

RECOMMENDATIONS

1. Characteristics of carers and the people they look after

There is little information in the Census on carers' health or on the characteristics of those being cared for. Research though has shown that there is a connection between the number of hours a person is caring and the negative effect that this has on the carer's health, particularly where people are caring in excess of 50 hours per week.

Census data does show that, in East Sussex, a majority of carers are caring in excess of 50 hours per week. The highest percentage of such carers is in Wealden. However, the highest percentage of the caring population who are caring in excess of 50 hours per week and reporting ill health is in Hastings, a finding likely to be connected to Hastings position of 38 on the Index of Deprivation.

Research also indicates that older carers suffer more ill health than younger carers. In total there are 7,247 carers aged 65 and over in East Sussex, of which 2,064 care in excess of 50 hours per week. One quarter of these live in Wealden.

In order to commission and provide appropriate services in step with the needs of carers, the County needs to take into account the health of the caring population. Collecting this data is not a task for the voluntary sector. In our view the only organisation with both a complete overview of the system and the capacity to undertake such data collection is the local authority.

ACTION:

- **Commission a survey to identify, in detail, the characteristics and health of carers and of those for whom they care. The survey should focus on older carers caring in excess of 50 hours per week.**

2. Location of Carers and Services in East Sussex

According to the GIS maps and census data, carers appear most likely to be located in and around the coastal towns of Hastings and Eastbourne. The density of carers in these areas is misleading, as the actual numbers of carers in Eastbourne is the second lowest in the county after Hastings and the percentage of carers per population is 9.77%, the smallest percentage in the county.

In contrast Wealden has the largest number of carers in the county and also has the most carers caring for more than 50 hours per week at 2,428.

The location of services does not entirely match the distribution of carers. Services are clustered around Eastbourne, Hastings, Lewes, Hailsham and Crowborough. Wealden is a very rural area with few services for carers, no respite care and no day centre provision for adults. Rother, also a rural area, has very few services for carers. There are no day centre provision for adults with mental health needs in Rother.

Many available services run well below 100% occupancy, though this is not necessarily because of lack of demand. More information is urgently needed on these services and their take up. At the moment there is a lack of consistency and regularity in the way in which information on services is recorded. In the statutory sector too, information is more likely to be gathered on the user rather than the carer, yet carers are normally the beneficiaries of services too.

ACTION:

- **Take account of available data to ensure a more even spread of services.**
- **Support and develop the diversity of voluntary sector services, not only those operating at county level but also the smaller, local organisations. Many of these latter address specific areas of need in rural areas.**
- **Reassess the efficacy of block contracts.**
- **Collect information on the amount spent on services and who they reach in a consistent and regular manner, in order to complete the picture of provision and assist forward planning.**

3. Respite Care

This report has shown clear evidence of the need for more respite care in the county, both residential and home based. Many carers would like respite in their own homes, including overnight breaks, respite for a day a week or a few hours in a day and day centre respite.

There is a need for **more flexibility** of respite and variation, e.g. available outside of the 10.0 am-3.0-pm time slot, traditional day care times. This is particularly true of people occupying the dual role of caring and working who require help to continue caring. It is also true for parents of school age children who find it difficult to get respite breaks after school hours and during the school holidays.

Respite breaks also need to take into account the condition of the person being cared for. Care of people with functional mental health illness can be

sporadic and therefore carers do not necessarily require regular respite breaks but may need intensive periods of 24-hour help at particular times.

There is a *particular* need for **more targeted** help, especially for those caring more than 50 hours per week who are statistically the most likely to become ill and whose associated costs of illness are the largest.

People caring for someone with dementia find it particularly difficult to locate services and often cope with arduous caring responsibilities without any help. These are likely to be older carers who are more susceptible to ill health themselves.

ACTION:

- **Commission more flexible services. This could be achieved by increasing support to those voluntary agencies who are currently providing exactly the type of flexible respite breaks required by carers.**
- **Commission more targeted services.**

4. Carer Assessments

All carers are entitled to an assessment of their needs. At present in East Sussex assessment only leads to respite care and the voucher scheme but the 2004 Carers (Equal Opportunities) Act includes a far more comprehensive assortment of services for carers.

ACTION:

- **Provide a greater variety of services for carers.**
- **Create a training programme, in partnership with the PCT, to enable the voluntary sector to assume the responsibilities of carrying out some of the carer's assessments.**
- **Devise a method for automatically prompting a review of a carer's assessment, incorporating a method for carers to contact Social Services if and when their caring situation alters.**

5. Information – signposting

Information is consistently rated as one of the main requirements for carers and one of the most valued services but, as this report shows, carers have many difficulties in locating the information they need. There is a need for clear, coherent information which signposts carers to the various sources of

help. Providing such information is a function which could well be fulfilled by the voluntary sector.

ACTION:

- **Develop a new information strategy for carers. There is a good model in West Sussex for this.**
- **Encourage GPs to signpost carers at an early stage. Training focused on the needs of carers for those working in GP surgeries would be valuable.**

6. *Overhaul of Carers Grant and Pooled Budget*

The Carers Grant and pooled Budget should be dispensed according to clear, explicit criteria, related to what carers want, i.e. respite, day care, signposting, assessments, 'low-level' practical support. It is no longer clear that the pooled budget should be attached to one organisation.

The PCTs should consider focusing support on health-relevant services i.e. respite, back-care support, physiotherapy, bathing.

Given the clear evidence of need for respite emerging from this and prior research, it is vitally important to maintain and increase residential and day respite care.

ACTION:

- **Review and extend the joint budget and the use of the pooled budget.**
- **Increase provision by the PCTs for preventative services for carers.**

7. *Performance Assessment*

Effective commissioning of services cannot take place without good quality intelligence and it is impossible to carry out meaningful performance assessments without accurate information on services, their costs and their recipients.

ACTION:

- **Include outcome monitoring and evaluation of services in performance assessment.**

- **Embed quality assurance in the planning and delivery of services for both the statutory and independent sectors.**
- **Review monitoring arrangements to ensure consistency in the collection of appropriate information**

8. *Capacity-building of the voluntary sector*

Carers have historically been the Cinderella service. Without the role of carers, and the contribution they make to keeping people independent and living in the community, the task for both social and health services would be enormous and costly. This report has gathered together information in a unique way which helps begin to build a picture of provision and need. It also provides a starting point from which the County Council, and its partners, can develop a robust and long-term commissioning strategy for carer's services.

Services provided by the voluntary sector are very important to carers and reach areas where no other services are available. The sector should be seen as a resource worthy of long term investment, rather than as a cost to the system.

It is not clear if the current system has the capacity to deal with the forthcoming move to Individualised Budgets. This needs to be explored with the voluntary sector, building on existing experience of Direct Payments and the Voucher Scheme.

ACTION:

- **Develop a strategy for building the capacity of the voluntary sector.**
- **Consider using other more innovative solutions such as 'community hubs' for providing services at reasonable cost.**
- **Collect information from other areas where innovative and imaginative services are being used**