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# *INTRODUCTION*

## Chapter One

### *THE STRATEGY FOR CARERS IN SCOTLAND*

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1. There are about 500,000 carers in Scotland. People who regularly provide voluntary care for relatives or friends who are unable to look after themselves. It is estimated that about 5,000 of these are young carers aged under 18.

2. The Scottish Executive made supporting carers a priority and under its Programme for Government committed itself, in its first year in office, to the introduction of a Strategy to support carers in the year 2000. The Strategy for Carers in Scotland was introduced on 24 November 1999. It has five main aims:

- to improve the information on help and support for carers
- to add to, and improve, the local services that help carers to cope
- to introduce new laws that will help carers
- to make sure there are consistent national standards for the kind of short breaks carers need
- to check that carers are getting the help they need.

3. Implementation of the Strategy is being taken forward in a variety of ways. Under the Strategy a Carers Legislation Working Group (referred to as the Group) was set up in January 2000 to take forward the commitment to introduce new laws to help carers. This report sets out the discussions of the Group and its main recommendations. The findings of the Group and its recommendations have been made to Scottish Executive Ministers, who have declared their intention to consult on them publicly.

4. Subject to the outcome of this consultation exercise the Scottish Executive has committed itself to introducing new legislation to help carers as soon as is possible.

## REPORT SUMMARY

## Chapter Two

1. Carers are a vital and central part of the whole health and community care system. Around 500,000 people in Scotland act as carers, giving their time, resources and energies to the care of others. Carers enable many thousands of disabled people and others who need some support to continue to lead independent lives in the community. And at the same time, carers reduce the amount of caring input that social services, NHS Scotland and other agencies need to make.

2. Against the background of the enormous contribution made by carers, the Group was acutely aware of increasing disincentives to caring, and the social and demographic trends, which threaten to reduce the extent of unpaid or informal caring in the future. We believe it is essential that Government / the Executive acts positively to protect the interests of carers. Through its commitment, the Executive should seek to foster a climate where people can continue to care for as long as they wish and are able to do so, without jeopardising their health or financial security, or reducing their own expectations of a reasonable quality of life.

3. Carers already have statutory rights, particularly to have their needs for support assessed in some circumstances. The Group was invited to consider whether these provisions are adequate, or whether further changes to the law are needed to ensure that the interests of carers are safeguarded more fully.

4. The Group benefited from the active involvement of a range of carers' organisations, carers and disabled people, and service providers (particularly local authorities). This enabled the Group to explore the wide range of issues that affect carers directly or indirectly, and to make recommendations for change that we believe will make a difference in the most important areas. The Group consciously did not limit itself to recommendations, which require legislative change alone – many of the changes that would make most difference to carers do not need a change in the law, but a change in how things are done.

5. While we believe some legislative changes are needed, it is equally important to ensure that existing as well as future legislation is implemented fully. Carers have had a right to an assessment of their own needs since the Carers (Recognition and Services) Act 1995, yet in practice very low numbers of assessments are being carried out – and even where they do take place, carers often do not realise that they have been assessed, or they feel the process does not meet their needs.

6. We also concluded that the most important and far-reaching changes to the lives of carers will be brought about by changes in the way statutory

agencies and other bodies view and treat carers. We hope and believe that the most important outcome of our work will be to encourage a new vision of carers, their contribution to society, and how society should support them.

## CARERS AS KEY PARTNERS

7. The Group's most fundamental conclusion is that carers should be recognised by Government, local authorities, the NHS and other agencies as *key partners in the provision of care*. By this we mean that carers should be seen as part – very often the only or major part – of the overall provision of care and support to the person they look after. A carer however has a unique relationship with the cared-for person. In their partnership with carers, other agencies or care-providers should value and recognise that relationship and the care given by the carer in their joint responsibility for the cared-for person. Carers must have equal status with other providers of care.

8. We do not believe the law needs to be changed to achieve this shift in approach – it can be brought about by clear messages and examples from Government and by encouraging other agencies to adopt good practice that already exists in many areas.

## CARERS NEED RESOURCES

9. Changing the emphasis to look at carers as integral partners in the provision of care allows the legitimate support needs of carers to be viewed in the right way too. Carers are involved in providing care, and like any other provider of care they need resources to carry out this role. Most of the resources which carers devote to caring are their own – their time and energy. Often there is also a wider cost to the carer's own financial position, employment prospects, or their personal health. We have no wish to undermine the intensely personal commitment involved for most carers, but no carer should be unduly disadvantaged by their caring activity.

10. In order to carry on caring, carers need support from time to time in a range of ways. This support may consist of information, advice, training for carers in lifting skills, or enabling the regular carer to take a much-needed break while another body provides care in place of the carer. Support of any kind which a carer receives which is *to enable them to continue caring* should be seen as the provision of a resource to the carer, which helps them play their role in the overall provision of care to the person they look after, not as a service used by the carer.

11. From this it follows directly that there should be no question of carers being asked to pay towards the cost of support they receive. Carers eloquently point out that they do not need this support for their own reasons, but simply in order to be able to continue as a carer. This is an area

of great concern to carers, and we believe that the Executive should take whatever action is necessary to clarify that carers have a legitimate right to support, and that they will not be required to pay for it.

12. We recognise that people who are carers may sometimes need support on their own behalf, for reasons not directly connected with their role as a carer. In these circumstances, the person will continue to be in the same position as others who need social care support, and may be asked to pay towards the cost under existing policies. Our proposals would not affect this position.

13. It is not possible to quantify the resource implications of our recommendations. We are not proposing changes in the way social care services are supplied or funded currently. To a large extent, our proposals are designed to make happen what is already possible under existing legislation. Alternative care arrangements, which may include short breaks services, still constitute a service to the cared-for person, although they may also be perceived as a resource which helps the carer to continue caring. These services should continue to be funded in the existing way from the budgets of statutory agencies, subject to the contribution from any charges which are levied on cared-for people. Where the resources for carers are supplied directly to the carer to enable them to continue caring, for example, advice, information, or training, the costs will fall to be met by statutory agencies themselves, as at present.

## SUPPORTING CARERS

14. The Group considered how far and how effectively carers are supported by other agencies at present. We concluded that while carers already have the right in many circumstances to have their needs assessed, in practice this does not happen enough. Statutory agencies should have a *duty* as well as a power to provide information to carers and to offer them an assessment of their care needs.

## THE ROLE OF THE NHS

15. The Group considered how carers might be recognised or identified in order to be offered advice and support. While local authorities take the predominant role in supporting carers in most cases, in practice the majority of carers are likely to be known to the health service first – either because of the health of the person they care for, or the impact of caring on their own health. We believe strongly that improving the capacity of NHSScotland to identify and refer carers on to other agencies is one of the most powerful ways of improving the lives of the large numbers of carers who currently get little or no support.

16. We recognise that work is going on in a number of local areas to develop links between NHSScotland and carers, and we applaud these initiatives. But we have concluded that this is a crucial area in ensuring adequate support for carers, and should not be left to variable local efforts. The Executive should consider imposing a formal requirement on NHSScotland to identify and support carers as part of its essential functions, which would provide both the necessary signal and would trigger the action needed on the ground.

## CARERS' ASSESSMENTS

17. Once a carer has made contact with one of the various support bodies and agencies, the process of assessment is the key to ensuring the carer can receive the support they need. Assessment is not only the gateway to carers receiving support, but is also an important process in itself in helping carers to define for themselves their own situation, and in having their caring role and support requirements publicly acknowledged.

18. Carers already have a right to an assessment so long as the person they care for is also willing to have their needs assessed. The Group believes strongly that the law needs to be changed so that carers are entitled to an assessment in *all* circumstances. Even when the cared-for person does not wish to be assessed, it is essential that the carer who is supporting them has an explicit right to have their own support needs considered so that they can continue to care for that person.

19. The Group believes that the nature of carers' assessments must be clearly recognised as different from assessments of the needs of cared-for people. Our recommended model, which defines carers as partners in providing care who may need resources, makes it clear that a carer's assessment should not be about identifying the personal needs of the carer, but establishing instead how the care needs of the cared-for person are to be met, and agreeing how responsibility for providing care will be shared between the carer and other support agencies.

20. We considered the process of assessment widely and make a number of other recommendations for improving how it works for carers. In particular, we concluded that it is essential that assessment should be carried out in a holistic way that considers the whole situation, that the process should be open and agreed with the person(s) whose situation is being assessed – in other words, assessment should be done with, not "done to", the carer. Ideally, a carer's assessment should be part of a wider assessment of the whole caring situation, including the needs of the cared-for person, though we recognise this is not always possible. A range of different approaches to carers' assessment are being tried in different areas, and we urge the Executive to review these, and then to issue comprehensive new guidance to statutory agencies on best practice in assessment for carers.

## YOUNG CARERS

21. The Group was asked specifically to look at the position of young carers and their entitlement to receive an assessment of their support requirements as a carer. We recognise that there are complex questions raised by the needs of young carers and the most appropriate responses to them by statutory agencies. But we believe it is essential that the pressing and real support needs of young people who are involved in caring now, and will continue to be, must be capable of being met fully. We therefore recommend that the law be changed if necessary so that all young carers are entitled to have their support requirements assessed in the same way as adult carers.

## CONCLUSIONS

22. Underpinning all our recommendations is the belief that carers are in a unique position. They require specific rights and support only because they are involved in caring for another person, not because of their own needs or condition. We are arguing for appropriate treatment for carers, not special treatment.

## RECOMMENDATIONS FOR LEGISLATIVE CHANGE:

(Numbers in brackets show the number of each recommendation in the full report.)

- New legislation should provide for carers to continue to be treated as carers for a limited period after their caring ends, eg, 8 weeks in line with existing rules on eligibility for Carer Premium and the UK Government's intention to allow Invalid Care Allowance to be extended for up to 8 weeks after the caring role has ended. (5)
- New legislation should require local authorities to provide information to carers about their rights and available support. (7)
- Scottish Executive to consider the case for a statutory duty on NHSScotland to identify carers, offer them information, and refer them on as appropriate. (10)
- New legislation should contain a right for carers to receive an assessment in their own right. (12)
- New legislation should place a duty on local authorities to offer carers an assessment. (13)
- New legislation should clarify if necessary the right of carers younger than 16 to receive an assessment, subject to appropriate provision for parental involvement. (18)

## LIST OF RECOMMENDATIONS

### Chapter Three

Recommendations marked \* appear to require legislative change.

1. Carers should be regarded by other caring bodies (eg, NHS and local authority Social Work Departments) as key partners in providing care.
2. Support to carers in their caring role to be treated as resources provided to help them continue their caring role, not services to clients.
3. Carers should not be required to contribute to the cost of support or other resources which help them to continue caring.
4. Guidance should make clear how disagreements between carers and cared-for people over assessments or services should be resolved, whilst respecting the rights of the cared-for person.
- 5.\* New legislation should provide for carers to continue to be treated as carers for a limited period after their caring ends, eg, 8 weeks in line with existing rules on eligibility for Carer Premium and the UK Government's intention to allow Invalid Care Allowance to be extended for up to 8 weeks after the caring role has ended.
6. Scottish Executive to pursue with the Health Education Board for Scotland how carers could be incorporated into future health-related campaigns.
- 7.\* New legislation should require local authorities to provide information to carers about their rights and available support.
8. Local authorities and NHSScotland should routinely include information on benefits, entitlements, and the statutory rights of carers in information offered to carers.
9. Guidance should stress the importance of agencies offering information in carers' own language and in accessible formats.
- 10.\* Scottish Executive to consider the case for a statutory duty on NHSScotland to identify carers, offer them information, and refer them on as appropriate.
11. The issues surrounding the identification of hidden carers should be explored further, preferably through the currently proposed UK-wide forum, or under the guidance of a separate Scottish Group if necessary.

12.\* New legislation should contain a right for carers to receive an assessment in their own right.

13.\* New legislation should place a duty on local authorities to offer carers an assessment

14. Guidance should spell out and emphasise the nature of an assessment of a carer, and how it differs from an assessment of the needs of a cared-for person.

15. Guidance should promote the development of more holistic approaches to assessment, including promoting family-based assessments, and self-assessment by carers.

16. Guidance on assessment should encourage the recognition of work-related issues for carers, and the reflection of these where appropriate in the support package.

17. The Executive should consider whether existing legislation provides adequate rights to parent carers, or whether the enhanced rights under new carers legislation should be extended to them.

18.\* New legislation should clarify if necessary the right of carers younger than 16 to receive an assessment, subject to appropriate provision for parental involvement.

19. Guidance should underline the importance of minimum intervention in assessments for young carers, promoting family-based assessments where possible, but recognising where this is not feasible, for example, where family members do not wish to co-operate.

20. Existing guidance on the need to involve health authorities and other relevant agencies in the assessment process should be reinforced.

21. Professionals involved in the assessment process should communicate and liaise closely in order to avoid multiple assessments and minimise disruption to the individuals being assessed.

22. The assessment process should identify the full range of support needs of the carer, and should not be constrained by the services currently available.

23. Staff carrying out assessments of carers should be fully trained in the issues faced by carers, and assessments should be conducted in a way that empowers the carer and provides full feedback at all stages.

24. The Scottish Executive should consider the case for a statutory right or entitlement to short breaks in defined circumstances, to ensure carers can continue to care.
25. The existing guidance to statutory agencies on provision of short breaks / respite care should be revised and re-launched to reflect the Carers Strategy and other recent policy developments.
26. Guidance should emphasise the value of advocacy support to carers.
27. Guidance should stress the importance of ensuring information, assessment processes and other resources are sensitive to the needs of carers from black and ethnic minorities, which should be planned in discussion with representatives of carers from these communities.
28. Guidance should take full account of the particular needs and circumstances of carers in rural areas, and should be developed in discussion with representatives of rural carers.
29. The gap between carers' identified needs and the support they receive should be routinely recorded by authorities carrying out assessments, and carers and their representatives should be closely involved in the work of the Data Standards Project in deciding how to define and measure unmet need.
30. The Executive should consider whether legislative change is needed to give parent carers of disabled children and 16 and 17 year old disabled children rights to direct payments to purchase care.
31. The Executive should consider whether there is a role for voucher schemes for short break services in order to facilitate breaks for carers, and if so, should pursue necessary legislative changes.

## *THE CONTEXT*

## Chapter Four

1. Carers may be seen as the threads that hold the complex web of community care together. A very large number of those people who receive community care services to help them manage their own lives are dependent on the care and support of a carer – or a number of carers. Carers, frequently without reward or recognition, spend much of their time looking after others, enabling the people they care for to carry on living in their own home and enjoy as full a life as possible.

2. Community care has undergone a revolution over the past 10 years or so. The range of services which can be offered, and the ways they can be provided, have expanded and diversified. A guiding principle underlying many of the changes has been that of enabling people to carry on independent life in the community. Thanks to these changes, fewer people who need care have to be cared for in hospitals or other institutions, and more are being helped to live among their friends and family, in familiar surroundings. These changes are good news. But the success of the new ways of supporting people in the community depends very heavily on unpaid carers, and as carers play an increasingly vital role, the importance of supporting them properly also increases.

3. Every caring situation is unique. We do not need to understand every individual's circumstances or motivations for what is often a very personal and private activity. But we all need to recognise the existence and the value of carers, both to the individual person they care for, and to the community more widely.

4. The importance of supporting carers is heightened by demographic trends. We are as a whole an ageing population, as the proportion of older people grows, and increasing numbers of people live longer. There will be progressively more people who need care, and fewer younger people to care for them. We are likely to see more caring situations where older people are cared for by other older people.

5. While the numbers of people needing care are set to rise, social trends seem likely to reduce the number of potential carers. Families have become less stable, smaller and more fragmented, and extended family networks which may support a person who needs care are becoming ever less common. In addition, the role of women in many families has changed, with increasing numbers active in paid employment and less available to act as carers. And while there is a strong personal commitment underpinning most caring relationships, there is evidence that some carers may be feeling increasingly that they are missing out on other opportunities as a consequence of their caring. All of which points to a

future where the numbers of people needing care will increase, while the number of those willing and able to act as carers may reduce. This reinforces the importance to all of us of valuing and supporting existing carers, and of removing disincentives or penalties that may be attached to caring at the moment.

6. An emerging area of carer recognition and support is the issue of carers and work. Recent research has indicated that 1 in 8 people in the workforce are carers. A number of government policies over recent years have sought to make an impact on this area. The introduction of the State Second Pension is intended to compensate for the loss of pension opportunities as a result of caring. The Employment Relations Act 1999 recognises the needs of people with caring responsibilities for emergency time off. The New Deal 50+ includes provision for former carers to return to work. Recent announcements of changes to Invalid Care Allowance (ICA), the main carers benefit, reinforce the message that carers need to be supported in balancing paid work with their caring responsibilities. We want to take account of the need to balance work and care responsibilities and, in particular, to emphasise the value of carer assessment in achieving that balance.

7. We take account of the context set by the Scottish Office's 1998 "Modernising Community Care" policy document, which emphasised strongly the aim of increasing support to people at home, and the key role of carers in enabling and supporting that. The Scottish Executive has made clear its intention to continue to improve the way community care services are provided, to encourage health and social work and other agencies to work seamlessly together. We are aware of the work of the Joint Futures Group which has reported to the Executive recommending new approaches across a wide range of community care and health service fields. We do not wish to pre-empt what may flow from this work, but it is essential that the Executive ensures carers feature as a central part of its plans to provide care for people in more effective, more sensitive ways.

8. We also recognise the examples of the Executive's recent Learning Disability Review, and its development of new care standards. Carers have been closely and directly involved in both these initiatives, and the needs of carers are being recognised as a result. We take account of the Executive's proposals on the way ahead for long term care for older people in Scotland in response to the Royal Commission's recommendations. We welcome the recognition given in that response to the contribution of carers, which will become increasingly crucial as more older people are cared for in the community. We are particularly pleased to see the commitment to providing resources for more short break services, to be targeted initially on those people whose carer has not had any break in recent years. We believe our own recommendations are in the same direction and spirit as the Executive's policies in this area.

9. In drawing up our own proposals for improving support to carers through legislation and supporting guidance, we have also taken account of key elements of the Executive's policies, including the central emphasis placed on social inclusion. By the very nature of what they do, carers are often invisible to most members of the community and to statutory agencies. Caring takes up a major part of many carers' time, and often means that carers are not able to have a full independent life or take up paid employment. And when the cared-for person needs additional help from the NHS or other services, the presence of a carer and the contribution they make are all too often ignored or disregarded. So carers as a whole may find it particularly hard to access the full range of opportunities available to others, and are a group of people likely to be overlooked in planning and decision-making. The Scottish Executive's Carers Strategy has already started to address this at a national, strategic level. We believe our proposals will go a significant way towards improving the position of carers in individual caring situations.

10. We believe that the recommendations made in this report reflect very closely the wider context of what is happening in community care and the NHS. We are also confident that our proposals fit clearly within the framework of the Executive's own strategy and vision for a more inclusive, fairer Scotland.

# *A NEW VISION FOR CARERS IN SCOTLAND*

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## Chapter Five

1. The Carers (Recognition and Services) Act 1995 brought a fundamental shift in the position of carers. It was the first time that legislation attempted to address specifically the needs of carers, and the first steps taken to define rights for carers. Unfortunately, while that legislation brought in new rights for carers to have an assessment of their own needs in some circumstances, the available evidence suggests that in practice far fewer carers are benefiting from these rights than would be expected or hoped. The first-hand experience of members of the Group supports this view. This situation can and must change: implementing this Group's recommendations would be a major step in that direction.

2. In practice, many carers are still unaware of their rights under the 1995 Act, and in some areas carers encounter difficulties in finding out about and accessing services or other support. The Group believes that the recognition and protection provided by the 1995 Act were extremely important, but in themselves have not proved enough to ensure carers consistently get the level of support they need and deserve.

3. The Group recognised that the potential impact of the 1995 Act was partly dissipated by the fact that its implementation coincided with the major reorganisation of local government in Scotland, which affected all social work departments. An additional factor was the introduction of the Children (Scotland) Act 1995 which also brought substantial changes for social work professionals at the same time. The Group's own recommendations should be seen as an attempt to give new impetus now to the policy and approach that underpinned the 1995 Act, and more importantly, to involve a wider range of agencies than just local authorities in supporting carers.

4. The Government's National Strategy for Carers in February 1999 and the Executive's Carers Strategy for Scotland in November 1999 brought further major steps forward for carers by spelling out clearly in Government policy statements the invaluable contribution made by carers and the Government's commitment to supporting them. A number of very important practical changes have already flowed from the Strategies – including the establishment of this Group - and we welcome these.

5. We believe the time is ripe to reinforce the legislative recognition and rights provided for carers. Our recommendations are intended to help achieve this. If the Executive implements our recommendations and supports them adequately, we believe they will be as important in moving

the agenda forward as the 1995 Act was in its time. Crucially, we do not believe that radical changes in legislation are needed to achieve these changes. What is needed is to redefine and clarify the way carers are viewed, and for statutory agencies and others involved in supporting carers to change the way they treat carers. The recommendations of this Group should be a lever to stimulate these subtle but important changes.

6. The Group considered a wide range of issues and potential changes. Some points became clear at an early stage – eg, the importance of ensuring that carers had a right to an assessment of their needs in all circumstances, and the need to develop and improve assessment processes. But other issues were less straightforward, and led the Group to complex discussions about the position of carers who needed support to continue their caring, and the resourcing of such support. The Group also considered at length the potential areas of conflict between the rights of the cared-for person and the carer.

## PROVIDING CARE

7. The foundation for our recommendations is the recognition that carers are essentially involved in providing care. Indeed, for very many of the hundreds of thousands of people who are looked after by carers, carers are the main or only providers of care. Previous attempts to put a financial value on the care provided by carers have drawn attention to the economic significance of unpaid care giving. The Institute of Actuaries 1993 report “Financing Long-Term Care in Great Britain” estimated that the value of the care provided by carers across the UK was in the region of £34 billion a year (a rough rule of thumb might suggest £3.4 billion in Scotland). While the Group recognises the power of this insight, it also believes that it is self-evident that the care provided by carers is beyond simple financial valuation – and that the impact on other support services of any single carer giving up caring is significant. The impact on other services of large numbers of carers ending their caring would be overwhelming. Quite apart from the moral arguments for supporting carers, there are therefore also powerful practical and financial reasons to ensure that as many carers as possible are enabled to continue to care as long as they wish.

8. We believe that the most fundamental changes to the position of carers can be made by formally recognising that carers are providing support, not consuming services. The 1995 Act already implicitly recognises this, but we believe there is a need for an unequivocal definition of the nature of caring. Everything else flows from that. Crucially, the recognition of carers as partners with other providers of care will underline to statutory agencies the central role played by carers (which they may acknowledge in theory, but which existing systems and approaches may not always recognise in practice) and the need for them to act in

partnership and complementary support with carers. In this way, the overall quality of care provided must also inevitably improve, as carers are often the best sources of information on the needs and resources of the cared-for person.

**Recommendation 1**

*Carers should be regarded by other caring bodies (eg, NHSScotland and local authority Social Work Departments) as key partners in providing care.*

## RESOURCING CARERS

9. Once the role of carers as support givers has been reinforced, the potentially perverse consequences of considering carers who receive external support as clients or users of services - like the people they care for - should disappear. Like all other care providers carers require resources to provide support. While there is no typical carer, every carer puts their own personal resources – physical, emotional, practical and financial - and time into supporting the person they care for. Many carers are caring for tens of hours every week, sometimes through the night as well. This is extremely challenging and tiring for the carer, and what many carers need most are regular short breaks (traditionally referred to as “respite care”) from the demands of caring in order to be able to carry on again. But carers may also need other kinds of help: eg, information about what services are available, emotional or practical support, or advocacy to help them express their own needs.

10. Carers can be supported in a range of ways. One of the most important ways of ensuring carers can continue to care is to allow them to take breaks from their caring responsibilities, most commonly through short break services. To allow this, alternative care needs to be given to the cared-for person. All forms of alternative care remain services provided to and used by the cared-for person, although the carer obviously benefits as well, and may be viewed as being indirectly resourced through them. Support that is provided directly to a carer to enable them to continue caring should properly be seen as a resource, which the carer needs in order to provide care to the cared-for person. Resources of this kind could include advice, information, or training.

11. We are not proposing changes in the way social care services are supplied or funded currently. Resources that are supplied directly to the carer should continue to be funded by statutory agencies as at present. Alternative care services provided to a cared-for person should continue to be funded in the existing way by statutory agencies, subject to the contribution from any charges paid by cared-for people. There should be no question of carers being asked to contribute to the costs of support they receive directly or benefit from which enables them to continue to provide their own (unpaid) service.

**Recommendation 2** *Support to carers in their caring role to be treated as resources provided to help them continue their caring role, not services to clients.*

**Recommendation 3** *Carers should not be required to contribute to the cost of support or other resources which help them to continue caring.*

12. There may be occasions of course when carers need support or help to meet their own needs for practical help to support their own independent living. When this happens we believe a carer should be treated in the same way as other people with personal support needs, ie, as a user of a service. Examples might include where a person who is a carer also needs meals on wheels, or home help assistance in their own right unrelated to their caring role. In these circumstances, a carer – as a service user – may be asked to contribute to the cost of such support, within the overall framework of local charging policies.

13. For the Group, the key distinction is that where a carer needs support solely or mainly in order to continue to be able to care, and in response to needs that the carer would otherwise not have, that support should be regarded as a resource required within the overall context of providing care. We recognise that there may be a small number of cases where there may be differences of interpretation between carers and statutory agencies about whether a carer needs support in their own right or in order to continue their caring role. We believe these should be limited, and should normally be capable of being resolved by sensitive consideration on the ground. In most cases, staff trained in mediation skills will be best placed to help reach agreement.

14. It is important to stress that the rationale for this approach is not a narrow one of simply avoiding carers having to pay towards the cost of support they get from other sources. Rather, it is about establishing the fundamental position and role of carers within the network of care, and ensuring that it is correctly defined and supported.

15. If legislation establishes as we recommend that a carer has a right to an assessment as part of defining the overall support package required, and that any help the carer needs is explicitly designed to allow them to continue their caring role rather than as a competing personal need, many tensions between carer and cared-for (which may centre round fears that the carer will impose alternative care options on the cared-for person) should be defused. We recognise that there will continue to be situations where the wishes of carer and cared-for person do not coincide, and in these circumstances assessment staff will need to mediate. It is important to acknowledge that there are a minority of caring situations, which are not positive and may even involve elements of exploitation or abuse by either party. The Group believes it is important that the needs of carers are not

regarded as inherently subordinate to those of the cared-for person – professionals from all support agencies owe an equal duty of care and protection to both carer and cared-for.

16. There is an argument that the potential for such differences should be recognised and specific channels formally identified to help resolve them. The Group concluded, however, that this was not necessary: mediation and resolution of different views is an integral element of existing social work functions, and there are established channels for pursuing complaints about decisions reached by social work staff if necessary. In some circumstances, advocacy support may help to resolve such differences.

**Recommendation 4**

*Guidance should make clear how disagreements between carers and cared-for people over assessments or services should be resolved, whilst respecting the rights of the cared-for person.*

## FORMER CARERS

17. The Group also identified particular concerns about the needs of “former carers” at the point where their caring role ends, for whatever reason. Carers invest huge personal resources in their caring role, which may have continued over a long period: the time when their caring stops can be very demanding, both practically and emotionally as the carer may experience very strong feelings of guilt and failure about ceasing to care. During this period carers may also face a range of additional pressures, including consequences for their own health, stress-related difficulties, housing and financial uncertainties. Many carers may also face the challenge of re-establishing their own identity and position in the community now their caring has ended.

18. During this very difficult transitional period carers may have particular acute support needs which are directly related to their former role as carers. We believe that the law should formally recognise this reality and provide that former carers continue to be treated as carers in all respects for a defined period after their caring role ends. The existing rules on eligibility for Carer Premium which extends for up to 8 weeks after the end of caring may offer a suitable precedent, as does the UK Government’s intention to allow Invalid Care Allowance to be extended for up to 8 weeks after the caring role has ended.

**Recommendation 5\***

*New legislation should provide for carers to continue to be treated as carers for a limited period after their caring ends, eg, 8 weeks in line with existing rules on eligibility for Carer Premium and the UK Government’s intention to allow Invalid Care Allowance to be extended for up to 8 weeks after caring has ended.*

# SUPPORTING AND RESOURCING CARERS

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## Chapter Six

1. The previous chapter sets out the Group's recommendations about the strategic vision of the role of carers which legislation and accompanying guidance should reinforce. To turn that vision into practical changes on the ground which will immediately and tangibly help carers, the Group identified a number of areas where specific changes are needed. Above all, existing processes, attitudes, approaches and services need to develop or improve in order to deliver the change of focus of carers as partner providers of care, rather than potential consumers of support services. While we recognise that there is a lot of goodwill to carers and some good practice amongst statutory agencies, there is a pressing need for these to become the rule.

2. We consider the areas where carers would benefit from change under headings which cover the chronological stages involved in supporting carers: information & awareness, identification and access, assessment, resources, and review.

### INFORMATION & AWARENESS

3. For all carers needing support, the first requirement (both chronologically, and often in priority terms) is ready access to a range of sources of information. Information which both clarifies and recognises the nature of the carer's role, explains the rights and entitlements of carers, and which points carers on towards sources of possible support. The Group recognises the work done by the Executive nationally to raise awareness of carers' issues and to improve the information available to carers. The Group felt there was particular scope for the Executive to seek to reflect the needs of carers in future health education and health promotion campaigns.

**Recommendation 6**

*Scottish Executive to pursue with the Health Education Board for Scotland how carers could be incorporated into future health-related campaigns.*

4. Despite this national publicity, the Group believes that at local level many carers are often unaware of the range of support or other resources which may be available to them. This may be due both to limited penetration of national publicity, and to inadequate commitment by some local agencies to inform carers of their rights. We know there is much good practice and that some agencies are very effective and proactive in identifying and offering information to carers, with effective support in

some areas by NHS staff. And we recognise the very important role played by high street “one-stop shop” centres for carers in making information available, particularly those affiliated to the Princess Royal Trust for Carers.

5. The Group believes that a more proactive and joint approach by all the main agencies with whom carers have contact should be encouraged to ensure carers are offered the information they need. People who care should not feel pressured into fitting a standard model of “carer” which may not be appropriate to an individual’s own view of themselves, or their personal motivation. But it is essential that any individual involved in caring has the opportunity to find out about and access support that is available, if they choose. The Group believes that wherever they are aware of or suspect the presence of a carer, local authorities should have a duty to offer information for the carer, which clearly identifies the support options available, and how to pursue these. The Group felt there was a case for a similar duty on the NHS: see paras 58-60 below.

**Recommendation 7\*** *New legislation should require local authorities to provide information to carers about their rights and available support.*

6. The Group’s main recommendations are likely progressively to lead to more carers having their support needs assessed and addressed. A crucial source of support available to many carers is that provided through the DSS benefits system, and the Group believes that information provided to carers by local authorities and other agencies should explicitly identify the main social security options which may be available, and provide clear advice on how to pursue these.

**Recommendation 8** *Local authorities and NHSScotland should routinely include information on benefits, entitlements and the statutory rights of carers in information offered to carers.*

7. The Group also concluded that it was important that information for carers, from whatever source, should be available in the carer’s own language or in a format accessible to them (eg, for deaf or blind carers). This is particularly important as many carers are as a result of their caring not necessarily closely involved in the life of the community, and are therefore less likely to come across or be offered information they can easily use. This is a key issue for carers from minority ethnic communities, who may find it even more difficult than other carers to find out about and access support.

**Recommendation 9** *Guidance should stress the importance of agencies offering information in carers’ own language and in accessible formats.*

## IDENTIFICATION & ACCESS

8. The majority of cared-for people will be in contact with the NHS at some time, either at the onset of their illness or disability, or when matters progress to the stage where they need the support of a carer. The Group believes that staff working within NHSScotland are usually best placed to identify carers, provide them with initial information and signpost them on to further support. We are aware of a number of projects under way in different localities which are working with GP practices to explore how front-line contacts between patients and NHSScotland could be developed to identify carers and offer information to them. Some of these projects are producing good results in identifying previously "hidden" carers. The full impact of this work will only become clear over the longer term, once it can be established whether the identification of these carers leads to them getting better support. The Executive should explore ways of ensuring that good practice in these areas which is being developed in local projects is shared more widely.

9. While the Group hoped that local projects would highlight ways of achieving lasting improvements for carers, they were concerned that the wide range of other priorities faced by the NHS might make it difficult to maintain the new approaches once specific projects had ended, and the associated support and encouragement had been withdrawn. The Group discussed whether a statutory duty should be placed on NHSScotland (perhaps on GP practices) to identify carers and offer information to them. An obligation like this might not sit easily with the general principle that NHSScotland should address the health needs of the population as a whole, rather than giving specific priority to particular needs or groups.

10. The Group believes very strongly that the frontline of the NHS holds the key to finding and beginning to support carers. Yet, while the NHS is likely to know most about who and where carers are, it is local authorities which have the statutory responsibility for supporting carers: it is essential to find a way of creating clear and firm links between these parts of the overall picture. The Group concluded that the Executive should consider seriously the introduction of a statutory duty on NHSScotland to identify carers, give them information, and refer them as appropriate to further support.

**Recommendation 10\*** *Scottish Executive to consider the case for a statutory duty on NHSScotland to identify carers, offer them information, and refer them on as appropriate.*

11. While working with NHSScotland appears the most obvious and immediate route for identifying "hidden" carers, the Group believes there are also other potential avenues and approaches, which should be explored. We understand that the Department of Health in London intends to take these issues forward through a UK-wide group, and the Group

believes that the Scottish Executive should ensure it is closely involved in this work.

**Recommendation 11** *The issues surrounding the identification of hidden carers should be explored further, preferably through the proposed UK-wide forum, or under the guidance of a separate Scottish Group if necessary.*

## ASSESSMENT

12. Members of the Group believe very strongly that the right to, and availability of, an assessment is the most important and powerful means of ensuring that carers can access the support they may need to enable them to carry on caring. A sensitive and open assessment process should provide the gateway to support, and thus the key to ensuring that carers can continue to provide care. Group members had extensive experience and knowledge of how the assessment process works in practice, and identified a number of ways in which current arrangements should improve. Assessments of carers were frequently felt by carers to be confusing and unclear – carers were not always aware that they had been assessed, and carers sometimes felt there was insufficient support available to them around the assessment process itself.

13. One issue that the Group was explicitly asked to consider was the extent to which the 1995 Act is adequate in allowing a carer to have their own support needs assessed only when the cared-for person agrees to have their own needs assessed. The Group believed that it is essential for carers to have a right to an assessment of their own needs, whether or not the cared-for person chooses to have an assessment.

**Recommendation 12\*** *New legislation should contain a right for carers to receive an assessment in their own right.*

14. We also concluded that the right to an assessment should be backed up by a duty for local authorities to offer a carer an assessment where they are aware of the presence of a carer. We believe this additional provision is necessary to ensure that local authorities take a more proactive approach to offering carers assessments, and that the provision of adequate information is recognised as an essential part of supporting carers.

15. The Group recognised the importance of ensuring that carers have complete choice over whether to have their needs assessed, or whether to accept any support offered to them. Nothing in our recommendations should undermine that principle. Local authorities and other agencies must ensure that in making carers aware of their rights, they also make clear that

carers are not obliged to make use of them if they do not wish to, and can be offered advice on other options for those who do not wish to have a formal assessment, eg, referral to a local carers' centre or other body.

**Recommendation 13\*** *New legislation should place a duty on local authorities to offer carers an assessment*

16. The nature and purpose of a carer's assessment also needs clarification. It follows from our main recommendations that carers should not be seen as needing services to meet their own needs, but resources to enable them to continue to provide caring support. An assessment of a carer should be seen not as a gateway to providing services to the carer in their own right, but as a means of identifying the full support needs of the cared-for person, whether directly or indirectly by maintaining the caring relationship. With the focus on the carer as a provider of care, in partnership with other agencies, the process of assessment for carers in practice should become a process under which:

- a. the carer and other support agencies (most often social work and NHS) agree the proportion of care that will be provided by each;
- b. other resources required by the carer are identified and agreed; and
- c. contingency arrangements are agreed to cover non-availability of the carer (eg, through illness, parenting or other caring responsibilities).

17. The Group discussed the case for adopting a different term for carers' assessments, but concluded that this could create unnecessary legal complexities and confusion for carers and agency staff. The Group believed, however, that it would be helpful to see carer's assessment as a "carer's resource assessment".

**Recommendation 14** *Guidance should spell out and emphasise the nature of an assessment of a carer, and how it differs from an assessment of the needs of a cared-for person.*

18. The Group discussed the range of approaches to assessment. The traditional approach of a structured interview between the subject and the social work professional was seen as limiting and often produced unsatisfactory outcomes, particularly for carers who often felt peripheral to the system. The Group felt that a wider range of approaches to assessment should be encouraged. The emphasis on carers as one element in the overall provision of support to the cared-for person points to the development of more holistic approaches to assessment that look at the total support needs of the situation, rather than distinguishing artificially

between the needs of the cared-for person and the carer. In particular, the Group was keen to encourage the use of self-assessment methods which were being trialled in some areas: self-assessment gives the carer an active role, ensures that the information in the assessment is agreed by the carer, and allows local authority social work staff to use their own time and resources more effectively.

19. The needs of carers from minority ethnic and black backgrounds need to be considered explicitly in developing assessment approaches. The Group believes that assessment processes need to become more flexible and culturally sensitive to the needs of carers from minority ethnic and black communities.

**Recommendation 15** *Guidance should promote the development of more holistic approaches to assessment, including promoting family-based assessments, and self-assessment by carers.*

20. In order for carers to return to work or continue to work, care services also need to be sensitive to the work/care balance. The Group agreed that there was a need for the assessment process also to offer an explicit opportunity to address the circumstances and needs of carers in relation to work, in order to assist those carers who are able and want to work to be able to do so.

**Recommendation 16** *Guidance on assessment should encourage the recognition of work-related issues for carers, and the reflection of these where appropriate in the support package.*

## PARENT CARERS

21. The Group is aware that the position of parent carers who look after disabled children (under 18) is not fully integrated into its recommendations for new legislation. The Carers (Recognition & Services) Act 1995, as it applies in Scotland, does not include a right to assessment for people with parental responsibility for a disabled child. However, parents who care for their own child already have a separate right to an assessment under section 24 of the Children (Scotland) Act 1995. The Group recognises that the position of parent carers and their children differs in significant ways from that of other carers, but believes that it would be desirable for parent carers to have as far as possible the same rights to an assessment in their own right as other carers.

**Recommendation 17** *The Executive should consider whether existing legislation provides adequate rights to parent carers, or whether the enhanced rights under new carers legislation should be extended to them.*

## YOUNG CARERS

22. There are particular issues around the question of assessments for young carers under the age of 16. The 1995 Act and its supporting guidance suggested that carers under the age of 16 may not in practice be legally entitled to receive an assessment as in view of the Age of Legal Capacity (Scotland) Act 1991 it would probably not be considered as a transaction commonly entered into by young people of that age. The Group felt this possible anomaly should be clarified in order to ensure that young carers, in common with all other carers of other ages, are able to have their needs assessed and additional resources offered to them if necessary.

23. The Group also considered arguments, however, that existing legislation and practice relating to children already provides in practice for the needs of young carers to be assessed and addressed adequately. The Children (Scotland) Act 1995 (section 23) provides for local authorities to assess a child when requested to do so by the child's parents. The guidance issued to local authorities by the Scottish Office on this Act stated that it was good practice for local authorities to consider any request for help made by the child directly and suggested that care managers could encourage the parent or guardian to request an assessment.

24. In seeking to ensure that young carers have equal access to assessment and support, the Group considered some of the basic principles involved. It is vital that the rights of disabled adults to establish families and live as other families and the rights of children to live in families that provide for their needs as children are seen as compatible and that assessment seeks to support this principle. We recognise that there will be difficult questions and that it may be necessary for the right to assessment for young carers to be linked with a requirement to show parental consent, in appropriate circumstances. We would, however, emphasise the need for family assessment as a means to recognise common and individual needs.

**Recommendation 18\*** *New legislation should clarify if necessary the right of carers younger than 16 to receive an assessment, subject to appropriate provision for parental involvement.*

25. For young carers therefore, it is particularly important that assessments are carried out in a way that is least disruptive or intrusive to family relationships, and which considers the support needs of the young carer within the context of the needs of the family as a whole. There may still be situations where this is not possible, for example, if family members cannot agree about the need for support: in these circumstances, it is essential that there are recognised arrangements for resolving differences. This might normally be facilitated by local authority social care professionals, although external mediation may have a part to play in some cases.

**Recommendation 19** *Guidance should underline the importance of minimum intervention in assessments for young carers, promoting family-based assessments where possible, but recognising where this is not feasible, for example, where family members do not wish to co-operate.*

26. While most assessments of carers and other people are led by local authority social work teams, the needs identified may be met from a variety of sources, including social work, NHSScotland, housing and education services, and benefit support. The Group discussed how different support agencies worked together to minimise the complications for the person assessed, and concluded that current arrangements were frequently fragmented, and regularly involved more than one assessment process during which the same information was collected by different bodies. Too often the assessment process is confusing to the assessed person and appears to be geared to the needs of the bodies carrying out the process. The Group recognises that improved joint working is an aim already being pursued by the Executive and other agencies, encouraged by the Joint Futures Group, and lends its support to this work which should bring major improvements for carers and the people they care for.

**Recommendation 20** *Existing guidance on the need to involve health authorities and other relevant agencies in the assessment process should be reinforced.*

**Recommendation 21** *Professionals involved in the assessment process should communicate and liaise closely in order to avoid multiple assessments and minimise disruption to the individuals being assessed.*

27. The Group also identified shortcomings with existing assessment approaches, which sometimes appeared to be driven by the availability of support services rather than the full range of needs expressed by the person(s) being assessed. The assessment process must be regarded by the professionals involved as a means of identifying the full range of support needs felt by the person(s) assessed, rather than a process which – perhaps unintentionally – expresses those needs in terms of the available range of services or solutions. This is an issue, which affects everyone who receives an assessment, not just carers, but the Group believed it should be addressed in guidance to social work and other professionals.

**Recommendation 22** *The assessment process should identify the full range of support needs of the carer, and should not be constrained by the services currently available.*

28. In our discussions about assessment, the Group recognised that the success or otherwise of any assessment depended more than anything else

on the training, skills and sensitivity of the professional staff involved in the process. This is true for everyone who receives an assessment, but the Group felt it was particularly true for carers as social work and other professionals had generally had fewer opportunities to build up experience with carers and become attuned to the issues carers faced. The Group believed that the implementation of changes in the law to clarify the role and support needs of carers should be supported by comprehensive and adequately resourced training for social work and NHSScotland staff, and staff in other agencies providing direct support.

**Recommendation 23** *Staff carrying out assessments of carers should be fully trained in the issues faced by carers, and assessments should be conducted in a way that empowers the carer and provides full feedback at all stages.*

## RESOURCES FOR CARERS

29. In line with our headline recommendations about the role of carers and their legitimate rights to resources to support them in providing care to others, the Group believes the term “services to carers” is inappropriate and unhelpful. We believe the correct focus should be on resourcing carers to enable them to continue their caring.

30. As discussed elsewhere in this report, the Group concluded that the existing structures and underpinning legislation for social work enable a flexible approach to providing carers with support or resources. The Group did not feel it was necessary to make detailed recommendations on particular kinds of support to carers, either direct or indirect, as in practice it believes that the current arrangements are already sufficient if used to the full. The Group decided to make specific recommendations only where it felt that there were issues about resources for carers that were not being properly addressed currently.

## BREAKS FROM CARING

31. A key form of support which benefits carers is the provision of short breaks to cared-for people. Such breaks, traditionally referred to as “respite care”, are provided to the cared-for person, but clearly directly benefit the carer as well as the person cared for. The Group recognised that the availability of appropriate short breaks, at a time that suits the cared-for person and the carer, is central to ensuring effective support for carers.

32. The Group considered the case for seeking a statutory minimum entitlement to a short break for carers who met certain criteria. On the one hand we recognised the importance of short breaks as one of the most

important kinds of concrete support for carers. On the other hand, there was a risk of reducing the flexibility of agencies to support carers in a range of ways and a risk of hindering the development of innovative alternatives to short breaks. There was also concern that the rights of cared-for people should not be infringed. The Group felt that the Executive should consider these issues raised by the possibility of providing for an entitlement to short breaks.

33. The Group believed that the current guidance to statutory and voluntary bodies on the provision of respite care (Scottish Office Circular No SWSG 10/96 and DD 7/96) was still a useful statement of policy and good practice. The Group felt that the Circular should be re-examined and updated in the light of the UK and Scottish Strategies for Carers and other recent policy developments.

**Recommendation 24** *The Scottish Executive should consider the case for a statutory right or entitlement to short breaks in defined circumstances, to ensure carers can continue to care.*

**Recommendation 25** *The existing guidance to statutory agencies on provision of short breaks / respite care should be revised and re-launched to reflect the Carers Strategy and other recent policy developments.*

34. The Group also felt that carers could benefit particularly from support in identifying and expressing their needs and the needs of the person they care for, through skilled advocacy services. Carers are not alone in having a need for advocacy support, and the Group recognises that this kind of support is not universally accessible across the country. Nonetheless, the Group wished to highlight the particular importance of advocacy support to carers. Advocacy support is particularly important to carers from minority ethnic backgrounds, who may face particular difficulties in approaching agencies.

**Recommendation 26** *Guidance should emphasise the value of advocacy support to carers.*

## CARERS FROM BLACK AND MINORITY ETHNIC COMMUNITIES

35. The Group commissioned a consultation exercise with minority ethnic carers in the Edinburgh area in order to increase its understanding of the particular issues faced by carers from black and minority ethnic backgrounds. The outcomes of this consultation reinforced the Group's own impressions that carers from these backgrounds encounter significantly greater difficulties than other carers in finding out about and accessing support. The Group identified a number of respects in which

carers from minority ethnic and black backgrounds might be particularly disadvantaged. It was not always easy for carers to access information in their own first language, and the Group also recognised that assessment processes might not be sensitive to important cultural differences which could have an influence on the carer's perceptions of their own role and support needs.

36. The Group concluded that it was essential that guidance to social work and other agencies highlighted explicitly the importance of considering the position of carers from black and minority ethnic backgrounds. The Group heard that the guidance which accompanied the Children (Scotland) Act 1995 was viewed as a good model, and urged the Executive to consider this approach in guidance accompanying future carers' legislation. The Group also considered it vital that support agencies involve representatives of these communities in planning and designing resources for carers to ensure they are sensitive to their particular needs.

**Recommendation 27** *Guidance should stress the importance of ensuring information, assessment processes and other resources are sensitive to the needs of carers from black and ethnic minorities, which should be planned in discussion with representatives of carers from these communities.*

## CARERS IN RURAL AREAS

37. The Group also considered in detail the particular issues faced by carers in rural areas. The Group recognises that rural areas are not all alike and there are significant cultural and geographical differences between differing rural communities. Ease of access to information and support can be dramatically different in some rural areas. Carers in rural areas also face greater difficulties and costs with transport, and often have fewer choices or alternatives about a wide range of day to day services. Some rural communities are very supportive of those needing care and their carers, while in other communities attitudes may be less open, which can make for increased isolation for carers and the people they care for. There is little information about how carers in rural areas cope, and approaches to supporting carers that are developed in urban or semi-urban areas may not work in rural areas. There is a need for agencies to think imaginatively about how best to provide support to carers in these areas. The Group believes that guidance should emphasise the importance of support agencies consulting carers who live in rural areas in developing local approaches.

**Recommendation 28** *Guidance should take full account of the particular needs and circumstances of carers in rural areas, and should be developed in discussion with representatives of rural carers.*

## REVIEW

38. An important area of concern to the Group was the extent to which carers' support needs, identified through an assessment process, cannot be fully met or met in a suitable timescale by other agencies. This issue, often termed "unmet need", is not unique to carers, and occurs across all services that seek to respond to the needs or demands of others. The Group believed though that it could be a particular issue for carers because carers were not yet widely recognised by local authorities or other agencies as a primary group requiring support, so there was a greater potential risk that where there was pressure on resources, the needs of carers might be neglected or given lesser priority.

39. The Group felt it was essential that the gap between the needs identified and the support or other resources which could be provided immediately was recorded and used as a tool to target and develop future services. The Group was pleased to learn that definitional work on carers and un-met need is shortly to be taken forward by the multi-agency Data Standards Project, sponsored by the Modernising Government Fund, and that carers and service users would be consulted throughout the exercise.

**Recommendation 29** *The gap between carers' identified needs and the support they receive should be routinely recorded by authorities carrying out assessments, and carers and their representatives should be closely involved in the work of the Data Standards Project in deciding how to define and measure unmet need.*

## FINANCIAL & RESOURCE IMPLICATIONS

40. The Group considered the potential implications of its recommendations for local authority social work and NHSScotland resources. It is impossible to predict accurately the effect of progressive changes in attitudes, linked with extended statutory rights for carers to assessment and support. But it is clear that if the Group's recommendations were implemented, the intended outcome would be that over time increasing numbers of carers would become more aware of their rights, and would seek information, assessment, and support in greater numbers. The potential resource implications of the Group's recommendations could be seen to fall in three areas.

## "FRONT END" / INITIAL IMPLEMENTATION AND SUPPORT COSTS

41. Our recommendations should stimulate the provision of information and advice to increasing numbers of carers, along with wider provision of advocacy support to carers, and more carers' assessments being carried out. Costs in these areas will inevitably rise if more carers come forward to seek support, but the Group believes these costs will increase gradually and will simply reflect carers as a whole receiving support at a level closer to that originally intended under the 1995 Act. Statutory bodies already seek to implement the provisions of the 1995 Act from their current resources, and the main effect of our recommendations should be to stimulate development of these services within the overall context of social care provision.

## SERVICES TO CARED-FOR PEOPLE

42. As more carers are assessed, and as a result more services are provided to cared-for people to help support carers, there are clear potential cost implications. The Group believes that changes of this type will also be incremental over a period of time, not immediate, and that the financial implications of volume increases should be addressed in the overall discussions between local authorities and the Scottish Executive about resourcing of social work services. This approach is appropriate as increases in service volumes resulting from improved support to carers cannot be viewed in isolation: there are complex interactions with other elements of community care, and potentially offsetting changes in other areas of expenditure, for example, in spending on long term residential care as many older people can continue to be cared for at home, or from increased use of home-based short break services rather than more expensive residential short break services.

43. The Executive already recognises and accepts the resource implications of shifts in provision of care – for example, in the substantial package of new money announced in October 2000 for initiatives to improve care for older people. This package includes new resources to fund increased volumes of short breaks for carers of older people who have never had a break: in practice these resources may go a long way to meeting the additional volume of services likely to be provided as a result of our recommendations.

## RESOURCING CARERS

44. As discussed earlier in this report, the Group does not believe that its recommendations will provide for new kinds of support to be offered to carers, as carers already have rights to most forms of support they may need, although they may not be universally or consistently available. The resource implications under this heading are also about unquantifiable volume increases as more carers are identified, assessed, and their need for resources is established and addressed. Volume changes will probably happen incrementally here too.

45. Cost implications flowing from our recommendations are likely to be progressive and gradual, and should be addressed in the wider context of funding for community care support generally. In many senses, implementation of the Group's recommendations would effectively re-launch the policy underpinning the 1995 Act, with a view to making more of it translate into practice.

46. The approach outlined in the Group's recommendations is about recognising fully and practically the enormous contribution made by carers, and doing the right thing to support carers. The Group believes that its recommendations will have progressive implications for local authorities by stimulating volumes of services and support. These should not be viewed in isolation but be considered in the wider context of funding for local authorities and shifts in service patterns. This can properly be seen as investing in carers in order to maintain a cost-effective and highly personal form of care provision, which would be irreplaceable by local authorities or other agencies. Any financial implications that surface will need to be balanced directly against the incalculably greater financial implications of failing to invest in carers properly, and the real danger of allowing caring to dwindle away.

## OTHER ISSUES

### DIRECT PAYMENTS

47. The Group was specifically tasked with considering the case for amending legislation to enable direct payments to be made by local authorities to carers. The Carers and Disabled Children Act 2000 provides for carers in England and Wales to receive direct payments to purchase services they receive under that Act. The 2000 Act also provides for parent carers of disabled children, and 16/17 year old disabled children themselves to receive direct payments to purchase care.

48. In Scotland carers cannot currently receive direct payments in their own right as they are not entitled to specific services. Carers may however receive direct payments on behalf of the person they care for if they are explicitly nominated by the cared-for person to act on their behalf. While direct payments may make sense in the context envisaged under the 2000 Act of carers as users of services, in the alternative approach we are proposing for Scotland there is no requirement for carers to receive direct payments as they are not expected to receive community care services in their capacity as a carer. The Group therefore concluded that there was no case for amending legislation to enable carers to receive direct payments.

49. The Group was concerned, however, to ensure that people in the other groups covered by the 2000 Act – parent carers of disabled children under 18, and 16/17 year old disabled children – should have the same rights to direct payments as their counterparts in England. The Group recommends that the Executive consider whether legislative change is necessary to achieve this in Scotland, and if so, introduce such change as soon as possible.

**Recommendation 30** *The Executive should consider whether legislative change is needed to give parent carers of disabled children and 16 and 17 year old disabled children rights to direct payments to purchase care.*

## VOUCHERS

50. The 2000 Act also provides for local authorities to run voucher schemes. Local authorities would issue vouchers either to a cared-for person, or to their carer, in order to enable them and their carer to benefit from a break. The voucher would be expressed either in monetary or time terms, and would entitle the cared-for person to purchase short break services or similar care from a body approved by the local authority, at a time and location that suited the cared-for person and their carer. The policy intention appears to be to give carers an entitlement to a break, and give the cared-for person flexibility and choice about how and when to arrange alternative care during the carer's break. These provisions will be brought into effect at a later date by Regulations, following consultation.

51. The Group has not considered these issues in detail. The pattern and tradition of service provision in Scotland may be significantly different, and voucher schemes may have less relevance in Scotland. There is probably a significantly less developed "market" in short break service provision in Scotland than has developed in England. Nevertheless, it would seem sensible for the Executive to consider carefully whether there is a place for voucher schemes of this kind in Scotland.

**Recommendation 31** *The Executive should consider whether there is a role for voucher schemes for short break services in order to facilitate breaks for carers, and if so, should pursue necessary legislative changes.*

## *CURRENT LEGISLATIVE POSITION OF CARERS*

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### Chapter Seven

1. The Carers (Recognition and Services) Act 1995 which came into force on 1 April 1996 applies to adults and young people aged 16 and over who provide or intend to provide a substantial amount of care on a regular basis for people in receipt of or who require community care services themselves. Community care services are those defined in Section 5A of the Social Work (Scotland) Act 1968, inserted by section 52 of the National Health Service and Community Care Act 1990.
2. The terms substantial and regular were not interpreted by Parliament at the time of the Act's introduction. Scottish Office guidance to statutory agencies on implementing the Act (SWSG 11/96 issued on 29 March 1996) stated that these terms should be interpreted in the everyday sense and gives some suggested factors which should be taken into account.
3. This means that not all carers may be eligible for assessment under the Act and it is up to local authorities to make that judgement.

#### RIGHT TO AN ASSESSMENT

4. The 1995 Act entitles carers to an assessment of their support needs on request but only as part of an overall assessment of the needs of the cared-for person, eg when the local authority is carrying out an initial assessment, or re-assessment, of the needs of the cared-for person. If a cared-for person refuses to have their needs assessed their carer is not entitled to an assessment of their needs under the 1995 Act. Re-assessment of the cared-for person's needs may arise because of changes in the cared-for person's or carer's circumstances. The Act requires the result of the carer's assessment to be taken into account when making decisions about the services to be provided to the user. It does not give local authorities powers to provide support directly to carers, although carers obviously benefit from a range of services that are provided to the people they care for.

#### PARENT CARERS

5. Unlike in England and Wales, parent carers are not covered in Scotland by the Carers (Recognition & Services) Act 1995. Parents who care for their own disabled child under the age of 18 and their child may receive holistic family services, including the right for the parents to have an assessment of their needs as carers, under the Children (Scotland) Act 1995 and the Disabled Persons (Services, Consultation and Representation) Act 1986.

6. Local authority social work departments have discretionary powers under Section 87(1A) of the Social Work (Scotland) Act 1968 to make a 'reasonable charge' for services provided to disabled children and their families, except the following, which they are not empowered to charge for: advice, guidance and counselling services.

#### WHAT CAN AUTHORITIES CURRENTLY DO TO SUPPORT CARERS?

7. The general powers in Section 12(1) of the Social Work (Scotland) Act 1968 can be used by authorities to provide support to carers' support groups and groups providing information to carers.

8. Section 12 of the 1968 Act empowers local authorities to make available any advice, guidance and assistance which it judges appropriate to promote social welfare, including assistance in the form of cash where this is the most cost-effective approach. And section 10 of the 1968 Act permits local authorities to give funds to voluntary organisations whose sole or main purpose is to promote social welfare.

9. Local authorities may also be able to help carers when the cared-for person refuses an assessment by using Section 12A(4) of the Social Work (Scotland) Act 1968. This allows authorities in extreme circumstances to make decisions about services required for the cared-for person without the person concerned having requested them to do so.

10. Carers may have community care needs of their own by reason of age, physical or mental well-being or disability. In that case they are entitled to an assessment of their care needs under Section 12A of the Social Work (Scotland) Act 1968 and can receive services directly from the local authority.

11. Local authorities and health boards have powers under the Local Government (Scotland) Act 1994 and Section 16A of the National Health Service (Scotland) Act 1978 respectively which gives them powers to provide funding and other resources to carers organisations and other bodies to enable them to support and promote the interests of carers.

#### INTER-AGENCY WORKING

12. Section 12A of the Social Work (Scotland) Act 1968 requires social work departments to bring housing and health care needs to the attention of the appropriate authorities and to invite them to assist in a person's assessment for community care services.

13. Scottish Office guidance on implementing the 1995 Carers Act stresses that social work departments should work closely with local education authorities when assessing the needs of young carers.

#### CARERS' RIGHT TO COMPLAIN

14. Under section 5B of the Social Work (Scotland) Act 1968 carers may complain in their own right about a local authority's failure to provide an assessment under the terms of the 1995 Carers Act or about the conduct of the assessment procedure. Carers can also complain on behalf of service users about the types and levels of services provided by or on behalf of local authorities including those provided in response to a carers' assessment.

15. Under the National Health Service (Scotland) Act 1978 carers and users also have a right to complain about any services provided by NHSScotland.

#### DIRECT PAYMENTS

16. Under the Community Care (Direct Payments) Act 1996 which came into force on 1 April 1997 carers are not eligible to receive direct payments in connection with their caring role. This is because carers are not able under the 1995 Carers Act to receive community care services directly from social work departments. Carers may be eligible for direct payments when they receive community care services in their own right.

#### YOUNG CARERS

17. Under the Carers (Recognition and Services) Act 1995 carers under the age of 16 do not have an entitlement to ask for an assessment under the Act. This is reinforced in the guidance issued by the then Scottish Office to accompany the Act, SWSG Circular 11/96. The guidance states that the Age of Legal Capacity (Scotland) Act 1991 provides a general rule that children under 16 do not have the capacity to enter into a transaction having legal effect. In such cases the parent(s) or guardian would have to act on behalf of the child. This legislative anomaly was not apparent at the time of introducing the Carers (Recognition and Services) Act 1995 which was intended to cover all carers, irrespective of age.

18. The guidance in SWSG 11/96 states however that for carers aged under 16 their needs may be assessed by authorities under general powers in Section 12(1) of the Social Work (Scotland) Act 1968 to promote social welfare, under Section 2 of the Chronically Sick and Disabled Persons' Act 1970 or under the Children (Scotland) Act 1995. In reality this means that

young carers aged under 16 can be supported in a variety of ways. The Scottish Executive has, however, acknowledged the need to remove any legislative anomaly through appropriate legislation. Doing so is therefore one of the main commitments in developing proposals for new carers legislation.

## EMPLOYMENT RELATIONS

19. Under the Employment Relations Act 1999, carers have the right to take a 'reasonable amount' of time off work to deal with an emergency involving a dependant. This includes taking time off to: deal with an unexpected disruption or breakdown in care arrangements (e.g. when a care worker fails to arrive); make longer-term arrangements for a dependant who is ill or injured; deal with the death of a dependant. 'Dependants' can be a partner, spouse, child, parent or someone who lives in the same household. This includes same sex relationships. The Act also includes rights to parental leave, with a special extension for parents of disabled children.

# *A DISTINCTIVE SCOTTISH APPROACH*

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## Chapter Eight

1. The Group was conscious that it was carrying out its work against the background of legislation already in progress in England and Wales to address similar issues. The Carers and Disabled Children Act 2000 came into force on 1 April 2001. This Act has as its basis similar concerns to those considered by the Group, and the Group's recommendations mirror closely some of the provisions in the Act. However, in some respects the Group decided that different approaches might be more suitable and successful in the particular context of Scotland, and that the new framework of devolution offered the opportunity to pursue separate solutions for Scotland. The Group recognises that it is important for it to justify to Ministers and the public the case for promoting carers' interests in different ways in Scotland.

2. The 2000 Act introduces a right for carers to have an assessment in all circumstances, as the Group has recommended for Scotland too. The 2000 Act takes a different approach from that recommended by the Group by providing for carers to receive services or other support in their own right as a different form of support to community care services, and allows local authorities to ask carers to contribute to the cost of such services. The 2000 Act provides for carers to receive direct payments to help them make their own decisions about how and when to purchase support services, and it also provides for the range of services that may be provided to carers to be defined and limited in Regulations.

3. The Group believes that a different approach is possible in Scotland because of the different background and structures of social work services. The statute on which social work provision in Scotland is founded, the Social Work (Scotland) Act 1968, takes a significantly different approach to the equivalent legislation in England and Wales. The 1968 Act allows local authorities to interpret need widely, and offers a flexible range of options for responding to need.

4. The Group concluded that this flexibility effectively means that in practice all the significant support needs of carers can already be met by local authorities under the 1968 Act – in conjunction as necessary with other agencies. The Group believes there is no need to change the law to provide for separate or new support to carers – the resources carers need should already be possible in Scotland. Where carers are not currently getting the support they need, the Group believes the difficulties spring from working practices, history and attitudes, which can be addressed without the need for legislation. The Group was also clear in its view that where external support is needed to maintain a caring relationship, such

support must be seen as part of the overall care package for the cared-for person, not a service provided to the carer in their own right.

5. Clearly, a significant consequence of the difference between this Group's proposals and the approach taken in the 2000 Act is that we do not envisage carers as direct recipients of services in so far as their caring role goes, and thus we do not see a case for carers being asked to contribute to the cost of services or support. This approach avoids the need for complex debate about whether the cared-for person or the carer is the "primary beneficiary" of a particular support service, which would often be difficult and time-consuming for social work professionals to decide, and potentially divisive between carers and cared-for persons.

6. More fundamentally, the Group believes that approaching the issue in a way that avoids the need to consider imposing charges on carers for caring support is in line with the central theme of the Carers Strategy for Scotland which emphasises the need to recognise and value the enormous contribution carers make. It will also avoid carers in future being asked to contribute to the cost of support services that they are currently entitled to receive without payment – which would be a perverse outcome to flow from the first Carers Strategy for Scotland. An inevitable further consequence of introducing charging would be the risk that some carers might be deterred from seeking support they need by concern about the costs they might face.

7. The Group also had concerns, which it understands are shared by carers and their representatives in England and Wales, about how comprehensive or useful the range of the services that can be provided to carers under the 2000 Act will be. This range is to be defined in Regulations, but the Act itself appears to establish that none of these services can be of an "intimate" nature. The exact range of this definition has still to be worked out, but the Group was concerned that it seemed possible that many of the forms of support which would help carers most directly were likely to be excluded from any definition, and thus not available to carers under the 2000 Act (eg, sitting services, or short breaks). The benefit to carers of this approach was not clear to the Group, which concluded that its alternative approach of avoiding the concept of services to carers was preferable.

## HOW THE REVIEW WAS DONE

### Chapter Nine

1. The Carers Legislation Working Group was set up in January 2000 by the then Deputy Minister for Community Care, Iain Gray.

#### GROUP MEMBERSHIP

2. The Group was made up of representatives from each of the 5 main carers' organisations in Scotland (Carers National Association Scotland, The Princess Royal Trust for Carers, The Coalition of Carers in Scotland, Crossroads Scotland and Shared Care Scotland) who had all been involved in drawing up the Strategy For Carers In Scotland. It also contained 1 carer and 1 service user representative, 1 joint representative from the Convention of Scottish Local Authorities (COSLA) and the Association of Directors of Social Work (ADSW) as well as officials from the Scottish Executive Community Care Policy Division, Solicitor's Department and Social Work Services Inspectorate.

3. For the Group Membership see Appendix A

#### REMIT

4. The Group's original remit was to:

- develop legislative proposals by end September 2000 which would empower statutory agencies to offer carers direct support. The proposals should address the specific needs of young carers aged under 16 and parent carers of disabled children, and should recognise the need to protect the rights of the cared-for person and;
- to consider the need for legislative change to provide for direct payments to carers.

5. It was subsequently agreed that the September deadline should be extended due to the complexities of some of the topics for discussion. The Group completed its work in January 2001.

## SUBJECTS DISCUSSED

6. These were agreed by the Group at its first meeting and reviewed towards the end of the Group's life to ensure that key topics had been adequately discussed. The key areas identified for discussion were:

- Carers Assessments
- Services To Carers
- Hidden Carers
- Former Carers
- Young Carers
- Carers from Black and Minority Ethnic Backgrounds
- Carers From Rural Areas
- Direct Payments For Carers
- Charging for Services to Support Carers

## OUTPUT

7. The Group was asked to consider at all stages of its considerations whether any recommendations for change could best be dealt with through legislation or through guidance, dissemination of best practice, or in other ways. This report covers that wider range in order to offer a comprehensive view of how carers should be supported better in the future.

8. The Group believes it is essential that the small number of legislative changes it has proposed should be supported and expanded upon by comprehensive and authoritative guidance from the Executive to statutory agencies. This new guidance on issues affecting carers will offer the opportunity to reinforce or clarify important messages given in previous guidance on carers' legislation and short breaks. The new guidance should be developed through an inclusive consultative process involving carers' representatives and organisations.



# *CARERS' LEGISLATION*

## *WORKING GROUP MEMBERS*

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Appendix A

Mrs Ivy Blair	Carer Representative (also representing Shared Care Scotland as a member of its Board of Directors)
Mrs Isobel Allan*	Carer Representative
Mrs Catherine Black*	Service User Representative
Mr John Wilkes*	Carers National Association Scotland (Director)
Ms Sheena Munro*	Coalition of Carers in Scotland – Executive Director of the Highland Community Care Forum
Mr Sebastian Fischer*	Coalition of Carers in Scotland
Mr Jack Ryan*	Crossroads Scotland (Chief Executive)
Mr Colin Williams OBE*	Princess Royal Trust For Carers (Director)
Mr John Leggate*	Shared Care Scotland (National Development Officer)
Mr Douglas Bulloch*	Convention of Scottish Local Authorities and the Association of Directors of Social Work
Mrs Liz Lewis	Scottish Executive, Health Department, Head of Community Care Division
Mr Felix Otton*	Scottish Executive, Health Department, Community Care Division, Carers Policy
Mrs Jean MacLellan	Scottish Executive, Social Work Services Inspectorate
Mr Colin Troup	Scottish Executive, Solicitors Office
Miss Morag Robertson*	Scottish Executive, Health Department, Community Care Division, Carers Policy

\* Core Group Members