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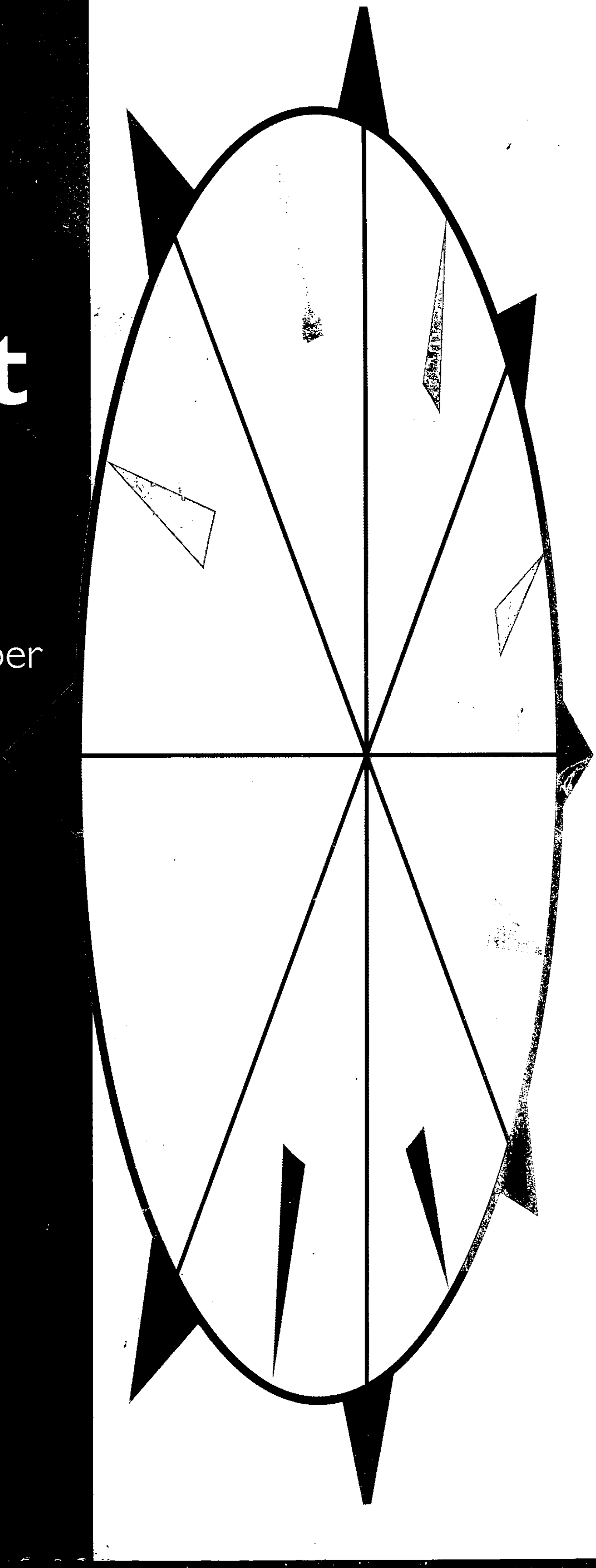
Carer Support

Time for a change of direction?

A policy discussion paper

Penny Banks



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Executive Summary

Key messages

- There is a gap between policy to support carers and practice, despite the increased awareness built up over a decade or more.
- There are contradictions in policies relating to carers which managers and practitioners on the ground have to manage, with a result that carers frequently lose out.
- Local joint work which has taken a broad view of carer support has shown some success in improving outcomes for carers but many areas continue to take a piecemeal approach that keeps carers issues on the margins.

Key recommendations

- There needs to be clearer and more consistent directions from the centre on policy priorities which should be based on the key principles of social inclusion, choice and prevention.
- At a local level more strategic approaches to carer support need to be bolstered and incentives given to effective partnerships between the NHS, local government, voluntary organisations and other local bodies working together with carers
- Specifically, a framework for integrating support across services, such as the Carers Compass, could help agencies to take a more strategic approach and develop ways of assessing their performance against priorities.

Introduction

The current development of a national carers' strategy is a significant milestone in two decades of campaigns and policy developments to draw attention to the unpaid help which families and friends provide. But just how far have we travelled in meeting the needs of carers? What has been achieved over the last years of raising the profile of carers and developing support services and benefits? In which direction should we be heading as the new health and social care agendas take shape and strive to improve the mesh between, and within, the formal and informal care systems?

This paper aims to describe the current picture, to discuss why it looks like this and to suggest what needs to be considered as national and local policies are developed and implemented. It draws on the work of the Carers Impact development programme based at the King's Fund and other recent research.

1 Background: current policy position

Carers are at the heart of community care policy which acknowledges the state alone cannot resource all the support needs that frail elderly and disabled people have in order to be able to continue living at home. Early policy statements saw families, friends, neighbours and other local people as the 'primary means by which people are enabled to live normal lives in community settings' (Griffiths 1988). The first task of publicly provided services has been spelt out as 'to support and where possible strengthen' informal networks (Griffiths 1988).

At the same time as relying on informal caring, policy has aimed to address the needs of carers. The previous Government's White Paper, Caring for People, underlined that a 'key responsibility of statutory service providers should be to do all they can to assist and support carers' (Department of Health 1989). The NHS and Community Care Act 1990 required local authorities to take into account the needs of carers when undertaking assessments and the Carers (Recognition and Services) Act 1995 turned this requirement into a duty. Guidance from the Department of Health (1996) emphasised the importance of taking an 'integrated family based approach which does not see the service user or carer in isolation' and 'intervention at the right time without destroying existing informal support networks.'

Whilst the new Labour Government has continued to support this approach, the announcement of the development of a national strategy indicates some acknowledgement of the need to clarify and strengthen policies.

Health and social care authorities have been challenged to find the right balance between the needs of users and carers and to steer an appropriate course between the differing relationships services have with carers (Twigg 1994). These range from seeing *carers as resources*, where most of the help comes from carers; *carers as co-workers*, where agencies blend their support with that given by the carer; *carers as co-clients*, where carers have needs in their own right; and *superseded carers,* where the object is to transcend or supersede the caring relationship. In practice these differences have tended to be skated over and local policies are often little more than broad statements of support and a general commitment to carers.

By the time the Carers Act came into force in April 1996, it was clear that policies and implementation strategies to support carers were at very different stages of development across the country. The findings of studies by the Social Services Inspectorate (SSI 1995) and the first Carers Impact programme (Powell 1996) indicated a broad spectrum of developments where:

- plans to support carers ranged from general principles encapsulated within charters and codes, usually initiated by social services and with some commitment from health services, to more detailed strategies with implementation plans, largely driven by social services but in some places jointly agreed with health authorities and trusts

- support to carers ranged from relying largely on special, usually, short- term funded projects often based within the voluntary sector, to some tentative moves to address carers' needs within mainstream health and social services

- monitoring the implementation of strategies and the impact of policies was scarcely at the starting blocks in some areas, although carers were being increasingly consulted and involved in planning by many local authorities.

2 The gap between policy and practice

Given this background, it was perhaps not surprising to hear from over 300 carers taking part in the first stages of the second Carers Impact programme during 1997 about their experiences of local services and the impact of these on their lives and the person they cared for. Nevertheless, it is still shocking to hear firsthand from the carers who took part in focus groups and semi-structured interviews about their experiences of coping alone with unremitting caring responsibilities, the lack of effective input from services and the struggle to use unreliable services which could not dovetail with their needs and those of the person cared for.

As one carer of a profoundly disabled child commented, *" I spend more time being a nurse, secretary, teacher and co-ordinator than actually being his mother. Constantly being on professionals' backs is more wearing than actually looking after the child."*

Good news, bad news

This must be balanced by considerable positive feedback from carers who had experienced sensitive and prompt responses from services, good information from staff and a mix of support from voluntary and statutory agencies. Once carers get 'into the system', many are satisfied, but there appears to be little consistency in who gets past the gatekeepers and the quality of support then offered.

Where one lives, one's age and ethnicity, and the nature of the disability of the person cared for, all seem to affect one's chances of getting support from health, social and community services. Findings from inspections by the Social Services Inspectorate of seven local authorities describe the wide variation in social services practices between individual workers, between teams, between areas within authorities and between authorities. (Department of Health 1998). Research on young carers has identified the need for more uniformity across regional boundaries in the kind of help and support that young carers and their families can expect (Dearden and Becker 1998).

As well as the lottery of location, two particular groups of carers appear to have problems in being heard and accessing support; these are carers of people with mental health problems and carers from black and minority ethnic communities. (Silvera M, Rukshana 1997)

Access to support and back-up in an emergency also continue to be a source of concern for many carers, although some carers have welcomed the introduction of local emergency contact schemes.

Carers' needs are modest; yet many carers find they are not receiving good information, recognition of their own health and well-being, services they can trust, some time off, emotional support and financial security.

Good information

Carers place great value on information offered on a one-to-one basis by a knowledgeable worker and the provision of good, clear information at critical points, such as in GP surgeries, at hospital discharge and at the time of assessments. But many carers report frustrating contacts with staff from health, community and social services. One carer likened service information to a web which is complex and difficult to penetrate. *"Once inside the system, however, it is possible to feel swamped by the vast amount of written material which has been produced."*

Carers find they are neither given sufficient information from health services staff about the personal and social consequences of medical conditions, nor are they routinely signposted to other sources of information and support.

These findings are highlighted in other recent research. The survey of carers' experiences of the NHS by the Carers National Association (Henwood 1998) found only 11% of carers reported that they had been given any information which would enable them to care more safely. The Princess Royal Trust for Carers study (Warner 1998) also found that carers are not given the right help and information to carry out the medical procedures which they routinely undertake. A study of carers' views on hospital discharge arrangements showed carers were concerned about the limited and partial information provided (Arksey 1997). Carers from black and minority ethnic communities have identified major difficulties in finding out about services and support (Katbamna 1998).

Recognition of carers' own health and well-being

Carers have found it particularly helpful where GPs and members of primary care teams have quickly responded to their needs and sensitive and comprehensive assessments have been undertaken in co-operation between health and social services. However, many carers report that a number of professional staff neither recognise nor listen to them - a particular concern voiced by carers of people with mental health problems (Allen 1998).

Some carers have benefited from assessments under the Carers Act, both for the services offered following the assessment and for the 'peace of mind' in knowing how to make contact should the need arise. However, there is evidence that many carers are not being offered an assessment nor do they know they have a right to ask for one (Holzhausen 1997). Many assessments remain strongly focused on the person cared for and carers' needs are marginalised. Assumptions are made about their capacity and willingness to care and black and minority ethnic carers frequently experience a stereotypical response and expectation that their own communities would support them. Carers are often unclear whether their needs have been assessed and are seldom given written confirmation or copies of what was agreed at the assessment meeting.

Emotional support

Carers value sensitive responses from staff who have contact with them, whether they are receptionists, care workers, consultants or drivers, and contrast this support with the difficulties and frustration when they are not listened to. Support from other carers through groups, telephone networks and newsletters are also important for many carers who easily become isolated.

The quality of services and opportunities for a break

Carers praise the tremendous support offered by services such as homecare and nursing coming into their home. However, many report experiences of poorly trained and constantly changing staff as well as insufficient time allotted to carry out either homecare or nursing tasks.

For many carers, however, there are real difficulties in obtaining some core health and social services such as therapy, nursing and continence services, home care and equipment, which can make a real difference to their lives. At the same time there are increasing expectations that carers take on a range of invasive clinical procedures which previously trained nurses and medical staff would undertake. They are also left to carry out lifting and handling with none of the protection from the health and safety legislation given to professional staff.

Gaps in respite care provision are logged up consistently, including more opportunities for a break for parent carers, particularly those caring for teenagers and young adults, and for carers of older people with difficult behaviour.

Liaison between services

Carers also underline the importance of other key services, such as good transport which makes it possible to use health and social care services and housing near to their relative. However, poor liaison between services is a recurrent theme, particularly where carers are caught in the middle of funding disputes (Henwood 1998). Carers can find they are the only point of liaison between services: *" ..there's no liaison at all. They're all acting independently. If there's a hiccup with one, I have to phone around and fix it."*

The difficulties experienced by families when children move out of educational and children's services to adult services were reported in many of the Carer Impact sites.

Financial security

The thread of financial insecurity runs through all the feedback from carers. Carers flag up their worries about charging, the lack of alternative affordable services, the limited benefits and in some cases the lack of flexible work opportunities. Most carers find that without their own financial resources, choice is purely a theoretical concept. *" I don't feel you get a choice, you're told what you can have and it's just too bad if you don't agree."*

Thus the picture from the feedback from carers taking part in the Carers Impact programme is extremely varied. Those in the service system may, although it is not consistent, receive good support. Others find they cannot access core services until there is a crisis.

3 Why is this the picture?

So why is the gap between policy to support carers and carers' everyday experience still so wide and even where considerable work is going on why is the gap so difficult to close? The following section will consider the part played by policy contradictions, the consequences of adopting too narrow a concept of 'carer support' and weaknesses in the capacity of local agencies to work together on a strategic approach.

Policy contradictions

Earlier research and analysis on the ambiguities underlying the relationship between the informal and formal care systems have already identified and examined some core tensions. Carers continue to "occupy an ambiguous position in relation to service provision. They lie on the margins of the social care system: in one sense within its remit, part of its concerns and responses; in another, beyond its remit, part of the taken-for-granted reality against which welfare services operate" (Twigg 1994).

It is these tensions which are at the heart of the ongoing debate about people's rights and responsibilities and those of the state. The commitment to support carers does not always sit comfortably with the increasing emphasis on family and citizens' responsibilities and the expectations that private, not public resources should be used where possible. There is no clear consensus about how much care family members should undertake, whether they should be given any real choice, at what point they can expect some help and what minimum level of support should be provided.

Achieving consensus is no easy task given the concerns of governments to control public expenditure and thus to find a balance between the costs of substituting informal care with paid care and the relatively small costs of providing emotional support in order to assist carers to continue. Fears have been expressed in the debate on long-term care, that if access to support is too easy, many carers will stop caring and government will be unable to resource the resulting care gap.

Alongside this, the demands of acute and long-term care have had a direct impact on carers leaving many carers suffering from the 'vicious circle' into which health and social services have got locked (Audit Commission 1997). People with failing health enter hospital for increasingly short periods of time and nursing and residential care has increased at a faster rate than homecare. Many carers are left either unable to obtain support in the home until a crisis or breakdown occurs, as priority has been given to people living alone, or they are faced with little choice other than to give up caring. The accompanying decline in rehabilitation opportunities over the last decade, particularly disadvantaging older people (Robinson 1998), has also had a detrimental impact. Carers are looking after increasingly frail partners and relatives at home who are losing out on services which could restore independence in full or part.

Policies beyond health and social services have also had adverse repercussions on caring; for example, the diminished role of local authorities in financing and providing housing has made it more difficult for users and carers alike to obtain housing support; employment policies to support carers are discretionary and there are financial disincentives to undertake paid work; social security policies have not provided protection for carers for their own old age nor adequately supported families with disabled members.

Tensions at policy and practice level

It has been left to local services to manage all these tensions, which has inevitably resulted in different interpretations and practices at both a policy and practice level.

Frontline staff face very real pressures in interpreting policies to support carers. When budgets are tight, there may be little incentive to view carers as anything more than a 'resource' or 'co-worker'. The tensions are not only at practice level. At a policy level, carers may be seen as purely instrumental in delivering health care policies and indeed where central directives are to reduce hospital waiting lists, support to carers may be seen as a very low priority, if not an irrelevance. The connections between effective support to carers and the potential to prevent re-admission to hospital and to prevent two people - the patient and carer- needing health and social care may remain theoretical.

Ever-tightening eligibility criteria have resulted in practices which negate the spirit of the Carers Act and quickly screen out carers who have little chance to identify their own needs, particularly where initial assessments take place over the phone (Davis 1997). It requires sensitive and unpressurised customer services and reception staff to be alert and responsive to the needs of carers, who are unlikely to express their difficulties at a first fraught call to local services.

A narrow concept of carer support

Even where carers are acknowledged, some staff are uncertain how carers can best be helped when resources are restricted. Support to carers is often seen solely as a range of specialist services, such as carer centres, self-help groups and carer support workers. The importance of carer-aware mainstream services, such as homecare, district nursing, housing and transport, and their role in sharing responsibility and giving the carer some time off is not always recognised. Many carers say their 'break' and support are offered through day-to-day services which they can trust, which communicate well and provide decent opportunities and a good quality of life for the person cared for. Carer support is not a stand-alone concept: it involves the relationship of the whole system of services with families.

Making the policy connections

Some areas are beginning to address these dilemmas and to make clear connections between health and local government corporate policies and the carers' agenda and to be more explicit as to how informal caring relates to the whole system. Progress has been evident on those Carer Impact sites which have worked to embed carers' issues into a wide range of policies and practices, both within and across departments and which relate to all local agencies. So, for example, urban regeneration schemes are building in strategies to address carers' health needs; work for Best Value initiatives on homecare specifications is including carer standards; employment policies are assisting staff who have caring responsibilities outside of their paid work; and housing policies are helping carers live nearby the relatives they are assisting.

A holistic approach is being tried out, which extends beyond the specialist support services and which sees carers as part of everyone's responsibilities rather than relying on discrete, specialist initiatives or projects which can become marginalised or cut when resources are tight. So, for example, joint health and social services and corporate strategies are addressing carers' information needs, working together with the specialist information offered through carer centres and carer projects.

Whilst this lateral thinking at a policy and operational level has been encouraged through developments such as Health Action Zones, in practice current systems and structures have presented a number of difficulties. Carer Impact sites have found the investment needed in joint working to take forward the carer agenda, to make the connections with other policy initiatives and to take carers into the mainstream has been impeded by:

- cutbacks in senior management, which have left few senior staff with adequate time to co-ordinate and drive the work
- uneasy or relatively early and untested relationships between the partner agencies, for example between health and social services or between health and the voluntary sector
- the different cultures of the partner organisations
- constant organisational changes resulting in ever-changing membership of joint groups progressing the carer agenda
- the difficulties in fitting carers' issues into planning structures categorised by care groups
- inexperience in engaging hidden carers and carers from minority communities
- the lack of systems to adequately monitor services and the impact of policies.

Inadequate monitoring

Many areas are at very early stages in monitoring the impact of their policies to support carers. Some areas have no clear joint strategies nor implementation plans and so developments remain ad hoc and uncoordinated, with pockets of good practice largely reliant on committed individuals or voluntary groups. Other areas do not have established processes nor have clear responsibility allocated for monitoring their joint policies through, for example, multi-agency groups, devoted to carer issues, with a brief to promote action, progress chase and keep up the momentum of the work.

This partly reflect the conflicts and contradictions apparent in developing carer policies and the varying importance afforded to carers by the different partner agencies, particularly without strong direction from the central government. It may also reflect the varied state of joint strategic work across the country.

Few authorities have the systems properly in place to collate unmet needs from recording carer assessments. Indeed, it appears that a number of areas are having difficulties in identifying carer assessments, particularly where there is confusion about its purpose. Many areas have commissioned ad hoc independent research and surveys or conducted other forms of consultation with carers to get a better picture of local need. Some areas are now trying to get feedback in a more systematic way, directly related to their joint action plans.

4 A time for change

There is an urgency to address these issues, not only from the perspective of the 6 million people caring for family and friends, but also from the state's viewpoint. It is clear that the state could never afford to fund the care provided by family and friends, particularly where 1.7 million people are devoting at least 20 hours per week to caring (Rowlands 1998).

There are also demographic trends, particularly the increased participation of women in the labour market and changing patterns in family life, which may reduce both the numbers of people available to care and the amount of caring that can be undertaken. The extra cost of replacing this informal caring has been estimated at £8 billion per year (Rowntree 1996). With the likely rising demands for long-term care as the numbers of very elderly people increase, there is an economic imperative to support informal caring and find ways of reducing the projected care gap.

Change is also needed to respond to central directives that service quality must improve and the public should be involved to achieve this. Quality and performance management, cornerstones of the new NHS, and Best Value initiatives present opportunities to address some of the issues raised by carers.

The development of a national strategy which could make the connections between all the different policies which impinge on carers does have the potential to bring more coherence to carers' relationship with the whole system of care. Whilst this will be no easy task, the real challenge will be in implementing a national strategy at a local level and measuring its impact on the lives of carers.

To move forward we need to find some solutions to the policy contradictions and ambiguities which lead to such varied practice on the ground; to take a fresh look at what we mean by carer support; and to build upon recent experience in partnership working and integrating support across the services.

A policy re-think

Given the contradictions and tensions, we need to achieve clarity about three key principles:

- ***Social inclusion and social justice***
  A society which is inclusive and seeks opportunities and participation by all citizens should ensure that people who give care and people who use support should not be excluded in any way. "We should not introduce a scheme for valuing caring which confines it to the home and hearth, isolating both the carer and the person cared for, and turning them and their environments into miniature embodiments of institutional care" (Jordan 1990).

Policies need to recognise the unique role of carers and the dangers in targeting services in a way which ignores the needs of carers. To achieve social justice for carers requires "recognition that caring affects health, education, employment and personal freedom. Social justice requires the development of systems to bring carers into the mainstream, help them back into employment if caring responsibilities end, and provide financial recognition both of the additional cost of caring and the loss of opportunity to be financially self sufficient" (Cayton 1998). The principle of 'compensation' for taking on the role of caring and of 'missed opportunities' needs to be considered alongside any targeting of services for vulnerable people.

- *Choice*
  It should be clear whether the policy aims to encourage people to become full-time carers or whether it encourages the sharing of responsibilities. There is a danger that formalising the carer's input may make it more difficult for carers to choose not to care (Parker 1994). Similarly, benefits and services could promote full-time caring at the expense of sharing the carer's role between members of the family.

  Policies should aim to create as much choice as possible for the person using support and for the people who provide care and opportunities to sensitively negotiate a solution. This may require the extension of some form of direct payments to disabled and elderly people who can opt for either paid and/or unpaid care.

- *Prevention and rehabilitation*
  Priority needs to be given to rehabilitation and preventative strategies so that people can live as independently as possible. There are clear connections between support to carers and preventative strategies which could minimise the responsibilities of carers and avoid the breakdown of caring situations.

A fresh look at 'carer support': the common agenda between users and carers

Community care policy which relies on carers is challenged by disabled people who question whether they should have to rely on relatives and friends for assistance. Jenny Morris (1993) has argued that "Once personal assistance is seen as 'care' then the 'carer', whether a professional or a relative, becomes the person in charge, the person in control."

Whilst the evidence shows it has been necessary to identify the special needs of carers, it is now time to re-examine the common agenda between users and carers, particularly when some commentators have queried whether the pendulum has swung too far in favour of carers. Carers say that the priority outcome for them is achieving a good quality of life for the person they care for. This not only requires appropriate and accessible services but also a society which does not discriminate against disabled people. Addressing the needs of carers thus must include meeting the needs of users;

carer support strategies cannot stand alone but must relate positively and coherently with strategies for services to disabled people, children and families, elderly people and people with mental health or learning disabilities.

The debate on young carers, children and young people who have taken on different levels and types of caring tasks, highlights some of these issues. There have been concerns that labelling young carers creates a new welfare category which diverts attention away from the underlying problems of poverty and discrimination associated with long-term illness and disability. It is argued if services to families were adequate there would be few young carers in need. There are now over 100 specialist young carer support projects across the country (Aldridge J, Becker S 1998). The challenge is to ensure that these specialist projects are balanced by the implementation of whole family support strategies and provision of quality services to disabled parents.

Respite care is another key area where the tensions between users and carers clearly surface. The term has many negative connotations, associated with relieving carers' 'burdens', with failures of families to cope and with attempts to compensate for service deficits required for the day-to-day support of disabled people and their families. More positive interpretations of a short-term break to benefit both users and carers embrace a wide range of services, from holidays to day services to rehabilitation, which can take place in a variety of locations, in people's homes, care homes, hospitals or hotels, and for varying durations.

Delivering the appropriate service is dependent on a sensitive assessment of both the needs of the user and the carer as well as clear policies about eligibility for any service offering a break. Carers' concerns about the quantity and the quality of respite care and the gaps in services, for example, for people with challenging behaviour or teenagers with profound disabilities, indicate the need for local and national action. This would include nationally agreed standards of respite care with baseline entitlements, clear local policies which address the needs of both users and carers, improved assessments so that unmet needs for a break can be collated and the development of joint commissioning arrangements.

Whilst there will always be some tensions between the needs of users and carers, sight should not be lost of the common agenda. Acknowledgement of the social model of disability and recognition that not all people will wish to have their needs for personal assistance met in the same way and that some people will want to give and receive help through informal relationships are shared principles underlying any strategy on carers. 'Think carer' at any level of policy making is not about putting carers before anyone else, but it is about challenging systems which make assumptions about who should and who should not take on the caring role.

Partnership working and a framework for integrating support

A common agenda thus is not about simply merging the needs of users and carers, but is about trying to ensure there is coherence between the policies to support carers and other health and community care policies.

From the Carers Impact experience it is clear that the most successful way of tackling this agenda is through effective partnership working involving the full range of statutory and voluntary sector players as well as carers. Health, housing, education, transport, community and social services need to work with carer and voluntary organisations and carers to agree, prioritise and monitor implementation plans. This work requires:

- a clear focus on the outcomes carers want
- effective partnership working where every partner takes responsibility
- ongoing monitoring to assess progress in achieving the outcomes.

From the experience on different sites across the country, Carers Impact has developed ***The Carers Compass*** as an audit and performance tool to assist in the joint work (Banks 1998). The Compass points towards the outcomes carers want and identifies all the policies and practices which the partner agencies need to have in place to meet the outcomes. It includes both specialist carer support services, such as carer centres, groups and support workers, as well as mainstream services such as hospitals, GPs, homecare, transport and housing.

Assessing performance

The Carers Compass also gives some pointers to ways of assessing performance and finding out the impact of the policies and practices on carers' and users' lives. The national strategy could develop the opportunities for authorities to compare their progress and develop better ways of measuring the impact of their work.

Carers are essential partners in order to keep the focus on carer outcomes and need to be involved at every stage, in planning, monitoring and evaluating services. There are good examples of carers being supported on planning groups through local carer networks; of managers going out regularly to consult with carer groups; and of outreach work to involve carers from minority groups. There are also examples of carers being directly involved in quality initiatives, auditing hospital discharges and planning and delivering training. The Taking Stock and Taking Action workshops run by Carers Impact have shown how carers can be successfully involved in prioritising, planning and monitoring local action. All of these offer valuable experience for the development of Health Improvement Programmes and for Primary Care Groups as they begin to develop strategies and engage with all the key partners.

Conclusion

The very real danger at a time of change in health and social care is that carers' issues may get sidelined because they are not yet embedded into mainstream thinking. This is partly because of the ambiguous relationship between carers and services and the pressures to treat carers simply as a resource.

Where carer support has not been built into other mainstream policies the evidence shows that carers' needs can quickly slip off local agendas, particularly when organisations undergo change and champions move on. Short-term projects and voluntary services are particularly vulnerable to cuts and sometimes only able to continue to operate on the margins. Progress on support to carers may be interrupted, or at the worst completely sidelined, if carers' needs have not been built into the local joint policies and priorities of health, social and community services.

It is not enough to bracket carers with users; instead, the service system should be very clear about the different and common needs of people who use and relate to services. This requires an ongoing dialogue at all levels, from policy to practice, so that users and carers, both separately and together, can have a voice in the development, implementation and monitoring of policies and strategies.

If the picture for carers is to change over the next few years, we will need more explicit and coherent policies at central and local levels, a fresh look at the shared user and carer agenda and incentives to deliver on effective partnership working. Carers deserve an imaginative and sensitive approach which engages with them as partners, which supports them as a matter of social justice and which recognises the uniqueness of every situation. Perhaps it is not so much a 'change of direction' but rather a clear 'sense of direction', with carers at the heart of the new agendas for health and social care.

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