we were bombarded with images of what might have been had his life not been so cruelly foreshortened by his accident: pictures of him as a healthy young man with his life before him were juxtaposed to descriptions of the apparently empty shell of his body around which his family kept vigil as the legal wheels which led to his eventual death turned.

Tony Bland's situation resonated with Kastenbaum's (1969) depiction of 'phenomenological death' in which seriously ill people are: '... being kept alive by heroic measures with no indication that *the person* inside the body continues to exist' (Sweeting and Gilhooly 1992: 255, my emphasis). Indeed, Bland was an exemplar of a new kind of person: one neither fully alive nor yet dead. Like the case of Karen Quinlan who died years earlier in the US and the much more recent case of Terry Schiavo, Bland was an exemplar par excellence of a paradigm shift in which medical technology was constitutive of new forms of existence, in which death became a matter of intense deliberation over the withdrawal or cessation of particular types of technology and where the notion of a 'living bereavement' became a feared dimension of the 'bad' death.

An important perspective on the dilemma of 'phenomenological death' comes from Sharon Kaufman in her brilliant ethnography of dying in America (2005). Kaufman argues that with new health technologies have come a 'zone of indistinction' between 'health, awareness, function and viable *life* on the one hand, and 'no longer a person', 'death in life' or '*death*' on the other' (2005: 62). For Kaufman, the primary dilemma for clinical staff and patients' companions is to negotiate a course of action to rescue those who are neither dead or alive by straddling on the one hand, the imperatives of rational medical science, and on the other, bioethics, the senses of human compassion, loss and co- suffering.

In my ethnography of the intensive care unit (Seymour, 2001), which took the form of 14 patient case studies followed over time, I paid special attention to the difficulties facing nurses as they tried to construct the 'good death' in the technological environment of the ICU while caught between these two polarities later identified by Kaufman. I observed how nurses struggled during the period of time between the cessation of active treatment and the emergence of a consensus agreement that a patient is now dying, and needs 'nursing care only'. What nurses tried to achieve during this time was the alignment of 'body work' with 'emotional work'. Where this was successful, it allowed the nurse to reproduce the patient's personhood and relocate death from the biomedical sphere to the arena of emotions and familial intimacy. However, in some situations, it was almost impossible for nurses to achieve this because of problems with the decision making process at the end of life. For some critically ill individuals, medical treatment was finally withdrawn moments before their death. In such cases bodily death had usually begun to occur before an agreement had been reached that the person was dying in a technical sense, i.e. informed by technical - medical data. In other cases, the trajectory of bodily death lagged behind the removal of medical treatment and attention.

These issues emerged particularly clearly in the case of 'Richard Morgan', a young man who had been fatally injured in a motorbike accident. Perhaps because of his youth, the assembly of a case to establish 'technical dying' took many days. When Richard was finally defined as 'technically' dying, 'bodily death' had already started to occur but was held at bay by the complex drug therapy, ventilation and circulatory support the young man was receiving. This is deeply disturbing for the nurse who was looking after him on that day. She described later how:

> ... we had to continue making up all his drips, washing him and cleaning, just doing the usual care that you give to other patients but I knew by looking at him, ... it was like 'Why am I doing this?' I knew I was doing it because they hadn't decided to withdraw but I just wanted to get someone in to look at him and say to them: 'How would you like your relative to look like this?' and: 'You're doing all this treatment but you're not doing anything. (from follow up interview)

In Richard's case, the dissonance between the requirement to care for his 'already dead' body and quintessential nursing ideology of 'whole person' seems to be solved by an attribution to Richard of particular personal qualities. Thus it becomes possible for the nurse to describe him as 'fighting', as 'still living' and later:

> ... he was strong and trying to say: 'I'm not giving up' although his body was saying: 'You can't survive with this,' I felt his heart and his brain was fighting everything. (from follow up interview)

In this way, this particular nurse achieved a sense of meaning in her nursing work, albeit at considerable personal cost. She recalled how his image remained in her mind long after his death:

> I: Does that memory stick out more in your mind than say, some other patients that you've looked after in the previous 2 years 9 months? [length of time she had worked in intensive care].
>
> Nurse: Yes, Richard, really, I was - - erm - - I couldn't stop thinking about him. I can still see him.
>
> (from follow up interview)

She later goes onto recall that Richard's family were 'devastated' by the eventual formal news given to them by the Consultant of Richard's imminent death, which occurred just a few minutes after drug therapy was withdrawn. She believes that the family misconstrued the activities around Richard as a sign of continuing hope of recovery.

In my conclusions to this study I argued that:

> In many ways the healthcare staff within intensive care carry an awesome responsibility to match, or counter, the pervasive [cultural] images of 'intensive care' that are represented in the media and absorbed by the rest of us. These are images that include not only the 'best' of medical care, that which is relied on in crisis and fear of acute illness when rapid competent action is needed to restore life; but also the worst of medical care: the medical or technical mistake, the exclusion of humanity and individual control. Further, intensive care is at the apex of a system of hospital organisation that is increasingly specialised and isolated. Such a system …is poorly suited to providing a comprehensive, co-ordinated or multi-disciplinary response to the needs of an increasingly elderly, socially disadvantaged and chronically ill population. (Seymour, 2001: 158)

I turn now to look at the pursuit of individual control as a solution to the paradigm shift in the uses of medical technology, before moving to examine the experience of living in the last stage of life death among older people: the majority of those who die.

Doing it my way[4]

Early hospice and palliative care in the UK involved the application of an Askelepian approach to end of life care: the empathic understanding of the suffering of the person for whom one is caring and the creation, through accompaniment, of a safe and secure environment in which it becomes possible for the dying person's relationships with self and others to be strengthened or restored (Kearney, 2000; Seymour et al, 2005a).

Parallel developments in the USA took a different form, reflecting the earlier preoccupation with individualism in that country (Field, 1996). Kübler Ross's description of *'Death: the final stage of growth'* (1975) perhaps best captures the voice of the hospice movement as it developed in the USA, in which psychological preparation for death was enhanced by a 'sharing of knowledge' (1975:32) with dying people and their companions. The 'right to be heard' (1975:7) was promoted by Kübler-Ross as the cornerstone of the reclaiming of death. The gradual merging of these various strands from either side of the Atlantic and their percolation into professional and public consciousness gave new meaning to the concept of 'ritual dying' (Williams, 1990: 121). This in turn gradually encouraged the institutionalization of a 'revivalist' and post-modern version of the 'good death' in which the authority of the individual intertwines not only with the expanding authority of the expert into areas of emotional and spiritual life previously regarded as outside the professional orbit, but also with essentially romantic notions of community and home as the best places in which to be cared for and to die (Walter, 1994: 41).

In the last ten years, particularly in the UK, it is this aspect of the philosophy of palliative and hospice movement that has been mainstreamed and promoted in health policy but, in keeping with trends in other aspects of healthcare, remolded and transformed yet again so that understandings of the 'good death' have become little more than a shallow caricature of the original rich vision of the hospice founders. Now, a person facing death is ideally a knowledgeable consumer, and end of life care a menu of choices or 'wishes' to be selected according to one's preferences. The highly publicized framework of the 'good death' produced by Age Concern (Age Concern, 1999) is a prime example of this, and has been followed by a plethora of policy statements and new legislation in which 'choice' and 'control' during end of life care feature prominently. One example is the Mental Capacity Act (Department of Constitutional Affairs, 2005), which creates provisions for antecedent control (Dworkin, 1983; Rich, 2002) through the device of an advance decision to refuse life prolonging medical treatment (colloquially known as a 'living will'). As Sanders et al observe (Sanders at el, forthcoming), this has been actively promoted in the 'Expert Patients' Programme' with little or no critical consideration of the impact such notions may have on

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[4] Tony Walter uses this phrase as a title for Part 1 of his book, the *'Revival of Death'*, which was published in 1994.

participants' individual ways of coping with illness.

Ironically, given a long standing opposition among promoters of palliative care to the legalization of euthanasia, or assisted suicide[5], with the contemporary emphasis on 'choice' the hospice and palliative care movement has moved into the same discursive territory as those who argue that the painless and 'easy' death is a fundamental expression of an inalienable human right to self-determination[6]. In one of the few sociological analyses of these trends, Howarth and Jefferys observed some years ago that 'the current debate on euthanasia is at least partly about agency, about who does and who should control the decisions to hasten or procure death' (1996: 381). The implication is that those who take a strongly pro-euthanasia stance see it as protecting patients' rights against the decision making power of the medical profession. However, recent evidence suggests that the picture is much more complex than this[7].

In a primarily bioethical analysis of euthanasia practice in the Netherlands, Henk ten Have (2005) has argued that in the daily practice of clinical work with the dying the primary justification of end of life decisions seems to turn upon the relief of suffering according to the judgement of the physician rather than being directed primarily by matters of 'autonomy' or 'patient choice'. Ten Have observes that in the Netherlands, only a minority of requests (approximately one third) for euthanasia are carried out and that also physician assisted suicide (requiring the patient to commit the act which ends their life) is much less common than euthanasia. Of the 4,700 cases of euthanasia committed in 2001 (van der Wal et al. 2003), 900 or almost one fifth, were without the patient's request. ten Have (2005) argues that these figures suggest that in relation to euthanasia in clinical practice 'two moral considerations compete with each other: respect for autonomy and relief from suffering' (2005: 157). However, the latter is often the prime motive underlying the practice of ending life.

One perspective, which focuses on the attempts of clinicians to resolve deeply entrenched and competing tensions towards and away from the role of medicine in end of life care, comes from a study in which I was involved during 2003/ 4. My colleagues and I studied how, since the legalisation of euthanasia in 2002, the practice of 'palliative sedation' has emerged as a possible alternative to euthanasia in the Netherlands, and compared this to trends in the UK and Belgium (Seymour et al, 2007). Palliative sedation, when successful, mimics a death

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[5] Euthanasia is killing on request and is defined as: a doctor intentionally killing a person by the administration of drugs at that person's voluntary and competent request' (Materstvedt, L.J., Clark, D., Ellershaw, J. *et al.* (2003) Euthanasia and physician assisted suicide: a view from an EAPC Ethics Task Force. *Palliative Medicine*, 17(2): 97–101. p98). Physician assisted suicide is defined as: a doctor intentionally helping a person to commit suicide by providing drugs for self administration, at that person's voluntary and competent request (Matersvedt et al., 2003: 98).

[6] Strong arguments are emerging in the field of bioethics which point to the paradox of arguing for euthanasia on the grounds of autonomy, when receiving euthanasia eliminates any future exercise of autonomy.

[7] In the last decade or so, there has been 'Natural Death' legislation enacted in the state of Oregon in the USA and the legalisation of voluntary euthanasia in the Netherlands, Belgium and, albeit temporarily, the Northern Territory of Australia. In the UK, both euthanasia and physician assisted suicide are illegal although subject to a periodic policy review in the UK, most recently in 2005.

occurring in deep sleep: one version of the good or 'natural' death, which is popular in the developed world (Elias, 1985). We found that in the Netherlands, palliative sedation was a recently discovered possibility that was assuming the status of a 'third way' between the polarised pro- and anti euthanasia stances of the past. Where previously euthanasia was seen as the use of medical techniques to service self determination, questions were beginning to be posed about whether, in some circumstances, death procured though euthanasia may signify precisely the opposite: an undermining of self determination because patients have had a restricted range of options. One source of evidence about this that was discussed was a Dutch 2001 newspaper article entitled '*Regret'* (Oostveen, 2001) in which some doctors spoke about cases of euthanasia they had committed and reflected retrospectively on other possibilities, including palliative sedation, that had since become known.

Key dilemmas in the euthanasia debate relate to whose interpretation of suffering takes precedence, the perceived lack of middle pathways between the discourses of 'cure or kill' (Seymour, 2007:118), and a lack of equality of access to the resources that might ensure quality of life, even in the face of great impairment. For some groups of people, this can give rise to very great fears of discrimination and exclusion from good care. In his discussion of how the disability rights movement has engaged with this issue, Shakespeare draws attention to how these themes coalesce in the concerns of people with disabilities, quoting the reflections of Ed Roberts, a US disability activist, on his situation:

> I've been on a respirator for twenty-six years, and I watch these people's cases. They're just as dependent on a respirator as I am. The major difference is that they know they are going to be forced to live in a nursing home-or they're already there- and I'm leading a quality of life. That's the only difference. It's not the respirator. It's the money. (Quoted in Shakespeare, 2007: 124).

Shakespeare points out that, for many people with disabilities, the euthanasia debate gives out implicit messages that their lives may be inferior to those of others, while the oft used strap line of the right to die movement -'death with dignity' - sends out messages that those who are dependent on others for assistance or care can perhaps only achieve dignity in death (Shakespeare, 2007: 123).

Living towards the end of life: understanding dying in older age

While Shakespeare's focus is on disabled people, many of his observations apply to the situation of older people: the group who die most commonly. There are several dimensions to this.

Firstly, as Field has observed, receiving a medical diagnosis of dying, one of the primary characteristics of the 'status passage' towards death (Field, 1996), as a result of chronic disease in older age- the primary route to death for us all- is perhaps less likely now than at any time hitherto. It is a paradox therefore that it remains the case that the label of 'dying' is often necessary to open the door to service provision. Yet among many older people, especially those who survive to late old age, there may be no definable moment at which 'dying' commences, and the complex factors that lead to death can only be understood retrospectively (Lloyd, 2004). As a result, increasingly it is older people who constitute the majority of those who exist betwixt and between life and death in critical care units and other acute hospital care environments.

Secondly, in the UK, evidence has been accumulating since the early 1970s which suggests that the experience of living in the last year of life for older of people and their carers

is marked by extreme disadvantage in terms of health and social care provision, particularly specialist palliative care (Grande et al., 1998). These result on the one hand from ageist stereotypes that dominated in the twentieth century and which, are only now coming under sustained critique (Seymour et al, 2005b) and on the other, from entrenched disease focused models of palliative care service delivery. Whilst the latter have served the needs of cancer patients well, they have probably been detrimental to the imaginative design of services to meet the complex intersection of health and social needs in the new circumstances in which the last year of life tends to be associated with 'problems caused by great old age and its troubles as well as any final illness' (Davies and Higginson, 2004).

As Liz Lloyd has observed in her essay on ageing and the ethics of care (Lloyd, 2004), we lack both the language and a set of policies that might adequately address the nature of social justice, or inform the sensitive delivery of care for those who are dependent upon others (2004: 236). Indeed, a preoccupation with independence in much of the policy literature obscures any meaningful debate about how to improve the quality of life of older people living towards the end of life. Most older people die in hospitals or care homes, where the provision of good quality end of life care is extremely hard to achieve in spite of the considerable efforts of hard-pressed staff. A complex range of factors have been identified as contributing this problem: the limitations of the physical environment, availability of basic equipment and the support and training of professional staff. The domestic home is often not an ideal alternative, with worries about dying alone, in pain and being a burden to others expressed in research studies relating to this issue (Gott et al, 2004; Clarke at al 2006). Early developments in extra care housing, and the beginnings of a discussion about how such environments may enable a better quality of living and dying for older people with their emphasis on independence and privacy, as well as security and support (Kaur, 2007) offer promise, and may hold the key to how we can ensure that older people are accompanied in the last phase of their lives without being infantilised (Lloyd, 2004: 242).

Thirdly, it is often assumed that the experience of illness and disability in late old age, especially when associated with a loss of cognition, is connected with a sense of a 'living death' both for the person themselves and for those providing care to them. This nihilistic view is portrayed in Kellehear's rather apocalyptic description of the inexorable rise of death in late old age as the 'shameful death' which occurs too late:

> …Taking so long to die when you are old so that you become confused, unmanageable and unrecognisable to friends or other professionals, are styles of dying that are both uncertain, ambiguous and a spoiled activity for all participants involved. Dying in the Cosmopolitan Age is increasingly tragic and antisocial. (Kellehear, 2007: 214)

This presentation of death in late old age seems to exclude serious consideration of other possible perspectives from older people themselves, and also falls into the trap of assuming that cognitive competence and bodily intactness are necessary attributes for an 'unspoiled' existence and a good death. Neither of these stands up well to empirical interrogation. For example, in one of my own studies, which included interviews with twelve older people over the age of 85, most communicated that their lives were enjoyable and highly valued in spite of sometimes considerable limitations. A highly developed awareness of the proximity of death often added value and enjoyment to life and was expressed by some in deeply spiritual or religious terms as a sense of connectedness with others and with the cosmos (Seymour, 2003).

More recently, Clarke and Warren (2007) have reported findings from a study of 23 older people aged 60-96 which suggest that even in the face of serious life limiting illness and the

knowledge that death can strike at any time, there are opportunities perceived for living, enjoying activities and looking forward to the future (Clarke and Warren, 2007). Moreover, while most of their respondents were aware that they could not influence the manner or timing of their deaths, many had planned their funerals or written wills which both enabled a sense of dignity and helped them to feel that they had helped those who would be left behind: their friends and family.

The death of an older person with dementia, particularly when it occurs in a care home, is posited by Kellehear (2007) as the archetypal 'shameful death' but again, empirical evidence seems to suggest that this is a simplistic depiction which, while probably accurately describing prevailing attitudes, does not adequately engage with the range of experience of people with dementia and those close to them, and forecloses on the possibility of conceptualising the situation of people with dementia in very different terms. For example, in their book on living and dying with dementia, Small et al (forthcoming) provide a number of moving cameos of relationships between people with advanced dementia and others surrounding them. These are not reliant on any residual cognitive ability of the person with dementia and, in spite a process of dying which is 'protracted, unglamorous and ordinary' (Small et al, forthcoming) hold the possibility of achieving a sense of accompaniment and connection in the face of sequential loss.

Concluding comments

In sharing with you some concerns and interests that have characterised both my clinical and academic careers, I am keenly aware that there have been many omissions in this lecture. For example, I have not talked about the challenges of end of life care in the resource poor countries of the world, nor have I addressed issues of bereavement and spiritual care. I have instead focused on issues that I perceive have been somewhat poorly served as subjects of sociological study. I have drawn attention to the ambiguities and dichotomies involved in the phenomenology of living towards the end of life in the new circumstances in which death tends to be an uncertain prospect, dying is commonly attended by technological intervention, and solutions to suffering are often framed as questions of choice, control and competence that resonate poorly with the realities of clinical care and the socially structured constraints placed around dying in older age: the commonest route to death for us all.

Sociologists have played a pivotal role in the critique of prevailing modes of managing death in the mid 20th century. Rich empirical studies of the experiences, dilemmas, hopes and fears of the dying and those who accompanied them have contributed to the emergence and development of the hospice and palliative care movement, which for many years has been a central point of reference of our expectations and hopes for care at the end of life. However, the promise of hospice and palliative care has never been fulfilled for the vast majority of those who die, and the problems posed by the rapidly changing demography of ageing and dying and the emergence of ever more complex innovative health technologies require new solutions.

In his masterly analysis of illness experience, Frank describes how, in the muddled times of postmodernity, illness, and the experience or fear of death linked to it, are associated with a variety of narratives:

> Restitution narratives attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to use it. (Frank, 1995: 115)

Arguably, two of these narrative forms are reflected in the major strands of existing sociological analyses of relevance to end of life care. For example, themes of restitution are present in the 'positive' ageing, independence and health promotion literature common in social gerontology, while themes of chaos have tended to be predominant in the anti technology and anti medicalisation literatures of the sociology of death and dying. But there has, to date, been little engagement with notions of a quest narrative in which new understandings and solutions might emerge for the challenges of end of life care in the 21st century that are neither a denial of death nor a simplistic critique of the medical management of the dying.

There are of course some exceptions. Kellehear's notion of 'compassionate cities' (Kellehear, 2005) is one example, in which care for those who are dying or experiencing loss is theorised as an issue that involves the whole community. Kellehear's vision involves the emergence of new forms of participatory social action, encouraged by programmes of public education, which have the potential to find new and innovative community based solutions to questions of quality of life during dying.

Other examples come from work that is the result of partnerships between social scientists, clinicians, the voluntary sector and service users. The 'My Home Life' programme seeks to find practical ways of overturning stereotypes of care home life as necessarily barren, isolated from the wider community and in which older people are somehow waiting for a death that has come 'too late'.

I represent the University of Nottingham in a national collaborative for the development of interdisciplinary research in supportive and palliative care. The Cancer Experiences Collaborative (see www.ceco.org.uk) is funded by the National Institute for Cancer Research, and is a socially science oriented network of academics, clinicians, service providers and users. One aspect of the collaborative's activity seeks to develop research around end of life care for older people, and we have a wide ranging programme of work in place including involvement in studies funded by the New Dynamic on Ageing Programme, major charities and the MRC.

Challenges of working as a social scientist in such an endeavour are significant and will be familiar to you all: loss of identity; challenges to credibility, the need to engage in repeated debates about appropriate research focus and meaningful research questions, evidence and outcomes. But the benefits are considerable in terms of achieving policy and practice impact, and in enabling the use of sociologically informed evidence and theoretical insights to build multi faceted interventions.

Sociological research in end of life care needs to be cognisant of the profound questions now raised by complex bioethical and biomedical issues at the end of life, and informed by concerns to further social justice and equality for all those living towards the end of life in the service of our common humanity (Wainwright, 2005). Opportunities are emerging for sociologists to work in partnerships with colleagues across a wide span of disciplines – for example, bioethics, the clinical sciences, epidemiology and public health- to further the critical and informed debate about a question that concerns us all: how to shape the compassionate and thoughtful care of persons facing the final stages of life and their companions.

Acknowledgements

have worked in addressing these themes , or on whose work I have drawn in this lecture.

References

Age Concern (1999) The *Future of Health and Care of Older People: The Best is Yet to Come.* The Millennium Papers. London: Age Concern.

Ariès, P. (1974) Western Attitudes Towards Death: From the Middle Ages to the Present. Baltimore: John Hopkins University Press.

Ariès, P. (1981) *The Hour of Our Death*. New York: Knopf.

British Medical Association (2007) Withholding and Withdrawing Life-Prolonging Medical Treatment. London: BMA.

Cassell, E. (2004) *The Nature of Suffering and the Goals of Medicine.* Oxford: Oxford University Press.

Clarke, A. and Warren, L. (2007) Hopes, fears and expectations about the future: what do older people's stories tell us about active ageing? *Ageing and Society*, 27: 465-488.

Clarke, A., Seymour, J.E. et al (2006) Opening the door for older people to explore end of life issues. London: Help the Aged.

Davies, E. and Higginson, I. (eds) (2004) *Better Palliative Care for Older People*. Copenhagen: World Health Organization Europe.

Department of Constitutional Affairs (2005) *Mental Capacity Act.* London: HMSO.

Small, N., Froggatt, K. and Downs, M. (forthcoming) *Living and Dying with Dementia-Dialogues about Palliative Care.* Oxford: Oxford University Press.

Dworkin, R. (1993) Life's dominion. An argument about abortion and euthanasia. London: Harper Collins.

Elias, N. (1985) *The Loneliness of the Dying*. Oxford: Blackwell.

Field, D. (1989) *Nursing the Dying*. London: Tavistock/ Routledge.

Field, D. (1996) Awareness and modern dying. *Mortality,* 1(3): 255–65.

Fox, R. (1959) *Experiment Perilous.* Illinois: Free Press of Glencoe.

Frank, A. (1995) *The Wounded Storyteller. Body, Illness and Ethics.* London and Chicago: University of Chicago Press.

Frank, A. (2004) *The Renewal of Generosity. Illness, Medicine and How to Live*. London and Chicago: University of Chicago Press.

Glaser, B. and Strauss, A. (1965) *Awareness of Dying*. Chicago: Aldine.

Glaser, B. and Strauss, A. (1967) *Time for Dying.* Chicago: Aldine.

Gott, M., Seymour, J.E., Bellamy, G., Clark, D. and Ahmedzai, S.H. (2004) Older people's views about home as a place of care at the end of life, *Palliative Medicine,* 18: 460-467.

Grande, G .E., and Addington- Hall, J.M., et al. (1998) 'Place of death and access to home care services: are certain patient groups at a disadvantage?', *Social Science and Medicine* 47(5), 565-578.

Habermas, J. (1987) *Theory of Communicative Action*. Cambridge: Polity.

House of Lords (1994) *Report of the Select Committee on Medical Ethics* (HL Paper 21-I) London: HMSO.

Howarth, G. (2007) *Death and Dying: A Sociological Introduction*. Cambridge: Polity Press.

Howarth, G. and Jeffreys, M. (1996) Euthanasia: sociological perspectives. *British Medical Bulletin,* 52: 376-385.

Illich, I. (1976) Limits to Medicine. Medical Nemesis: The Expropriation of Health. Harmondsworth: Penguin.

Jennett,_B. (1995) High technology therapies and older people. *Ageing and Society,* 15:185-198.

Kastenbaum, R. (1969) Psychological death. In L. Pearson (ed.) *Dying and Death*. Cleveland: Western Reserve University Press.

Kaufman, S. (2005) ….And a Time to Die. How American Hospitals Shape the End of Life. New York: Lisa Drew Books/ Scribner.

Kaur, J. (2007) Sheltered and Extra Care Housing: An Overview. Beaconsfield: Housing 21.

Kearney, M. (2000) A Place of Healing: Working with Suffering in Living and Dying. Oxford: Oxford University Press.

Kellehear, A. (2007) *A Social History of Dying*. Cambridge: Cambridge University Press.

Kellehear, A. (2005) Compassionate Cities: Public Health and End of Life Care. London: Routledge.

Kleinman, A. (1992) The Illness Narratives. Suffering, Healing and the Human Condition. New York: Basic Books.

Kübler- Ross, E. (1975) *Death: The Final Stage of Growth.* Englewood-Cliffs, New Jersey: Prentice Hall.

Lloyd, L. (2004) Morality and mortality: ageing and the ethics of care. *Ageing and Society*, 24: 235-256

Lock, M. (1996) Displacing suffering: the reconstruction of death in North America and Japan. *Daedalus. Journal of the American Academy of Arts and Sciences*, 125(1): 206-244.

Office of Technology Assessment (1987) Life Sustaining Technologies and the Elderly. US Congress Office of Technology Assessment. Washington: US Government Printing Office:.

Oostveen, M. (2001). Spijt. Voorvechters van euthanasie bezinnen zich. *NRC Handelsblad*, 10 November. (cited in Seymour et al 2007)

Peräkylä, A. (1991) Hope work in the care of seriously ill patients. *Qualitative Health Research,* 1: 407-33

Quint, J. (1967) *The Nurse and the Dying Patient*. New York: Macmillan.

Rich, B.A. (2002) The ethics of surrogate decision-making. *Western Journal of Medicine* ; 176:127-129.

Sanders, C., Rogers, A., Gately, C. and Kennedy, A. Planning for end of life care within chronic illness self-management training: the significance of 'death awareness' and biographical context in participant accounts. *Social Science and Medicin,* in press.

Seymour, J.E. (1999) Revisiting medicalisation and 'natural' death. *Social Science and Medicine,* 49: 691-704.

Seymour, J.E. (2001) *Critical Moments: Death and Dying in Intensive Care.* Buckingham: Open University Press.

Seymour, J.E. (2007) Quality of life to the end: commentary. *Communication and Medicine,* 4: 117-118.

Seymour, J.E., Gott, M., Clark, D. and Ahmedzai, S. (2003) *Technology and Natural death: A Study of Older People.* Grant no.: L218252047, Economic and Social Research Council.

Seymour. J.E., Clark, D. and Winslow, M. (2005a) Pain and palliative care: the emergence of new specialties. *Journal of Pain and Symptom Management,* 29: 2-13.

Seymour, J.E., Witherspoon, R., Gott, M., Ross, H. and Payne, S. (2005b) *End Of Life Care: Promoting Comfort, Choice And Well Being Among Older People Facing Death.* Bristol: Policy Press.

Seymour, J.E., Jansenns, R. And Broeckaert, B. (2007) Relieving suffering at the end of life: perspectives on palliative sedation from three European countries. *Social Science & Medicine,* 64: 1679-1691

Shakespeare, T. (2007) *Disability Rights and Wrongs*. Abingdon: Routledge.

Small, N., Froggatt, K. and Downs, M. (in press) *Living and Dying with Dementia.* Oxford: Oxford University Press.

Sudnow, D. (1967) *Passing On: The Social Organization of Dying*. Englewood Cliffs, New Jersey: Prentice Hall.

SUPPORT Project Principal Investigators (1995) A controlled trial to improve care of seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatment (SUPPORT). *Journal of the American Medical Association*, 174: 1591-8

Sweeting, H.N. and Gilhooly, M. (1992) Doctor, am I dead? A review of social death in modern societies. *Omega,* 24: 251-269.

ten Have, H. (2005) End of life decision making in the Netherlands. In: R. Blank and J.C. Merrick (eds.) *End of Life Decision Making: A Cross National Study*. London: MIT Press.

Timmermans, S. (1998) Resuscitation technology in the emergency department: towards a dignified death. *Sociology of Health and Illness,* 20: 144-167.

van der Wal, G., van der Maas, P.J. and Bosma, J.M. et al (2003) *Medische Besluitvorming aan het Einde van het Leven. De Praktijk en de Toetsingsprocedure Euthanasie.* Utrecht: De Tijdstroom (cited in ten Have, 2005).

Wainwright, I. (2005) *Suffering. A Sociological Introduction*. Cambridge: Polity Press.

Walter, T. (1994) *The Revival Of Death*. London: Routledge.

Wasson, K., Tate, H. et al. (2001) Food refusal and dysphagia in older people with dementia: ethical and practical issues *International Journal of Palliative Nursing,* 7: 465-71.

Williams, R. (1990) A Protestant Legacy: Attitudes to Death and Dying among Older Aberdonians. Oxford: Clarendon Press.

Following a degree in social science at Exeter University, Jane trained as a nurse and went on to work in acute and intensive care for more than a decade. She gained a Master's degree in sociology and community studies in 1991, and a doctorate examining the management of death in intensive care in 1997. After leaving clinical practice, Jane worked as a researcher and educator in palliative care in Sheffield, moving to Nottingham in 2005 where she is now head of the Sue Ryder Care Centre for Palliative and End of Life Studies.

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BOOK REVIEWS
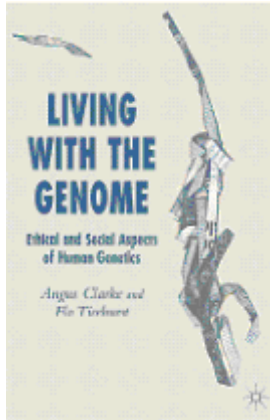
Angus Clarke and Flo Ticehurst (Editors)

Living with the Genome: Ethical and Social Aspects of Human Genetics

Palgrave Macmillan 2006 £19.99 (pbk)

(ISBN 1-4039-3621-8) 327pp

Reviewed by Martyn Pickersgill, *University of Nottingham*

Living with the Genome has its origins in the Encyclopaedia of the Human Genome, and comprises an edited collection of the 'ethical and social' (but not legal) contributions to the latter text. It is therefore a far more economical alternative for the non-scientist. The book is sensibly divided into six sections, each with a well-written introduction by the editors. These sections consist of 5-8 short chapters of around six pages each. Such short chapters cannot give a full account of the ideas or research the authors seek to present; however, they serve as a useful introduction to prominent projects or concepts.

The chapters include many of the 'big names' associated with work in genetics and society , including Ruth Chadwick, Troy Duster, Dorothy Nelkin, and Martin Richards, to name but a few. These are predominantly (UK based) social scientists, although there are contributions by notable ethicists: Donna Dickenson and John Harris, and prominent scientists; Patrick Bateson and Steven Rose. There is also the occasional surprise contribution, the biotechnology critic Jeremy Rifkin, for instance. Each author gives a somewhat partial (and sometimes partisan) appraisal of genetics. Nonetheless, the sheer variety of perspectives on offer in the 42 chapters ensures the dilution of any overriding dogma or theoretical bias.

Surprisingly, the book begins with a 13 page glossary. Given the wide-ranging terrain of the book, it contains scientific, sociological and philosophical terms. Few readers will be familiar with all the concepts dealt with in Living with the Genome, and the language through which they are discussed or expounded. This comprehensive glossary is therefore a useful addition. Following the glossary is an introduction by Angus Clarke. In it he argues that there is no particular agenda behind the book, reflected in the plethora of perspectives and disciplinary orientations. Clarke, a professor of genetics, also gives the reader a realistic appraisal of his science. Clearly he is excited by the advances and potential of genetics, but he is far from hyperbolic. His knowledge of the field is evident in the clarity with which he explains some of the more complex aspects of laboratory and clinical genetics. Moreover, Clarke is well aware of the social and ethical aspects of his work, including the concerns of feminists and disability rights campaigners, and is clearly well-placed to edit this volume.

Eventually, after the glossary and introduction, the reader reaches part 1 of Living with the Genome, 'The Human Genome Project: Genetic Research and Commercialisation'. This

section covers, perhaps unsurprisingly, varied ground, and helps to highlight the social construction of genetics. Gene sequencing and patenting are dealt with, and critical analyses of biobanking, informed consent and gene therapy follow, as does Michael Fortun's revealing account of the tensions between public and private ventures into the sequencing of 'the' human genome.

Part 2, 'Genetic Disease: Implications for Individuals, Families and Populations' primarily covers case studies related to clinical genetics; for example, Scriver and Mitchell look specifically at 'Carrier Screening of Adolescents in Montreal'. Well documented and theoretically informed, this section is perhaps the most useful for professionals working in clinical settings. It does, however, lack work in the anthropology of clinical genetics. A contribution by someone such as Margaret Lock would have been a valuable addition to this section.

Part 3, 'Disability, Genetics and Eugenics' deals with one of the more prominent fears about genetics; namely, that it has eugenic undertones that may become increasingly pronounced as the science develops. Links between contemporary developments and the eugenics of Nazi Germany, as well as that of Galton and colleagues in Anglo-American contexts, are well-made. However, as would be expected of writers such as Tom Shakespeare and Troy Duster, careful analysis and attention to the nuances of contemporary developments resonate far more strongly through the text than polemical claims-making. That said a chapter by a historian of eugenics might have been a fruitful addition.

Part 4, 'Genetics and Society: Information, Interpretation and Representation', is concerned with the popular representation of genetics, and the (mis)interpretations that follow from them. Consequently, it is no surprise that the section begins with a contribution from Dorothy Nelkin, discussing the 'Gene as a Cultural Icon'. Paul Atkinson and colleagues chapter on 'Inheritance and Society' is of particular note in this section, drawing on anthropological and sociological research in order to problematise understandings of inheritance embedded within 'Western' genetic science.

Part 5, 'Genetic Explanations: Understanding Origins and Outcomes', is a particularly 'science heavy' chapter, although it also includes a philosophical and social scientific contribution. It follows, then, that the analyses of genetic explanations are orientated towards scientific critique, rather than historical or sociological investigation. This makes a powerful point: genetic explanations are contested even within 'science', and not all understandings of genetics by scientists are 'reductionist'. However, the section would have benefited by including chapters from sociologists who have examined the complexity of genetics and genetic understandings empirically. For example, Anne Kerr and Adam Hedgecoe, who have critically examined the concept of 'geneticisation'. Indeed, it might also have been warranted to include a chapter by Abby Lippman, who coined the term geneticisation.

Part 6, 'Reproduction, Cloning and the Future', is arguably the most 'ethical' section within this ELSI-type collection. The contributions are strong, and represent various elements from a wide spectrum of viewpoints, including libertarian bioethics and feminist sociology. However, the space taken by Linzey and Barsam's chapter on animal cloning would have perhaps been more usefully occupied by a contribution on ethnographic work on reproductive decision-making.

Despite these few caveats, Living with the Genome is a very readable introduction to many of the key concerns and research foci of academics investigating the social and ethical aspects of human genetics. Whilst individual chapters might not serve to fully ground the reader in the issues at stake, the references included generally point towards journal articles that more deeply explore the authors' research or ideas. Living with the Genome is therefore

an economical and useful addition to the bookshelves of medical sociologists interested in human genetics.

Tom Shakespeare

Disability Rights and Wrongs

Routledge 2006 £19.99 (pbk)

(ISBN 978-0-415-34719-8) 240pp

Reviewed by Cassie Ogden, *University of Chester*

Tom Shakespeare's 'Disability Rights and Wrongs' is an engaging, well written book that tackles a range of issues surrounding disability and impairment in a sophisticated manner. It is suitable for academics as well as graduates and final year undergraduate students as Shakespeare's writing style is very accessible. The air of controversy evident in some chapters is gripping. Whether you agree or disagree with Shakespeare's criticisms of the social model of disability, you will feel the urge to keep on reading as the dominant sociological understanding of disability is turned on its head. There are more questions than answers on completion of the book, which is a reflection of the complex nature of the issue of 'disability' and the refusal of the author to oversimplify the topic.

The book is divided into three main sections with the first section discussing the conceptualisation of disability. Shakespeare highlights the dangers of dichotomising the medical and social model of disability and highlights a range of different approaches that could be used to theorise disability, that are not exclusively 'social'. He suggests research which falls into the 'medical' model is not necessarily bad and that it is time to reject the exclusive use of the social model in disability studies. Emerging from the political activism of disabled people, the social model of disability has been the dominant theory in disability studies over the past 30 years. Thus, Tom Shakespeare's critique is likely to disconcert many people. Statements such as 'there will always be residual disadvantage attached to many impairments', and 'what matters is that the social model is wrong', sit uneasily alongside our socially aware thinking.

Perhaps the author is being purposively provocative but the reasoned discussion about the importance of studying impairments alongside the social/economic oppression of people with impairments, is a discussion that has been long overdue in disability studies. Impairment is social phenomenon (as well as disability) argues Shakespeare, and if people with impairments have equal moral worth to non impaired peers then social arrangements that ensure inclusion will be made. Although this first section is arguably the most controversial, because of the critique of the dominant social model in disability politics, other texts such as Thomas's

(2007) have since been published that address the need to discuss impairment in a social manner. Shakespeare's activist influences however, allow his text to be hard hitting and in challenging the orthodoxy in British Disability Studies in such a manner, the first section of Shakespeare's book remains to me, the highlight of the book.

Shakespeare next turns his attentions to applying his new approach of conceptualising disability to exploring the lives of those with impairments. The second section on disability and bioethics presents debates on the issues of prenatal diagnosis, genetic screening, abortion, end of life issues, and also medical 'cures'. Shakespeare abhors the cultural representation of medical research being the answer to disabled people's lives, but he also believes the exclusive use of the social model is equally as damaging, as disabled people are deemed the victims of social oppression. This refreshing viewpoint gives a voice to those who rely on medical intervention to help improve their lives, whilst also appreciating that changes could be made in society to help alleviate their situations. This section strengthens the possibility of conceptualising disability *and* impairment in a way that still promotes disability activists' goals of independence and inclusion.

The final section focuses on the social relations of disability, including care and assistance, the future of charity, and love and friendship. In keeping with the main theme of the book, Shakespeare examines the predicament of impairment within these topics, alongside exploring the need for social change. The role of charity for example has been heavily neglected by disabled activists, yet Shakespeare argues their incompatibility with the disability rights movement should not be seen as inevitable. Charities in his opinion can actually contribute towards creating a more equal society for disabled individuals and have operated increasingly empowering campaigns in more recent years.

Inclusion of non disabled researchers within disability studies is also examined and Shakespeare believes being disabled oneself does not give an automatic insight about how other disabled people live. As a result non disabled people should be welcomed to research within disability studies, just as non disabled people can contribute positively to disabled peoples lives in their many different roles as carers, parents and professionals. Whilst not dismissing the oppression that can be (and has been) imposed on disabled people by able bodied people, Shakespeare also highlights that not all non disabled people are oppressive.

Some disability activists might feel this book dilutes their efforts as they need to adopt an exclusive social position as long as disablism is evident in society. In agreement with Shakespeare's conclusion however, the book encourages a practical research agenda that explores how disabled people experience their impairments as well as the social barriers. Overall I think the book is excellent at drawing attention to the flaws of the social model and through discussions such as identity, Shakespeare helps alleviate people with impairments from the guilt of not wishing to be associated with the disabled community, or for 'colluding' with the medical profession. This book should act as a catalyst for new research proposals, social agendas and further debate over this interesting and contentious topic.

References

Thomas, C. (2007). *Sociologies of Disability and Illness*. Hampshire: Palgrave Macmillan

Ellen Kuhlmann

Modernising Health Care: reinventing professions, the state and the public

Polity Press 2006 £65.00 (hbk)

(ISBN 9781861348586) 280pp

Reviewed by Justin Waring, *University of Nottingham*

Kuhlmann's work sits broadly at the often complex interface of the sociology of professions, organisational sociology and social policy. She explores the intersection of these domains through investigating transitions, principally in the context of German health policy, in order to identify and elaborate a new expression of healthcare professionalism and new forms of governance. This, she aptly defines as 'hybrid' regulation. A key feature of her study is an initial re-appraisal of the relationship between the professions, the state and the public, which provides a framework for her subsequent analysis. Through characterising "citizenship as a superstructure of governance" (p.15) she argues for the concept of 'citizen professionals' as a way of accounting for the mediating role of professions between the state and the citizen. Such a triangular relationship reflects Salters' (2000) 'regulatory bargain', but questions remain about how far this concept extends beyond what can be described as the welfare professions, and the extent to which the governance structures of citizenship are clearly articulated and explained.

The book then proceeds to examine the drivers and dynamics of professional change in three 'steps'. The first maps out the institutional context of change within a comparative perspective examining the commonalities found within the healthcare systems of Europe and North America. The significance of this comparative focus is found in her appreciation of the trans-national and globalising forces that appear to be shaping healthcare systems. The key dimensions identified include the growing role of the market in healthcare, the centrality of culture change, the demands for quality improvement, and importantly, changing working relationships as a consequence of teamwork and new gendered divisions of labour. Clearly these are issues that extend beyond the health policy context to reflect wider debates within public policy and New Public Management.

The following steps of her analysis then reveal these transitions within the German healthcare context to examine the re-invention of the 'citizen professional'. It is in these subsequent steps that the book explores the new dynamics of regulation, within and beyond Germany. It is in these hybridised forms of networked regulation, that Kuhlmann's work makes the most novel contributions (especially chapters 5 and 6). Her findings counter many established ideas within medical sociology that have long promoted the idea that marketisation and managerialism have introduced 'countervailing powers' (Light, 1995), or challenged the autonomy of medicine, by revealing the flexibility of healthcare professions and the 'permeable boundaries' between professions that adapt to change. Rather than seeing new governance structures or networks as eroding notions of medical autonomy and self-regulation, she shows how networks have been strategically co-opted, captured and colonised by professionals through hybridised forms of regulation. This moves beyond the

'professionalism versus managerialism' debate, but although the work goes on to question the capacity of either managers or consumers to truly engage with the knowledge-power underpinning healthcare professionalism, it could go further to explore in more detail how these new forms of regulation are in themselves expressions of governmentality (Flynn, 2004; Waring, 2007).

In sum Kuhlmann's work provides a fascinating and detailed account of the transitions witnessed within the German healthcare system, but in doing so, she makes a welcome contribution to our understanding of healthcare reform and professional regulation more generally, as well as wider theoretical contributions of the sociology of professions and public/social policy.

References

Flynn, R. (2004) Soft Bureaucracy', Governmentality and Clinical Governance: Theoretical Approaches to Emergent Policy, in A. Gray and S. Harrison (eds.) *Governing Medicine¸* Buckingham: Open University Press.

Light, D. (1995) Countervailing powers: a framework for professions in transition, in T.Johnson, G. Larkin, and M. Saks (eds.) *Health Professions and the state in Europe*, London: Routledge.

Salter, B. (2000) Change in the Governance of Medicine: The Politics of Self-regulation, in Gladstone, D. (ed.) *Regulating Doctors*, London: Institute for the Study of Civil Society

Waring, J. (2007) Adaptive regulation or governmentality: patient safety and the changing regulation of medicine. *Sociology of Health and Illness*, 29(2):163-79
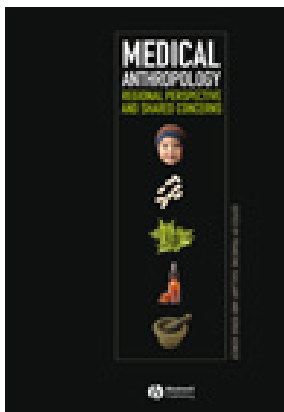
Saillant Francine & Serge Genest (Editors)

Medical Anthropology: regional perspectives and shared concerns

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(ISBN 9781405152501) 336pp

Reviewed by Ciara Kierans, *University of Liverpool*

Attempting to describe any field of inquiry can be a difficult task, particularly where, as is the case with medical anthropology, that field can have an unresolved relationship to its disciplinary progenitors: anthropology, medicine and the human sciences. More often than not attempts at description will raise many questions that cannot be answered, artificially or prematurely closing off certain lines of debate that less synoptic treatments would otherwise leave open. Real complexity is sacrificed for the sake of clarity of exposition. It is, therefore,

to the credit of Saillant and Genest that their volume does its best to tackle the multiform nature of medical anthropology, as a field of inquiry, head on.

Intended as both a synthesis and a prospectus, the book uses contributions from a number of influential international medical anthropologists to detail what it means, and has meant, to do medical anthropology in Canada, the United States, Brazil, Mexico, France, Spain, Italy, Germany, the Netherlands, the United Kingdom and Switzerland. In drawing upon the reflections of these practitioners, the collection offers multiple views of the discipline as it has developed in and through an ongoing dialogue between different national contexts, intellectual and political traditions, investigative practices and substantive concerns.

As the contributors make clear, in the thirty years since the term 'medical anthropology' came to prominence in a series of landmark research manuals (see Eisenberg and Kleinman 1981; Foster and Anderson 1978; Logan and Hunt 1978; and McElroy and Townsend 1979), what it means to be a medical anthropologist has continued to change, to branch-off and mutate. Setting considered perspectives alongside each other, therefore, adds real depth to our understanding of the field. This is turn provides us with a welcome opportunity to take stock of an expanding field of thought and practice, and to consider the key debates, theoretical perspectives, epistemological paradigms and diverse topics that currently inspire and shape the work of researchers and practitioners throughout the globe.

One of the major themes of this book is the need to move beyond an often unexamined Anglo-American unitarism towards a consideration of the multiple trajectories and diverse influences which contribute to current developments in the field, and which situate both the practice of fieldwork and the theoretical relationships between culture, society, health and the human condition. In privileging diversity, the book usefully highlights the field's "legitimacy and visibility particularly [in] those traditions developed in languages other than English" (Comelles et al. pp. 103).

As the contributors attest, in many countries the relation between anthropology and medicine emerged from national problematics and a practical need to deal with issues within their own countries. In Mexico, for example, the grassroots approach to the field pioneered by the work of physician-anthropologists, such as Gonzalo Aguirre-Beltran, reflect the health needs of indigenous communities and the growing institutionalisation of indigenous cultures. Brazilian anthropologists, working on problems of inequality and poverty alongside the paradoxical new consumption of health by Brazil's rich, have focussed on how these work together to produce a complex of regionalised health problems in the context of the country's health services. In contrast to North American and Western European anthropological traditions, the work of Brazilian anthropologists is described by Annette Leibing as involving a "constant awareness or preoccupation with what is considered Brazilian" (p. 61). In Italy, similarly, medical anthropology has been driven by the country's internal regional problems and fragmented political character. This has produced a marked critical and socio-political anthropology indebted to the philosophical historicism of Benedetto Croce and Antonio Gramsci's Marxist analyses.

By comparison, those chapters detailing the emergence of the field in the US, UK and France, largely reflect the development of its intellectual and philosophical traditions and its gaze on peoples and concerns much further a field. Focusing on the US, Castro and Farmer embed their descriptions of the passage of medical anthropology in early 20th century, non-western medical systems with a concern for the relationship between magic, religion and health; through to the culture and personality studies of the 1940s; to applied anthropological work in the 1950s and on to later participatory and critical approaches to public health medicine and global health inequalities. Frankenberg's chapter on the UK and Fainzang's

chapter on France describes similar reflections on the theoretical and conceptual underpinning of the field. In countries such as these, the problem of the 'national' appears to operate as an 'unseen' backdrop to the wider field's intellectual development.

A central tension between medicine and anthropology, however, underlies most of the chapters in this volume. This is due to how their epistemological distinctions are organised, alongside the question; are anthropologists doing medicine or anthropology? Additionally, problems in translating knowledge and understanding across disciplinary domains, and the relationships between ideological positions and data pose the problems of power, knowledge, and the medical gaze. This questions in whose interests the field of medical anthropology serves. While the book's contributors pay homage to the work of physician-anthropologists such as, WH Rivers, Rudolf Virchow, and Vincent van Amelsvoort, whose writings have helped establish the field, they are also clear to assert anthropology as not simply a hand-maiden to medical knowledge and intervention. It is also for our understanding of social processes, practices and culture, which often lead us to very different conclusions and debates. Sylvie Fainzang's chapter is particularly useful in drawing attention to the growing political orientation of the field and emerging critiques of medical specialities like public health medicine.

While the book's chief focus is on national contributions to the field, it is, however, clear that the practical realities shaping the development of medical anthropology at present are chiefly concerned with processes operating beyond national arenas. This is clearly illustrated from the two chapters on Canada, whose universities and researchers are leading the field in ethnographies of scientific and political-economic cultures, examining topic areas such as, the relationships between biosciences, global markets and venture capital; ethical and legal concerns relating to bio banks; the marketing or regulation of pharmaceutical products, genetic testing and so on. Similarly, migration, infectious diseases and the increasing incidence of chronic conditions and the concerns for care and access to services across borders exemplifies the centrality of globalisation and the growing importance of interdisciplinary working between the biosciences and the social sciences. Many of the contributors point out, however, that this cannot be done at the expense of the local and the particular, which is one of the distinctive contributions of medical anthropology.

Salliant and Genest's collection helps us reassess the contributions and developments of various medical anthropologies as well as, perhaps to problematise the field as a complex family of research practices, topics and theories. The concluding section by Margaret Lock leaves behind some of that diversity to discuss important new directions for medical anthropology as well as reassess the key concepts of culture, the body, technology and medical pluralism. While these are, without question, critical to the theoretical and conceptual apparatus of the field, there is a danger that conclusions of this sort seek to re-impose an artificial unity on the field at the expense of its regional contributors. A further postscript on behalf of the editors would have proved beneficial to a series of reflections on the status of the field and its scholars.
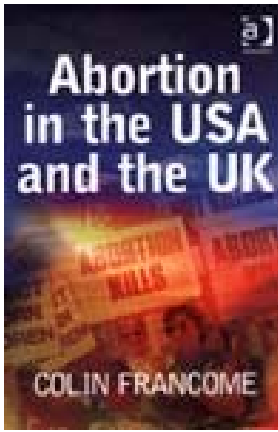
Colin Francome

Abortion in the USA and the UK

Ashgate Publishing 2004 £45.00 (hbk)

(ISBN 0 7546 3015 3) 180pp

Reviewed by Pam Lowe, *Aston University*

This book sets out to provide a historical and comparative approach to the legal and political positions of abortion within the US and UK. It outlines the movements to legalise abortion in both countries and discusses the ways in which the level of legal restrictions do not necessarily translate into practical access to legal services. The book gives a broad overview which could prove useful to those coming new to the debates, and it sets out the history of the law in both countries. However, in places it lacks attention to fine details and oversimplifies the nuances of the debates.

The book begins with descriptions of what Francome argues are the main social forces of either side of the debate about abortion, such as 'women's movements' and 'religious groups'. As these are all short descriptions, it would not be possible to give anything other than generalisations or one or two specific examples. Yet this is not made very clear. For example, the section on 'religious groups' concentrates on Catholicism, and does not mention the role of Evangelical Christians. Consequently, it seems to suggest that the only religious opposition to abortion was linked to the Catholic Church. Whilst the typology outlined in the introduction might be useful if it was going to be used later on, this does not really happen. This is one of the places that I feel that the book does not really do justice to the subject.

The next chapters set out the history of abortion law and details experiences of abortion in each country with comparisons between them. Confusingly, the chapters are not set out in chronological order, beginning with the situation today and ending with when abortion was illegal. It is not clear why the story is told backwards, and it means that the description of the situation today cannot be clearly seen as the outcome of the earlier battles over the legalisation of abortion. Chapters 2 and 3 describe the current situation in each country, focusing particularly on statistical evidence of the number of abortions, types of abortion, regional differences in service provision, and giving details of the main current opponents to abortion.

Chapters 4 and 5 describe the processes of legalisation in each of the different countries, clearly illustrating the ways in which the different political climates lead to abortion law being debated. In both chapters, Francome shows how the social and political context is the key to understanding the different ways in which abortion became legal. In the UK, he argues, abortion was defined as a health issue and as such decisions about abortion were granted to the medical profession. In contrast in the US, the legalisation of abortion was debated as a constitutional issue, with the right of privacy becoming the key factor.

The next two chapters examine the political movements on both sides of the abortion debate. In Chapter 6, Francome focuses on the US and gives brief descriptions of some of the

main players such as the *National Right to Life Committee* and *Planned Parenthood Federation.* This is followed by an outline of what Francome believes to be the most important Supreme Court decisions on abortion. Chapter 7, follows a similar pattern, looking at UK organisations of both sides of the debate and some of the parliamentary attempts to restrict abortion. Yet, the last successful attempt to restrict abortion, the Human Fertilization and Embryology Act 1990, is barely mentioned. Considering this set a precedent that abortion could be legitimately restricted on the basis of foetal development and new medical technologies, which has been the main thrust of all subsequent attempts to change the law, the lack of detail on this change seems a significant omission. Whilst some might find the overview of these chapters useful, they do not really give sufficient detail for a novice to the area to understand the complexity of the relationships.

The last two substantive chapters look at the period from the eighteenth century to the early twentieth century, illustrating how the social context has always been closely interrelated to attitudes and practices of abortion. They show how abortion was widespread, and how its illegal status contributed to risks to women's health. Chapter nine also looks at how campaigners for birth control successfully sought to separate the issues of abortion and contraception, and argued that acceptance of contraception could prevent the need for abortions. These ideas are still prevalent today, but the book does not highlight their continuing importance, most probably because of the way that the chapters are ordered.

The final chapter does not set out any detailed conclusions, but gives Francome's assessment of future risks to abortion, particularly in the US. Whilst I entirely agree with Francome's argument, I feel it would have been more useful to have linked the themes of book together more systematically.

Overall, I feel that the book gives useful information about the trends of abortion in both countries, but it does so at an outline level rather than in detail. It could serve as a useful resource to the broad trends, but does not always do justice to the intricacies of the debates.

Anne Murcott (Editor)

Sociology and Medicine: Selected essay by P.M. Strong

Ashgate Publishing 2006 £55.00 (hbk)

(ISBN 0 7546 3844 8) 296pp

Reviewed by Tiago Moreira, *Durham University*

Sociology and Medicine gathers in one book a variety of essays written by Phil M. Strong between 1976 and 1995, the year of his death. Strong's role in and influence on British medical sociology would alone justify the publication of this book which joins widely known

and cited essays such as 'Sociological Imperialism and the Profession of Medicine' with lesser known pieces published in books no longer in print. But rather than being the Complete Works of P.M. Strong, the selection of essays aims to 'display elements of Strong's thinking that persisted throughout the twenty years or so he was publishing, but which would be evident only to those familiar with his complete output', as Anne Murcott, the editor of the book, explains in her preface (p. ix).

Indeed, here one can find examples of Strong's work on ceremonial orders, of his extension of Goffman's theory of ceremony to links with wider social structures, of his concern with relationship between sociology and medicine, between science and medicine, and between sociology and the wider polity, and of his methodological contributions. If this wasn't enough, another advantage of having these essays in one book is that links across Strong's concerns become visible.

One example of this has to do with medicalisation. It is common to view Strong's critique of the 'medicalisation thesis' with reference to the 'Sociological Imperialism' paper from 1979. Three years before, in 'Aren't Children Wonderful?'(Chapter 1), Strong and his co-author A. G. Davis argue that in child development assessment consultations doctors de-medicalise the encounter as a way of normalising a population that was in doubt regarding its illness status, and that 'medicalisation was used to indicate that a child's normality was still at issue' (p. 21).

While in 'Sociological Imperialism' Strong himself seemed to draw mainly on his (then unpublished) work on alcoholism to ground his claim about medical pragmatism, his analysis of developmental screening is a clear demonstration of how medicalisation is better seen as a possible strategy within a configuration of factors than as a general feature or impulse of medicine. This re-articulation of the meaning of medicalisation stems, in turn, from Strong's commitment to detailed analysis of empirical data. Here too the book provides an opportunity to rethink this aspect of Strong's work.

Reading Strong's work before, it always struck me how different his empirical papers were from his 'essays': on the one hand, close, systematic analysis of large sets of data, backed up by robust and thought through methodological principles; on the other, wide reflections on large issues, drawing on history, literature and philosophy. Anne Murcott argues in her preface that Strong's style is unified by his exploration of the essay form (p. xi-xii). Although this cannot be denied, Strong could also be described as a 'social naturalist', a term used by Goffman to describe his own identity in a letter to Strong (quoted in Minor Courtesies and Macro Structures, Chapter 3: 38). Like a naturalist's, a social naturalist's interests are diverse, albeit always driven by observation, sometimes focusing on one specific aspect of the world, or a particular group of phenomena, others reflecting on the use of the discipline and its relation to the social and political world.

This said, it is important not to make too much of the editor or this reader's attempts to present a coherent picture of Strong's work because a significant part of its present relevance lies in his different modes of engagement with a multiplicity of topics with a varying degree of depth. He wrote both traditional academic sociological papers (e.g. 'Two Types of Ceremonial Order', Chapter 4) and pieces such as 'Doctors and Nurses' (Chapter 8) where he uses 'new forms of writing', a type of collage of interview quotes to develop his argument. To build an official version of Strong's legacy would be a mistake. The fact that it is possible and enlightening to read Strong's work to think through current changes in medicine, health care, and sociology is the best proof of his legacy. In this respect, Strong's analysis of the possible consequences of normalising a 'social model of health' (p. 117-118) should be required reading for analysts and practitioners involved in current policy attempts to tackle health

inequalities.

Another case in point concerns his reflections on 'The academic encirclement of medicine' (Chapter 7). In this piece, Strong asks how likely are non-clinical disciplines to re-shape medical practice, and predicted that the academic disciplines that successfully encroached in clinical medicine would 'depend as much on the wider success of their patrons as on their own academic effort'. Current work on the forms of mediating between research and practice is coming to reflect and extend this view (Timmermans and Berg 2003). His ideas on the importance of networks in the diffusion of research ('One Branch of Moral Science', Chapter 12: 238-39) also find resonance in current attempts to systematise knowledge about research implementation processes in health care organisations (Greenhalgh, Robert, Macfarlane, Bate and Kyriakidou 2004). Finally, Strong's ideas on the role of sociology and his defence of liberalism seem particularly relevant for current discussions around 'public sociology' (Burawoy 2004).

These were some of the suggestive ideas this reader found stimulating. I am sure anyone else would find others that would fit and extend his/her observations of the social world.

References

Burawoy, M. (2004) For Public Sociology: 2004 ASA Presidential Address. *American Sociological Review* 70: 4-28.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P. and Kyriakidou, O. (2004) Diffusion of innovations in service organizations: Systematic review and recommendations. *Milbank Quarterly* 82(4): 581-629.

Timmermans, Stefan and Berg, Marc (2003) *The Gold Standard: The challenge of EBM and Standardization in Medicine* (Philadelphia: Temple University Press).
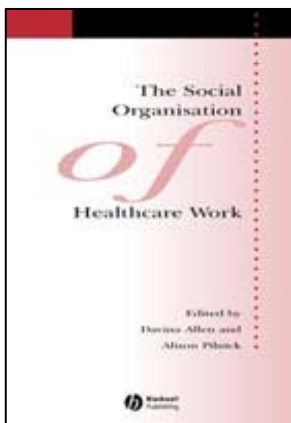
Davina Allen and Alison Pilnick (Editors)

The Social Organisation of Healthcare Work

Blackwell Publishing 2006 £20.99 (pbk)

(ISBN 1-4051-334-1) 208pp

Reviewed by Stephen Timmons, *University of Nottingham*

There is a continuing interest is sociological studies both of the workplace, and of health care. Thus, as Allen and Pilnick argue in their introduction to this monograph, there is a continuing

need for this body of work that considers issues like the division of labour and professionalism in health care. What is immediately striking about this book is the continuation of this field's strong empirical tradition, perhaps in part due to the fact that many sociologists of health and illness work in schools of medicine or nursing, rather than sociology. Indeed, several authors of this monograph are themselves practitioners, or former practitioners.

The introduction situates all of the papers in the book within the context of wider sociological theory. The papers are then divided into three sections. One section comprises studies integrating macro-micro-meso approaches in order to understand the organisation of health care. A second section incorporates studies which focus on organisational attempts to control and standardise professional practice, principally through technology. A final section examines occupations and their boundaries. The first section in particular, is strongly international in focus, though most of the other studies reported are UK-based.

One of the overarching themes that struck me in this volume was the tension between managerial-rational approaches to health care, especially mediated via technology, and professionals seeking to defend their autonomy. Elements of this can be found in the papers by Germov, Pinder et al, Will, Greatbatch et al and Goodwin. What was interesting was how successfully the professionals have been able to defend their autonomy, using the systems (both managerial and technical) in flexible ways not anticipated by the managers. Whether this is genuinely in an attempt to provide better patient care, as the professionals claim, is hard to judge. It does, however, suggest that much of the coverage in the mainstream and professional media that presents an image of professionals increasingly circumscribed by 'bureaucratic' requirements is not, perhaps, telling the whole story.

A second theme of interest is that of professional boundaries. Pinder et al, in their study of care pathways present a more positive view of professional boundaries than is usually found in the literature. For these authors, 'professional boundaries are not just bastions of rigidity, but important sources of identity and belonging'. This suggests an interesting new direction for research in this area. Goodwin et al show how working across professional boundaries can cause practical problems, especially for lower status professionals like nurses and Operating Department Practitioners. They suggest that expanded roles for these groups of professionals, governed (as they are likely to be) by medical-controlled protocols may even exacerbate the kinds of difficulties they describe. I think both of these chapters show very nicely how sociological theories and analysis can explain genuine practical problems in the delivery of health care. The difficult bit, in my experience, is persuading some doctors and NHS managers of the value of these insights.

The difficulty with any edited volume is making the connections between the different chapters. In this case, the connections are there, made easier to see by a helpful introduction, although it does still demand some thought on the part of the reader. The real strength of this monograph is the up-to-date, high quality empirical work reported, which sheds real light on important issues, both theoretical and practical.
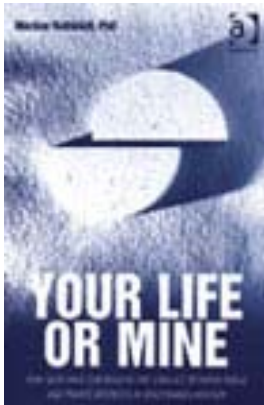
Martine Rothblatt

Your Life or Mine: How Geoethics Can Resolve The Conflict Between Public and Private Interests in Xenotransplantation

Ashgate Publishing Limited 2004 £55.00 (hbk)

(ISBN: 0 7546 2391 2) 198pp

Reviewed by Kelly Joyce, *College of William and Mary*

As of September 30th, 2007, the United Network for Organ Sharing [UNOS] reported that 97,515 people are on the waiting list for organ transplants in the United States. UK Transplant states that 7,416 people are actively waiting for organ donations in the United Kingdom. Yet, the demand for organs far exceeds the supply. People can wait for a transplant for long periods of time, and some will die before a match is found. For Martine Rothblatt (p.2), this problem is not a small one that can be solved by simply increasing volunteer organ donations, but is instead a large problem, one that requires sustained analysis and a creative, innovative solution.

In *Your Life or Mine,* Rothblatt focuses on the United States and the United Kingdom in exploring the issue of organ transplantation. Although she occasionally extends her analysis to include Canada, Japan, and other European countries, the U.S. and U.K. provide the main sources of data for this book. In Chapter 1, Rothblatt provides an overview of the history and current state of organ transplantation. She also examines possible legal solutions to organ shortages such as laws that mandate cadaver organ donation and/or giving up spare organs to those in need, as well as laws that permit the selling of spare organs. These laws could alleviate organ shortages, but they are unlikely to be created. Popular resistance to both government regulations requiring donations and the practice of paying individuals for body parts create cultural barriers to their implementation.

In Chapter 2, Rothblatt explores technological solutions to organ shortages, investigating pure machine replacement organs, hybrid bio-artificial organs, and biological replacement parts grown in labs or in animals. Beginning with historical efforts to replace human limbs with mechanical substitutes, the chapter surveys attempts to create machine organs, hybrid bio-artificial organs, and organs grown from the intended recipient's own, or another person's cells. Such technological solutions, however, are not developed enough to successfully address organ shortages. Although some of these efforts may prove fruitful in future years, they are in early stages of research and innovation and cannot provide organs for recipients now.

After explaining why many of the legal and technological solutions will not work, Rothblatt presents her main argument: xenotransplantation, or the grafting of animal organs or tissues into humans, as the solution to organ shortages. For Rothblatt, xenotransplantation is a viable solution because; (a) the public is likely to accept it, and (b) there is a body of work that demonstrates successful short term liver and pancreas transplants from animals to humans as well as successful transplants of hearts from pigs to primates. Although further research and development is needed to make xenotransplantation a usable technique, Rothblatt

suggests that this option is the most feasible of the technological fixes.

The remaining chapters of the book are dedicated to exploring the details of xenotransplantation implementation. In Chapters 3 and 4, Rothblatt discusses possible risks to humans and to animals. Infectious diseases are the main risk to humans, and there is concern that diseases could hop from animal organ to human recipient, causing them to spread more widely among the human population. Proper screening of animal donors and human recipients, however, should be able to counter this risk (p.48). The risks to animals receive sustained analysis. Rothblatt concludes that pig, the most likely animal to be used in xenotransplantation, can be used for organ harvesting if they are ethically treated during their lifetime and are killed in a way that does not prolong pain or suffering (p.95).

Your Life or Mine concludes with the transformation of bioethics (with its focus on how doctors treat individual patients) into geoethics, or a set of world-focused norms (p.141). Due to the possible public health effects, a global organization, that Rothblatt calls a global enforcement organization, for xenobiology (GEOX), will have to be created to monitor porcine organ transplants. A GEOX would 'certify that porcine organs used in xenografts come from specified pathogen free herds that are raised and sacrificed in an ethical manner' (p.144), oversee a network of surveillance stations aimed to monitor disease in human recipients, and ensure global inclusiveness so poorer countries could participate in transplant programs. The organization would be funded from a xenotransplant tax of $13,000 per organ levied on the pharmaceutical companies selling porcine organs (p.153). A GEOX enacts geoethics since it will protect and serve the interests of all nations not just individual patients.

Your Life or Mine will engage those who work in bioethics. It allows readers to wrestle with conceptions of rights in relation to animal welfare as well as weigh individual rights versus public health concerns. Rothblatt's development of the concept geoethics pushes discussions of ethics into rewarding directions that recognize the importance of thinking about risk and disease through a global lens.

The book, however, lacks a sustained analysis of the relations between power, inequality, and the implementation of a geoethics program. For example, Rothblatt notes that the United States did not adopt the 'Cartagena Protocol on Biosafety to the Convention on Biological Diversity' in 2000. Yet analysis of the reasons why the U.S. may or may not join a GEOX are missing from her work. In-depth discussion of the reasons pharmaceutical companies may or may not pay the GEOX tax are also absent. The neglect of such issues makes it harder to imagine how a GEOX would be formed and maintained. Nonetheless, the historical and empirical data on transplantation practices provide a good resource for readers. Rothblatt is to be credited for her descriptive work and willingness to wrestle with the ethical dilemmas of organ transplantation.

Submitting a book review

MSo welcomes the submission of book reviews within the discipline of medical sociology. A list of books available for review will be published in each edition (see below), and books may be obtained from the editorial team. However, the editorial team will also be happy to consider reviews of books not listed, provided they are of relevance to the medical sociology community. There is no prescribed format for reviews, although reviewers should provide the full reference of the book, including the price, number of pages and the ISBN. Book reviews should be no longer than 1000 words. Completed reviews should be submitted as a Microsoft Word document via email to mso@liverpool.ac.uk. Book reviews will not be subject to peer review, and the decision to publish will be made by the editorial team. The editorial team also reserve the right to edit articles prior to publication.

The editorial team would also strongly encourage readers of MSo to specify particular areas of medical sociology that they would like to see book reviews in, or key medical sociology texts they would be interested to read a review on.

Books available for review

Johan Fritzell and Olle Lundberg (Eds) (2007). Health Inequalities and Welfare Resources. Continuity and Change in Sweden. Bristol: The Policy Press.

Penney Lewis (2007) *Assisted Dying and Legal Change.* Oxford: Oxford University Press.

Raymond De Vries, Leigh Turner, Kristina Orfali and Charles L. Bosk (Eds) (2007) *The View from Here: Bioethics and the Social Sciences.* Oxford: Blackwell.

William Cockerham (2007) *Social Causes of Health and Disease.* Cambridge: Polity Press.

Andrew Webster (2007) *Health Technology & Society: A Sociological Critique.* Basingstoke: Palgrave Macmillan.

Sahra Gibbon and Carlos Novas (Eds) (2007) *Biosocialities, Genetics and the Social Sciences: Making Biologies and Identities.* Oxford: Routledge (Taylor and Francis Group).

Elizabeth Dowler and Nick Spencer (Eds) (2007) *Challenging Health Inequalities: From Acheson to 'Choosing Health'.* Bristol: The Policy Press

If you wish to review one of books listed above please contact the editorial team, mso@liverpool.ac.uk

Sociology of Health and Illness Book Prize 2007

The British Sociological Association (BSA) Medical Sociology Group is pleased to announce the winner of the 2007 Sociology of Health and Illness book prize which was awarded at the groups Annual General Meeting (on 7th September 2007, Adelphi Hotel, Liverpool).

The prize of £1,000 was awarded to Stefan Timmermans (UCLA) for his publication **Postmortem: How Medical Examiners Explain Suspicious Deaths.** Published by the University of Chicago Press, 2006.

Stefan's book was nominated by Professor Jonathan Gabe (Royal Holloway, University of London).

This excellent book investigates how medical examiners do their work, and their connections to groups they usually serve: the criminal justice system, the medical establishment, bereaved family members and public health interests. Based on a three-year study of a single examiner's office in the USA (serving a population of more than a million) Timmermans traces how medical examiners remain near the bottom of the medical hierarchy, finding it difficult to attract new practitioners and governmental resources. They are also wary of their critics: grief struck families wishing to avoid the stigma of death by suicide certification, distraught parents that could be charged with crimes of child abuse, and public ridicule if their autopsy findings are found to be deficient in criminal investigations, leading its practitioners to take a conservative stance. Now the profession confronts new challenges as organ and procurement organisations seek to compromise its tradition roles.

Timmermans' book stands out for a number of reasons. First it took considerable courage to venture into a place that few sociologists would dream to tread to undertake sociological observations: the autopsy room of a medical examiner's office, where he observed more than 200 autopsies over a three year period. In our death-denying culture, observing death and the sights and odours that those who perform death-work experience daily at such close quarters took a steely determination.

Second, Timmermans makes a good case for what he calls a 'medical sociology of practice' - a sociology that privileges what pathologists actually do rather than what they say they do. Using this approach has enabled him to reconstitute the 'network of their work' in a nuanced way. And it has also highlighted how the substantive content of medicine is shaped by policies, relationships and other structural elements.

Third, and finally, Timmermans makes an important contribution to the sociology of the professions. He shows how the work of medical examiners can be understood in terms of both professional and cultural authority, and argues for an analysis which takes a middle path between Light's countervailing powers with its focus on the larger organisational context, and Freidson's privileging of the autonomy of the workplace. Timmermans shows that in the case of medical examiners the distinction between the workplace and the broader organisational arena is untenable. In order to maintain forensic authority medical examiners are required to consider the interests and needs of various external parties while investigating death, but the work itself determines the extent of third party involvement.

In sum Timmermans has produced an insightful and conceptually astute analysis, which has made a major contribution to our understanding of both the everyday work of the medical examiner and their status as members of a medical profession whose power is being challenged.

CURRENT RESEARCH

This section allows researchers and postgraduates to share details of new and current research projects and recently awarded research grants of specific interest to medical sociologists. If you would like to include details of your own current research or recent award in the next edition of MSo please go to: http://www.medicalsociologyonline.org

Rheumatoid arthritis (RA), well-being and the development of a patient-generated core-set (working title)

PhD Candidate:

Ms Tessa Sanderson,

University of West of England (UWE)

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Tessa Sanderson began her PhD in October 2006 on a full-time basis and expects to complete in September 2009. Funded by the Arthritis Research Campaign, the thesis currently has the working title of: 'Rheumatoid arthritis (RA), well-being and the development of a patient-generated core-set.'

Supervisors

Professor Sarah Hewlett (UWE)

Professor Michael Calnan (Bristol University)

Dr Marianne Morris (UWE)

Ms Pam Richards (Patient Research Partner)

Aims and Objectives

To establish treatment outcomes which are important to patients and explore perceptions of well-being, normality and health in RA;

To develop a patient-generated core set of treatment outcomes with RA patients and pilot a comparison of their responsiveness to professional core sets.

Methods

A multi-phase, mixed method approach will be used. The collection of treatment outcomes and the exploration of well-being and normality will be undertaken through in-depth interviews with rheumatoid arthritis patients on anti-TNF therapy and other types of medication. The second phase will use Nominal Group Technique with patients at the Bristol Royal Infirmary and a postal questionnaire with members of a national arthritis charity to prioritise treatment outcomes and decide what outcomes are chosen for the patient-generated core-set. The third phase will pilot a comparison of the patient core-set and existing professional core-sets.

Description of argument/results to date

RA treatment includes biologic agents which are a group of drugs called anti-tumour necrosis factor (anti-TNF) therapy. Anti-TNF therapy has been shown to be highly effective in the treatment of RA in randomised controlled trials and clinical practice (Bathon, Martin et al. 2000); (Geborek, Crnkic et al. 2000). Improvements have been observed in both symptoms and function. In addition, patients have reported feeling well in themselves, often for the first time in years, and that the improvement has been 'life-changing' (Marshall, Wilson et al. 2004). However, the study did not define what concepts such as well-being mean to patients. In addition, current assessments of RA to measure disease activity and regulate access to treatments do not address well-being or normality.

References

Bathon, J.M., Martin, R.W. and Fleischmann, R. (2000) A comparison of etanercept and methotrexate in patients with early rheumatoid arthritis. *New England Journal of Medicine,* 343: 1586-1593.

Geborek, P., Crnkic, M., Petersson, I.F. and Saxne, T. South Swedish Arthritis Treatment Group (2000) Etanercept, infliximab, and leflunomide in established rheumatoid arthritis: clinical experience using a structured follow up programme in southern Sweden. *Ann. Rheum. Dis.,* 61(793): 798.

Marshall, N.J., Wilson, G., Lapworth, K. and Kay, L.J. (2004) Patients' perceptions of treatment with anti-TNF therapy for rheumatoid arthritis: a qualitative study. *Rheumatology,* 43: 1034-1038.

Stage of Research Process

The literature review has been completed and formed a conceptual framework for the interviews. The patient interviews are currently being analysed and recruitment is due to begin for the nominal groups in the autumn.

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CONGRATULATIONS

Carol Kingdon

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Congratulations to Carol Kingdon who was awarded her PhD in November 2007 for her thesis entitled 'Re-visioning choice through situated knowledges: women's preferences for vaginal or caesarean birth.' Carol's PhD was awarded by Lancaster University and was funded by a Department of Health Training Fellowship Award.

Abstract

Two of the most contentious issues in contemporary British obstetrics are whether planned caesarean sections are as safe as planned vaginal births, and whether maternal choice should extend to a woman's right to a planned caesarean section without a medical indication. The purpose of the thesis is to increase understanding of the pivotal, yet relatively unexplored relationships of women experiencing pregnancy and birth for the first time to these debates. The thesis is primarily concerned with *how* individual women come to know, and to express a preference for a vaginal or planned caesarean birth. Through the application of Donna Haraway's notion of 'Situated Knowledges' the thesis locates existing claims to knowledge about women's views of vaginal and caesarean birth in the particular contexts in which they were produced. I argue for the importance of recognising knowledge production as both located and embodied. Drawing on interview and questionnaire data from 443 women who participated in the empirical aspects of the thesis, I demonstrate how women come to know vaginal and caesarean birth. I argue that these women demonstrate a never ending process of *'coming to know'*, where knowledge about birth is located in their bodies as well as their understanding.   I assert that these hitherto unreported insights into *how* women are continuously coming to know different ways of giving birth adds weight to the need to acknowledge the situated character of all knowledge production. Moreover, to recognise the 'situatedness of knowledges' has implications for the notion of choice that currently prevails in contemporary debates about childbirth. The thesis concludes by arguing for a re-visioning of the concept of maternal choice in the current debates about vaginal and planned caesarean birth in Britain.

Related publications

Kingdon (2005) Reflexivity: Not just a qualitative methodological tool. *British Journal of Midwifery*, 13 (10): 622-627.

Kingdon C, Baker L, Lavender T. (2006) A review of nulliparous women's views of planned cesarean birth: The missing component in the debate about a term cephalic trial. *Birth: Issues in Perinatal Care,* 33 (3): 229-237.

Kingdon, C. (in-press) Do British newspapers promote the idea that women are demanding caesarean birth? *New Digest*.

Related conference presentations

Kingdon, C. (2007) Changing childbirth? Women's accounts of vaginal and planned caesarean birth. *Birth: The cultural politics of reproduction an interdisciplinary conference.* Lancaster University, 7th March

Kingdon,C. (2007) 'There is no choice':Women's accounts of vaginal and caesarean birth during pregnancy and after their first experience of childbirth. *BSA Medical Sociology Group 39th Annual Conference*, Adelphi Hotel. Liverpool, 7th September

Current and future work

Carol has a number of papers arising from her PhD in preparation. During the next twelve months she hopes to complete these papers, secure funding for post-doctoral work and submit a book proposal for a single-author monograph. Carol will also continue in her current role as a Research Fellow in the Department of Midwifery Studies at the University of Central Lancashire (UCLan) gaining teaching experience and completing a commissioned book entitled 'Sociology for Midwives.'

Sara E. Shaw

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Congratulations to Sara Shaw who was awarded her PhD on the 26th of October 2006 for her thesis entitled, 'Out of Utopia: The Re(Production) of Primary Care Research Policy.' Her PhD was funded through a Department of Health Researcher Development Award.

Abstract

This research challenges conventional approaches to policy analysis and shows how a discursive approach can add essential insights to contemporary policy debates. I investigate primary care research policy-making as a socially accepted set of practices, asking: what are the origins of primary care research in England? Which discourses have dominated the debate, and why? What are the tensions between discourses and any potential means for coping with these?

I draw on the theoretical and methodological approach of discourse analysis and use Ian Parker's framework for distinguishing discourses to inform the selection and analysis of 29 policy documents (from 1971 to 2005) and 16 historical and contemporary policy stakeholders for in-depth interview. Identification of discourses is aided through importing relevant theory; applying focused questions; exploring the use of rhetorical devices; incorporating contextual information to appreciate how and why discourses are shaped; and comparing and contrasting policy language.

Findings show how primary care research policies have shaped and been shaped by prevailing discourses. Political emphasis on a primary care-led NHS in the 1990s led to increased political recognition and favourable changes in the research budget. However, the utopian era that followed fell into decline as primary care research no longer aligned with scientific, economic and global discourses emphasising microscopic 'discovery'; exploitation of information; large-scale consumption; and the contribution of highly technological activities to 'UK plc'. Unable to compete on these terms, primary care research has been repositioned as a strategic resource and population laboratory for epidemiological research.

Related publications

Shaw, S.E. Driving out alternative ways of seeing: the significance of neo-liberal policy mechanisms for UK primary care research. *Social Theory & Health*, in press.

Shaw, S.E., Carter, Y.H, Greenhalgh, T. and Macfarlane, F. Can health research policy be shaped? Lessons from the UK experience. *Harvard Health Policy Review*, in press.

Written work in progress

Shaw, S.E. and Greenhalgh, T. Best research – for what? Best health – for whom? A critical exploration of primary care research policy using discourse analysis.

Shaw S.E. Policy-as-discourse: reaching the parts that other theories and methods can't reach.

Related conference presentations

Shaw S.E. (2007) Research policy as discourse: what does it mean and where does it get us? Liverpool, BSA Medical Sociology Annual Conference 6-8 September.

Shaw, S. and Greenhalgh, T. (2006) 'Out of Utopia': a critical analysis of primary care research policy in England. Keele: Society of Academic Primary Care (published in *Family Practice* 2006; 3(S1). Awarded plenary session as one of highest scoring abstracts.

Shaw, S.E. (2007) Controlling primary care research: whose fingers in whose pies? Oxford, Politics of Health Group Annual Conference 30-31 August.

Shaw, S. and Greenhalgh, T. (2005) In the eye of the storm: politics, power and primary care research policy in England. Federation of Primary Care Research Organisations, Bristol, 28-29th November. Awarded first prize for best paper presentation.

Current and future work

Based at University College London, Sara is now supported by an ESRC/MRC Interdisciplinary Postdoctoral Fellowship until October 2008. This is allowing her to build on her PhD research and develop a programme of work focused on the development and implementation of health research policy; as well as wider methodological and theoretical work relating to policy and research.

CONFERENCE REPORTS

This section provides an opportunity for members of the medical sociology community to report on recent conferences or other events that they have attended. We welcome brief, insightful commentaries on events that are likely to be of interest to readers of MSo, and if anyone who is attending a conference wishes to write a review, please get in touch with Clare Thetford at MSo@liv.ac.uk.

Making connections between organisation studies and medical sociology to study the management of change in health care systems

Report of a symposium organised as part of the BSA Medical Sociology Group Annual Conference, Liverpool, 6-8 September 2007

Graham Currie

Nottingham University

At this year's Medical Sociology Conference in Liverpool, Professor Graeme Currie from Nottingham University Business School convened a symposium to discuss connections between organisational studies [OS] and medical sociology [MS] to study the management of change in health care systems. The symposium panel consisted of Graeme Currie, Rachael Finn, Justin Waring (University of Nottingham), Celia Davies (London School of Economics), Sue Dopson (University of Oxford), Cathy Pope (University of Southampton).

The symposium represented a response to calls for MS to reach out to other disciplines. Lesley Griffiths, for example, in the silver anniversary issue of *Sociology of Health and Illness* argued that MS should move beyond the boundaries of its increasingly narrow sub-field to incorporate insights from other disciplines and so enhance our understanding of health care delivery (Griffiths, 2003).

With respect to its relationship with OS, commentators have argued that MS has given limited attention to the significance of new organisational forms and approaches to health care management, 'with no strong sense of a growing corpus of work on the theme of organisations' (Davies, 2003: 178). At the same time, the OS perspective has often been informed by managerialist assumptions, potentially marginalising the voices and issues of certain stakeholders. For OS, it is argued that the need for more critical analysis can be met by a more sociologically informed approach to change management (Learmonth, 2003). Consequently both disciplines might benefit from a more integrated approach, which draws upon their respective theoretical and empirical contributions, to understanding health and healthcare in contemporary society.

Panel speakers were drawn from across the OS (Currie & Dopson) and MS (Davies, Finn, Pope & Waring) divide and invited to make connections between MS and OS. Each speaker was invited to make a short presentation that focused upon the following to engender wider audience discussion:

- Why have MS and OS diverged?

- What are the possibilities and value-added of connecting MS and OS?

- What are the limits to making connections between MS and OS?

- What does the future hold for making connections across MS and OS?

Currie and Dopson presented a spirited defence of business schools in which organisational studies is located. They highlighted that business schools were pluralist places in disciplinary and methodological terms and that organisational sociologists were well represented in organisational behaviour divisions within business schools. Further, they argued business schools (at least some of them that were more critical in Europe) were increasingly serving a wider group of stakeholders beyond shareholders and management. This move away from the

'bottom line' was aligned to a business in society perspective. The less managerialist emphasis of business schools was reflected in a number of conferences in the OS field where MS academics might find a 'home' community: for example, Critical Management Studies [CMS]; European Group for Organisational Studies [EGOS]; Organisational Behaviour in Healthcare [OBHC].

Finn and Waring provided a reflexive account of their career development and the difficulties of working in the liminal space between MS and OS. Integrating OS and MS offered opportunities for academic study, but didn't fit comfortably with institutionalised career paths, which were likely to drive you down a business school or sociology/social policy trajectory. All presenters lamented the influence of the Research Assessment Exercise [RAE] upon this.

Pope explained the development of MS as a consequence of its Marxist roots within the context of Thatcherism in the 1980s. Pope suggested it made sense, at the time, to keep a low profile and identify with the 'underdog'. In the case of MS, the focus of research moved towards the patient and their interaction with clinicians.

Davies suggested that both communities 'should get out more' otherwise they risked marginalisation from policy in the case of MS and missing important, long standing sociological insights in the case of OS. Davies referred to a recent paper by Carl May (2007) in *Sociology* that argued it was time for MS academics to put its traditional concerns about the clinical encounter in its context, notably that it was constrained or facilitated by organisational and managerial arrangements. In particular, MS academics might attend more to funding offered by the NIHR SDO programme to drive their research.

Given the positive audience response to presentations, with David Hughes and Robert Dingwall prominent amongst those in the audience reinforcing the need to more effectively build a bridge between OS and MS, the debate will continue. We are hopeful that we can obtain funding to develop a seminar series focused upon making connections between OS and MS. Let's waltz together!

Symposium Convenor: Professor Graeme Currie (Nottingham University Business School)

Contact: graeme.currie@nottingham.ac.uk

References

Davies, C. (2003) Some of our concepts are missing: reflections on the absence of a sociology of organisations. *Sociology of Health and Illness*, 25(Silver Anniversary Issue): 172-90.

Griffiths, L. (2003) Making connections: studies of the social organisation of healthcare, *Sociology of Health and Illness*. 25(Silver anniversary issue): 155-71.

Learmonth, M. (2003) Making health services management research critical: a review and suggestion, *Sociology of Health and Illness*, 25,1, 93-119.

May, C. (2007). The clinical encounter and the problem of context. *Sociology*, 41(1): 29-45

Thinking through science, technology and medicine: what medical sociology and science and technology studies (STS) can learn from each other

Report of a symposium organised as part of the BSA Medical Sociology Group Annual Conference, Liverpool, 6-8 September 2007

Richard Tutton

Lancaster University

In recent years, partly perhaps as a consequence of a growing interest in the implications of the life sciences, the medical sociology conference has attracted an increasing number of presenters from the social studies of science and technology, bringing new theoretical frameworks, questions, problems, and areas of research to discussions at these meetings. The purpose of the symposium, 'Thinking through science, technology and medicine: what medical sociology and science and technology studies (STS) can learn from each other', was to build on existing exchanges between the broad fields of social studies of science and technology and medical sociology, and continue a dialogue that has the potential to enrich both disciplines.

The symposium was organised around two key – and interrelated -- themes that are in many ways central to both fields of inquiry: the construction and contestation of different forms of scientific, medical, technical and experiential knowledge; and the development, shaping and impact of technologies in relation to social practice (in its broadest sense).

The symposium was organised by Richard Tutton (formerly of the Institute of Science and Society, University of Nottingham and now of the ESRC Centre for the Economic and Social Aspects of Genomics – Cesagen – at Lancaster University) and involved four invited speakers. These speakers were selected to represent their 'discipline': the first two speakers were David Armstrong, Professor of Medicine and Sociology, (Kings College London) and Sujatha Raman, Lecturer in Science and Technology Studies at the ISS, University of Nottingham. They addressed the theme of knowledge from their respective backgrounds of medical sociology and STS. On the theme of technology, the speakers were Steven Wainwright, Professor Sociology of Medicine, Science & the Arts at the Centre for Biomedicine and Society (CBAS) and Nik Brown, Senior Lecturer in the Sociology of Science and Technology (University of York). Somewhere in the region of 35-40 delegates attended the symposium and actively contributed to the lively debate.

In summary, speakers at the symposium both from the podium and the floor spoke positively about the relationship between the fields of medical sociology and STS, which have seen some productive convergences in the last decade thanks in part to the 'biomedical turn' within the latter. Substantial public funding of social science research into new health technologies and developments in human genomics, and the 'life sciences' more generally has been an important driver in this context. Convergences between the two fields has also been given some institutional depth by the creation of the Centre for Biomedicine and Society (CBAS) and other centres such as the Department of Sociology at Sussex and ISS at Nottingham that position themselves as drawing upon both medical sociology and STS. Steve Wainwright also pointed out that four of the last six SHI book prize winning titles were authored by researchers associated with the broad field of STS (Lock, Mol, Hedgecoe and Timmermans).

There were, however, some asymmetries in the relationship between medical sociology and STS. While researchers in the latter had become greatly interested in medicine and medical technologies, medical sociologists had not engaged as much with the production of medical knowledge itself either in the clinic or in the lab. David Armstrong in particular was concerned that medical sociology was still being drawn into medicine's own agenda without looking critically at these issues of knowledge production. While medical sociology had many strengths relative to STS when it came to studying the 'downstream' use of technologies for instance, Armstrong argued that medical sociologists still have yet to grasp the opportunities of STS in relation to the study of biomedicine. Therefore, while medical sociology could contribute meaningfully to inform discussions within STS about medicine, perhaps STS could also shape the way medical sociologists thought about technology.

The success of this symposium and the one that was organised by Graeme Currie (University of Nottingham) earlier in the morning of the second day of the conference (as reported in this issue) has encouraged the conference committee to canvass ideas for future symposia. If you have a suggestion for a symposium at the 2008 conference, then please email Richard Tutton at r.tutton@lancaster.ac.uk by 31 January 2008.

Mental Health and Human Rights: Sociological Perspectives

Report of the second British Sociological Association Medical Sociology Group Sociology of Mental Health Study Group symposium, 22nd June 2007, University of Warwick

Lydia Lewis

University of Warwick

This year's event was again a resounding success with fifty delegates from a variety of organisational backgrounds, including academics and students, those working in the voluntary sector, including members of service users groups, and health service providers and practitioners, attending from across the UK and Ireland. Funding was gratefully received from the Sociology for Health and Illness Foundation, and the Study Group was also grateful for support from the British Sociological Association [BSA] and the University of Warwick.

The day began with an introduction to the Sociology of Mental Health Study Group, the sociological study of mental health and human rights, and the event from Lydia Lewis, Study Group co-convenor. It was noted that the volume of abstracts received had made for an interesting introduction of parallel sessions during the day, and that a variety of themes relating to mental health and human rights would be addressed, encompassing:

- Conceptual and historical background to the area

- The current mental health policy and political milieu

- Experiences of using mental health services and the social regulation function of services

- Medicalisation and the social framing of mental health and distress

- The effect of social inequalities on mental distress

- The mental health consequences of violence for women and women's service responses

- The actions of user/survivor groups

- Societal reactions to those experiencing distress

Delegates were invited to browse the display stands, which included promotional materials for the *British Sociological Association*, including its 'sociologists outside academia' initiative, and materials and publications from the *Social Perspectives Network*.

The morning plenary session, **Understanding human rights: policy and political responses**, was subsequently introduced. Presentations were received as follows: *Beyond libertarianism and the behavioural state: Towards a framework for analysing fundamental (mental health) rights,* Mick Carpenter, University of Warwick; *The 'Rights' of 'Self-Harm Survivors' and the Role of the State,* Mark Cresswell, University of Manchester; *Social Inclusion: a human right or another form of oppression?,* Helen Spandler, University of Central Lancashire. All three presentations were extremely well received, spawning a number of questions and a great deal of discussion among audience members.

The lunch break provided a valued opportunity for discussion of the morning's proceedings to continue, and for delegates to meet and talk with colleagues, old and new. This

was followed by the screening of a film, *Bewitched, bothered and bewildered,* directed by Didem Pekun, Goldsmiths College, and featuring Margaret Jessop, Service User Reference Panel for the Mental Health Act Commission. Delegates enthusiastically discussed with the presenters the film which included the personal experience of coercive treatment within mental health services. Issues to emerge included how human rights abuses within mental health services can relate to a lack of knowledge and understanding, and the importance of simply talking and listening to those using services. The discussion closed with a request from Didem for anyone interested in participating in or using a subsequent film about mental health she is planning to make to contact her (didemp@yahoo.com). Lydia noted such films to be a powerful medium and thanked the presenters for their contribution.

The symposium then broke into parallel sessions as follows:

Parallel session (a): Contested knowledges and the politics of experience

Chaired by Mark Cresswell, University of Manchester, and Suzanne Hodge, University of Liverpool. Presentations were delivered as follows: *The Annihilation of Subjective Experience in Schizophrenia Research: Whither Human Rights?,* Alastair Morgan, University of Nottingham, Tim Calton, University of Nottingham and Caroline Flood, Nottinghamshire Healthcare NHS Trust; *An investigation of controversies around human rights of patients with ADHD,* Pooria Sarrami-Foroushani, University of Nottingham. Following a break, the session resumed with two further presentations: *Myths and their objects: social and political implications of women's alcohol use,* Patsy Staddon, University of Plymouth; *Why women?* (film screening about the effects of violence on women's mental health), discussion facilitated by Lydia Lewis.

Parallel session (b): Service responses and the experiences of service users

Chaired by Mick Carpenter, University of Warwick. The following presentations were received: *The adverse effects of imprisonment on Deaf prisoners' mental health: a Human Rights perspective'?,* Amy Izycky and Manjit Gahir, Nottinghamshire NHS Trust; *Going up in smoke? Human rights, smoking and governance of the body in mental health,* Jo Warner, University of Kent; *Confidentiality in Mental Health Services: Negotiating the negotiated order?,* Tony Evans, University of York. Following a break there were two further presentations: *Experiences of Acute Mental Health Services among Black and Minority Ethnic Groups,* Rubina Jasani, Sarah Pemberton and Laura Griffith, Warwick Medical School; *Mental Heath Victimisation: A Hidden Barrier to Recovery,* Tony Colombo, University of Coventry.

All presentations were again extremely well received, each generating a variety of questions and comments, as well as lively discussion and debate during the interval.

Delegates then convened for a closing discussion of the day's proceedings. A number of themes that had emerged during the day were raised, including:

- the overlooking of subjective, or personal, experience within mental health research, policy and services as a form of human rights violation;

- the dominance of medicalised understandings and responses in the mental health field as bound up with human rights abuses;

- coercive treatment in services and how debates about 'capacity' seem to

forestall challenges to this;

- the regulation of mental health professionals and the provisions of the new Mental Health legislation being debated in England and Wales;

- the current crisis within mental health services in Britain, in which there seems to be a lack of reflection about what services should be providing, with service change instead being driven by managerialism.

Delegates also discussed the work of sociologists of mental health in light of the day's proceedings. The following points were made:

- One role for those engaged in qualitative social research is to engage in a critique of the idea that you can 'measure' social phenomena in a concrete, accountable way. Social research can therefore contribute to knowledge and understanding by collating people's stories, speaking out about experiences, and problematising issues which can become submerged.

- The need to reflexively consider the relationship between grassroots organisations and social research – how research collaborations can be forged and how such organisations contribute to knowledge and impact the way we think about our own research. Reference in the film screenings to user groups and women's organisations had highlighted this.

- The screening of the 'Why Women' film had also highlighted how women's subjective experiences are often sidelined and how the feminist agenda still needs elevating. It was felt that consideration of women's rights and women's subjective experiences, and of the challenges that still exist in this arena, needs to be at the forefront of debate if this is to empower women and men and service users, and if progress is to be made.

- In sociology and social policy, and in order to receive funding, the emphasis now seems to be more on applied work, and in this light we need to openly consider the politics of our own work and 'whose side we are on'.

- In sociological work relating to mental health and human rights, there can be a danger in focusing too much on negative actions that damage people or else on questioning good health, at the expense of considering the positive social factors which enhance mental health. Thus one of the attractions of a capabilities approach is that it tries to direct you to the conditions which help people to flourish. A human rights approach offers us a way of bringing all of these matters together.

In summary, it was noted that the proceedings of the day had highlighted the relevance and contribution of a human rights approach to matters of mental health and distress, along with our role as sociologists - and as public sociologists – in addressing concerns in this area through: research work and teaching practices; (critical) discourse practices; and political engagement with those working outside academia. The BSA's public sociology agenda was acknowledged in this regard.

Everyone was thanked for their attendance and for making the day such a success. Mark Cresswell thanked Lydia Lewis for organising the day.

A longer report of the event, including a summary of evaluation feedback, is available on the

Sociology of Mental Health Study Group web site:

http://www.britsoc.co.uk/specialisms/MedSocMentalHealth.htm

Acknowledgements

Well Spoken: Storytelling and Narrative in Healthcare

Report of a conference co-organised by the University of Central Lancashire and the Northern Centre for Storytelling. Grasmere, The Lake District, 15-17 June, 2007

Julie Ellis

University of Sheffield

After relentless and heavy rain had been pummelling South Yorkshire in an unusually damp June, I arrived in the Lakes feeling somewhat washed out but hoping to be rejuvenated by the beautiful scenery and the diverse and promising schedule which lay ahead. It was evident from the advertised programme that this would be no 'ordinary' conference and I have to say, in search for something a little different, I was not disappointed.

Presented as an opportunity for practitioners, researchers and storytellers alike, to explore the interface between storytelling, research and practice, the weekend not only delivered what was promised; but also surpassed these aims in many ways. Taffy Thomas (an exceptional storyteller and Artistic Director for the Northern Centre for Storytelling) and his wife, and co-organiser of the centre, Chrissy Thomas, used their own illness story to facilitate an experiential and emotive learning environment which added something, that I had not previously encountered, to the conference experience. Taffy's performance entitled 'Take these chains from my heart' which opened the conference on day one, told his biographical story of living with illness. It was a tale which was energised with moving prose, powerful songs and a beautiful musical accompaniment. For me, it was this initial story which brought the subsequently presented strands of theory to life, and enabled the themes of the weekend to remain with me, and in my thoughts about research for some time.

The format of the two days was a mixture of papers, performance and creative workshops, with time after each for questions, discussion and reflection. There were excellent and thought-provoking papers given by Professor Arthur Frank, Professor Mike Wilson and Professor Bernie Carter which posed, amongst others, questions about storytelling in relation to identity, ideology, morality, sense-making, context, form and process. Frank in particular made an interesting point in exploring the distinction between 'thinking with stories' and narrative analysis in social science research. In a presentation which made some useful parallels between stories collected in everyday life and stories as a method of communication in research encounters, the accomplished storyteller Peter Chand shared experiences from his work as a storyteller within communities in India and the UK. Later that evening, using only his voice and a memory crammed with stories, we were treated to a magical performance of 'Mangoes on the Beach'. For that hour or so I certainly was not on familiar 'academic' conference territory, as I found myself transported from the village hall in Grasmere to the shores of places far away from the Lakes, and from my usual imaginative boundaries.

Such a range of presentations, reflecting the different disciplinary and experiential backgrounds of the presenters, sparked interesting debate among the equally diverse delegates. Important theoretical and practice-related questions were raised that more often than not cohered differing viewpoints in discussion about a common purpose of attendance. This being to think about the place and significance of storytelling in the arena of healthcare. The interdisciplinary nature of the event meant that many of our own stories about working, researching or storytelling in a healthcare context were shared over the course of the two days. This added an extra reflexive dimension to the conference as we each tried to convey and communicate to others from different backgrounds, how the experiences in our lives as

situated people, seeking to understand particular stories in a particular context, brought us to Grasmere for the weekend. In addition there was also ample opportunity for delegates to actively participate and contribute to the shape of the two days with their involvement extending beyond the usual conference format of asking questions. Creativity was encouraged in sessions where attendees could try their hand at the art of storytelling with instruction and guidance from the master Taffy, and also in written tasks such as the 'graffiti wall' and 'a postcard home', where there was the opportunity to reflect on the place of story within one's own personal and professional life.

The weekend generated a theme which we returned to again and again. The notion that human beings tell stories as a means of making sense, of ordering and understanding experiences and of affirming or negotiating identity and a sense of who they are in their world, is particularly significant when illness, or the threat of it, affects day-to-day life. It has reminded me of the importance of acknowledging that 'my' data is not only 'my' data and encouraged me to consider that how I respond to, handle and represent the insight I gain from participants is about much more than retelling and organising experiences into themes and categories. I'm wondering more critically about the power of stories, about what makes a story a story, about whether there are 'good' stories or 'bad' stories, whether silence can tell a story and about issues of ownership. Since the conference I have indeed been exploring the interface between storytelling, research and practice and as a result have much to consider and work through in the context of my own research.

Acknowledgements

For more information about the Northern Centre for Storytelling, a not-for-profit charitable organisation, please see www.taffythomas.co.uk

Transitions: Health and Mobility in Asia and the Pacific

Report of a Signature Conference of the Australian Research Council's Asia-Pacific Futures Research Network

Organised by the Social Sciences and Health Research Unit, School of Psychology, Psychiatry and Psychological Medicine, Monash University, Melbourne, Victoria, Australia

Terence H. Hull

Australian Demographic and Social Research Institute, The Australian National University

It is seldom that a report on a conference on health and mobility rates comment on performances, poetry, cinematography, and food. But equally, it is rare that all those issues would be integral to an academic program of high quality and true intellectual excitement. This is what happened in Melbourne at the ***Transitions*** conference. It is worth reviewing how the funding body and the organizers brought this about.

The conference was organized around five themes: disaster and violence; population mobility; spread of disease; relationship of health, identity and wellbeing; and politics of health, health activism and social movements. On this foundation, the organisers pulled together 12 plenary presentations and 20 parallel sessions with 62 papers.

Lenore Manderson opened the Conference with acknowledgment of the ownership and custodianship of the land by the Wurundjeri people, the Aboriginal group that lived in the area around Caulfield prior to white settlement. This form of respect for the traditional owners has become an integral part of conferences held in Australia. It is regarded as especially important today, when popular efforts at Reconciliation have not been matched by supportive action from leading politicians including the Prime Minister. Manderson's words were in stark contrast to the stories in the morning newspapers of the Federal Government's announcement of an "emergency" policy in response to reports of sexual abuse of Indigenous children. International visitors were bewildered to read that this policy would resume Aboriginal land in the Northern Territory, place soldiers in communities, and institute a practice of compulsory physical examinations for all children, specifically to identify any kids who had been sexually molested. One Australian participant commented that this policy set Indigenous relations back to 1967, when voting rights and full citizenship were finally given to Aboriginal people. Another commented that the regression was greater than that – more like 1788 when the convict boats arrived in Sydney Cove to take the first bits of land from the traditional owners.

The Plenary sessions were held in a room that had just enough seats for all the participants – not the huge halls that make some conference plenaries look like a Tuesday matinee at the cinema.

Ian Wishart from Plan International and Anthony Zwi from the School of Public Health and Community Medicine at the University of New South Wales led off Theme 1 on Conflict and Violence with presentations on Timor Leste. As with all the other Plenary talks, the presentations served as effective platforms for comment by other experts in the audience. In this case there were a number of Timor Leste citizens – some students and some NGO leaders – who greatly enhanced the points being made by the speakers. This was all the more effective because of the intimate nature of the room that fostered a sense of closeness among

those present.

Parallel sessions caused some concern for a few of the participants. When you have 100 or so participants on site at any given time, and five simultaneous sessions each with three papers, it is expected that there will be some attempt to "paper jump" around the meeting rooms and end up with people being caught in the hallways, deep in networking. Usually that means that some poor graduate student will end up with an audience of three, comprising the session chair and the authors of the other two papers. This did not occur in the sessions I attended, and from what I heard in the tea breaks there were fairly good audiences in all the sessions. Certainly there were good questions and comments, and that is the important thing for the presenters. The papers covered a wide range of topics. I was not surprised to see so many presentations using the now ubiquitous methods of qualitative social science, and as a demographer I was often wishing that the speakers had taken a more explicit population perspective to their discussions of HIV, violence, illness and social wellbeing. But overall, the papers were sound and the authors engaged their audiences well. It was a good sign that so many people emerged from the sessions saying that they would like to follow up on the ideas presented.

The most spine chilling parts of the conference were performance pieces presented as part of the plenary sessions. For some years a group of Melbourne actors (www.actorsforrefugees.org.au) has engaged with the problems of refugees in Australia by volunteering to go to schools and community groups to read pieces that capture the tragic experiences that people have endured in their efforts to flee oppression. With the theme *Disaster and Violence: Flight and Forced Movement*, the conference was an ideal venue for a reading. Playwright Michael Gurr had prepared most of the scripts, drawing on verbatim accounts given by survivors who had reached Australia. The events they described included the sinking of the SIEVX (an acronym for Suspected Illegal Entry Vessel – X for unknown) with the loss of 353 lives in 2001, and the notorious "children overboard" affair in the same year when Federal politicians accused asylum seekers of tossing their children into the water to attract sympathy from Australian naval vessels during a ship interception. Participants asked whether the group had ever encountered resistance or criticism from community members who might hold attitudes opposed to refugees. No, they said, more often it is surprise, and a feeling of concern that they had never been told these stories before. Many otherwise unsympathetic people attend the readings out of curiosity. Michael Gurr welcomes this. 'Curiosity is the first step on the road to compassion' he said in thanking the conference participants for their interest.

Two performances by Philippine-born Australian novelist/poet/academic Merlinda Bobis dealt with the commodification of the body, and the way conflicts displace, expel, or kill so many people in the world today. Her sound drama *River, River* takes the story of Estrella, a young village woman whose long hair is used to trawl for the corpses of the victims of military violence. One night she learns that the body to be retrieved is that of her Australian lover and as she dips her hair in the water, and raises her voice in the chant of mourning, her anguish encompasses the whole village. Though written to be performed with professional actors, including a mezzo-soprano, Bobis gave a stunning performance without any accompaniment. By the end it felt as if she had become Estrella, using her long hair and gripping voice to trawl souls from the rivers of ignorance and awaken them from their apathy. The conference participants were transfixed.

The excitement of performance continued throughout the three days. Video installations by Wendy Woodson of Amherst College explored notions of home, belonging and immigration. Photos taken by young Timorese captured the feelings of community that persist

in neighbourhoods rent by violence. Some participants discussed the way dance or advertising images can reflect multiple meanings of social processes, be they in the displacement of Pacific Islanders, or the implementation of family planning by an authoritarian government in Java. It seemed wherever you turned the conference was building new understandings by breaking down disciplinary boundaries.

Finally, the food. In Australia it is common for conference organisers to provide morning and afternoon tea, and a sandwich lunch for all participants. People accustomed to the conference circuit know that this can be a real trial. There is the obligatory separate tray for vegetarians, and looks of concern among those seeking halal or kosher options. Usually the sandwiches have some form of meat or cheese, and garnishes of beetroot or avocado are added to make them posh. In short, the food is dull but sufficient to keep most of the participants from wandering off to a nearby café. At the *Transitions* conference, the organisers reached for and achieved the sublime. Over three days all the participants were continuously delighted by the fare, and this delight sparked conversations throughout the room. Consider this luncheon menu: Vietnamese rice paper rolls with lime, coconut and crunchy Asian greens; Beef and burgundy pie with chunky tomato sauce; Camembert, quince paste, peppered pear and spinach rolled in flat bread; Pot roasted ruby red quince tartlet; and fresh fruit. Each day was different, each tea a similar surprise of delights, and it was no wonder that on the third day the assembled participants gave an ovation to the caterers and servers. Every dietary need was met with care and gastronomic excellence. The organisers obviously appreciated that attention to the cuisine is the way to ensure positive social interactions.

To sum up, the Monash *Transitions* conference succeeded on all levels to foster good scholarship. The right number and mix of people met in appropriately sized venues to talk, perform, listen and reflect. New friendships were made, and everything about the organisation reflected care, creativity and inclusiveness. It would be hard to match this standard, but I certainly hope other conference organisers will try.

Durban delegates look beyond the conference centre…

Escaping the watchful gaze of security guards in Durban at the International Sociological Association Conference last summer, British delegates saw a different side to South Africa on a daytrip to a local community project.

Here, Jonathan Gabe reports on the work of the Phakamisa Project, a community group trying to rebuild local lives devastated by AIDS. Later, Linda McKie reflects on the sociological implications of the delegates' sometimes uneasy experiences in South Africa and explains how the end of the conference was only the beginning of the delegates' relationship with the Phakamisa Project.

Phakamisa Visit

Jonathan Gabe

Royal Holloway, University of London

Sitting in the bus at Durban International Airport in July 2006, I overheard a local radio news bulletin announcing that two delegates to the 16th World Congress of Sociology had been mugged and were in hospital. As I was arriving to attend the same congress and was already aware that levels of violence in South African cities was considerably higher than was the case in the UK, such news made me feel rather uncomfortable. Worse was to come over the next few days as rumours started to circulate round the Congress that at least twenty sociologists had been hospitalised and a further hundred had reported an `incident' to the police. We also heard that the conference organisers had been in discussions with the local police and that the police presence around the conference centre in central Durban had been increased significantly. We were told not to walk the hundred metres between conference venues alone, after dark or to display conference badges as this would indicate that we were foreign visitors.

It was against this backdrop that I signed up for a trip to the Phakamisa Project on the outskirts of Durban. The trip had been organised by Robert Dingwall who had close links with the Project through the church he attends in Nottingham.

When we arrived at the Project a meeting was already in full swing in the Church. We were ushered into the nave and the six of us joined the audience. Other than the community worker, we were the only white people there – the `congregation' being made up of around forty women, mostly over sixty years of age, some of whom had been travelling on foot since 4am in order to reach the church on time. They were listening to a talk from a volunteer who was telling them about how to grow vegetables to supplement their diet of maize. After we had been introduced as `international guests', members of the congregation were invited to come up to the front and tell us about their circumstances. At this point the impact of the HIV/AIDS epidemic in South Africa became clear. One woman after another recounted how their children had died of the disease leaving them to bring up their grandchildren on their own. Without a wage they did not know how they were going to feed these children or provide for them.

Faced with this situation the church helped set up a series of projects to enable the women of Durban to help themselves and we were witnessing one such effort – giving women horticultural advice which they could use in the 'community gardens' that the church had helped set up in townships on the outskirts of the city. Around forty such gardens had been

established run entirely by women, initially to provide them with fresh vegetables such as spinach, tomatoes, cabbage and turnips to help them improve their diet. In the longer term the plan is to buy a van to transport the surplus from the gardens to sell in the central market to generate income.

In addition the Phakamisa Project had had a major impact on pre-school education in the townships. It had already trained a substantial number of local women as pre-school teachers and had been responsible for setting up around 300 centres catering for 10,000 children under the age of six. The Project then offers continuing support and mentoring for the teachers to help them with the children.

After visiting the church, we were taken by mini bus to the township of Claremont to visit a school and community garden. Perched on the side of a hill the school was housed in a one-room timber hut that had recently been built. Thirty small children sat cross-legged on the floor listening to their teacher and repeating the names of various colours in English. We were told that all the children were orphans and that two already had HIV.

Next to the hut was the garden, a small immaculately kept plot with rows of cabbages, spinach and tomatoes. While we were visiting the women were presented with a cheque for the equivalent of seventy pounds to pay for a fence to protect the garden from animals. The announcement that they were being given this small amount of money was greeted with rapturous applause and singing and dancing. We were honoured to be invited into one of the gardener's houses – a one-room shack with no running water, electricity or sanitation. This little house was home to seven people, five children, their father and grandmother. The only financial support came from occasional child benefit.

In addition to the community gardens and `educare' projects, Phakamisa also offers classes in adult literacy and basic trade skills. Some of the women caregivers attending the Project had learnt how to use beads to make necklaces, earrings and Christmas decorations. We visiting sociologists were soon purchasing these items as presents for relatives and partners back in the UK and we subsequently learnt that donations from the group had generated almost eight thousand rand (£580), a useful start to fundraising for kitchen utensils that the Project is hoping to buy for a teaching kitchen. The full cost of this project is put at R150,000 (£11,900).

With hindsight the trip to the Phakamisa Project proved an extremely important antidote to the safety concerns that I had had on arriving in Durban. Post apartheid South Africa faces some huge problems, not least of which is how to support the growing number of orphans in the face of the HIV/AIDS epidemic. The visit to the project was both humbling and uplifting. It made me feel that there is hope when there are people who are willing to devote their lives to helping others to regain lost skills which will enable them to become independent again.

If you want to help why not visit www.phakamisa.org or consider making a financial contribution. Bank charges for money transfers to South Africa are quite high but there is a UK account. Please contact Bob Atkinson if you wish to make a deposit, BobandNorma@dsl.pipex.com.

Some Sociological Reflections

Linda McKie

Glasgow Caledonian University

As Jonathan reports above, on arrival in Durban congress participants were met with reports of crime and warnings about personal safety. As the week progressed the congress venue, and hotels, became physical and sociological enclaves. In many ways this was not surprising as incidents of theft and violence led organisers to insist that delegates were 'bussed' to and from venues, did not venture out alone, or carry items we might take for granted such as bags or mobile phones. As we moved around in buses and taxis we saw evidence of poverty and vast socio-economic inequalities. People were living on the streets, housing could be makeshift and barely offer shelter from the elements, and groups of young people and unemployed men seemed listless and alienated as they stood around street corners. Local people, who worked at the conference venue and hotels, spoke with both pride and concern about the challenges facing South Africa. It was not uncommon for workers to travel several hours a day to and from work and to support several generations of their families and friends on low incomes. I met several people who also found time and energy to undertake voluntary work on social and church projects for those suffering from, or managing, the implications of HIV/AIDS.

Congress participants grappled with personal interpretations of a sociological gaze that illuminated the inequities experienced by so many South Africans while we were physically positioned in the sights of security guards, concerned congress organisers, and stayed in pleasant hotels. It seemed we could 'gaze', return to the UK relatively unscathed (provided we managed to avoid the spate of thefts), but could we look away? As reports of the visit to the Phakamisa Project circulated around the congress BSA members were keen to explore ways to support this, and other projects, working to develop skills and opportunities. At the Medical Sociology Conference in Edinburgh in September a number of us discussed the sociological implications of our experiences. We also debated how we might aid developments in projects, research, policies and practices. The article by Jonathan Gabe offers a starting point for BSA members to reflect on these issues. A number of study groups are also debating ways to get involved in projects and research.

A Day in the Life…

Narelle Warren, *Research Fellow, Social Science and Health Research Unit, Monash University*

Narelle sailing around the Whitsundays, just after submitting her PhD in June 2007!

14 August, 2007

One day each week, I work from home which gives me a valuable block of time to dedicate to writing. Today is not one of those days…

My position as a research fellow generally involves managing multiple tasks and demands. I use strategies to manage my time and workload. Firstly, I break my day up into loose 'segments:' this helps me deal with interruptions. My second strategy, to make sure that everything gets done, involves making weekly lists. Today's is pretty long, but there are some fun things too… finish one article, travel plans, start another article, teaching, back to article, supervision, and some meetings. It only takes a few minutes yet I find that it helps me feel like I'm on top of things, rather than the other way around. Emails also require management: as with most academics, I could spend all day responding to them but they're usually either junk or not urgent. To minimise email drain, I only check my emails three times each day. I use these strategies consistently throughout my week, adapting them depending on what needs to be done each day and in response to unplanned events.

Next, I resume working on a paper that we're writing for *Clinical Rehabilitation*. My supervisor, Professor Lenore Manderson, and I conducted an ethnographic study (ADAPT) on lower limb amputation in Victoria and are now disseminating the results. This paper considers measures of function, wellbeing and adaptation, and discusses them in light of the International Classification of Functioning (ICF). I'm a little stuck on what to write, so I read about rehabilitation outcomes and assessment.

After a quick cup of tea, I meet with Lenore. We are teaching a course on Ethnographic and Qualitative Research Methods. Though we've done it before, we review the syllabus and course outline, revisit the prescribed readings, and design new practical exercises. The course is shaped by our recent articles; for example, we will use a paper on gender dynamics in interviews (Manderson et al. 2006). The course also functions as a supervision device – which our PhD students will attend.

After our meeting, it's time to organise travel to the US. I'm presenting a paper at the International Society of Quality of Life Studies Annual Meeting in San Diego; I'll also meet with collaborators. I book my ticket, pay the registration fee, and arrange accommodation. To do the latter, I need to call them: the booking itself isn't a problem but the woman at the other

end of the phone can't understand my accent when giving my email address: she thinks that I'm saying 'E' when I am actually saying 'A.' Eventually, we get it – via my version of radio code: "No, A for Alpha, not E for… ahh… Elephant." Fortunately, she's extremely patient and kind.

Time for lunch before checking my emails and voicemail, and preparing for a meeting with Lenore and our ADAPT study collaborator. I need to send a message to our students, so I post a message to our Yahoo Groups student list-serve. This is an example of how we aim to work efficiently and effectively with students, allowing regular communication between staff and students, sharing knowledge, experiences, and relevant articles. Students (and staff) can pace themselves, feel empowered and know that their input is important and valuable.

I've also missed a call from a study participant, who is sick and feeling miserable, so I send her a card to say 'get well soon.' When doing research, I like to send regular study updates to participants. They appreciate it and I think that its good research practice. Just as I'm leaving for the meeting, a student arrives to talk about a dilemma she's having planning her fieldwork. I ask her to come back after the meeting.

Meeting with our collaborator is wonderful, not only because of the cake he brings to share. We plan a new project on technological medicine, which will build research capacity. It is also innovative, nationally significant and it complements a current PhD project. This emphasises something we try to do in research training: build on our existing knowledge and skills in developing subsequent research projects, and supervise students in areas that are cognate with our own research interests. Like many junior academics, I am employed entirely on 'soft' (grant) money: the cycle of meeting potential partners, developing project ideas, and applying for grants is a necessary part of my job. 'Soft' money employment, whilst giving variety and flexibility to the work itself, is also frustrating: contracts are short and there's no long-term job security.

After the meeting, my student returns and we discuss her fieldwork, which she will do in her home country. I then meet with a student who has been writing her PhD for a while but is anxious about her ability to write a good thesis. I share my strategies: stop thinking, start writing; develop a 'skeleton' and write around it; schedule regular meetings with your supervisor; make deadlines and set goals that are meaningful to you; and write anything because you can edit rubbish but you can't edit blank (that tip is from Jodi Picoult).

Getting back to my desk, I'm reminded that abstracts for another conference are due tomorrow. I haven't really thought about it, so I look on the website and find the session that interests me – on masculinity. Last week, I had an idea about masculinity, physicality, emotions and silence, so I spend the last 45 minutes of my day developing an abstract. In the end, it doesn't look too bad, so I leave the office just after 5.30. Can't stay any later because I've got swimming! I arrive at the pool with its chlorine-laced air, breathe in deeply and slide into the water.

Reference

Manderson L, Bennett E & Andajani-Sutjahjo S (2006) The social dynamics of the interview: age, class and gender. *Qualitative Health Research*, 16(10): 1317-1334

CALL FOR PAPERS

INTERNATIONAL SOCIOLOGICAL ASSOCIATION

Research Committee on
The Sociology of Health (RC15)
Interim Meeting
&
The Canadian Medical Sociology Association
Inaugural Meeting

"Making Connections for Health"
Montréal, Canada, May 13-16 2008

The Joint Interim Meeting of the Research Committee on the Sociology of Health (RC 15) of the International Sociological Association (ISA) and Inaugural Meeting of the Canadian Medical Sociology Association will be co-organised by Ivy Lynn Bourgeault (McMaster) and Amélie Quesnel-Vallée (McGill) and held at McGill University in Montréal, Canada, from May 13th to 16th 2008.

We cordially invite paper submissions for this joint meeting which will be officially bilingual (English/French). We encourage submission of papers on all topics relevant to the sociology of health and health care including, but not limited to:

- aboriginal health and health care

- complementary and alternative health care

- ethnicity, health and health care

- experiences of Health and Illness

- gender, health and health care

- genetics/health technology/ethics & risk

- health services and policy research

- health work/health professions

- international/comparative perspectives on health and health care

- health and health care across the lifecourse

- mental health and health care

- social determinants of health/population health

Deadlines

- The deadline for abstracts will be January 15th 2008; the online abstract submission process will be available in the early fall 2007; extended abstracts will be required of 750 words, succinctly describing research questions, data, methods, and findings (even if expected or preliminary).

- You will have the option of an oral or poster presentation.

- Notices of acceptance (and format) will be sent out and the online registration process will be available Feb. 15th 2008

- The deadline for the submission of papers will be April 1st 2008

- In the spirit of a bilingual conference, the abstracts will be made available in both languages and the slides for oral presentations must be in the alternate language of the presentation; oral presentation slides should also be forwarded to us by April 1st 2008 (we are aiming to fund these translation costs for presenters).

For further details about the call for papers, proposals for thematic session or about the meeting itself, please feel free to email Ivy Lynn Bourgeault at bourgea@mcmaster.ca or Amélie Quesnel-Vallée at amelie.quesnelvallee@mcgill.ca

The **Sociology of Health and Illness Book of the Year** is now accepting nominations for the 2008 prize. The prize of £1,000 is awarded annually at the BSA Medical Sociology Group Annual Conference to the author(s) or editor(s) of the book making the most significant contribution to the sub-discipline of medical sociology / sociology of health and illness and having been published over the three years preceding the 1st January of the year in which the award is made, ie: January 2005 to December 2007 for the 2008 prize. A Nomination Form and Book Prize Rules are available to download at:

http://www.britsoc.co.uk/medical/MedSoc_SHI.htm where you shall also find a list of previous winners.

Next year's Medical Sociology Annual Conference will take place at the University of Sussex from the 4th to 6th September 2008. Further details will be announced shortly at: http://www.britsoc.co.uk/events/msconf.htm

Should you have an enquiry about the book prize, please contact Debbie Brown at: Debbie.Brown@britsoc.org.uk

BRITISH SOCIOLOGICAL ASSOCATION

MEDICAL SOCIOLOGY GROUP

PHIL STRONG MEMORIAL PRIZE

We are pleased to announce the Phil Strong Memorial Prize for the Academic year 2007-8. It is anticipated that there will be one prize to the value of £1000. The purpose of the prize is to contribute to the **advancement of medical sociology by supporting post-graduate research in medical sociology.**

Applicants must show that they are unwaged, working in the field of Medical Sociology and that they are registered for a higher degree at a British University or other recognised British research institution, with a named supervisor who is a member of the BSA.

Applications must be submitted to arrive no later than **17th August 2007.** Incomplete applications and applications received after this date will not be considered   The draw and announcement of the winner for this year's prizes will be made at the Medical Sociology Study Group's AGM during their Annual Conference to be held at the Adelphi Hotel, Liverpool from 6-8th September 2007.

All applications **must be submitted as email attachments** to:

bsamedsoc@britsoc.org.uk

Subject line: Phil Strong Prize

Further details on **How to Enter and Conditions of the award of the Phil Strong prize** are available at: http://www.britsoc.co.uk/specialisms/102