



The University of Reading



## 'Care': Research, Policy and Practice Briefing Paper 4

This is the final briefing paper in a seminar series on the topic of care: - on how societies address the need to look after those who are dependent or vulnerable. While childcare often comes to mind, demographic changes, and trends in chronic illness, mean that a growing number of adults can anticipate organizing, delivering, or receiving care. Further, practical issues in accessing care services in both the public and private sectors, and the costs of care, are on-going concerns for many. Thus many issues about the delivery and resourcing of care remain unresolved.

The aims of the seminar series included:

- a review of new ideas and research on care from cradle to grave, and across nations.
- the generation of debates on how to develop, implement and evaluate policies and practice.
- a range of outputs, including a website, briefing papers, articles and an edited book.
- the establishment of networks and support for continued developments.

### Seminar 4: Theory and Policy

The content of this final day reflected key issues and ideas drawn from earlier seminars. These included how care is defined, understood and organised in policy and practice, and in debates in the social sciences. A particular concern noted was the potential for research and theory to inform policy-making. To reflect these interests the day was organised around two panel sessions: social theory and informing policy work. Short presentations helped to inform discussions in small groups. The over-arching aim of the day was to produce this briefing paper as a record of our debates and ideas for future work on the topic of care.

## Debate One: Exploring and Explaining Care

Perspectives on 'care' in medical sociology and disability studies. Carol Thomas, Reader in Sociology Lancaster University

Medical sociology and disability studies have approached 'care needs' and 'care provision' associated with disability and chronic illness in contrasting ways. Though sociology is the parent discipline in both cases, medical sociologists and disability studies scholars formulate 'the problem of care' very differently, and seek incompatible solutions.

In medical sociology, the older discipline, chronic illnesses and other impairments are seen to cause disability – that is, 'restricted activity'. Disability brings dependency (to varying degrees) and generates individual care needs. The 'problem' is that chronic illness and disability create a significant demand for care. Academics study and critique the social responses in contemporary society: formal and informal care services, policies and structures. Variations in theoretical perspective have thrown up different interpretations and assessments of society's response to care needs, and some are set on reforming care provision in the interests of 'users'.

In disability studies, contemporary social arrangements and cultural practices are understood to be the source of 'disability' and disablism (the marginalisation and oppression of people with impairments). The provision of institutionalised or community-based 'care' in society in the last two centuries is viewed as having key disablist consequences. The 'problem' is 'care' itself – especially systems of formal care: health and social care professionals have controlled the lives of disabled people and created the stark realities of dependency. Disability studies supports disabled people's struggles for independent living and self-determination.

People, place and care: a geographical perspective. Christine Milligan, Institute for Health Research, Lancaster University

Any attempt to resolve the tensions between the nature, organisation and resourcing of care needs to incorporate an understanding of the role of place in the care-giving relationship. In particular, it is important to understand how and why spatial inequities in the availability of and access to care arise, as well as how care impacts on the meaning of place. The relational nature of people and place within the care-giving experience, and why this is manifest in different ways in different care settings – from the community, to the home to residential care home settings – is of particular relevance. Data from studies undertaken in the UK and New Zealand demonstrate how an engagement with spatial concepts and theory can offer new insights into the ways in which care for frail older people is constructed and experienced in post-industrial societies. I illustrate these points by drawing upon three overlapping areas of my work around care and older people: the place of the voluntary care sector; care work and the meaning of home; and informal carers' experiences of the care transition. The notion of 'integrated spaces of care' is introduced to stimulate debate about how greater harmonisation between formal and informal care practices might be achieved as a means of providing an enhanced quality of care.

## Debate 2: Researching Care

Why policy fails – the rationality mistake. Simon Duncan, University of Bradford

Consider the following statements from 'Sylvia', a lone mother interviewed in 1995. First:

I'd love to go out to work, I'd love to go back full-time ... I think I'd be better off financially if I was working than I am now because I only get £68 a week on benefit. My sister gets £185 a week working in a nursing home and I think I could live off that.

and later in the interview:

My mum is a one parent and she thinks, like most old people, that if you have children you should be with them. You don't have children to bugger off and leave them with someone else is how she sees it. She didn't do it. Sometimes I agree with her. That's the idea, isn't it, of parenting, being with them, isn't it? Well I think it is. Like, you know, I would go to work and not see the kids all day and just see them in the evenings. But even when I ask her to babysit she says she wasn't able to go out when she was in my position. I have to go by what my mum says otherwise there'd be an argument. She's good with the children but I'd have to argue with her to get her to agree to look after the kids while I worked.

This statement illustrates results from over 400 in-depth interviews with mothers over a set of linked projects (See summary in Duncan S. and Irwin S. (2004) 'The social patterning of values and rationalities: mothers' choices in combining caring and employment. *Social Policy and Society*, 3,4, 391-400.) These showed three general points:

1. Simple questionnaire surveys are likely to produce superficial and misleading results (quote 1 v. quote 2).
2. Mothers' decisions about taking employment and choosing childcare are socially negotiated judgments about what is morally right – economic considerations are secondary and subordinate. We called this 'gendered moral rationality'. These gendered moral rationalities, and hence the type of decision made, varied between different class, ethnic and social groups of mother.
3. In contrast Government policy assumes, as its behavioural foundation, that people universally make individualistic, economic cost-benefit type, decision making (as in Sylvia's quote 1), not the socially negotiated moral rationality we found in practice (Sylvia's quote 2). This may not be the only 'rationality assumption' made by policy makers and shapers, but it is the dominant, foundational assumption – and it tends to be more dominant the higher the level of power and responsibility, and in the more dominant government departments like the Treasury and Department of Trade and Industry.

This leads to what we call the 'rationality mistake': people act according to a different form of rationality to that policy makers assume; and thus their actions will then proceed according to different criteria, and what may appear as problematical behaviour for policy makers and shapers may not be at all problematical for them. Worse, when government policy is thereby ineffective, then policy shapers go on to make a 'morality mistake'. They assume that people are behaving irrationally because they are ignorant, or immoral, or both.

We develop worked examples of these 'mistakes' looking at the New Deal for lone mothers, family law, and teenage parenting (See Barlow, A. and Duncan S. (2000) 'Family law, moral rationalities and New Labour's communitarianism', *Journal of Social Welfare and Family Law*, 22, 1 23-42; Duncan, S (2005) 'Why don't they marry? Cohabitation, the common law marriage myth and commitment', *Child and Family Law Quarterly*, 17, 3, 383-398; Duncan, S (2005) 'What's the problem? Teenage parents: a critical review' Families and Social Capital Working Paper, London South Bank University.)

### Direct payments for disabled people and user empowerment: tensions in policy and practice. Sheila Riddell, Centre for Research in Education, Inclusion and Diversity, University of Edinburgh

Direct payments represent a new way of delivering welfare by making a direct cash payment to an individual to purchase the services they have been assessed as requiring. These have been heralded by the disability movement as an important means to achieving independent living and hence greater social justice for disabled people through enhanced recognition as well as financial redistribution. Disabled people using direct payments regard them as providing flexibility and freedom, whilst recognising problems with accountability mechanisms and the supply of personal assistants. By way of contrast, research on older direct payments users has provided a less rosy view, arguing that this group has difficulty in adapting to the role of consumer. Why this discrepancy of views arisen? Analysis of use of direct payments in the UK points to inequalities in access in relation to country, region, political complexion of the local authority and impairment group. It is evident that

only a minority of disabled people are accessing direct payments at the present time. If the use of direct payments were to expand, then the type of problems encountered by older people might become more evident.

This presentation drew upon an ESRC project, Disabled People and Direct Payments: A UK Comparative Perspective. The project team comprises, Charlotte Pearson, University of Glasgow, and Debbie Jolly, Colin Barnes, Mark Priestly and Geoff Mercer, all at the University of Leeds.

### Debate 3: Informing Policy Development

Research, Policy and Dialogue in Scotland. Helen Chambers, Partnership Drugs Initiative, Lloyds TSB Foundation for Scotland

Research has, and will continue, to form a vital part of policy development especially with the continued governmental focus on evidenced-based policy-making. A key question remains of how research that is not commissioned by government, or its agents, can influence policy development.

Often research findings form the start of a linear, set-piece approach where key points are used in developing media work and conferences. Conference outcomes and the initial research are used in developing Parliamentary Questions, debate at Cross-Party Parliamentary groups, letters to Ministers etc.; and as leverage to gain meetings with Ministers. This approach often meets with rebuttals from government, and at best minor concessions from Ministers. This approach is rooted in an intrinsic 'oppositional' mind-set developed in the decades that government in Scotland was at odds with most of Scotland's civic and campaigning groups. This environment has radically changed in the last 8 years with a political direction in government much more in-line with that of its population, and that Scotland now has a general left-of-centre, social justice-focused direction of travel with regard to care and social policy. This has been matched by a much greater degree of openness by the Scottish Executive and a desire to gain higher participation in policy development by individuals and organisations outside government.

However, these environmental and cultural changes have not always been matched by organisations using research in their lobbying for change. We now have the opportunity to have research used in a more constructive, mature dialogue with policy makers at much earlier stages of policy development. The often underlying assumption by researchers and campaigners of the rejection of their ideas when engaging with policy makers is out-moded and can be unhelpful in the process of policy development and societal change. In Scotland we are now in a position to have a more constructive partnership between researchers and policy makers couched in terms of reaching positive solutions rather than using research findings as weapons in confrontational engagement.

### Workshop Discussions on Theory and Policy

Building on the debates outlined above, the following points have been distilled from the working group discussions:

#### Social theory and care

Issues considered across working groups included:

- problematising definitions of care. The clarity of the division between formal and informal care was questioned. Features often thought characteristic of informal care, such as emotional involvement, are also present in formal care situations and vice versa
- there is a care spectrum in terms of the relationship between the carer and cared for person. This ranges from situations in which the cared for person has very limited ability to express their needs or demand that they are satisfied (eg. caring for a very small baby or brain damaged adult) to those in

which they are in a position to both express their needs and demand their satisfaction. In the former situation there is a greater risk of abuse than in the latter.

- there are variations in the ways in which individual needs are communicated; the rights of individuals; the emotional attachments that can become part of caring; and the way in which modes of caring can become part of everyday life
- care, or rather the need for the provision of care by someone outside of the home, leads to a renegotiation of public and private spaces within the home
- care usually involves a reciprocal relationship in which the carer can receive satisfaction as well as other forms of socially constructed emotional or material reward. Care also acts as an identifier. It does so across a wide range of identities including in terms of gender, in terms disabled versus non-disabled, or in terms of identifying someone as a burden or contributor
- the ethics of care versus the ethics of work. We spend a lot of time researching an individual's care duties for others but place little emphasis on time for care for self. Perhaps we need a 'care time' directive in the same way that there is a work time directive

## Policy

The relationship between academics and policy makers operating in the care domain, and the need to translate theoretical developments into a language that was policy friendly, are crucial to future work. Both parties had yet to make the transition to a knowledge economy and to develop a streamlined knowledge transfer process. Academics do not understand the levels of complexity and the 'normal chaos' that prevails within the 'policy making beast'. In Scotland there have been massive changes in the machinery of policy making and the layers of apparatuses involved in making caring policy – including the Scottish Executive, the local state and departments with specific responsibilities – can mean that accountability is amorphous and mistakes policy failures inevitable.

Policy makers in the domains of health and social care are confused by the esoteric language of academics and academics are not sure whether or not 'research' – in a knowledge economy - includes 'translating' findings in a way that draws out the policy implications and sets out a policy agenda. The system presents numerous opportunities for non-communication and key issues and basic questions around the relationship between care and justice; what we mean by sick and healthy; which constituencies and social groups will be advantaged or disadvantaged by particular policies; what are the tensions that beset the relationship between care givers and recipients; how do we distinguish between formal and informal care. Many issues become 'lost in translation' and are obscured by the different domain assumptions and how academic and policy makers prioritize these respectively.

We concluded that, in order to enhance the work of the knowledge economy and make the process of knowledge transfer much more transparent, a 'half-way-house' or brokerage system to mediate between the producers and users of knowledge was essential.

## Endnotes

Participants at the final seminar held on 13th December 2005 wrote this briefing paper. This briefing paper was edited by Linda McKie. This and earlier briefing papers can be found at <http://www.gcal.ac.uk/lss/ESRC.html>.

The organising group for the series comprised Bill Hughes, Linda McKie and Arbory McNulty (Glasgow Caledonian University), Sophie Bowlby (University of Reading), Debra Hopkins and Nick Watson (University of Glasgow) and Heather Wilkinson (University of Edinburgh). The organising group would like to acknowledge the support of the Gill Hogg, and thank the staff of the Department of Marketing at the University of Strathclyde for their help in the running of the final seminar.