

Executive Summary

1. Introduction

This report provides a comprehensive assessment of the location of carers, the services available to carers in the statutory and voluntary sectors and carers' views on the services they need.

- a) The population of the UK is ageing and this will place greater demands on Social Services and on carers.
- b) In this report a carer is defined as a person who cares for a sick, disabled or frail family member, friend or neighbour, is not working for a voluntary organisation and whose caring role is unpaid.
- c) The 2001 Census requested information about carers, their age, gender, the hours spent caring and self-reported state of health.
- d) Carers have a legal entitlement to an assessment in their own right. Local authorities have a duty to inform carers of that right and enable carers to live normal lives on a par with people who do not have caring responsibilities.
- e) The White Paper '*Our health, Our care, Our say*' (2006) has provided a new direction for community services, proposing to shift services away from hospitals to the community and create more accessible services.
- f) The White Paper will affect carers' services through the requirement for individualised budgets and increased direct payments, both of which offer carers payment for their services by the people for whom they care.

2. Carers in East Sussex: background data

Statistical data was drawn from the 2001 Census covering East Sussex. The information showed area data for Hastings, Lewes, Eastbourne, Rother and Wealden and illustrated the number of carers, the state of their health and numbers of Black and Ethnic minority carers. Data was presented at ward level giving detailed numbers of carers as well as a percentage in the individual wards.

- a) According to the 2001 Census data, East Sussex has a total of 50,993 unpaid carers representing 10.35% of the total population of the county (492,324).

- b) Wealden is the authority with the highest percentage of carers in the county as well as the highest percentage of carers with caring responsibilities in excess of 50 hours per week.
- c) The percentage of carers in poor health in the county, at 11.5%, is lower than the national average of 12%. This should be viewed in the context of the general health of the county, which also appears to be better than the national average.
- d) The greatest proportion of carers suffering from ill health is found in the Hastings area. Hastings has a higher than national and county average of carers in poor health as well as higher levels of those caring for someone in excess of 50 hours per week
- e) Rother has the highest number of wards where the caring population is in excess of the county average, with three wards containing in excess of 12% and one more than 13%.
- f) Eastbourne has the smallest number and percentage of carers in the overall population.
- g) Research indicates that older carers suffer more poor health than younger carers. In East Sussex 15.73% of the 7,242 older carers who care for more than 20 hours per week stated that they were not in good health.
- h) The majority of carers in East Sussex fall within the age group 50-64, with the exception of Hastings, where most carers were aged between 25-49. In all cases the majority of carers are also of working age.
- i) Black and Ethnic minority carers may not represent a large proportion of the caring population; as a small group it is unlikely that their particular needs are being met.
- j) County-wide the average percentage of carers in the population is around 10%; however, this hides pockets where the percentage of people caring is very much higher.
- k) Detailed tables, regarding the health of the caring population, correlate with prior research revealing that, the higher the area on the indices of deprivation, the more likely it will be that carers are in ill health. This would explain the high levels of poor health of carers among Hastings.
- l) The facilities for carers in rural Sussex are not as plentiful or accessible as those for carers in urban areas.

3. Services for Carers: Mapping and Expenditure

Information on the funding and provision of services for carers, with details on the statutory sector, including social services and health, and the voluntary sector has been gathered together for the first time.

3.1 Statutory Sector

- a) There has been great difficulty gathering data on the number of carers accessing services and the expenditure on carers' services.
- b) Services for users can be a direct or indirect service for carers.
- c) Statutory services are clustered around the coastal towns, especially Eastbourne and Hastings; other services are located around the small towns of Lewes, Hailsham and Crowborough.
- d) There are very few services in Rother.
- e) Many statutory services run well below 100% occupancy. This is not due to lack of demand.
- f) No clear picture is available on ESCC expenditure on carers' services, other than the breakdown of the Carers Grant.
- g) For older people, residential respite is located at Robertsbridge, Hastings, Seaford and Bexhill. There is no residential respite in Wealden for this group.
- h) Most of the provision for people with learning disabilities is in and around Hastings, and some in Wealden. There is none or little in Rother district, Lewes and Eastbourne. Some of the provision is taken up by out of county placements.
- i) For adults of working age with mental health needs, there is some clustering of day services around the coast, Eastbourne and Hastings, with no provision in North Wealden or Rother.
- j) There were 922 Carer Assessments completed in 2004/5, for the year April – December 2005 the figure had risen to 1,011.
- k) The Short-break Voucher Scheme usage shows a strong clustering around the coastal towns. Hastings had the largest number issued and Eastbourne had the lowest percentage redeemed.
- l) The PCT's main contribution is financial – they contribute to the pooled budget for Care for the Carers and fund home respite provided by Crossroads schemes. Some in-house respite is provided, however this varies across the PCTs.

- m) There is a lack of consistency and regularity, or simply absence, in the way in which information on services is recorded. In the statutory sector, the focus of information has been on the user, rather than the carer.

3.2 Voluntary Organisations

- a) Some voluntary organisations exist specifically to help carers; these include Care for the Carers; Crossroads, Association of Carers and Friends of William Daley.
- b) Other organisations which provide help for specific groups, such as MIND, Mencap and Rethink, also provide support for the carers in their client group.
- c) Crossroads is the major voluntary sector provider of respite across the county and operates Care Attendant Schemes in Lewes, Hastings and Rother and Eastbourne and Wealden (although not north Wealden).
- d) Care for the Carers is the other main carers' organisation, working both as a provider of outreach services, back protection, training, information and advice, assessment and as a policy adviser.
- e) The main source of exclusive funding for the voluntary sector is through the Carers Grant of £1.2m, plus around £340k from various social care budgets. Health contributes around £400k directly to the voluntary sector. The voluntary sector contributes over £100k from its own fundraising.
- f) There is an unknown amount spent in the independent sector by people who are buying services directly, or those commissioned by social services through spot contracts.
- g) Performance assessment needs to develop beyond a focus on output monitoring which dominates both statutory and voluntary sector. Outcome monitoring and evaluation of services; quality assurance should become embedded in the planning and delivery of services. This applies to both the voluntary and statutory sectors.

4. Results from the questionnaires and interviews

Part of the research included a short questionnaire and follow-up interviews covering 257 carers. The purpose of the questionnaire was to find out what services carers were using, how they found out about the services, what they thought of the services, if they wanted any different types of service and if so, what kind of services they required.

4.1 Carers

- a) Carers stated that they were not able to access information and as a result were probably missing out on services.
- b) Carers who had managed to mix private, voluntary and statutory care were pleased with the result; the main problem though was that these people were a minority. Carers in particular valued day care provision and respite care.
- c) Carers assessment became critical for those carers who found that the people they cared for were resistant to services in their own right. Help under the carers assessment therefore became their only option.
- d) There is a particular problem when carers feel that their caring roles are not being acknowledged by professionals.
- e) Carers did not fit neatly into prescribed areas; for carers who are both in need of care themselves and who are carers in their own right, services seemed to fail them in one aspect of their lives.
- f) For some carers there were unacceptable delays in getting help, either from Social Services or from voluntary agencies.
- g) In many cases carers in receipt of services from Crossroads found this particular type of help very useful.
- h) Carers found that when they did receive services they were sometimes inappropriate for the person they cared for.
- i) Carers of people with functional mental health illness faced particular problems as the need for assistance was episodic.
- j) Same sex couples had in the past found Social Services unhelpful; however they had found that the Disability Discrimination Act 2004 had assisted with making their needs heard.
- k) Carers wanted more help to assist them in maintaining both their role as a carer and their work.
- l) Carers found gaps in the services, in particular in the bathing service, and in cases where time and expertise was not being replaced through the care agency staff.
- m) Carers wanted ad hoc, informal, services that they could call upon when needed.

4.2 Voluntary Organisations

- a) Voluntary organisations felt that they were in a unique position to meet the needs of carers aided by East Sussex Social Services funding. Services were still cash rather than needs led.

- b) Voluntary organisations would function better with secure long-term funding and full cost recovery.
- c) More out of hours services and services for short term respite are required. A reliable service appears to be limited
- d) Voluntary organisations find it problematic identifying hidden carers, especially rural carers, and providing them with information. Additionally, carers are not always signposted to carer agencies. Further research needs to be conducted on the numbers of hidden carers and their needs.
- e) Carers' assessments should be universally available.

5. Focus group analysis

Discussions were held with carers in three focus groups and one reference group meeting. There were twenty participants in all, with ages ranging from mid 30s to 80 years old. Between them they cared for adults and children with a range of disability and frailty including older people, severe mental illness, children and adults with learning difficulties and physical disability; one participant worked in a freelance capacity, two worked fulltime.

- a) Currently carers are getting information more from other carers rather than from Social services who they perceive as gatekeepers to services.
- b) Carers of people with recognised medical conditions perceive hospital staff to be a good source of information. Carers of people who gradually become frailer find it a lot more difficult to access information or know where to go. Information access can therefore be dependent upon the condition of the person being cared for.
- c) A tension exists between patient confidentiality and the need for the carer to be involved and to get enough information for their caring responsibilities. This is particularly the case for carers of people with mental health problems and when children leave children's services and enter adult services.
- d) A rapid turnover of staff is especially problematic for people with mental health problems.
- e) There was a struggle to get assessment, especially for people caring for someone with mental health problems.
- f) The services that support assessment were too often lacking and there were negative feelings about the assessment process and outcome

from members of staff undertaking the assessment. There was the feeling that services were still resource led.

- g) Lack of training for assessors was considered detrimental to the assessment process.
- h) Respondents approved of the Crossroads Playscheme and felt that the care agencies were doing a good job disseminating information.
- i) Respite provision in the holidays was fragmented and the quality and appropriateness of the care was sometimes questionable.
- j) There would appear to be a lack of facilities for people with mental health problems.

6. Conclusions and recommendations

6.1 Location of Carers and Services in East Sussex

- a) Carers are 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 number 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.
- b) The location of services does not match the distribution of carers.
- c) 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.
- d) There is a lack of consistency and regularity in the way in which information on services is recorded. In the statutory sector, also, information is more likely to be gathered on the user rather than the carer yet carers are normally the beneficiaries of services too.

. ACTION:

- I. Take account of available data to ensure a more even spread of services.**
- II. Support and develop the diversity of voluntary sector services, not only those operating at county level but also the smaller organisations. Many of these latter address specific areas of need in rural areas.**
- III. Reassess the efficacy of block contracts.**

- IV. **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.**

6.2 Characteristics of carers and the people they look after

- a) There is little information in the census on carers' health or on the characteristics of those being cared for. Research confirms a connection between the number of hours caring and poor health.

ACTION:

- I. **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.**

6.3 Respite Care

- a) 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.
- b) There is a need for **more flexibility** of respite and variation, e.g. available out of the 10.0 am-3.0-pm time slot, traditional day care times.
- c) Respite breaks need to take into account the condition of the person being cared for.
- d) There is a *particular* need for **more targeted** help, especially for those caring more than 50 hours per week.
- e) People caring for someone with dementia find it particularly difficult to locate services.

ACTION:

- I. **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**
- II. **Commission more targeted services**

6.4 Carer Assessments

- a) All carers are entitled to an assessment of their needs. 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:

- I. Provide a greater variety of services for carers.**
- II. 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.**
- III. 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.**

6.5 Information – signposting

- a) 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:

- I. Develop a new information strategy for carers. There is a good model in West Sussex for this.**
- II. 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.**

6.6 Overhaul of Carers Grant and Pooled Budget

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

- c) 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:

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

6.7 Performance Assessment

- a) 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:

- I. Include outcome monitoring and evaluation of services in performance assessment.**
- II. Embed quality assurance in the planning and delivery of services for both the statutory and independent sectors.**
- III. Review monitoring arrangements to ensure consistency in the collection of appropriate information**

6.8 Capacity-building of the voluntary sector

- a) 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.
- b) 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:

- I. Develop a strategy for building the capacity of the voluntary sector.**

- II. Consider using other more innovative solutions such as 'community hubs' for providing services at reasonable cost.**
- III. Collect information from other areas where innovative and imaginative services are being used**