

VALUING CARERS

Proposals for a Strategy for Carers in Northern Ireland

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INTRODUCTION

Ms Bairbre de Brún, Minister for Health, Social Services and Public Safety commissioned a strategy for carers in Northern Ireland in October 2000. She asked for a strategy that would contain practical measures that would make a real difference to carers here.

A working group was formed to draw up proposals for a strategy. The membership of the group is set out at Appendix A.

The terms of reference adopted by the working group were -

“ To identify the needs of carers; to identify any unmet need; to gather information about policies, practices, and services that affect carers and to set out an integrated strategy for future action.”

The working group asked Carers Northern Ireland to convene a reference group of carers and their representatives to let the group know what carers themselves thought could be done to help them to carry out their caring duties. The working group wishes to record its appreciation for the time and effort that reference group members devoted to this task. The proposals that we make are firmly rooted in what they told us.

STRATEGIES FOR CARERS ELSEWHERE

We considered that an appropriate starting point for the development of the strategy for carers in Northern Ireland would be to take account of recent work done in developing similar strategies elsewhere, strategies produced by the Scottish Executive and the National Assembly for Wales and, in particular, “Caring about Carers”, the national strategy for carers which was launched in February 1999 by the Department of Health in England. The development of that strategy involved Ministers and officials from all interested Government departments together with representatives from the NHS, local authorities, carers’ organisations and a range of other voluntary organisations which help to support carers and the people they care for. Representatives from a number of carers’ organisations here and from the then Department of Health and Social Services were involved in the development work.

“Caring about Carers” was built around three key elements – information, support and care. It

- recognised carers’ rights to have their own health needs met;
- promised encouragement for flexibility for carers in employment;
- recognised the need for better sources of information;
- recognised the need for carers to be involved in planning and providing services.

A number of actions which flowed directly from “Caring about Carers” have been of benefit to carers in Northern Ireland. These include

- changes to Invalid Care Allowance to
 - (a) allow carers over the age of 65 to claim the allowance

- (b) allow payment of the allowance to continue for up to eight weeks after the death of the person being cared for
- (c) increase the earnings threshold to allow carers to earn more before it affected their benefit;
- a rise in the carer premium paid with income related benefits such as Income Support;
- allowing time spent caring to entitle carers to a second pension;
- introducing a new census question in the 2001 census to improve the information that is held about carers. This will for example allow local service planners to produce better estimates of the need for services in their areas.

CONTEXT

Who are carers?

Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people under 18 who care for another family member.

Caring is an issue which can affect us all at any time irrespective of job or status and every caring situation is unique.

Why should we care about carers?

We do not need to understand each individual's circumstances or motivation in what is often a very personal and private activity but we do need to recognise the existence and the value of carers, both to the person they care for, and to the wider community.

It is expected that in the future there will be an increasing demand for care largely due to the growth in the numbers of old and frail people living in the community. By 2031 the number of people over 65 will increase from 13% in 1998 to 21% in 2031. The most significant increase over the next 30 years will occur in the older age groups. Those over 75 will account for 10% of the population in 2031 compared to 6% in 1998 that is from 97,000 to 164,000 people. The numbers over 85 will double from 23,000 to 45,000. At present there are five people of working age for every pensioner but by 2031 there will only be three. These demographic changes have obvious implications in terms of the availability of carers.

While the numbers of people needing care are set to rise, social trends could in the future have an effect on the number of potential carers. The growth in the number of lone parents, falls in birth rates, higher divorce rates, the increase in the numbers of people living alone and greater family mobility may all have an impact on the numbers of people available to assume a caring role. In addition, the growing number of women who are employed outside the home will have implications for the number of carers since women have traditionally fulfilled the caring role.

A very large number of those people who receive community care services to help them to manage their own lives are dependent on the care and support of a carer. Government policies for community care depend in large part upon the continuing contribution of carers; indeed carers are increasingly seen as forming the backbone of care in the community. People First - Community Care for Northern Ireland in the 1990s¹ acknowledged the crucial role that carers play in providing care. The paper states, “ the family ...continue to be the major supplier of social and personal care, and the obligations of kin and affection will remain powerful motivators. It is in society’s interest to sustain that motivation and to see that appropriate packages of support are assembled for people who are able and willing to care for others”.

What we know about carers in Northern Ireland

It is estimated that there are 250,000 carers in Northern Ireland and about 18 per cent of households here contain a carer. The Health and Social Well-being Survey 1997² provides an important source of information about carers and the relationship between caring and other health and lifestyle factors such as stress.

On the prevalence of caring the survey indicated that -

¹ People First Community Care in the 1990s - DHSS 1991

² Informal Carers Report Health and Social Well-being Survey 1997– DHSSPS 2001

- 18 per cent of respondents acted as carers with 6 per cent providing care for 20 hours or more per week.
- Women were more likely than men to be carers (20 per cent compared to 14 per cent). There was only a small difference, however, between women and men in the proportion providing care for 20 hours or more per week (7 per cent compared to 5 per cent).
- The peak age for caring was 45 to 64, with just under a quarter of respondents in this age group providing care. Women in all age groups were more likely than men to provide care, with the exception of the over 65 group.
- 8 per cent of respondents cared for someone living with them whilst 10 per cent provided care for someone living outside their household.
- 48 per cent of carers were economically inactive and 34 per cent were in full-time employment. There was, however, considerable variation depending on the location of the dependant. For example, 66 per cent of carers living with a dependant were economically inactive in comparison to 33 per cent of those who cared for a dependant living outside their household.

On who is caring for whom the survey indicated that -

- Nine out of ten carers care for someone related to them – 46 per cent care for a parent and 22 per cent care for a partner or spouse.
- Carers with a dependant in the household were most likely to care for a partner or spouse (48 per cent), a child (30 per cent) or a parent (26 per cent).
- Carers with a dependant living outside the household were most likely to care for a parent (61 per cent), a parent-in-law (13 per cent) or a friend or neighbour (13 per cent).

- 31 per cent of male carers cared for a partner or spouse compared to 17 per cent of female carers.
- 85 per cent of carers were looking after someone with a physical disability.

On the lifestyle and well being of carers the survey indicated that -

- Half of all carers (both male and female) who look after someone living with them had a long-standing illness compared to one third of those who look after someone living outside the household.
- 58 per cent of men who provide care for 20 or more hours per week had a long-standing illness, compared to 34 per cent of men who provide care for less than 20 hours per week. Women's level of long-standing illness did not vary with the length of time spent caring.
- Carers were more likely to suffer from a great deal of stress (17 per cent) than non-carers (9 per cent). This applied to both men and women.
- Approximately twice as many carers looking after someone for 20 hours or more per week suffered a great deal of worry or stress (25 per cent) in comparison with those looking after someone for less than 20 hours per week (13 per cent). This applied to both men and women.

Conclusion

It is clear that carers enable many thousands of vulnerable people who need support to continue to lead independent lives in the community. At the same time carers reduce the amount of input that social services and other agencies need to make. It is essential that we act positively to protect the interests of carers and to foster a climate where they can continue to care for as long as they wish and are able to do so, without jeopardising their own health or financial security or reducing their expectations of a reasonable quality of life.

WHAT CARERS TOLD US

At the outset we decided to ask carers what they thought the strategy should contain. In order to find out what carers wanted from the strategy Carers Northern Ireland convened a reference group made up of carers and of organisations representing or working closely with carers on behalf of the working group. A list of those invited to take part in the reference group is at Appendix B and a list of participants is at Appendix C. The reference group met on three occasions and firstly identified the 5 key principles set out below which they considered should underpin the strategy. The Carers Strategy Working Group unreservedly accepted these principles as the foundation for the strategy.

Key principles

1. **Carers are real and equal partners in the provision of care.** Carers must be recognised and included as real and equal partners at every level of public sector planning and service delivery – from designing a service to individual care planning. A carer has a unique relationship with the person they care for. In their partnership with carers other agencies or care providers should recognise and value 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.
2. **Carers need flexible and responsive support.** All carers are individuals with their own needs caring for people with a huge range of needs and abilities in what can be very complex and emotionally charged relationships. One solution will not fit all – carers need real choices based on relevant, timely and accessible information.

3. **Carers have a right to a life outside caring.** Carers need rest, relaxation and a social life and if they wish to work outside the home, they should have the opportunity to do so.

4. **Caring should be freely chosen.** Carers should be allowed to decide what level of caring support, if any, they can offer at any particular time.

5. **Government should invest in carers.** To make any real impact on carers' lives resources are required. 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 but in order to carry on caring carers need support. Support of any kind which a carer receives which is to enable them to continue caring should be seen as a legitimate right.

Priorities for action

The reference group then identified a number of areas where action could be taken to help carers

- Information and training
- Support services
- Employment
- Help for young carers.

We now go on to deal with each of these in turn.

INFORMATION AND TRAINING

Information

Easily accessible, relevant, factually correct information is of critical importance to carers. They need the right kind of information in the right format and at the right time. Many are not getting it.

On taking up their caring role carers need information about the condition of the person to be cared for and about what will be expected of the carer then and in the future. Such information is vital in enabling potential carers to decide what, if any, care they can provide and what support they will need to enable them to provide and to continue to provide care should they choose to do so.

Carers need good information on the health needs and treatment of the person they are caring for. They especially need information about medication such as when it is to be taken and about recognising side effects. They need information to enable them to deal with the symptoms of some illnesses and to know when to ask for professional help.

RECOMMENDATION

General practitioners and other clinicians should seek their patient's consent to provide information to the carer about the patient's illness or disability, medication and symptoms.

At the time of discharge from hospital, carers must be fully informed and involved in the planning of future care of the patient so that assumptions are not made about their ability or willingness to care. The Guidance on Discharge

of Hospital Patients³ issued by the then Department of Health and Social Services to Health and Social Services Boards and Trusts in November 1998 says that users and carers should be fully involved in assessments prior to discharge, that they should be aware of the implications of any decisions taken, that care plans should be agreed with them, that there should be opportunities for them to disagree and sufficient time for alternative acceptable arrangements to be made. It is clear that these standards are not always met.

RECOMMENDATION

The Department of Health, Social Services and Public Safety should remind Health and Social Services Boards and Trusts that carers should be fully involved in the timing of discharge from hospital and that carers should be given all the information that they require about the future care of the patient. Hospital discharge processes should ensure that carers are identified and that the presence of a carer is included in the discharge letter to the GP.

Carers also need information about where to go to get help. Some carers will begin to find out where to get such information from initial contact with the social security benefits system. Carers also make contact with voluntary organisations concerned with carers. Carers who are looking after someone with a particular health problem may contact a voluntary organisation which specialises in helping people with that condition.

RECOMMENDATION

All organisations that have contact with carers, whether statutory or voluntary, need to see their role as part of a wider network of support for carers and be able to refer them to services which can help them.

³ Discharge of Hospital Patients – DHSS 1998

The majority of carers here identified their GP practice as the place that they would first look to for information about how to get help but many GPs do not feel equipped to fulfil this “signposting” role. The working group considers that the new Local Health and Social Care Groups announced by the Minister for Health, Social Services and Public Safety on 16 October 2001 offer the opportunity to make progress on this.

Despite the integrated structure of the health and personal social services in Northern Ireland, until now the opportunity to have primary care teams encompassing both health and social care practitioners has not been taken. Social workers have not generally been members of primary care teams but have worked under separate management and organisational arrangements. Encouraging the development of integrated teams will increase the capacity of primary care to support carers.

The working group fully appreciates that it will take time for the Local Health and Social Care Groups to become properly established but considers that the Groups have the potential to play a pivotal role in identifying carers. Identifying carers at the earliest possible time is important in ensuring that they get the right information at the right time. Many people who are currently carrying out a caring role do not identify themselves as carers and are not aware of the support services available to them.

The Groups also have a crucial role to play in addressing carers’ needs by providing comprehensive multi-disciplinary assessments leading to a range of services that are flexible and targeted.

RECOMMENDATION

- (a) The new Local Health and Social Care Groups should have a central role to play in identifying carers.**

- (b) It should be a key objective for the Groups that they have mechanisms in place to enable them to take a holistic view of health and well being and address the health, social care and associated needs of both the person being cared for and the carer linking closely with other local agencies especially community and voluntary organisations.**

Whilst almost all the information that carers need is already available somewhere, carers may not be aware of the existence of particular information which can help them. As we pointed out at the start of this section, it is important that information for carers is accessible. The working group considers that carers should have access to up to date information about where to get help locally. We are aware that Craigavon and Banbridge Health and Social Services Trust for example has been working with the local Carers' Forum to provide Carers' Information Packs to new carers.

RECOMMENDATION

Health and Social Services Trusts and organisations representing carers should consider developing handbooks for carers about local services.

It is also important that full use is made of information technology in providing information that is up to date and easily accessible. Young carers in particular have suggested providing information in this way. The working group is aware that some work has already been done in this area as a result of the National Strategy – for example the “Looking after Someone” life episode on UK Online but more needs to be done to improve the information available about services for carers in Northern Ireland.

RECOMMENDATION

The Department of Health, Social Services and Public Safety working with other government departments as appropriate should look at ways of improving the information available on the Internet about services to carers in Northern Ireland and should work to increase awareness of the availability of such information.

Training

As we indicated above, carers are involved in providing care and like any other care provider they need resources to carry out this role. It would be unacceptable to expect a care provider to do their job without training. It is clear that training is very important in alleviating the burdens placed on carers in the community. The comments and recommendations that we go on to make in this part rely heavily on the report “Training for Carers in Northern Ireland – Issues and Opportunities”⁴. The report, which was published in May of this year, examines the training currently available to carers in Northern Ireland and looks at the extent to which such training is accessible and relevant to the needs of carers. The carers who put forward their views to the authors of the report listed some of the areas where they considered training was required. These included -

- Training on the use of aids and equipment
- Training on lifting and bathing
- Training on giving medicine and first aid and on dealing with for example catheters, PEG tubes and colostomies
- Training on behavioural management

⁴ Training for Carers in Northern Ireland – Issues and Opportunities – TOPSS NI and Carers National Association Northern Ireland - May 2001

- Specialist training such as sign language.

The report found that the organisations providing training to carers are for the most part voluntary and that coverage is very patchy across Northern Ireland and concluded that support should be provided to allow local services responsive to local needs to be expanded and developed through partnership, planning and the dissemination of best practice. The report contains some 20 detailed recommendations and indicates that the lead responsibility for developing policy with regard to carers and training should rest with the Department of Health, Social Services and Public Safety. We endorse this view and the recommendations contained in the report and recommend that the Department ensure that the Health and Social Services Boards and Trusts play appropriate roles in assessing need and providing training for carers.

RECOMMENDATION

The Department of Health, Social Services and Public Safety should ensure that Health and Social Services Boards and Trusts play appropriate roles in assessing training needs and providing training for carers taking account of the recommendations of “Training for Carers in Northern Ireland – Issues and Opportunities”.

SUPPORT SERVICES

Clearly carers need support in carrying out their caring responsibilities and if carers are to be seen as real and equal partners in the provision of care, as we believe they must, it is vital that they are involved in service planning.

Involving carers and their organisations is an important way of ensuring that services are responsive to their needs. Service providers should establish what services are available in their areas and the extent to which they are used.

Services should be tailored to fit the needs of users and carers and not those of the provider.

RECOMMENDATION

Health and Social Services Boards, Trusts and other providers should review their service provision for carers with carers.

A range of flexible, practical support services needs to be in place for the person being cared for and the carer. Clearly the provision of a proper service to the person being cared for is crucial to alleviating the burden on the carer.

Carers have told us that they place a particular value on low intensity services.

There was a strong feeling among carers that the level of community care services in general is not adequate to support users or carers and that this needed to be addressed during the current Review of Community Care Services.

Carers Assessments

The Carers (Recognition and Services) Act 1995, which came into force on 1 April 1996, gave carers in Great Britain a right on request (at the time the person they care for is assessed for community care services) to an assessment

of their ability to care and to continue caring. Although that Act did not extend to Northern Ireland, Health and Social Services Boards and Trusts were required from 1 April 1996 to assess the needs of carers here if so requested. The results of the assessment should be taken into account when decisions are made about the type and level of community care services to be provided to the person being cared for. The assessment is of the carer's ability to provide care and of his or her ability to sustain the care that he or she has been providing. Current legislation does not allow carers to receive help in their own right but legislation⁵ is shortly to be introduced to the Northern Ireland Assembly that will allow Health and Social Services Boards and Trusts to offer services direct to carers.

The working group welcomes the proposed legislation allowing services to be provided to carers and extending the direct payments scheme to carers but we believe that it will only achieve its objective of helping carers if there is sufficient funding available to enable services to be put in place.

Early intervention individually tailored to the needs of the carer and the person being cared for can be crucial in avoiding breakdown in the caring situation and good assessment processes are key in developing appropriate and quality services for carers. The carer's assessment should be focussed on identifying what information, training or services is required to support the carer.

At present most carers do not know that they have the right to ask for a separate assessment. All carers providing or intending to provide care on a regular and substantial basis should have their needs assessed and the results of the assessment should be recorded separately from that of the person being cared for.

⁵ Personal Social Services (Amendment) Bill

RECOMMENDATION

Guidance on carers' assessments should make it clear that Health and Social Services Trusts should inform carers of their right to a separate assessment and should require that the results of such an assessment be separately recorded.

Breaks from Caring

One of the key principles that we listed earlier in this report is that carers have a right to a life outside caring. This means time to pursue their own interests, see their friends, go to church or catch up with work around the house. Carers need breaks from caring but too often they do not get breaks or the breaks are provided in an inappropriate way. Carers often have little choice about the timing or the type of break. A range of respite care must be provided to suit the needs of both the carer and the person being cared for – week-long, one evening a week, weekend, overnight, short breaks in residential care – different options will suit different people. Respite care should not be seen exclusively as alternative residential care. Respite could also, often more appropriately, be provided by somebody coming into the home. There is also a need for emergency cover to be available for example for carer illness.

What carers want most of all during a break from caring is that the person being cared for is well looked after and secure. Carers' needs should be considered on an individual basis and they should have a choice about the type of service available to give them a break and about the timing of the break.

RECOMMENDATION

Health and Social Services Boards and Trusts should review the provision currently being made for carers' breaks and the information on which

they base their funding decisions to determine what carers want. Carers and people needing care must be involved in the review. This should form part of the general review of services for carers mentioned above.

Carers groups

Carers also need emotional support in coping with their caring role. Many carers obtain this through contact with other carers in a similar situation to them. Such contact can help to provide carers with information about the services that they need but also about how to cope with caring and with reassurance that they are not alone in feeling the strains and stresses of caring. Carers have told us that they value carers groups and the groups are a good means of involving carers in the community by providing a focus for their involvement in local decision-making.

Groups for carers of people with specific illnesses such as Cause or the National Schizophrenia Fellowship groups for carers of people with mental health problems can be valuable sources of information as well as providing support for carers. Groups open to all carers can be helpful in encouraging carers to focus on themselves. The Mencap “Parent to Parent Support” scheme offers both group and one to one support to parents from diagnosis at a level and pace that the parent feels they need and can cope with.

All carers should have access to local carer support services which we believe are best run and managed by the voluntary sector particularly when carers themselves are involved in the management arrangements.

RECOMMENDATION

Both localities based and disability specific groups should be encouraged and supported at local level.

Complaints

Carers have told us that they find it difficult to make complaints about community care services. They are dependent on the services and are often anxious about the possible withdrawal of the service should they make a complaint.

Research by the Eastern Health and Social Services Council after the first 6 months of their Patient Advocate Scheme at Belfast City Hospital showed that patients did not use the scheme to complain about their care until at or after discharge that is until they were no longer dependent on the service or on those providing it. How much more difficult is it likely to be then for people needing community care services whose needs will if, anything, increase over time. As well as being anxious about complaining, carers tell us that they have great difficulty in sustaining the time and energy needed to pursue a complaint. These difficulties are exacerbated by two particular problems that carers report about the complaints system.

Firstly, they regard it as slow, complicated and confusing. The system is off-putting to those who are already tired and under stress.

Secondly, many carers lack confidence in the current system because they do not perceive it as independent. Generally the people dealing with the complaint are the same people as are responsible for delivering the service.

In the long term most carers would like to see the current system replaced by one that is simpler, quicker, more transparent and more independent.

We make the following recommendations for improving the system in the short term.

RECOMMENDATION

- (a) The training of front line staff should be improved so as to ensure that they understand the value of dealing sympathetically with, and learning from, complaints. The importance of conveying an open and positive attitude to those who have issues to raise should be stressed.**
- (b) Support should be provided for the training and development of carer advocates who could guide and support carers through the process.**

Support for Older Carers

Before moving on to other areas where action could be taken to help carers, we want to make some comments about support for older carers.

As stated earlier the Health and Social Well-being Survey indicates that the peak age for caring is 45 to 64 with just under a quarter of respondents in this age group providing care. The survey also indicates that 15 per cent of respondents in the over 65-age group are providing care. A new report⁶ commissioned by Help the Aged with support from Carers UK suggests that the number of older carers is increasing and that they form an increasing number of all carers probably as a result of policies aimed at enabling older ill or disabled people to remain in their own homes for as long as possible. The report indicates that older carers are likely to offer higher levels of personal and physical care than other carers and that nearly 40 per cent are providing care for over 20 hours per week. Many older carers are not only caring intensively for many hours per week, but often they have been caring over a long period of time and in addition are caring for others while suffering from a serious health condition themselves.

⁶ Caring in Later Life – Reviewing the Role of Older Carers – Help the Aged/University of Kent 2001

More overall support is needed for older carers so as to alleviate the impact of caring in old age.

RECOMMENDATION

Health and Social Services Boards and Trusts need to be particularly proactive in seeking out and supporting older carers.

EMPLOYMENT

Many people who are providing care may be trying to balance paid work with their caring responsibilities. As we pointed out earlier in this report, the Health and Social Well Being Survey found that the peak age for caring here is 45 to 64 and that some 34 per cent of carers are in full-time employment. Carers will often be amongst the most experienced employees.

Carers in paid employment value their work as an important part of their lives. It not only provides much needed financial security and a break from caring but increased self-esteem and a sense of identity separate from their role as a carer. However, combining paid work with caring can be a difficult balancing act and the resulting stress can lead to an employee having to give up work particularly if they feel unsupported or if there is a lack of flexibility in the workplace.

Carers' needs can be quite simple – the assurance that they can leave work on time or access to a telephone during the day to ensure that all is well at home. As caring responsibilities increase, greater flexibility may be required to allow carers to continue to work. They may need time off for emergencies or time out of the workplace to attend hospital appointments. They may need to rearrange or reduce their working hours.

Many employers understand the business benefits of accommodating carers' needs. Replacing a carer who resigns can be difficult and expensive; a clear policy of support for carers reduces absenteeism and improves productivity. Support for working carers enhances the corporate image of social responsibility and enables the employer to demonstrate commitment to equality of opportunity.

Legislation has already been put in place to give all employees including carers the right to time off to deal with a family emergency. Article 10 of the Employment Relations (Northern Ireland) Order 1999 which came into operation on 15 December 1999 gave employees a right to time off work to deal with unexpected or sudden emergencies affecting dependants and to make any necessary longer-term arrangements. Employees do not have to complete a qualifying period in order to be entitled to take time off in an emergency. They have this right from day one. More details can be found in the Department of Employment and Learning guidance “Time off for Dependants”.⁷

In accordance with the key principle that carers have a right to a life outside caring we believe that carers of working age should be encouraged and enabled to remain in work. Where carers are unable to, or do not wish to, combine paid work with caring, help should be provided to enable them to return to work when their caring responsibilities cease.

We believe that there are a number of actions that employers can take to encourage and enable carers to remain in work. Employers should -

- ensure that managers are aware of the business reasons for supporting carers and that they understand the organisation’s employment policies.
- train and support managers to ensure that employment policies are applied consistently and fairly.
- identify and publicise employment policies and support provision that will assist carers.
- ensure that all employees understand the needs of carers. Staff who work in personnel, welfare or occupational health should be aware of the organisation’s employment policies and local support services for carers

⁷ Employment Rights Booklet Series ER 24 – Time off for Dependants

- use flexible employment policies to accommodate the needs of carers. Flexible working patterns such as part time working, job sharing, annualised working hours and flexitime are already offered by many employers and can help carers remain in work. Special leave provisions such as unpaid leave and career breaks which are often targeted at parents could also be explicitly extended to carers.

We recognise that employers here face many challenges but we believe that more employers should be encouraged to adopt carer-friendly policies. Many employers already have significant numbers of carers in their employment and all indications point to the numbers rising in the future with for example the higher levels of employment among middle aged women – the group which has traditionally taken on the major share of caring.

RECOMMENDATION

We recommend that the relevant departments draw up and put in place a programme of work to promote the adoption of good practice in carer-friendly employment.

Carers who give up paid employment in order to meet their caring responsibilities can find it difficult to return to work when caring comes to an end. They may have lost confidence and feel out of touch with the world of work and its changes. They need return to work training and measures to build their confidence.

RECOMMENDATION

The Department for Employment and Learning should ensure that the range of training schemes available includes schemes designed to meet the needs of former carers.

YOUNG CARERS

Young carers generally care for members of their immediate family whether a parent with a physical illness, disability, mental health problem or alcohol or drug dependency; a grandparent who is frail, ill or disabled or a brother or sister who is ill or disabled. The experience of growing up in a family where either a parent or a brother or sister is ill or disabled can bring both rewards and difficulties and it is important to record that many young carers want to care – they see their role as being part of the dynamics in their family and would not want to stop caring. They do, however, need recognition, understanding and support. All carers need support but because of the potential for adverse impact in the longer term on their educational, social and emotional development, children undertaking caring responsibilities have particular needs.

Clearly young carers must be seen and treated by all service providers as children or young people first and as carers second and as a general principle a sufficient level of service should be provided to the ill or disabled person so as to prevent children having to take on inappropriate levels of responsibility for providing care. Implementing the recommendations made in this report should assist in achieving this objective.

Currently the Children (Northern Ireland) Order enables Health and Social Services Boards and Trusts to provide help to young carers. In addition, guidance issued in February 1996⁸ to Boards and Trusts on carers' assessments drew attention to the special considerations that should apply to young carers and required Trusts to work closely with Education and Library Boards when carrying out assessments of young carers. New guidance on carers' assessments will be required when the Personal Social Services (Amendment) Bill is enacted. The Department of Health, Social Services and Public Safety

⁸ Guidance on Carers' Assessments – DHSS 1996

should take that opportunity to stress the responsibility that Boards and Trusts have to ensure that children whose parents or other relatives have specific needs because of illness or disability, enjoy the same life chances as all other children in their area. Boards and Trusts need to identify children with additional family burdens and to provide services to ensure that these children's education and development do not suffer.

RECOMMENDATION

Guidance to Boards and Trusts on carers' assessments should stress the need to ensure that young carers are identified and that services are put in place to ensure that their education and development do not suffer because of their caring responsibilities.

Young carers often choose to remain hidden because they are afraid of what may happen to them and their families should it become known that they are caring for someone. They also may not want other young people to know about their situation. This is especially true in the case of adolescents who feel that the need to be the same as everyone else and not stand out is important.

Whatever the reason, this self enforced secrecy leads some young carers to feel isolated from other young people within their school or community. This hampers them from getting information about services and support and many young carers do not realise that there are people who can help them. They have told us that they need information that is easily accessible. As with all carers, they mentioned information on the health of the person being cared for, how to do practical things for the cared for person such as help them go to the toilet and where to get help if they want it. They suggested a website as the most practical method of making such information available. We recommend above that the Department of Health, Social Services and Public Safety should look at ways of improving the information available on the Internet about services to

carers and consider that the needs of young carers should be specifically taken account of in so doing.

RECOMMENDATION

The Department of Health, Social Services and Public Safety should make the information needs of young carers a specific consideration when looking at ways of improving the information about services to carers available on the Internet.

Young carers have told us that school is a big issue for them. Homework and performance at school can be affected by their caring responsibilities. They can find it hard to concentrate because of worrying about their situation and the person that they are caring for but many of them would be reluctant to talk about their situation. Nevertheless teachers can provide valuable, sensitive support to young carers. Teachers already have duties to promote the general progress and well being of children and to provide guidance as well as advice to them on educational and social matters. This is done by teachers playing their part in implementing the school's pastoral care policy. The Department of Education document *Evaluating Pastoral Care*⁹ sets out how a school's pastoral care arrangements should support young carers. We would endorse the guidance and suggest it might be timely to remind schools and teachers of the important part that they have to play in identifying and alleviating the problems faced by young carers.

RECOMMENDATION

The Department of Education should remind schools and teachers of their role in supporting young carers.

⁹ *Evaluating Pastoral Care* – DENI/ETI 1998

We consider that establishing and maintaining links with schools and advising and assisting them in supporting young carers should be a key task for the coordinators that we recommend be appointed in each Trust area.

CO-ORDINATING SUPPORT FOR CARERS

Research into carers' experiences demonstrates that their relationships with statutory organisations are of key importance. Not knowing or understanding "the system", they rely on the social worker, district nurse or GP to tell them what to do or who to go to for help. It can even take carers a long time to recognise themselves as carers and to acknowledge that they need help.

More resources for services such as respite care, rehabilitation and day care would clearly make a huge difference to carers' lives. However, changes in awareness of and attitude to, carers could also make a significant difference. For example of the ten recommendations made in the Carers UK research into hospital discharge¹⁰ seven were about improving awareness, sensitivity, providing information, communication, referral and signposting.

We consider that the creation of a carer liaison or co-ordinator post in each Trust could help to bring about improvements in these areas and could provide a focal point for dealing with issues affecting carers. The aim would be for the postholder to work with for example Trust officers, carers' groups and disability organisations to improve awareness of, communication with and support to carers.

Key objectives would include

- Promoting awareness of the role of carers' – to provide information and training for professionals within Health and Personal Social Services and primary care settings on the role of carers and their needs, policy on carers and support and service options

¹⁰ You Can Take Him Home Now – Carers UK June 2001

- Improving access to information – to create and maintain an information resource and referral system for use by carers’ groups and professionals
- Training for carers – to design and arrange training to empower and support carers
- Networking – to create networking opportunities for carers’ groups to help them to gain skills and improve the service they offer to carers
- Mainstreaming – to liaise effectively with planners, community development and training teams within the Trust and other agencies
- Supporting schools and young carers – establishing and maintaining links with schools and advising and assisting them on supporting young carers.

RECOMMENDATION

A carer liaison or co-ordinator post should be created in each Health and Social Services Trust.

CONCLUSION

We consider that the most important and far-reaching improvements in the lives of carers will be brought about by changes in the way statutory agencies and other bodies view and treat carers. The Group's most fundamental conclusion is that carers should be recognised as key partners in the provision of care. Carers are in a unique position and require specific rights and support because they are providing care to another person and not because of their own condition. Our recommendations are designed to bring about appropriate treatment for carers, not special treatment.

Whilst we believe that many of our recommendations can be implemented without incurring significant costs we do, nevertheless, consider that it is vital to invest in improving services to support carers. We have called our report "Valuing Carers" and we hope that the outcome of our work and that of the reference group of carers and organisations representing carers will be to recognise and value the contribution that carers make to society by providing them with the support they clearly need. In order to achieve this we believe that it is vital not only to invest in services to support carers but also to put in place robust mechanisms to monitor the implementation of the strategy.

LIST OF RECOMMENDATIONS

Information and Training

General practitioners and other clinicians should seek their patient's consent to provide information to the carer about the patient's illness or disability, medication and symptoms.

Page 12

The Department of Health, Social Services and Public Safety should remind Health and Social Services Boards and Trusts that carers should be fully involved in the timing of discharge from hospital and that carers should be given all the information that they require about the future care of the patient. Hospital discharge processes should ensure that carers are identified and that the presence of a carer is included in the discharge letter to the GP.

Page 13

All organisations which have contact with carers, whether statutory or voluntary, need to see their role as part of a wider network of support for carers and be able to refer them to services which can help them.

Page 13

- (a) The new Local Health and Social Care Groups should have a central role to play in identifying carers
- (b) It should be a key objective for the Groups that they have mechanisms in place to enable them to take a holistic view of health and well being and to address the health, social care and associated needs of both the person being cared for and the carer linking closely with other local agencies especially community and voluntary organisations.

Page 14/15

Health and Social Services Trusts and organisations representing carers should consider developing handbooks for carers about local services.

Page 15

The Department of Health, Social Services and Public Safety working with other government departments as appropriate should look at ways of improving the information available on the Internet about services to carers in Northern Ireland and should work to increase awareness of the availability of such information.

Page 16

The Department of Health, Social Services and Public Safety should ensure that Health and Social Services Boards and Trusts play appropriate roles in assessing training needs and providing training for carers taking account of the recommendations of “Training for Carers in Northern Ireland – Issues and Opportunities”.

Page 17

Support Services

Health and Social Services Boards, Trusts and other providers should review their service provision for carers with carers.

Page 18

Guidance on carers’ assessments should make it clear that Health and Social Services Trusts should inform carers of their right to a separate assessment and should require that the results of such an assessment be separately recorded.

Page 20

Health and Social Services Boards and Trusts should review the provision currently being made for carers' breaks and the information on which they base their funding decisions to determine what carers want. Carers and people needing care should be involved in the review. This should form part of the general review of services for carers mentioned above.

Page 20/21

Both localities based and disability specific groups should be encouraged and supported at local level.

Page 21

- (a) The training of front line staff should be improved so as to ensure that they understand the value of dealing sympathetically with, and learning from, complaints. The importance of conveying an open and positive attitude to those who have issues to raise should be stressed.
- (b) Support should be provided for the training and development of carer advocates who could guide and support carers through the process.

Page 23

Health and Social Services Boards and Trusts need to be particularly proactive in seeking out and supporting older carers.

Page 24

Employment

We recommend that the relevant departments draw up and put in place a programme of work to promote the adoption of good practice in carer-friendly employment.

Page 27

The Department for Employment and Learning should ensure that the range of training schemes available includes schemes designed to meet the needs of former carers.

Page 27

Young Carers

Guidance to Boards and Trusts on carers' assessments should stress the need to ensure that young carers are identified and that services are put in place to ensure that their education and development do not suffer because of their caring responsibilities.

Page 29

The Department of Health, Social Services and Public Safety should make the information needs of young carers a specific consideration when looking at ways of improving the information about services to carers available on the Internet.

Page 30

The Department of Education should remind schools and teachers of their role in supporting young carers.

Page 30

Co-ordinating Support for Carers

A carer liaison or co-ordinator post should be created in each Health and Social Services Trust

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APPENDIX A

Working Group Members

Charles Bamford	Social Services Inspectorate DHSSPS
Sue Cunningham	
Peter Deazley	DHSSPS
Brian Dornan	Director of Social Services SHSSB
Helen Ferguson	Carers Northern Ireland
Tom Haverty	Assistant Director of Social Services WHSSB
Tom McNeill	Carer Representative
Margaret Sisk	DHSSPS

APPENDIX B

Organisations Invited to Attend the Reference Group

Carers Network

Contact a Family

Extracare

Alzheimers Society

Age Sector Reference Group

National Schizophrenia Fellowship

Barnardos Young Carers Project

Multiple Sclerosis Society

Mencap

Chest, Heart and Stroke Association

Disability Action

Aids Helpline

Citizens Advice Bureaux Carers Outreach Project

Multi-cultural Centre Health and Well Being Project

Omagh/Fermanagh Older People's Consortium

North West Association of Hearing Concern

Representative of Northern Ireland wide Sensory Disability organisations

Representatives of Health and Social Services Boards and Trusts

Observers from the Carers Strategy Working Group

APPENDIX C

Reference Group Participants

Maura Barker	Ballymena CAB Carers Outreach Project
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Helen Ferguson	Carers Northern Ireland
Val Hanna	Service User, Multiple Sclerosis Society
Bill Johnson	Carer, Extracare
Norah Lavery	Carer, NSF
Margery Magee	Alzheimers Society
Kenny McAdams	Disability Action
Derek McCambley	Multiple Sclerosis Society
Julie McCullins	Northern Ireland Chest, Heart and Stroke Association
Tony McGurk	Barnardos Young Carers Project
Brendan McKeever	Carer, Family Information Group/Contact a Family
Paschal McKeown	Mencap
Tom McNeill	Carer, Carers Northern Ireland/Mencap
Valerie Megraw	Carer, Alzheimers Society
Maura Riordan	Extracare
Nuala Rowan	Contact a Family
Kerry Tansey	Carer, Barnardos Young Carers Project
Caryl Williamson	Age Concern
Barbara Graham	Down Lisburn Health and Social Services Trust
Alan Richardson	Eastern Health and Social Services Board

Observer

Charles Bamford	Carers Strategy Working Group
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