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# **Carers and Services for Carers in East Sussex**

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**Faculty of Health**  
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# 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 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.
- d) 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%.
- e) Eastbourne has the smallest number and percentage of carers in the overall population.
- f) 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.
- g) The majority of carers in East Sussex fall within the age group 50-64, with the exception of Hastings, where most carers are aged between 25-49. In all cases the majority of carers are also of working age.
- h) Black and Minority Ethnic 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.
- i) 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.
- j) 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.
- k) 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 PCTs' 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 and 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 full time.

- 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 carers' 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.**

# 1. Introduction

This report on Carers in East Sussex has been prepared by the Health and Social Policy Research Centre at the University of Brighton for East Sussex County Council. Its four main sections provide 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.

In many ways the report is timely. In the Performance Rating for Social Services in England 2005, the Chief Inspector for Social Services, David Behan, noted that one of the problems affecting all councils is that of services for carers. A new indicator has revealed that across England only 65,000 carers are recorded as receiving direct services – a very small proportion of these are estimated to be putting in over 50 hours caring a week. The urgency to commission more information services and support groups for carers, as noted by the Chief Inspector, is underlined by the data presented in this report.

The population of the United Kingdom is ageing. In 2003 there were 9.5 million people aged 65 and over, representing a 28 per cent increase since 1971 (Summerfield and Gill, 2005). The number of people aged 65 and over is predicted to exceed those aged 16 and under and, in some cases, such as in the South East, this has already occurred.

This ageing of the population has significant policy implications, placing greater demands on Social Services and on carers who have been described over the years as the 'cornerstone' of community care. Attempts have been made to quantify the costs of caring in terms of money saved. The main calculation used over the years has been that of William Laing (1993) who, using data from 1992, calculated the value of carers support to be £39.1 billion per year (Carers UK, 2002). Laing's calculation is based on a wage value of £7.00 per hour. More recently, this total has been superseded by later calculations that put the value of carers support in the region of £58 billion in care cost savings to the treasury (Summerfield and Babb, 2004).

In this report chapter 2 presents data from the 2001 census on the location of the 51,000 plus adult carers in East Sussex, showing the extent to which they are clustered in coastal and urban areas. It identifies the number of hours that they are caring, their age, gender, ethnicity and health, with the data presented in tables, histograms and maps. Chapter 3 reviews the extensive data collected between July and November 2005 on the financing of statutory and voluntary services and the services delivered by social services, health and voluntary sector agencies. Services reviewed include day centres, respite care, the voucher system, Carers Assessment and Direct Payments. Chapters 4 and 5 parts are based on primary research. In chapter 4 the findings from a short questionnaire and follow up interviews covering 240 carers are presented while chapter 5 details the discussions of three focus groups with twenty carers looking after children and adults with a range of physical and mental health needs. Chapter 6 summarises the findings and chapter 7 presents conclusions and recommendations.

## 1.1 Background

A single definition of a carer does not exist and over the years legislation has referred to carers in many different contexts and guises. However, for the purposes of this research and the report the definition used is that of a person who cares for a sick, disabled or frail family member, friend or neighbour and who is not working for a voluntary organisation and whose caring role is unpaid. Some reports refer to this type of caring as 'informal' however, as Luke Clements argues, it is a term actively disliked by many people who care and who see their role as far from informal, especially those who caring for long hours in the week (Clements, 2005).

Under this definition there are large numbers of people who may be referred to as carers and who for the first time became quantifiable through the 2001 Census, which included a question about unpaid care. The General Household Survey, Carers 2000, gives additional complementary data on caring. This report, comprising interviews with 14,000 adults aged 16 and above, was scheduled for renewal every five years. There is currently no plan to re-do the exercise, which is somewhat surprising in view of The Chief Inspector's concern about services for carers. Currently the national data is therefore reliant on figures over six years old. This may appear to render any statistical data useless by virtue of age; but we do know that, while the figure of 6.5 to 7 million carers remains fairly static, in any one year 300,000 new carers enter the system and a similar number cease their caring responsibilities. Over the last decade research has confirmed that carers suffer more stress, poorer health and generally have a lower income than those who are without caring responsibilities (Hirst, 2004, Fyvie-Gauld, 2004, Frost, 1997, Twigg & Atkin, 1994, Frost, 1990)

According to Maher and Green (2002) there were an estimated 6.8 million adult carers in 5 million household in the United Kingdom. These carers are an essential part of current Government policy which is, and has been for many years now, directed towards the maintenance of people in their own homes as the preferred choice of older people. The fact that it presents less cost to the government owes much to the carers and in recognition of this policy has emphasised the role of family and carers in providing a mixed economy of care. The legislation that has been directly concerned with carers includes the Carers (Recognition & Services) Act, 1995; the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004. Each of these Acts began life as a Private Members Bill rather than as a consequence of central Government policy.

The Carers (Recognition and Services) Act, 1995, implemented in April 1996, gave carers the right to an assessment of their ability to continue caring but did not provide any new funding, nor guarantee direct support of carers beyond assessment. It may be said that the name of the Act itself stressed the importance of services concentrating noticeably on policy and practice of the local authorities, rather than the work carried out by the carers. A review carried out by the Social Services Inspectorate (now part of The Commission

for Social Care Inspection) in 1998 revealed the carers assessment part of the Act was very rarely conducted (SSI, 1998).

The Carers and Disabled Children Act 2000, enacted from April 2001, built on the previous Act by giving carers rights separate from those of the person for whom they care. Carers now have the right to an assessment even when the person cared for has refused assessment and local council has the power to provide services for carers following their assessment. Parents of children with disabilities also have the right to ask for an assessment. The Carers and Disabled Children Act 2000 charged local authorities with the responsibility of placing carers' preferred outcomes at the centre of the assessment, rather than merely looking at the type of services provided by the local authority and fitting the assessment to the available services. This Act heralded a change of direction in policy, moving the emphasis from the services to the needs and requirements of the carer. Under this Act carers theoretically were able to receive driving lessons and procure a mobile phone. The Act also extended local authority power from the Community Care (Direct Payments) Act, 1996, to make direct payments to carers (Department of Health, 2003). It also allowed local authorities to charge carers for non-residential services, amending the Health and Social Services Adjudication Act 1983.

The Carers (Equal Opportunities) Act 2004 sought to plug some of the holes left by the previous Acts. The central tenet of the Act was to provide a milieu where carers could avail themselves of the same opportunities and life chances that people without caring responsibilities take for granted, including, under Clause 2 of the Act, the ability to take up work, education, training or leisure opportunities. Prior to the Act legislation looked at the carers' ability to provide and continue to provide care, whereas the Carers (Equal Opportunities) Act, 2004, enshrined in law the right of the carer to work or take up other opportunities, changing fundamentally the way in which services are offered.

The Carers (Equal Opportunities) Act 2004 emphasises the importance of seeing carers as individuals with their own rights. The Act effectively provides an environment that gives carers the opportunity of living a lifestyle equal to that of people without caring responsibilities. Clause 1 of the Act introduced new provisions into the Carers (Recognition and Services) Act, 1994, and the Carers and Disabled Children Act, 2000, by ensuring that all carers are made aware of their right to assessment. Assessment needs to be requested and the ability to request is dependent on the knowledge that such a right exists. Under the provision of the Act, Social Services now have to inform carers of this right.

In particular the Act emphasises the requirement to include carers' aspirations and charges local authorities under section two of the Act to include carers' wishes with regard to education, training, work or leisure opportunities within the assessment process. In order to help achieve these aspirations the Act has given local authorities new powers to enlist the help of housing, health, education and other local authorities in providing support for carers (Parliamentary Briefing, 2004). In this way the Act seeks to increase

partnership working between Social Services, Health Authorities and local councils to assist carers to maintain their caring responsibilities so that when carers request help all agencies are charged with taking consideration of the carers' requests.

As this report was being written, a new White Paper '*Our health, Our care, Our say*' (DoH 2006) *provided* a new direction for community services. It aims to achieve four main goals – to provide better prevention services with earlier intervention, to give people more choice and a louder voice, to tackle inequalities and improve access to community services and to provide more support for people with long term needs. All of these have the potential to improve life for both carers and those for whom they care. A number of strategies are proposed for achieving these aims, including practice based commissioning, shifting resources into prevention, providing more care outside hospitals and in the home, joining up services more effectively at local level and encouraging innovation. Again all of these are highly likely to improve services for carers if implemented effectively.

Throughout, the White Paper highlights the importance of preventative measures to increase health, including the establishment of more healthcare teams to deliver better care across institutional boundaries. This research found that many carers in East Sussex deliver in excess of 50 hours caring per week and it is this group which undertake the heavy end of caring and are the most prone to ill health, impacting negatively on the health service. The research team welcome the proposal that more will be done to help this very vulnerable group of people, most of whom are also older carers.

The White Paper's call for increased choice is particularly welcome and will be achieved through underpinning direct payments or care budgets for people to pay for their own home help or residential care. This will herald a major shift for carers and may increase the likelihood of carers gaining recognition of their services through payments from the people they care for. It should also facilitate carers' ability to obtain respite care and short breaks as and when they want them.

This research has taken place against a background of changing legislation and guidance, all of which has increased recognition of carers' rights. The research team express their thanks to all who have taken part – commissioners, officers in statutory and voluntary organisations and, especially, the carers themselves. It is hoped that the information in the report and its conclusions and recommendations can play a useful role in improving services for carers in East Sussex and in meeting the White Paper's ambitious goals.

## 2. Carers in East Sussex: background data

### Key points:

- 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).
- 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.
- 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.
- 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.
- 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%.
- Eastbourne has the smallest number and percentage of carers in the overall population.
- 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.
- 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.
- Black and Minority Ethnic 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.
- 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.
- 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.

- The facilities for carers in rural Sussex are not as plentiful or accessible as those for carers in urban areas.

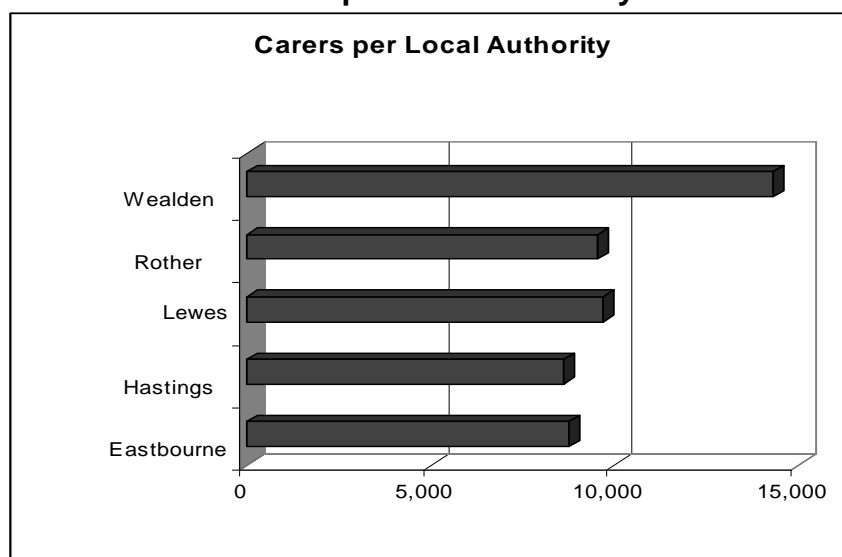
## 2.1 Introduction

This section covers statistical data drawn from the 2001 Census covering East Sussex. The information is presented in area data for Hastings, Lewes, Eastbourne, Rother and Wealden and illustrates the numbers of carers, the state of their health and numbers of Black and Ethnic minorities. Additional data is presented at ward level giving detailed numbers of carers as well as a percentage of the people in the individual wards.

The source for all this data is the 2001 Census, [Key Statistics for Local Authorities]. Crown copyright 2004. Crown copyright material is reproduced with the permission of the Controller of HMSO.

## 2.2 Results

**Figure 2.1**  
**Carers per Local Authority**



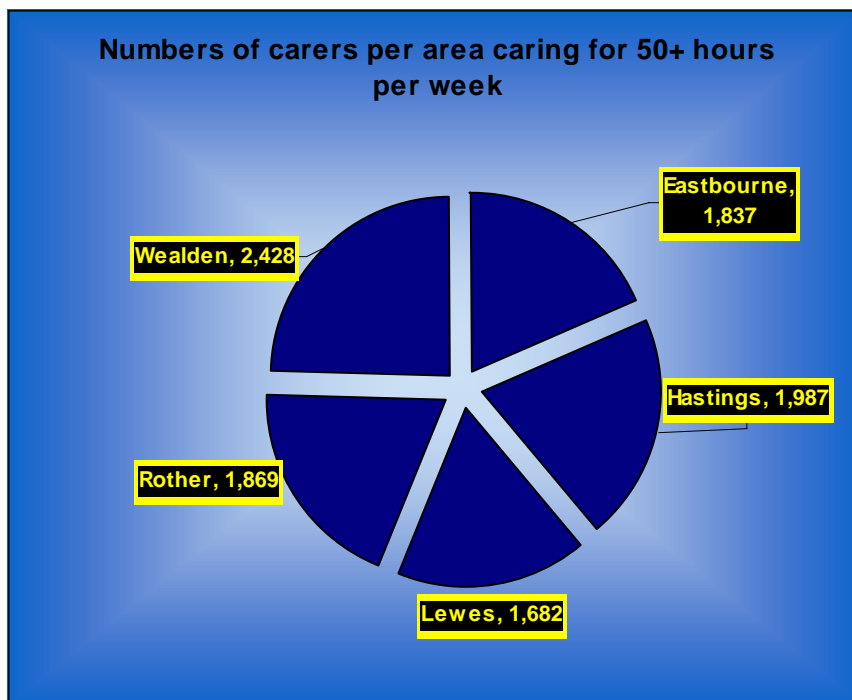
According to the 2001 Census data, East Sussex has a total of 50,648 unpaid carers representing 10.35% of the total population (492,324).

Figure 2.1 and table 2.1 indicate that Wealden is the authority with the highest percentage of carers both as a percentage of the total number of carers and as a percentage of the population of the county. It also shows that Eastbourne has fewer carers than other areas and also a smaller percentage of the population are carers. This is because Eastbourne is a smaller area than the others but, as can be seen in the GIS maps there are more carers per square foot than elsewhere.

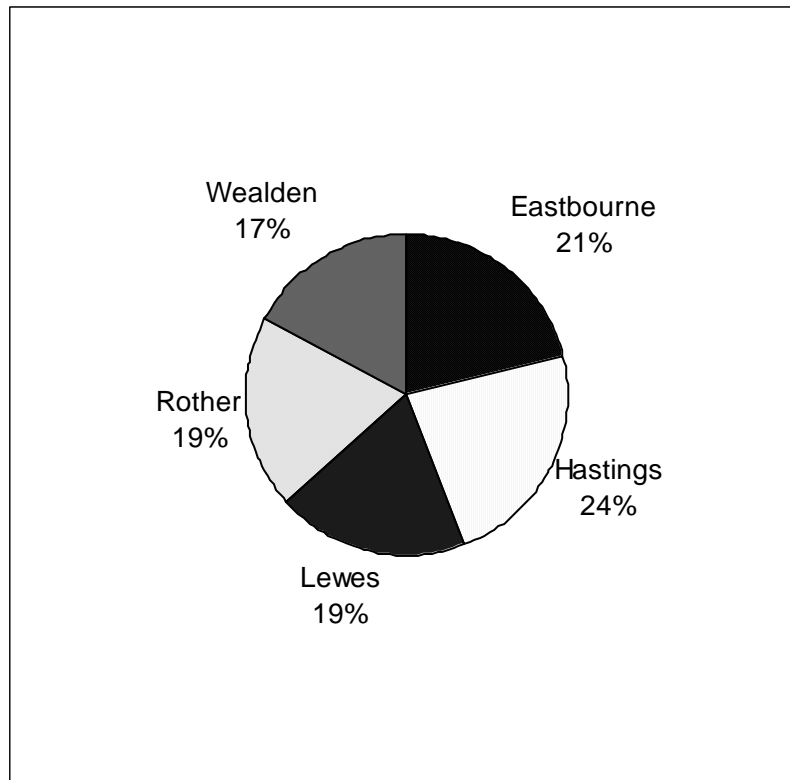
**Table 2.1**

<b>Area</b>	<b>Percentage of carers out of the total carers</b>	<b>Numbers of carers in each area</b>	<b>Percentage of carers in each area</b>	<b>Place on the Index of Deprivation</b>
Eastbourne	17%	8,767	9.77%	117
Hastings	19%	8,635	10.15%	38
Lewes	19%	9,695	10.51%	243
Rother	18%	14,343	10.24%	307
Wealden	28%	9,553	11.18%	191

**Figure 2.2**  
**Numbers of carers per area caring for 50+ hours per week**



**Figure 2.3**  
**Percentage of carers caring 50+ hours per week and reporting ill health**



Figures 2.2 and 2.3 illustrate the numbers of carers in each area who are caring for more than 50 hours per week, they also show the percentage of those reporting ill health. When the position of each area on the Index of Deprivation is factored in there would appear to be a causal link between that and the percentage of carers reporting ill health. Hastings data revealed that the numbers of carers is fewer than that of Wealden but the percentage of those reporting ill health (24%) is the highest in the county. Hastings is number 38 on the Index of Deprivation while Wealden's position is much higher at 191.

Carers in Lewes number 1,682 but the percentage of those reporting ill health is 19% and the position on the Index of Deprivation is 243. Higher than Lewes on the Index of Deprivation is Rother positioned at 307 with 19% of carers caring in excess of 50 hours per week reporting poor health.

## Age of carers

Table 2.2 reveals that the majority of carers in East Sussex are in the age group 50-64 with the exception of Hastings where the majority of carers fall into the age group 25-49.

**Table 2.2**  
**Numbers of carers in age groups**

	Total number of carers	Numbers of carers aged 16-24	Numbers of carers aged 25-49	Numbers of carers aged 50-64	Numbers of carers aged 65-80	Numbers of carers 90+	Main Carer Group
<b>East Sussex County</b>	<b>50,648</b>	<b>1,729</b>	<b>16,734</b>	<b>19,070</b>	<b>12,179</b>	<b>145</b>	<b>50-64</b>
Eastbourne	8,512	313	2,921	2,956	2,290	32	<b>50-64</b>
Hastings	8,471	489	3,470	2,942	1,557	13	<b>25-49</b>
Lewes	9,510	278	3,128	3,736	2,349	19	<b>50-64</b>
Rother	9,324	247	2,730	3,583	2,719	45	<b>50-64</b>
Wealden	14,040	402	4,485	5,853	3,264	36	<b>50-64</b>

Cells in this table have been randomly adjusted to avoid the release of confidential data accounting for an apparent discrepancy in total data.

**Figure 2.4**

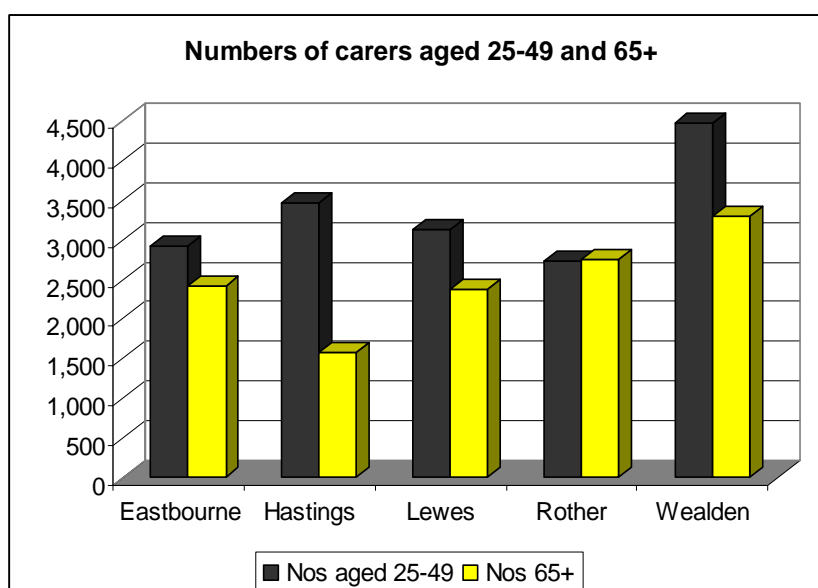


Figure 2.4 reveals that the largest number of carers falls in the working age adult group (25-49), except for Rother where the numbers are equal. This has implications for carer policy in view of the Carers (Equal Opportunities) Act 2004 which enshrines help for carers where they wish to return to work or for those within the workplace. Figure 2.4 also illustrates that there are large numbers of older carers aged 65+ and this group has particular issues associated with older age, especially the heightened risk of illness.

## **Gender and Health**

Table 2.3 shows the numbers, intensity and gender of older carers in each of the five areas. The data shows that the vast number of older carers (n=3740) care for 1-19 hours per week and that of these the majority are women. In most areas the gendered nature of caring is very apparent with the exception of Lewes where the difference is minimal, 671 males compared to 694 females.

The data also shows the lack of good health among carers who care in excess of 50 hours per week and reveals that there is little difference between the number of men and women reporting ill health.

One reason why carers require assistance is that without it many of them develop health related problems and they themselves become in need of intervention from health and social services. When that happens the person they care for may well require far more expensive care if their carer is not available. This is why providing timely and appropriate help is essential to carers to assist them in maintaining their caring duties.

Over half of all carers nationally have a caring related health condition (Census 2001) and carers who provide high levels of care are more than twice as likely to suffer from poor health (Carers UK 2004).

Census data from 2001 revealed that 12% of the total carers in England, Wales, Northern Ireland and Scotland stated that they are not in good health while 20.7% of carers caring in excess of 50 hours per week stated that they were not in good health against 11.04% of the population without caring responsibilities.

In East Sussex the percentage of carers stating that they were not in good health was 11.5%, lower than the national average of 12%. Of those carers caring in excess of 50 hours per week 18.77% suggested that they were not in good health, again lower than the national average. These figures should be viewed against the general health of the county where health would appear to be better and where 10.22% of the overall population were in poor health against the 11.04% nationally. This perhaps suggests that carers' health when they begin caring is also probably better than elsewhere in the country. This percentage does hide significant areas of deprivation within the county as can be seen in the section covering the local census data.

There is ample evidence that caring also has a negative effect on carers' mental health. Research carried out in 2004 revealed that stress and distress, including high levels of anxiety, were more prevalent among carers than physical ailments (Hirst, 2005). Carers UK (2004) research indicates that much of the problem is created through a lack of appropriate support and information, leading to isolation and financial stresses as well as inappropriate or no assistance impacting on the mental health of carers.

Carers looking after people with dementia play a vital role in maintaining the mental health of the people they care for and research has shown that placing dementia sufferers into residential homes increases their levels of dementia by a factor of eight (Philip et al, 1997). Research into carers of people with mental health problems revealed that they are affected by the severity of the mental health of the person for whom they care (Gilleard, *et al*, 1982) and additional research has shown that carers are more likely to suffer from depression themselves (Carers UK, 2004; Moriarty, *et al*, 1993; Rose-Rego, *et al*, 1998) as well as be in poor physical health (Wenger, *et al*, 2002). The law defines disabled people as '*persons who are: blind, deaf or dumb or who suffer from mental disorder of any description*'. This being the case, carers with depression fall within the definition of a disabled person requiring assistance themselves as users, making the division between the carer and the cared for indistinct.

Table 2.4 above indicates that the greatest proportion of carers suffering from ill-health are to be found in the Hastings area, where the average percentage of carers in poor health was 12.67%. Although not dramatically above the national average of 12% it was significantly higher than the rest of the county, where the average is 10.22%. Again the average numbers of carers who are in poor health and caring for in excess of 50 hours per week was also higher in Hastings at 21.58% against the county average of 18.77%.

Many of the carers suffering from poor health also come from areas which are high on the index of deprivation. This would appear to be borne out from the tables above when looking at Hastings in comparison with Wealden. The tables show the numbers of carers in Wealden was significantly higher than Hastings (14,040 against 8,471) and that the reported percentage of carers in poor health in Wealden is 8.19% overall. For those carers caring in excess of 50+ hours per week the percentage increases to 16.32%, some 5.26% lower than Hastings.

This may suggest that carers in Hastings start their caring careers in poorer health than other carers in the county. Many areas in the UK with high levels of deprivation share a legacy of long term limiting illness (Hirst, 2005) and this would seem to coincide with data from Hastings.

**Table 2.3: Older carers by health and number of hours caring**

	Good Health: 1 to 19 hours	Good Health: 20 to 49 hours	Good Health 50 +	Not Good Health: 1 to 19 hours	Not Good Health: 20 to 49 hours	Not Good Health: 50 +	<b>Total</b>
<b><i>Hastings</i></b>							
65-89 Male	166	31	54	60	18	70	<b>399</b>
65-89 Female	207	22	89	50	21	66	<b>455</b>
90+ Male	0	0	0	0	3	3	<b>6</b>
90+ Female	0	0	0	0	0	0	<b>0</b>
<b>Total</b>	<b>373</b>	<b>53</b>	<b>143</b>	<b>110</b>	<b>42</b>	<b>139</b>	<b>860</b>
<b><i>Eastbourne</i></b>							
65-89 Male	234	48	98	72	27	84	<b>563</b>
65-89 Female	537	62	153	83	32	113	<b>980</b>
90+ Male	0	0	0	0	0	0	<b>0</b>
90+ Female	0	0	3	0	0	4	<b>7</b>
<b>Total</b>	<b>771</b>	<b>110</b>	<b>254</b>	<b>155</b>	<b>59</b>	<b>201</b>	<b>1550</b>
<b><i>Lewes</i></b>							
65-89 Male	340	33	95	83	30	83	<b>664</b>
65-89 Female	385	45	105	65	16	78	<b>694</b>
90+ Male	4	0	0	0	0	3	<b>7</b>
90+ Female	0	0	0	0	0	0	<b>0</b>
<b>Total</b>	<b>729</b>	<b>78</b>	<b>200</b>	<b>148</b>	<b>46</b>	<b>164</b>	<b>1365</b>
<b><i>Wealden</i></b>							
65-89 Male	466	54	127	97	27	95	<b>866</b>
65-89 Female	566	44	172	105	31	102	<b>1020</b>
90+ Male	3	0	0	0	0	4	<b>7</b>
90+ Female	3	0	3	3	0	4	<b>13</b>
<b>Total</b>	<b>1038</b>	<b>98</b>	<b>302</b>	<b>205</b>	<b>58</b>	<b>205</b>	<b>1906</b>
<b><i>Rother</i></b>							
65-89 Male	385	44	121	77	21	88	<b>736</b>
65-89 Female	434	43	142	75	18	92	<b>804</b>
90+ Male	5	0	3	0	0	4	<b>12</b>
90+ Female	5	0	3	3	0	3	<b>14</b>
<b>Total</b>	<b>829</b>	<b>87</b>	<b>269</b>	<b>155</b>	<b>39</b>	<b>187</b>	<b>1566</b>
<b>Grand Total</b>	<b>3740</b>	<b>426</b>	<b>1168</b>	<b>773</b>	<b>244</b>	<b>896</b>	<b>7247</b>



**Table 2.4: Carers as a percentage of the total caring population by gender, health and Black and Ethnic Minority**

	Total number of carers	total number of carers providing 20-49 hours of caring per week	Number of carers providing 50+ hours of caring per week	% of carers providing 50+ hours of caring	Total number of female carers	Total number of male carers	Total number of carers from black and ethnic minority groups	% of carers in poor health	% of carers providing 50+ hours of caring per week and also in poor health
<b>East Sussex County</b>	<b>50,648</b>	<b>4,633</b>	<b>9,803</b>	<b>19.35%</b>	<b>29,643</b>	<b>21,005</b>	<b>2,094</b>	<b>10.22%</b>	<b>18.77%</b>
Eastbourne	8,512	911	1,837	20.95%	5,143	3,514	471	11.27%	19.91%
Hastings	8,471	896	1,987	23.01%	4,991	3,635	429	12.67%	21.58%
Lewes	9,510	862	1,682	17.34%	5,607	4,053	395	9.70%	18.22%
Rother	9,324	861	1,869	19.56%	5,566	3,892	393	10.62%	18.18%
Wealden	14,040	1,103	2,428	16.92%	8,336	5,911	506	8.19%	16.32%

The census data also reveals that the age of the carer plays an important role in their state of health, with the older carers feeling less well than younger ones, particularly people caring in excess of 50 hours per week. When comparing the age groups nationally, only 8.3% those aged 16-24 stated that they were not in good health, against 19.6% in the age group 45-54 which contains the highest number of carers and the age groups 75-84 and 85+ where 35.2% and 20.7% reported that they were not in good health. Table II above indicates that there are some 7,242 older carers of whom 15.73% of carers caring in excess of 20 hours per week stated that they did not feel well against 22% whose health was good.

The following section looks in more detail at each of the areas in East Sussex. Of relevance are the numbers of carers from Black and Minority Ethnic groups. It is important to note that the numbers include the category 'White Irish' and that removing this significantly alters the number of people from Black Minority groups. This in turn could imply that the numbers of carers from those groups are so small that the likelihood of receiving services to meet their particular needs is remote.

## 2.3 Hastings

Although Hastings has the fewest carers in East Sussex it has the highest percentage of carers caring in excess of 50 hours per week and the highest percentage reporting poor health. This may reflect previous research suggesting there is a causal link between ill health and the place of an area on the Index of Deprivation, where the lower the place the higher the deprivation; Hastings is placed at number 38 (Figure 2.6).

Table 2.5 reveals that, with the exception of 7 wards, the majority of Hastings wards have higher than the county average of carers, but that the overall percentage is lower.

More female than male carers report ill health as shown in Table 2.6, but in the age group 65-89 this becomes less so and the six carers in Hastings over 90 years old reporting ill health are men.

Table 2.7 reveals that Hastings does not have a strong representation of Black and Ethnic Minority groups especially when the group White Irish is removed.

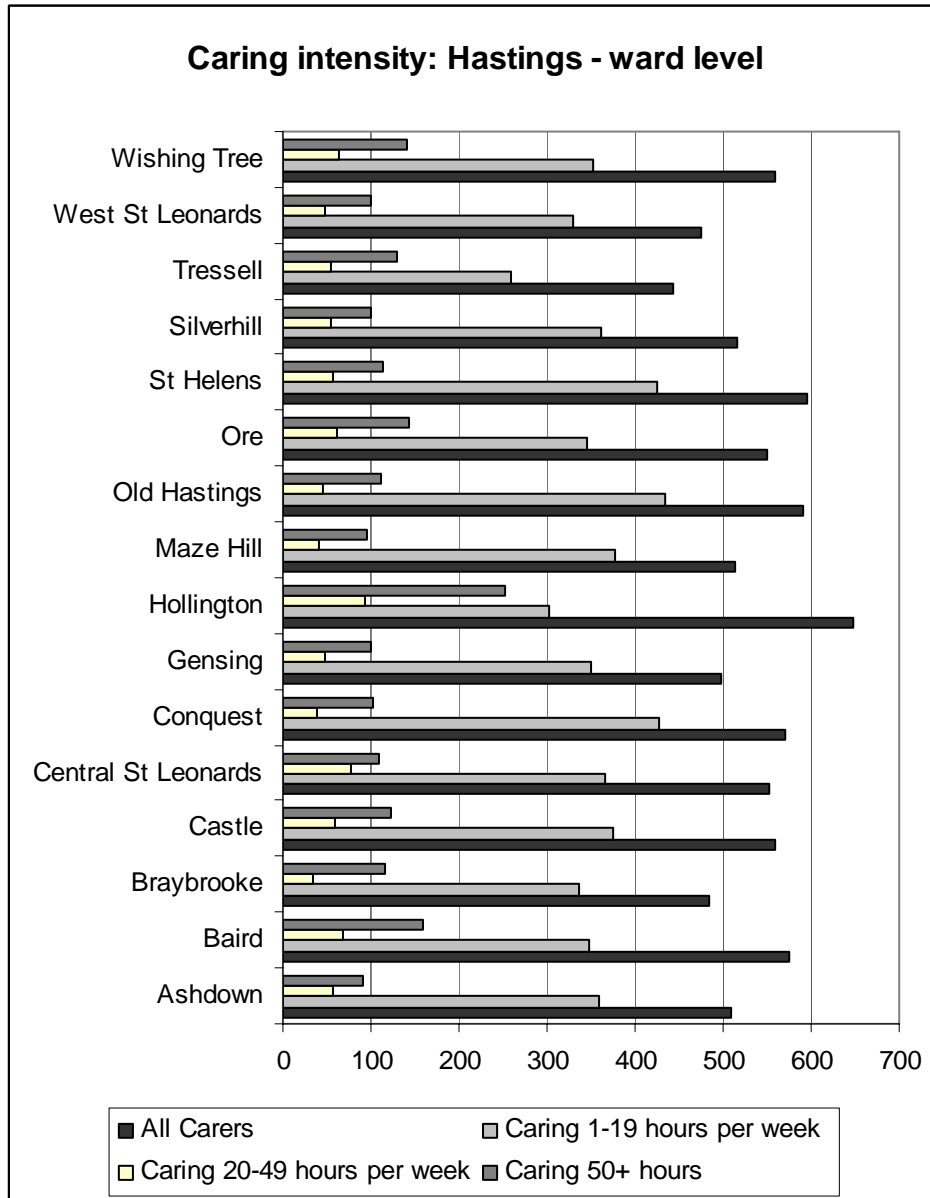
**Table 2.5**  
**Carers as a percentage of the population**  
**(wards)**

Ward	Total Population	Total carers		Percentage of carers
Ashdown	5158	508		10.00%
<b>Baird</b>	<b>5243</b>	<b>575</b>		<b>11.00%</b>
Braybrooke	5178	485		9.30%
Castle	6091	558		9.20%
Central St Leonards	5775	552		9.60%
<b>Conquest</b>	<b>4985</b>	<b>570</b>		<b>11.40%</b>
Gensing	5808	497		8.60%
<b>Hollington</b>	<b>6347</b>	<b>648</b>		<b>10.20%</b>
<b>Maze Hill</b>	<b>5069</b>	<b>514</b>		<b>10.10%</b>
<b>Old Hastings</b>	<b>5812</b>	<b>590</b>		<b>10.20%</b>
<b>Ore</b>	<b>5117</b>	<b>549</b>		<b>11.00%</b>
<b>St Helens</b>	<b>4943</b>	<b>595</b>		<b>12.03%</b>
Silverhill	4666	517		9.02%
Tressell	4975	444		8.92%
West St Leonards	4907	475		9.68%
<b>Wishing Tree</b>	<b>4955</b>	<b>558</b>		<b>11.26%</b>
<b>TOTAL</b>	<b>85029</b>	<b>8635</b>		<b>10.15%</b>

Table 2.5 above and Figure 2.5 below reveal that the vast majority, 67.1%, of carers have caring responsibilities of 1-19 hours per week, 10.4% care between 20-49 hours a week and 23.1% have caring responsibilities in excess

of 50 hours per week. The average percentage of carers in East Sussex stands at 10%, the above table though shows values higher than this and as a result of this those wards that present numbers in excess of 10% have been put in bold.

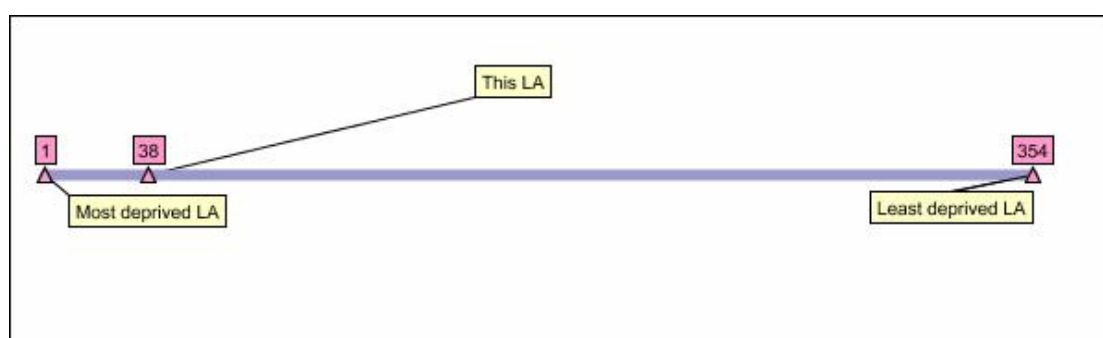
**Figure 2.5**



**Table 2.6**  
**The state of carers' health in Hastings in age groups by gender**

	Good Health	Good Health	Good Health	Not Good Health	Not Good Health	Not Good Health
	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours
0-15 Male	8	0	3	0	3	0
0-15 Female	63		3	0	0	0
16-24 Male	103	12	21	19	3	6
16-24 Female	124	17	36	21	3	3
25-49 Male	564	59	144	111	27	44
25-49 Female	807	104	198	152	35	77
50-64 Male	528	44	90	121	29	81
50-64 Female	607	76	156	123	28	75
65-89 Male	166	31	54	60	18	70
65-89 Female	207	22	89	50	21	66
90+ Male	0	0	0	0	3	3
90+ Female	0	0	0	0	0	0

**Figure 2.6**  
**Position of Hastings on the Index of Deprivation**



**Table 2.7  
Hastings Black and Ethnic Minority Carers by gender**

	<b>Total</b>	<b>Males</b>	<b>Females</b>
Total numbers of carers in Hastings	8,657	3,632	5,025
Ethnic Group Division			
White Irish	103	37	66
White Other	145	56	89
White & Black Caribbean	17	6	11
White & Black African	12	6	6
White & Asian	9	0	9
Other Mixed	21	15	6
Indian	15	3	12
Pakistani	0	0	0
Bangladeshi	19	7	12
Other Asian	9	3	6
Black Caribbean	21	12	9
Black African	12	6	6
Black other	3	0	3
Chinese	21	9	12
Other ethnic group	22	9	13
Total Black and Ethnic Minority Carers in Hastings	429	169	260

## 2.4 Eastbourne

The following census information revealed that Eastbourne has not only the smallest percentage of carers but also the fewest number out of the East Sussex areas. In addition, Table 2.8 indicates that only three of the wards have a higher percentage of carers than the county average and that the majority have a far smaller percentage.

Table 2.9 shows that the majority of carers are in good health and that there is a degree of parity between male and female carers reporting ill health.

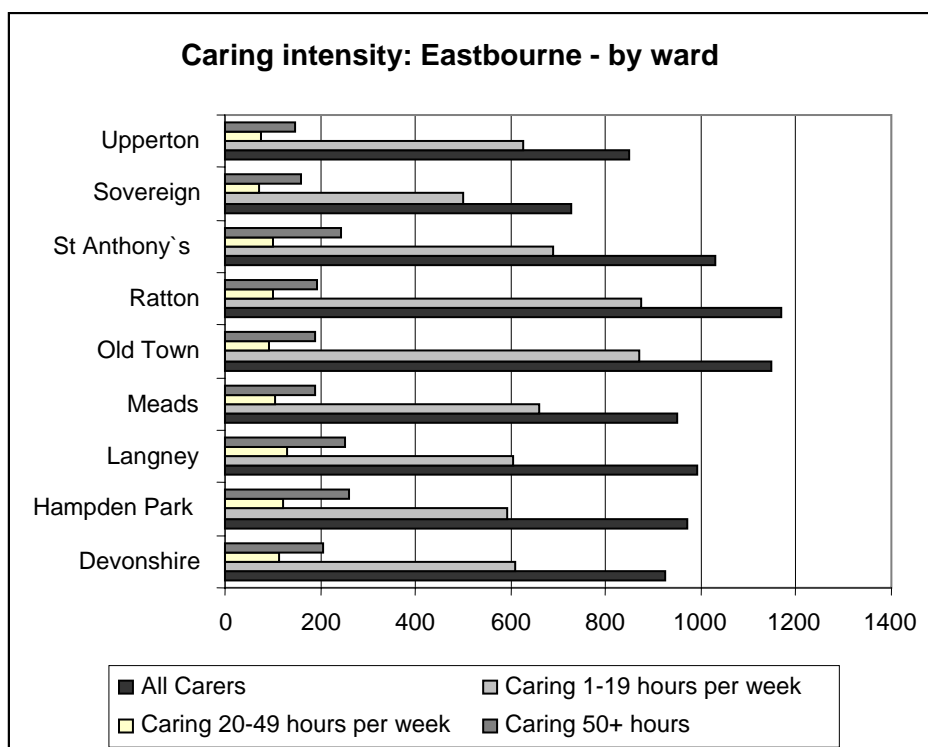
According to the census, Eastbourne has a low number of people from Black and Ethnic Minority groups, especially if the number of people from White ethnic groups is removed.

**Table 2.8**  
**Carers as a percentage of the population**  
**(wards)**

Wards	Total Population	Total carers		Percentage of carers
Devonshire	11108	927		8.34
Hampden Park	10576	971		9.18
Langney	11118	992		8.92
Meads	9785	951		9.71
<b>Old Town</b>	<b>10731</b>	<b>1149</b>		<b>10.70</b>
<b>Ratton</b>	<b>9384</b>	<b>1169</b>		<b>12.45</b>
St Anthony`s	10777	1030		9.55
<b>Sovereign</b>	<b>7014</b>	<b>729</b>		<b>10.39</b>
Upperton	9174	849		9.25
<b>TOTAL</b>	<b>89667</b>	<b>8767</b>		<b>9.77</b>

Table 2.8 above and Figure 2.9 below revealed that 69% of carers care between 1-19 hours per week, 10.4% care between 20-49 hours per week and 21% care in excess of 50 hours per week. The average percentage of carers in East Sussex stands at 10%, the above table though shows values higher than this and as a result of this those wards that present numbers in excess of 10% have been emphasised in bold.

**Figure 2.7**



**Table 2.9**  
**The state of carers' health in Eastbourne in age groups by gender**

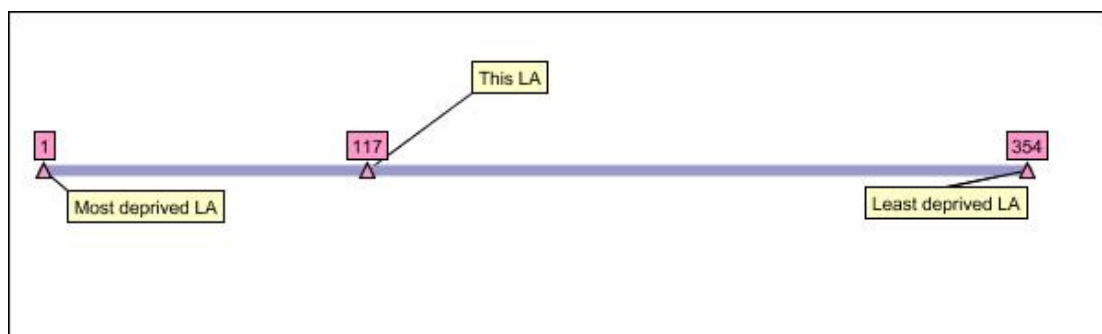
	Good Health	Good Health	Good Health	Not Good Health	Not Good Health	Not Good Health
	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours
0-15 Male	43	6	0	0	0	0
0-15 Female	58	6	6	0	0	0
16-24 Male	86	11	6	8	0	3
16-24 Female	70	10	11	12		7
25-49 Male	546	89	83	70	14	21
25-49 Female	746	97	172	123	30	46
50-64 Male	539	36	79	110	17	39
50-64 Female	724	92	135	108	32	55
65-89 Male	234	48	98	72	27	84
65-89 Female	537	62	153	83	32	113
90+ Male	0	0	0	0	0	0
90+ Female	0	0	3	0	0	4



**Table 2.10  
Eastbourne Black and Ethnic Minority Carers by gender**

	<b>Total</b>	<b>Males</b>	<b>Females</b>
Total numbers of carers in Eastbourne	8,751	3,556	5,195
Ethnic Group division			
White Irish	108	45	63
White Other	221	86	135
White & Black Caribbean	6	0	6
White & Black African	0	0	0
White & Asian	9	3	6
Other Mixed	27	13	14
Indian	20	8	12
Pakistani	6	3	3
Bangladeshi	12	3	9
Other Asian	14	10	4
Black Caribbean	3	0	3
Black African	3	3	0
Black other	0	0	0
Chinese	13	6	7
Other ethnic group	29	10	19
Total Ethnic Group Carers in Eastbourne	471	190	281

**Figure 2.8  
Position of Eastbourne on the Index of Deprivation**



## 2.5 Lewes

Table 2.11 reveals that Lewes has 14 wards where the percentage of carers is above the county average and only six wards which are below. Overall the percentage of carers is above the average and two wards had an excess of 12% of their population as carers.

**Table 2.11**  
**Carers as a percentage of the population (wards)**

Wards	Total Population	Total carers	Percentage of carers
<b>Barcombe and Hamsey</b>	<b>1976</b>	<b>200</b>	<b>10.12</b>
<b>Chailey and Wivelsfield</b>	<b>4684</b>	<b>518</b>	<b>11.05</b>
Ditchling and Westmeston	2099	204	9.71
<b>East Saltdean and Telscombe Cliffs</b>	<b>7133</b>	<b>744</b>	<b>10.43</b>
<b>Kingston</b>	<b>2038</b>	<b>252</b>	<b>12.36</b>
Lewes Bridge	4255	393	9.23
Lewes Castle	4571	432	9.45
<b>Lewes Priory</b>	<b>7162</b>	<b>720</b>	<b>10.05</b>
<b>Newhaven Denton and Meeching</b>	<b>7294</b>	<b>816</b>	<b>11.18</b>
Newhaven Valley	3877	300	7.73
Newick	2318	215	9.27
<b>Ouse Valley and Ringmer</b>	<b>6421</b>	<b>707</b>	<b>11.01</b>
<b>Peacehaven East</b>	<b>4319</b>	<b>530</b>	<b>12.27</b>
Peacehaven North	4859	453	9.32
<b>Peacehaven West</b>	<b>4039</b>	<b>413</b>	<b>10.22</b>
<b>Plumpton Streat East Chilmington and St John (Without)</b>	<b>2306</b>	<b>234</b>	<b>10.14</b>
Seaford Central	4629	429	9.26
<b>Seaford East</b>	<b>4783</b>	<b>563</b>	<b>11.77</b>
<b>Seaford North</b>	<b>4838</b>	<b>541</b>	<b>11.18</b>
<b>Seaford South</b>	<b>4208</b>	<b>500</b>	<b>11.88</b>
<b>Seaford West</b>	<b>4368</b>	<b>531</b>	<b>12.15</b>
<b>TOTAL</b>	<b>92177</b>	<b>9695</b>	<b>10.51</b>

Table 2.11 above and Figure 2.9 below reveal that 73.8% of carers care between 1-19 hours per week, 9.0% care for 20-49 hours per week and 17.4% have caring responsibilities in excess of 50 hours per week. The average percentage of carers in East Sussex stands at 10%, the above table though shows values higher than this and as a result of this those wards that present numbers in excess of 10% have been emphasised in bold.

**Figure 2.9**

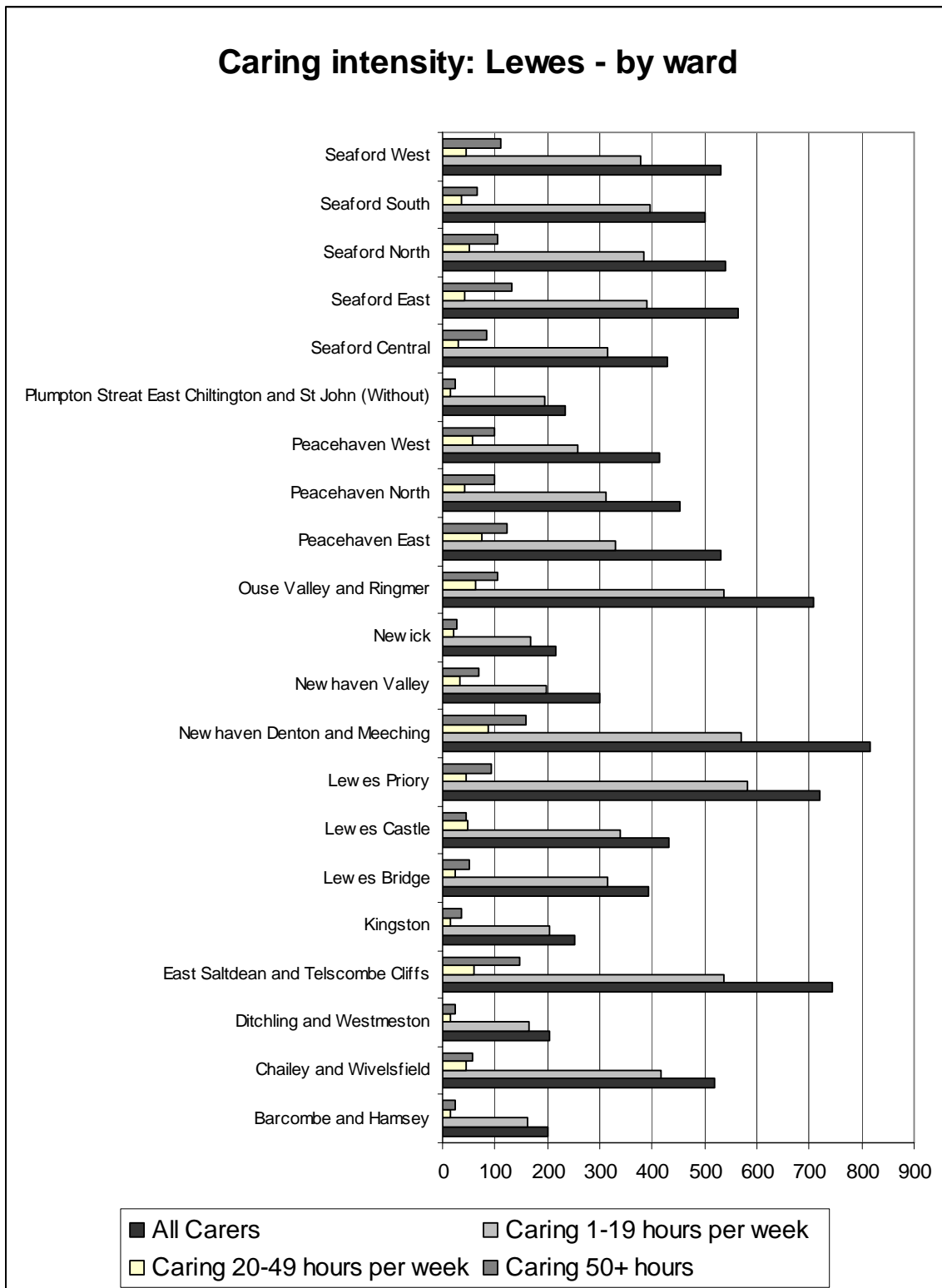


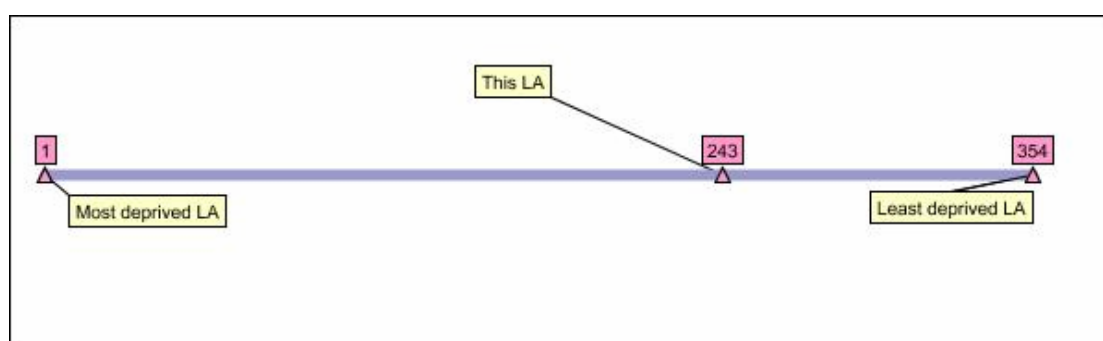
Table 2.12 shows that the vast majority of carers are in good health and this corresponds with the position of Lewes on the Index of Deprivation at 243 (Figure 2.10).

Table 2.13 shows that Lewes has a very small number of carers from Black and Ethnic Minority groups, particularly if the white ethnic groups are removed

**Table 2.12**  
**The state of carers' health in Lewes in age groups by gender**

	Good Health	Good Health	Good Health	Not Good Health	Not Good Health	Not Good Health
	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours
0-15 Male	46	6	6	0	0	0
0-15 Female	59	0	0	6	0	0
16-24 Male	89	13	0	3	3	0
16-24 Female	85	3	13	10	0	0
25-49 Male	631	61	94	66	10	17
25-49 Female	917	108	165	97	23	47
50-64 Male	790	57	91	115	17	39
50-64 Female	1056	106	152	143	31	45
65-89 Male	340	33	95	83	30	83
65-89 Female	385	45	105	65	16	78
90+ Male	4	0	0	0	0	3
90+ Female	0	0	0	0	0	0

**Figure 2.10**  
**Position of Lewes on the Index of Deprivation**



**Table 2.13**  
**Lewes Black and Ethnic Minority carers by gender**

	<b>Total</b>	<b>Males</b>	<b>Females</b>
Total number of carers in Lewes	9,697	4,058	5,639
Ethnic Group Division			
White Irish	94	39	55
White Other	175	65	110
White & Black Caribbean	12	3	9
White & Black African	3	3	0
White & Asian	12	6	6
Other Mixed	9	3	6
Indian	36	25	11
Pakistani	4	0	4
Bangladeshi	7	0	7
Other Asian	6	6	0
Black Caribbean	3	3	0
Black African	6	0	6
Black other	0	0	0
Chinese	25	10	15
Other ethnic group	3	0	3
Total Black and Ethnic Minority Carers in Lewes	395	163	232

## 2.6 Wealden

Wealden has the highest number of carers and the most wards out of all the areas in East Sussex. The census data, as illustrated in Table 2.15, reveals that two-thirds of the wards contain a higher percentage of carers than the county average but that the other third has a far lower percentage than the county average.

Table 2.14 indicates that the vast majority of carers in Wealden are in good health, corresponding with the position of Wealden on the Index of Deprivation at 307 (Figure 2.12), where 354 is the least deprived.

Wealden has the highest number of Black and Ethnic Minority carers, both white and other, but since it has the largest number of carers in East Sussex these carers might be invisible to services.

**Table 2.14**  
**The state of carers' health in Wealden in age groups by gender**

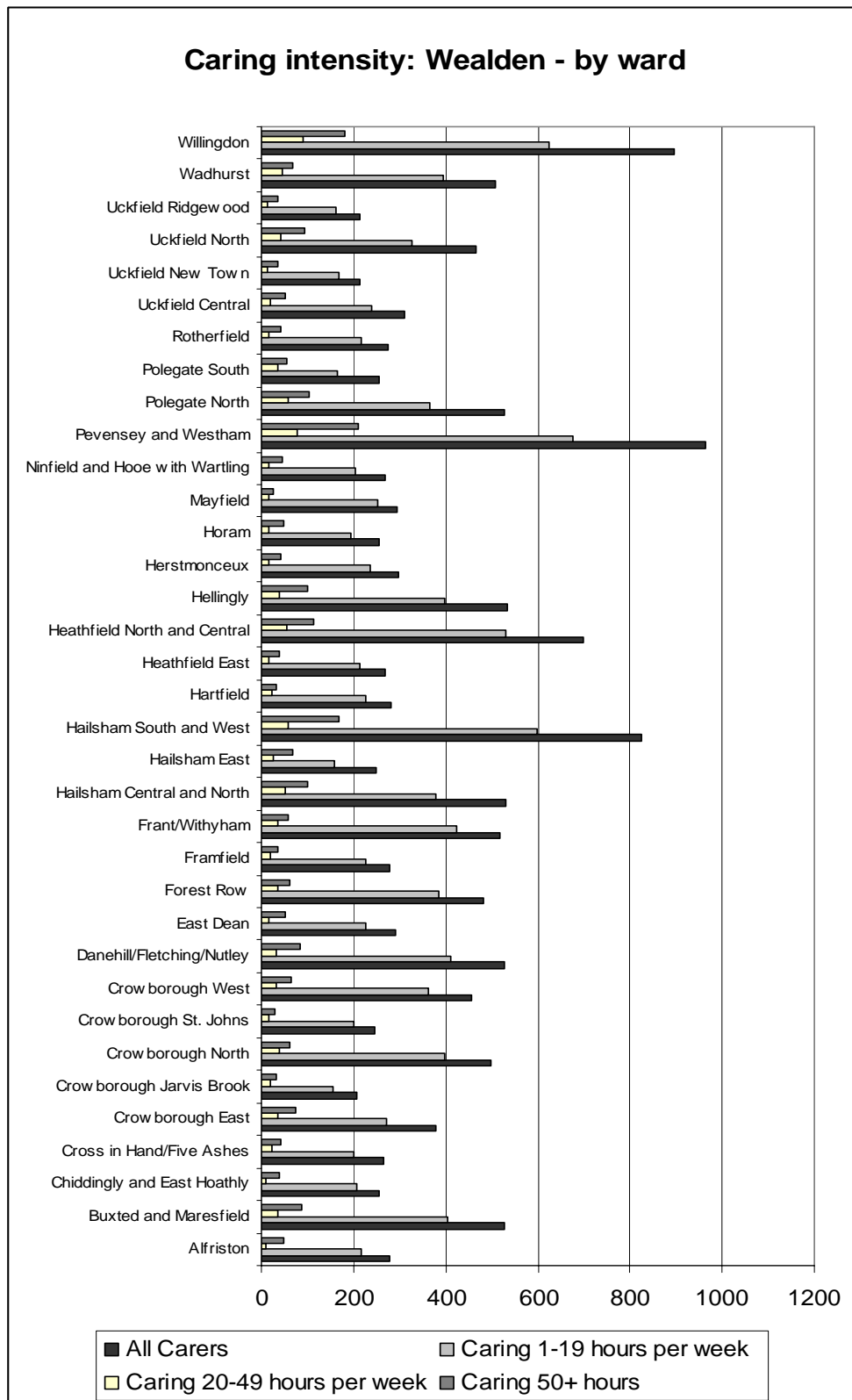
	Good Health	Good Health	Good Health	Not Good Health	Not Good Health	Not Good Health
	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours
0-15 Male	84	0	6	0	0	0
0-15 Female	79	3	0	0	0	0
16-24 Male	132	10	7	6	0	3
16-24 Female	125	8	16	7	0	0
25-49 Male	953	91	123	67	15	28
25-49 Female	1454	124	296	139	23	49
50-64 Male	1328	76	106	147	24	51
50-64 Female	1705	160	234	199	30	54
65-89 Male	466	54	127	97	27	95
65-89 Female	566	44	172	105	31	102
90+ Male	3	0	0	0	0	4
90+ Female	3	0	3	3	0	4

**Table 2.15  
Carers as a percentage of the population (wards)**

Wards	Total population	All carers	Percentage of carers
<b>Alfriston</b>	<b>2295</b>	<b>279</b>	<b>12.15</b>
<b>Buxted and Maresfield</b>	<b>4969</b>	<b>528</b>	<b>10.62</b>
Chiddingly and East Hoathly	2727	256	9.38
<b>Cross in Hand/Five Ashes</b>	<b>2291</b>	<b>265</b>	<b>11.56</b>
Crowborough East	5247	378	7.20
Crowborough Jarvis Brook	2686	207	7.70
Crowborough North	5054	497	9.83
<b>Crowborough St. Johns</b>	<b>2193</b>	<b>245</b>	<b>11.17</b>
Crowborough West	4759	457	9.60
<b>Danehill/Fletching/Nutley</b>	<b>5049</b>	<b>527</b>	<b>10.43</b>
<b>East Dean</b>	<b>2164</b>	<b>292</b>	<b>13.49</b>
Forest Row	5198	483	9.29
<b>Framfield</b>	<b>2544</b>	<b>277</b>	<b>10.88</b>
<b>Frant/Withyham</b>	<b>4791</b>	<b>517</b>	<b>10.79</b>
Hailsham Central and North	5500	529	9.61
Hailsham East	2769	250	9.02
Hailsham South and West	8330	826	9.91
<b>Hartfield</b>	<b>2523</b>	<b>283</b>	<b>11.21</b>
<b>Heathfield East</b>	<b>2351</b>	<b>270</b>	<b>11.48</b>
Heathfield North and Central	7722	698	9.03
<b>Hellingly</b>	<b>4974</b>	<b>535</b>	<b>10.75</b>
<b>Herstmonceux</b>	<b>2532</b>	<b>296</b>	<b>11.69</b>
Horam	2578	256	9.93
<b>Mayfield</b>	<b>2677</b>	<b>294</b>	<b>10.98</b>
<b>Ninfield and Hooe with Wartling</b>	<b>2327</b>	<b>267</b>	<b>11.47</b>
<b>Pevensey and Westham</b>	<b>8545</b>	<b>964</b>	<b>11.28</b>
<b>Polegate North</b>	<b>4713</b>	<b>527</b>	<b>11.18</b>
<b>Polegate South</b>	<b>2250</b>	<b>255</b>	<b>11.33</b>
<b>Rotherfield</b>	<b>2327</b>	<b>276</b>	<b>11.86</b>
<b>Uckfield Central</b>	<b>2792</b>	<b>310</b>	<b>11.10</b>
Uckfield New Town	2559	213	8.32
Uckfield North	5372	466	8.67
Uckfield Ridgewood	2974	214	7.19
<b>Wadhurst</b>	<b>5057</b>	<b>509</b>	<b>10.06</b>
<b>Willingdon</b>	<b>7184</b>	<b>897</b>	<b>12.48</b>
<b>TOTAL</b>	<b>140023</b>	<b>14343</b>	<b>10.24</b>

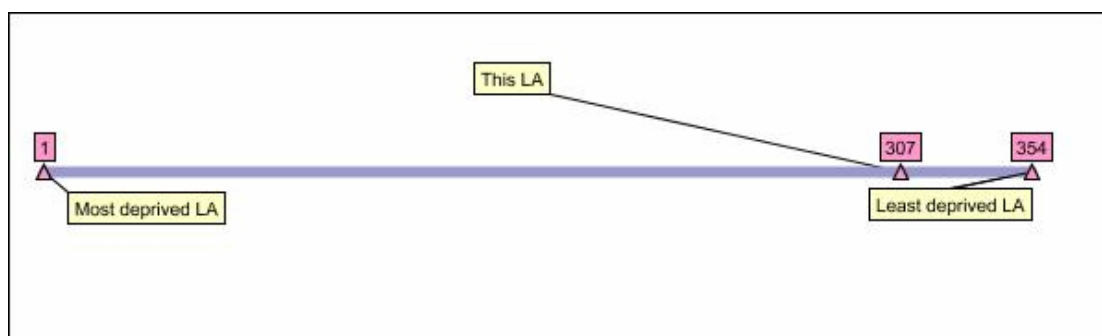
Table 2.14 and Figure 2.11 reveal that 75.4% of carers care between 1-19 hours per week, 7.6% care between 20-49 hours and 17% have caring responsibilities in excess of 50 hours per week.

Figure 2.11





**Figure 2.12**  
**Position of Wealden on the Index of Deprivation**



**Table 2.16**  
**Wealden Black and Ethnic Minority Carers by gender**

	Total	Males	Females
Total numbers of carers in Wealden	14,332	5,945	8,387
Ethnic Group Division			
White Irish	83	29	54
White Other	277	93	184
White & Black Caribbean	9	0	9
White & Black African	3	0	3
White & Asian	17	12	5
Other Mixed	6	0	6
Indian	12	6	6
Pakistani	9	6	3
Bangladeshi	13	7	6
Other Asian	12	6	6
Black Caribbean	3	3	0
Black African	12	3	9
Black other	3	0	3
Chinese	22	7	15
Other ethnic group	25	6	19
Total Black and Ethnic Minority Carers in Wealden	506	178	328

## 2.7 Rother

According to the census data Rother has 18 out of 20 wards with more than the average number of carers, three of which have in excess of 12% and one with more than 13%. It also has the highest percentage of carers in the county, well above the county average.

Although many of the carers report being in good health there are a number that have said their health is not good corresponding with the position of Rother on the Index of Deprivation (Figure 2.14).

Table 2.19 shows a small number of carers from Black and Ethnic Minority Groups and once white Irish and white other groups have been removed the number becomes very small which has implications for service delivery.

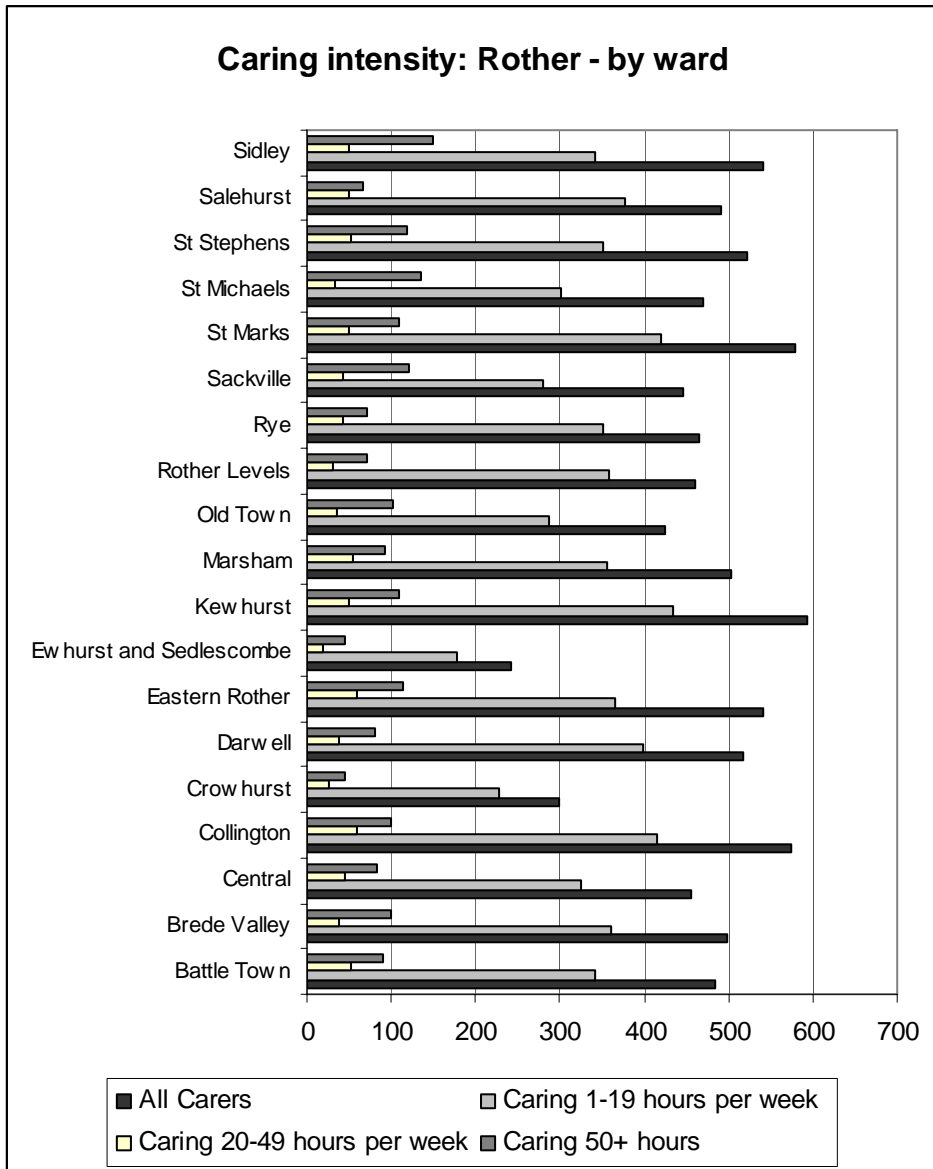
**Table 2.17**  
**Carers as a percentage of the population (wards)**

Ward	Total population	All Carers	Percentage of carers
<b>Battle Town</b>	<b>4780</b>	<b>483</b>	<b>10.10</b>
<b>Brede Valley</b>	<b>4627</b>	<b>498</b>	<b>10.76</b>
Central	4947	455	9.19
<b>Collington</b>	<b>4248</b>	<b>575</b>	<b>13.53</b>
<b>Crowhurst</b>	<b>2583</b>	<b>298</b>	<b>11.53</b>
<b>Darwell</b>	<b>4882</b>	<b>518</b>	<b>10.61</b>
<b>Eastern Rother</b>	<b>4713</b>	<b>541</b>	<b>11.47</b>
<b>Ewhurst and Sedlescombe</b>	<b>2372</b>	<b>242</b>	<b>10.20</b>
<b>Kewhurst</b>	<b>4605</b>	<b>593</b>	<b>12.87</b>
<b>Marsham</b>	<b>3697</b>	<b>502</b>	<b>13.57</b>
<b>Old Town</b>	<b>3798</b>	<b>425</b>	<b>11.19</b>
Rother Levels	4627	460	9.94
<b>Rye</b>	<b>4009</b>	<b>466</b>	<b>11.62</b>
<b>Sackville</b>	<b>4213</b>	<b>445</b>	<b>10.56</b>
<b>St Marks</b>	<b>4542</b>	<b>579</b>	<b>12.74</b>
<b>St Michaels</b>	<b>4615</b>	<b>471</b>	<b>10.20</b>
<b>St Stephens</b>	<b>4189</b>	<b>523</b>	<b>12.48</b>
<b>Salehurst</b>	<b>4484</b>	<b>492</b>	<b>10.97</b>
<b>Sidley</b>	<b>5338</b>	<b>541</b>	<b>10.13</b>
<b>Ticehurst and Etchingam</b>	<b>4159</b>	<b>446</b>	<b>10.72</b>
<b>TOTAL</b>	<b>85428</b>	<b>9553</b>	<b>11.18</b>

Table 2.17 and Figure 2.13 below reveal that 71.4% of carers care between 1-19 hours per week, 9.0% care between 20-49 hours per week and 19.5% have caring responsibilities in excess of 50 hours per week. The average percentage of carers in East Sussex stands at 10%, the above table though

shows values higher than this and as a result of this those wards that present numbers in excess of 10% have been emphasised in bold.

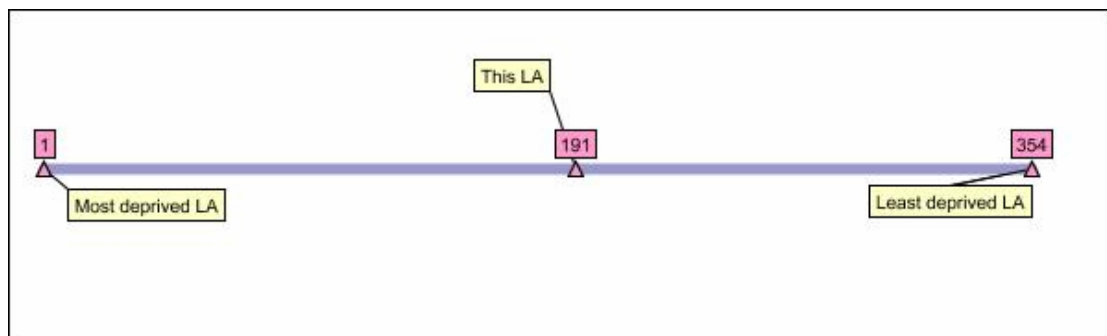
**Figure 2.13**



**Table 2.18**  
**The state of carers' health in Rother in age groups by gender**

	Good Health	Good Health	Good Health	Not Good Health	Not Good Health	Not Good Health
	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours	Provides care: 1 to 19 hours	Provides care :20 to 49 hours	Provides care: 50 or more hours
0-15 Male	51	6	6	0	0	0
0-15 Female	50	3	3	0	0	0
16-24 Male	59	6	3	9	3	0
16-24 Female	82	10	9	3	0	0
25-49 Male	568	54	78	38	9	21
25-49 Female	824	77	167	77	15	43
50-64 Male	717	49	83	111	18	29
50-64 Female	973	127	157	132	20	54
65-89 Male	385	44	121	77	21	88
65-89 Female	434	43	142	75	18	92
90+ Male	5	0	3	0	0	4
90+ Female	5	0	3	3	0	3

**Figure 2.14**  
**Position of Rother on the Index of Deprivation**



**Table 2.19**  
**Rother Black and Ethnic Minority carers by gender**

	<b>Total</b>	<b>Males</b>	<b>Females</b>
Total numbers of carers in Rother	9,541	3,920	5,621
Ethnic Group Division			
White Irish	91	34	57
White Other	215	80	135
White & Black Caribbean	6	3	3
White & Black African	3	0	3
White & Asian	12	3	9
Other Mixed	6	3	3
Indian	11	11	0
Pakistani	3	0	3
Bangladeshi	6	0	6
Other Asian	15	0	15
Black Caribbean	13	6	7
Black African	3	3	0
Black other	0	0	0
Chinese	3	0	3
Other ethnic group	6	3	3
Total Black and Ethnic Minority Carers in Rother	393	146	247

## 2.8 GIS maps

This section refers to the GIS (Geographical Information System) maps, located on the following pages, illustrating the distribution of carers in East Sussex in terms of numbers of hours spent caring in areas, wards and PCT areas.

Map 2.1 illustrates the distribution of total numbers of carers in East Sussex, indicating a concentration of carer numbers, in terms of carers per square meter, around the populated areas of Eastbourne, Peacehaven, a small area of Hastings and Heathfield North and Central, with the greatest concentration in Eastbourne and its immediate surroundings. In comparison the rural areas would appear to have far fewer carers with wards such as East Dean, Chiddingly and East Hoathly, in central East Sussex and Ditchling and Westmeston, located at the western edge of East Sussex, having between 2001-3005 carers.

Although rural carers appear to be less concentrated, the wards of Buxted and Maresfield and Danehill, Fletching and Nutley give the impression of having more carers, when viewed as a percentage of the population and coincide with the 11-12% average found in all the rural wards in East Sussex.

Similarly, where carer numbers indicate the lowest level (201-305) the proportion of carers related to the population remains fairly stable, around the 10% mark.

Maps 2.2, 2.3, and 2.4 illustrate the number of carers in terms of the numbers of hours spent caring, with Map 2.2 showing low intensity, Map 2.3 medium intensity and Map 2.4 high intensity carer numbers. The distribution of carers correlates with the carer numbers found in Map 2.1 revealing that areas with high concentration of carers are also those where caring hours are the highest across the three ranges of intensity.

According to the maps there would appear to be a degree of consistency among the carers of East Sussex, both in terms of the percentage of the population who have caring responsibilities and the number of hours spent caring. While overall this may be the case, the figures hide pockets where carers are caring in excess of 50 hours per week and where wards reveal higher percentages of carers than the county average of 10%. In addition it may also be said that facilities for carers in rural Sussex are not as plentiful or accessible when compared with those on offer for carers in urban areas, and the lack of facilities and opportunities may increase levels of isolation and depression.



### **3. Services for carers: mapping and expenditure**

#### **Key Points**

##### **Statutory Sector**

- There has been great difficulty gathering data on the number of carers accessing services and the expenditure on carers' services.
- Services for users can be a direct or indirect service for carers.
- 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.
- There are very few services in Rother.
- Many statutory services run well below 100% occupancy. This is not due to lack of demand.
- No clear picture is available on ESCC expenditure on carers' services, other than the breakdown of the Carers Grant.
- For older people, residential respite is located at Robertsbridge, Hastings, Seaford and Bexhill. There is no residential respite in Wealden for this group.
- 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.
- 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.
- There were 922 Carer Assessments completed in 2004/5, for the year April – December 2005 the figure had risen to 1,011.
- 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.
- 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.



- 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.

### **Voluntary Organisations**

- Some voluntary organisations exist specifically to help carers; these include Care for the Carers, Crossroads, Association of Carers and Friends of William Daley.
- Other organisations which provide help for specific groups, such as MIND, Mencap and Rethink, also provide support for the carers in their client group.
- 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).
- 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.
- 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.
- 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.
- 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.

## **3.1 Background**

The delivery of statutory social services for adults and children in East Sussex is based on Area Teams: Hastings and Rother; Lewes and Wealden; and Eastbourne, including Polegate. This is the way services are organised for adults and older people and for children and family services. There are also specialist county-wide teams for adults with learning disabilities and with mental health problems. Many of these clients are looked after, helped or supported by family or friends, i.e. carers. The help provided by carers includes personal care, administering medication, practical care and emotional support. Many carers assume this role and do it without support for themselves regarding information, advice or training. The work and responsibilities of a carer can be demanding and relentless. Thus one of the most needed services is respite care. The need for respite can also apply to the cared-for person who might need respite from their surroundings and/or their carer. Respite care describes separate periods of care, if the client or the carer needs to have a short-term break. A short-term break might range from between a few hours in the day to overnight, week-end, a week or longer. Respite is not usually longer than three months of continuous care and can either be provided in residential care or in the home of the carer and cared-for. East Sussex County Council (ESCC) has a statutory responsibility, under the Carers Equalities Act (2004) to provide help and support to carers. ESCC provides information about the different types of service available to help carers, including help to provide a respite break. In addition, there are a variety of voluntary sector organisations providing information, support and respite care, the principal providers being Care for the Carers (CftC) and Crossroads Care Attendant Schemes.

## **3.2 Introduction**

The information on the provision and funding of services for carers presented in this section of the report has been gathered together for the first time. It provides details on provision by the statutory sector, including social services and health services, and also on provision by the voluntary sector. It does not however, provide information on private sector provision and the services purchased by private individuals who never come into contact with social services. This is because the time and costs involved were prohibitive. In part this explains why, of the nearly 51,000 carers in East Sussex, only a small number appear to be accessing statutory and voluntary services. The findings from this chapter are also presented in tables which can be found in appendix 1 at the end of the report.

### **3.2.1 Choice of financial year**

It was decided early on in the research to focus on a whole financial year, in this case 2004/5, in order for complete sets of figures to be gathered. This decision was made on the assumption that figures for the preceding year were more likely to be available and easier to obtain than data for the year in which the research was taking place.

### 3.2.2 Data collection issues

Whilst the data gathered does offer a quite detailed and unique picture of statutory and voluntary sector funding and service provision, there are significant gaps. Information gathering has hitherto been focused on the service users rather than the carers. Where there is a specific function relating to carers, information was generally more easily obtainable, for example, the Carers Grant and the Short-Break Voucher Scheme. However, in day service provision, which is a service for people in various 'need' categories, it was harder to get a full picture. This is in part because the service offered provides a double benefit – it is both a direct service to the user and an indirect service to the carer, by providing a respite opportunity. Even the provision of respite is subject to this ambiguity – is respite only a break for the carer or is it also a break for the service user? Quantifying this and attaching a financial cost was particularly difficult. Another issue was the move away from respite to intermediate care beds, which reflects new developments in health and social care.<sup>1</sup>

A considerable effort was put into gathering information, but there were frequent cases of information being hard to track or simply not being produced. Information on carers from some service areas was either not collected (mental health), embedded in existing monitoring information and not able to be extracted (learning disabilities), or patchy (day care for older people). In addition, the monitoring forms of the Carers Grant for 2004/5 were missing; a breakdown of expenditure of the Spot Contracts could not be produced; figures on the numbers of Carers Assessments were not easily obtainable and there was anxiety about the sensitivity of contractual information (this report has endeavoured to respect this latter concern). It was particularly difficult to track additional finance from budgets other than those relating to the Carers Grant. This means that the picture is partial, with possible unknown inaccuracies and the report shows not only the findings but also the gaps, in order for improvements in information gathering and co-ordination to be made. Good quality intelligence is vital to inform the commissioning of services.

This section begins with the mapping of service provision, both statutory and voluntary, and direct and indirect provision. This information needs to be read in conjunction with the following section on funding. A final section draws out the key issues.

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<sup>1</sup> This refers to the way social services are taking respite care beds and turning them over to intermediate care beds, which come attached with up to 8 weeks free multi-disciplinary services to enable people, especially elderly people, to be discharged from hospital earlier. This enables social services to avoid the £100 daily fine from health when a patient stays in hospital after they are able to return home.

## 3.3 Social Services

### 3.3.1 Carers Assessments

Carers are entitled to receive an assessment by ESCC Social Services of their needs. A social worker or occupational therapist undertakes this and as a result decides what services a carer is entitled to. The carers' assessment is arguably the most important tool needed for carers to obtain the help they need. Legislation has progressively addressed the need for helping carers, moving away from defining carer needs only in terms of the person they look after to viewing them as individuals in their own rights. However, in practice much assessment of carers is undertaken at the time of assessment for the client, and many carers are unaware of this. Many carers do not know that they can ask for an assessment in their own right by contacting the adult services team. In 2004/5 the only services available as a result of assessment were Direct Payments and the Short-Break Vouchers for adults. ESCC Children's Services had taken the decision to focus solely on the provision of Direct Payments and so the Voucher Scheme does not apply to parents of disabled children.

There were 922 Carer Assessments completed for 2004/5, but no information is available of breakdown by area. Between 1<sup>st</sup> April and 30<sup>th</sup> November 2005 892 carers received an assessment and Table 3.1 shows the breakdown according to Primary Care Trust area (not ESCC team area). The figure up to the end of December 2005 was 1,011, clearly an increase on the previous year. These figures, however, do not give any indication of the assessment outcome, in terms of whether services were provided or not. Despite the clear increase this year, there is evidence (see Chapter 4) that a large number of assessments are not being done<sup>2</sup> and the latest Commission for Social Care Inspection (CSCI) Performance Review Report (20/09/05) for ESCC Adult Social Care states that around 50% of Carer Assessments were not being undertaken. Part of the reason for this may be due to staff attitudes and some evidence for this can be seen in a Carers Day workshop for Community Mental Health Teams run by Mental Health Services in the summer of 2005. This highlighted the 'blocks' to Carers Assessments from a professional's point of view:

- time pressures / the amount of time it would take to fill in a carer's assessment.
- workers' belief that service users/patients are their core concern, not carers and fear of a 'conflict of interest'.
- confidentiality and data protection issues.
- fear that carers' expectations of receiving support services would be unfairly/unrealistically raised by offering an assessment.
- 'Carers don't want an assessment – they find it intrusive'
- what to do with the information.
- carers assessment seen as extra bureaucracy and also the role for social workers not CMHT.

These views need to be set against the findings of carers reported in Chapter 4.

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<sup>2</sup> Parents of disabled children do get an assessment.

### **3.3.2. Provision of day and residential respite**

This is done directly 'in-house' i.e. by social services' own establishments and comprises a mix of residential only, day care only and residential/day care combined. Residential respite is perhaps seen more clearly as respite for the carer. However, it is clear from some of the data on day services for older people that it is often the case that the primary reason for admission of the user to day care is in order to provide respite for their carer. In addition Social Services also commission the independent sector through the use of block contracts and spot contracts for respite care.

#### **i) In-house**

##### *Carers of Older People*

There are no available estimates of numbers of carers of older people, although this group is likely to be the largest number of carers.

Table 3.2 shows the residential respite and day care provision for older people across the county and Table 3.3 gives some indication of percentage of occupancy. There are four residential only units: 2 for older people/intermediate care and 1 for intermediate care only (now transferred to health). The two residential units for older people/intermediate care have fifteen respite beds (82% occupancy) and 29 beds (73% occupancy) respectively. There are also two residential units with day centres attached for older people, Gilda Crescent with 18 respite beds (78% occupancy) and Ridgewood, with 35 respite beds (87% occupancy). These units have 12 and 20 day care places, with 50% and 55% occupancy respectively.

There are 6 day centres for older people, some of which collected information on the number of users with carers. There was some evidence of their use in providing respite for carers, as some day centres collected information on the primary reason for admittance, carer respite being one reason. One centre had 32 users with carers, 15 admitted for carer support/respite; another had 32 users with carers, 29 of whom were admitted for carer support/respite. Of the remaining four centres, there were no figures for users admitted for carer respite, only figures for users with carers, those were 57, 58, 32, 31, respectively. Occupancy rates varied from 43% to 93%, with many below 80%.

Services for Older People includes people over 65 with mental health problems – this information is summarised below.

##### *Carers of people with learning disabilities:*

There are no estimates of numbers of carers of people with learning disabilities. However there are estimates of the numbers of people/adults with a learning disability, around 9,500 with a mild learning disability and 1,575 with a moderate/severe learning disability. Many of the latter category will have one or more carers (Source: *A Needs Analysis of Adult Learning Disability*, 30/04/2003, Maycrest Consulting for the East Sussex Learning Disability Partnership Board).

Table 3.5 contains details of the three residential respite units for people with learning disabilities although, according to the Maycrest Report, almost half the people with learning disabilities in residential care homes originally come from outside East Sussex. The Unit in Bexhill provides care for 126 users, for which there are 122 carers, with occupancy of 81%. The Unit in Hailsham has 40 regular users, 12 at any one time, with occupancy of 23%. The Unit in Crowborough has 19 regular users, with 4 users at any one time and occupancy of 84%.

Table 3.7 shows the day centres for people with learning disabilities. ESCC operates 7 day centres, providing services for 463 people. The table shows numbers of users and average daily attendance, but not occupancy levels. In addition there are 20 independent day service providers, providing services for 662 people..

Three Community Support Teams covering Eastbourne, Wealden and Lewes, provide support in the community to around 100 vulnerable people and their carers.

The East Sussex Supported Accommodation Team (SAT), incorporating the Adult Placement Team, provides permanent and respite accommodation for vulnerable adults in family homes across the county. Respite costs under this scheme are £50 per day for up to three days and then weekly charges at £200-£350 per week, depending on level of need. The vouchers issued under the Short-break Voucher Scheme (see below) can be used to access this service. Adult Placements can be arranged to provide overnight respite services for carers for short or long periods of time. Although there were no figures on usage, as figures on respite for 2004/5 were tied up in other monitoring figures, Learning Disabilities services reported there was spare capacity that could be greater utilised in the North Wealden area.

There are 12 small group residential care homes in East Sussex (managed by Social Services) providing 24 hour residential care for people with learning disabilities. Eastbourne Downs Primary Care Trust owns the freehold to all twelve buildings. Kelsey Housing Association is the registered proprietor of all the homes and Social Services provide staff and management. There is a registered manager for each of the 12 homes, in addition to senior care and day and night care staff. The homes, between 3 and 7 bed spaces in size, provide 63 registered care beds and all are fully occupied. Service users are aged between 53 and 85 years of age.

*Carers of people with mental health problems:*

There are no estimated figures of carers of people with mental health problems. Information on carers is not collected<sup>3</sup>. There are two main types

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<sup>3</sup> The problems about confidentiality are that, after the person being cared for reaches 18 parents/carers have no rights over their offspring/charges etc and issues of confidentiality about patient records can conflict with the need of the carers/parents to get information. When people have episodic mental health conditions it can be incredibly difficult for

of mental health condition, functional mental health which includes depression, bi-polar disorders and schizophrenia and organic mental health, which includes the various dementias e.g. Alzheimer's, or dementia brought on by substance misuse and some neurological conditions. Most of the adults of working age with mental health problems have the former condition, whereas the latter condition is more associated with older age. Services are divided into those for adults of working age and those for older people, ie over 65 years of age.

Table 3.2 and 3.3 shows respite and day care for older people with mental health problems. There is one in-house residential only unit for people with mental health problems, in Hastings, providing 5 respite beds, with 76% occupancy. In 2004/5 there were four residential units with day centres attached (one now closed), providing a further 44 respite beds. Occupancy levels ranged from 63% to 82%. Table 3.8 identifies the 23 day service units, for 1168 adults of working age with mental health problems. Two of these are run by social services, the remainder being either health or non-statutory, usually voluntary sector.

In addition there are an unknown number of residential respite places for adults of working age commissioned by social services from the independent sector (including housing associations).

#### *Parent Carers:*

Estimated numbers of parents caring for disabled children is based on assumptions that at there is at least one parent carer for each disabled child. According to estimates by Children Services, there are 2909 disabled children aged 0-14 and a further 1554 disabled children aged 15-19 years. Fourteen thousand of the 2909 have moderate to severe disabilities. This suggests there could be at least 4-5,000 parent carers.

Tables 3.9 and 3.10 show the respite provision of parent carers of children with a disability. There are two residential respite units, providing overnight care for sixty eight children, a total of 3765 bed nights. An outreach service is also provided from the units to around 73 children. In addition there is the Link Scheme, providing family-based respite to 53 children and from 45 foster carers comprising 4716 nights and 2314 hours of day care. Thirty three children are placed in residential schools offering overnight respite, in and out of the county.

During 2004/05 around 116 children were supported by ESCC Outreach services. This included support in the home (various individual packages of weekly or fortnightly care); the provision of after school and holiday activities as well as supporting children to attend leisure activities in the community (usually taking a child out on a Saturday or during school holidays to give

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families/carers to get the help they need for the patient because the patient has not asked for the help. However, when they do receive help the medical/social services professionals are not permitted to pass on any information without the permission of the patient. In addition, there is the problem of some instances when the carers/parents are inclined to take over the lives of the patient and think that their voice is the one that should be heard.

parents a break).

In addition, Crossroads provide support to children in the home (see Table 3.14); ESCC commission Triangle in Brighton to provide similar support and the Family Intensive Support Service (health) also provide support to children in the home. All, in effect, are a form of respite.

### **ii) Independent sector**

The independent sector is commissioned to provide residential and day respite by two mechanisms, block contracts and spot contracts. Block contracts are where a contractor is paid for the space annually, irrespective of whether it is used or not by social services referrals. Spot contracts are where the contractor is paid for the actual usage.

In East Sussex there are block contracts for respite beds with 7 contractors. Table 3.4 shows there to be about 15 beds, located in homes in Seaford, Bexhill, Robertsbridge and St Leonards. These are mostly for older people. The occupancy levels range from as low as 58% up to 85%.

An unknown figure from the mainstream Social Services budget is used to purchase spot contracts for respite from independent providers. In addition £56,756 was allocated from the Carers Grant to the Spot Purchase of Emergency Respite. It is likely that this grant allocation was put into a large pot of funding, which included monies from the mainstream budget; this is distributed by funding panels in the 3 operational areas, and these panels meet weekly to decide the allocation of funding.

It is not clear how many carers in total benefit from the wider use of spot contracts or from the more specific allocation of the Carers Grant for emergency respite, as monitoring information could not be provided. However there is some information for the area of learning disability. At the end of 2004, ESCC was funding 730 learning disability residential placements in independent residential and nursing homes, 139 of which are out of the county. All the placements were made on a spot purchase basis. Almost half the residents living in independent residential and nursing homes in the county were placed there by other authorities (Source: Pre-Scrutiny Review Position Statement, 14/12/2004).

### **3.3.3. Provision of other services across the county**

#### ***i) Short-break Voucher Scheme***

The Short-Break Voucher Scheme is designed to enable carers and the cared-for to purchase their own services directly from a provider, using a voucher as payment. Carers can take a break in their own home or away from it. The scheme in 2004/5 was for an adult caring for an adult or person over 65 with either a physical disability, a hearing or sight difficulty, a learning disability or a mental health problem. In order to be eligible for the scheme a social worker has to carry out a social care assessment of the cared-for and a carer's assessment.



A number of providers in the independent sector are signed up to the scheme, covering home care, day opportunities in day centres (costs range from £25 to £120 per day) provision of homecare, daycare, respite and transport services.

Vouchers range from £1 to £50. For an organisation such as Crossroads, they set a fixed charge per hour which includes all extra costs e.g. £16 per hour for someone in a rural area. The vouchers have often been used to top up an existing service (which Crossroads provides for free). The private sector providers often have an hourly rate, where travel is charged as extra. What is not clear is how far vouchers are being used specifically for respite rather than for a service which should be provided for by Social Services and funded by the mainstream budget.

Table 3.11 provides information on the scheme, in 2004/5 310 vouchers were issued and 183 redeemed, showing 59% usage. The high percentage of unredeemed vouchers may have been the result of a lack of supply by providers. It is important to note that the scheme increased fourfold in 2005/6. There were 52 providers, the main ones being Crossroads, Survivors of Suicide, and the William Daley Centre, where 10%, 9% and 8% of vouchers respectively, were redeemed.

#### **ii) Direct Payments**

Direct Payments are available to adults with a disability or parent carers of disabled children to enable them to purchase a service, instead of the Council buying and arranging services on their behalf. To be eligible for Direct Payments carers must first have their needs identified through a carer's assessment. ESDA is contracted to provide the support service to the scheme. Direct Payments for carers of disabled children is administered by Children's Services, in 2004/5 there were 28 recipients, 27 of whom are in the western side of the county, the remaining one being from Hastings.

The CSCI Performance Review Report noted that 'whilst direct payments have improved this year, outturn is still considerably lower than comparator councils'; this refers to all Direct Payments, and not specifically to those received by parent carers.

### **3.4 Health Services**

Table 3.13 provides a summary of provision by the various Primary Care Trusts and other parts of the health service. Their main contribution is financial, in terms of their joint contribution of the pooled budget which funds Care for the Carers (see funding section). All four PCTs also fund home respite which is provided by the Crossroads Care Attendant Schemes. Some in-house respite is provided, however this varies across the PCTs, in some cases this is formally recognised, in others not, thus access to those services depends on postcode. The East Sussex Mental Health Trust also provide day services for adults of working age with mental health needs.

### 3.5 The Voluntary Sector

A number of voluntary organisations in East Sussex exist specifically to provide help and support to carers. These include Care for the Carers, Crossroad, Association of Carers and Friends of William Daley. In addition several other organisations, which provide help for specific groups, such as MIND, Mencap and Rethink, also provide support for the carers of their client group.

Crossroads is the major voluntary sector provider of respite across the county and operates Care Attendant Schemes in Hastings and Rother, Lewes and Eastbourne and Wealden. Crossroads provide a free service for carers looking after a disabled or ill person at home and the Care Attendant Scheme takes over the caring tasks to provide a respite break for the regular carer. The service is provided for carers with dependents of all ages including children with disabilities.

Care for the Carers (CftC) is the main organisation providing a forum for carers views and outreach work across the County. Outreach work includes information on services, referrals to services, advocacy, benefits and practical information. Outreach workers also work with professionals to increase awareness and referrals to CftC which also provides a back protection service, training courses and a service for young carers. CftC campaigns for better services for carers and organises consultations on issues that affect carers. CftC brings together senior policy makers in the county, the County Carers Strategy Group and also organises the East Sussex Carers Development Group, which enables carers' views to influence service planning. CftC is involved in Health Improvement Partnerships, which develop local plans to improve carers' health and well-being.

Re-Think and Mencap work across the county, but for specific carers, those caring for people with mental health problems and those with learning disabilities, respectively. There are a number of area-specific providers such as Friends of William Daley and the Association of Carers. Mostly services offer some form of respite or home visiting, although advocacy and advice are sometimes provided. Further information on their services, and that of other organisations, is contained in Table 3.14. This table is based on an analysis of voluntary sector contracts with ESCC social services and specifies the funding source, purpose, area of coverage and service level agreement specification. There are however, still gaps in information, as there is no overall summary of voluntary sector provision.

Table 3.15 provides an analysis of service provision. Due to the missing monitoring forms provided by the voluntary organisations for 2004/5, this information had to be gathered retrospectively and varies in detail. The three Crossroads schemes were the only organisations able to provide an immediate, detailed, breakdown of their provision.

Table 3.15.1 provides a summary of all organisations, except Crossroads. Care for the Carers received 1217 referrals to its outreach service, averaging

around 185 hours per week, 854 of these were new referrals. The service has also undertaken 359 back care referrals; provided 76 information sessions; drop-ins were attended by 173 carers and 213 carers received 246 training hours. Six families were supported as part of the Independent Budget Management Scheme. Although CftC provided direct services to 1217 carers, it is in touch with a wider group of four thousand carers whose details are kept on its database and who all receive the *Careline* newsletter.

ESDA provided holiday respite for 21 people who accessed 7,560 hours of holiday respite. There was no evidence provided of support to parent carers regarding Direct Payments. Rethink provided a short-break scheme which benefited 53 carers, in addition its support service ran a one day Time Out Day for 200 carers and had 15 regular carer clients as 'cases'.

There are area-specific organisations, such as the Association of Carers, which provided 44 carers in the Hastings area with home-based respite; the William Daley Centre, which provided day care for 100 older people in the Eastbourne Area and Mencap, which provided day care support for 30 families in the Eastbourne area.

Crossroads monitoring information is contained in Table 3.15.2. This shows that in 2004/5 Crossroads provided 49,260 direct care hours, for 597 primary carers. However this figure is an underestimate of the carers benefiting, as in at least 50% of cases there are two carers and in at least 30% of cases carers are caring for more than one person. This means that Crossroads is helping around one thousand carers, but the total figure of beneficiaries is even higher. Seaford, Eastbourne and Wealden Crossroads provide the most hours, followed by Hastings and Rother, then Lewes District. Crossroads also has identified unmet needs: the Hastings and Rother scheme has 130 people on its waiting list, compared to 81 in Seaford, Eastbourne and Wealden and 6 in Lewes District. Crossroads currently does not have the capacity to meet this need. The age breakdown of users shows that most of the cared for are in the 70-89 aged range, followed closely by high figures in the 0-18 age range. Most referrals to Crossroads come from either social services or family/self. The three Crossroads schemes complete a quality assurance process each year which asks carers their views about the service they receive.

Table 3.19 provides an analysis of the performance monitoring requirements of the voluntary sector contracts. The main point to note is that there is a strong output focus to the requirements i.e. quantifying numbers of users, units of service. Given the need of carers to have a break, one could reasonably assume that outputs of respite care would make a difference. However, it is important also to be able to demonstrate that the provision of a respite break is a good quality intervention, of the appropriate type and improves the life of the carer. This point applies equally to any of the similar statutory interventions.

There is very little that is consistently required on outcome reporting, namely how the service has made a difference or improved the lives of the users.

This means a lot of monitoring information is collected but does not then get translated into evaluation i.e. some form of assessing whether or not the services are effective, of good quality and making a difference. For Care for the Carers – what are the outcomes of its 1217 referrals, its training etc? Again, this applies equally to the statutory sector – for Social Services, what are the outcomes of the Carer Assessments?

The arrangements for monitoring are organised separately, the contracts department draws up the Service Level Agreement; the operational managers meet with the organisation to review progress approximately every six months and the monitoring forms are returned to the grants section. Given the difficulty in gathering data on performance assessment, it is possible that there is a lack of co-ordination and these arrangements should be reviewed.

### **3.6 The Independent Sector**

There are 433 independent sector homes registered with the Commission for Social Care Inspection in East Sussex. We are aware that many carers purchase services from the private sector but there is currently no information available on these. In addition, an unknown number of private sector organisations provide beds for ESCC under the spot contract method.

In the area of learning disability there are over 120 CSCI registered care homes for people with learning disabilities in East Sussex, but no indication of which are used to provide respite. East Sussex Social Services also place a number of people in homes outside of the County. There are also around forty independent sector day centres, clubs, and associations providing a range of services, activities and support for young people and adults with learning disabilities, their families and carers. A number of these day services are delivered on the sites of residential care homes. Approximately 650 people use these services with an average daily attendance of around 430.

In the area of mental health there are an unknown number of residential respite places for adults of working age commissioned by social services from the independent sector (including housing associations).

### **3.7 Costs and financing of carers services**

For various reasons this data was very difficult to obtain and co-ordinate. It is clear from what is presented that there is a lack of consistency in the way such data is collected, both across the County, and across institutions and agencies. It has been particularly difficult to identify funding for services such as Direct Payments and Spot Contracts, which come from other Social Services budgets. Some of the terminology has been difficult, for example, funding from Carers Grant and Community Partnership Finance is relatively easy to identify and these come with contracts attached, however other amounts from Social Services are variously referred to as 'contracted', from Adult and Older People's Services or Children and Families Services, or from

Community Care or from Mainstream. The structure of financing and funding is not clear and that confusion is reflected in the findings, some of the information covers the costs of the services for users, which have an indirect benefit for carers; some cover costs of a service where it is not possible to locate the carers elements; others are quite clearly a cost of a service directly provided to a carer. In addition, there were inconsistencies between the information supplied by the Contracts Department, the Finance Department and the voluntary organisations themselves. These findings are the best available, given these constraints.

### **Carers Grant**

The main source of funding to the voluntary sector comes from the Carers Grant, ring-fenced funding provided by central government to local authorities social services departments. In 2004/5 this was £1,174,593, of which the main elements comprised:

- £111,750 to CfC for adult work and £36,144 for young carers
- £323,827 to Crossroads Adult work and £62,735 for young carers/children
- £120,080 to Rethink
- £46,964 to Friends of William Daley
- £79,503 to Sorrel Drive Respite Extension
- £40,123 for direct payments for short breaks for parent carers
- £74,653 for the Voucher Scheme<sup>4</sup>
- £56,756 for Spot Contracts for Emergency Care

The basis of the distribution of the Carers Grant appears to have been historic: as organisations have presented need, funding has been allocated. There was no evidence of a clear indication of priority areas for funding. The main attempt at a planned approach has been through the pooling of health and social services budgets for the funding of Care for the Carers (CftC). CftC also receives funding from the mainstream social services budget (see below) and Crossroads receives funding from the PCTs, as well as mainstream social services funding.

Table 3.14 provides a breakdown of the grants to voluntary organisations. CfC receives £484,895 from health and social services (including the carers grant) and the three Crossroads schemes receive £653,753. These two organisations receive the majority of funding for carers services.

### **Direct Payments**

There is no evidence of the total Direct Payment spend on carers, only the Carers Grant element of £26,653 for adults and not the contribution of the mainstream Social Services budget. The figure for children's services was £40,123 from Carers Grant plus £40,000 from the mainstream Children and Families budget. The average payment was £3,000 to £4,000 per year and the maximum payment was £12,000.

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<sup>4</sup> This figure is the budgeted figure – the actual expenditure figure was lower, see over.

### **Short-break Voucher Scheme.**

This was entirely funded from Carers Grant, at £36,517 for the year, although this has subsequently been expanded significantly.

### **Spot Contracts**

£56,756 was allocated from Carers Grant to the Spot Purchase of Emergency Respite. There was a larger figure from the mainstream social services budget for Spot Contract funding generally, as well as for emergency respite and there was no information on what the total figure was. Nor was it clear whether or not the monies have been spent on respite, in this case whether the £56,756 was spent on emergency carer respite or on regular care packages, aside from the issue of how many carers benefited.

### **Mainstream Social Services budget**

Tables 3.3,3.4,3.5,3.6,3.9 and 3.10, provide details of costs and expenditure of services to users, identifying respite services or direct support to carers, where possible.

#### **Voluntary Sector:**

Association of Carers	£10,870	
CfC Pooled budget	£91,175	
CfC other social services	£8,516 <sup>5</sup>	
Hastings Crossroads	£51,710	OP
Lewes Crossroads	£41,370	OP
Seaford Crossroads	£45,260	OP
	£20,105	C&F
Friends Wm Daley Centre	£27,000	OP
Hastings & Rother Family Friends	£43,800	C&F
<i>Total</i>	<i>£338,806</i>	

#### **Adult Services:**

It was not possible to calculate a figure of expenditure on services for carers. The services listed benefit users and their carers.

#### **Older People:**

##### **Day Services**

- Unable to provide an accurate estimate. Net costs possibly £1.3m.

##### **Block Contracts**

- An estimated £233,412 was spent on block contracts for residential respite care, from the Community Care budget.

#### **Older People/Mental Health:**

##### **Residential Respite**

- Gross costs of residential only, £2.92m (nb contains element of intermediate care)
- Gross costs of residential element of combined residential/day care are £3.34m

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<sup>5</sup> This does not include the ESCC grant of £57,530 for Youthability

Learning disabilities:

- £3,935,000 on day services
- £1,573,000 on community support, including adult placement respite
- £1,551,000 for three residential respite units

Mental health:

Unable to provide an accurate estimate

- Possible figure of net costs of two ESCC run centres for older people of £521,000 plus £922,000 net day costs from combined residential/day centres run by ESCC.
- £768,902 total spend on Day Services, for non-elderly by ESCHT
- £358,533 total spend on non-Statutory contracts managed by SSD
- £269,000 spend on SSD provided Centres in Lewes and Bexhill

Children and Families:

- £315,700 on outreach services for parent carers
- £1,123,800 on respite units in East Sussex
- £249,003 on residential schools offering overnight respite
- £30,000 on commissioning Triangle in Brighton to help parent carers

## Health

Table 3.13 shows some of the expenditure from health on services for carers.

Contribution to the Pooled Budget for CftC by four Primary Care Trusts':

- £221,026, comprising £165,370 from all four PCTs, plus £32,737 from South Downs & Wealden PCT and £22,919 from Bexhill & Rother PCT.
- £149,465 to Crossroads schemes for home sitting service
- £32,866 to Association of Carers for home sitting service

Unknown: the Family Intensive Support Service support to parent carers

Unknown: Health contribution to day care for adults of working age

Unknown: Social services commissioning of independent providers for respite

## Voluntary Sector contribution

The total raised from non-statutory sources (fundraising, members fees, donations etc) which contributes to the delivery of services for carers in East Sussex:

Crossroads	£47,000
CfC	£16,111
Association of Carers	£14,000
Others	£32,000
<b>Total</b>	<b>£107,000</b>

## 3.8 Mapping results

### Methodology issues

The information gathered on services has been 'mapped', that is placed on maps of the county area, by district. There has been some difficulty in this

process as in some cases there are no figures available and in other instances the data is not broken down by district. Where it has been possible to locate the position of a service this has been done. Where there are gaps or county-wide services with no breakdown these have been identified in separate, adjacent boxes.

Notwithstanding these limitations, the advantage of these maps is that they give a good spatial representation of the data and enable an interpretation about distribution and location to be made. It also allows us to make some linkages with the census data from chapter 2 of this report. It has already been noted that there are limitations to the census information – it does not enable us to fill the gaps in information on types of carers that are lacking in the ESCC data. The census information does not provide us with numbers and location of carers of older people, carers of disabled children, carers of people with either learning disabilities or carers of people with mental health needs i.e. the principle service user groups around which social care is organised.

Nor does the information show the distribution of carers assessments, spot contract respite, Direct Payments and the carers in receipt of county-wide support services. Thus the maps are incomplete.

#### *Location and Distribution of services*

Map 3.1 shows statutory services (health and social care), day and residential services, directly or indirectly of benefit to carers. It shows a clustering of services around coastal towns, particularly the larger ones of Hastings and Eastbourne. Other services are located around small towns such as Lewes, Hailsham and Crowborough whilst there are very few services in Rother. Although the GIS mapping shows a concentration of carers in Eastbourne, this is in terms of people per square metre (and what you would expect of an urban area). The percentage of carers per total population is 9.77% and the percentage of carers in Eastbourne out of total carers is 17%. The actual numbers of carers in Eastbourne is the second to lowest in the county, after Hastings.

Map 3.2 shows numbers of carers accessing or benefiting from different services and sets these against the number of carers caring for 20-49 hours and for over 50 hours. Of course, there will be an unknown number of carers paying for their own private home care and respite care. It is clear that there is a huge gap between potential need and provision, and this is borne out by the findings in Chapter 4. What is particularly important to note is the number of those caring 50+ hours per week, which was larger than the number of those caring 20-49 hours per week. The largest number of carers who care for more than 50 hours per week was in Wealden, that number being 2,428. However the highest percentage of carers out of all carers in the county, providing 50+ hours of caring, was 23.01%, in Hastings.

Map 3.3 shows services to older people by ESCC. Again provision by the voluntary and independent sectors is absent. This shows slightly more dispersal around the county than is indicated by Map 3.1 on all services. However, important services such as residential respite are grouped in pairs



at Robertsbridge, Hastings, Seaford, with one in Bexhill. There is no residential respite in Wealden. Many older people are cared for by other older people (although not exclusively). In Chapter 2 it can be seen that there are 7,247 carers aged 65 and over; 2,064 caring for 50+ hours (a quarter in Wealden). Of these 2,064 1,168 were in good health and 896 in not good health.

Map 3.4 shows services to people with learning disabilities, which includes some provision by the voluntary and independent sector. The map shows most provision to be in and around Hastings, with virtually none in the rural hinterland. There was more provision in Wealden for this group and little in Lewes and Eastbourne. Some provision was taken up by out of county placements.

Map 3.5 shows Day Centres for adults of working age with mental health needs. This shows some clustering around the coast and Eastbourne and Hastings, with no provision in North Wealden or Rother.

Map 3.6 shows services for parents with a disabled child, but only in East Sussex but not including out of county. The map shows relatively little provision, although it must be noted that special schools are not included.

Map 3.7 shows the coverage of the Short-break Voucher Scheme, both in terms of vouchers issued and vouchers redeemed. The map shows a strong clustering around the coastal towns in terms of redemption. Table 3.11 shows the amounts issued and sets this figure against the redemption rates. Hastings had the largest amount issued and Eastbourne had the lowest percentage redeemed, this is most likely connected to problems in supply. Interestingly, there was a breakdown for mental health and learning disability, both of which had high redemption rates, 77% and 71% respectively.

## **Other issues**

### *Occupancy levels*

Tables 3.2- 3.5 show many services ran well below 100% occupancy. From information discussed elsewhere in this report it appears that this could be due to a range of factors, including lack of information, location of services, lack of carer's assessment and inappropriate provision. It cannot be assumed that low occupancy means the demand is not there.

### *Distribution of Finance*

It is difficult to draw any firm conclusions about the financial contribution of East Sussex County Council social services to carers services as much is either invisible or indirect. The main exclusive funding of 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 and the voluntary sector contributes just over £100k of its own funds. An unknown figure is provided indirectly through other Social services budgets. Finally, there is an unknown amount spent in the independent sector by people who are buying services directly.

### *Performance Assessment*

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 has been on the user, rather than the carer. In the future priority should be attached to longitudinal monitoring and comparison of different organisations. In that case, use of similar indices will be important to establish such consistency. In addition, performance assessment needs to develop beyond a focus on output monitoring which dominates both the statutory and voluntary sectors. Outcome monitoring and evaluation of services, as well as quality assurance, should become embedded in the planning and delivery of services.

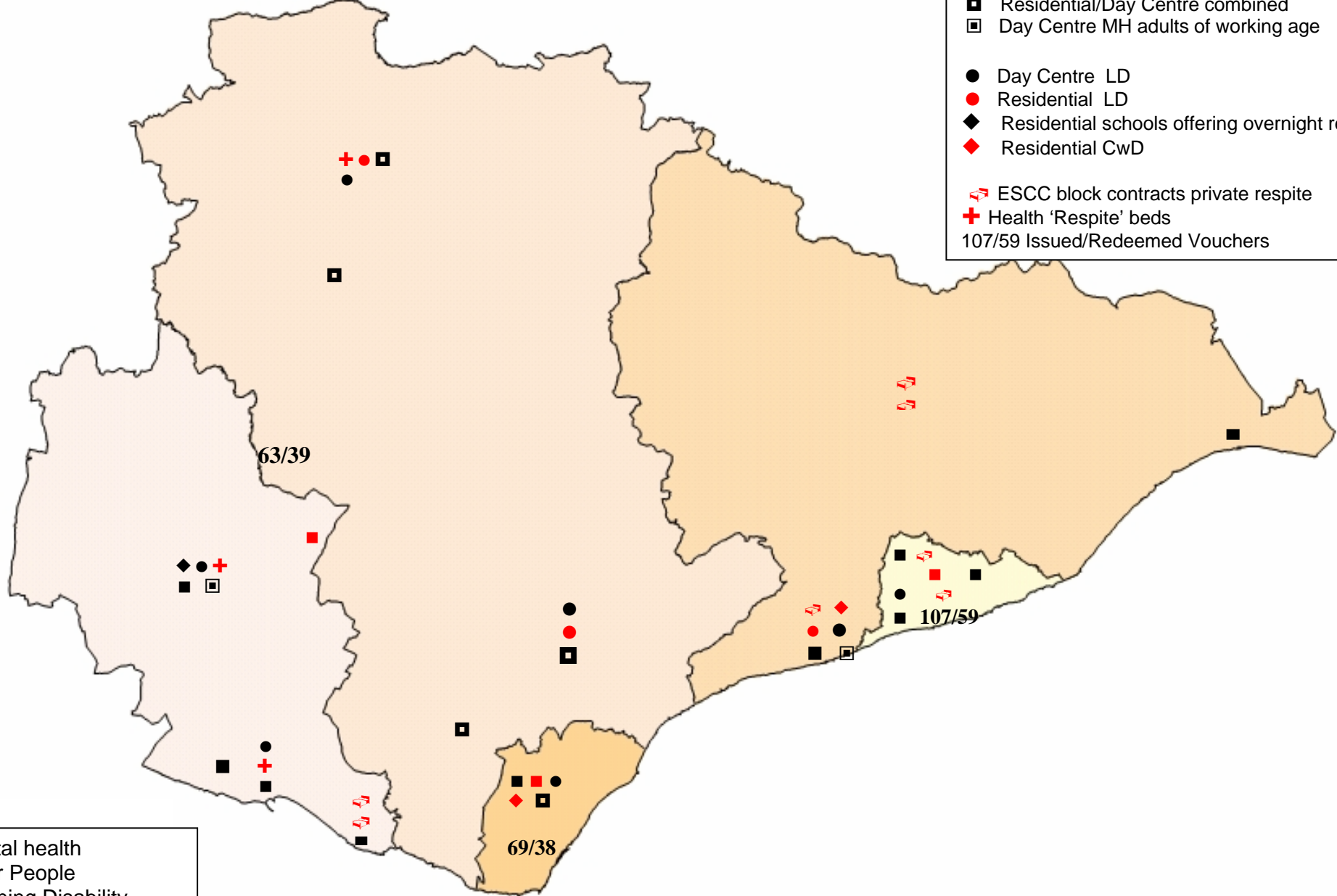


**Map 3.1: Map of Statutory Services (health and social care): day and residential, directly or indirectly of benefit to carers**

**ESCC**

- Day Centre OP/MH
- Residential “ “
- Residential/Day Centre combined
- Day Centre MH adults of working age
- Day Centre LD
- Residential LD
- ◆ Residential schools offering overnight respite
- ◆ Residential CwD
- ↔ ESCC block contracts private respite
- +

Health ‘Respite’ beds  
107/59 Issued/Redeemed Vouchers

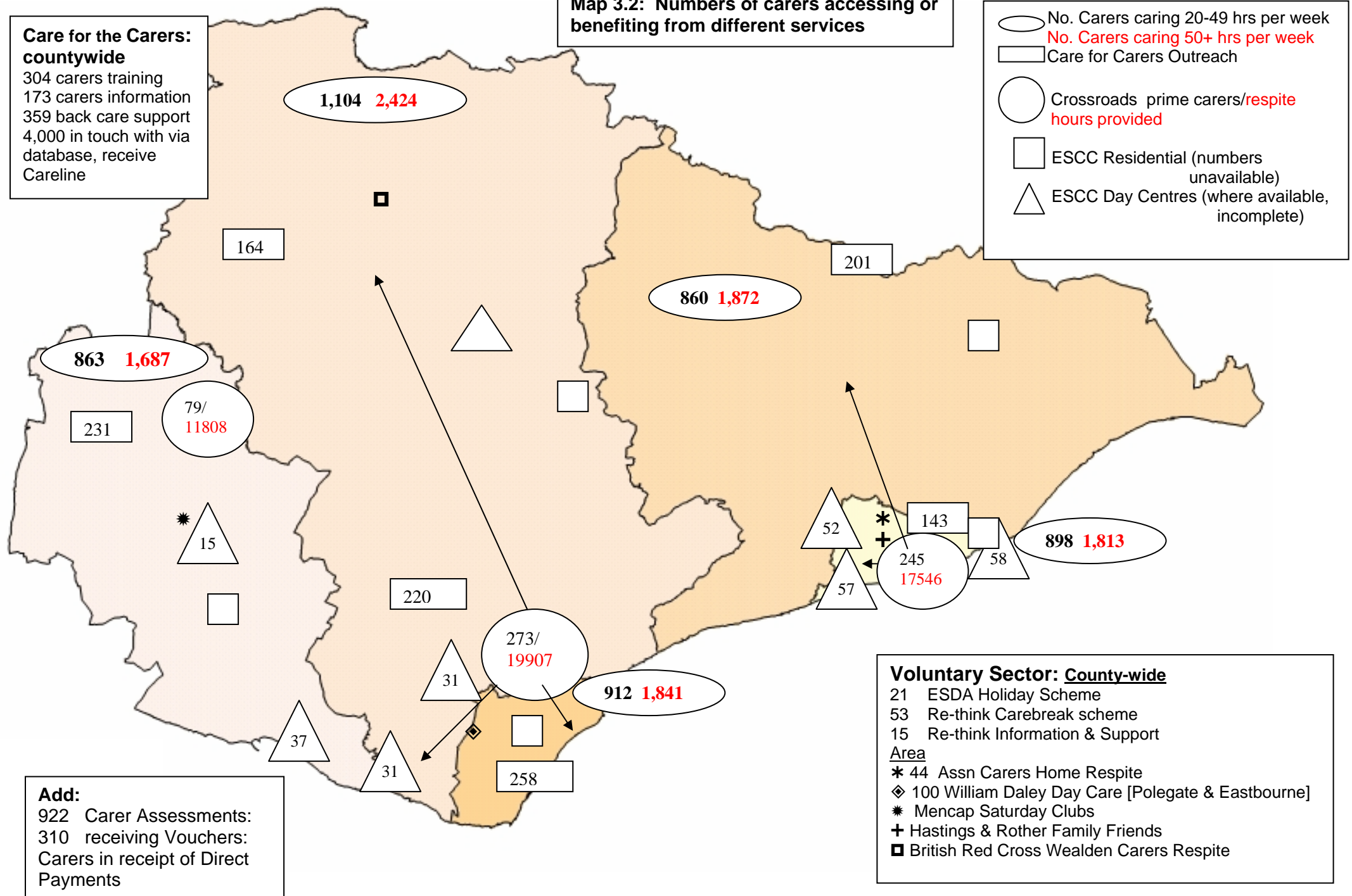


MH Mental health  
OP Older People  
LD Learning Disability  
CwD Children with Disability

**Map 3.2: Numbers of carers accessing or benefiting from different services**

**Care for the Carers: countywide**  
 304 carers training  
 173 carers information  
 359 back care support  
 4,000 in touch with via database, receive Careline

1,104 2,424 No. Carers caring 20-49 hrs per week  
No. Carers caring 50+ hrs per week  
164 Care for Carers Outreach  
79/ 11808 Crossroads prime carers/respite hours provided  
231 ESCC Residential (numbers unavailable)  
15 ESCC Day Centres (where available, incomplete)



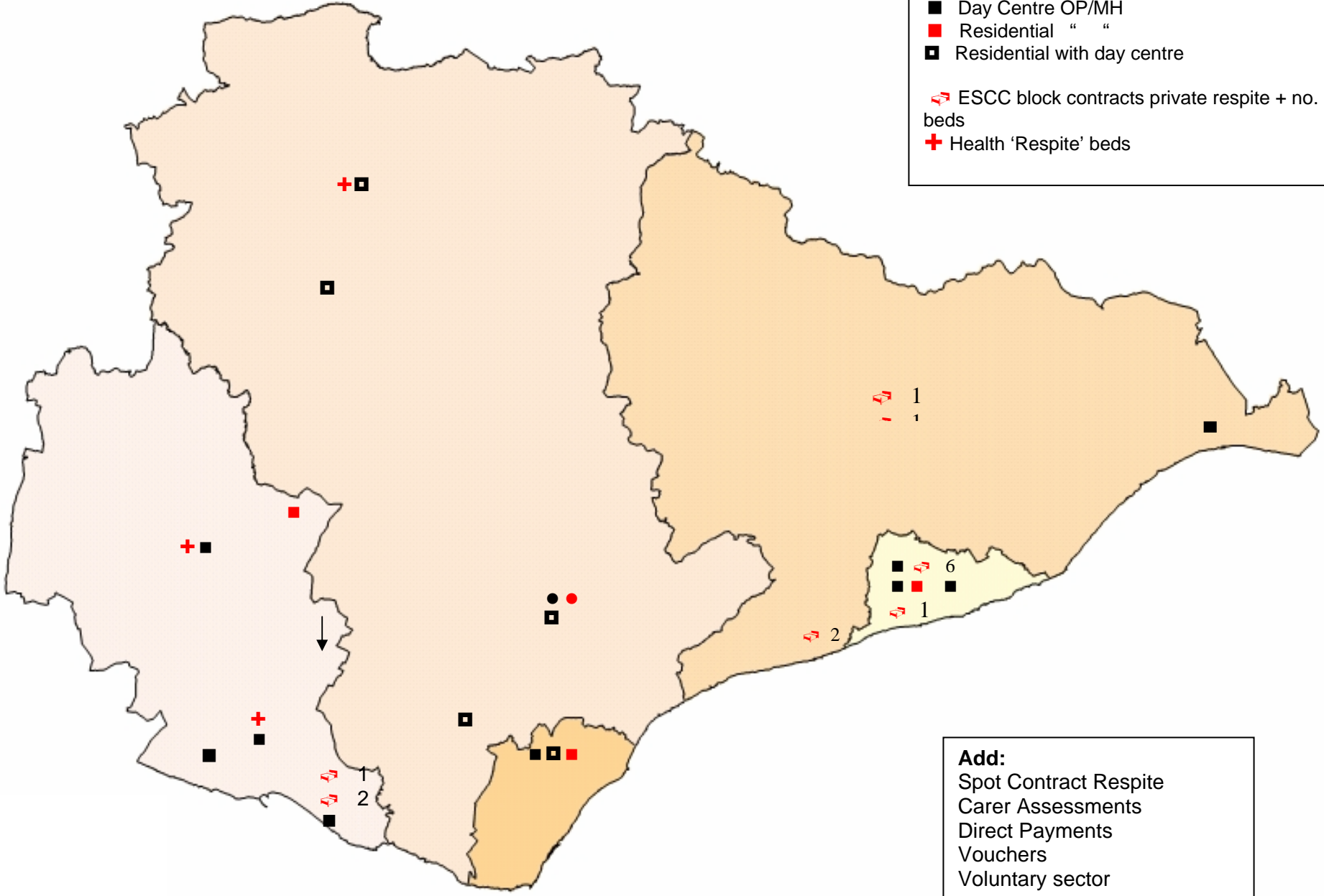
**Add:**  
 922 Carer Assessments:  
 310 receiving Vouchers:  
 Carers in receipt of Direct Payments

- Voluntary Sector: County-wide**
- 21 ESDA Holiday Scheme
  - 53 Re-think Carebreak scheme
  - 15 Re-think Information & Support
- Area**
- \* 44 Assn Carers Home Respite
  - ◆ 100 William Daley Day Care [Polegate & Eastbourne]
  - \* Mencap Saturday Clubs
  - † Hastings & Rother Family Friends
  - British Red Cross Wealden Carers Respite

**Map 3.3: Services to Older People by ESCC**

ESCC

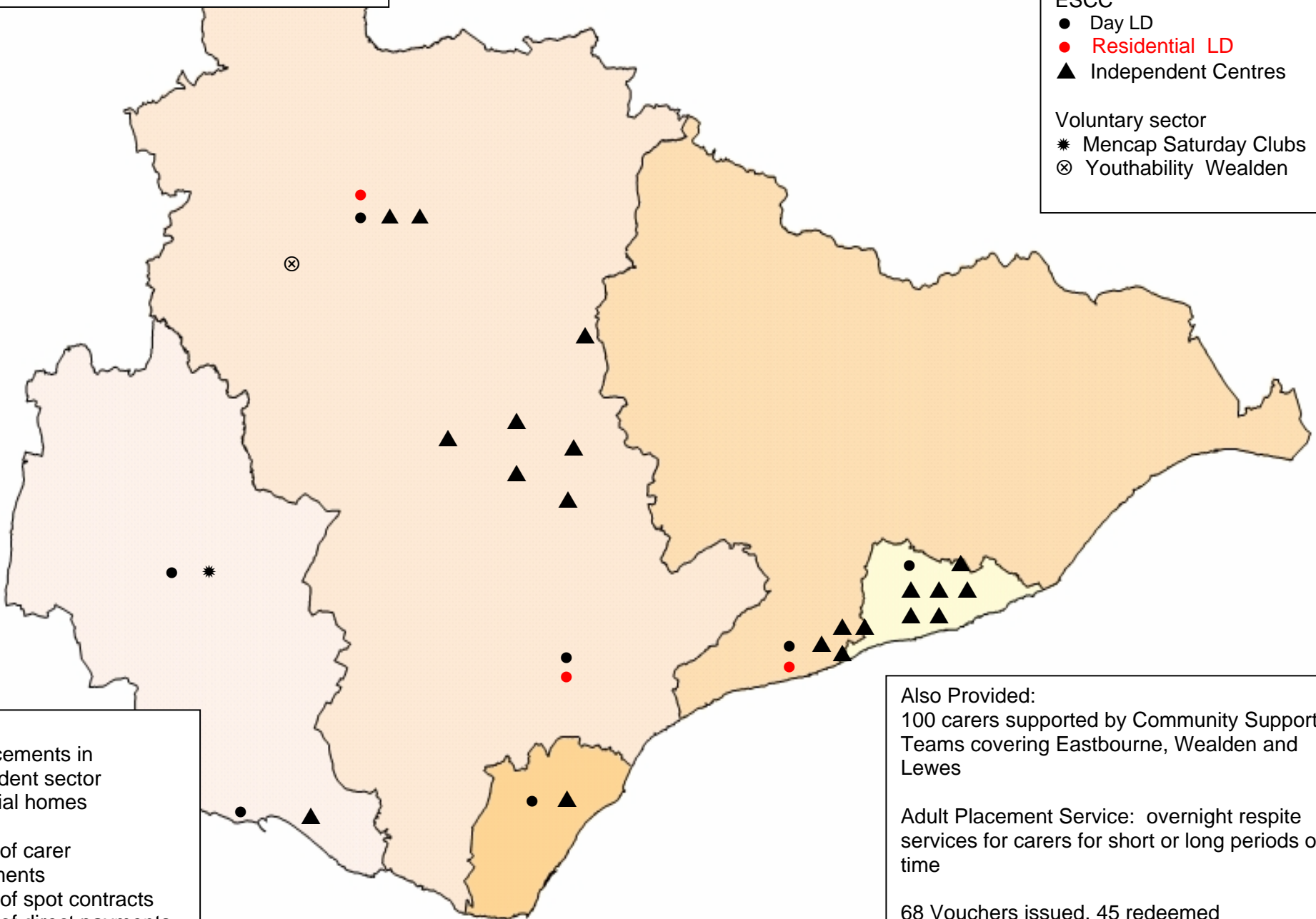
- Day Centre OP/MH
- Residential “ “
- Residential with day centre
- ↪ ESCC block contracts private respite + no. beds
- ⊕ Health ‘Respite’ beds



**Add:**  
 Spot Contract Respite  
 Carer Assessments  
 Direct Payments  
 Vouchers  
 Voluntary sector

**Map 3.4: Services for People with Learning Disabilities**

- Key:**  
 ESCC  
 ● Day LD  
 ● Residential LD  
 ▲ Independent Centres
- Voluntary sector  
 \* Mencap Saturday Clubs  
 ⊗ Youthability Wealden



Add:  
 591 placements in independent sector residential homes

number of carer assessments  
 number of spot contracts  
 number of direct payments

Also Provided:  
 100 carers supported by Community Support Teams covering Eastbourne, Wealden and Lewes

Adult Placement Service: overnight respite services for carers for short or long periods of time

68 Vouchers issued, 45 redeemed

**Map 3.5: Day Centres for adults of working age with mental health needs in East Sussex**

**Key:**

- Health Day Services
- SSD Day Services
- Non Statutory Service
- SSD Non-Stat Service
- △ SSD, PCT part fund. Non-Stat Service

Source: Day Services Report  
5/7/2004  
D. Verschuren

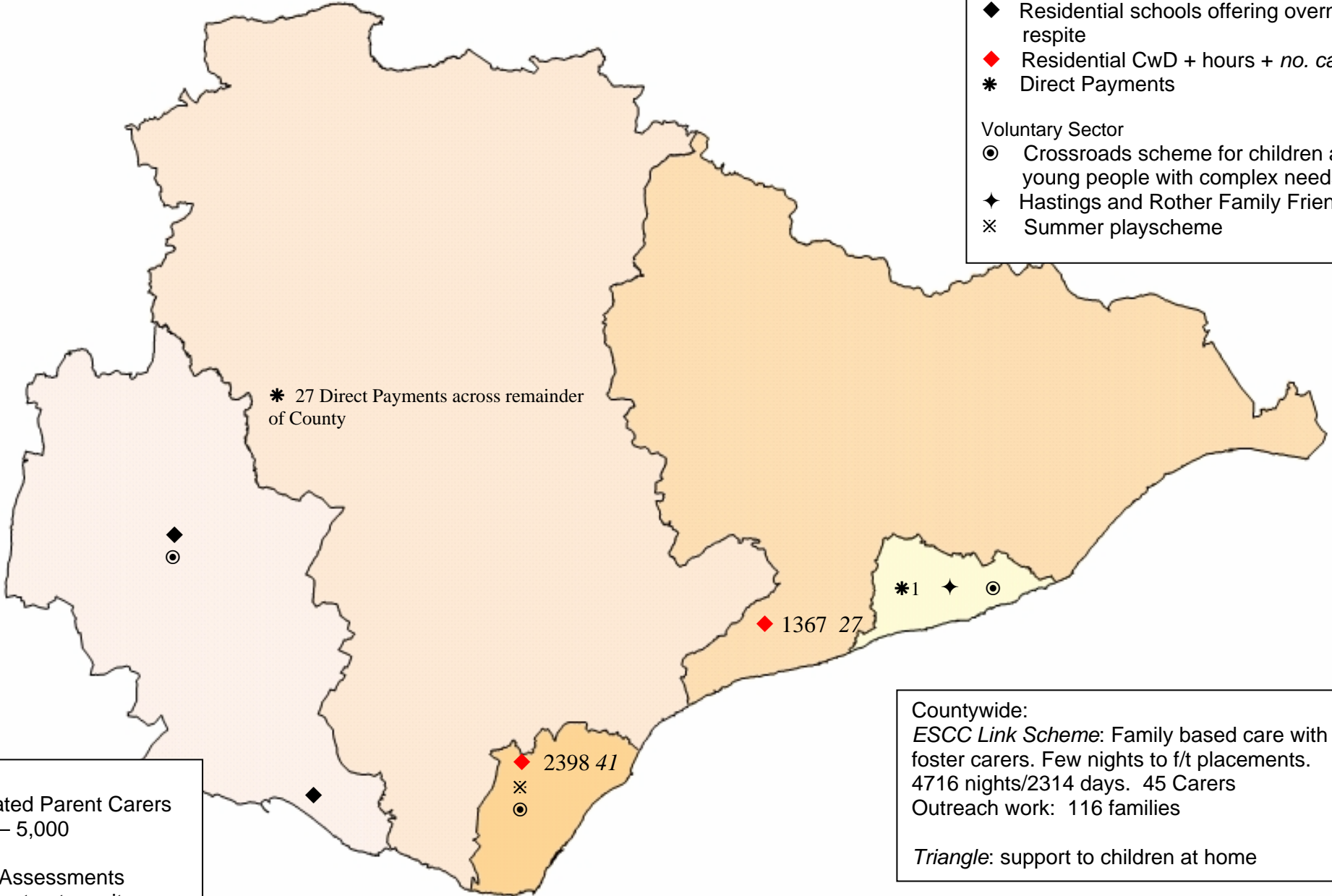




**Map 3.6: Services for Parents with a disabled child**

**Key:**  
**ESCC**  
 ◆ Residential schools offering overnight respite  
 ◆ Residential CwD + hours + *no. carers*  
 \* Direct Payments

**Voluntary Sector**  
 ◎ Crossroads scheme for children and young people with complex needs  
 ◆ Hastings and Rother Family Friends  
 ✕ Summer playscheme

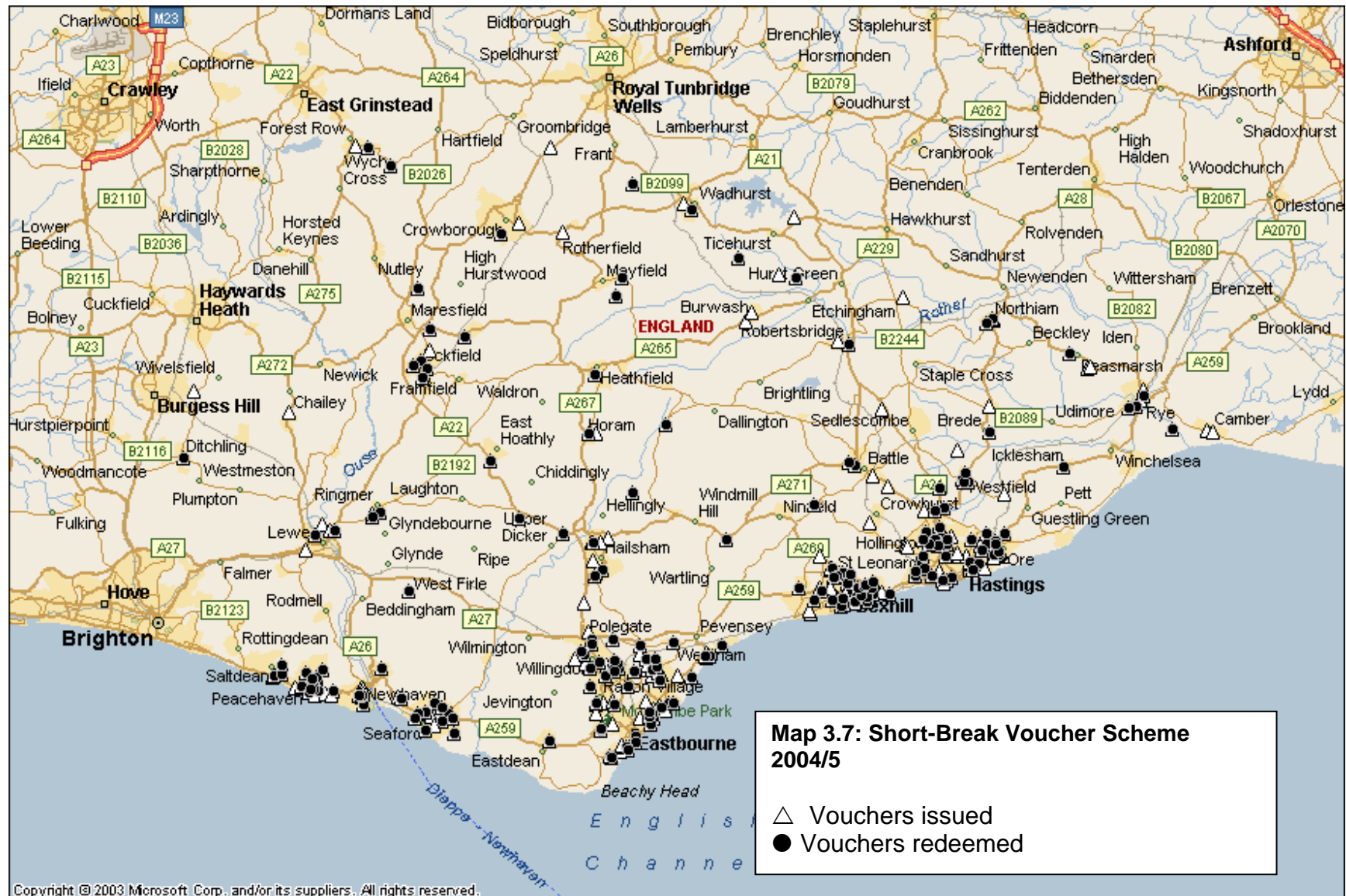


Add:  
 Estimated Parent Carers  
 4,000 – 5,000

Carer Assessments  
 Spot contract respite

Countywide:  
*ESCC Link Scheme:* Family based care with foster carers. Few nights to f/t placements. 4716 nights/2314 days. 45 Carers  
 Outreach work: 116 families

*Triangle:* support to children at home



## 4. Results from the Questionnaire and Interviews

### Key Points:

#### Carers

- Carers stated that they were not able to access information and as a result were probably missing out on services.
- 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.
- 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.
- There is a particular problem when carers feel that their caring roles are not being acknowledged by professionals.
- 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.
- For some carers there were unacceptable delays in getting help, either from Social Services or from voluntary agencies.
- In many cases carers in receipt of services from Crossroads found this particular type of help very useful.
- Carers found that when they did receive services they were sometimes inappropriate for the person they cared for.
- Carers of people with functional mental health illness faced particular problems as the need for assistance was episodic.
- 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.
- Carers wanted more help to assist them in maintaining both their role as a carer and their work.
- 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.

- Carers wanted ad hoc, informal, services that they could call upon when needed.

### **Voluntary Organisations**

- 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.
- Voluntary organisations would function better with secure long-term funding and full cost recovery.
- More out of hours services and services for short term respite are required. A reliable service appears to be limited
- 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.
- Carers' assessments should be universally available.

## 4.1 Introduction

This section comprises the primary research from the findings of a short questionnaire and follow-up interviews covering two hundred and fifty seven carers, as well as the results from a set of four questions sent out to the care agencies. A further section follows detailing the discussions of three focus groups with twenty carers looking after children and adults with a range of physical and mental health needs.

The section covering the response from the questionnaire is, by its nature, rather negative as the questions were designed to elicit information from carers about the services they wanted rather than attempting to discover levels of satisfaction with their current services.

## 4.2 Methodology

A questionnaire was designed to reach as many carers as possible who were not attached to the main carer agencies. The purpose of the questionnaire was to find out what services carers were using, how they found out about the services, if the services they received were sufficient, if they wanted any different types of services and if so, what kind of services they did require.

The questionnaire was designed to cover two sides of an A4 sheet using number 16 font. Black ink on yellow paper was used for the questionnaire as research has indicated that people are more likely to respond to this colour (Paterson and Tinker, 1940). The questionnaire design comprised 5 sets of straightforward questions as shown below, requiring mainly tick box answers:

Where do you get information on caring?  
Which of the following services do you receive?  
How much help do you receive from social services or other agencies?  
Are these services adequate for your needs?  
Which services would you like to receive that you do not already get?

The questionnaire also collected personal information on the gender and age of the respondent and of the person for whom they were caring. A full copy of the questionnaire is available in Appendix 2.

The questionnaire was distributed in various ways:

- A total of 2,500 questionnaires were distributed via GP surgeries, through voluntary organisations such as Care for the Carers and Crossroads and a number of other smaller groups.
- Advertisements were placed in the larger newspapers requesting that people telephone a dedicated line leaving their names and telephone numbers. These people were later telephoned back and taken through the questionnaire.

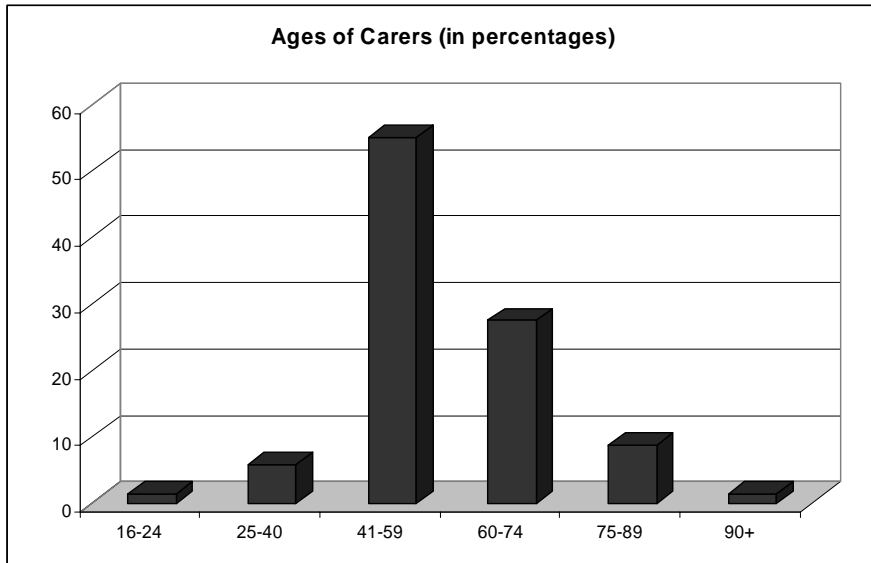
- An electronic version of the advertisement was put out on the websites of East Sussex Social Services, the PCTs and the University of Brighton inviting people to email a response to a dedicated email address and electronic versions of the questionnaire were sent out on request.
- A copy of the advertisement was included in Care for the Carers 'CareLine' magazine asking people to call the dedicated telephone number at the University of Brighton. These people were later telephoned back and taken through the questionnaire.
- A space at the end of the questionnaire gave people the option of supplying contact details for more in-depth telephone interviews. A total of 30 people were contacted and the results have been included in the following section.

The cut off date for the questionnaire was set for the end of November 2005, by which time a total return of 257 (10.28%) had been recorded. This low return was not unexpected and has not affected the findings overall as the questionnaire was only one of the research tools deployed. As the information below shows, the findings are mostly consistent with those of the census, other research and the findings from the focus groups.

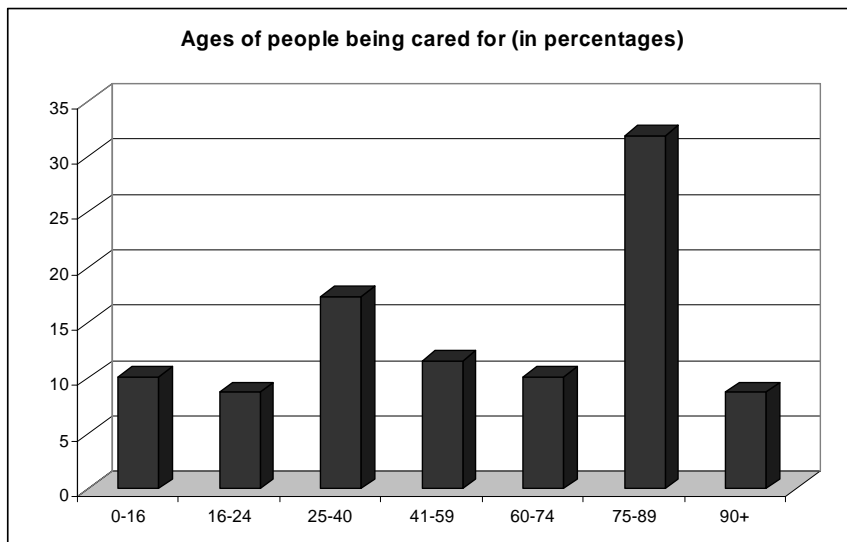
### **4.3 Characteristics of the carers**

The majority of the carers who responded to the survey were female (71.8%) as compared with male respondents (27.8%). This corresponds with national figures from the 2001 census which revealed that the majority of carers nationally were women. The largest group of carers fell into the age group 41-59 (33.3%, n=85) , as shown in Figure 4.1 below, analogous with the census data from 2001 which showed that the peak age for caring is between 50-59. However, it should be noted that a large number of older carers aged between 60 and 89 also responded. Together these two age groups made up the largest number in this research (55.7%, n=142)

**Figure 4.1**  
**Age of carers**

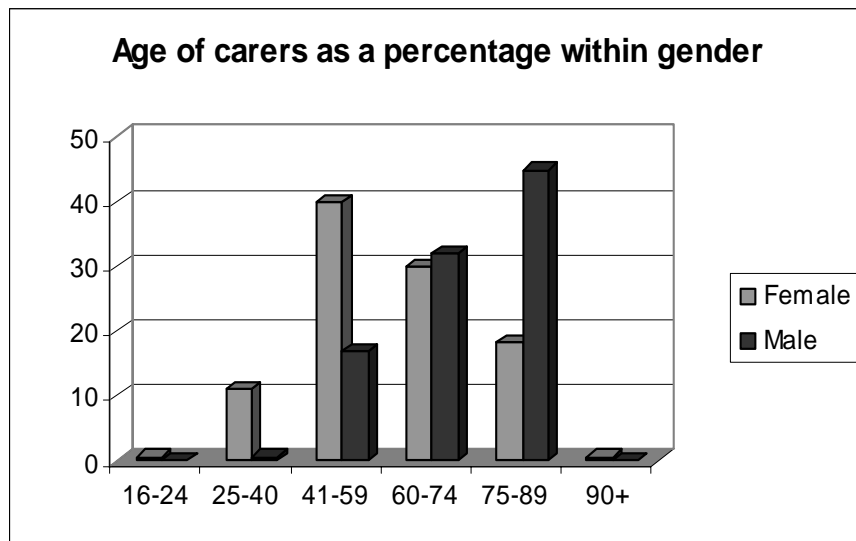


**Figure 4.2**  
**Age of people being cared for**



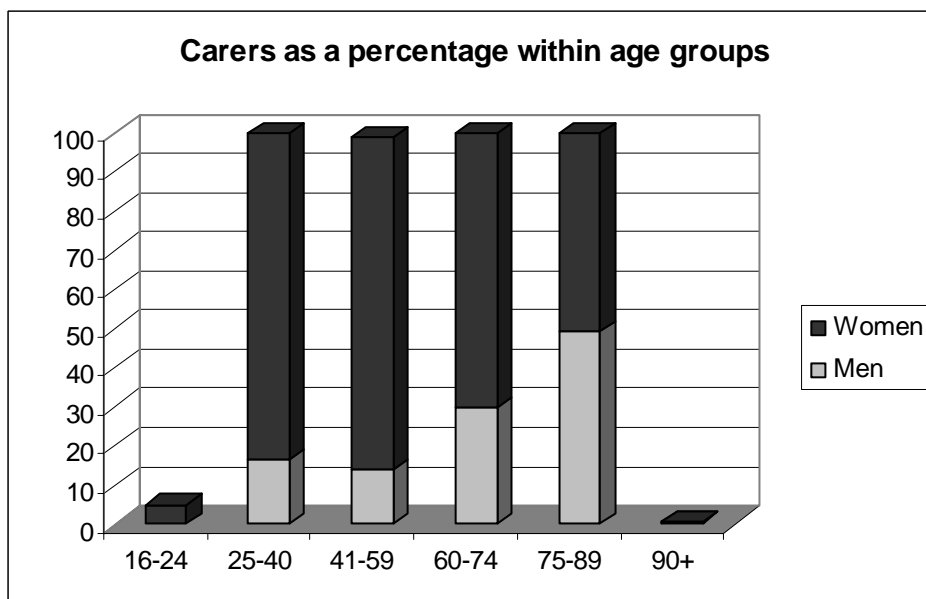
The majority of people being cared for fell within the age group 75-89 (41.2%, n=105). According to the General Household survey 70% of those cared for are 65 and over. This figure is comparable to the research sample which indicated that 64.7% of the people being cared for were aged 60 and over.

**Figure 4.3**



When looking at the ages of carers by gender, as illustrated in Figure 4.3 above, it is clear that in the older age group of 75-89 more men are carers than women, unlike the younger age group of 41-59. It is not entirely clear why this is the case. National figures indicate that older women are more likely than older men to enter residential care (23% of the population compared to 12%) and this may provide part of the explanation; this has been attributed to gender differences in marital and widowed status (Social Trends 34) but this explanation too is incomplete.

**Figure 4.4**



In comparison to Figure 4.3, Figure 4.4 above clearly showed the gendered nature of caring when looking at the percentage of carers within the particular age groups. The data would indicate that women carry out the majority of

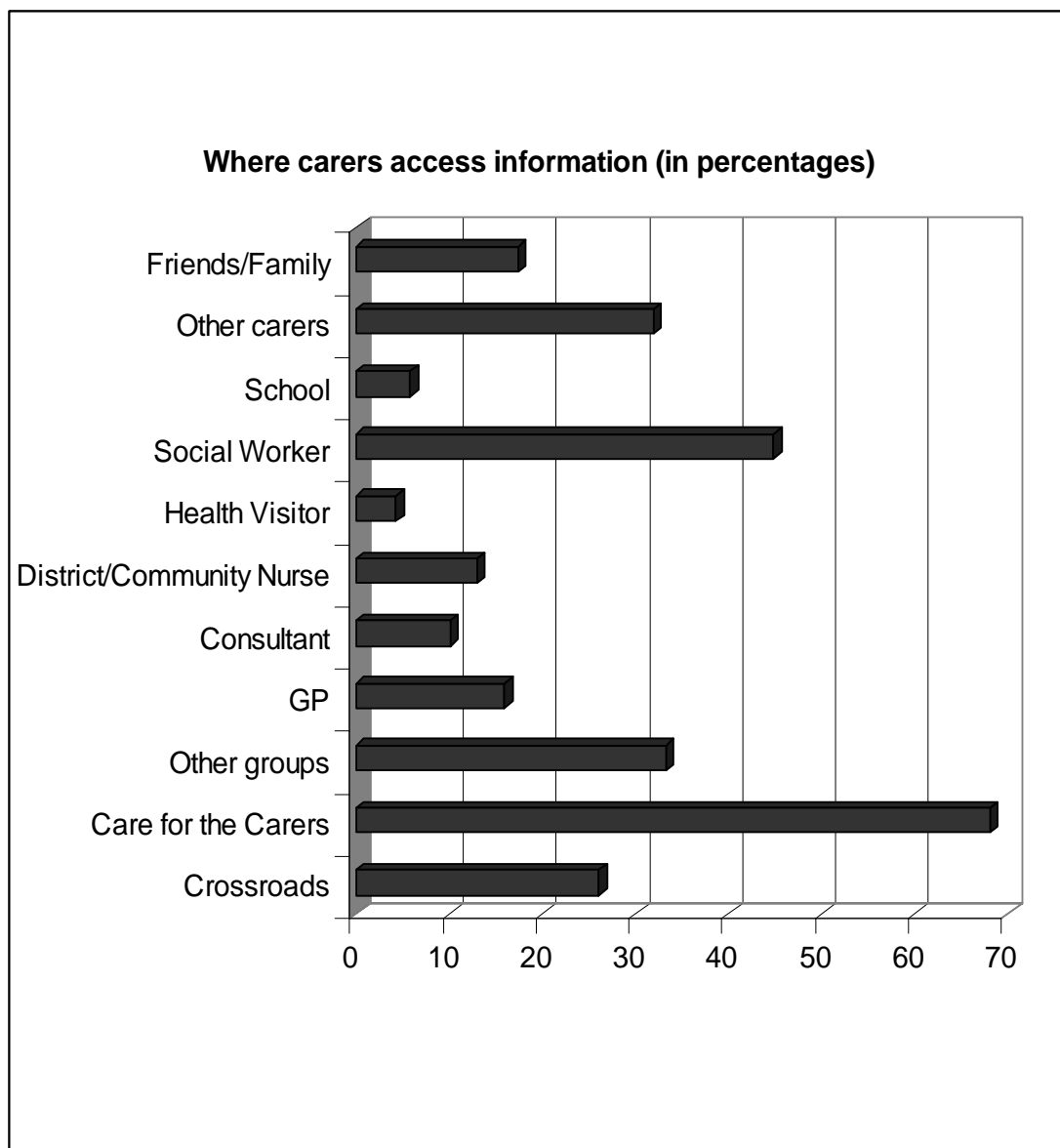


caring responsibilities over all the age groups and especially within the working age group of carers.

#### 4.4 Accessing information

Figure 4.5 shows that the majority of carers accessed the major care agencies for information or asked a social worker. A smaller number of carers went to GPs (19.2%, n=49) and an even smaller number asked consultants for information (9.8%, n=25).

Figure 4.5



However, these figures require a caveat since it would appear that 100% of the population in the research were able to access information and clearly the open ended questions and interviews revealed that this was not the case, it is therefore more than probable that those people who knew how to retrieve information were accessing it from more than one source.

It is noteworthy that a minority of people are now accessing the web for their information. This source of information will undoubtedly become more used as the computer-literate generations enter older age. Other carers specified that they had been accessing information via specialist groups associated with the condition of the person they are caring for. These groups play a vital role for carers, not only as a source for information but also as a social network for this commonly isolated section of society.

Many of the carers taking part in the research felt that they had no idea where to get information from, even those who had gone to outside agencies to seek advice felt that they did not know what was available or how to access it.

*'A support group? Counselling for me? Certainly to know what was available'*

(Female 41-49)

*'Don't know what else is available'*

(Female 16-24)

*'I should have liked to have been able to receive professional advice regarding local provision'*

(Female 41-49)

*'Advice on what services are available. Advice on equipment to make life easier'*

(Female 41-59)

*'My parents are both now in long term care, I wish someone had told me that when this happened that they would be financially assessed separately'*

(Female 41-59)

*'I would like more information automatically sent to me'*

(Female 25-40)

*'Don't know where to go to get information'*

(Female 41-59)

*People don't inform on who to inform if they are a carer*

(Female 41-59)

Although the majority of the people who participated in the in-depth interviews had heard of the main carer agencies, over half had not contacted them. One had remembered seeing notices about an agency in her doctor's surgery but

had not chosen to contact them because she did not want, as she put it, 'to join a group of people sitting around a table'. This carer had not recognised agencies as a source of information in addition to their other more social activities.

Although some carers were managing to find out what was available they felt that they needed more assistance when it came to planning for the future. This was particularly the case for when means-tested help would replace self-funding once their resources were exhausted, or when carers returned to the workplace.

*'The family would like to know what is going to happen later on when the money runs out. They need a phone number, or speak to someone face-to-face...It should be a process and not just crisis management. I don't want my mother to run out of money and then have to face a stressful caseworker looking only at a budget'*

*'I am hoping to return to work in the near future and don't know what will happen then. There doesn't seem to be good quality information around to suit this issue'*

Lack of information seemed particularly significant for those carers without any type of benefit. Carers had been asking for general information, as well as advice on which care agency was appropriate/best and felt that they were not receiving the help they required.

*'Social services have been asked to offer support in the past, but as she is financially independent she does not qualify for their help'*

A small number of respondents were experiencing specific problems related to Direct Payments, indicating a lack of information about how to access the scheme. One female respondent (aged 25-40) argued that since Social Services had been unable to find appropriate support in the last 19 years she doubted she would be able to either and was therefore not applying to receive direct payment. Another carer (aged 41-59) said that she was finding it difficult to get any information at all about Direct Payments.

## **4.5 Services used**

The questionnaire asked people about the types of statutory and/or voluntary services they used.

Figure 4.6

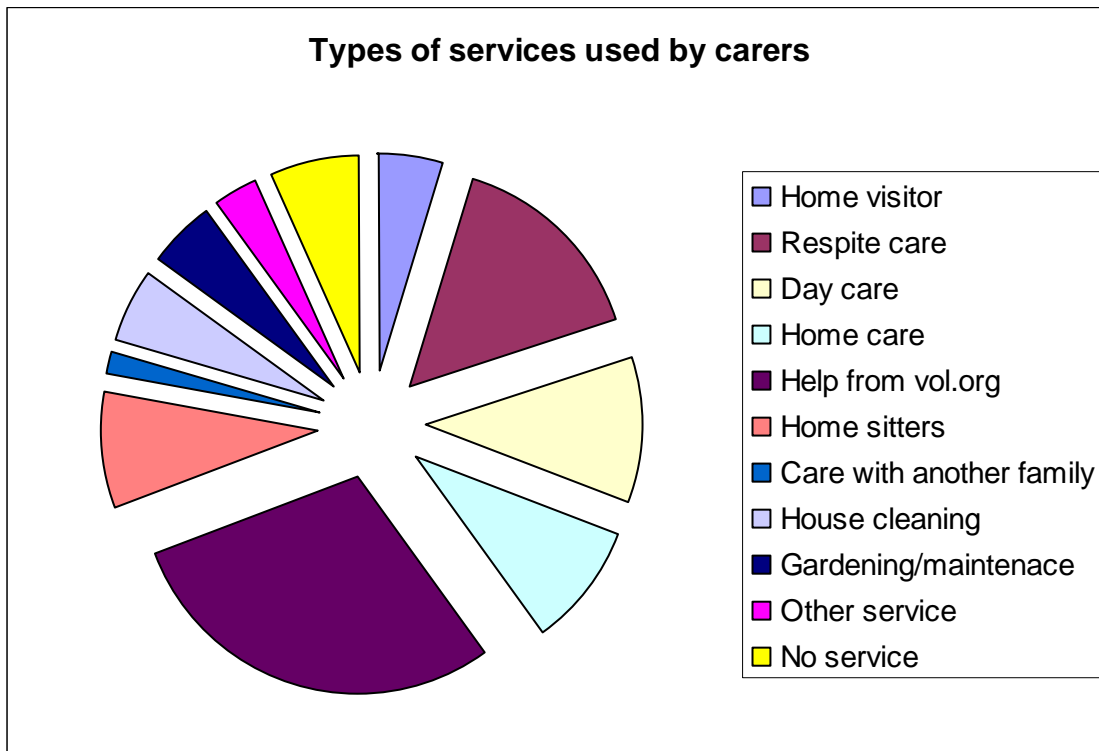


Figure 4.6 above indicates that for those carers in receipt of services there would appear to be a good mix between the statutory sector, voluntary sector and family help. As one female carer aged 41-59 said:

*'We have a good support system set up to care for my elderly mother through co-ordinating family, social services and volunteers'*

Another female carer, aged 60-74, reported that her husband attended a day centre for part of the day and a sitter from Crossroads came in the evening if she needed to go out.

The Green Paper *'Independence, Well-being and Choice'* (2005) recognises the mix in care provision as important for the future of social care, it states that *'Care and support are provided as a community and are part of the core values of our society. Where support by family and friends is not enough, it is supplemented by more formal models offered by the statutory, independent and voluntary and community sectors'* (page 25). It may be said that the Green Paper could herald a sea change in attitudes, from provision of a service for people where people have to take what is offered, to one where people are supported to make their own choices by creating individual budgets which promote independent living and certainly its ethos is in keeping with the Carers (Equal Opportunities) Act 2004. However, the Green Paper stipulates that this alteration in the way in which services are provided has to be executed within existing budgets and recommends that, in order to do this, changes take place over the next 10 to 15 years.

Figure 4.6 also indicates that day services featured as an important service for carers. One carer, relieved at someone staying the night to help, was also very pleased that the person she cared for was able to access day centre services during the day. Part of this could be that carer/parents preferred a safe option for the people they care for and this could be represented in the day centre. Although there is the requirement to provide a range of options for people using day centres the King's Fund '*Changing Days Programme*', which ran from 1995-2000, found that many services felt that a decade of budget cuts jeopardised their ability to provide individualised support. The Programme also revealed that, while the day centre culture was both busy and friendly, most of the energy went into maintaining existing routine and that it was an exception to find examples of planning which moved towards other approaches. Research suggests that current systems of day care use models and practices that are thirty years old and those people who are the most severely disabled receive the poorest service (McIntosh, 2002).

This research revealed that a significant minority of 22.4% of those receiving some form of respite were securing day care services and that carers felt that provision was too little.

*'More day centre care so that I can get out of the house'*

*'Some day care would be useful'*

Services for dementia sufferers in the Bexhill areas were, according to one carer, far short of what they should be, due to particular problems with health and safety regulations affecting admission of people with dementia to day care centres. In addition, this carer also complained that there was a general lack of information about the quality of provision for people with dementia.

Carers managing to get some day centre care had noticed that there had been a noticeable cut in services.

*'Day centre hours have suddenly been cut and respite care is getting more difficult to obtain'*

This latter remark has been partially due to respite care beds being used for intermediate care places around the county in an attempt to remove people from hospital quickly and to avoid additional costs to Social Services in the form of fine from Health. As a consequence many carers felt that they wished to have more day services and increased regular and guaranteed respite provision.

Previous research has indicated that respite care is enjoyed only by the minority (Fyvie-Gauld, 2004; Frost, 1997, 1990). This research corresponds with previous research indicating that only 30% of respondents were in receipt of respite care. Carers argued that they required increased respite provision.

*'I need more respite. I get £3,000 yearly which gives me 4-hours off every month with Everycare. I have paid for the last 6 months'*

*'More respite if possible, especially as the girls are out of school at the moment'*

*'More help would be nice, more of anything, particularly respite care would help'*

Lack of Social Services in-house provision of residential respite care has meant that people increasingly look to the private sector for respite care. Technically residential respite provision is as extensive as the numbers of beds in the private residential care market, since any bed can be used as a respite bed. In reality care homes will only offer respite provision if they do not have a full time occupant for that place. Effectively this means that even when residential respite has been reserved there is no guarantee provided that the place is secure, since at any time a long-stay occupant will take precedence over the respite provision. This highlights the tension in the private care sector between care and the need to maintain financial prudence.

Figure 4.6 indicates that there were still some carers getting no help at all (13.3%). However, it should be noted that where questionnaires were distributed via Crossroads and Care for the Cares all the respondents would have received help from those agencies. This was not the case for the general caring population and previous research supports this assertion.

For those carers with no help at all life was very difficult. One woman caring for her mother with the dual diagnosis of Parkinson's Disease and dementia found it very difficult to get care. This particular carer managed to organise an assessment for her mother but when the department called to make an appointment her mother said that she was not in need of care since her daughter was caring for her. Previous research found that carers can meet with opposition from the person they care for and this reduces access to services (Fyvie-Gauld, 2004). For this reason a carers' assessment is of critical importance to ensure that carers are receiving some form of assistance.

Another carer looking after her daughter single handed had to accompany her to all outside activities and suggested that help to take her daughter out would be useful.

Even though some carers were in receipt of services they complained that they felt invisible. Carers wanted their caring role to be recognised.

*'I feel as if I am being air-brushed out'*

This carer wanted the acknowledgement that she was her son's carer. She complained that decisions were being made about her son without her involvement or indeed without the involvement of her son, she said that she was feeling *'very angry and frustrated'*.

Another carer aged between 60-70 said that she just felt *'forgotten'*.

Legislation has emphasised the need to place the carer at the centre of provision but there is a tension between including the carer and respecting the confidentiality of the person being cared for, who also needs to be at the centre of their own care provision. The lines of what is appropriate and what is not are easily blurred at this point.

Some carers complained about the length of time it took them to get some help. One male carer aged 41-59 who was waiting to hear from Social Services said:

*'I am not very happy with them [Social Services] at all. No-one wants to know to help. Everything takes ages and I am always getting fobbed off'*

The length of time it took to receive services was echoed by some other carers. One carer had to make 32 telephone calls to get an assessment:

*'Social Services wasted a year by messing up the administration; we have gone to the panel'*

This particular carer felt that there were specific obstacles associated with severe or profound disabilities where, in this case, health and social services were still debating who was to fund the necessary support.

Problems associated with dual caring also arose for one carer who was a wheelchair user and who was caring for someone with mental health problems. While she was in receipt of assistance regarding her own caring needs she was told that there was nothing available to help her in her caring role.

Another carer had been waiting eight months, at the time of writing, to receive help from Crossroads or Social Services and said:

*'They hint at help but it takes weeks and months to get to the next stage'*

Another carer stated that getting an assessment had taken a long time and during that time her mother had been in a home where was *'very badly treated'*.

One carer had felt that, after waiting from February to June for an assessment, the only way she had achieved a result was by threatening to complain. A mother caring for her autistic son had to wait 2 years before she received help for 3-hours per week.

Carers in receipt of help from Crossroads in many cases regarded this type of help as what they wanted from an agency.

## 4.6 Inappropriate services

Although many of the respondents were in receipt of services many of them said that the services they received were not appropriate.

One female carer aged 41-49 and looking after her son felt that it was not so much a deficiency of outside help but rather a lack of appropriate care that presented a problem:

*'There seems to be nothing available'*

This was also the case for a single parent father caring for two sons with disabilities:

*'No-one is offering any help'*

Another carer, aged 75-89, caring for his wife found that most of the services offered were of no practical help and that the one that was appropriate was a course in caring which was barred to him as no care was offered for his wife.

A female carer, aged 41-59, argued that the information she had received for her son was not age appropriate in that the assistance and schemes offered were only suitable for younger children and consequently there was nothing she could find for her son's age group. This was a complaint echoed by another carer who said that the services offered to her daughter were also not age appropriate. This theme found resonance for a carer who felt that her husband was too young for respite.

One carer found that the services she wanted were not available stating:

*'We found a while ago that weekly physio [therapy] was a help in keeping X moving and his muscles in good condition, but Social Services will not pay for this'*

Previous research revealed that physiotherapy, fully accessible by people under sixty-five, becomes occupational therapy for those over sixty-five, impacting negatively on older peoples' ability to maintain a level of independence (Fyvie-Gauld, 2004). Another carer aged 75-89 also requested physiotherapy for her husband who was attending yoga for people who are physically impaired.

Having to purchase services privately was not just confined to older people. One female, aged 41-49, caring for her son with mental health problems had been told that there is a two-year waiting list for treatment and as a result had to fund the care herself at a cost of £500 per month.

Carers of people with mental health issues faced particular problems due to the fact that the intensity of their caring responsibilities may fluctuate in accordance with the needs of the person they are looking after. One carer of a person with schizophrenia argued that there was not enough appropriate



accommodation but that people with schizophrenia were *'lumped in with other people'*. This carer argued that many people with mental health issues had other problems and that, more often than not, appropriate places will not take anyone with dual problems, especially those with drug and alcohol abuse issues. Another carer argued that her needs were variable and found that at a time of crisis no help was available.

Another carer felt that the level of training for people within Social Services was insufficient for caring for people with dementia. The Forget-Me-Not Report, section 2.3, clearly recommends that agencies should provide training in mental health for home care workers and that information needs to be presented in a way that is easily understood by people and their carers. However, this particular carer stated that she always found getting help a *'battle'*, and that she was always being *'passed from department to department'*.

One carer felt that the treatment she had received from Social Services had, in the past, been most unhelpful. As a same sex carer she was not accorded the same rights as she would have been in a traditional relationship, in that she was not listened to and in some cases pathologised as the problem for the person she cared for.

Carers UK (2003) addresses this particular problem, arguing that prejudice and lack of legal recognition means that same sex carers face additional barriers. In this case the carer faced discrimination and was blamed for the condition of her partner. However, the Disability Discrimination Act (2004) has, in this case, greatly helped and she now feels far more listened to and included.

Care UK (2003) argued that many professionals evidence a complete lack of understanding of same sex carers through their treatment and their failure to try and understand. *'Back in the Closet'* in Community Care (2002) suggested that homophobia by service staff can create feelings of depression and suicide in users. Lack of recognition of same-sex couples will have changed by December 2005 with the introduction of the Government's *'Civil Partnerships, legal recognition of same-sex couples'* (HM, 2005) when same sex couples will have to be treated in exactly the same way as heterosexual couples. The document argues that *'there have been many anecdotal cases of same-sex partners being excluded from consultation, access to information and even denied the right to visit a critically ill partner where there is no basis for doing so'* (page 21).

Hopefully, as a result of this legislation, awareness among health and social care staff will increase and they will be encouraged to treat same-sex couples in the same way as heterosexual couples.

## 4.7 Working carers

It has long been a government objective to encourage and enable carers to remain in, or go back to, work (SSI, 1999). Indeed, a central tenet of the Carers (Equal Opportunities) Act 2004 is to assist carers to take up work, education and training opportunities by placing a duty upon the local authority to take work or study arrangements into account when carrying out assessment. The vast majority of carers nationally are of working age (Census 2001) and approximately three million carers already combine work and care. Recent research undertaken by Carers UK indicated that one in three carers not working wanted to return to work but only if the right alternative carer was available (Careers UK, 2004). Carers who combine work and care lose approximately £9,000 per annum through taking on caring responsibilities (Clements, 2005).

Those carers who also work sometimes find it a bonus, or as one career argued, '*Work is my sanity*'. This supports earlier research that suggests enabling carers to work helps them overcome feelings of isolation, as well as providing additional income (Salvage, 1995). However, carers who work require help during the hours when they are not at home. The majority of working carers wanted someone to go into their home and check up on the person they were caring for and perhaps give them some lunch.

One carer felt that at present not enough help was provided for people who work and argued that in order to continue working they required additional help to enable them to operate in both roles.

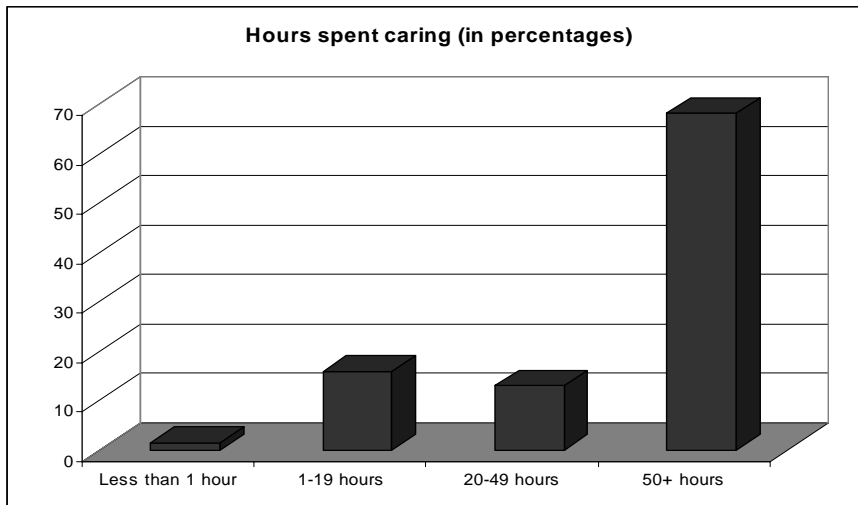
Another carer was forced to leave work as she could not leave her mother at home alone. When her mother died she was left feeling that there should also be support for ex-carers. According to research, undertaken by Careers UK, six out of ten carers have had to give up work and therefore found themselves financially far worse off (Carers UK, 2004).

It would make economic sense to support working carers. Future work predictions indicate that an extra two million people will be needed in the working population, at the same time there will be an increase in the demand for carers for the aging population (Cares UK, 2004). A further problem for carers and the treasury, due to the workforce of carers still being very much gendered and with women still earning less than men, is the impact of ex-carers in later years. Without support to remain in the workplace ex-carers who have been forced to quit work in order to maintain their caring responsibilities will become another group of women living in poverty and reliant on state benefits.

## 4.8 Caring duties

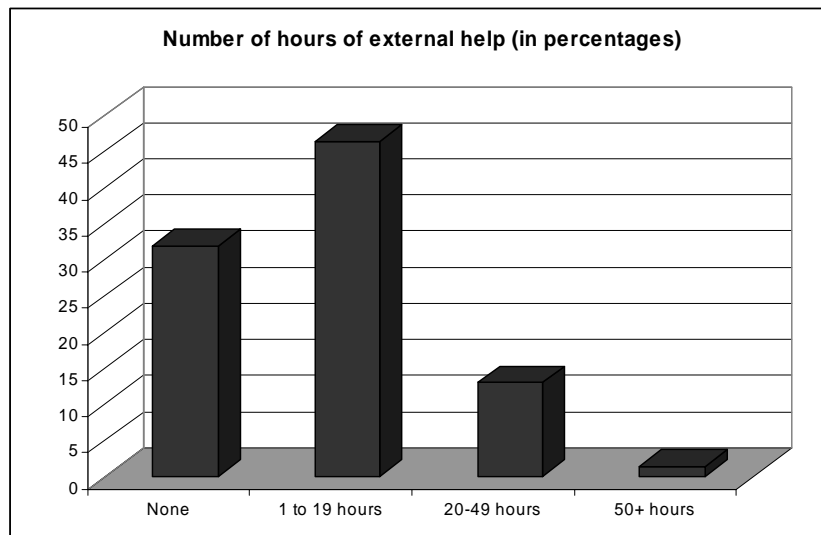
The research questioned how many hours people spent in caring responsibilities as well as determining how much outside help they received.

**Figure 4.7**  
**Hours spent caring**



Figures 4.7 and 4.8 reveal how many hours carers spent on their caring duties per week and how many hours of external help they were receiving. There would appear to be a negative correlation between the carers caring for 50+ hours per week and the amount of external assistance they receive.

**Figure 4.8**  
**Number of hours of external help**



The research found that there was a statistical significance between the number of hours caring and the hours of outside help received ( $p = >0.035$ ). The majority of carers caring in excess of 50 hours per week were in receipt of some form of outside help. The majority (87.5%) received between 1-19 hours of help and 75% received 20-49 hours of outside help per week. There

was though a significant minority of carers (45.5%) who received no form of outside help at all.

#### **4.8.1 Gaps in services**

For some, service provision had gaps that needed filling. One carer identified missing services in terms of adapting a house to accommodate disabilities. A number of carers wanted an out of hours services or somewhere to call in an emergency. For one older carer this was more of a necessity since her own health was deteriorating.

Other carers identified the lack of continuity in external help, with one carer arguing that:

*'It's a waste of time teaching people. What do you do when they don't come again?'*

#### **Bathing services**

Many of the carers wanted help with bathing and personal care.

*'Home help with bathing'*

*'More help bathing'*

*'Help with personal care'*

According to one carer the bathing service in East Sussex has been cut. This particular service was carried out by an NHS nurse and so gave the opportunity for them to medically check the person being bathed, ask about their general health and make timely suggestions about visits to the GP, and as such acted as a bathing and a preventative service. In this particular case the reason why the service had been removed was directly due to the use of a care agency. The carer was told that the bath had to be fitted in during the agency time of 1 hour per day between Monday and Thursday. Since the nurse had taken approximately 45 minutes to bath the person there was therefore very little time for the agency staff to prepare lunch, which was the primary reason for the care agency to be there in the first place. As a result the carer informed the researcher that this person had just received her first bath in two months. Worryingly, lack of training also featured in this case as care staff suggested that this person should use the towel rail to help herself out of the bath. The towel rail was heated and so agency staff lagged it with towels. Not only did this make holding the rail problematic and extremely unsafe but in the event the towel rail could not withstand the pressure and came off the wall, necessitating the services of an emergency plumber.

Other carers felt that they could manage the bathing problems but only with help from Social Services to alter their bathrooms into wet rooms. A few carers had already had their bathrooms altered and this was very much appreciated.

### **Flexible help**

Many of the carers responding to the research said that they needed flexible assistance, someone to sit with the person they cared for, someone to stay the night and give them a break. The Carers (Equal Opportunities) Act 2004 addresses exactly this point, enshrining in law the right of carers to have a life similar to people without the same caring duties.

*'It would be nice to have one evening a week and a lay-in once in a while'*

*'Someone to stay with my mother if I have a day away'*

*'An occasional sitter in the evenings or weekend so that Mum and Dad could spend time together'*

*'I would just like to have one whole day off each week, 24-hours'*

There is a need for more flexible care in the home to help avoid having to send people into residential care.

*'I would like to have the odd night out when something special or out of the blue happens'*

For some carers residential respite care is not an option

*'A live-in carer for my mother whilst my husband and I have a holiday as my mother is too ill and frail to be moved'*.

### **Gardening, maintenance and cleaning**

A number of carers wanted help with gardening and maintenance, not only because they wanted to spend time with the people they care for but also because, as they were older, this kind of help allowed them to remain in their own homes.

Many carers (mostly men) wanted help with cleaning the home. This type of service, aimed at the lighter end of help, has been shown to be very effective in maintaining people within their homes and thus reduce the burden on Social Services to find appropriate residential care, which is both against the principles of the law as it stands and the feelings of carers themselves.

## **4.9 Results from the carer agencies questionnaire**

In November 2005 a short questionnaire was distributed to the fifteen members of the East Sussex Carers Development Group and five replies were received. There were four questions, asking for their views, as organisations, on services for carers, on carers' needs and the priorities for the County Council in the next five years. The key findings are summarised below.

**What does your organisation feel is good about services for carers provided in East Sussex?**

- Voluntary organisations fill a huge gap
- Responsive and 'closer' to the user
- Voluntary organisations serve all ages and have no artificial boundaries as with ESCC
- ESCC now recognise the need to support Carers at an early stage
- Higher profile now for carers and their needs
- Specific respite fund and specific service for carers of people with mental health needs
- Funding by ESCC of a variety of organisations
- Direct Payments scheme

**What does your organisation feel is not so good about services for carers provided in East Sussex?**

- Carers placed in services for older people
- ESCC might recognise the problem but still fail to act in time
- In theory carers have services, i.e. on paper, in practice reality is very different
- Barrier of boundary of health and social services
- Problems of age transition especially around 16-18 years, mental health services by CAMHS stop at 16
- No services for carers of children with ADHD
- Patchy coverage by voluntary sector
- Variation in non-specific services carers can access
- ESCC always strapped for cash – prevents proper needs-led development
- Carers Assessments are hugely problematic
- Lack of long term funding for voluntary sector means planning is very difficult
- Statutory sector too slow to respond
- Direct Payments a mixed blessing, because of responsibility of employing someone
- Often have to wait and it is more difficult to obtain support in rural areas

**What are the main issues for you as organisations working with and for carers?**

- Identifying hidden carers
- No information route for carers that is easy and accessible
- Carers not seeking support early enough
- Support is flexible
- Users need confidence in service
- Secure, long-term funding
- Better communication between health and social services

- Confidentiality re: mental health service users being used as a barrier to avoid engaging with carers
- Carers not being properly signposted to us
- When mental health service user fails to engage with service, seems to be interpreted as reason to discontinue service, despite pleas from Carers
- Carers assessments not being offered as standard and often given to carers to self-complete, and without appropriate guidance on services available.
- Signposting for special needs

**What do you think should be the priorities for ESCC in next 5 years?**

- More research on numbers of carers in community, their caring needs
- More help to encourage them to seek support at an early stage
- Health and Social Services should streamline services
- One Stop Shop, well advertised and conveniently placed in the county
- Development of 'Out of Hours' service to provide short term respite at home during weekends and evenings
- Carers are assessed and funded separately from community care for service user
- Cost-benefit recognition i.e. cost of supporting someone caring for someone in the home saves money in terms of care in hospital/care homes
- Improvements in transitional care between children and adult services
- Improved assessment and response time
- Choice of services
- Recognition of contribution from voluntary sector in terms of extra funds raised and volunteer time
- Full cost recovery
- Universal application of carers assessments
- Involving carers in CPA and discharge assessments
- Providing respite appropriate to needs and outside the 10am-3pm time period





## 5. Focus group analysis

### Key Points:

- Currently carers are getting information more from other carers rather than from Social services who they perceive as gatekeepers to services.
- 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.
- 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.
- A rapid turnover of staff is especially problematic for people with mental health problems.
- There was a struggle to get assessment, especially for people caring for someone with mental health problems.
- 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.
- Lack of training for assessors was considered detrimental to the assessment process.
- Respondents approved of the Crossroads Playscheme and felt that the care agencies were doing a good job disseminating information.
- Respite provision in the holidays was fragmented and the quality and appropriateness of the care was sometimes questionable.
- There would appear to be a lack of facilities for people with mental health problems.

## 5.1 The groups

This analysis is of discussions with carers held 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.

## 5.2 Methodology

One of the best ways to encourage people to talk about a subject such as the services they receive as a carer is to use focus group methodology. Focus groups are a qualitative research tool often used to bridge gaps between professionals and service users, or customers, who are unused or reluctant to discuss complex or sensitive subjects (Kocher 1998, Kocher & Williamson 1996, Kitzinger 1996). The groups should not be large, no more than eight people, and are best when they are held in a neutral and convenient environment. In the event, each of the groups was small and because the participants came from all over the county, three of the groups were held in the Eastbourne area.

A topic guide was devised (see Appendix 2) so that the researcher could facilitate a discussion about the participants' ideas for carer support in East Sussex. A funnel technique was used so that the discussion focussed on the carers' own situation before the discussion turned to more general ideas around support for carers in East Sussex.

## 5.3 Information

There were strong reactions to the question related to sources of information about services for carers and the people they care for; the immediate response from parent carers was that they got information from *“other parents.”* They thought that agencies such as Social Services were *“reluctant to share [information] about the services out there, because if you know about them, they might have to provide them.”*

There was consensus when one parent carer said, *“I mean, I think that on occasions the information thing can be a bit of a red herring, because when you ask people whether they get good information about services, you need to have the services there, [...] If the services aren't in place then you think information is important, but actually the key thing is the service provision in the first place.”* They all agreed with this and another said *“And that's why the information from parents is more useful, because they usually know what services are up and running, and accessible.”* [Nods of agreement.] From the parent carers' perspective they thought initial contacts were more often than not from national charities & organisations, London hospitals and so on, rather

than from the local area. There was a comment about the 'need to know' that summed it up for the majority. *"You don't know you need to know it, until somebody tells you about it. You keep saying, what services are there, and they say, well what do you want, and you say, well I don't know until I know what's there.... To me it seems to go around in a big circle."*

One parent carer participant found Care for the Carers (CftCs) quite helpful and they spoke with warmth about the Scott Unit (the Children's Outpatients unit) but they did not like the changes in staffing arrangements. *"There have been some ridiculous changes just recently..... for some reason the health authority has decided to move [community nurses] to Avenue House which is where nobody ever goes, so they are not actually in the Scott Unit anymore supporting families in there."* Avenue House was not somewhere, they agreed, that anyone would pop into.

For carers of older people finding out about services, either for themselves or the person they cared for, depended a great deal on how that person became ill or frail; for a carer of a stroke victim the hospital had been a good source of information. But if the frailty is more gradual then the consensus in the group was that, at first, you do not recognise that you are carer so you don't go out to find help/services. They all agreed when one carer said, *"even if you know you are a carer, you don't know where to start."*

They felt that Care for the Carers and other voluntary organisations did a good job with regard to informing people. However, one carer felt strongly that; *"Carers are just fed with red tape and being pushed from one information point to another, nobody ever actually giving anything constructive and being told it's not our remit, or it's not our job[...] what carers want is a one stop shop where they can go in and they can be pointed to and be told where they can access an information service and how they can get help."*

A number of carers spoke about getting leaflets from Social Services and finding them useless.

## **5.4 Information versus confidentiality**

The majority of carers agreed that they got the best information from other carers but that the GP should *"know about these things."* However, the patient's right to confidentiality was a big issue for many of the carer participants. A carer of an older person spoke of a GP withholding information from him about his mother, *"And even when the GP might know that there is a caring relationship there, because of the GP's relationship with patient the carer is outside that relationship and there is no way that the carer can even talk to the GP and the chances of getting anything constructive out of that GP is absolutely zilch"*

The issue of confidentiality was a huge one for carers of people with mental health problems; a frequent and recurring theme for these carers was that *"....when somebody goes into hospital for the first time, the first few days*

*there is no communication with the carer at all on the basis that they are not allowed to talk [to the carer] because of patient confidentiality. And you get little bits of often contradicting information or information that is not meaty with no clear instructions about this will happen and that will happen and this and that's how it will proceed; it's all very woolly and general. And then it's pot luck which Team you get when the person is discharged whether you get good communication after that."*

For a fulltime working carer there was a distinct and marked change in the attitude of professionals when her child became 18 years old; she had plenty of help when he was deemed a 'child' *"...when he was under 18 it was automatic you were given information, you know, you were the parent therefore you were given information. As soon as he turned 18 it was no longer automatic and it became, if my child said I could have information I got information, which is extremely difficult to deal with [...] in fact, that issue about information has become critical and difficult."*

One carer whose son had mental health problems had had a good experience with services and the staff. But she felt that this was because she was, until quite recently, a nurse working for the same Trust. She was angry on behalf of the others, *"... it all sounds terribly unfair but I've often wondered if it happens to somebody who hasn't got pulling power, experience, or knowing what questions to ask, do you know what I mean. You see people, have treated me with respect and answered my questions... And it shouldn't be like that."*

## **5.5 The Carer Assessment**

Six out of the twenty participants had had a Carers Assessment. In each one of the focus groups all the carers described very similar experiences; it was a struggle to get a Carers Assessment.

Carers of people with mental health problems found it particularly hard to get an Assessment in their own right; one had had one a long time ago *"...but since then, no, and I've been asking for one and even my own doctor has asked and we get nowhere."* Another carer said, *"We've been asking for one for 4 years.....we've asked in various places and thrown it back at the Rothermay [ward at EDGH], quite often because we're not knowing where to ask for one."*

One described their 'fight' to get an assessment. *"We had to fight, just verbally fight, make yourself a complete nuisance, totally. We were never approached by Social Services, the Carers Assessment was done by the Outreach Team. We have had no contact at all with Social Services...no formal contact with Social Services as such it's always been through Rothermay [ward at EDGH], the hospital or the Outreach Team."*

One carer in this group spoke of the long negotiations she had before she got an Assessment (see over page) and a recurring theme through this

## Case study of one carer's negotiation to have a Carers Assessment

Over a year as the cared for (a child) became ill the carer also became ill, so much so that their job was under threat. The carer phoned Social Services but was put through to various departments. *I then spoke with Care for the Carers who did a 'core referral;' the core referral came back, no further action."*

The carer spoke to the psychiatrist at CAMS who did a referral [to Social Services] and *"it came back with a few more words but basically no further action."* At this point the carer went to the organisation Rethink, talked to Social Services Complaints and the local MP, all simultaneously.

*" .... Eventually after numerous letters, they decide OK, you can have an assessment, but they couldn't decide who should do it, because we are in the Transition stage of 16, so Social Services Children's aren't particularly bothered about taking someone that's going to come out of their services, and Adults doesn't want X yet, Disability didn't want X because they didn't deem X disabled, but because X was receiving DLA, the fact that X is stated, and all these things doesn't count as a disability. So eventually they sent me out someone from Children's to do an assessment but it wasn't a Carers Assessment".*

It became clear to the carer that people were not aware of the Carers Assessment. The carer wrote more letters asking for a Carers Assessment; one to a senior Social Services officer. Finally, after a lot of negotiation the carer was able to have one but it still took time to get an outcome.

*. "I took X from Care for the Carers with me, and we had this Carers Assessment, but it's the first time Children's Services in.... had done one, hadn't got a clue what they're supposed to do, there wasn't the extra back-page bit that said, you know, the outcomes bit. So, you know, had this done, and then nothing. So, I went back to kicking up the fuss and everything, and eventually they decide which department to move me on to, and they moved me on to Children and Families, and they allocated me a [pause] Social Worker, and that was the outcome."*

The carer is happy with the social worker, *" he is working with us and he will help me with practical things as well, and he's looking at doing some, meeting with X and doing some things which will help with his independence which was the bit that I was trying to get in the first place. So things are starting to move but the wodge of paperwork that I've got, and I'm not that sort of paperwork kind of person at all. "*

The carer also pointed out that having once been in the system as a [paid] carer *"I knew how to speak the language and talk to people ..but without knowing all of that you are absolutely lost."*

## 5.5 (continued)

discussion was that people were not aware of what they were entitled to as carers and that "...[we] find out about Carers Assessments almost by accident."

The two working carers had both had an assessment but had not had much in the way of an outcome. One said, "well, you get told respite care is a jolly good idea but again you have to, but they've closed one of the homes, which means there's fewer beds to go round, so therefore it's not easy to get in, and when they've got special needs like bed raisers, oh, we haven't got the room free that's got the bed raiser.... spontaneity would be good.... it would be nice to not plan 4-6, 12 months in advance" When asked what she actually got "err, nothing."

The other carer has had an assessment some time ago: she was offered a support group, "...other than that, I can't say that there was much in the way of what I would have needed in the way of support, it's not there, not for X's .category of caring."

The parent carers had strong views about the Carer Assessment; the consensus was why have one if nothing changes.

*M: There's no obligation to provide services*

*Facilitator: No, no, they have to take into consideration certain things from April this year, including your work and leisure opportunities.*

*F: I saw that in Careline and I just laughed like a drain, when I saw that about work opportunities.*

*F: When I asked for my assessment, which I did as soon as I knew that they were available. I had it done, they were quite reluctant to do it and when they finished it, they actually said that nothing would come of it. They couldn't see why it was being done because it would just be put in a drawer and forgotten about, which is what happened.*

*F: The thing around children is they just look at the needs of the child, they don't, I don't think they really truly look at the need of the family or the parent when you're talking about children.*

There was also a strong consensus in this group that the Carer Assessment was an intrusive and somewhat unpleasant experience to go through.

*M: Well, I've got a bit of a thing about having to be assessed to get a break in care, I think in a way. You see most people get a break in care because they can ask a grandparent, they can ask a childcare provider to provide them with a break in care. Now, in a sense I think we should have that right to able to have breaks in care that everybody else has without the need to be assessed.*

*F: Because when somebody goes to a childcare provider, like, who hasn't got a child with disabilities, they don't say 'do you deserve this break. [Nods of agreement.]*

*Facilitator: So a Carers Assessment is a real turn-off?*

*M: Well, certainly, because there are no services attached to it, usually, then I certainly wouldn't bother (yeses, nods) you know it really isn't worth it*

They were asked how Social Services should offer an assessment to make it palatable, they all agreed that:

*M: I think if you know it means something (nods, yeses)*

*F: If you're going to get something.*

*M: If there are services attached to it. Or likely to be attached to it, then I think it is worth doing, but if it's a paper exercise then it is a total waste of everybody's time.*

*F: And a very intrusive paper exercise, they ask questions that just don't need to be asked. You only have to look at the children and see, well you may have difficulties.*

Older carers also spoke about the problem of getting their own needs formally assessed, “*you cannot get an assessment if you want one.*” There was also a perception that assessors are young and somewhat under-trained; these carers felt that they were training the assessors, “*you wonder who is helping who, actually, who is teaching who...?*” And they all believed that services were resource and money led rather than led by the needs of the users and carers.

### **Ideas for improvement**

- The overall consensus from participants was that they wanted one individual to assess them who was Knowledgeable, had empathy was and well trained.
- There was a strongly held view that the Carer Assessment should have meaning and an outcome; it should make a difference to their lives and not be a paper exercise.

## **5.6 Services – what they liked**

There were a few compliments about services; the parent carers universally liked, even loved, their school provision. They thought that the Crossroads Playscheme was very good, although the scheme can't deal with high medical need and there were some reservations about holiday provision which is discussed below. One parent carer liked the out of county provision for her child (paid for by Social Services but run by a charity) partly because the people looking after her child are quite young and enthusiastic and ‘*not ground down by the system and completely institutionalised by the system. It feels like X's having a break with peers and I like that. And they actually go out on outings and do stuff with the children. It's quite active.*’ Another parent carer felt that 8 hours a week Direct Payments for her child was working well; she used it to pay two young people to go out with her child for two outings a week.

One carer of a young person with a dual diagnosis of drug addiction and mental health problems (who had been a general nurse working in the same

Trust) had a good relationship with professionals and praised the help and services both she and her child had received.

As already stated, older carers felt that Care for the Carers and other voluntary organisation did a good job informing carers of their rights to assessment and services and supporting them to get these services.

## **5.7 Services – what they didn't like**

Parent carers had some very specific and explicit views on services for their children (that also gave them respite). First, holiday provision is somewhat fragmented between services and therefore can be unsettling for the child:

*F: ...you've got a child with learning difficulties that finds it hard to know about where they are going and make sense of their situation, yet they are supposed to be able to go to Crossroads one day, Social Services another day, here another day. I would like them to go to the same place, so if they are going to have Crossroads.*

*M: They need a routine.*

*F: Yes, Crossroads 3 days a week in the summer holidays, not one day here, one day there and one day, because we didn't mention Youthability and we didn't really go there because I thought it was the most dreadfully badly organised set-up [...] and how can you make sense of that if you've got a disability whether you are on the autistic spectrum or not,'*

*F: Yes, 'where am I today?'*

*F: I could hardly keep up never mind her, it's ridiculous.*

### **Ideas for improvement**

- They wondered whether different funding and/or arrangements could be organised to get over this way of providing holiday care and respite.

The parent carers also had some very strong views about the quality of care in one of the children's facilities in East Sussex

*F: Social Services, what they can provide is, well, I wouldn't take them up on their services if they offered them to me anyway, things like ..... wouldn't dream of leaving my daughter there.*

*Facilitator: Why, is it the people?*

*F: No I'm sure they're fine, but my [child] uses a communication book and things like that and they wouldn't know where to begin with anything like that, and I believe they spend quite a lot of time watching telly and doing not very much else.*

*Facilitator: So the training?*

*F: I think it's the institutionalisation that I was referring to.*



These parent carers were very aware of the limitations of provision but also were realistic about the problems of providing services for individuals; they debated whether this was possible.

*F: I think that Social Services has this idea that if they are providing for their basic needs, if they are warm and dry and relatively fed, that will do, and safe that will do, but that's not, you wouldn't do that to an able bodied child. You know for a child like mine someone's got to sit with the child.*

*F: To a certain extent it's the same for X they've got to have the materials available to ensure, X can use photos to choose from, but they've got to be very relevant, very specific, and got to be very individualised and there lies the problem, Social Services, and I think it's a difficult task, and in my opinion, is not able to focus on the individual needs of the child and neither are their services. They are services to support a group of children with disabilities and it's so hard for them to narrow it down any more than that because of the range. So therefore we always remain a little dissatisfied or a great deal dissatisfied depending on where we are at. But I do think it's quite a hard task.*

### **Ideas for improvement**

- Training in communication systems – other than Makaton
- Changes in the culture of children's facilities – move on from keeping children clean and sitting them in front of the TV
- Better communication between staff and parents

Apart from the retired nurse, there were no positive views about the support for people with mental illness or their carers. The carers spoke of the lack of support/advice/help after 5pm, at night, during weekends and on Bank Holidays. If they did get through they were usually told call the Police, which would probably get their child or partner on to a Section quicker but would also destroy trust between the parent and the child or the partner.

However, the lack of communication between staff and carers was a key and a most emotive issue for carers of people with mental health problem.

*"It's a terrible feeling of isolation, of being alone in your predicament, and we've all gone down this road.....now I feel we know more about mental health than those caring from him [in hospital] because we are the one at the front, at the cutting edge, aren't we, totally. People see him or come round for 45 minutes, we've got him 24/7 and we know how that person reacts.....we should be an integral part of any links of communication, they should listen to us, whether they take it on board or not, they should listen."*

The worker thought that, *"the slant seems to be unless the service user actually says yes, I want them involved, you automatically get barred, whereas it should be the other way round, that carers should automatically be involved unless the service user specifically says no.."*

The consensus was that for mental health professionals the therapeutic relationship is key to mental health care, where they aim to achieve trust with

the patient and this includes, *“not talking to the carer.”* The worker thought that *“this was possibly true for some people in a certain paranoid state but it is something that should be temporary and it needs to be addressed as carers now have a right to certain information which they’re not getting still. But mental health has still got this preciousness about confidentiality because of this myth about the therapeutic relationship.”*

These carers also thought the rate of staff turnover was a problem: *3-6 months and the CPN moves on. Staff are not polite, don’t say good morning or goodbye to carers on the ward, they’re very abrupt.* They agreed that staff are very overburdened, many become drained of energy and just see carers as *“trouble.”* But they also all agreed it would be so much more cost-effective not to alienate but to inform and support the carer.

## **5.8 What changes they would make – carers of people with mental health problems**

- More staff, more investment
- Support, both emotional and practical, after hours/weekends/Bank Holidays etc
- Better communication between organisations and staff especially with regard to the Carer Assessment
- Better communication between staff and carers. Bring the carer into the system from the initial onset of illness *“when someone comes to see the person who is ill, at the same time, crickey, they’re sitting in your home, make an assessment of you and what you will need to carry on looking after this person in their absence, because they haven’t got the time or the staff. We are crucial, as the carer, we are completing the health team, we are the unpaid carers.”* Another carer had been going to CAMS every 6-8 weeks since her child was 4 *“but at no point through all of that has anybody said and how are you doing and whether what services out there for you. CAMS didn’t know what I was entitled to, it’s this communication bit of them not knowing about Carers Assessments and who should do it as well. You just go and see the Consultant Psychiatrist, you know there may be other people within the system that know about these things but they’re not there.”*

### **Ideas for improvement for carers of people with mental health problems**

- Devise a ‘critical pathway’ to include the carer from the onset of illness
- Agree the role of the carer when the person cared for is well

## 5.9 What changes they would make – carers of older people

- Appropriate day care – from Monday to Friday, 9-5.30
- Appropriate overnight respite care – giving carers a proper night's rest

This group of carers thought of respite care as a “joke” and felt that “*there is no choice, it's take it or leave it, and there's no choice, and you're not even, half the time, allowed to take it because it's not there to take.*”

### Ideas for improvement for carers of older people

- Professionals that listen and respond to the carer
- A decent assessment of both user and carer
- East Sussex to use good practice and fresh ideas from outside the county

## 5.10 What changes they would make – parent carers of children and adults

- Family Link has very long waiting list and is limited as it cannot be used if equipment is needed or the child is over a certain weight. Families are, they reported, not supported and do not get much, or very little, training
- Young adults need more support during their work placements and help/training to live in the community
- Help with transport – one carer of a 20 year old has to drive her child everywhere. She is also training X to go on the bus alone. She is, as she said, “*forever taking X somewhere but if X was able X would do this with mates.*”
- Benefits –they become very low when their child becomes an adult.

This group of carers were acutely aware of the problems Social Services were up against; their view was that most of the time the services were reasonable but disability costs both them and society. They were in agreement when one carer said,

*“ I think that Social Services provision is one area where they've just got to bite the bullet and accept that they've got to spend more money, because you can only do reorganisation, re-jigging things about here and there they can improve certain bits but in order to do that they've got take stuff away from something else. And most of the services that are provided on the whole are well thought of, you know, apart from reservations, but a lot of services, a lot of people who use services are happy to have them and are usually reasonably content, the issue is that there are so many people out there who don't get services and who will probably never get services and I think there are massive issues around services for Young Adults, they are incredibly under-resourced, and so I think they've really got to invest in that kind of provision and accept that disability costs money – it costs us money, it costs us a fortune and there is masses of research that show that, and local*

*authorities has to accept that and the government has to accept that , disability isn't cheap."*

The three single women wanted better after-school provision, and holiday provision so they could go to work *"I think we've already said this but just to take the issue that quite a lot of us [carers] would like to work, a bit more seriously, it should get higher on people's agendas, we are so financially impoverished, most of us."* They thought that the school buildings that are empty after school and during holidays should be used for this.

One participant is setting up after-school provision *"This could be respite for them, if they could have the after school child till 6 o'clock then they could maybe work until 4.30 and go and do their shopping and go home and get their child. And going to work is respite, it is at least different to caring..."* They debated whether this would be too costly but the participant setting up the pilot after-school provision said it would not but it was a complex model, *"But if it's done well, it shouldn't cost anybody that much money but it's very tricky and we're very dependent on the co-operation of other schools because we're setting up as a cluster – so it will only work if we do it on a partnership basis."*

They all agreed with one carer who wanted joined up funding, as in, she has health funding from Continuing Care but she would like it see it joined up with her Social Services funding so that her package could be more flexible

*"..... rather than looking at my package as a certain amount of nights here and certain amount there I'd like to look at it as a financial package and say it's say, £15,000 a year for arguments sake, Ok, so here you are £15,000, how are we going to spend it in the best way that meets her needs and I shouldn't be forced to use XX as the only local respite situation because maybe I want to buy in overnight carer to come and stay in my house, not saying I do but I just think it's not joined up enough.....it should be joined up and work together.....and not be tied up so and so specific."*

They also thought that Direct Payments had been great for some families but if in a rural area it's difficult to find [paid] carers and its also difficult if you get low hours, e.g. 11 hours a month like one participant – *"you can't find someone to do that – so that also should be more flexible - too much paper work for 11 hours a month."* They agreed that Direct Payments should therefore consist of meaningful numbers of hours; however, as already discussed, another carer felt that 8 hours a week Direct Payments for her son was working well.

### **Ideas for improvement for parent carers**

- More investment
- Respite and after-school provision that allows parents to work
- Joined up financial arrangements and packages

## 5.11 Final points

Carers were, on the whole, realistic about the problems besetting Social Services but there was a perception in one group that:

*“there is this vast swathe of management that’s issuing very impressive documents, they’ve got all the policies either in place or getting into place, they’re designing new teams, they’re doing all the things according to the latest new plans, they’re all good and say great things, but the people who are actually working, they haven’t got this information, haven’t got the training to actually implement it, and they’re not being led in a way where they are forced to implement it.”*

To sum up carers would like:

- Information at the onset of illness or disability
- A sensitively handled Carers Assessment with outcomes
- Meaningful communication with staff about the person they care for
- Respite that allows people to go out to work and have a proper rest



## 6. Findings

### 6.1 Issues from the 2001 Census

#### 6.1.1 Numbers

According to data derived from the 2001 Census, East Sussex has a total of 50,648 unpaid carers, representing 10.35% of the county's total population 492,324. Census data provides a picture of East Sussex carers, presenting information about their ages, gender, ethnicity, location and the hours they spend caring. However it does not provide information about the age or the condition of the person they care for and, while it indicates whether the carer is well or in poor health, nor does it specify the nature of the ill health.

At an area level the Census revealed that of the five districts in East Sussex Wealden has the highest number of carers at 14,040, the next highest is Lewes with 9,510 carers followed by Rother at 9,324 and Eastbourne at 8,512. The area with the lowest number of carers is Hastings at 8,471.

#### 6.1.2 Distribution

The GIS maps reveal that the caring population of East Sussex is not evenly spread throughout the county and, as expected, there are high levels of concentration in terms of carer numbers per square metre around the urban conurbations of Peacehaven, Eastbourne, Hastings and Lewes. In comparison, rural areas would appear to have few fewer carers per square metre with the exception of Buxted and Maresfield and Danehill, Fletchling and Nutley.

Eastbourne had the lowest percentage of carers out of the total population at 9.77% whereas Rother had the highest with 11.18% of carers. Eastbourne also has the lowest percentage of carers out the total carers in the county at 17% compared to Wealden which has 28% of all carers. However, Eastbourne is geographically a much smaller area and would therefore contain less carers. In addition, when looking at the GIS maps it is clear that the number of carers per square metre is higher than elsewhere so while there may be fewer carers they are all grouped together in a smaller area.

At ward level, the wards with 11% or more carers (i.e. above the county average of 10.35%) were:

- *Hastings:* Baird, Conquest, Ore, St Helens, Wishing Tree
- *Eastbourne:* Ratton
- *Lewes:* Chailey & Wivelsfield, Kingston, Newhaven Meeching & Denton, Ouse Valley & Ringmer, Peacehaven East, Seaford East, North, West, South
- *Wealden:* Alfriston, Cross in Hand/Five Ashes, East Dean, Hartfield, Healthfield East, Herstmonceaux, Ninfield, Hooe & Watling, Pevensey & Westham, Polegate North & Polegate South, Rotherfield, Uckfield Central, Willingdon

- *Rother*: Collington, Crowhurst. Eastern Rother, Kewhurst, Marsham, Old Town, Rye, St Marks, St Stephens

### **6.1.3 Intensity of caring and health**

Nationally the percentage of carers reporting ill health is greater than the average in East Sussex (11.5% against 12%). Of those carers in East Sussex caring for more than 50 hours per week 18.77% said that their health was poor against a national average of 20.7%. Census data revealed that reported ill health in the county, at 10.22%, is less than the 11.04% of the national population reporting poor health. This perhaps suggests that carers' health when they start caring is also probably better than elsewhere in the county. The percentage though hides significant areas of deprivation within the county.

What is particularly important to note in East Sussex is the number of those caring in excess of 50 hours per week which, at 9,803, is larger than the 2,428 caring for 10-49 hours per week.

The Wealden area has the largest number of carers, both as a percentage of the total number of carers in the county and carers with caring responsibilities in excess of 50 hours per week. However, the percentage of these carers suffering ill health is lower than that found in any of the other areas in East Sussex.

Although Hastings has the lowest number of carers in East Sussex it has the highest percentage of carers within the caring population providing 50 hours or more caring in a week. In addition, these carers represent the highest percentage of all carers in East Sussex reporting ill health. This corresponds with other research illustrating a causal link between ill health and position of an area on the Index of Deprivation, where Hastings position is at number 30 in comparison with Wealden's at 307.

### **6.1.4 Age**

The average age range of most carers was between 50-64, except in Hastings where it was age 25-49. This means that most carers fall within the working age category with corresponding issues of caring.

East Sussex has 12,179 carers aged 65-80, with Wealden having the largest number. There are far fewer carers aged 90+ (145 in East Sussex) but Rother, with 45, has the largest number. There are 7,247 carers aged 65 and above in the county; of these 2,064 are caring for 50+ hours per week. A quarter of these are in Wealden.

### **6.1.5 Gender**

East Sussex corresponds with the national picture of gendered caring. There were 29,643 female carers and 21,005 male carers. The area with the highest proportion of male carers was Hastings

### **6.1.6 Ethnicity**

The total numbers of carers from Black and Ethnic Minority Groups is small (2,094 including White Irish) and this may create a lack of visibility as well as a



paucity of services as a result. In comparison with the other areas Wealden has the largest number of carers from Black and Ethnic Minority Groups at 506.

## **6.2 Issues from the mapping of services and expenditure**

### **6.2.1 Difficulties in gathering data**

It has been very difficult to gather precise information on either the numbers of carers accessing services or on the exact expenditure on services for carers. Information gathering has hitherto been focused on the service users rather than the carers and there is also the issue of what counts as a service for a carer rather than a user – much of social services provision could be considered an indirect benefit or service to carers. Simply by providing somewhere for the service user to go, a form of respite is provided (both for carer and cared-for).

### **6.2.2 Social Services**

Statutory services tend to be clustered around coastal towns, particularly the larger ones of Hastings and Eastbourne. Other services are located around the smaller towns such as Lewes, Hailsham and Crowborough. There are hardly any services in the rural areas of Rother and Wealden, and the latter is the district with the highest number of carers. Wealden also has a quarter of the carers in the county who are caring for 50+ hours per week.

Many statutory services run well below 100% occupancy. From information discussed elsewhere in this report it appears that this could be due to a range of factors, including lack of information, location of services, lack of carer's assessment and inappropriate provision. It cannot be assumed that low occupancy means the demand is not there.

It is difficult to draw any firm conclusions about the financial contribution of East Sussex County Council Social Services to carers' services as much is either invisible or indirect. The Carers Grant allocation of £1.2m is the most identifiable source of funding, although identifying exactly how this was spent on carer services was not completely possible.

#### **i) Gaps in services provision to carers**

The number of carers receiving a statutory or voluntary service set against the total number of carers, especially those caring 20+ hours per week, is very small. Of course there is the unknown quantity of those who use the independent sector. However, it seems likely that there is a gap, and possibly a large gap, between potential need and actual provision. Without further information there is little more that can be concluded, other than the points made below under service user type.

#### **ii) Carer Assessments**

There were 922 Carer Assessments completed for 2004/5 and for the year April – December 2005 the figure had risen to 1,011. At the time of writing, there were no national figures to use as a point of comparison nor any clear picture of

the distribution of these assessments and the characteristics of carer and cared-for.

### **iii) Short-break Voucher Scheme**

The Short-break Voucher Scheme usage shows a strong clustering around the coastal towns. Hastings had the largest amount issued and Eastbourne had the lowest percentage redeemed.

### **iv) Services according to user type**

- **Older people**

For older people important services, such as residential respite, are grouped in pairs at Robertsbridge, Hastings, Seaford, with one in Bexhill. There is no residential respite in Wealden for this group.

- **Learning disabilities**

For people with learning disabilities – and thus indirectly their carers - most provision is in and around Hastings, with virtually none in the rural hinterland. There is more provision in Wealden for this group and little in Lewes and Eastbourne. Some provision is taken up by out of county placements.

- **Mental health**

For adults of working age with mental health needs, there is some clustering of day services around the coast and Eastbourne and Hastings, with no provision in North Wealden or Rother.

- **The Health sector**

Their main contribution is financial, in terms of their joint contribution of the pooled budget with funds Care for the Carers (see funding section). All four PCTs also fund home respite provided by Crossroads Care Attendant Schemes. Some in-house respite is provided, however this varies across the PCTs.

- ***The Voluntary Sector***

A number of voluntary organisations in East Sussex exist specifically to provide help and support to carers. These include Care for the Carers, Crossroads, Association of Carers and Friends of William Daley. In addition several other organisations providing help for specific groups, such as MIND, Mencap and Rethink, also provide support for the carers of their client group.

Crossroads and Care for the Carers are the two main organisations providing services and support to carers. Crossroads is the major voluntary sector provider of respite across the county and operates Care Attendant Schemes in Lewes, Hastings and Rother, Eastbourne and Wealden. Care for the Carers role is different as it provides both services such as outreach, back protection, training, information and advice and it also performs a policy advisory role, which is not done by any other group.

### **6.2.3 Funding the Voluntary Sector**

The main exclusive funding of 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 and the voluntary sector itself contributes over £100k to carers services.

### **6.2.4 Funding in the Independent Sector**

There is an unknown amount spent within the independent sector by people who are buying services directly or commissioned by social services through spot contracts.

### **6.2.5 Performance assessment**

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 has been on the user, rather than the carer. In the future priority should be attached to longitudinal monitoring and comparison of different organisations. In that case, use of similar indices will be important to establish such consistency. In addition, performance assessment needs to develop beyond a focus on output monitoring, which dominates both the statutory and voluntary sectors. Outcome monitoring and evaluation of services should become embedded in the planning and delivery of services.

## **6.3 What do carers want**

There are high levels of satisfaction for carers who had managed to mix private, voluntary and statutory care; the main problem though was that this was a minority of carers. The voluntary organisations suggested that while there may appear to be a catalogue of services on offer for carers many of these are theoretical. They argue that not all the services are translated into concrete amenities for carers.

Help for carers can be viewed as a spectrum, with low level help such as a care worker ensuring that someone has taken their pills, to high level intervention such as rolling respite.

### **6.3.1 Respite**

Carers in particular valued respite care (which overall quantity has not increased from the total of 30% recorded in 1990). Respite care is currently being restricted in preference to intermediate care and the consequential dwindling provision of respite and day care has been noticed by carers.

- Carers asked for increased levels of respite and day care.

### **6.3.2 Flexible respite**

There is also a requirement for more flexibility within the system. Parent carers wish for improved holiday and after school coverage; carers looking after someone with a functional mental illness require help according to the episodic nature of the illness and so do not want the routine help but intense assistance

as and when it is required. 24-hour emergency replacement care services would provide help for when carers are faced with an emergency.

- Carers asked for more flexibility within the system

### **6.3.3 Appropriate respite**

Carers complained that in some cases where they are receiving respite it is not age appropriate, this is particularly the case for middle aged and young adults. Respite care, including day care, requires a flexibility corresponding with a needs led rather than a service led provision.

Lack of training of staff was highlighted as a problem area for carers looking after a person with dementia. In Bexhill the problem is exacerbated by health and safety regulations negatively affecting admission of dementia sufferers to day care centres.

- Carers asked for appropriate respite

### **6.3.4 Respite for working carers**

Lack of respite and day care facilities have particular considerations for people who have the dual role of caring and working. Carers can lose up to £9,000 per annum when they assume caring responsibilities (Clements, 2005). In some cases carers are sometimes forced to give up work and since many of them are women this could impact negatively on their own finances in old age and increase the burden on Social Services as a result.

- Carers wanted more help to assist them in maintaining both their role as a carer and their work

### **6.3.5 'Low-level' help**

'Low-level' does not mean less important or low importance.

One of the problems with the current situation is that not enough attention is paid to the very low level help required, especially by carers who are also employed, and essential in allowing them to continue in their dual role.

Much of this low-level help is practical in nature. Carers have asked for help such as garden and house maintenance, cleaning and washing up. This type of assistance can help guard against the need to send people into residential homes, which is both against the desire of older people and their carers as well as against the government endeavours to maintain people in their own homes. People who have achieved low level help have praised it but also pointed out that it can take months before it is realised, which rather suggests that the system is in need of enlargement. This requirement fits in exactly with the spirit of the Carers (Equal Opportunities) Act 2004 which argues that carers should be able to have an equivalent lifestyle as those without caring responsibilities.

- Carers asked for low-level practical help

### **6.3.6 Health-related help: physiotherapy and bathing**

Physiotherapy is not on offer, unless privately funded, for people over 65 years. Carers also wanted help with bathing, but this service is being phased out by health and the time and expertise is not being replaced through care agency staff. Some carers had help converting their bathrooms into wet rooms and those that had received this help were very satisfied with the results.

- Carers felt that physiotherapy was a service that would benefit the people they looked after and as a consequence help them as carers. They also want help with bathing the person they look after.

### **6.3.7 Signposting**

The survey of users, the voluntary organisations and the focus group findings showed that carers are not being signposted to the appropriate agencies for assistance. This lack of signposting means that carers do not receive appropriate and timely information, nor access to services. The majority of carers in the survey were either in contact with Care for the Carers or Crossroads, so while it would appear that the voluntary agencies are committed to and carrying out the important function of signposting it is quite possible that this could be greatly enhanced if the GP surgeries would also take on the role of signposting.

This research found that carers who have assumed a caring role due to a recognised medical condition of the person they care for, receive good advice and help, while those who drift into caring gradually, as a result of the person they care for becoming increasingly frail, find it difficult to access information. The implication here is that GPs, district nurses etc., are not providing appropriate information and, it would seem, not pointing carers in the direction of the carer agencies.

The voluntary agencies have suggested that a problem is that many carers are hidden. While this may be the case sometimes, it is also true that many carers do not identify themselves as such, perceiving the role as an extension of being a wife, partner, mother, child or friend, rather than caring being a named occupation in itself. The implication of this is that the main point where carers are able to access information is via the GP surgery. It would also seem that, where carer agencies have got signs in GP surgeries, some carers are not recognising that these agencies are more than just social forums but places where they can access information and practical help.

- Carers, especially those who gradually become carers, need to be signposted to the appropriate agencies for assistance

### **6.3.8 Information**

A main aspect of carer legislation to date has been to ensure that carers receive the information they require to enable them to continue caring and now, through the Carers (Equal Opportunities) Act, local authorities are charged with including carers' wishes within the carers' assessment. The purpose behind this is to assist carers with aspirational choices such as:

- helping them to work

- Giving them the chance to take up educational and training opportunities
- Allowing them to have the chance to engage in leisure pursuits.

In order to create appropriate and timely information it is first necessary to understand the nature and characteristics of the caring population and although the census data can provide information about the age, gender, ethnicity, concentration and state of health of carers it does not provide sufficient data for informed service delivery. The voluntary organisations also felt that the lack of data on the caring population was restricting the availability of good information. The deficiency of data also has policy implication as it is problematic to assess carers' needs without first knowing the size and type of the caring population.

The research revealed that the majority of carers who were managing to obtain some information were getting it from carer agencies and social workers. However, carers were also getting information from other carers rather than going to social services, whom they perceived as gatekeepers. Carers in particular wanted help with forward planning especially when their private funding was exhausted; specifically carers did not want either themselves or the people they cared for to be involved in crisis management of their affairs. Self-funding carers were having particular problems in accessing advice on appropriate services from any source. A small number of carers stated that they had trouble obtaining information on direct payments. In view of the proposed individualised budgets this situation needs addressing.

Same sex couples, who had in the past found Social Services most unhelpful, had found that the Disability Discrimination Act 2004 had been helpful and now felt listened to. The Government's '*Civil Partnerships, legal recognition of same-sex couples*' should further improve the situation by giving same sex carers the equivalent rights as those accorded to other carers.

- Carers require information to fulfil their caring responsibilities and consistently rate information and information gathering very highly.

### **6.3.9 Assessments**

The Carers (Equal Opportunities) Act 2004 placed a duty on local authorities to inform carers about their entitlement to an assessment, rather than waiting for carers to apply for an assessment. Although the number of assessments is increasing there is still a backlog for assessors to complete. The voluntary organisations suggest that the assessment process requires universal application. The mapping of assessment services found a limited amount of evidence on numbers of assessments but none on outcomes. The focus group respondents felt that they found it difficult to get an assessment and this was corroborated by the survey of voluntary organisations. Less than half of the focus group respondents had received an assessment and those that had said that there were negative feelings about the assessment process and the outcome from members of staff undertaking the assessment. Carers felt that part of the problem regarding the number of assessment undertaken was a lack of trained assessors to carry out the work. There was also the feeling that the services were still resource-led and that even when the assessment had been

carried out there was a lack of services available for the carers to use. This corresponds with the voluntary sector organisations who also felt that services were resource rather than needs led. Assessments in East Sussex is carried out as a gateway to the voucher scheme and respite care and nothing else, although the Carers (Equal Opportunities) Act 2004 states that it should be an assessment of what carers want, in terms of helping them work, undertake education or training or partake in leisure pursuits.

The Department of Health has been requested to supply the national figures of assessment for comparison purposes but at the time of writing there has been no response.

- Carers are not only asking that it be easier to access the assessment process, they also want it to be a more positive, meaningful experience.

### **6.3.10 Consistency of care**

Inconsistency can have a negative effect on both people being cared for and carers. Carers have sometimes spent a great deal of time explaining the individual needs of the people they care for to someone coming into their homes, only to find that suddenly someone new is sent to them. For people with dementia in particular consistency of care is essential.

- Carers particularly value consistency and continuity in care and have found that this is often missing.

### **6.3.11 Confidentiality**

There is a particular problem when carers feel that their caring roles are not being acknowledged by professionals. This is specifically the case for people caring for someone with mental health issues or when a child becomes 18 years old, the transition period.

There is a tension between the carers' rights and the confidentiality of those being cared for. The Carers (Equal Opportunities) Act 2004 requires the carer to be taken into account when Social Services is undertaking a community care assessment (Clements, 2005), but does not give them the right to patient sensitive information.

- Carers argue that without comprehensive information their ability to care is compromised.





## 7. Recommendations

### 7.1 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 spent 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 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.**

### 7.2 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.

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 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:**

- **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 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.**

### **7.3 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 more variation, e.g. available out 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 in this dual role. 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. The care needs 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 susceptible to ill health themselves.

### **ACTION:**

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

## **7.4 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.**

## **7.5 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.**

## **7.6 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.**
- 

## **7.7 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.**

## **7.8 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.**

## **7.9 Evidence for good practice**

Finally, it seems important to mention that there are initiatives around the country that provide excellent examples of good practice and food for thought for future strategy.

The Beacon council Scheme is a cross Government initiative to identify and recognise excellence in local government. Run by the Office of the Deputy Prime Minister, in conjunction with the Improvement and Development Agency, the Department of Health has been heavily involved in short listing the Beacon

process where '*Supporting Carers*' was one of the themes in Round 6 of The Beacon Council Scheme in 2004.

The subsequent report from the Beacon Status argues that by providing services which promote independence and choice, and by providing flexible responsive support for carers, the sustainable caring situation can be maintained.

The results of good practice for carers found that many authorities were demonstrating a variety of innovative ways to reach out and provide information to carers who may not yet identify themselves as such, including use of local media; poster events; information booklets; information on plasma screens in pharmacies, hospitals and other places where carers might go and even using pay-slips for working carers to access information. The information provided had to be inclusive and many authorities provided information in large print and different languages as well as providing language skills to carers from Black and Minority Ethnic groups.

Authorities were judged against their ability to reach unknown or hidden carers. Bury, for example, held carer awareness training sessions for hospital staff, and other authorities held training for all front line staff. Somerset organised GP based carer support workers and many authorities undertook partnership working so that PCTs, GP services and Social Services worked together to develop carers registers.

It was found that a number of authorities were ensuring that assessment took account of carers' needs outside their caring role. Councils established their own carer friendly working strategies, training opportunities for carers such as IT and confidence building. Other authorities created partnership working with leisure services to develop new ways of respite that are more inclusive with the local community.

A number of authorities were found to be working with colleagues within their organisations and other public authorities such as housing, education, transport and health to support carers in their caring role.

### **Action:**

- **Collect evidence of good practice from other local authorities, PCTs, GPs and voluntary organisations.**

# **Appendix 1: Mapping of Services**









**Table 3.1: Carers Assessments**

**Number of carers having an assessment  
between 01.04.2005 and 30.11.2005**

<b>PCT Area</b>	<b>Number of carer's having assessments</b>
Bexhill and Rother	150
Eastbourne Downs	319
Hastings and St. Leonards	111
Sussex Downs and Weald	244
Brighton and Hove	7
Not defined	3
	56
South West Kent	1
Western Sussex	1
<b>Whole County</b>	<b>892</b>

**Table 3.2: Respite and day care- older people**

<b>Charter Day Centre, Bexhill,</b>	26 places a day open 7 days a week	11 male and 49 female users, 57 have carers 93% occupancy
<b>Downlands Day Centre, Peacehaven</b>	25 places a day Monday to Friday.  Also Stepping Stones drop in centre for 8 places 4 days a week (Monday to Thursday)	77 users, 32 with carers, 29 admitted for carer support/respite* 74% occupancy  Stepping Stones mostly rehab, 25 users, 5 of whom have carers
<b>Gilda Crescent Residential and Day Care, Polegate,</b>	18 [38] Respite beds  12 places a day (day care)  open 7 days a week	78% occupancy  15 male users, 24 female users, 31 users with carers
<b>Grangemead Residential and Day Care, Hailsham,</b>	16 respite beds (mental health)  25 places a day (day Care) Monday – Friday. 20 places a day Saturday and Sunday	82% occupancy
<b>Harvard Road Residential, Ringmer</b>	29 [36] respite beds	73% occupancy
<b>Hookstead Residential and Day care, Crowborough</b>	18 [22] Respite beds  20 places a day (day care) Monday to Friday – mental health services	78% occupancy
<b>Homefield Place Day Centre, Seaford</b>	20 places a day Monday to Friday (mental health)	15 male and 24 female users, 31 users with carers  68% occupancy
<b>Isabel Blackman Day Centre, Hastings</b>	30 places a day 7 days a week	21 male, 56 female users, 58 service users with carers  64% occupancy
<b>Milton Court Residential and Day Care, Eastbourne, Tel: 01323 731695</b>	10 Respite beds - day care 40 places a day Monday to Friday  20 places a day Saturday and Sunday – mental health	83% occupancy

<b>Moreton Day Centre, St Leonards</b>	25 places a day Monday to Friday 15 places a day Saturday and Sunday	62% occupancy
<b>Mt Denys, Residential, Hastings</b>	5 respite beds – mental health [31 residential places according to returns]	76% occupancy
<b>Pembury Road Day Centre, Eastbourne</b>	41 places a day Monday to Friday	23 male, 46 female users. 32 users with carers 43% occupancy
<b>Phoenix Day Centre, Lewes</b>	25 places a day Monday to Friday	48 users, 32 with carers, 15 for carer support/respite* 72% occupancy
<b>Pinehill Day Centre, Hastings</b>	25 places a day 7 days a week – mental health	27 male and 46 female users, 52 with carers 63% occupancy
<b>Rye Memorial, Rye</b>	25 places a day Monday to Friday 12 places a day Saturday and Sunday	79% occupancy
<b>Ridgewood Residential and Day Care, Uckfield</b>	35 respite beds [38] 16 places a day (day care) Monday to Friday	87% occupancy
<b>St Anthony's Residential, Eastbourne</b>	15 [28] respite beds	82% occupancy

Missing: data for Deanland Wood, Golden Cross, and Friary, Hastings

Some of these places offer Intermediate care, Assessment beds, drop in services

\* initial reason for admission to Centre

**Table 3.3: Residential and Day Care Services- older people, usage and costs [Returns 04/05]**

**3.3.1 Day care**

EXISTING SERVICES	Pembury Rd	Downlands	Phoenix Cntr	Deanland Wd	Charter Cntr	IB Centre	Pinehill	Rye Mem'l
Centre	E/BOURNE	PEACEHAVEN	LEWES	GOLDEN X	BEXHILL	HASTINGS	HASTINGS	RYE
OP (Older people) – MH (MentalHealth)	OP	OP	MH	OP	OP	OP	MH	OP
Day Care places	41	25	20	10	17.7	30	30	20
Open Days	5	5	5	4	7	7	7	7
Actual occupancy per day	17.62	18.50	14.34	6.08	16.52	19.10	18.91	15.89
% occupancy	43%	74%	72%	61%	93%	64%	63%	79%
Actual occupancy per week	88.10	92.50	71.70	24.32	115.64	133.70	132.37	111.23
Placement days per year	4581.20	4810.00	3728.40	1264.64	6013.28	6952.40	6883.24	5783.96
<b>DAY CARE GROSS COSTS</b>	<b>186211</b>	<b>279473</b>	<b>258535</b>	<b>33773</b>	<b>249910</b>	<b>305879</b>	<b>327989</b>	<b>411541</b>
<b>DAY CARE NET COSTS 2004/05</b>	<b>160349</b>	<b>248184</b>	<b>238156</b>	<b>28435</b>	<b>218909</b>	<b>268475</b>	<b>282655</b>	<b>372972</b>

**3.3.2 Residential only**

EXISTING SERVICES	St Anthony's	Firwood House*	Harvard Rd	Mount Denys
Centre	E/BOURNE	E/BOURNE	RINGMER	HASTINGS
OP /MH/IC intermediate care	OP/IC	IC	OP/IC	MH
Residential Places	28	22	36	31
Actual occupancy	22.84	13.92	26.4	23.65
% occupancy	82%	63%	73%	76%
Costs				
<b>GROSS COSTS</b>	<b>716011</b>	<b>480623</b>	<b>832085</b>	<b>892713</b>
NET COSTS				

\*Firwood House, combined in 04/05 into ESCC/PCT rehab = £873.41 per bed week

### 3.3.3 Residential and day centre- older people

EXISTING SERVICES	Milton Ct	Hookstead	Grangemead	Gilda Cr.	Homefield PI*	R/wood Rise	Moreton *
Centre	E/BOURNE	CROWBGH	HAILSHAM	POLEGATE	SEAFORD	UCKFIELD	ST.L'NARDS
OP (Older people) - MH (MentalHealth)	MH	MH	MH	OP	MH	OP	OP
<b>Residential places</b>	10	22	16	38		38	
Actual occupancy	8.25	17.2	13.19	29.75		33.08	
% occupancy	83%	78%	82%	78%		87%	
<b>Day Care places</b>	34	20	24	12	20	20	24
Open Days	7	5	7	7	5	5	7
Actual occupancy per day	24.00	17.83	15.39	5.94	13.65	10.95	14.76
% occupancy	71%	89%	64%	50%	68%	55%	62%
Actual occupancy per week	168.00	89.15	107.73	41.58	68.25	54.75	103.32
<b>DAY CARE GROSS COSTS</b>	<b>278716</b>	<b>174880</b>	<b>258395</b>	<b>133577</b>	<b>210474</b>	<b>138248</b>	<b>326438</b>
<b>Day Care Net Costs??</b>							
RESIDENTIAL CARE GROSS COSTS 2004/05	294121	744860	500078	862409	179798	763543	
<b>RESIDENTIAL CARE NET COSTS 2004/05</b>	<b>219960</b>	<b>143208</b>	<b>231062</b>	<b>121354</b>	<b>184043</b>	<b>126908</b>	<b>297061</b>

\* Homefield residential services run down 03/04 and transfer to ESCH [health] from April 04

\*\* Morton residential part closed down 03.

**Table 3.4: Block contracts****Older people and with a disability**

<b>Location of Home</b>	<b>Category</b>	<b>No.Beds</b>	<b>Respite element of contract</b>	<b>Occupancy levels</b>
Robertsbridge	Nursing & Respite	4 Nursing & 1 Respite	<b>£30,108</b>	<b>85</b>
Robertsbridge	Physical Disability	1 short-term/respite	<b>£34,216</b>	<b>68</b>
St Leonards On Sea	Residential & Long-term respite	6 Respite & 1 Long Term	<b>£102,648</b>	<b>70</b>
Bexhill	Residential & Long-term respite	2	<b>£16,900</b>	<b>85</b>
Seaford	Respite	1	<b>£14,700</b>	<b>61</b>
Seaford	Respite	2	<b>£16,900</b>	<b>58</b>
St Leonards on Sea	Elderly Mentally ill Residential	9 Long Stay 1 respite	<b>£17,940</b>	<b>82</b>
<b>Total</b>			<b>£233,412</b>	



**Table 3.5: Residential Respite Services. East Sussex County Council, for people with learning disabilities**

Unit	No of users/carers	
Greenwood Hill, Bexhill	Open 365 days pa; Care for 126 users; 122 carers	16 respite beds + 4 sessions non-residential respites; + 2 sessions individual outreach support per week
Sandbanks, Hailsham	Open 365 nights pa 12 users at any one time; 40 regular users	Provides variable lengths of respite support, incl. Breaks of 2 weeks or more to enable carers to take holidays. Also provides emergency respite.
Southview Close, Crowborough	Open 163 nights pa 4 users at any one time; 19 regular users	Currently working at full capacity.
<b>Total costs</b>	<b>1,551,000</b>	

**Table 3.6: Costs and budgets- learning disability services**

**3.6.1: Residential costs and usage breakdown, learning disabilities' service**

	Greenwood	Sandbanks	Southview Close
Av occupancy	12.94	4.42	3.35
Max places	16	19	4
% occupancy	81	23	84
<b>Net costs + management costs</b>	<b>£912,540</b>	<b>£784,890</b>	<b>£172,612</b>

**3.6.2: Budget summary: learning disabilities**

Type of expenditure	Mainstream budget	Community Care
Respite services	1.551m	-
Day Services	2.764	1.171
Community Support [including adult placement?]	0.821	0.752
<b>Gross</b>	<b>5.136</b>	<b>1.923</b>
Net [ie less resident contributions and health income]		

**Table 3.7: People with Learning disabilities- day centres**

[average daily attendance in brackets]

Lewes & Weald	ESCC	Southview Close Centre, Crowborough	55 users [42]
		St Nicholas Centre, Lewes	60 users [40]
		Avis Way, Newhaven	58 users [48]
	7 independent centres, all linked to Residential provider, with a few spaces for non-residents	The Barn, Crowborough	30[15]
		Grange Court, Maynards Gn	12[8]
		Halland House, Halland	30 [15]
		Oakdown House, Burwash	42 [24]
		Saxon Court, Buxted	24[12]
		St Anthony, Crowborough	28[25]
		Tinkers Hatch, Cross in Hand	24[20]
Eastbourne & Downs	ESCC	Linden Court, Eastbourne	70[50]
		Firstfields, Hailsham	60[40]
	2 independent	The Hive of Activity, Eastbourne	42[30]
		Seeability, Seaford	20[12]

Hastings & Rother	ESCC	Conquest Centre, Hastings	90[65]
		Beeching Park, Bexhill	73[53]
	10 independent providers	Open Door, St Leonards	42[30]
		Active Arts, St Leonards	54[12]
		Sussex Autistic Trust, Hastings	20[12]
		Friary Gardeners, Hastings	51[20]
		The Co-op Centre, Hastings	28[17]
		The Studio, Hastings	33[24]
		Reiley House, Bexhill	33[25]
		High Glades, St Leonards	64+4
		Outlook Centre, Hastings	50[30]
		Evelyn Juden Centre, Hastings	24[18]
		Communitas Resource Centre, Hastings	7[5]

**Table 3.8: Day services for people with mental health problems, adults of working age**

The current day services are as follows: [figs = places unless stated otherwise]

• 47a Western Road, Lewes	[SSD]	45
• 73a London Road, Bexhill	[SSD]	100
• Bexhill Day Service	[Health]	64
• Cuckmere Work Opportunities, Hailsham	[Health]	15
• Eastbourne Mind	[Non-Stat]	60-65
• Furniture Now!	[Non-Stat]	
• Greenwich House, Peacehaven	[Health]	100
• Hastings Resource Centre (MACA)	[Non-Stat – SSD contract]	76
• Hastings Sheltered Workshop	[Non-Stat]	69
• Lewes and Wealden District Mind	[Non-Stat – SSD/PCT contract]	
• Middlebridge, Hailsham	[Health]	80-100
• Millwood, Uckfield	[Health]	20
• New Road Nurseries, Hellingly	[Health]	26
• Oak Grove Day Centre, Crowborough	[Health]	80
• Ridgewood House, Uckfield	[Private] (3days)	15
• Rural Rother Wellbeing network	[Non-Stat – PCT contract]	87
• Saffrons Lodge, Eastbourne	[Health]	60
• Seaview, Hastings	[Non-Stat – SSD contract]	90
• Summerhayes, Newhaven	[Non-Stat – SSD contract]	
• The Bourne, Eastbourne	[Health]	83
• The Cottage, Eastbourne	[Non-Stat /SSD/PCT contract]	185 pw
• Westwood House, Hastings	[Health]	120
• Workability (Impact Initiatives)	[Non-Stat – SSD contract]	79 referrals

**Table 3.9: Parent carers of children with a disability, ESCC respite provision**

<b>Unit</b>	<b>Area</b>	<b>No. beds</b>	<b>No. children</b>	<b>No. carers</b>	<b>Type of respite</b>	<b>Age</b>	<b>Bed nights/day places</b>	<b>Cost</b>
Acorns, Dorset Road	Bexhill	5	27	27 <sub>approx</sub>	Range from a few nights in school holidays to almost full time care	10-19	1367	£405,000
The Bungalow, Sorrel Drive	Eastbourne	7	41	41 <sub>approx</sub>	Few nights to full time care	10-19	2398	£535,600
ESCC Link Scheme	Countywide	N/a	53	45	Family based care with foster carers. Few nights to f/t placements	0-19	4716 nights 2314 hours day care	£183,200
<b>Total</b>			<b>124</b>	<b>113</b> approx			<b>8481 bed nights and 2314 hours day care</b>	<b>£1,123,800</b>

**Table 3.10 : Residential schools offering overnight respite**

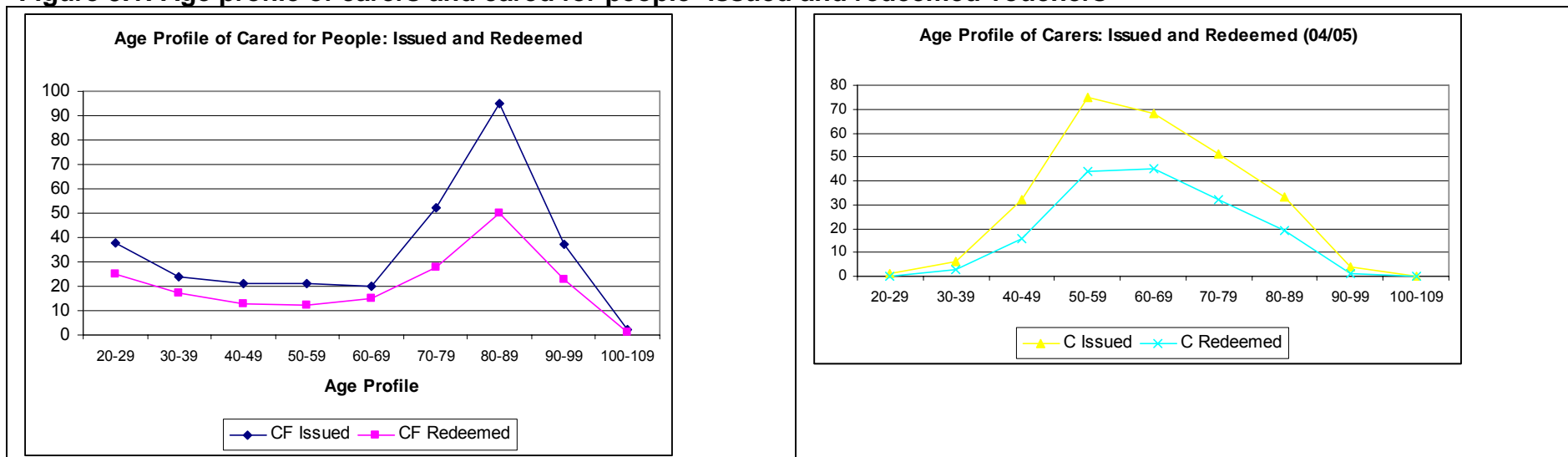
Unit	Area		No. Children		Type of respite	Age	Bed nights	Cost
Chailey Heritage	Lewes		17		Residential school. Respite purchased on an individual basis for East Sussex children who attend.	5-19	Varies according to need	£176,653
St Johns	Seaford							
Finches	Burgess Hill		7		Respite unit linked to Chailey Heritage for younger children with complex & severe health needs.	5-16	Varies according to need	£23,092 plus health funding?
St Mary's Wrestwood & Royal School for the Deaf	Bexhill Margate		4		Residential schools. Respite purchased on an individual basis for East Sussex children who attend.	5-19	Varies according to need	£9,481
Agency Foster Care	Countywide		2		Specialist respite foster placements	0-19	Varies according to need	£6,000
Regard	Wealden		1		Residential children's home	5-19	Varies according to need	£17,000
Footsteps (Kent Kids Miles of Smiles)	Kent		2		Holiday respite care	5-19	Varies according to need	£16,777
<b>Total</b>			<b>33</b>					<b>249,003</b>

**Table 3.11: The Short-break Voucher Scheme**

area breakdown of issue versus redemption

Sum of commitment		Sum of Amounts Invoiced		% Redeemed
Panel	Total	Panel	Total	
Eastbourne	16,860	Eastbourne	8,684	52%
Hastings	17,477	Hastings	10,175	58%
Learning Disability	15,090	Learning Disability	10,778	71%
Lewes/Wealden	9,463	Lewes/Wealden	5,955	63%
Mental Health	1,200	Mental Health	925	77%
Grand Total	60,090	Grand Total	36,517	61%

**Figure 3.1: Age profile of carers and cared for people- issued and redeemed vouchers**



**Table 3.12: Providers\* against the total number of vouchers redeemed**

<b>Provider</b>	<b>Total £</b>	<b>Percentage</b>
Crossroads - Hastings	3,477	10%
SOS	3,427	9%
William Daly Centre	2,810	8%
Companions	2,479	7%
Everycare	2,228	6%
Crossroads - Wealden	1,995	5%
Carewatch (Lewes)	1,651	5%
Care UK	1,222	3%
Freshford	1,170	3%
Queen Mary's Lodge	1,141	3%
Wealden Community Care	1,034	3%
Tusker House	1,031	3%
Hazelbrae	1,031	3%
Nurses Direct	754	2%

\*These were not the total number of providers. There were another 38 providers, where 1% of vouchers were redeemed.



**Table 3.13: Health Service provision**

<b>Year 2004/5</b>	<b>Sussex Downs &amp; Weald PCT</b>	<b>Eastbourne Downs PCT</b>	<b>Bexhill &amp; Rother PCT</b>	<b>Hastings/St Leonards</b>
<b>Care for Carers:</b> Pooled Budget contribution	£32,737 for pooled budget	£165,370 combined 3 PCTs SDW, B&R and Eastbourne	£22,919 for pooled budget	
<b>Respite – beds</b>	<p><b>i) Crowborough hospital*</b> 2 beds/22 patients/ existing budget</p> <p><b>ii) Newhaven Rehab Centre*</b> 5 clients/up to 4 x yr /existing budget</p> <p><b>iii) Meadow Lodge, Lewes*</b> 2 beds/21 patients/existing budget</p> <p>*Average 2004/5 unit cost per bed /per day for PCT = £150</p>	<p>Informal arrangements on an ad hoc basis e.g. ‘step-up’ beds for carer in need.</p> <p>Also informal ad hoc arrangements for carers having surgery – but beds not always appropriate for under 60s</p>	No respite – all beds in community are intermediate beds including ‘step-up’ and ‘step-down’. These are focused on the patient not the carer – who is the responsibility of Social Services*	* This covers both PCTS
<b>Respite – home sitter</b>	<b>Lewes Xrds</b> £42,500	<b>Eastbourne Xrds</b> , £73,000	<b>Rother &amp; Hastings Xrds</b> £33,965. <b>Assoc of Carers</b> £32,866*	* Both orgs cover both PCTS
<b>Respite – day care</b> ** see below	<b>Crowborough Day Centre</b> 87 clients/32 live with families	Saffrons Lodge, Eastbourne – mental health	Bexhill Day Services – mental health	
<b>Respite – other</b>	<b>Youthability</b> /£6,400,	NB. Increased input from Continuing Care team as and when necessary		
<b>Advocacy</b>	Staff refer carers to ACES/Brighton Housing Assoc	District Nurses refer to CAB		
<b>Information</b>	Information & Vol Services Co-ordinator post has links	Hospital Discharge Support worker (CfCs) £5000		

	with many caring groups & issues. Community Matron/APNs inform carers of benefits	District Nurses refer to vol agencies and CAB		
<b>Development Work</b>	Chronic Disease Management/SAP process/Health Matters patient & carers advisory group	District Nurse beds in Firwood x 2 being considered	Views & opinions of carers taken into consideration	
<b>Marie Curie Nurses*</b>	4 nurses/28 patients/730 hours *8hrs respite at night/occasionally day	5 nurses/25 patients/892 hrs	8 nurses/2,273 hours*	* Covers both PCTs
<b>Macmillan Nurses</b>				

### **Learning Disabilities**

Joint health and social services Community Learning Disability Service provides social and health care assessment and specialist healthcare services to people with learning disabilities over 19 years of age (18 years if not in full-time education). The service primarily works with those people with profound, complex and multiple needs, and facilitates access to services and support.

East Sussex County Healthcare has a residential service for 12 adults with learning disability and complex challenging needs. This is made up of 6 homes located on 5 sites in the Eastbourne area. A range of services is provided including group homes, separate flats and individual services. In addition an intensive “day service” is provided to individuals living in the family home. In East Sussex the NHS places around 170 adults with learning disabilities in independent residential homes in the county, and 52 in independent residential homes outside the county.

### **Mental Health provision**

Health Day Services Provision for adults of working age highlighted in Table 3.8: Middle Bridge, Hailsham; Millwood, Uckfield; New Road Nurseries, Hellingly; Oakk Grove Day Centre, Crowborough; Westwood House, Hastings; The Bourne, Eastbourne; Greenwich House, Peacehaven.

**Children with a disability:** Family Intensive Support Service – provide help for parent carers

**Table 3.14: Voluntary Sector, analysis of contracts**

<b>Contract</b>	<b>Funding</b>	<b>Purpose</b>	<b>Area</b>	<b>SLA Specification</b>																		
Seaford, Eastbourne and Wealden Crossroads Care Attendent Scheme 309 with ESCC and ED PCT	Total: £235,983  From Carers Grant £49,000 £30,000 £42,500 total: £121,500  From mainstream £43,167  From PCT: £69,223	To provide care and support to people in their own home to enable carers to have a respite from caring  Provision of Care: Assess carer and dependent's needs Home-based respite Flexible-hours Practical, personal and emotional support  <b>Co-ordination</b> Of Care Attendants With other services  <b>Training</b>	Wealden DC Eastbourne BC Seaford area of LDC	Main Services: 162 hours per week (to include travel time, training time etc) Av of 130 hours direct care per week <b>Promoting Independence</b> 76 hours per week, av of 60 hours direct care Additional 54 direct hours No spec.																		
Seaford, Eastbourne and Wealden Crossroads Care Attendant Scheme 579 with ESCC SS	Total: £24,105  Kids Plus £10,000 Children's Service £9,000 <table border="1"> <thead> <tr> <th>Item</th> <th>£</th> <th>£</th> </tr> </thead> <tbody> <tr> <td>Admin/Staff/Insurance</td> <td>6600</td> <td>5940</td> </tr> <tr> <td>Training</td> <td>600</td> <td>540</td> </tr> <tr> <td>Accomm/Equipmt</td> <td>1800</td> <td>1620</td> </tr> <tr> <td>Management Fee</td> <td>1000</td> <td>900</td> </tr> <tr> <td><b>Total</b></td> <td><b>10000</b></td> <td><b>9000</b></td> </tr> </tbody> </table> Children's Service £5,105	Item	£	£	Admin/Staff/Insurance	6600	5940	Training	600	540	Accomm/Equipmt	1800	1620	Management Fee	1000	900	<b>Total</b>	<b>10000</b>	<b>9000</b>	Provision of leisure and play activities for Children with Special Needs and 'their families respite care'  4 Play Schemes places  **seems to be indirectly	<ul style="list-style-type: none"> <li>• Seaford</li> <li>• Eastbourne</li> <li>• Wealden</li> </ul> For: Children with special needs, from both special and mainstream schools, who live in E Sussex	1 day per week for 5 weeks at each of the 4 playscheme sites, over summer holiday for max of 20 young people per day
Item	£	£																				
Admin/Staff/Insurance	6600	5940																				
Training	600	540																				
Accomm/Equipmt	1800	1620																				
Management Fee	1000	900																				
<b>Total</b>	<b>10000</b>	<b>9000</b>																				

<p>Seaford, Eastbourne &amp; Wealden Crossroads Care Attendant Scheme</p> <p>ESCC</p> <p>637</p>	<p>£6,000 Children and Families budget</p>	<p>Services to children &amp; young adults with Complex needs and their carers</p> <p>Part: to assist family carers by giving practical support and short periods of respite care</p> <p>An expansion of existing sitting services to children/young adults aged 1-25 years</p>	<p>Seaford, Eastbourne and Wealden</p>	<p>27 hours to each eligible service user, giving support to 18 families</p>
<p>Hastings and Rother Crossroads Care Attendant Scheme</p> <p>581</p> <p>with ESCC SS</p>	<p>Total: £88,192</p> <p>Carers Grant: £88,192</p>	<p>Services to children and young adults with Complex Needs and respite for their family carer. Home sitting service to children and young adults aged 1-25, and home-based respite to the carer.</p>	<p>Hastings and Rother DC</p>	<p>Sitting services 106 hours per week of direct care, for 20-30 families less hours if unsocial hours</p> <p>Children's co-ordinator 18 hours per week</p>
<p>Hastings &amp; Rother Crossroads Care Attendant Scheme</p> <p>With ESCC</p> <p>B&amp;R PCT and H &amp; SL PCT</p> <p>600</p>	<p>Total: £189,697</p> <p>Social Services Mainstream £51,710</p> <p>Health £29,241</p> <p>Carers Grant: GP Rural Practice £34,393</p> <p>Adult services £74,353</p> <p>[Total: £108,746]</p>	<p>Services to carers of adults and older people</p>	<p>Hastings and Rother, Ninfield and Hooe Villages</p>	<p>Respite breaks service 249 hours per week</p>

<p>Lewes Area Crossroads</p> <p>SDPCT &amp; ESCC</p> <p>583</p>	<p>Total: £141,143 PCT £42,350 ESCC mainstream £41,370 Carers Grant: Adcare £57,423 Cygnet £32,630</p>	<p>Care and support to people in their home, to enable Carers to have a respite from caring</p> <p>Relief for carers who care for people of all ages, who are frail, have sensory impairments or disabilities, and children with special needs</p> <p>Assess individual needs of carers Provide home-based respite service Provide flexible-hours service</p>	<p>Lewes District, excluding Seaford</p>	<p>Main SS Budget: 4,732 hours (adults) + 500 hours per annum for a Children's School Holiday Project</p> <p>Carers Grant: Adcare 5,232 hours Cygnet 2,938 hours</p> <p>Manager 28 hours p wk Asst Manager 18 hrs pw Admin/Accounts “ “</p>
<p>Lewes Area Crossroads</p> <p>ESCC</p> <p>638</p>	<p>Carers Grant: £32,630 Of which: 2938 direct care hours @ £8 per hour</p>	<p>Cygnet Home-based respite service. Now expanded to include families caring for children aged 1-18</p>	<p>?</p>	<p>Asst Co-ordinator 6 hours per week 56.5 hours per week, supporting 21-25 families</p>
<p>Care for Carers</p> <p>With ESCC</p> <p>Contracts: 752 (pooled budget)</p> <p>531 595</p>	<p><b>Total: £432,467 for adults</b></p> <p>Pooled budget, Health and Social Services:</p> <p>Health: £221,026, comprising £165,370 from all 4 PCTs plus £32,737 SDW PCT and £22,919 BR PCT + Social Care Mainstream: £91,175 + Carers Grant £111,750</p> <p>Social Care mainstream £8,516 for IBMS scheme [in addition £36,144 from Carers Grant for</p>	<p>Provision of Carers Services in East Sussex: Planning &amp; Consultation</p> <p><b>Information</b></p> <p><b>Outreach</b></p> <p><b>Support</b></p>	<p>County</p> <p>Hastings &amp; St Leonards</p>	<p>East Sussex Carers Development Group</p> <p>Bi-monthly Careline Newsletter Information leaflets to carers Information to organisations providing service</p> <p>37 hours</p> <p>37 hours 55.5 hours</p>

669 623/661	Young Carers; and £57,530 from Social Care Mainstream for Youthability].  Plus: £400 from Social Services discretionary budget £10,000 contracted for Website: mainstream?? £14,400 for Family Support Service: mainstream??	<b>Training &amp; Education</b>	Bexhill & Rother Eastbourne S Downs/Weald  County  Rye	55.5 hours 44 hours per week to 80-120 young carers  37 hours Back Protection  After school club in Rye
Care for the Carers  664	Carers Grant: £52,240 £5,290	Youthability Youthability Wealden	Countywide Wealden	
Care for the Carers  No contract numbers	Youthability scheme – short term care £2,300			
RETHINK ESCC 643 644	Total: £120,080 from Carers Grant  1. Service Manager and Development Worker £59,014 2. Short term breaks Scheme £61,066	Carers Support: Service Manager and Development Worker – offer support to carers of people with mental health problems. To include identifying gaps in services; facilitate carers taking short term breaks; to develop a peer support system for carers; distribute information to carers and their support groups, facilitate consultation with carers, contribute to strategic planning groups, and advise on	East Sussex	7 nights (24 hour period) respite for 107 carers

		operational policies re. carers needs		
Friends of William Daley Centre With ESCC 574	Mainstream: Older People's Services £3,700	Polegate & District Carers Group  Advocacy service for Social Services users	Polegate & District	6 hours advocacy time per week
Friends of William Daley Centre With ESCC 575	Mainstream: £23,400 Older People's Services	Respite Care and Support Service for Carers Assessment of Carers' needs Operation of Respite Care Service Run support group for Carers Provide information for carers on services and benefits	Polegate and District  Same geographical area covered by Warwick House Independent Living Team, excluding Seaford	Project Worker for 15 hours per week Clerical Assistant for 3 hours per week 50 hours per week care hours 40 hours direct respite care hours
The Friends of William Daley Centre ESCC 580	Total £46,964  Carers Grant: Polegate short breaks £11,000 WD Carers support £12,000 Enhanced Respite £10,180 WD Respite and Support £13,784	Polegate and District Carers Group Home-based respite in evening, overnight or weekend short-break  Co-ordination Training	Polegate & District	Respite in the home for 100 families 40 hours per week direct respite care 7 hours training/supervision per week 10 hours administration per week
Association of Carers Hastings & St Leonards And Hastings & St Leonards	Total: £30,555  PCT: £13,435 Council mainstream: £10,870 Carers Grant: £6,250  [Discrepancy here as PCTs indicate £32,866 is paid to cover 2 PCT areas for	Home Visiting Service, by volunteer visitors, to enable carers to go out Provision of information to carers by visitor on services available	Hastings & St Leonards and neighbourhood	Service Manager 25 hours per week Admin/Fundraising/PR @ 25 hours per week 80 volunteer visitor hours per week

PCT	home sitting service]													
ESCC 599														
Lewes District & Wealden MIND  ESCC 613	£149,824 total budget £52,400 core social services, to include £3,700 for the weekend service £27,424 SD&W PCT £35,000 ESBHHA – User Q PPI - £15,000 <b>£10,000 from the Carers Grant for Minders Scheme</b> £10,000 towards core costs from Community Partnership Finance	MINDERS	Lewes District											
Lewes District Mencap  ESCC 634	Total: £10,205 <b>Carers Grant: £9,140</b> Other £1,065 <table border="1" data-bbox="405 858 790 1023"> <tr> <td>Staff costs</td> <td>7,662</td> </tr> <tr> <td>Club costs</td> <td>1978</td> </tr> <tr> <td>Admin costs</td> <td>1253</td> </tr> <tr> <td>Mencap contrib.</td> <td>688</td> </tr> <tr> <td><b>Total</b></td> <td><b>10,893</b></td> </tr> </table>	Staff costs	7,662	Club costs	1978	Admin costs	1253	Mencap contrib.	688	<b>Total</b>	<b>10,893</b>	Saturday Club for people aged 19-40 with a learning disability and their siblings Provide them with an opportunity to socialise, develop decision making skills, participate in community based activities, become aware of other people's needs	Lewes – for anyone in the Lewes area	Club at St Nicholas Centre, Spital Road, Lewes  Open 10.30 am – 4pm, alternate Saturdays, 26 days a year  Provision of transport to the Club
Staff costs	7,662													
Club costs	1978													
Admin costs	1253													
Mencap contrib.	688													
<b>Total</b>	<b>10,893</b>													
Lewes District Mencap  ESCC 635	Carers Grant: £12,860 Mencap contribution £935 <table border="1" data-bbox="405 1198 813 1327"> <tr> <td>Staff Costs</td> <td>9,495</td> </tr> <tr> <td>Club costs</td> <td>2713</td> </tr> <tr> <td>Admin costs</td> <td>1,587</td> </tr> <tr> <td><b>Total</b></td> <td><b>£13,795</b></td> </tr> </table>	Staff Costs	9,495	Club costs	2713	Admin costs	1,587	<b>Total</b>	<b>£13,795</b>	Saturday Club for children aged 9 –14 years with a learning disability Provision of fun activities, enhance self-awareness, stimulate skills development  Also to provide respite breaks	Lewes – for anyone in the Lewes area	Club at St Nicholas Centre, Spital Road, Lewes  Open 10.30 am – 4pm, alternate Saturdays, 26 days a year  Provision of transport to the Club		
Staff Costs	9,495													
Club costs	2713													
Admin costs	1,587													
<b>Total</b>	<b>£13,795</b>													



		for parents, carers and families		Co-ordinator 14 hours, Asst Co-ordinator 8 hours, 2 Support Workers 7 hours: all per fortnight
Lewes District Mencap  ESCC  680	Carers Grant: £3,000 out of a total budget of £16,082 [Mencap funding the remainder]	Saturday Club for teenagers aged 14-19 years with a learning disability Provide them with an opportunity to socialise, develop decision making skills, participate in community based activities, become aware of other people's needs	?Lewes District	Club at St Nicholas Centre, Spital Road, Lewes  Open 10.30 am – 4pm, alternate Saturdays, 26 days a year  Provision of transport to the Club
Mencap Eastbourne Hive of Activity	£16,900 Carers Grant		Eastbourne	
Hastings & Rother Family Friends  With ESCC  588	Children & Families budget £43,800	Respite care for families of children with a learning disability aged 0-19 years in the child's home, the carer's home or in the community  linking a carer with a family and drawing up an agreement	Hastings & Rother	Organiser at 25 hours per week  90 hours per week to be provided by the standard contract Approximately 35 hours per week from the additional grant.
East Sussex Disability Association  646	£6,300 in 2005/6 out of a total budget of £11,264 via Occupational Therapy	Holiday scheme for disabled people to provide respite for carers  ESDA to provide an assessment of applicant	East Sussex	8 group holidays provide subsidised places
East Sussex Disability	£80k in 2001/2 - letter renewing contract to September 2005	County wide support service for people receiving 'Direct	East Sussex	

Association ESCC 530		Payments' Appears to include carers		
British Red Cross Wealden Carers Respite	£3,178	Respite for carers in Wealden		
CAPE [Carers and Parents Enterprise] summer playscheme	£2,500 Carers Grant		Eastbourne	
PACT Cherish  ESCC 584	£3010 from Community Partnership Finance Carers Grant £6,350 [Project Now Ceased – not clear whether this money was ever spent]			

**Table 3.15: Voluntary Sector, analysis of service provision**

**3.15.1 All except Crossroads**

<p><b>Care for the Carers</b></p>	<p>Adult Carers Services                  Outreach-185 hours of outreach support work per week for 1217 carers [854 were newly identified and these were all carers of older people]. Of these carers, 465 were aged 19-60; 503 aged 61-75 and 265 aged 75+. There were 919 were female carers and 24 were from BME communities.</p> <p>The breakdown across the county was as follows:</p> <table border="1"> <thead> <tr> <th><b>Area</b></th> <th><b>Hours</b></th> <th><b>No Carers</b></th> </tr> </thead> <tbody> <tr> <td>Hastings &amp; St Leonards</td> <td>37</td> <td>143</td> </tr> <tr> <td>Bexhill &amp; Rother</td> <td>37</td> <td>201</td> </tr> <tr> <td>Eastbourne</td> <td>30.5</td> <td>258</td> </tr> <tr> <td>High Weald</td> <td>20</td> <td>164</td> </tr> <tr> <td>South Weald &amp; Seaford</td> <td>25</td> <td>220</td> </tr> <tr> <td>Lewes/Heathfield</td> <td>35.5</td> <td>231</td> </tr> </tbody> </table> <p>Of the 854 referrals, 239 were from Eastbourne, 105 from Hastings and St Leonards, 131 from Bexhill and Rother, 109 from High Weald, 114 from South Weald and Seaford and 176 from Lewes District.</p> <p>Outreach covers a wide range of activity including the provision of information on voluntary and statutory services, referrals to services, carer assessment, advocacy, benefits, practical information etc.                  Outreach workers also work with professionals to increase awareness and referrals.</p> <p>Information services                  Careline magazine has a current circulation of 4700 carers                  CfC website received 7294 hits                  6500 new leaflet have been distributed                  76 information sessions and drop-ins were held across East Sussex at which 173 carers contacted</p>	<b>Area</b>	<b>Hours</b>	<b>No Carers</b>	Hastings & St Leonards	37	143	Bexhill & Rother	37	201	Eastbourne	30.5	258	High Weald	20	164	South Weald & Seaford	25	220	Lewes/Heathfield	35.5	231
<b>Area</b>	<b>Hours</b>	<b>No Carers</b>																				
Hastings & St Leonards	37	143																				
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Eastbourne	30.5	258																				
High Weald	20	164																				
South Weald & Seaford	25	220																				
Lewes/Heathfield	35.5	231																				

	<p>Carers Skills Training  213 carers attended 39 two-hour courses  91 carers attended 10 x 8 weekly courses  These ranged from back care, legal rights to aromatherapy and pilates.  Most carers came from Wealden and least from Hastings/St Leonards.</p> <p>359 carers received Back Care support  6 families were supported as part of the Independent Budget Management Scheme</p> <p>Young Carers  Youthability Clubs provided breaks for 64 families</p>
Re-Think	<p>53 Carers and 47 cared for benefited from the Carebreak scheme  200 carers attended a one-day Carers Time Out Day  15 carers accessed the Carers Support and Information Service</p>
Association of Carers	44 carers received home-based respite
William Daley Centre	Up to 100 older people/users receive day care
Advocacy Service	
Lewes MIND	
MENCAP	<p>5 residential homes with 45 residents  3x10 members of adult, teenager, children's clubs  30 families receive a day care service from Mencap's Hive of Activity</p>
Hastings & Rother Family Friends	
ESDA: Holiday Scheme Direct Payments Support Scheme	21 people received 7,560 hours of holiday respite
British Red Cross Wealden Carers	70 people pa receive a short-term befriending services
PACT Cherish	This group appears to have ceased operating in the area
PHAB Eastbourne	This group ceased operating over one year ago but are hoping to start up again in the near future
MENCAP Older Carers	Funding for this project was requested by Mencap from Older People's Service, but was refused

Support	as it was deemed too expensive. Currently Care for the Carers is in negotiation with East Sussex Policy Manager, Philip Pragnell and Mencap are hoping to support any forthcoming project with their expertise and knowledge when requested.
CAPE	
Hastings and Rother Family Friends	

### 3.15.2 Crossroads

#### Numbers of carers, care hours

	Direct Care Hours ^	Number of cared for with service	Referrals	Carers +	Number on waiting list
Hastings & Rother	17546	255	142	245	130
Seaford Eastbourne & Wealden	19906.5	287	199	273	81
Lewes	11808	77	70	79	6
<b>East Sussex Total</b>	<b>49260.5</b>	<b>619</b>	<b>411</b>	<b>597</b>	<b>217</b>

^These figures do not include hours relating to travel, supervision, meetings, sick leave, training or holidays.

+ These figures relate to number of prime carers and not the total number of carers, as some people will have only one carer and others two or more. Also some carers care for more than one person We do not keep statistical information on the total number of carers except on the carers file and this would be a time consuming exercise.

**Table 3.16: Breakdown of stats on smaller areas where possible e.g. district/borough PCT etc**

Area covered	Direct Care Hours	Number of cared for with service	Referrals	Carers	Number on waiting list
Lewes Town	/	15	/	15	/
Lewes Rural	/	18	/	18	/
Havens	/	44	/	46	/
Smaller areas not recorded in H & R & SEW					

**Table 3.17: Source of referrals**

	H & R	SEW	Lewes	East Sussex Total
Referring Source	Referrals	Referrals	Referrals	Referrals
Social Services	42	63	31	136
Health	35	17	1	53
Voluntary Agencies	16	54	13	83
Family / Self	62	46	21	129
GP's	4	2	0	6
Other	0	5	0	5
Total	159	187	66	412

Note: Information provided cover all three East Sussex Crossroads Schemes

H & R = Hastings & Rother Crossroads

SEW = Seaford Eastbourne & Wealden Crossroads

Lewes Crossroads

**Table 3.18: Age breakdown of cared for**

No Assisted	0-10	11-18	19-29	30-39	40-49	50-59	60-69	70-79	80-89	90+
H & R	39	22	15	7	4	9	13	47	77	22
SEW	39	58	3	5	3	9	21	50	69	30
Lewes	4	21	4	0	3	4	9	14	14	4
East Sussex Total	82	101	22	12	10	22	43	111	160	56



**Table 3.19: Analysis of Voluntary Sector Performance Indicators**

Organisation	Contract Number	Performance Indicators
Seaford, Eastbourne and Wealden Crossroads Care Attendant Scheme	309	<ul style="list-style-type: none"> <li>• Number of referrals received, the source of referral and the age range of cared for person being referred.</li> <li>• Number of assessment visits undertaken.</li> <li>• Number of new Service Users receiving a Service.</li> <li>• Number of Service Users waiting to receive a Service.</li> <li>• Number of Service Users no longer receiving a Service.</li> <li>• Categories of Cared for Person's disabilities.</li> <li>• Age banding of Cared for Persons.</li> <li>• Total of direct care hours provided per week.</li> <li>• Number of direct care hours provided per person per week.</li> <li>• Number of indirect care hours per week identifying training, supervision, travel, sickness and annual leave.</li> <li>• Evidence of Carer and Cared for Persons feedback and consultation.</li> </ul>
Friends of William Daley Centre	574	<ul style="list-style-type: none"> <li>• Number of Service Users interviewed</li> <li>• Time spent on each interview</li> <li>• Number of hours of services delivered each week</li> <li>• Number of indirect staff hours, e.g. training, supervision, travel</li> <li>• Evidence of Service User feedback</li> <li>• Number of people referred and by whom</li> <li>• Type of service enquiry or details of help provided</li> <li>• Any other relevant information to enable the services to be monitored effectively.</li> </ul>
Friends of William Daley Centre	575	<ul style="list-style-type: none"> <li>• Number of referrals received, the source of referral and the age range of the Cared for Persons being referred</li> <li>• Number of assessment visits undertaken.</li> <li>• Number of new Carers receiving a Service.</li> <li>• Number of Carers waiting to receive a Service.</li> <li>• Number of Carers no longer receiving a Service.</li> <li>• Categories of Cared for Persons' disabilities.</li> <li>• Age banding of Cared for Persons.</li> <li>• Age banding of Carers.</li> <li>• Number of direct care hours provided per week.</li> <li>• Number of indirect care hours per week identifying training, supervision, travel, sickness and annual leave.</li> </ul>

		<ul style="list-style-type: none"> <li>• Evidence of Carer and Cared for Person feedback and consultation.</li> </ul>
Seaford, Eastbourne and Wealden Crossroads Care Attendant Scheme	579	<ul style="list-style-type: none"> <li>• The age, gender and post code of each East Sussex Child attending</li> <li>• The numbers of children and staff at each session</li> <li>• Details of parental contributions requested</li> <li>• Numbers of children where East Sussex Social Services funded the parental contribution</li> <li>• A budget statement for the project.</li> <li>• The promotional material advertising the scheme</li> <li>• A copy of the outline programme plan</li> <li>• Evidence of staff supervision and training</li> <li>• Evidence of public liability and employers liability insurance cover;</li> <li>• Accident/incident records</li> </ul>
Hastings and Rother Crossroads Care Attendant Scheme	581	<p>The performance of the Service shall be measured by the following indicators:</p> <ul style="list-style-type: none"> <li>• Feedback from Service User and Dependent Relative</li> <li>• Review of comments and complaints</li> </ul> <p>The Service Provider will record the following statistics:</p> <ul style="list-style-type: none"> <li>• Number of referrals received</li> <li>• Number of assessments undertaken</li> <li>• Number of Service hours provided</li> <li>• Gender, age and postcode of children receiving a service.</li> <li>• Number of visits allocated to each child</li> </ul> <p>Number of monitoring meetings with Care Attendants</p>
Lewes Crossroads	583	<p>Number of referrals received, the source of referral and the age range and Ethnicity of cared for person being referred.</p> <p>Number of assessment visits undertaken.</p> <p>Number of new Service Users receiving a Service.</p> <p>Number of Service Users waiting to receive a Service.</p> <p>Number of Service Users no longer receiving a Service.</p> <p>Categories of Cared for Person's disabilities.</p> <p>Age banding of Cared for Persons.</p> <p>Age banding of Carers</p> <p>Total of direct care hours provided per week.</p> <p>Number of direct care hours provided per person per week.</p> <p>Number of indirect care hours per week identifying training, supervision, travel, sickness and annual leave.</p> <p>Evidence of Carer and Cared for Persons feedback and consultation.</p>

Hastings & Rother Family Friends	588	<ul style="list-style-type: none"> <li>• The number of applications to be carers</li> <li>• The number of carers attending information sessions</li> <li>• The number of applicants starting registration</li> <li>• The number of registrations agreed by Panel</li> <li>• The number of links started</li> <li>• The number of breakdowns or links finishing</li> <li>• Monitoring of expenditure/budget, including annual audit of accounts</li> <li>• Management Committee meetings minutes, which will include the Organiser's report, and evaluation of the User questionnaires</li> <li>• Complaints and compliments</li> </ul>
Association of Carers Hastings & St Leonards	599	<ul style="list-style-type: none"> <li>• A general statement on the performance during the period since the last review.</li> <li>• Action taken to resolve issues identified at last review.</li> <li>• A summary of referral records.</li> <li>• Number of direct care hours provided per week.</li> <li>• Number of indirect care hours per week identifying training, supervision, travel, sickness and annual leave.</li> <li>• Evidence of Service User feedback and consultation.</li> <li>• Results of the current quality control system being operated by the Service Provider in accordance with paragraph 3.1 above.</li> <li>• An income and expenditure statement for the review period.</li> <li>• Details of issues the Service Provider would like addressed as part of the review. These should include any proposed amendments to the Contract and Service Specification.</li> </ul>
Hastings & Rother Crossroads Care Attendant Scheme	600	
Lewes District & Wealden MIND	Letter connected to contract 613	<p>No of breaks provided from the Carers Grant [1 break = 1 hour]</p> <p>No of breaks provided to BME carers</p> <p>No of carers receiving breaks, by client group [older people, physically disabled adults, adults with mental health problems, learning disabled adults, parent carers of disabled children]</p> <p>No of young carers receiving a break</p> <p>No of BME carers receiving a break</p> <p>No of older carers receiving a break</p>
Lewes District Mencap	634,635 and 680	<p>Outputs</p> <ul style="list-style-type: none"> <li>• Actual number of staff employed and volunteers used throughout the term of the Contract.</li> <li>• Number of days/hours facility operates, against specification.</li> <li>• Range of activities and services provided.</li> </ul>

		<ul style="list-style-type: none"> <li>• Number of direct care hours per person per week.</li> <li>• Number of non-direct care hours and how used in the following categories: <ul style="list-style-type: none"> <li>i) training (including a list of training activities attended)</li> <li>ii) travel</li> <li>iii) sickness</li> <li>iv) annual leave/Bank Holidays</li> </ul> </li> </ul> <p>Outcomes</p> <ul style="list-style-type: none"> <li>• User's comments</li> <li>• Examples of outcomes</li> <li>• Occupancy/attendance or take-up levels</li> <li>• Use of the Complaints Procedure and outcomes</li> <li>• Duration of placements</li> <li>• The number of individuals who stop attending and their reasons for leaving.</li> <li>• The number of new clients during the period under review</li> <li>• The results of monitoring activity undertaken by the Co-ordinator.</li> </ul>
Seaford, Eastbourne & Wealden Crossroads Care Attendant Scheme	637	<p>performance indicators:</p> <ul style="list-style-type: none"> <li>• Feedback from Service User and Dependent Relative</li> <li>• Review of comments and complaints</li> </ul> <p>The Service Provider will record the following statistics:</p> <ul style="list-style-type: none"> <li>• Number of referrals received</li> <li>• Number of assessments undertaken</li> <li>• Number of Service hours provided</li> <li>• Gender age and post code of children and young adults receiving a service.</li> <li>• Number of visits allocated</li> <li>• Number of monitoring meetings with Care Attendants.</li> </ul>
Lewes Area Crossroads	638	<p>performance indicators:</p> <ul style="list-style-type: none"> <li>• Feedback from Service User and Dependent Relative</li> <li>• Review of comments and complaints</li> </ul> <p>The Service Provider will record the following statistics:</p> <ul style="list-style-type: none"> <li>• Number of referrals received</li> <li>• Number of assessments undertaken</li> <li>• Number of Service hours provided</li> <li>• Gender age and post code of children receiving a service.</li> <li>• Number of visits allocated</li> <li>• Number of monitoring meetings with Care Attendants</li> </ul>

RETHINK	643	<p>Rethink will keep written records of meetings attended and contact with individuals or groups of carers:</p> <ul style="list-style-type: none"> <li>• Number of people referred ( including ethnicity, age and source of referral )</li> <li>• Number of people placed ( including ethnicity, age and source.)</li> <li>• Whether or not the person cared for had received a social care CPA assessment</li> <li>• The number of carers assisted to complete a Carers Assessment</li> <li>• The dates of short- term breaks</li> <li>• Amounts paid</li> <li>• Where the service was provided</li> </ul> <p>Effectiveness of Service Delivery Outcomes</p> <ul style="list-style-type: none"> <li>• Numbers of people being added to the Rethink carers database will be reported and discussed at contract monitoring meetings.</li> <li>• A report will be produced by Rethink summarising: <ul style="list-style-type: none"> <li>○ Development activity undertaken</li> <li>○ Involvement or liaison with CESP training programmes</li> <li>○ Volunteer recruitment and training activities undertaken</li> <li>○ Information distributed to support group carers</li> <li>○ Numbers of carers on the Rethink database at the beginning and end of the contract period</li> <li>○ The number of carers assisted to complete a Carers Assessment</li> <li>○ The number of service descriptions returned to CMHT's to form the basis of carer care plans.</li> <li>○ The figures showing the use of the funds for respite/ short term breaks</li> </ul> </li> </ul> <p>Quality of Services for Users and Carers</p> <ul style="list-style-type: none"> <li>• Records of meetings attended and contact with carers database will be reported and discussed at contract monitoring meetings.</li> <li>• Development activity undertaken to assist in the creation of self-help groups and numbers of volunteers recruited will be summarised for discussion at contract monitoring meetings.</li> <li>• Publicity material explaining the project will be agreed at contract monitoring meetings.</li> </ul>
East Sussex Disability Assn	646	<ul style="list-style-type: none"> <li>• number of enquiries received,</li> <li>• the source of the enquiry (i.e. how the service user knew about the scheme)</li> <li>• the residential district of the enquirer (i.e. Lewes, Wealden, Eastbourne, Hastings or Rother)</li> <li>• the type of enquirer, i.e. Carer, Service User or Other</li> <li>• records of each holiday, to include the following: <ul style="list-style-type: none"> <li>○ Holiday advertisements (where and when)</li> <li>○ Holiday venue</li> </ul> </li> </ul>

		<ul style="list-style-type: none"> <li>○ Unsubsidised cost of each holiday place</li> <li>○ Residential district of each Service User</li> <li>○ Age of each Service User (i.e. under or over 65)</li> <li>○ Gender of each Service User</li> <li>○ Disability of each Service User (physical, learning, mental health)</li> <li>○ Level of subsidy (where applicable)</li> </ul> <ul style="list-style-type: none"> <li>● details of the mechanism used to prioritise the award of subsidies</li> </ul> <p>Complaints and compliments received</p>
Care for Carers Youthability	664	
Care for the Carers	752	<p>To inform the September review, the Service Provider will forward to the Pooled Fund Manager a report on the performance of the Agreement. This report is to be forwarded two weeks prior to the review meeting and will contain the following information:</p> <ul style="list-style-type: none"> <li>● A brief general statement on the performance of the Service during the period under review, including new services developed and potential development.</li> <li>● Staffing structure including names of post-holders and hours of posts.</li> <li>● Board of Directors membership and notification of changes.</li> <li>● Number, sources, age, gender, ethnicity and caring situation of referrals.</li> <li>● Number of new Carers identified.</li> <li>● Feedback on Carer awareness from Primary Care Practices.</li> <li>● Overview of annual survey of Service User reviews.</li> <li>● The number of young carers reached and their ages.</li> <li>● The average number of hours spent with young carers on an individual or group basis.</li> <li>● The number of hours provided away from the care environment to provide a break from caring.</li> <li>● Extent and content of Carers skills training.</li> <li>● Information provided, including means of communication and to whom the information was given.</li> <li>● Number of carers helped by the Back Care Service.</li> <li>● Number of referrals to advocacy services.</li> <li>● Details of outcomes of complaint investigations undertaken.</li> <li>● Details of Health and Safety incidents and actions taken following such incidents.</li> <li>● Copies of insurance documentation showing currency of Public and Employers Liability and levels of indemnity limits.</li> <li>● Income and expenditure statement for the review period.</li> <li>● Audited accounts for the previous financial year.</li> <li>● The proposed budget for Care for the Carers for the next financial year.</li> </ul> <p>Such other documents as the Purchasers may from time to time require in writing</p>

CAPE Summer Play scheme	Letter	<ul style="list-style-type: none"> <li>• No of breaks provided from the Carers Grant [1 break = 1 hour]</li> <li>• No of breaks provided to BME carers</li> <li>• No of carers receiving breaks, by client group [older people, physically disabled adults, adults with mental health problems, learning disabled adults, parent carers of disabled children]</li> <li>• No young carers receiving a break</li> <li>• No of BME carers receiving a break</li> <li>• No of older carers receiving a break</li> </ul>
Mencap Eastbourne Hive of Activity	Letter	<ul style="list-style-type: none"> <li>• No of breaks provided from the Carers Grant [1 break = 1 hour]</li> <li>• No of breaks provided to BME carers</li> <li>• No of carers receiving breaks, by client group [older people, physically disabled adults, adults with mental health problems, learning disabled adults, parent carers of disabled children]</li> <li>• No young carers receiving a break</li> <li>• No of BME carers receiving a break</li> <li>• No of older carers receiving a break</li> </ul>







# **Appendix 2: Questionnaire**

**UNIVERSITY OF BRIGHTON  
RESEARCH INTO CARERS SERVICES FOR EAST SUSSEX  
SOCIAL SERVICES**

If you are a carer please help us by filling in the questionnaire below.

**1. Where do you get information on caring?**

*(Please tick all that apply)*

- |                         |                          |                          |                          |
|-------------------------|--------------------------|--------------------------|--------------------------|
| Crossroads              | <input type="checkbox"/> | District/Community Nurse | <input type="checkbox"/> |
| Care for the Carers     | <input type="checkbox"/> | Health Visitor           | <input type="checkbox"/> |
| Other national/local    |                          | Social Worker            | <input type="checkbox"/> |
| Voluntary organisations | <input type="checkbox"/> | School                   | <input type="checkbox"/> |
| GP                      | <input type="checkbox"/> | Other carers             | <input type="checkbox"/> |
| Consultant (hospital)   | <input type="checkbox"/> | Friends/family           | <input type="checkbox"/> |
| Don't know              | <input type="checkbox"/> |                          |                          |
| Other (please specify)  | -----                    |                          |                          |

**2. Which of the following services do you receive?**

*(Please tick all that apply)*

- |   |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|
| Home visitor  | <input type="checkbox"/> | Home Sitters             | <input type="checkbox"/> |
| Respite care  | <input type="checkbox"/> | Care with another family | <input type="checkbox"/> |
| Day care  | <input type="checkbox"/> | House cleaning           | <input type="checkbox"/> |
| Home care   | <input type="checkbox"/> | Gardening/maintenance    | <input type="checkbox"/> |
| Help from voluntary organisation i.e. Care for the Carers | <input type="checkbox"/> | No services received     | <input type="checkbox"/> |
| Other service (please specify)                            | -----                    |                          |                          |

**3. How much help do you receive from social services or other agencies *(Please tick one box only)***

- None       1-19 hours       20-49 hours       50+ hours





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