Policy into Practice

Traditionally, *Research, Policy and Planning* has had a number of key strengths which have marked it out from other journals. It is able to span the boundary between practice and academia, and, by focusing on 'research', 'policy' and 'planning', it is able to cover a broad range of topics and contribute to the development of evidence-based policy and practice in a large number of areas. However, at times the journal has perhaps been better at focusing on the 'research' and 'planning' aspects of its remit rather than on 'policy.'

Against this background, *Research, Policy and Planning* is proud to announce a new section of the journal to develop this policy focus in more detail. Entitled 'Policy into Practice', the new section will ask contributors to introduce and critique a particular policy, exploring its implications for the front-line. In particular, contributors will be asked to produce a 2,000-3,000 word piece which:

- (Briefly) summarises the policy in question.
- Explains its background/relevance.
- Highlights the strengths and limitations of the approach adopted.
- Explores implications for practice.

In this edition of the journal, we launch 'Policy into Practice' with Kirsten Stalker's overview of recent measures to support carers. Future topics are likely to include partnership working between health and social care, growing older with a learning difficulty, hospital discharge and the reform of the Mental Health Act. However, if anyone wishes to propose a topic or submit a piece for this section of the journal, please contact Jon Glasby at J.Glasby@bham.ac.uk.

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Carers

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Background

For many years, successive UK governments have relied on the activities of carers - usually relatives or partners, sometimes friends and neighbours - to provide the bulk of 'community care' to people with support needs. Although Invalid Care Allowance was available to some carers from 1975, throughout the 1980s their input remained largely taken for granted. It was generally assumed that individuals, especially women, were willing and able to support older, disabled or ill family members. However, the late 1980s and early '90s saw a rapid rise in the growth and political influence of carers' organisations. These had started in 1965 with the formation of the National Council for the Single Woman and her Dependants which by 1986 had become the Carers National Association (CAN, now Carers UK). Partly as a result of pressure from carers' organisations, the White Paper, *Caring for People* (Secretaries of State, 1989), which preceded the NHS and Community Care Act 1990, stated that the second objective of the community care 'reforms' was to prioritise practical support for carers: users' assessments 'should always take account of "carers" needs' (1.11). Where significant differences emerged between users' and carers' views, the practice guidance suggested that separate consultation, or even separate assessment, of carers' needs might be advisable. Nevertheless, 'so long as they are competent, the users' views should be given more weight' (SSI/SWSG, 1991, 3.34).

Subsequent research showed considerable variation in the extent to which care managers were paying attention to carers' needs and views (Warner, 1994; SSI, 1995). Warner (1995) reported that, since 1993 (when the relevant part of the Act was implemented), only a quarter of carers had received an assessment of their own needs and that they were less satisfied with their own assessment than that of the person they supported. Watson and

Taylor (1996) suggested that care managers tended to under-estimate carers' needs.

Carers (Recognition and Services) Act (1995)

Supported by this research, and other studies which reported the continuing stress and strains of caring, (eg: Twigg and Atkin, 1994; Walker and Ahmad, 1994) the 'carers' lobby' ran a campaign for a statutory right to assessment. This culminated in the passing of a private member's bill - the Carers (Recognition and Services) Act 1995 (implemented 1996). Its main provisions were:

- When, under the 1990 Act, an assessment was being conducted of a person's need for community care, the carer could request an assessment of his (sic) ability to provide care and continue caring.
- The results of the carer's assessment were to be taken into account when deciding on services for the 'user'.

On the positive side, the Act acknowledged that carers had needs of their own which might conflict with those of the user, but guidance stated that practitioners should aim for an 'assessment of the caring system' and an 'integrated family approach' (SSI, 1996a, 3). At the same time, practitioners were warned not to assume that a carer was necessarily willing to continue caring, or to provide the same level of support: thus the Act had the potential to help carers reduce or cease their activities if they wished.

The 1995 Act did not give carers any statutory right to services, to have their assessed needs met. Where services were provided, these would be to the 'user'. Nevertheless the emphasis on an integrated family approach was to be welcomed, not least because, as Bythway and Johnson (1998) have argued, the success of the carers' lobby has relied in part on an eclipsing of users' perspectives. These authors suggest that the campaign for carers' rights was driven by anecdotal accounts, focusing on the 'burden' of care and the restrictions imposed on the carer's life. Similarly, the carers' literature, although extensive, tends to exclude the user's voice and seldom explores the implications for them of carers' demands - such as the right to two weeks annual 'respite care'.

On the less positive side, the Act only applied to carers who were providing or intending to provide *substantial* amounts of care on a *regular* basis. While there were obvious reasons for targeting those at the so-called 'heavy end' of caring, this led to a form of rationing: the guidance stated that authorities 'may need to make decisions about the relative needs of carers in their area' (SSI, 1996b: 11). In practice, this signalled – and legitimated – a decrease in preventive work. Thus, it was not surprising that research identified benefits for carers providing significant levels of support, while others fared less well (CNA, 1997a). Because the terms 'regular' and 'substantial' were to be interpreted 'in their everyday sense', there was significant room for local discretion. Carers living in different parts of the country but undertaking comparable tasks had inequitable access to assessment (Qureshi et al, 2003), those in Scotland apparently doing better than their English counterparts (CNA, 1997a). In addition, there was evidence that some groups of carers - older people and those from ethnic minority communities - benefited less than others (Qureshi et al, 2003).

Many carers were unaware of their right to request an assessment, and practitioners often failed to inform them (CNA, 1997a; CNA, 1997b). In particular, the fact that a carer's assessment could only take place *alongside* that of the person they supported meant that many were unable to access one, or could not do so at the time they really wanted it. This was particularly critical when a potential user of services declined the offer of assessment, thus effectively – albeit perhaps inadvertently – blocking support for the carer.

National Strategies for Carers

Mounting pressure from carers' organisations and research showing uneven implementation of the 1995 Act led to the development of carers' strategies at national level (Department of Health, 1999; Scottish Executive, 1999; National Assembly for Wales, 2000). The main policy thrust was, again, to support but not take over family care, and also to raise the status of unpaid caring, not least by linking it to other New Labour policies of promoting social inclusion and responsible citizenship. The English strategy had three broad themes - information, support and care for carers.

Key proposals included:

- Legislation giving carers a right to assessment.
- Carers to be consulted in decisions about the person they support.
- Carers' views to be taken into account when planning services.
- Information about services to be routinely provided to carers.
- Regular breaks from caring, with extra funding for local authorities to provide this.
- Increased attention to carers' health, including training in avoiding injury caused by lifting.
- Local authorities to support the development of carers' organisations, which were to represent carers in local consultation exercises on service provision and be invited to develop quality assurance schemes for carers' services.
- Local authorities to increase their awareness of young carers' needs and find better ways to support them.
- Support for carers in employment, and help for those whose caring responsibilities have ended and who wish to take up work.
- A campaign to persuade the business community of the benefits of employing carers.
- The introduction of a second pension for carers who are unemployed or on low incomes.

The Scottish strategy was a much briefer document. It made similar proposals in terms of promoting flexible new services, strengthening carers' rights to assessment, better information provision, attention to the needs of young carers, employment and pensions, and active monitoring of the strategy by government, aided by carers' organisations.

So what were the strengths and limitations of these strategies? From an individual carer's perspective, they emphasised the importance of developing services for carers in their own right, rather than leaving them to benefit indirectly from provision made to the 'user'. Thus, the strategies could be seen as 'redressing the balance' between carers' needs and rights and those of the people they supported. From a collective perspective, the new policy gave carers' organisations a central role in monitoring local authorities' performance and spending plans, thus significantly extending their influence. The strategies can also be seen as a genuine attempt to implement 'joined-up' government, since they crossed traditional departmental boundaries and placed support for carers within the broader context of employment, pensions and health.

On the other hand, most of the 'plus points' had a down side. By focusing on support to carers, the strategies marked a departure from the 1995 Act, with its focus on the integrated caring system. Some commentators believed the strategy did little to resolve, and potentially increased, the tension between users' and carers' rights. For example, while local authorities were now obliged to consult with carers' organisations about their community care plans and submit a letter to government from such agencies approving the plan, there was no requirement to show evidence of having consulted with users' organisations. Indeed the English strategy stated that 'empowerment of carers should be a key aim' of local authorities' activities, which raises questions about the intended effect on users. Lloyd (2000) argued that the English strategy revealed an attitude to caring which diminished the caring relationship and its importance to both parties. The strategy did not reflect the importance of interdependence (highlighted by disabled writers such as Morris, 1995 and Keith, 1990).

Like the 1995 Act, the strategies are aimed at those on the 'heavy end' of caring while at the same time apparently stressing the commonplace nature of caring. This again reinforces a narrow view of carers, creating a tension between inclusiveness and targeting (Lloyd, 2000).

The Carers and Disabled Children Act 2000

As promised in the carers' strategies, legislation was passed to strengthen carers' rights to assessment and support. The Carers and Disabled Children (2000) Act, which applies to England and Wales, introduced four changes:

1. It gave carers and parents of disabled children a right to assessment of their ability to provide care, matched by a right to services, irrespective of whether the person they supported was being assessed or receiving services.

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2. It allowed carers, including parents of disabled children (and disabled people aged 16 and 17) to apply for direct payments to meet their own needs.
3. It introduced a voucher system for short-term breaks.
4. It gave local authorities the power to charge carers for services received.

This legislation had some obvious strengths. It was designed to overcome the isolation faced by carers whose family members refused assessment and/or services. The difficulties experienced by families with disabled children in accessing flexible support had long been documented: enabling them to apply for direct payments, whereby they could purchase the support of their choice, including personal assistants if they so wished, was a huge step forward. Qureshi et al (2003) commented that the guidance accompanying the Act had much to commend it, although they noted that it might not reach front line staff and, if it did, that lack of new resources might hamper implementation.

The main difficulty in the 2000 Act was that it allowed local authorities to charge carers for services received: this caused widespread anger among carers' organisations who saw it, rather, as a charge for services rendered. They were saving local and/or central government many millions of pounds through their unpaid caring activities: to be charged for doing so was, understandably, unacceptable to many. At the same time, there was concern within the disability movement that enabling carers to apply for direct payments in their own right was contrary to the underlying ethos of direct payments, namely, to increase choice and control for disabled people.

The Community Care and Health (Scotland) Act 2002

It is interesting, then, that the equivalent legislation in Scotland, which came two years later, contained significant differences. Although the Community Care and Health Act (Scotland) 2002 gives carers, including parents of disabled children, the same rights to assessment and direct payments as those south of the border, it is predicated on the notion of carers as a *resource* rather than users in their own right. This appears to be based on both principle and pragmatism. As in England, carers' organisations were represented on an independent working group which had a significant influence in formulating the legislation. They made it clear that they wished to be recognised as care providers, as partners with professionals in caring for the 'user' (Scottish Executive, 2001a). Thus, the Scottish legislation is broadly based on the concept of carers as *co-workers* while in the English Act, they are closer to *co-users* (Twigg, 1989). At the same time, the 2002 Act makes it explicit that, since carers are receiving resources (in order to carry out their provider role) rather than services, they cannot be charged for them. Nor is there any voucher system for short-term care in Scotland as there is in England. The working party was well aware of the difficulties surrounding charging carers for services south of the border and neatly avoided that pitfall in their formulation of carers as service providers.

The most radical difference between Scotland and the rest of the UK however, is that the Community Care and Health Act introduces free personal care for older people. The Care Development Group (CDG), set up to bring forward proposals for long-term care for older people in Scotland, considered how free personal care might impact on carers' activities (although reducing informal care was not the policy aim). As carers were generally seen as very committed to their role, widespread 'throwing in the towel' was not envisaged. However CDG envisaged that some carers, particularly those who had made personal compromises to enable them to support a relative or friend, would choose to supplement informal care with some service provision. Drawing on American research, CDG estimated that about 12 per cent of informal care could be substituted by formal provision (Scottish Executive, 2001b).

It is too soon to judge the accuracy of this prediction, nor the effectiveness of the 2002 Act across the board. However the notion that carers require resources while those they support require services does raise interesting questions. When does a carer, through the pressure or fatigue of her role, become a potential user? Will this policy allow carers to become 'users' or exert pressure on them to remain 'carers'? What of mutually supportive relationships, such as those described by

Williams and Robinson (2000), between adults with learning disabilities and their ageing parents? Or between disabled people and their partners, if both parties resist labels of 'cared' and 'cared for'? The 2002 Act does mark an increased 'professionalisation' of carers and, arguably, has the potential to increase the dependency of users on their families and friends, unless of course they take up the offer of free personal care. A crucial factor then will be the extent to which central and local government continue to publicise and proactively offer care where it is currently being provided informally.

Conclusions

Carers have come a long way in the last 40 years. From the 1970s to the mid-1990s, there was a fairly clear progression in the way they were perceived, from being little known about or supported, to increasing recognition, assessment and support. The Carers Act promoted the notion of supporting an integrated caring system but this has given way to an increasing 'professionalisation' of carers, particularly, it seems, in Scotland. A recurring question, is whether it is better to resource carers to support 'users', or to offer support to the older, ill or disabled person directly, thus reducing the need to rely on informal care and maximising the individual's independence, choice and control. Several commentators have called for a more integrated approach, (eg: Olsen, 2000; Graham, 1997). Shakespeare (2000) argues the need to recognise the value of 'caring solidarity', pointing to the feminist ethic of care (Sevenhuijsen, 1998) as a possible way forward. Ideally, policies would be developed which reduce or remove the social barriers which cause disability, which respect individuals' preferences about the support they receive and which embrace the interdependence which is part of the human condition. Such polices however are still some way off.

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