

10. The Carers' Viewpoint

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The contribution of so-called 'informal carers' to community care and to the care which is provided for people with disabilities has been well documented. So indeed has the stress – financial, physical and emotional – which can result. It is not necessary for me to report these. Nor is it my intention to argue that the needs of carers should be addressed in opposition to the needs and wishes of people with disabilities. Carers National Association is a membership association – open to all carers – and our policy is made by carers. It is very rare indeed to hear any carer say that they want *more* consideration, *more* help, *more* money than the person for whom they are caring. Rather, they almost invariably take the view that the needs of both people must be considered together and separately in order to ensure a better deal for *both*. That too is the view of Carers National Association.

It is not difficult to get agreement about what carers need in order to achieve this 'better deal'. On the contrary, you can sit down with any group – politicians, service providers, social workers, health workers, carers themselves – and in a very short time get a consensus around some kind of 'Carers Charter'. What you will come up with is a list of carers' needs which will inevitably include the following:

Recognition

Carers are expected to take on great responsibility, to provide huge amounts of care, with their own needs unacknowledged. For too long the presence of a carer in a household has been the signal for service deliverers to breath a sigh of relief and think that is one 'problem' they

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can ignore. The carer needs to feel trusted and valued by professionals, to know that her experience and knowledge of her own situation is understood and that her needs as well as those of the person for whom she cares are being met. (The word 'she' is used as a convenience and is not meant to ignore the role of Britain's 2.5 million male carers.)

This means that if she feels she wants to continue working at a much liked or much needed job, that is what she should be helped to do. It is not enough to start from the premise that, if the carer gives the job up, *then* help will be provided. It is not for anyone else to make the judgement about whether she should go on working or not: she herself should decide, and support services should be arranged accordingly. The aim should be to work towards partnerships in caring, with the carer being seen as at least an equal partner, not a passive recipient of services.

Active ways must be sought to help carers identify themselves; many do not even begin to recognise the work or the role.

Information

Carers badly need information – about the services available in their area, about the benefits to which they are entitled, about being a carer, about changes in legislation which will affect them and, if appropriate, about the condition of the person for whom they are caring.

A 'saturation' policy is necessary when trying to get information over to carers. You have to use not only every professional and voluntary agency with whom they may come into contact, but also make information available in doctors' surgeries, libraries, post offices, launderettes, newsagents – even via milkmen. Carers' handbooks, newsletters, fact-sheets and packs are useful. Great care must be taken not to use professional jargon and to present material as accessibly as possible. The design of leaflets and other material is very important, and it is vital that the illustrations reflect the multi-cultural nature of our society. However good the written material is, many people have difficulty absorbing things which must be read, and here the local radio and television can be extremely effective.

Local carers' groups can, of course, be vital in passing on information, and local authorities should always ensure that they use them as a communication channel. They should ensure, too, that their

personnel have good communication skills and understand that carers are often so distressed that this may act as a barrier to hearing the information.

Above all, a carer's need for information should be regarded as positive and not as a nuisance, and it should be seen as everyone's job to provide them with as much information as possible.

Practical help

Because much of the practical help available in the home has been developed to suit the needs of people living alone, it is often not well suited to the needs of carers, so that policy-makers may have to face difficult decisions about whether the existing service can be adapted in a way which will make it suitable for carers or whether something completely new will have to be provided. It is vital that the carers' need for practical help should be regularly reviewed and the help must always be offered with real regard to the particular circumstances of the carer.

Money

The financial effects of providing care can be devastating. Extra heating, laundry, special food and equipment, transport and substitute care all put a huge strain on household budgets. A cost which is much less easy to quantify is the loss of income for a carer who has to give up work. So carers need better benefits, opportunities to maximise the benefits which currently exist and the ability to continue in paid work or to take up employment whenever possible and appropriate.

Time off

Relief from caring is vital and, in order to be effective and really valuable to carers, it must be flexible and appropriate to their circumstances. Because there is a wide variety of need, there must be a wide variety of provision. Some want respite care which is provided in the house, some want it in some kind of residential setting, or a mixture of both. It should always be borne in mind that time off should not always mean they have to leave the house; the value of privacy in one's own home is only too easy to forget.

These five issues will usually be the ones most frequently mentioned when any group is focusing on the needs of carers. Other

elements will almost invariably include: receiving support, getting in touch with others in the same situation, being valued, being in control of their own situations and coming to terms with their own feelings.

It seems very likely that all the points set out above would be of similar importance if it was the needs and wishes of people with disabilities which were under discussion.

What we have to remember above all is that caring – in the sense of ‘informal’ caring – takes place within a relationship. The relationship gives rise to caring, not the other way round as is the case with other forms of care. As a consequence the history, pattern and quality of that relationship have a fundamental effect on caring. It is for this reason that it is almost impossible to generalise about what is or is not acceptable within a caring situation. Only the person with disabilities and the carer can make these judgements.

It is extremely important to take into account the variety of relationships which exist and not to make unwarranted assumptions. We should never assume, for example, that because a person has a physical disability he or she is receiving care. On the contrary, they may be completely independent and may in fact be providing care for another member of their family. On the other hand, a person who is completely able-bodied but suffering from some form of dementia may be almost entirely dependent on the relative who is their carer.

Similarly the reasons for caring vary greatly. Love, duty, moral imperatives, family history, family expectations and lack of acceptable alternatives are all involved. It may well be that the two people who are involved in the relationship meet each other’s needs extremely well. The need of the person with a disability may be to have care provided in their own home in a way which is acceptable to them. The need of the carer may be to feel needed and useful.

If the situation meets both these needs, it may be quite acceptable to both participants. However, people have other needs too – to be a martyr, to feel powerful, to be dependent, to be hard done by, to be in control. Caring relationships, like all other relationships, have positive and negative elements. Clearly there is often a mis-match between what the carer wants and what the person in need of care wants. Can care in the home which meets one person’s needs only be given at the expense of the needs of the other? At the very least, the two elements are inextricably entwined and must be looked at together,

so that each individual can be helped to address the inevitable conflicts.

Carers National Association has, of course, been particularly concerned about how the new arrangements for community care services will work when (if?) they are finally implemented. We believe that the aim of community care policies should be to enable carers and people who need care to have their separate and combined needs met within a framework of discussion, negotiation and choice. We all know that this is easy to call for, but how can we ensure that it actually happens?

First, we have to ensure that discussion, negotiation and choice happen within the caring relationship itself. Frequently they do not, because one or other of the parties to the relationship has given up 'negotiation rights' at an earlier stage.

This may be because the person in need of care is not easy to negotiate with – owing to some impairment of faculties such as dementia; it may be because the carer gave up the 'negotiation rights' in the interests of a quiet life; or because the person with a disability feels reluctant to put forward his or her own point of view. People in this situation often feel that some of the emotions they feel are inadmissible; it is not easy to admit that you feel anger and resentment towards someone who is seen to be dependent on you or to whom you are supposed to be grateful. Those who are in a caring situation often need help with expressing these feelings and with coming to terms with them, allowing each person to be free to decide what is, and what is not, acceptable.

Second, we must recognise that we are asking paid workers who act as gatekeepers to take on a new and often unfamiliar role.

As far as paid workers are concerned, developing a framework of discussion and negotiation often means acquiring a new set of skills and developing a willingness to abandon a 'provider' role and to take on the role of partner or facilitator. It may also mean asking some difficult questions like 'who is the client/patient/customer?' with accompanying questions about loyalty and confidentiality.

For example, what is the role of the social worker when she knows that telling the carer about the likely cause of an illness would be extremely helpful to the carer, but her respect for confidentiality of information about the disabled person forbids her to mention this? Should she encourage the sufferer to share the knowledge with the

carer? Should she tell the carer anyway even though this may mean going against the wishes of the sufferer?

Many of these problems can be tackled through training and through a willingness on the part of the paid workers to abdicate their power position, but we all know that changes in long-held attitudes are the hardest of all to bring about. The advocacy called for by this new situation may be difficult for paid workers to acknowledge.

When the new legislation was being proposed and discussed, much was made of the importance of consumer choice. For most carers, as for most people with disabilities, the stark reality is that virtually no choice is available except to those with sufficient money. Carers on the whole neither know nor care who provides a service. They judge the service not by who provides it, but by its reliability, its quality and by whether or not they feel demeaned by using it.

Above all, they judge a service by how well it meets their needs and the needs of the person for whom they are caring. For carers, 'better' services do not always mean 'more' services, but rather services which are specifically designed or adapted to meet their individual circumstances.

I have deliberately avoided discussion of the question of extra resources for carers and those for whom they care. This is not because I want to ignore the issue, but for two other specific reasons. It is too easy to allow service providers the excuse that if only there were more resources they would provide better services, but as there aren't they can't! Changing attitudes to carers and to those for whom they care can result in a better deal for them, within relatively few extra resources. Similarly, even in a climate where unlimited resources were available, we would still have to tackle the difficult problems of balancing needs, family and society expectations and unresolved relationships.

I cannot, of course, conclude this discussion without referring to the vital need to increase the power of the carers' lobby in partnership with those of people with disabilities, older people, people with a mental illness and many others. All political parties and candidates must be aware that enormous numbers of votes are represented by people who have for too long not had an opportunity to make their voice heard.

Opportunities will also exist in the period preceding a general election for carers' organisations and organisations representing other

groups to work together. We must be mindful of the propensities of government towards 'divide and rule' tactics with the voluntary sector and must work for close co-operation to ensure that this does not happen. The needs of *both* parties, in the individual situation and organisationally, *must* be acknowledged.