

Carers rights – or “Could you do what I do?”

The aim of this section is to:

- Define what is meant by the term ‘carer’,
- Chart the development of carer awareness in public policy,
- Raise awareness of the statutory rights of carers to both an assessment and support in current legislation,
- Identify the key issues facing carers.

Carers want:

- *“Support to continue caring but minimise stress and disadvantage.”*
- *“Be seen as people in their own right.”*

Diana Whitworth – Carers National Association

1 What do we mean by the term ‘carer’?

Defining what we mean by ‘carer’ is important. People can and do get confused by the term. ‘Carer’ can sometimes mean someone who works in carer services as a care worker. Or it can refer to a person who offers support and care to someone on an unpaid basis. The confusion about who and what a carer is has led some people to differentiate between paid carers and informal or non-paid carers.

“Many people, who, on a daily basis, are offering care and support to a loved one, prefer to stress the family aspect of the relationship as in;

- *Family carer,*
- *Parent carer,*
- *Or plain – mum, dad or brother or sisters, aunt, etc.”*

In the work for the DoH on the Learning Disability White Paper (*Valuing People*, DoH. 2001) – the sub-group consulting with families of people with learning disabilities wanted to stress the family dimension of the relationships and called themselves family carers.

So, we can see the term ‘carer’ is at best elastic, at worst somewhat confusing. As we will see below, in legislation the definition is broadly inclusive and does not confine itself to family relationships.

The fact remains that many families caring for a learning disabled person have difficulty relating to the term, even though they might benefit if they did, in terms of the sort of support on offer to ‘carers’, and the high priority carers have in public policy.

Growth of carer awareness

JOB VACANCY

Qualifications

No formal qualifications required.

The successful applicant will have the ability to work long hours, up to 24 hours per day.

The applicant will be required to carry out tasks that normally require at least two workers to do.

The applicant will have to be able to work in a very stressful environment.

The applicant will have start immediately and learn on the job with no help or instruction.

Pay and Conditions

21 pence per hour with no overtime or shift premiums.

No holidays.

No days off.

No sick pay as working through periods of sickness is required.

No occupational pension scheme.

Retirement and resignation is not permitted.

All out of pocket expenses to be paid by the applicant.

There will be no prospects of promotion.

Social life of successful applicant will cease during the normal working week (7 days).

Pay and conditions not negotiable.

Please Note

Any applicant wishing to die will be required to give as much notice as possible to help social services to prepare the team that will be required to try and replace you.

THE SUCCESSFUL APPLICANT WILL THEN BECOME A PARENT/CARER OF A PERSON WITH A LEARNING DISABILITY.

devised by Sheffield Family Carers

The term 'carer' is a relatively new category and lacks clarity. No wonder many people are confused about who it precisely refers to. No wonder many people find it hard to see themselves as 'carers'.

The Carers lobby has been slowly emerging over the last 20 years, when it came to be recognised that there were more people caring for relatives at home than there were mothers staying at home looking after small children.

For the majority of old and vulnerable, sick or disabled people 'community care' actually means care and support from their nearest and dearest, (usually, but not always, family members). It has been suggested that these carers save the public purse

billions of pounds a year and the community care system would literally fall apart if all the unpaid carers stopped caring.

The Community Care legislation of the 1990's, heralded by the White Paper *'Caring for People'* (DoH. 1993), recognised the invaluable role played by informal carers. It had as one of its key objectives a commitment;

"To ensure that service providers make practical support for carers a 'high priority' and that 'assessment of care needs should always take into account the needs of caring family, friends and neighbours."

Yet, despite the growing awareness of the contribution of this army of unpaid carers, it was not until 1995 that they had any specific rights of their own in law.

2 The Carers (Recognition and Services) Act 1995

This piece of legislation represented a significant milestone for carers. For the first time carers became entitled to an assessment of their needs as a carer. The results of this carers assessment had to be taken into account when the Local Authority made a decision about providing services for the 'service user' that they were caring for.

For the purposes of the Act, the term 'carer' includes people who may or may not be a relative and who may or may not be living with the person for whom they are caring. The provisions of the Act cover adults, children and parents of disabled children who provide a substantial amount of care on a regular basis. Suggestions for what should be covered in a carer's assessment came in guidance from the DoH and included the following:

What might a carer's assessment cover?

- Their perception of the situation,
- The nature of their relationship with the user,
- The tasks undertaken and consequent impact,
- Tasks carers would like help with,
- Their social contacts and support received from family, friends and neighbours,
- Their emotional, mental and physical health,
- Their willingness and/or ability to continue to provide care; options available to the carer, particularly carers who are in employment,
- Their understanding of the illness or disability of the patient, and its likely/possible development,
- Other responsibilities eg, work, education, family/child care commitments,
- Carer's strengths and ways of coping.

Any particular stress factors and/or aspects of the caring task which the carer finds particularly difficult.

Has it made a difference?

Juliet Cheetham, writing in *Community Care* in 1999, said the Act had raised hopes amongst carers but has not always delivered its potential. Cheetham identified a number of barriers to using the Act effectively:

- Carers simply aren't always **aware of their statutory rights**. They don't ask for an assessment because they don't know they are entitled to one!
- Many people are **hesitant to define themselves as 'carers'**. People see themselves as parents, husbands or wives, families or friend caring for and about loved ones.
- People are **sceptical about the practical value** of an assessment.
- **Worker's own ignorance** or ambivalence about the legislation. Many staff are not aware either and carers do not get offered them.

Some important research on the effectiveness of the Carers Recognition Act for families of people with learning disabilities has been undertaken by the Norah Fry Research Centre in Bristol. The study, *'In their Own Right'* (Robinson V. & Williams C. 1999) concluded that family carers of people with learning disabilities were not well served by the Act. Many families had either not been offered a carer assessment, or were not sure, when asked, if they had had one! The process was not clear to people and they did not feel informed.

Where assessments had been undertaken there was a concern that the vital aspects of the carer's situation had not been assessed. This included the carer's own health and the fact they often have multiple caring responsibilities, older parents, younger grandchildren, as well as caring for a learning disabled son or daughter. Even more worryingly, the small number who had a Carers assessment carried out were visited a year later and for the majority, nothing had changed as a result of the assessment. Assessment should never be seen as an end in itself, but as apart of a process of targetting and focussing the right level of support for families. It should make a difference in people's lives.

Another limitation of the Carers (Recognition and Services) Act was that the carers rights to assessment are linked integrally to the Community Care Assessment of the 'cared' for person. If that person refuses to have an assessment, then their carer has no right to one in their own right. Even if their role as carer is having a major impact on their life.

This piece of legislation was undoubtedly a step in the right direction, but it did not go far enough. The Carers campaigning lobby has been advocating for an extension of carers rights for some time. This has been more fully realised in the last few years with first, the publication of the '*Carers National Strategy: Caring for the Carers*' (DoH. 1999) and the passing of the '*Carers and Disabled Children Act 2000*' (HMSO. 2000), which came into effect in April 2001.

3 The Carers National Strategy

In 1999 the government published the National Strategy for carers called '*Caring For The Carers*'. In the Foreword Tony Blair talked of the 'extraordinary work which carers do... devoting a large part of their own lives to the lives of others'. Describing carers as 'unsung heroes' the strategy document argues that they need to be recognised and valued for what they contribute and be properly supported to continue their caring role. The strategy calls for developments in three areas:

- More and better information,
- More and better support,
- More targeted support for carers themselves – care for the carers.

As part of the strategy a new special grant was made available to enable Local authorities to develop short-term breaks, called the Carers Special Grant. Local authorities were required to undertake extensive consultations with local carers to help decide local priorities. In some areas they simply failed to talk to the organisations representing family carers of people with learning disabilities.

In the first year the Special Grant only 65% of the money went directly on developing short term breaks and some local authorities were criticised for spending the grant money on things like carers workers and administration costs. Some local authorities were also criticised for **failing to reach out and find the more hard to reach carers**, like older family carers of people with learning disabilities and families from black and ethnic minority communities. In its discussion of support to carers the White Paper, *Valuing People* (DoH. 2001) recommends targetting both these groups for particular attention.

Discussion of carers in *Valuing People*

Concern for carers has been reflected in *Valuing People* in one of the eleven key objectives... **to increase the help and support carers' receive from all local agencies in order to fulfil their family and caring roles effectively.**

Valuing People stresses the importance of listening to carers, providing them with information and ensuring they get the right support they need to continue in their caring role.

As part of this it is recognised that carers need financial support and the benefit system needs reforming. Legislation is promised to:

- Allow carers over 65 to claim Invalid Carers Allowance – (ICA),
- Extend ICA to 8 weeks after the death of the cared for person,
- Change the name from ICA to Carers Allowance,
- From April 2001 – the Carer Premium has risen by £10.00 and the earning limit has risen to £72.00.

4 The Carers and Disabled Children Act 2000

This Act takes the rights of carers further than the 1995 Act and develops the intentions of the national strategy to improve the support and care carers receive in their own right.

The Carers and Disabled Children Act extends the rights of carers in the following ways:

- Carers have the right to ask for an assessment even if the disabled person refused services or an assessment.
- Local authorities can provide services to meet carers own needs.

- It makes provision for extending the voucher schemes for breaks thus extending flexibility and empowering carers through giving them more choice.
- It provides greater opportunities for the development of direct payments for carer's own services, as well as parents of disabled children and young disabled people between 16/17 years old.

The act also makes provision for the local Authority to charge for carer services and this could be a major **disincentive** for carers to take up the benefits of the Act.

Clare's Story

Clare is a 34-year-old woman with mild learning disabilities and some mental health problems. She has lived in the family home by herself since her mother died a few years ago. Her sister Eunice supports her on a regular basis. She visits her daily, ensures Clare is taking her medication, supports her with budgeting, cooking and cleaning. She is 'on call' and available for Clare for 24 hours a day and Clare does make demands on her sister, as Eunice is her only source of support. Eunice finds it hard to cope with all the responsibility of her vulnerable sister as she has three small children and a husband who is not very sympathetic to Clare's situation. He feels she should be in supported accommodation and social services should 'do something'. Clare refuses to have a Community Care Assessment. Up until April 2001 and the new Act coming into force, Eunice was not eligible to a carers assessment because Clare was not prepared to have any contact with services. Now the new Act means Eunice can get some help to make her life easier, and continue to support Clare.

Diana Whitworth, Chief Executive of the Carers National Association, has said that for the new act to work well and deliver its good intentions, the following things need to happen:

- Local Authorities need to use imagination to create flexible services for carers.
- Local Authority should use their discretion not to charge.
- Local Authorities will need to produce good information to promote Direct Payment schemes.
- Local Authorities will need to develop their capacity to listen to what carers want.

5 Carers and the Primary Health Care Team

A lot of emphasis has gone into what Local Authorities Social Service Departments should, and must do, to support carers, but health services have an enormous contribution to make in this area too.

Carers have a high regard for their GP and are more likely to be in touch with their doctor than any other professional. Carers are more likely to turn to their doctors as the first port of call if they are worried or feeling unwell or stressed. Many carers, as we have already seen, have a very limited knowledge about what services are available for them locally. The doctor's surgery could be the lynchpin in accessing services for many carers. It is therefore vital that GPs are 'carer aware' and link carers to the right support in their local communities.

Other members of the primary health team are also important, like community and district nurses and health visitors, especially where older carers might have health problems themselves and are getting support around their own health needs. Remember, Mary was introduced to services after a 40 year gap because her father had a stroke and the district nurse was visiting him when she met Mary and realised she was not getting any support from learning disability services. (See page 2.11)

Members of the primary health care team are in a key position to:

- Identify carers, especially carers who are particularly vulnerable, frail, or at risk,
- Take early action and nip problems in the bud,
- Direct them to services and supports,
- Treat any health needs.

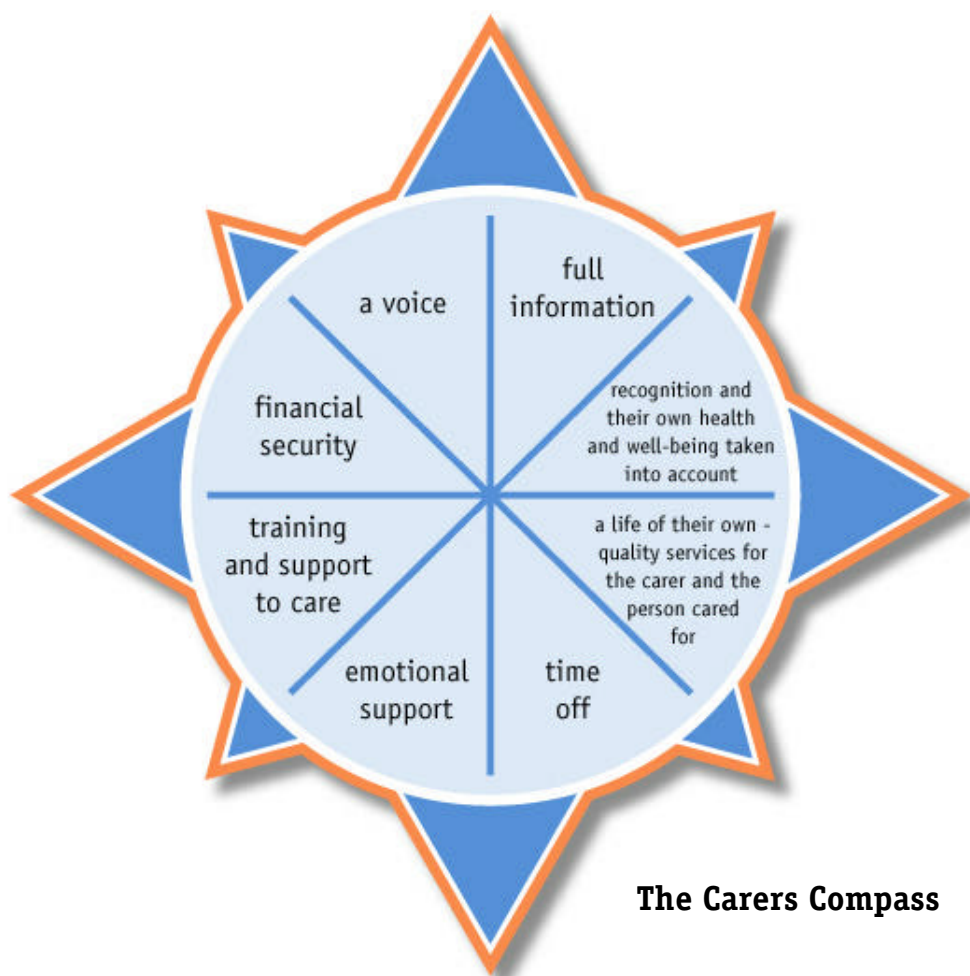
A checklist for assessing the health care needs of family carers, might cover the following areas:

- General health,
- Sleeping,
- Mental health,
- Stress,
- Physical strain,
- Mobility,
- Feelings.

Actually focusing on the health needs of carers is an important step in the right targeting the right levels of support.

Valuing People falls short of the targets set out for carers in the Mental Health National Service framework. Here it is recommended that all carers had their own Care Plan and that this is reviewed annually.

The Carers Compass has been designed by the King's Fund Centre as a tool to help primary health care teams develop a quality service for carers by developing and meeting eight areas of need. The compass is a useful tool for all services, as it provides a yardstick by which to judge both how carer aware services actually are and how much support is being offered.



The Carers Compass

The King's Fund has also developed a set of standards that all organisations purporting to support carers should meet. (Banks P., King's Fund. 1998)

Exercise 15

Try this for yourself in relation to your own organisation:

Think about the carers that you know and have contact with your service or organisation.

- List the different ways carers have a voice? In what ways do you think they are listened to?
- Describe the ways your organisation is ensuring carers are kept fully informed, both about their family member, but also about changes in the service?
- Describe any efforts to keep in touch with carers and assess how their needs are being met- including their health?
- In how many different ways are the families you are in contact with getting a break?
- Describe how carers emotional needs are being catered for?
- What training is offered to support carers in their caring role?
- Are the carers you have contact or dealings with receiving all the financial help they are entitled to?
- What rights do carers have?

6 Things are not always as simple as they seem

Family carers of people with learning disabilities have a great deal to gain from the generic developments for all carers. Clearly, many of the key issues are common. But, as it's an important distinction, carers of people with learning disabilities do have a different experience of caring, because of the duration or length of time their caring career. This has led some commentators to describe it as 'non-normative'. Research on the population of all carers indicates that the time spent caring is not always that long. A decade would be deemed a significant span. Between 1988 and 1991 only 48% of those identified in 1988 were still doing so in 1991 – whereas some older family carers of people with learning disabilities have been caring for over half a century!

We have already discussed in the section on – **Growing Older Together** – the fact is that as families grow older together, the clear distinctions between cared for and carer become less clear. Val Williams and Carol Robinson from the Norah Fry Centre (Robinson V. & Williams C. 2001) criticise current community care policy for 'dividing people up in to two camps', which does not always reflect reality. They argue for a model of care that '**supports caring relationships**' rather than categorises people as 'carer', or 'cared for'.

Assessments of families need to consider mutual interdependence and seek to bolster and support families to cope in ways that are appropriate and right for them. This is the **dual approach** that we have been trying to advocate all along, whether you are a carers service, a learning disability service or a service for older people.

Remember one of the characteristics of the experience that sets family carers of people with learning disabilities apart from other carers experience is the sheer length of time they have been caring. For many it literally is – a lifetime of caring.



In this section you have had the opportunity to reflect upon:

- What it meant in social policy terms, by the term 'carer'.
- How carers have come to prominence in social policy.
- The statutory rights that carers have in English law.
- And identify the key issues that carers highlight as important.

References

Department Of Health
(2001)

**Valuing People: A New Strategy For People With Learning
Disabilities In The 21st Century**

Robinson V. & Williams C.
(1998)

In Their Own Right
Norah Fry Centre, Bristol

Department Of Health
(1993)

Caring For People

HMSO (1995)

The Carers (Recognition And Services) Act

Cheetham J. (1999)

The Carers Act
Community Care

Department Of Health
(1999)
HMSO (2000)

Caring For The Carers: Carers National Strategy

The Carers And Disabled Children Act

Banks P. (1998)

The Carers Compass
KIng's Fund, London

Robinson V. & Williams C

He Will Finish Up Looking After Me
BILD