



'Care': Research, Policy and Practice Briefing Paper 2

In post-industrial societies many issues about the delivery and resourcing of care remain unresolved. Debates on care have highlighted the growing tensions concerning the links between care services and economic participation, and the provision of formal and informal care. Attempts to develop policies that consider caring needs of adults and older relatives have had limited success. Services appear over-stretched, with demographic trends indicating that tensions around the nature, organisation and resourcing of care services will remain centre stage in social and public policies and political debates.

The aims of the seminar series include:

- a review of new theoretical work and empirical studies on the various aspects of care over the lifecourse and across nations.
- the generation of debates on how to develop, implement and evaluate policies and practice. These debates will involve policy makers, researchers, practitioners and representatives from relevant organisations. Further, by ensuring that we bring together those at earlier and later stages of their careers we can share experiences and ideas.
- a range of outputs, including a website, briefing papers, articles and an edited book.
- the establishment of networks and support for continued developments within a lifecourse perspective. The topic of care is of relevance to the quality of life and social inclusion of those in need and/ or in receipt of care, alongside those providing and organising care.

Seminar 2: Citizenship and Social Movements

The social movements that dominate current local and national political activities have their origins in the production and consumption of knowledge and cultural values. Touraine (1981) argued that the evolution of these movements parallel the development of post-industrial societies. The politics of personal identity and of cultural and emotional emancipation have come to the fore in recent decades in what Habermas (1973) terms the socio-cultural lifeworld (Beck, 1992; Hetherington, 1998). Politics driven through new social movements operates instrumentally and symbolically in achieving an improved social role for minority communities. By challenging structural exclusion and disempowerment, the constituents of the new social movements may become by that very process, empowered. This impacts both on the state and the economy, but also at a local level in the creation of positive political identities. This seminar explores how these and other movements theorise care, what policies do they propose and how far their ideas and experiences have informed policy and service developments.

The revolt of the pathological: Medical knowledge, care work, and the challenge of new social movement

Linda McKie, Professor of Sociology at Glasgow Caledonian University and Nick Watson, Strathclyde Centre for Disability Research, University of Glasgow

It can be argued that the new social movements that champion the cause of women and disabled people bring together members of their constituency to expose the conspiracy and to challenge the negative representations about, them that are embedded in professional discourses. Using care as an example this paper has as its objective the clarification of the different ways in which new social movements have contributed to the de-professionalization of knowledge. It will address, through a comparative analysis, the different ways in which the Disability Movement and the Women's Movement have contributed to this epistemological revolution

Disability and feminist movements have had similar goals. Both are concerned with the elimination of the exploitation and oppression of their respective constituencies. The organisation, delivery of and access to health and care services have been a focus of debate and activity for both movements but the approach to these matters has been very different. Theoretical variety within feminism in general is reflected in the significant diversity of specific approaches to health and care and the place of health and care work in domestic labour. However, the focus of attention has been the carer rather than the 'cared for'. In contrast, for the disability movement, health and social care have been addressed predominantly in instrumental terms as these have been conceived as practices that contribute significantly to the marginalization and confinement of people who are 'cared for'. In this respect, the disability movement has proposed the 'Personal Assistant' (PA) as the solution to replace the 'carer'. This pivotal figure is regarded as the means of breaking the link between care and dependency, but given that the PA is likely to be a woman, then there is significant scope for a clash of standpoint between the emancipatory goal of the two movements.

The paper comprises four further sections. Firstly, we consider the evolution of what we term new social movements and the increasingly individualised manner in which people engage with issues and campaigns. Subsequently, and over two sections, we outline how critical dimensions of the Disabled People's Movement (DPM) and Feminist Movement (FM) have addressed issues concerning health and aspects of care. In the final section, we reflect on the potential for these social movements to inform the development and critique of services, policies and future research.

The field of psychiatric contention

Nick Crossley, Reader at the University of Manchester

In this paper I discuss: 1) the way in which mental health issues in the UK have attracted a number of competing social movements and 'social movement organisations' (SMOs); 2) the manner in which interaction and relationships between these various SMOs has given rise to an irreducible social field (a field of psychiatric contention).

In addition I discuss the concept of 'fields of contention' (its definition, properties etc.) and its implication for an understanding of the social movement politics of mental health. In particular I draw out the significance of network structures within field

Troubled care/untroubled identities. A discourse analysis of carers' talk.

Dr Liz Forbat, Research Fellow, Centre for Research on Families and Relationships, University of Edinburgh

Informal carers are experiencing changing times as UK social policy and cultural characterisations respond to the demands of user groups. Where once informal carers occupied a marginalised position, with little or no public recognition of the services they provided, the government now has specific policies and guidance to ensure that their positive status is recognised and reinforced. Through carer organisations, this group have managed to create positive identities, and challenge the legacy of disempowerment and invisible labour.

Drawing on a social constructionist framework I use discourse analysis to illustrate and theorise the identity work of carers. I juxtapose the emergent positive identities of carers, against the backdrop of their own talk

about difficulties within relationships. I indicate how it is possible for speakers to create positive social identities, even in the face of potentially troubling relationship talk. Several factors enable carers to manage this delicate discursive balancing act, including: taking on increasingly professionalized roles, drawing on medical discourses and invoking excuses/justifications for difficulties. These features are discussed to illuminate the processes whereby troubled care relationships don't necessarily lead to troubled identities.

I conclude by reflecting on the implications identity construction for the relationship with care-receivers, policy, practice, power and knowledge.

Just being there. Buddy work as a concept of care for people with HIV/AIDS.

Jochen Kleres, PhD student at Leipzig University, Germany

When AIDS was first identified in the U.S. and started to unfold as an epidemic, the social and political context was such that volunteers and their organisations were the first and, for a considerable time, virtually the only ones to address the issue. Long before the state finally took interest in the matter, severely affected communities started to take care of their own issues created by the epidemic. These volunteer organisations not only played a crucial political role in forging AIDS policies, they also became pivotal institutions for the care of people with HIV/AIDS. To varying degrees they have provided a forum for and have been actors in defining the needs of people with HIV/AIDS. But not only were they crucial in devising concepts of appropriate care for all people affected by the disease, they have been in many ways providers of the actual care work. In this function, AIDS organisations were in a position to invent new concepts of care, some of which have become widely used paradigms in the field and have been adopted across national borders.

One such concept of care that dates back to the early phase of volunteer mobilisation is the model of buddy work. Buddies are volunteers who are assigned to a person with AIDS to take care of the day-to-day chores of their client. This may involve practical assistance, light housework and also emotional support or rather, just being there for the client. In many cases a buddy accompanies the client until the client dies from the consequences of the HIV-infection. Buddies provide care in a situation where other providers have often failed to step in, for instance because family bonds were broken for instance due to the stigma associated with homosexuality and/or the AIDS-disease itself. Importantly, buddy work as defined here is always embedded in an organisational context. AIDS organisations provide the infrastructure for matching buddies with clients. But more importantly they play a crucial role in managing buddies and their performance. This gains further significance as most AIDS organisations have been institutionalised to considerable degrees over the course of the epidemic. Under the paradigm of so-called new public health they have established close relationship to state agencies and have thus grown increasingly professionalised. This has also changed the context in which buddy work is carried out.

Further changes stem from medical developments, most notably the invention of highly active retroviral therapies that have tremendously improved the survival rate of people with HIV/AIDS. As people with HIV/AIDS are able to live a life with the virus, the nature of buddy work had to change equally.

From this vantage point and drawing on interviews with buddies, their clients and social worker in Germany, the presentation will outline how buddy work as a particular kind of care in the context of AIDS is presently conceptualised and what precepts inform this kind of work. Particular focus will be placed on the role of emotions in the buddy relationship, how these emotions are managed and the organisational context of emotion management. The changing context of buddy work and the possibilities to sustain buddy programs under these conditions will also be addressed.

Personal Assistance and the negotiation of (inter)dependence

Kevin Paterson, Research Assistant at Glasgow Caledonian University

This paper will consider everyday lived experience of negotiating (inter)dependence and care/assistance. It will seek to expose the complexities of the caring/helping interrelationship which are often considered separately by social movement constituencies. The disability movement emphasising the needs of the 'cared for' has sought to transform 'care' into a mechanical, contractual arrangement of Personal Assistance. The feminist movement

has sought to emphasise the exploitative situation many carers (usually women) are forced into and also the psycho-emotional aspects of caring. 'Carers organisations' have emphasised the need for respite from the 'burden' of caring. This paper starts from disability theory and politics, understanding of 'caring' and will attempt to weave in these differing constituent perspectives.

The disabled people's movement has exposed how being 'cared for' is a disempowering experience for disabled people. It has developed the idea that independence can best be achieved through disabled people becoming employers and buyers of Personal Assistance instead of passive objects of care. This paper suggests that while the philosophy of Independent Living has led to disabled people gaining autonomy and control in their daily lives, the idea that Personal Assistance is a 'tidy', mechanical replacement for the caring relationship is sometimes overstated. The disability movement admits that the PA / PA employer relationship can be complex at times, but sees these 'problems' as managerial and contractual. The movement has been concerned to avoid the exploitation of PAs and user-led organisations have published codes of good practice for PA employers. The movement has also sought to engage with the demands of 'carers groups'. There is an acknowledgement that caring for/assisting a disabled person can be stressful and 'difficult'. However, this is due to a lack of provision of outside assistance, and not because a disabled person is a 'curse' that needs to be exorcised from households. Members of most households require some avenue of respite from each other regardless of the presence of disability/impairment.

Still, the disability movement has been slow to acknowledge the fact that Personal Assistance is not always purely instrumental and mechanical. It can be 'messy' and involve a variety of sensibilities. The use of Personal Assistance does not totally end a reliance on informal 'carers' by intention or necessity. There is also a psycho-emotional dimension to caring/helping which Personal Assistance does not always escape from. Both the PA and the disabled person may develop attachments and friendships towards each other, making employee/employer formalities difficult to uphold when necessary. Furthermore, the introduction of outside Personal Assistance into the household can disrupt the homespace and interpersonal dynamics. Disability theory's reliance on a structural analysis of disability and (inter)dependency has resulted in a failure to consider the everyday lived experience of negotiating assistance. This paper will seek a point of departure for developing an embodied, experiential and psycho-emotional understanding of assistance. I will draw on the work of disabled feminists who object to compartmentalising of personal experience and public theory. I will also draw on my own work on a phenomenological sociology of impairment.

Feminist approaches to citizenship: the implications for policies and practices in care

Ruth Lister, Professor of Social Policy at the University of Loughborough

The first part of the paper will provide an overview of how feminist analysis has challenged traditional ways of thinking about citizenship. It will focus, in particular, on how feminism has revealed citizenship's 'false universalism', rooted in the public-private dichotomy, and has raised the question of the status accorded to unpaid care work in relation to the rights and responsibilities of citizenship and the gendered division of domestic labour. It will look at the ways in which feminism has attempted to 're-gender' citizenship broadly in lines with principles of 'equality' or 'difference'.

Care and the ethic of care have been central to non-maternalist attempts to develop an explicitly gender-differentiated but non-essentialist model of citizenship. From the perspective of political citizenship, the argument has been that care constitutes a resource for political citizenship. From the perspective of social citizenship, it has been argued that care should be recognised as an expression of citizenship responsibility akin to paid work and therefore providing similar access to social citizenship rights.

The paper will then explore some of the tensions and dilemmas that a care-oriented conceptualisation of citizenship can raise at the levels of theory, policy/politics and practice. This underlines how there is no single feminist approach to citizenship and its relationship to care.

Citizenship, Ageing and Cultural Change: 'Baby Boomers' and Others

Mike Hepworth, Reader at University of Aberdeen

It is frequently argued that attitudes in western culture towards older people remain largely negative and at best ambivalent and older people in an ageist culture are regularly described as effectively excluded from full social acceptance. Equally those concerned with the care of older people and promoting their interests as fully participating citizens are actively engaged with the potential for resisting endemic ageism and the quest for resources to promote the inclusion of older people.

Following a short historical introduction this paper this paper adopts a sociological perspective on citizenship and the care of the self and the body in later life and identifies social constructionism as the key to challenging ageism and creating positive conceptions of ageing. The preparatory discussion compares two approaches to the ageing body and social inclusion: Norbert Elias' conception of the 'civilizing process' and its consequences for what he described as the 'loneliness' or exclusion of older people and Margaret Gulleto's argument in favour of resisting traditional conceptions of ageing as decline and constructing alternative radical vocabularies and images of ageing. For Elias biological decline tends towards the social exclusion of older people because it is deeply embedded in the long historical change (the 'civilizing process') which requires mastery over the body and the emotions as a condition of maturity and citizenship. From a different theoretical point of departure Gulleto forcefully argues that older people are, in her phrase, 'aged by culture' through the pervasive influence of a dominant ideology of ageing as 'decline' in western culture.

In relation to these influential sociologies of decline and exclusion in later life this paper asks what kinds of cultural resource are available to challenge ageism and to offer new models of ageing and later life? If many of the negative characteristics of ageing are in fact social constructs how much scope there is in contemporary culture for fostering positive attitudes towards ageing and citizenship? One response is that from the perspective of cultural change baby boomers (those born between 1946 – 1964) are may be regarded as occupying a strategic position in the reconstruction of attitudes to ageing and older people; the care of the self and the care of others. In other words, positive change in attitudes to ageing will be spearheaded through generational change and the baby boomers can be identified as a 'movement' towards social inclusion in later life. In the third part of the paper empirical evidence from recent research into baby boomers is drawn upon to explore this view: is there any evidence that the attitudes of baby boomers to their own ageing and the ageing of others represents a radical departure from the past and a promising development for the future of care?

Rights, care and relationships: supporting disabled people in the twenty first century

Tom Shakespeare, Director of Outreach (Policy, Ethics and Life Sciences), Newcastle University

For 25 years, the disabled people's movement has challenged the care tradition, developing independent living as a solution to the support needs of people with impairments. The direct payments model has spread from adults with physical impairments to people with learning difficulties, mental health problems, children and older people. However, the vast majority of social services clients still receive homecare, not personal assistance. This paper will raise questions about the fetishisation of independence, and the limits of the direct payments model, using perspectives from the feminist ethic of care literature. Is there a risk of neglecting the rights of personal assistants and other care workers? Do we need a range of different ways of meeting the support needs of disabled people? Is it too soon to dispense with the concept of care?

This is the second in a three part series of briefing papers produced in this ESRC seminar series. Please contact Dr Arbory McNulty, Glasgow Caledonian University (a.mcnulty@gcal.ac.uk, 0141 331 8503) for more details.