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Understanding Health and Social Care

An Introductory Reader

SECOND EDITION

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Chapter 26

The social construction of carers

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In this chapter we trace the dramatic history of this concept and attempt to explain how it has acquired its statutory status. There are two distinct threads to this history: that of pressure groups seeking to improve the situation of those looking after disabled and older people, and that of researchers and policy-makers who have been concerned to develop the policies and practices of service and support agencies. Both interest groups have focused primarily on the policies of central government and have frequently collaborated. Nevertheless, as will become apparent, their distinct interests have also generated tension in the course of the category of carer being constructed and promoted.

Constructing the 'carer'

In 1995 the Carers (Recognition and Services) Act entered the statute book: carers now have legal status. It is perhaps difficult to appreciate that, less than forty years before this Act, the term 'carer' was barely in the English language, and particularly difficult for those many people who perceive themselves to be carers and who are indeed devoting themselves to the care of sick or disabled people. For people with such experience, the idea that 'being a carer' is a recent social invention will seem absurd. Yet people who were in the same situation in the 1950s would not have used the word 'carer' and, more to the point, would not have thought of themselves as distinctive in the sense of belonging to a special category of people. It is for this reason that we can think of the concept of 'carer' as a social construction, a category created through the interplay between individual experience and various interest groups – policy-makers, researchers and pressure groups.

The literature on care has grown rapidly since the emergence of this concept, and in this there is no ambiguity: 'the carer' is one particular person providing care for one other particular person. The care relationship so conceived is essentially asymmetric and one-to-one: A cares for B. In the development of care services in the community, policy

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has focused on the needs of B, the person receiving care. This means that the role of carer often appears in practice guidelines to be taken for granted, not unlike that of 'the GP', an individual – not indeed necessarily always the same individual – who is always 'there'. Other people are incidental in the conceptualisation of this relationship and the multiplicity and reciprocal nature of many caring relationships are overlooked.

The emergence of the individual female carer

To a large extent, contemporary policy and research is being developed by people who graduated in the social sciences in the 1960s and the 1970s. Many current beliefs about the value of community and family can be traced back to Townsend's seminal text, *The Family Life of Old People* (1957). In the 1950s the term 'carer' did not figure in either research or policy but, in a chapter titled, 'The Family System of Care', Townsend created an image of how care was provided by relatives within the context of ongoing family life. He argued for the central importance of the *family* rather than *individuals* (that is, carers) in the conceptualisation of how care was routinely provided within the community. However, he made it quite clear that the responsibility to provide care in London families of the 1950s fell primarily on women, although he also emphasised that older women played an active part in the early adult lives of their children: they provided care as much as they received it. We return to this point later in this chapter.

Townsend also discussed the various roles of unmarried adult children and was particularly interested in the extent of co-residence among older siblings. Many women were of course unmarried or widowed because of the huge numbers of men who had been killed in the First World War. With time, many had taken up a caring or supporting role within their (extended) families but, in the 1950s, some in turn were beginning to need support themselves. It was in the context of such demographic trends and changing pressures that the National Council for the Single Woman and Her Dependants was formed to campaign on behalf of single women. [...] In our view, it is important to the history of 'the carer' that this organization initially directed attention on one particular category of – largely middle-class – individuals: 'single women'. In so doing it challenged Townsend's more diffuse focus on care needs within the working class family.

The impact of feminism

The concern of the Labour governments of the 1960s and 1970s with social security and the financial welfare of chronically sick and disabled people led, in 1975, to the introduction of Invalid Care Allowance (ICA). This was intended to 'protect the current incomes and future retirement pensions of members of the labour market whose full-time employment was prematurely terminated by the care of elderly relatives' (Glendinning, 1988: 131). Arguably this was the first significant gesture made by central government towards people providing care. However, being focused upon the financial cost of leaving

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employment, it was not payable initially to married and cohabiting women who it presumed would be at home anyhow (Baldwin 1994: 187). After a long and active campaign ICA was eventually in 1986 to include them. It was only then that it could be construed to be a payment for care rather than a benefit to (partially) replace lost earnings.

In 1981, in the course of the campaign to extend the ICA to married women, the Association of Carers was formed. It defined a carer as 'anyone who was leading a restricted life because of the need to look after a person who is mentally or physically handicapped, or ill, or impaired by old age', and among its aims was 'to encourage carers to recognise that their own needs are just as important as those of the person they are looking after'. One year later, the National Council for the Single Woman and Her Dependents reconstituted itself as the National Council for Carers and Their Elderly Dependents. Although clearly competing with the Association for Carers to represent married women carers, it maintained its focus on the needs of the 'elderly infirm relatives'. The competition was short-lived, however, and in 1986 the two were merged to form the Carers National Association.

The campaign to extend ICA to all women politicised the issue of care and, as a result, the assumption that women 'naturally volunteer' to provide family care began to be seriously questioned. In particular, attention was drawn to how this expectation denied middle-aged women opportunities to gain paid employment, or to regain it when children had left home (Finch and Groves, 1980). Responding to this concern, the Equal Opportunities Commission produced the first authoritative assessment of the unpaid and unacknowledged contribution of women to informal care. Following its own research, it concluded that:

it remains the case that families are expected to provide care for the vast majority of the handicapped, the sick and the elderly, and, as is demonstrated in this study, it is the closest female relative to whom the task of caring usually falls. (EOC, 1980: 1)

This report also provided another early definition of carers: 'those adults who are responsible for the care of the sick, handicapped or elderly' (p. 1). The author of the report suggested that the term 'carers' was not entirely satisfactory, but was 'probably the best available'. The conclusion that the task of caring fell on the 'closest female relative' implies that the EOC conceptualised care as an asymmetric one-to-one relationship, and that it saw individuals as the social unit that was primarily involved in the provision of care. The author, in noting that the majority of carers were women, added the words 'of course' and went on to explain that, because of this, the feminine pronoun would be used throughout the report. This, we would argue, was a crucial step in the feminisation of the concept of carer in the UK, one reinforced by the publication of Finch and Groves (1983) influential collection of studies of women and caring. Effectively, by definition, a male carer had become anomalous. But more significantly, so too had the idea that caring might be produced collectively by 'relatives' as part and parcel of ordinary family life.

The White Paper *Growing Older* (DHSS, 1981), reflecting the priorities of the newly elected Conservative government, issued the now famous decree that: 'care in the community must increasingly mean care by the community'. Far from confirming the importance of the role of the carer, this policy document did not refer to carers. Rather, it associated the concept of informal care with 'the community', not just the family but 'kinship, friendship and neighbourhood' (p. 3), although it acknowledged that caring 'may

involve considerable personal sacrifice, particularly where the "family" is one person, often a single woman, caring for an elderly relative' (p. 37).

The government's conceptualisation and promotion of 'care by the community' was widely interpreted to mean 'care by women'. A series of research studies developed out of this and many reports and seminars were given titles such as 'Caring for the Carer'. In this way the term 'the carer' became established in the professional vocabulary.

In much of this research, carers were identified through the users of services. For example, the study of Charlesworth et al. (1984) was based on a sample of older people who had been referred to specialist services in two urban areas in the North West during 1979 and 1980: 'Wherever possible a principal carer was identified (following initial contact with the specialist service and an assessment by a psychiatrist) and this person was interviewed by a social scientist' (Charlesworth et al., 1984: 8).

Through this procedure, a sample of carers was obtained, each caring for one of the older people in the initial sample. Likewise, the sample for the well-known and influential study of Nissel and Bonnerjea (1982) was located primarily through the health services and voluntary agencies in Oxford. There were many other similar local studies that identified carers through the users of formal services. This sampling strategy was appropriate at that time in that two widely expressed concerns were the adequacy of the support provided by the formal sector, and the suspicion that men were offered support more readily, and more generously, than were women. The effect, however, was to define carers as one more 'newly discovered' element in the system of support that surrounded service users: people living in the community who were already receiving health or social services. This dependence on the 'service provider route' meant not only that the ability of the researchers to generalise to all carers was limited (Twigg and Atkin, 1994: 157), but also that policy began to be related to the apparent needs of such carers – needs that the service agencies that were already involved could and should be taking into account.

Overall, the extensive body of small-scale research undertaken in the 1980s reinforced the assumption that informal care is largely about the relationship between one carer, a middle-aged woman, and one dependent person – usually an older parent. It could be argued that the feminist critique, intended to expose the 'burden borne' by middle-aged women, only served to reinforce the expectation that, despite the apparent injustice, women would continue to provide the care that was required. As Arber and Ginn comment: 'caring has been portrayed primarily as work done by daughters for parents.... There has been little examination of the concept of caring, or questioning of the stereotype of "carers as middle-aged women"' (1991: 130).

Many commentators concluded from the early research studies not only that women provided by far the greater proportion of informal care, but also that the contribution of men was negligible. In fact, the percentage of male carers in these samples ranged from 23 per cent to 41 per cent (Arber and Gilbert, 1989: 73) – certainly under 50 per cent, but not negligible percentages at all.

The first authoritative national survey of the population to address the question of care was the 1985 General Household Survey (Green, 1988). On the basis of this, it was estimated that there were 6 million carers in Great Britain, of whom 40 per cent were male. Both statistics came as a shock to the policy world. [...]

Doubts about the legitimacy of the huge number of carers ... were raised by Parker (1992), who undertook a secondary analysis of the data. She suggested that accepting the

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figure of 6 million was 'not helpful' and that a more appropriate figure would be between 1.3 and 1.7 million. By examining findings on caring activities and taking some account of the time spent in caring, she distinguished between *informal care* defined as being heavily involved in personal and physical assistance and *informal help* defined as practical support, often provided 'as part of a network where others take main responsibility' (1992: 14) ...

Not surprisingly, Pitkeathley, the director of the Carers National Association, disputed Parker's revised conceptualisation. [...] Whereas Parker's concern was to assist policy-makers and service agencies to target those primary carers who should be given practical support, Pitkeathley's concern was to sustain the strength of the carers movement and to develop a powerful case for the contribution of all carers to the overall provision of care to be properly recognised.

Regarding the explanation of the unexpectedly high proportion of male carers identified in the General Household Survey, Arber and Ginn (1990) focused attention on 'spouse care'. Their analysis showed that four in ten carers were spouses, mainly 'elderly', and half of these were men. They suggested that the high percentage of males in the General Household Survey was due largely to the contribution of older husbands caring for ill wives. In doing so they also pointed to the ageism implicit in much of the earlier informal care literature:

The prevailing view of elderly people as a 'social problem' emphasises the 'burden' of elderly people and concentrates on the problems for the rest of society of the increasing number of elderly people in the population. This negative and blinkered vision has almost entirely neglected the provision of care by the elderly themselves. (Arber and Ginn, 1990: 446)

This same point was made by Townsend thirty years earlier: 'In previous surveys the fact that old people perform services for others has had less attention than the fact that others perform services for them' (1957: 62).

Disaggregating carers

With the extension of ICA to all carers, the formation of the National Carers Association and the impressive national statistics from the 1985 survey, the category of 'carer' was secured. A 'generic' approach to research on carers began to be adopted (Twigg, 1992). The archetypical question was no longer 'who *provides* care?' but 'who *are* the carers?' Paradoxically, however, this new question meant that the category of 'carers' required disaggregation. Arber and Ginn had started this by challenging the stereotype of the carer as a middle-aged daughter and drawing attention to 'the forgotten male carer'. The implications of this for social workers were developed by Fisher (1994: 677):

We will have to develop a new appreciation of the caring capacities of men, particularly older husbands. There are circumstances where men accept the obligation to care, undertake intimate personal care, and derive identity and reward from their caring work.

Similarly, Atkin (1992) argued that 'differences need to be recognised if appropriate services are to be developed' and to that end he distinguished between: spouse, parental, filial, sibling, child and non-kin carers. The King's Fund Centre established a carers unit in the