

Carers in Kent



**A REVIEW BY A SELECT COMMITTEE APPOINTED BY
THE ADULT SOCIAL SERVICES POLICY OVERVIEW
COMMITTEE**

PARTS I AND II

CHAIRMAN: MR L CHRISTIE



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FOREWORD

If ever there was an opportune time for this issue of unpaid “Carers” to be considered it would be now. There are approximately 128,000 unpaid carers in Kent ranging from mothers with children with learning difficulties; young carers looking after their parents to octogenarians caring for their spouses with dementia. The whole community owes a great debt to those unpaid carers without whom the whole system would undoubtedly collapse. Thanks to improved Health Care the number of people requiring Carers will inevitably increase over future years so this is an issue which cannot and should not be ignored.

There is no doubt that “social care” including Carers will, over the next few years, take centre stage in the political arena and Government has recognised this by creating a Standing Commission on carers and by committing to an imminent Green Paper on Social Care. The Select Committee hope their considerations and recommendations will form a significant part of Kent County Council’s input to the Green Paper. Through this review a number of key issues have been identified that are crucial and fundamental in supporting carers to continue to care. These include the importance and need for respite and short breaks for carers; improved sign-posting to services, identification of carers and referral for carers assessments; and in particular to find ways to support young carers.

We are grateful to those in the Caring Community who took time to provide evidence to the Select Committee and hope that they feel that many of their concerns are reflected in the Select Committee’s Report. The role played by the Voluntary Organisations is invaluable. We recognise that there are finite resources available and limits to what the dedicated staff of Kent County Council can do, but hope perhaps we have helped to set an Agenda which will find support from both Government and Kent County Council for the future.

I would like to thank all my colleagues on this Committee for their contributions and support as well as the many professionals and individuals who provided evidence.

Thank you all

Mr Leslie Christie
Chair of the Select Committee

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Abbreviations and Terminology

AIF	Area Investment Framework
ASPU	Adult Services Provider Unit
CATT	Crisis Assessment and Treatment Team
CAF	Common assessment Framework
CBT	Cognitive Behaviour Therapy
CSS	Children's Social Services
CPN	Community Psychiatric Nurse
CRHT	Crisis Resolution Home Treatment
DoH	Department of Health
GSF	Golden Standard Framework
ICT	Information Communications Technology
KASS	Kent Adult Social Services
KCC	Kent County Council
KTA	Kent Tourism Alliance
LAC	Looked After Children
MIST	Mental Illness Support Team
NHS	National Health Service
OoH	Out Of Hours
PCT	Primary Care Trust
POC	Policy Overview Committee
QAF	Quality Assessment Framework
VCO	Voluntary Carer Organisations
¹²³	End Note to report to give source of information or reference

Acute Mental Illness

Acute mental illness is characterised by significant and distressing symptoms of a mental illness requiring immediate treatment. This may be the person's first experience of mental illness, a repeat episode or the worsening of symptoms of an often continuing mental illness. The onset is sudden or rapid and the symptoms usually respond to treatment.

Alzheimer's Disease

A form of dementia characterised by the gradual deterioration of brain tissues and brain function. The effects progress from mild forgetfulness and confusion to a permanent inability to perform routine life tasks, for example making a cup of coffee or putting on one's clothes.

Dementia

A group of brain disorders that most commonly occur in old age, although sometimes could develop earlier. They are the result of brain tissue deterioration. Common features include decline in the ability to recall recent and past events, decline in mental functioning (for example, may not be able to make simple calculations or organise a routine task) and the person behaving in ways considered out of character for him/her.

Mental Health

Describes the capacity of an individual to interact with other people and with the person's environment in ways that promote the person's sense of well being, enhance their personal development and allow the person to achieve their life goals.

Psychiatric Crisis

Psychiatric crisis describes the situation where a person with a mental illness or severe mental disorder experiences thoughts, feelings or behaviours which cause severe distress to him/her and those around him/her requiring immediate psychiatric treatment to assess and manage risk and alleviate distress. The acute stage of a mental illness is characterised by infrequent yet severely distressing symptoms that require immediate treatment. This may be the person's first experience of mental illness, a repeat episode or the worsening of symptoms of an often continuing mental illness.

Severe Mental Illness

A mental illness in which a person's ability to think, communicate and behave appropriately is so impaired that it interferes with the person's ability to deal with ordinary demands of life. Without effective treatment and support, the outcome for the person may be significant impairment, disability and/or disadvantage.

Executive Summary and Recommendations

Carers have identified a number of needs as crucial and fundamental in supporting them to continue to care. These include breaks from caring, adequate respite care for the person being cared for (the client), better services from both the local authority and health authority, access to information, and greater involvement in decision making relating to the client.

Information is a key priority as carers use it to have choice and control, access available services, claim benefits and understand the system. A common theme emerged was in relation to the difficulty people have of accessing the right information at the right time. Once Carers are 'in the system' or known to the Carer Support Organisations there was general consensus that access to information was good, it was more an issue of finding out about services in the first place or discovering what path to follow. Many carers are unaware of the services that are available from voluntary organisations and statutory bodies or how to access them. There was a clear need for co-ordination especially around where to go for help initially.

Communication is paramount and key messages to carers need to be repeated and targeted at, for example people new to caring and hidden carers. Improving awareness and early sign-posting of carer support organisations and targeting of information at carers in the first year of caring is crucial. As well as Social Services, the Health Sector, General Practices, and others such as pharmacies have a key role to play as they are most likely to be the first point of contact with many carers. Information, advice and support is a 24/7 requirement, but this is not currently available. The identification of hidden carers remains a priority, and is the joint responsibility of Social Services as well as education services and Health as early identification and referral to carer support services can prevent crisis and carer breakdown. An Adult Carers Strategy could have the potential to develop joint action to target hidden and new carers, and raise the profile of carers and carer support organisations, potentially pooling resources.

Carers need assessments backed up by preventative support, essential to sustaining the carer role. Carers needs often change due to changing circumstances and it emerged that these are often not identified or met before crisis. There is a need for a two way process between care managers and carers and to reinforce the relationship that exists, and a smoother process for regularity of reviews. There should be regular contact and carer reviews annually as a minimum.

KCC has developed and supported a wide range of preventative services and invested in/financially supported the Voluntary Sector, who provide a broad range of services to carers. The services provided by the Voluntary Sector are numerous and can appear fragmented, growing/changing over time in response to area needs and resources available. There is a perception that allocation of funds is also partly historic and does not take full account of the number of carers supported or service being provided. The services provided by the sector are highly valued but there is concern that many services have considerable waiting lists, with a lack of resources to meet demand, increases in numbers referring and increased levels of need for support and distress.

Respite and short breaks are essential to carers welfare, providing a break and enabling many to continue to care. KCC has developed a system of short breaks and longer-term respite and sees its continued partnership and investment in the Voluntary sector as crucial. However it is clear that the quantity of respite provided in the locality is not enough for a substantial number of carers and that flexible respite options need to be extended further, and a more co-ordinated approach taken.

The development of a multi agency Adult Carers strategy and action plan is a clear priority. It would give a clear direction to commissioners about the future services that need continued support and those that need to be developed. It is important that all organisations acknowledge their responsibility for supporting carers and actively work together to do so. A broad range of issues has been identified by this review and there is an underlying need for a more strategic joined up approach to addressing them. Although the need for a multi Agency strategy was agreed in October 2006, there is little evidence of progress and should now be taken forward as a priority.

Young carers are one of the most vulnerable group of children and young people for whom KCC has responsibility. The impact of being a young carer can be significant. Only a small proportion of young carers in Kent access the young carers projects and it is estimated that only a small proportion of young people accessing these projects are known to services. It is important to recognise that other than education, young carers may not access services provided by local authorities and are unlikely to have knowledge about services available. It was clear that often young carers remain unknown to their schools. It is also important to acknowledge that not all young carers will want schools to know that they are caring, and that some young carers will actively seek to hide their caring role for fear of ridicule by peers or the intervention of statutory agencies. Education has a key role in supporting young carers, especially as this may be the only service in contact with young carers. The young carers multi-agency strategy 'Invisible People' was welcomed, and the recent development of an accompanying commissioning strategy to back this up should ensure that steps to improve support for young carers are evident on the ground.

The health sector has a key role to play through identifying carers and sign-posting carer support services/organisations, and it was clear that more could be done in partnership with General practices. The need to support carers of mental health patients was particularly highlighted especially at times of crisis and out of hours.

Confidentiality continues to be an issue. Carers reported that their views are not listened to, that there is a lack of information due to privacy laws, which can create barriers for carers and that carers of people with mental health needs find it difficult to access the support they need. Carers particularly expressed the need for support to help with coping strategies and the importance of improving communication with and for carers.

Recommendations to improve outcomes for carers

Communication and Access to information (section 6.0)

1. **Need to raise awareness and profile of carers and carer support services and make information available out of standard hours.** Initial contact is difficult, but once in the system information is readily available. Need to consider campaign about local services and find innovative ways to raise the profile of carers, where to find support and what support services are available. Access gateways to services need to be knowledgeable of services for carers in area. However raising the profile and access to information needs to be backed up by tangible support (whether financial, emotional or practical) to remain credible. The focus of information services should be reviewed to assess options for providing support and information outside of normal office hours.
2. **Promote single point of contact for carers** – Carers are often unaware of entitlements, support networks and help available and the diversity of sources of information are confusing and often overwhelming. Need simplified way to make contact for initial guidance, and possibility of a one-stop shop approach should be explored. It should also be ensured that the contact centre has the knowledge/training in order to refer carers appropriately.

Carers Assessments (section 7.0)

3. **The involvement of the Carer Support Organisations at assessment and subject to carers consent sharing the statutory assessment should be considered**, and need to ensure carers are informed that they can have someone present at their assessment – e.g. a friend, advocate or interpreter.
4. **Reviews or contact from Care managers should be regular with annual reviews as a minimum.** This issue needs to be addressed. Case management to have systems in place so improved contact and carers regularly asked if circumstances have changed and ensure reviews are carried out annually (as a minimum). There should also be a general target for time taken following a request for a review before it is undertaken.

Support Services (section 8.0)

5. **District Social Services Teams to address and overcome issues around call management** and ensure improvements are made around response and accessibility of team members.

Emergency Support for Carers (section 9.0)

6. **Emergency Card Schemes, backed up by emergency plans and response teams should be expanded and developed kent wide if the pilot is successful.** If successful a Kent Carers Emergency Card scheme, rather than individual district based schemes should be considered with a commitment to have an emergency plan for all carers, with every carer to be offered access to a scheme.

Respite and Short Breaks (section 10.0)

7. **KCC together with Health and VCO's need to ensure that provision of respite/breaks is flexible, of the right type and that provision meets the needs of carers as well as the cared for person.** It was clear that carers value this service and that there is simply not enough, and not always the right type of respite available to meet growing demand. There needs to be a multi agency plan and commissioning strategy to address identified issues and gaps, developing a more co-ordinated approach to access and provision of respite locally for carers. KCC to pursue with Health the need for **appropriate respite options for people with mental health needs and their carers and issues around levels of provision in the county.**

Adult Carers Strategy (section 11.00)

8. **Multi Agency Adult Carers Strategy to be progressed as a priority** and agreed within a mutually agreed time frame, suggested within a year as a maximum. The strategy needs to be realistic and developed through a commissioning plan.

Young Carers (section 12.00)

9. **Need to ensure that awareness is raised within schools to increase understanding of what it means to be a 'young carer', and find ways to identify and support Young carers.** Each identified young carer should have a support plan and also ensure that specific reference to young carers is incorporated in anti bullying policies. The support for young carers in schools needs to develop an understanding of their needs, developing a flexible approach to meet those needs and referring them onto other resources and agencies as appropriate. The Common Assessment Framework (CAF) will be key to identifying the needs of young carers for all services.
10. **Consider the need for a clearly identified lead professional for young carers on CSS operational front and education, alongside those for policy/strategy.** Young Carer support projects give the opportunity to support young carers, for young carers to meet together and also provide a good contact point for services. There is an opportunity for lead professionals to build on the relationships that already exist and harness knowledge/experience of young carer projects to increase awareness/understanding within schools and other services. The Committee hope that the CAF will help in the identification of Lead professionals for young Carers.
11. **Need to ensure clear responsibilities and referral pathway for young carers between Kent Adult Social Services, and CFE and other agencies, and ensure that protocols between Kent Adult Social Services and Children's Social Services are developed as a matter of urgency.**
12. Invisible People – the multi agency young carers strategy and accompanying commissioning strategy (currently in draft) should be implemented urgently and monitored to ensure objectives and targets are met. Regular updates on progress and issues should be reported to the Children's Trust Board, Chief Executive and Policy Overview Committee.

Health sector (section 13.0)

13. KCC in partnership with Health and the VCO's need to **improve understanding and signposting from Health sector** to available help and support for carers in the county. (Multi Agency action).
14. KCC to pursue with Health the **need to consider how carers of mental health patients (and service users) can be better supported, particularly at times of crisis and out of hours**. Access to response support service in crisis is a key issue for carers, and needed especially out of hours and for those not meeting CATT criteria, as timely support can prevent harm and further deterioration and increased pressure on the carer. Need to give consideration to response times, communication, and consider how carers/families can be better supported, to enable them to cope more effectively with crises, psychotic episodes and emotional strain of caring.

NB: see also recommendation 7 on type and provision of respite services in the county (respite was discussed in section 10.0 and 13.25).

SECTION ONE: INTRODUCTION

1.0 The Carers Select Committee

1.1 Kent County Council is the democratically elected strategic authority for Kent. It has the broad power to promote and improve the social, economic and environmental well being of the area and has the statutory responsibility for the provision of a range of services. The Local Government Act 2000 laid out new procedures for the reform and modernising of local government. One of its main aims was to increase openness and accountability within local government, with local people playing a greater part in shaping and receiving better services. On 1st September 2001 Kent County Council adopted a new Constitution introducing a new political structure with a Leader and a single-party Cabinet taking most of the decisions previously taken by all-party service committees.

1.2 Under the new Constitution elected Members outside the Cabinet can contribute to the development of policy through the appointment of Policy Overview Committees, which focus on different services provided by the County Council. The Policy Overview Committees help and advise the Council, the Leader and the Cabinet on the development of the Council's policies and review the Council's performance compared with objectives and targets. The Policy Overview Committees have the power to set up smaller Select Committees to look in depth and review particular policy issues by way of topic reviews. The all party Select Committees are made up of Members from the different political parties proportional to the number of Council seats held by each party.

1.3 In June 2007, an eight Member Select Committee was set up to carry out a review of key issues for carers. The Members of this Select Committee were Mr L Christie (Chairman); Mrs M Newell; Mr A Chell; Mrs V Dagger; Mr G Curwood, Mr G Koowaree, Mr D Hirst, Mr G Horne

1.4 The Terms of Reference for the Select Committee were to:

- (a) consider what support carers require to assist them in their caring role, how needs are met and how this can be delivered
- (b) consider all carers, including young carers and hard to reach carers
- (c) understand what needs to change to improve outcomes for carers

1.5 Kent County Council has adopted the following definitions of carers, and this was mirrored by the Select Committee.

“Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.” Carers UK

“Young carers are, regardless of their cultural, social, ethnic and religious background, under the age of 18 years looking after or helping to look after, a family member suffering from a long term illness, disability or dependency on substances. They may undertake a range of caring tasks and assume physical and emotional responsibilities normally carried out by an adult.”

1.6 The list of witnesses to the review is given in Appendix One.

2.0 The National and Local Policy Context

The National and Local Policy Context are given as a summary in Appendix Two.

3.0 Overview of issues facing carers nationally

3.1 There are a range of different support needs:

- Carers need a break from caring, which includes adequate respite care
- Access to information and advocacy
- Greater involvement in decision making in relation to the service user

3.2 Research shows concerns are:

- Lack of information
- Knowing where to go initially to get help
- lack of understanding of eligibility for financial assistance and support
- Undertaking work, education, training and leisure opportunities can be difficult to fit around their caring role, and often do not have the support to enable them to do that ... Carers assessments could address some of these issues.

3.3 Carers UK (Back me up) ¹² research found that:

- Carers do not know who to contact to sort out alternative care
- Emergency services take too long to respond
- Replacement care often not available in an emergency, unreliability
- Carers unable to support family members at critical times such as through terminal illness or bereavement, as no replacement care.

3.4 Research (National Carers Strategy)¹ suggests what is significant in helping carers to continue to care includes

- Time off from caring
- Relief from isolation
- Receipt of reliable and satisfactory services
- Information
- Recognition of their role and contribution.

3.5 Lack of appropriate support can have significant impact on Carers. Caring can be both physically and mentally demanding. Carers who provide substantial care may be on 24 hour call. Research indicates that Carers are twice as likely to suffer from mental illness if they do not get a break from caring, and a 1/3 of carers (35%) without good social support suffered ill-health compared to those with good support (15%).²

3.6 Carers also report that care which is not appropriate, either poor quality, not the right kind, or not sufficiently flexible places extra stresses and strains on them.³

SECTION TWO: THE NUMBER OF CARERS

4.0 The National Picture

4.1 The 2001 Census provides a national and local picture of the number of carers with age, ethnicity, housing conditions, employment and educational status. It suggests that:-

- There are around 5.2 million carers in England and Wales.
- Since 1990 the number of carers providing support for 20 hours or more every week has increased substantially from 1.5 million to 1.9 million in 2001.
- The number of carers providing 50 plus hours or more a week has also increased.
- There are many explanations for this rise, but likely the trend towards caring for people in their own homes, the ageing population, advances in medical treatment increasing survival rates for children with profound or multiple learning disabilities all contribute to this.
- Women are more likely to become carers than men (58 % of carers are women)
- The peak age for caring is 50-59 (more than 20% of people and 25% of females in this age bracket provide some form of unpaid care).
- Nationally there are 175, 000 young people under the age of 18 who regularly provide care, with just over 13, 000 providing care for more than 50 hours a week.
- The number of carers is set to grow from 6 million to 9 million by 2037.

(Source: National report for England and Wales, Census 2001, National statistics; Carers UK, 2005 Facts About Carers).

Table 1: Number of carers providing care by age in the United Kingdom

United Kingdom				
	All providing care¹		Percentage providing 50 hours or more care	
	(thousands)			
	Males	Females	Males %	Females %
5-15	53	61	7	8
16-24	125	165	8	13
25-34	230	376	15	23
35-44	422	665	17	21
45-54	613	896	15	17
55-64	519	697	19	23
65-74	319	370	31	34
75-84	155	149	44	44
85 and over	24	20	54	47
Total	2,460	3,399	20%	22%

¹ Those who provide unpaid care, giving help or support to family members, neighbours, relatives or friends.
Source: Census 2001, Office for National statistics.

5.0 The Kent Picture

5.1 The 2001 Census 'Key statistics for local people' suggests that there are an estimated 127,848 carers in the KCC area. This equates to 12.6% of the population and is higher compared to the national average of 10% (illustrated in Graph One below).

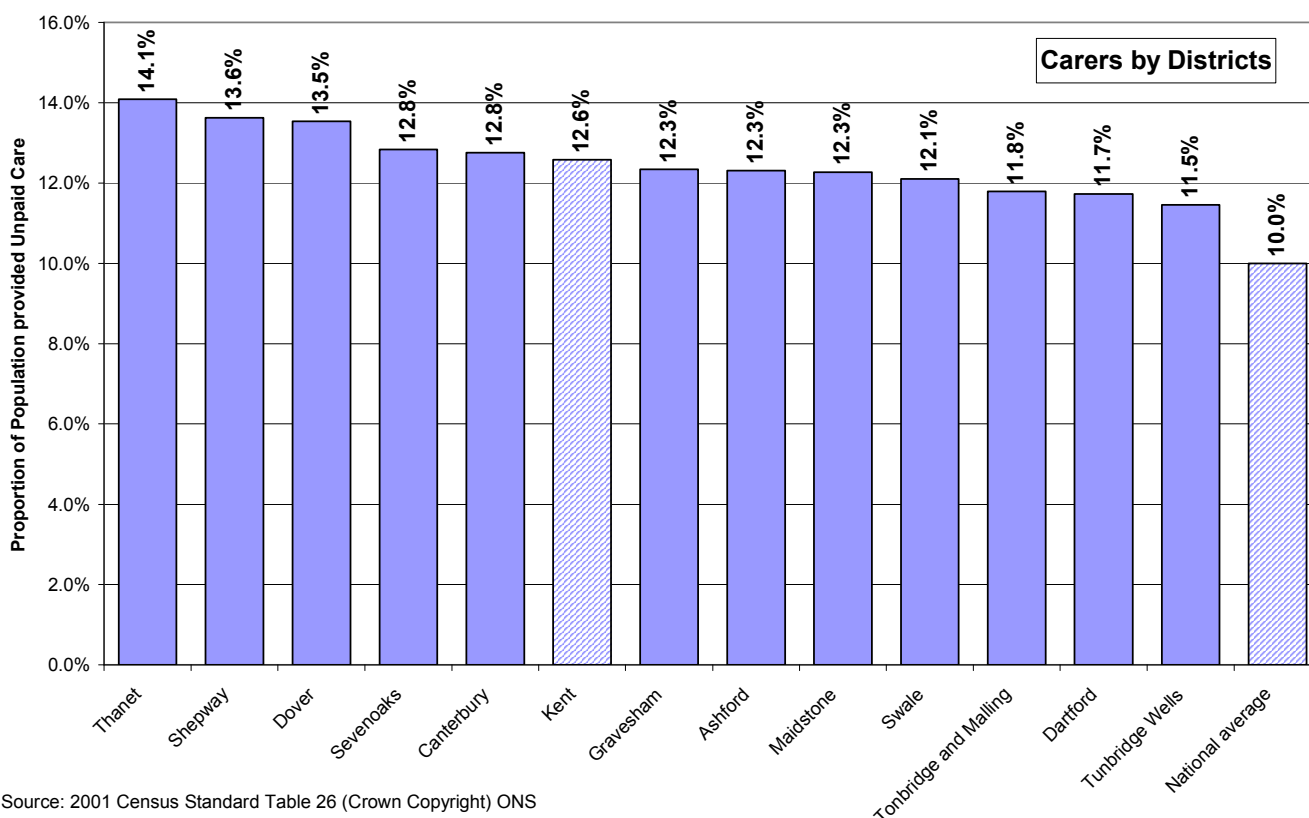
5.2 The census also indicates that there are 25,203 carers who provide more than 50 hours care every week. Table 2 below shows the number of carers by hours of care provided per week as a percentage of all carers.

Table 2: number of carers in KCC area by hours of care provided

All carers (KCC area) – 127,848		
Hours of care per week	Number of carers	% of all carers
1-19	90,752	71%
20-49	11, 893	9.3%
50+	25, 203	19.7%

Source: Census 2001 ONS

Graph 1: proportion of the population providing care by KCC district areas.



5.3 Older Carers:

Of the total number of carers in the KCC area the number of people over 50 with caring responsibilities was 16% of the over 50's population compared to 12.6% of the general population. 19% of Carers in the KCC area are over the age of 65. There are 8,110 older carers over 65 providing more than 50 hours care a week i.e. 33% of

carers over 65. The statistics point to a disproportionate number of older people being involved in caring for friends, relatives or partners. Table 3 gives further detail of carers by age and number of hours of care provided per week.

Table 3: number of carers by number of hours of care provided

All Carers KCC Area			
	All providing care		
	1 to 19 hours	20-49 hours	50 or more hours
5-15	1,806	145	151
16-24	3,996	492	474
25-34	7,477	1,059	2,288
35-44	15,063	2,242	4,231
45-54	26,541	2,921	4,803
55-64	21,743	2,722	5,146
65-74	10,175	1,451	4,564
75-84	3,530	731	3,009
85 and over	421	130	537
Source: Census 2001, Office for National statistics, standard table 25			

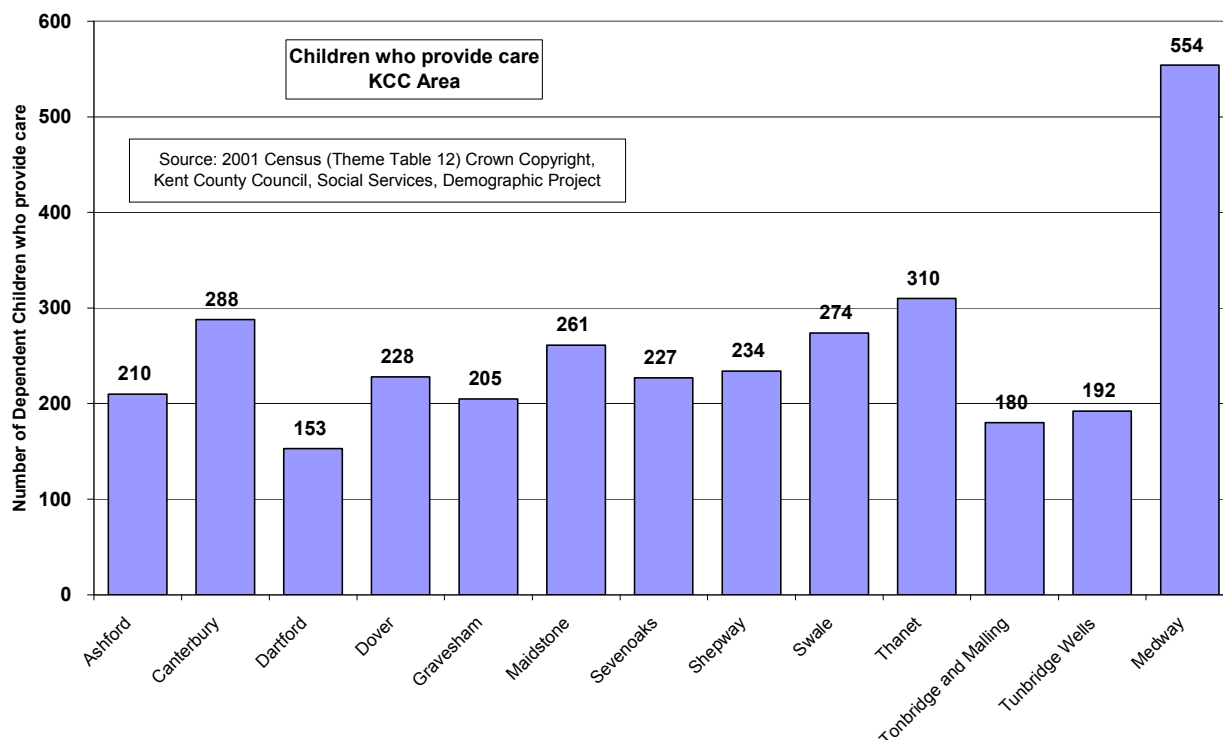
5.4 Young Carers:

Of the total number of carers in Kent there are an estimated 3,324 young carers, 2.6% of all carers.⁴ Table 4 illustrates the number of hours of care provided by young carers by age group, and Graph 2 illustrates the number of young carers by district, including those over 17 still in full time education.

Table 4: Young Carers by age and number of hours of care provided in the KCC area

All carers – 127,848			
Young carers	1 to 19 hours	20-49 hours	50 or more hours
0-4	-	-	-
5 to 7	106	6	24
8 to 9	148	15	15
10 to 11	334	30	27
12 to 14	848	57	67
15	370	37	18
16-17	942	85	57
(Source: Census 2001 Standard Table 25, Office for National Statistics)			

Graph 2: Numbers of Young Carers by District



5.5 Number of carers:

It is acknowledged that the Census 2001 figures reported are possibly substantially lower than actually exists and that there are a large number of hidden carers. These estimates are often in sharp contrast with the number of people who are known to services and number of carers registered on a Carers register. There are probably many carers who provide care but do not recognise themselves as carers, and see caring as a natural responsibility or as a 'duty', or who may provide a few hours of care each week and do not class themselves as carers. Others, in particular young carers can be fearful about coming forward, families can be fearful of statutory intervention and a reluctance to have their role recognised by their peers. The next census in 2011 will provide a clearer picture of the changes and numbers of carers as much may have changed since 2001.

5.6 There is a need for responsive and flexible services and recognition of the role of the carer to enable people to stay at home and remain independent for as long as possible. A concern is some carers are unknown to statutory or voluntary agencies, and are therefore not known by support services and are unaware of available help or support to help them to continue to care and live their own lives. There is a need for effective local strategies to identify carers and to refer them to services or for help where needed.

5.7 Type of care given by carers:

Carers carry out a range of tasks to support the person they care for. This may vary from visiting neighbours to check they are alright to intensive physical care and support for the person they care for. The type of care provided will be dependent on the condition of the cared for person. For some carers the care they provide can be particularly demanding, as the cared for person could be highly dependent, have challenging behaviour and have care needs that do not diminish as they become older.

SECTION THREE: FINDINGS/ SERVICE GAPS

6.0 Communication and Access to information and support

6.1 Information is a key priority for Carers in Kent as they use this to have choice and control over their lives, apply for benefits that could make a difference to their lives, or to access support services and understand 'how the system works'.

6.2 It was highlighted that information needs to lead to tangible support, whether financial, emotional or practical to continue to be credible with carers.

6.3 Information, Hidden Carers and Turnover of Carers

Many carers are hidden as they are not known to services and perhaps do not identify themselves as carers. If a carer is hidden it is possible that they may not access the benefits they are entitled to or practical support available to them. If carers do not get the financial and practical support they need they are vulnerable to a poor quality of life, cutting back, having their health and well being seriously affected, and their ability to continue to care diminished.

6.4 It is acknowledged that reaching new carers can be difficult and that this is compounded by the high rate of turnover of carers, those new to caring and those who cease caring. 'IN The KNOW', a report by Carers UK estimates that in Kent there are around 47,000 new carers every year, around 37% of carers, and a similar proportion who cease caring, based on census 2001 data. The turnover rates of people who start caring and those that cease caring can help inform planners of local services when targeting information to carers. The report states that it is critical that information strategies target carers in that crucial first year of caring, that messages are repeated and carefully targetted to ensure that carers do not miss out on their entitlements, and that they access support to enable them to continue to care.⁵

6.5 The Carers (Equal Opportunities) Act 2004 places a duty on local authorities to find 'hidden carers' and reinforces the duty of the NHS to co-operate with LA's in order to advance people's health and welfare, yet ensuring carers have access to useful information remains difficult. The NHS has a clear role and responsibility in identifying carers and signposting them to appropriate support services. This is discussed in greater detail in paragraphs 6.8-6.9.

6.6 A Kent Adult Carers strategy should clearly acknowledge new carers and demonstrate practical steps in which to address information needs and the turnover of carers. There is a need to advise carers who are at the end of caring, helping them to return to work or plan for the future, to plan for people new to caring and to reach hidden carers who might have been caring for years unaware of their benefits and entitlements.

6.7 Access to information:

Information at the right time is of key importance, as 'little knowledge about support provided by the NHS, Social Services, other parts of the local authority and voluntary organisations can have a long term negative impact on carers' health and well-being'. (Carers UK – in poor health).⁶

6.8 A common theme that emerged was the difficulties carers had in gaining access to the right information and support at the right time. Carers were **unsure of where to go for initial information**, relying on word of mouth, many telephone calls or until assessment to find out about carer support organisations. Many Carers may have been some considerable time without support, and for some a while before they realised they were a carer.

“most carers referring to our service will have cared for prolonged periods prior to making contact ... the vast majority of referrals are from carers normally with an immediate need and increasingly from families facing some form of crisis or carer breakdown”

The responses **clearly identified a lack of awareness of what support is available and difficulties in accessing the system/finding the right path to follow**. The process of finding out what exists is difficult and takes too long, while some carers who access services feel they are unaware of all the services available to them. For many carers it takes a long time to find out about the carer support organisations, despite distribution of leaflets to G.P. surgeries and Mental Health Teams etc. It was commented that Reception Staff who deal with incoming calls and can be the first point of contact for carers often do not know where to refer carers. It was noted that **once carers were in touch with Carer support projects there was very positive feedback for the support received and the information and advocacy provided**. The services provided by Carer support organisations were reported as excellent by the majority of carers who highlighted these services. (Two projects that were particularly highlighted by carers writing to the Select Committee were Maidstone Carers Project and Dover District Carers Support, and information leaflets produced by the Maidstone Carers Support Service were highlighted as good examples and very useful.)

6.9 Accessing information from KCC for carers is described as difficult, and not well supported. Carers require immediate access to timely information and support, particularly from KCC and Health, and early referral to Carer Support organisations as

“Earlier referral to a carer service would in many cases have prevented or alleviated the results of the crisis or possible carer breakdown”.

Information is critical to carers in their first year of caring, therefore there is a clear need to engage with carers where they are likely to visit and request advice. **Improving the referral process and sign-posting is key by social workers, but also GPs and hospital staff as carers may have contact with these professionals before social services or the voluntary sector**. It was suggested that this did not need to be complicated and that an auto referral process could be adopted subject to consent. It is also key that as carers often do not acknowledge that they are carers for some time that assumptions are not made about longer term carers knowing all about their rights and entitlements. **Information strategies need to repeat simple messages, target new carers at point of contact and equally to plan to support those carers who cease caring**.

6.10 Some carers have the perception that KCC does nothing for carers, although these carers receive support from Voluntary Organisations substantially funded by KCC. It is clear that the Voluntary Sector Carer support organisations are the key

route to accessing information for Carers. **Carers highlighted the excellent service provided by carer support projects locally**, commenting on the reassurance that support was just a telephone call away. The committee also heard that information is a 24/7 requirement and that access to information and support to carers is too focused on office hours Monday to Friday. The need to **make information available out of standard hours** was highlighted. Many informal carers provide care 24/7 and may need support and information outside office hours. Working carers also found it difficult to access carer support groups and information. It can be difficult to attend groups, make contact in private or to see someone individually. It was suggested that carer support groups could be run on different days/or at different times and that the focus of services be reviewed to assess options for support and information outside of normal office hours.

6.11 Having information available is important but there is still concern remaining about **making contact with the vast number of carers who are not known**. In some cases this is matter of individual choice and should be respected. However people must know what is available and how it can be accessed. Raising the profile of carers and wider understanding and recognition of the role carers play is also important as many carers will not access information for carers as they do not recognise themselves as one.⁵ The recent 'Carers Week' was praised for the work it did to give carers a voice and raise the profile of carers in Kent.

6.12 Volume of literature/information

Carers highlighted the need for a single point of entry to services and information. It was apparent that the diversity of sources of help can be confusing and the volume of information overwhelming, and can make it difficult to discover what route to take. The Voluntary Organisations praised the 'Thistle packs' given to new clients by social services, but found that clients were often overwhelmed by the mass of literature. The Voluntary Organisations can help prevent crisis if they are involved with carers in the early stages and commented on the benefits of staff directly referring clients to them (not all do). The Carer Support organisations should be jointly promoted as initial contact points or as "one stop shop" for carers, and continue to work closely with other voluntary organisations providing support.

6.13 Carers website

The Kent Carers website should be celebrated but also need to acknowledge that it will not solve all the issues. It is important that carers have the information they need at the first point of call. Generally awareness of KCC carers website is low. It was highlighted that websites were not always the best way of communicating information, that an assumption that because information is on the 'www' everyone has access and that information providers should not be complacent that the job is done because www exists. Carers commented that in contrast a real human voice is less overwhelming, reassuring and positive. The impact and effectiveness of information strategies need to be assessed/considered to develop a more strategic approach that ensures information is received by carers at the right time. Information needs to be targeted at key contact points with carers (many of whom may not come into contact with social services), new carers and carers that cease caring.

6.14 Language

There is a continued need to reduce confusion around the term carer by using clear language distinguishing between paid careworkers and carers – who care, unpaid, for family, relatives, friends who have a disability, chronic illness or frailty. Many do not recognise themselves as carers – clear understanding would help carers to access the support they need.

6.15 Benefits

It has long been recognised that there is a considerable under claiming of Social Security benefits nationwide. Claiming entitlements can have significant impact on carers lives through additional spending on essential items such as food, heating, increased mobility, respite and practical support. Further improvements include greater independence, greater choice, more participation in the community and an improved sense of identity.⁷ Three reasons for non take up are lack of information about eligibility and impact of carers allowance on other benefits, not recognising themselves as a carer and difficulty of claiming (time to fill in forms, length and complexity of forms).

6.16 Research by Carers UK highlights the length of time it takes for carers to be recognised as carers and also the high turnover of new carers. As a result a significant amount of benefits are unclaimed and that a significant proportion of carers had not accessed their benefit entitlement over three years. It was reported that this is indicative in that many carers not receiving benefits are often not receiving other forms of support and are not in touch with ‘the system’.

6.17 The Select Committee heard how KCC supports the take up benefits through care managers, designated benefit advice workers and through information and support from Carer Support projects. Increasing the take up of benefits supports the carer/cared for person directly and also benefits Kent through the allocation of central government monies to local government as there is a relationship between the numbers of people in receipt of certain benefits and expected demand for services.

6.18 Members of the Select Committee acknowledged the importance of this work and were keen that this work continued to be supported. Many carers still do not access benefits they are entitled to – continue to raise awareness.

6.19 Register or Database of carers

The views on the benefits of a register of carers are mixed. On the one hand it could ensure that carers on the data base receive information and are referred to carer services. On the other carers are happy with information once they are in contact with the carer support organisations. The national GMS (General Medical Services) GP contract, awards points for the establishment of a system to identify carers and refer them to the Local Authority for an assessment. It is possible to gain the points for this whilst still only identifying a small proportion of carers. This refers to a process and not an outcome.⁸⁹ It was reported to the Committee that currently the carer register held by GPs is of limited benefit as information is not shared with statutory or Voluntary sector services or information targeted at those on the list, and that uptake is inconsistent. It was suggested that if additional services were attached to being registered that some of the hidden carers may come forward and be known

to services. Lists are of little benefit unless there is something tangible attached to them for carers. It was noted that if there is a register of known carers it could support KCC in ensuring its statutory duty of offering/carrying out carers assessments is carried out. The GP lists could also be linked and promoted to ensure well-being assessments are carried out for the carer.

6:20 Recommendations to improve communication and access to information

- **Need to raise awareness and profile of carers and carer support services and make information available out of standard hours.** Initial contact is difficult, but once in the system information is readily available. Need to consider campaign about local services and find innovative ways to raise the profile of carers, where to find support and what support services are available. Access gateways to services need to be knowledgeable of services for carers in area. However raising the profile and access to information needs to be backed up by tangible support (whether financial, emotional or practical) to remain credible. The focus of information services should be reviewed to assess options for providing support and information outside of normal office hours.
- **Promote single point of contact for carers** – Carers are often unaware of entitlements, support networks and help available and the diversity of sources of information are confusing and often overwhelming. Need simplified way to make contact for initial guidance, and possibility of a one-stop shop approach should be explored. It should also be ensured that the contact centre has the knowledge/training in order to refer carers appropriately.

7.0 Carers Assessments

7.1 Under the 2004 Carers and Equal Opportunities Act a carers assessment must take account of a carers willingness and ability to care. There is a requirement to consider the carers wishes in respect of education, training, employment and leisure, and be focused on the desired outcomes and needs as stated by the carer. Carers UK found that only half of eligible carers in one survey were aware of their right to a Carers' assessment – an important step to getting support and enabling carers to continue to care (Missed Opportunities). In order to ensure that both carers and the 'cared for' are receiving all of the benefits and assistance that they require and entitled to, it is important that all carers have the right information and access to an assessment.

7.2 Unfortunately the committee heard that although Kent has made considerable progress with regards to carers assessments there was still a long way to go and could do better. It was reported that it appears that there are minimal carer assessments carried out in some areas, with implementation described as 'weak or patchy'. It was also commented that reviews are not often generated so changes to circumstances go unnoticed by KCC, and perception that reviews do not happen in an effort not to raise hopes and aspirations as limited funds available to address needs identified.

7.3 Quality of Assessments

In October 2006 some issues relating to carers assessment were raised with the strategic management Team (SMT).

“current practice indicates that Carers are in the main assessed jointly with the cared for person ... This practice has developed partly because of time constraints facing care managers. From a Carers point of view it is not only important they are assessed but that their needs are monitored and reviewed. The assessment, planning, monitoring and review process for Carers is no different to the process for service users. Discussions with Carers have highlighted that they are not aware of their rights, are often not sure if they have been assessed and if they have been assessed do not have a copy of their support plan and are not reviewed on a regular basis. “

It was recommended and agreed “to support development of awareness raising/practice workshops for operational staff to clarify duties and responsibilities.” These issues seem to be ongoing and are still a concern.

Almost one third of carers who contacted the Committee were unaware of Carers assessments, and of the carers that were aware there was uncertainty around what these entailed, when to access them or the benefits. It was noted that Carer Support Project Newsletters had considerable impact on raising the profile of those that are aware of carer assessments. There was limited awareness that carers could have this separately from the cared for person or one had not been offered. The Voluntary Sector Carer Organisations supported these findings, commenting that many carers had not been offered a separate statutory assessment of their needs, if at all for some. It was also concerning to hear that assessments for the carer as part of the

cared for persons assessment did not take proper account of the carers willingness to the extent of their caring role or of their own individual needs.

7.4 A significant concern the Committee heard from Carers is that assessments often do not lead to increased support or that such services have long waiting lists, so it can be sometime before support is accessed, unduly raising expectations. Targetted early interventions that enable carers to carry on caring and prevent or defer the need for more costly intensive support are key.¹⁰ For many carers, flexible, client centred, preventative support services are essential to sustain the caring role. Carers need an assessment that leads to these forms of support, backed up by sufficient services if they are to be valued by carers.

7.5 It is acknowledged that area teams carry out carers' assessments as part of their existing workloads, and are working at full capacity. Assessments are a key element of any prevention strategy and need to be promoted, adequately backed up by staff resources and preventative support services. It is concerning that the approach to carers assessments seems to vary. It emerged that not all staff responded equally and that some carers experience a lack of continuity. It was reported by both the Voluntary Sector and Carers that carers do not always feel acknowledged, often do not realise they are being assessed, some do not recognise themselves as carers, and some remain fearful of assessments.

7.6 It was highlighted to the committee that a pilot by Carers First conducting 100 statutory carer assessments had been very effective and valued by KCC and carers, but funding constraints meant the process could not cost effectively be rolled out or continue. The Committee was informed that there was no further funding available to meet the numbers now referring or to continue the pilot and a potential conflict of interest where a carer needs support in an advocacy role to enable a successful assessment if that organisation is carrying out the assessment. It was commented that it would be helpful if the Support Organisations could see the assessment report (with Carers agreement) and to attend the assessment if the carer wishes. The Carer Support Organisations develop close working relationships with their clients and are aware that many do not give a full account of their circumstances to Social Services (because they may not be aware of the relevance of certain pieces of information, or are focused on the cared for person). Involving the Carer Support Organisations at the outset would ensure that all carers identified by Social services were referred directly to the support organisations. Despite the stated shortfalls it was also commented that there are many examples of individual carers and their families receiving excellent support from individual care managers, but this did not amount to successful implementation of Carers rights to their own assessment or quality joint assessment. It is clear that improvements can be made and that the involvement of the Voluntary Sector Carer Support organisations is one way forward, to make a difference and impact on outcomes for carers. **The involvement of the Carer Support Organisations at assessment should be considered, and subject to carers consent sharing the statutory assessment.** Possibilities of extending the pilot following its success re –explored once funding for 2008 is known.

7.7 To improve assessments Kent has developed a Carers checklist CM4 listing things a carer should think about to help them identify their needs and own desired outcomes. Kent has also introduced a self referral assessment which is available on line, to try and reach carers previously unknown to social services, used as a first step to a full carers assessment with a care manager. It is reported that this has for

some carers led to confusion and is allegedly regarded as a tool to confirm 'the criteria for services is not met'.

7.8 It was also highlighted that there was frequent changing of care managers without notice, frequent postponements and cancellations of meetings and a wish from Carers to be able to give 'updates' rather than repeating complete histories. Delays in assessment or allocation of a care manager also impacted considerably on some carers, and Carers reported inconsistent and different responses from Care managers.

7.9 It is essential for carers that assessments for carers (joint and separate) are promoted, that their quality is ensured, and that carer's views about the assessment process are reflected in future approaches.

7.10 Regularity of reviews for Carers

The regularity of assessment reviews emerged as a key issue. Reviews are important as they take account of changes in circumstances, identify unmet needs and can enable a carer to continue caring without reaching crisis, however the regularity and approach to reviews seems to vary. Overall the majority of carers were concerned over the length of time between reviews and felt there should be a more proactive approach, a two way process. For many it appears that reviews are only generated when the carer makes contact, unfortunately many carers do not make contact and therefore a review does not occur or only contact when at crisis. As a result changes in circumstances and the needs of carers are unnoticed and not met. It was also highlighted that when Carers request a re-assessment they often have to wait a considerable time to be seen, despite making the request as their situation has changed. Annual reviews are not consistent, with some carers not experiencing one over a period of several years (2-5years). It should be noted that some carers were happy with regularity of reviews, had discussed the next review with their care manager or were happy that they could make contact to request a review or identify a change in needs.

7.11 Overall it was clear that carers valued the contact from Care managers, especially home visits when at crisis point, but contact needed to be more frequent and that reviews or contact should be generated from the care manager as-well as the carer, a two way process. It was highlighted to the committee that some Voluntary Organisations made regular phone contact with the carers they supported, and overall that the regularity of reviews should be a smoother process. **It is suggested that reviews or contact from Care managers should be regular with annual reviews as a minimum.** Issues around access to care managers are also discussed in paragraphs 8.5 to 8.7 are also relevant and should be noted.

7.12 It was also raised that when care manager's closed the case of a cared for person it was not possible for the support services (VCO) to keep contact. Therefore if the situation changed there was no one to encourage the carer to get another assessment in order to put services in place before a crisis occurred and there were two people, the cared for and the carer, who were unwell.

7.13 Person to accompany carers at assessment

Under the 2004 Act it is a requirement to consider the carers wishes in respect of education, leisure, training and employment alongside their ability and willingness to care. There was uncertainty amongst carers of who could be present at assessments. Some Carers reported that they found the presence of a member of staff from the carer support projects very beneficial at assessment to support them as a carer, and some carers said this is something they wish they could have had. All carers should be informed that they can have someone present at their assessment – e.g. a friend, advocate or interpreter and be encouraged to do so. A difficulty arises in that many carers do not know about the carer support projects or advocacy until assessment and this needs to be addressed.

7.14 Data on Assessments:

It is essential to have good data about carers assessments and carers' services, however national changes in recording requirements combined with inconsistencies in approach have impacted on production of management data. It should be noted that information is collected by number of carers (as per RAPS return) and that detailed data on number of assessments is not known. (ie. Carers are only counted once within any reporting period, in accordance with their most recent assessment /review). This has meant the directorate can not centrally monitor the number of carers being assessed as new carers, the number being reviewed, nor the regularity of reviews, but monitor for the statutory returns on number of carer services. The Performance Management Team has acknowledged this and that more data should be available from the 'swift system' in the future.

From responses it is clear that approaches to reviews and assessments are inconsistent and need to be highlighted within the areas and monitored more closely, as these assessments and assessment reviews are the gateway to support and sustainability of the caring role.

7.15 Recommendations to improve outcomes for carers through assessments:

- **The involvement of the Carer Support Organisations at assessment and subject to carers consent sharing the statutory assessment** should be considered, and **need to ensure carers are informed that they can have someone present at their assessment** – e.g. a friend, advocate or interpreter.
- **reviews or contact from Care managers should be regular with annual reviews as a minimum.** This issue needs to be addressed. Case management to have systems in place so improved contact and carers regularly asked if circumstances have changed and ensure reviews are carried out annually (as a minimum). There should also be a general target for time taken following a request for a review before it is undertaken.

8.0 Support Services

8.1 It is not just quantity of support that is important, but also quality and flexibility. Support which is flexible and allows carers to achieve personal goals and have a life outside of caring has a positive effect on carers' lives.

8.2 There is a need to plan around the turnover of caring as some carers will be longer term carers than others. Each group has particular needs that need to be recognised, and individual carers will need different support. For example the longer-term carer is likely to be on increasingly low income, have poorer health and give up work to care, and it is also important to keep social contacts going when a carer stops caring.¹¹ Carers initially may not need support, but as levels of caring responsibility increase the carer may need increased support. Also as a new carer there is a period of support needed to get into the system, finding out what is available, accessing information and being counselled or supported through becoming a carer themselves.

Many carers appreciate support for simple tasks before full care package, such as help with shopping, cleaning etc and regular respite. Support services have a critical role in preventing health breakdown, in keeping social contacts, preventing isolation, helping carers continue working and supporting them to continue to care.

8.3 Support is critical for carers and in summary some carers were clearly very happy with the support they received, had a good relationship with their care manager and Voluntary organisations, and this should be acknowledged.

“Support received is a lifeline and essential to maintain physical and mental health of carers, prevents feeling of isolation, improved ability of carer to function helps the impaired person to have a better quality of life”

8.4 However, evidence from carers and carer representatives also highlighted a number of issues, raising some concerns about consistency of service and delivery. As already discussed practice is not uniform across care managers as reported differences in terms of response to carers and comprehensiveness of assessments for carers. Communication was an underlying issue. There is a need to continue to communicate and repeat messages about carers' assessment, process, entitlements etc (even if someone is a long time carer). For some carers it was felt that staff did not really understand what it was like or the impact caring had on the carer and that Voluntary Organisations had a better understanding. Training of front line staff could be attended by carers groups, carer representatives to try to resolve these issues and give a greater understanding of the impacts of caring on carers and why support is critical if they are to continue to be able to care. Other key points highlighted were

- difficulties accessing support for weekends, limited weekend support
- the need to battle with KCC /service providers becoming too much on top of caring (disabled childrens service)
- extra hours not being available, high demand on Voluntary organisations
- problems with waiting lists for support services
- transition for multiple disabilities is limited...offered what is available not what is appropriate

- limited or no services for deaf /blind multi sensory impaired. Few services for those who use British Sign Language to communicate

The Increasing numbers of carers is an issue for VCOs in general, with some reporting a 50% increase in carers coming to them, and that this was a challenge to manage, reporting that response times and waiting lists have increased dramatically. For example for Carers First 2 years ago response time (except in emergency) was 5-6 days, typically the wait now was 20 days before they were able to respond. Demand for services is also discussed in 10.3 on respite/short breaks).

8.5 Access to Care managers

A key issue arising was communication and access to care managers. The section on assessments is also key as highlighted the need for strengthening the two way process between care manager and carer to make contact or generate reviews. It was recognised by Carers that Care Managers are under pressure (and that their support is valued), and this impacts on their accessibility and support for carers; and although some are excellent some are not.

8.6 Carers highlighted that accessibility of some social services staff was poor as there was often a lack of response. Carers experience particular difficulties in contacting part time staff, no sickness cover for cases or being asked to wait until the next time someone is in to deal with concern, constant answer phones and non return of telephone calls. It was the opinion of some Carers that KCC responds in crisis but does not plan for the future. Carers also highlighted the need for regular contact from their care manager, even a phone call on an annual to 6 monthly basis, a two way process, preventing feelings of isolation, tackling things alone, identifying and meeting changed needs before being near or at crisis point before making contact. Carers wanted more and easier contact with Care managers, for issues to be dealt with and not referred on.

8.7 It is **important that no calls are lost and that teams continue to look at call management**. Need to consider how calls are captured and handled in the standard working week and out of hours, how calls for part time staff can be supported, to improve contact between carers and Care managers. Need to ensure that the Out of hours contact detail is on all CM answer phones, if not already or automatically re-routed. Carers also reported that the Out of Hours service was not responsive enough and that no one was available out of hours to talk to or for reassurance.

8.8 Recommendation to improve outcomes for carers:

- **District Social Services Teams to address and overcome issues around call management** and ensure improvements are made around response and accessibility of team members.

8.9 Working carers

For working carers juggling both a career and caring responsibility can be difficult. It is estimated that 1 in 8 people in the workforce is a carer and that 1 in 5 carers give up work to care (equal opportunities Commission). They give up work due to inflexibility or unsuitability of care services...often only available between 9am and

5pm which doesn't always fit with peoples needs. Caring and employment responsibilities don't always fit together, and increased physical and emotional demands. KCC have launched a new carer policy for staff. The Carer Leave is being run as a pilot from June 2007 – 2008.

8.10 It was highlighted that one of the particular gaps in service provision is for those who are in employment and need a comprehensive package to support them to stay in work, and that the support and advice they receive is often lacking. It was raised that this type of support is expensive but would enable a person to stay at work knowing there was sufficient support in their absence. It was highlighted that there is a need to cover a carers working day, and this is becoming a particular issue for carers of people with early onset dementia.

8.11 Equipment Services – OT and Sensory Services

Equipment is an important issue as it helps the cared for person be more independent, meaning less input from the carer, and other equipment protects carers backs and also helps them when washing or bathing the person they care for. Access to the right equipment, aids and adaptations both NHS and KCC is crucial. A main concern of carers is accessing an occupational therapist for assessing the persons needs, and then having to wait a considerable amount of time for the assessment appointment and the equipment to help them. It was noted that this issue causes the carer and families much stress and often causes physical difficulties in their role. Delays in meeting with care managers had the knock on effect of leading to delays in accessing equipment. Although once assessed as needing certain equipment the response was considered good. Carers reported having to buy and fix hoists themselves due to the length of wait.

8.12 The diversity of sources for help is also an issue for Carers as it is not always clear what they can access from where and how. Carers reported the necessity of accuracy when ordering, getting the right equipment first time. It would be useful for carers to have a single administrator or clear guidance about what is available from whom in one place. Responses from the NHS identified the major pressure affecting the delivery of services to carers as lack of resources, with the view that a reduction in beds has meant increased pressure on carers, and that it was considered more time, more staff and more resources could improve assessments.

8.13 Communication and information for the carer has been highlighted as an important issue, but so is communication between the carer and cared for person. It was highlighted that communication aids can be of great benefit to both carer and user, but that they can cost up to £6,000. 'Find A Voice' a voluntary organisation in Kent provides a loan bank for communication aids and equipment, IT support for people with Learning Disabilities and advocacy support for people requiring a communication aid, and helps to identify aids that would help individuals. It was raised that people are often not told about what was available which was frustrating for both the carer and cared for person and that once a person had left hospital referrals were patchy, partly due to the lack of speech therapists and lack of resources for follow up. It was difficult to get Government recognition of the need for communication devices and there is never significant funding. There is often a wait for devices as obtaining funding for can take considerable time (up to 4 months), and only a few self fund due to the high costs. It was highlighted that this is service that could be expanded.

8.14 Time and Support Services

The length of time it took for assessments and to set up services or for paid carers to be available was a recurrent theme. Following set up carers reported services were ok and felt fully supported, although services and support available are part time, but carers are 24/7. There was a need for general support for carers out of hours, whether information, counselling or reassurance and also for more respite out of standard hours.

8.15 Carers also highlighted difficulties in relying on support or planning their day as they do not know when support is coming from domiciliary agencies to the cared for person and varies within a four hour slot. Carers commented that paid care assistants do the minimum and rarely stay for the fully allocated time. Support from paid care assistants was valued as this provided carers with a break, valuable support and protected their health through safer handling and lifting. There are concerns around some agency staff and quality of care, as paid carers were not always trained to offer the right support, travel time was taken out of care time and often too many tasks were allocated to the care time. The Committee acknowledged that a previous select Committee had highlighted these issues and expected that a current review of domiciliary services would tackle these issues, in particular the monitoring of contracts.

8.16 Administration and Commissioning

A summary of the concerns raised by the Voluntary Carer Organisations (VCO) with regards to administration and commissioning are set out below. The time constraints of the review meant KASS did not have an opportunity to comment. It was noted by the Committee that this is a two way process, with responsibilities for both VCO's and KASS.

- Two main pressures affecting delivery of carers services are a) increasing demands on service from increased numbers of carers referring and breakdown in family structures, and b) financial constraints which brings pressure on resources.
- All VCO's apply individually for funds/grants both KCC and external using a lot of resource across Kent. Could they be supported to apply in clusters?
- Commissioning criteria for allocation of funds should better reflect the number of carers supported by the project/service.
- Lack of communication on local level and feedback on suggestions for improvement after review of services
- VCO service agreements/reviews are out of date.
- Lack of continuity in KCC Contracts Team, and no link person to deal with VCO/carer issues

8.17 There was a view that there needed to be better cross co-ordination of carer organisations – an integration of services with minimum overlap. Better communications between the Council and the voluntary sector and within the voluntary sector itself were seen as crucial for the success of any Adult Carers Strategy. For services to be integrated with minimum overlap the Voluntary sector need to be supported to work together, exchange ideas, explore the possibility of pooled resources and continue to make referrals to other agencies. There is scope for closer partnership with voluntary sector, through the development of carers

strategy, and subsequent commissioning strategy and implementation, supporting the development of projects to benefit carers.

8.18 Transition

Concerns were raised regarding Transition and that there was a need to be more proactive both for the transition into adult services and the transition for family carers. The issue of Transition was considered in depth by a Select Committee on Transition and included the consideration of issues for carers. The implementation of the agreed recommendations in the transition report should improve outcomes.

8.19 Direct Payments for Carers or voucher scheme

The evidence to support or not the use of Direct payments/voucher scheme for carers (NB: not care agency care workers) was limited. Of those that did highlight this as an issue there was a mixed response. The Voluntary carer organisations like to know that they have x funds allocated. The introduction of a different carers scheme could mean carers access the support they need when they want it and how they need it, with no guarantee for a particular service. It was noted that not all carers necessarily want this extra responsibility to manage, and it would also clearly impact on commissioning of services as funds would need to be released to support this.

8.20 Other issues raised

- Lack of awareness of KCC financial support to Voluntary sector to provide services to carers. Organisations should flag part funding (some do)
- Uncertainty around how Voluntary Care organisations were assessed/ monitored as delivering service on behalf of KCC
- Fear of Social services – people don't want to speak out. Also many carers don't want to be recognised and also don't realise that they are carers.

9.0 Emergency Support for Carers

9.1 Support is essential for carers when the unexpected happens. This can range from support for the carer being late home, an unexpected event, overnight admission to hospital or more serious situations. Support may be through contacting family or friends to step in or through a single point of contact with someone to sort out replacement/emergency care. 'Back me up', a report by Carers UK¹² found that carers are not getting support in an emergency and do not know who to contact.

“ when I had a heart attack and was rushed to A and E there was no-one I could contact to arrange care for my disabled husband. I had to arrange everything by phone and spent more time in the phone box than in my hospital bed”

“when my father died I asked for help to cover at the weekend so I could be with my mother. I was told it was impossible and I should have booked in advance for the emergency”

“..When the police turned up in the middle of the night I knew something terrible had happened. They told me that my son, who was away at university, had fallen from a balcony and was seriously ill in a hospital some 150 miles away. Like most mothers my first instinct was to get in the car and drive there immediately. However I care for my husband, Philip, who is severely disabled and cannot be left on his own. I desperately needed a suitably qualified professional to come and look after my husband. Although I have regular contact with social services, I had no idea who to call in an emergency. I phoned the Council offices and a security guard gave me a number for the emergency social services team. When I got through I was told that there was nothing they could do and that I should phone my local office at 9am the next morning. ...”

(Source: Back me up- Supporting carers when they need it most, Carers UK 2005)

These issues were also reflected in responses from Kent Carers. In summary the key issues around replacement/emergency care highlighted by carers in Kent are

- Carers do not know or are uncertain who to contact in an emergency
- takes too long to respond or set up
- not always available when needed
- Lack of awareness of emergency support services or how to access them
- Out of hours service is not easy to contact or very beneficial
- Carers asked for a quicker response when asking for help, to make it easier to contact Social Services and arrange emergency support. Also the flexibility to support carers who manage without help most of the time but need to access support for unplanned events or emergencies.

9.2 'Back Me Up' also recognised that the unpredictable nature of emergencies or unplanned events mean some impact is unavoidable on carers and the person they care for but some simple solutions could make a significant difference to carers and minimise impact. Emergencies often lead to informal caring breaking down so

support at this time is important. For many carers the thought of an emergency or being unable to get back home causes anxiety and worry. The committee was informed that Kent Social services try to encourage carers to think ahead about emergencies, discussing contingency plans with care managers. Care managers told the committee that some carers do not want to think of the future, are busy coping with now and do not think anything will happen to them.

9.3 The committee found that many solutions that make a difference are already



in place – for example rapid response teams, replacement care from Voluntary organisations, social workers helping draw up and emergency/contingency plans. One scheme particularly highlighted was a Carers Emergency Card Scheme, a current pilot run by Carers Support in Ashford. This involves carrying a credit card sized carers card for identification, emergency contact number to scheme operator and unique identification number which gives access to

an emergency plan to put into action, backed up by response services. This gives peace of mind should the carer be in an emergency or delayed in getting home. Carers emergency schemes are different to simple emergency cards, which allow a carer to write down contact details as they are backed up by a pre-arranged plan and response services. Kent has recently been awarded money from the new deal for carers, part of which is to build on services for carers in an emergency. Key areas are identifying that someone has caring responsibilities in an emergency, accessing an emergency plan, and resources being available to offer the support needed in an emergency or unplanned event. The Committee looks forward to the increased investment in emergency care following allocation of funds from the new deal for carers.

9.4 Recommendations for improving outcomes for carers:

- **Emergency Card Schemes, backed up by emergency plans and response teams should be expanded and developed Kent wide if the pilot is successful.** If successful a Kent Carers Emergency Card scheme, rather than individual district based schemes should be considered with a commitment to have an emergency plan for all carers, with every carer to be offered access to a scheme.

10.0 Day Care, Respite and short breaks

10.1 Practical help was critical in reducing carers stress and improving their health and wellbeing, especially enabling a break from their caring role. Respite was particularly highlighted as the one service enabling them to continue to care and have a break from caring without which carers felt they couldn't continue, it is valued and absolutely essential and planned respite can help to prevent crisis. Respite is provided through for example sitter services, day care, respite beds etc. A major priority is keeping people out of residential care, and providing the opportunity for a break for the carer is key to achieving this. KCC continues to develop support services offering carers 'short breaks' to support them in their caring roles. In developing services for carers close work and investment in the voluntary sector will continue to be crucial.

"Age concern day centre and transport, enables me to carry on caring at home, without day centre 3 times a week I would not be able to manage"

"respite provides light at the end of the tunnel"

"without respite could not continue"

"rely on and look forward to my 2 week break every year"

10.2 There has been commitment to providing short term, home based respite at National level for carers in crisis or emergency. Respite needs to be available for sustained and occasional support, and also respite at short notice, for when things crop up unplanned or carers are at or near crisis.

10.3 Demand for Respite/short breaks:

It was estimated that for carers to be able to continue in the role of caring for longer and to maintain their own health they need a minimum of a weekly break, with knowledge of how to access longer breaks. Councils are shifting towards more flexible short breaks and Kent has made excellent progress, but as witnesses expressed **there is simply not enough respite**. A significant number of carers responded that more funding needs to be allocated for respite as **current resources are not enough to meet demand, demand is high and options are limited**.

10.4 Currently a substantial amount of respite is provided by the Voluntary Sector, supported financially by Kent County Council. The Voluntary Carer Organisations (VCO) reported that **more people are referring** than ever and **there are now considerable waiting lists** for services (some up to two years). It was reported that the Voluntary organisations are funded to meet needs of carers well under the number that are now referring to them, which has led to difficult choices. There is a substantial increase in the numbers of people referring and some organisations now only offer one session free as budgets are over stretched and this means they can continue to offer some support to more people. The increased pressure on available resources is due to the number of families in need of support growing quickly e.g. dementia cases are amongst the fastest growing group, increased/raised profile, and also the level of need increasing with more families in greater need and distress. Carers report waiting over a year to 18 months (July 07) for respite. For some carers the advice given by care managers is that they would be better off contacting their GP for access to respite.

“role is 24/7/52 without respite....if not doing this can't understand the social exclusion, isolation, loneliness, acute disappointment at giving up own social activities...entitled to 3 hrs respite a week have been waiting a year ...as not enough trained people to sit with husband or take him out” (carer of person with Alzheimers).

Two branches of Crossroads gave details of their waiting lists, Branch one had 203 carers on their waiting list, and Branch Two had 265 carers on waiting list, including 120 parent carers who they were unable to assist. One impact of the level of demand and waiting lists is a lack of ability to respond when carers ask for extra hours of respite, which is a frequent request.

10.5 Adult Services Provider Unit and Carers of people with Learning disabilities

The Adult Service Provider Unit (ASPU) is an in-house unit supporting adults with learning disabilities and some with physical disabilities. Since 1998 services for adults with LD has been going through a programme of change and modernisation. It was reported that many clients with LD and carers are unconvinced and fearful of the new arrangements, and fear cuts to services that people have come to rely upon and provide respite for carers, and that their caring responsibilities could increase.

10.6 It was reported that in the future it is envisaged more services will be delivered by external providers (currently about 80% of day services are delivered by KCC providers) and will be person centred and not focus around buildings, but in communities to enable growing independence and opportunities for people with learning disabilities. The Committee was assured that services would not be removed until there was something working in place. It was stated that change could bring opportunities from the re-use of the same resources. As an example the closure of Satis House, Ramsgate, which provided for up to five people with very challenging needs and its modernisation resulted in an independent living scheme in Thanet being developed, with greater links with the community. The funding and staff were retained and used more flexibly and innovatively to support a greater number of people. It was highlighted that funds released from other changes have been redirected to develop the Thanet Independent Living scheme enabling the provision of non-residential emergency support services. It was noted that there is no blueprint for the changes but opportunities are taken as they arise to respond to clients' changing needs. It was reported that Young adults have told the services that they want to work, make friends and have a social network, have their own flat etc.

10.7 It was clearly recognised that there is also an identified need for respite for carers of those with complex and more challenging needs. Yew Tree offers 22 day places for those with enhanced care needs, offering a range of opportunities both in the centre and out in the community ie taking clients out using public transport.

10.8 It was highlighted that there is tension around providing support to the service user and support to carers, as the service although focused on the user the respite provided is a break for the carer. The Committee heard that ASPU has looked at different ways of spending available funding to provide dependency 'units' of care based on the individual level of practical support, which can be used more flexibly to meet assessed need, as opposed to reference to number of beds. This allows the service to be more responsive to users' needs, to check bookings and identify spare

capacity. Agency staff can be brought in to meet any emergency need that may arise over and above planned and booked needs. It was reported that Carers had feared losing the level of service they had before the changes were introduced but apparently have been happy with the new patterns of provision.

10.9 Although carers are often concerned by the change in focus of services the development of person-centred services, and promoting independence is a key aim for services. Convincing carers of the benefits is a key factor in encouraging parent carers to support their children participating in schemes that promote independence. The Committee heard that as a result of being supported on independent living schemes, individuals could for example live independently, own their own home or achieve a qualification, and that this can be achieved if the carer is supported and it is approached in planned, gradual stages.

10.10 It was highlighted that there is a need to deliver both practical help and develop a good standard of living for both people with learning disabilities and their carers, and despite some national progress in the last five years a significant shift towards supporting carers in Kent was required. The Committee heard that many carers faced the adulthood of their loved one in dread, and that often families accept they will be carers until death. It was confirmed that the biggest element of expenditure was on residential care, resulting in a £6m overspend, and therefore necessary to develop a major strategy to establish significant methods of support to enable carers to live positive lives, and support the independence agenda for people with learning disabilities. In Kent, between NHS/KCC almost £150m, nearly two-thirds was spent on residential care. It was highlighted that more cost effective methods, investment in different sorts of support and redistribution of the funds that were available was crucial. It was noted some carers resented the intrusion of external support coming into their home, and were wary of people they viewed as strangers. Whilst options needed to be considered, personal choice was the overriding factor and should not be imposed.

10.11 Booking Respite and short-breaks:

Respite provision and breaks are also fragmented into a wide variety of schemes from various organisations. Contacting a care manager can sometimes prove difficult, and this is sometimes the access route to essential respite. Carers commented that it would be good if they could book respite direct rather than needing to go through a care manager who then contacts the respite service. Carers suggested direct booking system for respite to track availability and demand.

10.12 The Voluntary organisations and ASPU reported experiencing difficulties where sessions are lost due to cancellations of pre booked spaces. Reviews have shown that some people book respite care in advance but do not attend, so that place is wasted and is not available for someone else who could benefit from it and it doesn't make best use of resources and facilities. There is a high number of late cancellations and where possible cancellation needs to be as early possible in order to give the benefit of the session to another carer. A system that could reallocate sessions in the event of cancellation would be useful, perhaps, where carers could check availability easily at short notice or mark an interest in a slot should it become available at short notice.

10.13 Type of service:

Having stated that simply there is not enough respite available, the type of respite is an important issue. Firstly much of the respite available is available 9am-5pm, or 10am – 3pm only, and there is a need for more respite in the evenings and weekends. It was highlighted that if you cared for a person with dementia then between 4 and 9pm was the one time when the person with dementia was most likely to be agitated and the carer feel unsafe and there was no day care on weekends. There is a need for more night respite (waking night/overnight) either in the home or out of the home, to enable carers to get good nights sleep.

10.14 Secondly, Carers reported that there was limited dementia respite, especially for people with early onset dementia, and although respite beds are available in care homes these are often inappropriate for the cared for person. Also despite organisations such as Age Concern having specialist Day care facilities for people with Alzheimer's or dementia these were not necessarily appropriate for someone in their 50's. There is also a need for more sitter-services for people with dementia or Alzheimer's as sufferers often feel safer at home. The Committee is also concerned at the PCT/NHS reduction in respite beds in community hospitals. The difficulty obtaining annual respite for people with severe mental health issues was highlighted, and responses to carers requesting respite are reported as discouraging.

“told funding might not be available to allow break and if forthcoming there were few if any places available to take x for a couple of weeks, as lack of establishments willing or able to accommodate x – told such facilities cater for permanent residents not respite” (carer of person with severe mental health needs)

10.15 Thirdly some carers want the opportunity to be at home without the cared for person rather than having to be out or away. Fourthly, an apparent lack of support for families was highlighted. Parent carers and married carers emphasised the importance of time to be together as a couple. For example to be able to go out in the evenings together with services at home with cared for person/child or to be at home as a couple or to spend time with the rest of the family. It was highlighted that there is a need for more sitter-services for families and that the Kent Link Scheme although valued was limited, as many parents wanted their child supported in their own home, and the link scheme was run by volunteers who needed to be matched and trained. Carers also reported difficulties in booking sitter services, and that the problem for parents was more acute in school holidays.

“principle relief needed is opportunity of carers being together and living together the ordinary life of a married couple if only for a short while. ...even a trip to the shops is a nerve wracking experience with x” (carer of person with severe Mental health needs)

This is an issue affecting carers nationally as illustrated by a recent Carers UK survey (June 2007) looking at the impact of caring on relationships. It states that two thirds of carers (66% of some 3,500 surveyed) said their relationships had suffered as a result of caring, while 60% said they had little quality time with their partners. ¹³

10.16 Transport and Travel Time:

For many carers respite support is only available in a restricted way so the carers travel time eats up the respite time by taking the cared for person to a centre for respite breaks. For example an issue with regards to transport not readily available for clients who use day centres means that carers have to transport the person they care for to and from the centre. This often means that they do not have much of a break from their caring role once they have dropped the cared for person at the venue. It was also noted that some paid agency care staff use support/respite slot for travel to and from appointments, (referred to some agencies, KCC and Voluntary organisations reported as generally building in travel time in to paid care staffs day).

10.17 Summary of the key messages from carers:

- increase resources allocated for respite, increase availability of respite to enable reduction of waiting lists and length of wait for services
- more respite for unsociable hours
- find ways to give easier access and booking of respite
- increase flexibility and type of respite available, including more evening and weekend respite and sitter services
- need short notice respite for non-emergency situations
- Need for appropriate services for people with early/young onset dementia
- ensure suitable respite available for people with mental health needs – for example vascular dementia, people with severe mental health needs, .
- 3hours is often not enough time to get things done, especially if need to travel
- Carers often cancel their own hospital appointments as they can not leave the cared for person, as not possible for appointment to coincide with day care/respite.
- Reported that if self funding there can be a lack of support finding respite

10.18 Regular and reliable respite makes a real difference. Local commissioning strategies need to take further account of the need for respite by carers and develop solutions alongside the voluntary sector and carers to meet the identified service gaps and increased numbers of carers referring for services. Continuing and developing community respite provision is much needed and essential for carers. Continued investment in the Voluntary Sector is crucial.

10.19 Recommendation to improve respite for carers:

- **KCC with Health and VCOs need to ensure that provision of respite/breaks is flexible, of the right type and that provision meets the needs of carers as well as the cared for person.** It was clear that carers value this service and that there is simply not enough, and not always the right type of respite available to meet growing demand. There needs to be a multi agency plan and commissioning strategy to address identified issues and gaps, developing a more co-ordinated approach to access and provision of respite locally for carers. KCC to pursue with Health the need for **appropriate respite options for people with mental health needs and their carers and issues around levels of provision in the county.**

11.0 Adult Carers Strategy

11.1 A broad range of issues have been identified by this review and there is an underlying need for a more strategic joined up approach to addressing these issues and service gaps for all carers. Although the need for and development of a multi Agency Adult carers strategy was agreed in October 2006, there was little evidence of progress, and leads for carers of some key parties had not yet been identified partly due to the reorganisation of the local NHS. This must be pursued as a priority and be focused on achieving actual improvements in outcomes for carers, identifying future priorities and how these will be delivered and resourced in practice.

11.2 As discussed in paragraph 6.6 the carers strategy should clearly acknowledge new carers and demonstrate practical steps in which to address information needs and the turnover of carers. There is a need to advise carers who are at the end of caring, helping them to return to work or plan for the future, to plan for people new to caring and to reach hidden carers who might have been caring for years unaware of their benefits and entitlements. It is necessary to continue to raise the profile of carers to increase recognition by carers that they are carers, and target particular groups of carers whether young, in remote areas, have learning disabilities, with information to help them to access carer support services.

11.3 The key role the health sector should play is widely acknowledged. The Health sector has a key role as they are an initial contact point with carers to help identify them and signpost them to carer support organisations. This is discussed in detail in Section 3, 13.0 Health Sector. Closer integration of health and social care services is central to government policy, such as commissioning joined up services outlined in DoH white paper 'Our health, our care, our say, Jan 2006'. There is a clearly identified need to provide better information and sign-posting for carers, and a need to demonstrate integration with measures to reach hidden carers. There is a clear need to develop an information plan as part of a Multi Agency Carers Strategy (including Health, Voluntary Organisations, KCC, Borough Councils and others such as pharmacies), with clearly identified responsibilities, and also to explore possibilities of joint funding targeted information initiatives (see also Section 6).

11.4 As discussed earlier in the report access to information is a key issue as it enables carers to access the support they need and find out what is available. Carers of mental health patients stated that they often spend their time going in circles, and commented that it would be useful to have a 'multi-agency' carers handbook to be given to new carers on diagnosis of mental illness. It was essential that this was readily available and ability to update to reflect ongoing changes, containing details of the support and services available within the County, statutory and voluntary specific to diagnosis. This could be encompassed within the carers strategy in relation to information and access to services.

11.5 Recommendation to improve outcomes for carers:

- **Multi Agency Adult Carers Strategy to be progressed as a priority** and agreed within a mutually agreed time frame, suggested within a year as a maximum. This needs to be realistic and developed through a commissioning plan.

12.0 Young carers

12.1 After Children in care young carers are one of the most vulnerable group of children and young people for whom KCC has responsibility. The impact of being a young carer can be significant, with many young carers suffering from depression or low self esteem (about 40%), social problems and physical difficulties, long term psychological effects (about 70%), health problems such as bad backs from lifting, and education affected leading to poor exam results. Bullying is also an issue for young carers, 71 % have been bullied, 51% physically hit or grabbed, 79 % called names and 20% missed school as a result of bullying ^{14, 15}.

12.2 It is unclear exactly how many young carers there are in Kent. Census 2001 data estimates that there are 3,324 young carers in Kent¹⁶. All elements of service need to be considered in achieving improved outcomes for these young carers. Only a proportion of these young carers access the young carer support projects in Kent, and not all of these young carers are known to other services. It is important to recognise that other than education, young carers may not access services provided by local authorities, and are unlikely to have knowledge about support services available, although some for example may also access Youth and Community Services (see Section Two for more detail of the estimated numbers of young carers).

12.3 There is high impact on the education for young carers. The third national survey of young carers¹⁷ found that

- 2/3rds of young carers provide domestic help in the home, 48% provide general nursing type care, 82% provide emotional support and supervision, 18% provide intimate personal care, 11% also provide child care
- one fifth of young carers and families receive no other support except for their contact with a specialist young carers project
- more than one fifth of young carers experience educational difficulties, particularly in the 11-15 age group – the age when young people are making educational decisions, taking formal examinations and preparing for the future
- the overall incidence of educational difficulties decreased since 1997 survey, however where caring for relative with drug or alcohol problems incidence of missed school or educational difficulties is up to 40% of young carers regularly experience problems with their education.

12.4 The Committee took evidence relating to young carers and heard that it is extremely difficult to establish their numbers and that much support is still needed. It was highlighted that an estimated 86% of young carers are of compulsory school age, 20% of young carers are missing school and many experience difficulties with learning.¹⁸ The Select Committee were encouraged by the work of the young carer projects in Kent, but were informed that these only supported a fraction of the young carers in Kent. The young carer projects provide support, information and advice, advocacy, respite and were highly valued by young carers.

“the young carer project gives time to forget worries, mix with friends who do not laugh and understand situation”

12.5 Some of the problems faced by young carers in Kent each day are:

Getting to and from school	Getting homework or coursework in on time	Generally achieving in school	Making and keeping friends
Having time for leisure activities	Establishing relationships	Being bullied	Constantly worrying about the person they care for.

(Source: Swale Young Carers Service 2007)

12.6 Some of the effects of caring on young carers are

- loss of childhood: restricts time available for friendships, socialising and hobbies, all important aspects of childhood
- Missed education /career opportunities: a significant proportion of young carers of compulsory school age miss school or have educational difficulty. Young carers responsibilities may result in absenteeism and lateness, difficulties concentrating on schoolwork, and may not achieve their potential
- Loss of leisure: caring impinges on normal childhood activities, little time to relax, be alone or participate in social activities inside or outside of school
- Social isolation from a peer group
- Traumatic impact on emotional wellbeing – disturbed sleep patterns, worry about relatives condition and affected by emotional strain of coping
- Poverty- associated with loss of a parental income, particularly lone parent families and increased costs associated with long term illness or disability.

(Source: Swale Young Carers Service 2007)

12.7 A key issue is the relationship between support offered to families by Kent Adult Social Services (KASS), the care needs to be met by family members, and support for young carers. It was reported many young carers are unknown to their schools and/or other services. From evidence to the Committee it was clear that for many young carers there is stigma in relation to statutory services and a fear of involving them, that young carers can feel embarrassed and also fear being bullied or ridiculed. It is also recognised that not all young carers wish their caring status to be acknowledged. Education has a key role in supporting young carers, especially as this may be the only service in contact with young carers and young carers in rural areas in particular may find it difficult to access the young carer support projects. It was commented that some schools are working proactively with young carers and work was currently taking place in the east of the county where some projects have dedicated workers to work with schools and that positive relationships are

developing. A number of issues were raised with the Committee, and are summarised below.

- Lack of awareness of school of situation but also fear of coming forward or being identified as a young carer
- Lack of information on where to access help
- Limited support from school and limited engagement by schools with young carer projects.
- Perceived lack of understanding from teachers and perception that teachers / mentors are unapproachable on care issues.
- Contact with young carers by schools often negative due to absenteeism or missing homework - 'not asked why or if you are ok'
- Fear of being bullied.

12.8 Young carers highlighted that the support they needed was:

- Better understanding of situation at home and a need for greater understanding in schools of the situations young carers found themselves in
- Understanding - particularly regarding lateness or absenteeism
- Someone to talk to
- Ability to check on cared for during the school day - Ability to phone/text home
- More time and support with homework
- PHSE classes and/or assemblies to raise awareness of young carers
- Help to access other support
- Ability to follow after school activities or hobby, or socialise with friends
- Need for more satisfactory briefing/information for young carer on cared for persons condition, and being involved and knowing what to expect

“Teachers should know more about the problems we deal with.”

“Being a young carer is difficult but with help it can be easier”

12.9 Other issues raised with the Committee are:

- Service delivery to young carers was fragmented and had developed based on funds and resources available, needed a more coordinated approach, and continued investment
- Young carers in rural areas are particularly isolated. Young carer projects were limited and had difficulties supporting young carers from rural communities as transport/access was an issue
- Children’s Social Services focuses on children at risk, and that there is a lack of clear responsibilities between Kent Adult Social Services (KASS) and Children’s Social Services (CSS) of young carers if it is an adult being cared for.
- Lack of assessment of young carers and support needed to support young carers life, choices, education, leisure etc. Perception that assessments of young carers generally did not happen, or viewed as a tick box exercise as no support available and caution at raising expectations without back up of resources for support.

12.10 It was clearly apparent that the young carers projects were very dedicated and that there was a willingness to work in partnership with education to raise the understanding and profile of young carers. Carer support projects suggested visits to school assemblies or lessons to raise profile and awareness of young carers and a willingness to support PHSE or meet with staff. The committee welcomed the idea of engaging with the young carers projects with training for headteachers, and understood that Swale Carers centre had been approached.

12.11 Clear it is not just education but also a role for other bodies to play in raising profile of young carers and addressing issues, for example role also for school governors, for GPs to acknowledge role and help identify young carers, and KCC role as corporate parents. The Committee was advised that the Common Assessment Framework would play a major role for young carers and other young people.

The Common Assessment Framework (CAF) is a key component in *Every Child Matters: Change for Children* Programme. The aim of this programme is to ensure that every Child receives the universal services to which they are entitled and any additional services they need at the earliest opportunity. The CAF is a key part of delivering frontline services that are integrated and focused around the needs of children and young people. All local authorities are expected to implement CAF by the end of 2008. It is intended that the CAF will promote more effective, earlier identification of additional needs through a simple process of holistic assessment of a child's needs and strengths, taking into account the role of parents/carers and environmental factors on their development. The CAF is an assessment tool that can be used by any agency or service to promote early intervention, a tool to support practice rather than an administrative process.

Kent County Council established a multi agency CAF working Group in October 2006, to scope and plan the work requirements to progress the CAF implementation in Kent by end of 2008.

12.12 The issues relating to young carers were of great importance and the Committee is of the opinion that **action needs to be taken to support and protect this group of children**. The Multi agency strategy for young carers 'Invisible People' is eagerly anticipated and the committee are keen that the implementation plan and commissioning strategy are made a high priority for KCC and Multi agency partners. The Multi agency strategy 'Invisible People' will have significant impact following successful implementation of the action and commissioning plan by all parties – however the priority is for young carers were there is risk due to drugs and alcohol. KCC needs to explore how it can bring about improvements for all young carers through its services and address issues raised by young carers in this report. The Committee noted that at time of drafting this report the final version of the Young Carers Strategy and commissioning strategy were being updated, but would be shared on completion. This is an **essential area for action and the Committee would like the POCs and NHS OSC to take an active role in ensuring objectives and targets are met**.

12.13 Recommendations to improve outcomes for young carers:

- **Need to ensure that awareness is raised within schools to increase understanding of what it means to be a ‘young carer’, and find ways to identify and support Young carers.** Each identified young carer should have a support plan and also ensure that specific reference to young carers is incorporated in anti bullying policies. The support for young carers in schools needs to develop an understanding of their needs, developing a flexible approach to meet those needs and referring them onto other resources and agencies as appropriate. The Common Assessment Framework (CAF) will be key to identifying the needs of young carers for all services.
- **Consider the need for a clearly identified lead professional for young carers on CSS operational front and education, alongside those for policy/strategy.** Young Carer support projects give the opportunity to support young carers, for young carers to meet together and also provide a good contact point for services. There is an opportunity for lead professionals to build on the relationships that already exist and harness knowledge/experience of young carer projects to increase awareness/understanding within schools and other services. The Committee hope that the CAF will help in the identification of Lead professionals for young Carers.
- **Need to ensure clear responsibilities and referral pathway for young carers between Kent Adult Social Services, and CFE and other agencies, and ensure that protocols between Kent Adult Social Services and Children’s Social Services are developed as a matter of urgency.**
- Invisible People – the multi agency young carers strategy and accompanying commissioning strategy (currently in draft) should be implemented urgently and monitored to ensure objectives and targets are met. Regular updates on progress and issues should be reported to the Childrens Trust Board, Chief Executive and Policy Overview Committee.

13.0 Health Sector

13.1 Hospital Discharge

It is essential that on admission to hospital healthcare professionals consider the carer. There is evidence that involving carers at each stage throughout admission, treatment, recovery and discharge have a greater level of patient and carer satisfaction and lower rates of readmission, ensuring carers know what they are taking on upon discharge and are fully prepared and that support is accessed.^{19, 20, 21}

The government guidance highlights the key role that carers have in the discharge process and states that carers organisations continue to report concerns that carers issues are often marginalised and patients continue to be sent home too early, with carers left to cope in the community with unacceptable caring situations. With carers UK reporting that 43 per cent of carers considered they were not given adequate support when the person returned home. There are many reasons why carers may not be involved, for example they are not identified by staff, they do not identify themselves as a carer, the cared for person discharges themselves, the carer is focused on the cared for person, or feel they don't require help at this time.

13.2 Kent social service hospital based teams are involved with carers during the discharge process. It was reported to the Committee that carers are considered and integral to the discharge process. West Kent PCT stated that a care manager and multi-disciplinary team are involved in the discharge process together and they make up an "Impact Team" to bridge the hospital and home environments, and works all across the West Kent area. There is a special referral protocol for carers with special needs, and the PCTs work with GPs on the Quality Assessment Framework (QAF). In addition to this, the Gold Standard Framework (GSF) was recently brought in to address the carer pathway. The Committee noted that the Terms of reference for the GSF are currently being put together, and that carers are being actively involved and good and bad experiences are being used as examples of best practice and cases where improvement is needed. Work on the GSF will bring the practices of all agencies involved in the discharge process together into one package. As this standard was in its infancy there was limited information available at the time of the review. It was acknowledged that the discharge team normally do a carer's assessment but occasionally it is possible for a case to slip through if people in a multi-disciplinary team each think another person in the team is doing the assessment, due to occasional lapses in communication. It was also recognised that not all carers identify themselves as carers or a cared for person may discharge themselves and not involve the carer.

13.3 However, there is the perception and reported view of some organisations in the Voluntary sector that staff based in hospitals rarely think about carers, and that when carers known to them have been in hospital their home circumstances are not always taken into account. It was suggested that a single joint carers guide should be given at discharge for that particular specialism and service of the key contacts for information and support available.

13.4 The Select Committee welcomes these steps by the WK PCT to ensure patients and carers requirements are addressed prior to discharge. However the Committee are concerned at the reported number of out of hours discharges and the impact this can have. It was commented that the NHS is a 24/7 service often discharging late on a Friday, but that Social services does not run a corresponding

service 24/7. It is concerning especially as carers reported the out of hours service was difficult to contact, services took time to be set up following assessment and it takes time to understand the implications of the caring role once you are to be discharged.

13.5 Assessments of carers own health was highlighted as an area of importance and that could be improved. Carers often neglect their own health and often cancel or miss appointments due to caring commitments. The West Kent PCT commented that GPs' surgeries are given practical guidance and advice on identifying carers' own health needs. It is important that carers are offered a health assessment and that they are assessed as individuals when patients are assessed. This was recognised as an important area and possible gap in services for improvement.

13.6 Health sector, General Practices and information

GPs and other primary care workers are vital in supporting patients and their carers, with carers responsibilities closely linked to the patients own health and abilities. As discussed earlier the Carers (Equal Opportunities) Act 2004 places a duty on local authorities to find 'hidden carers' and reinforces the duty of the NHS to co-operate with Local Authorities in order to advance people's health and welfare, yet ensuring carers have access to information remains difficult. (Access to information is also discussed in section 6.7 – 6.11.)

13.7 The Select Committee recognises the dedication and professionalism of our local GPs and primary care workers in supporting patients and carers. The Committee noted that many hidden carers come into contact with the health sector before contacting personal social services or voluntary organisations like the carers centres. Therefore it is important for people working in the health sector to acknowledge their responsibility to identify carers and that they are able to signpost them to other sources of help and support, as "if carers are supported then ultimately the patient gets better support."²²

13.8 The key role the health sector should play was widely acknowledged. The General Medical Services Contract with GPs encourages identification of carers and their referral, however it was commented that the response of GPs in Kent is varied. It was reported that some GP practices are very positive and proactive with GPS visiting Voluntary organisations, Voluntary Organisations being able to attend practice meetings, and the presence of Carer Support projects encouraged at the practice once a month/week, but this was inconsistent. A clear theme emerged that the response of GPS was inconsistent and that there was a lack of integration in identifying and sign-posting carers. The Committee is concerned that there is a reported

- reluctance to display 'non-health' information (from Voluntary Carer Organisations) on surgery boards
- reluctance to contact or visit Voluntary organisations
- lack of referral of carers to carer organisations
- lack of consistency of response due to GP specialisation
- and that the Carers register was patchy, and that little was done with the information collected, and was therefore of limited benefit to carers.

13.9 Closer integration of health and social care services is central to government policy, such as commissioning joined up services outlined in DoH white paper 'Our health, our care, our say, Jan 2006'. There is a clearly identified need to provide better information and signposting for carers, and a need to demonstrate integration with measures to reach hidden carers. GP practices could be more proactive for carers that they come into contact with, by displaying information and as a minimum ensuring a leaflet was available/given to direct carers to services available, and becoming more aware of what help is available. Other County Councils have –

- encouraged targets in PCT local delivery plan to increase number of carers registering (Hertfordshire)
- jointly funded GP based Carer Support Workers (Somerset and West Sussex)
- have carer awareness training sessions for all hospital staff (Bury)
- in Oxfordshire, PCT funding enabled the secondment of a Carer Support worker from a carers centre to work in a GP surgery. It is suggested that this improves awareness of carer issues amongst practice staff, leads to quicker interaction and intervention, has a preventative effect, helps provide a seamless service and increases carers feeling supported.²³

13.10 Involving Carers - Appointments:

When multi agency reviews take place carers want to be involved in setting up and asked what fits in their diary not told when it is, which could be a bad time of day for them.

13.11 Mental Health

Support for carers of people with mental health issues emerged as a key issue. It was highlighted the prime requirement to help carers involved with mental health sufferers is the improvement of all professional services relative to the care plan in which they are involved.

13.12 Service delivery by the secondary mental health trust is primarily medication lead. Talking and behaviour therapies were valued by carers as these services gave a positive alternative to medication, help empower sufferers of severe mental illness, and could be used to defuse build up to crisis and therefore reduce pressure on carers. Carers and the Voluntary sector however highlighted that there is a severe shortage of therapeutic services including CBT (Cognitive Behaviour Therapy).

13.13 The Committee was informed that guidelines (NSF and DoH) are not followed with regards to for example care plans, crisis resolution home treatment and dual diagnosis, and that poor basic care and staff not complying with trust policies and procedures is a concern. The consequence of these reported gaps and shortfalls means that the potential for the service user recovery is affected and the consequence is an increase in burden on the carer.

13.14 It was reported that the one area that causes particular concern and stress to carers is crisis response, which is viewed as continuing to be inadequate. Carers cope with difficult situations including crisis, acute distress and difficult behaviour. The Committee heard this often occurs at times when professional support is not available, for example in the middle of the night or at weekends. Carers are particularly concerned about the service offered out of hours (1700 – 0800),

weekends and bank holidays as difficulties in accessing prompt, professional attention.

13.15 Crisis Resolution Home Treatment (CRHT) teams deliver acute treatment and observation at home to mental health patients suffering a temporary crisis in their condition. They are intended to provide an alternative to inpatient admission, allowing patients to be treated in the least restrictive environment with the minimum of disruption to their lives. These services have been a key Department of Health priority in recent years, and are also one of the 10 High-impact Changes recommended by the Care Services Improvement Partnership to modernise mental health services. Independent clinical evaluation of the working of CRHT shows that this model of services is preferable to inpatient treatment in appropriate cases, resulting in higher patient satisfaction and equal or better patient outcomes. However, these benefits can only be fully realised through effective implementation and integration of CRHT within the acute mental health care pathway.²⁴

13.16 It was a concern to carers that CRHT are not available 24/7, carers are not given out of hours contact for a person in their team who they can contact reliably and that crisis response takes too long and should ideally be within one hour. Carers reported a lack of co-ordination between Drs, mental health workers, and police when support is needed to control a severe crisis. It was highlighted that trying to get support and advice when a crisis happens is extremely difficult and stressful. Good communication and contact between professionals is essential for a joined up service. Carers commented on the lack of response and lack of access to out of hours support. It was reported that most CPNs, Drs and social workers do not visit out of hours. The Committee were informed that GPs may only have basic training in mental health and no access to clients notes and so are reluctant to visit or treat mentally ill clients. Social services Out of hours covers all emergency social service care needs from 5pm to 9.00am weekdays, weekends and bank holidays, refers to GP out of hours or crisis teams, but most social workers do not visit out of hours unless need for an immediate Mental Health Act Assessment. The policy is often to refer carers to Accident and Emergency as the first port of call. This can be extremely difficult for carers when handling a psychotic situation, e.g. as they need to encourage/get a distressed psychotic person in the car to hospital. This is also an issue when trying to access out of hours GPs at a clinic.

13.17 The East Kent Crisis Assessment and Treatment Team (CATT) is available 24 hrs/365 days a year to provide immediate assessment and support to residents of East Kent experiencing a major Mental health crisis. CATT prevents people being automatically admitted to an acute mental health inpatient bed, and replaced the Mental Illness Support Team (MIST), however there is concern that a gap has been created by the demise of MIST. It was reported that CATT responds only to those who would otherwise need hospitalisation in a few hours, and that there is a consequent service shortfall. It was highlighted that there is no professional mental health response support available for those who do not meet CATT referral criteria but who need support to prevent deterioration to the CATT criteria level. It was stated that about 30% of those referred by professionals acting on CATT referral criteria are not accepted for CATT support, and that there is no other mental health active response out of hours. The Trust in East Kent has acknowledged these concerns and it was noted that planned improvements may narrow the gap in service but carers are concerned that the issue will not be fully addressed. It was raised that as CATT is the only specialist mental health service available out of hours, clients who go to

Accident and Emergency out of hours, who do not meet the CATT criteria will not be able to access support, and may need to wait for in hours services to be available.

13.18 Community mental health teams (CMHT) work standard hours on weekdays. The Committee was informed that there were plans to extend these hours to 8/9pm, which would be extremely valued by carers and service users. This was however not certain at this stage and not expected until 2008/9, and would still leave a gap out of hours unless meeting CATT criteria for support. It was noted that within East Kent there is an ongoing consultation regarding the redesign of Community Mental Health Services and that the Carers representatives were being consulted, and that these issues had been raised directly with the Trust.

13.19 It was commented that apart from NHS direct help lines were not a 24/7 service. Although Mental Health matters, offers talking support and referral to other services 5 till midnight on weekdays and 2pm till midnight at weekends and bank holidays, help lines were only as good as the services they could signpost and access, especially out of hours.

13.20 There is a clear shortfall in service outside standard office hours, and that more cover is needed out of hours. Carers need support of professionals who understand the diagnosis and can help both sufferer and family handle volatile and potentially dangerous episodes, defusing build up to crisis and need for hospital admission. **Access to response support service in crisis is a key issue for carers, and needed especially out of hours and for those not meeting CATT criteria, as timely support can prevent harm and further deterioration and increased pressure on the carer.**

13.21 The UK National Audit Office are currently undertaking a study of Crisis Resolution Home Treatment (CRHT) Services, and are due to publish their report at the end of 2007. The key questions of the study are:

- Are CRHT services seeing the patients they are supposed to see?
- Is England served by the correct number and distribution of CRHT teams to achieve the Department of Health's desired impacts?
- Do CRHT services remain economical and appreciated by service users?

The study is being undertaken in conjunction with the Mental Health Advisory Group, the Healthcare Concordat and the Acute Care Steering Group and CSIP CRHT regional leads. The outcomes of this will be of interest to carers and the support for service users, and should be considered by the NHS overview and scrutiny committee alongside the issues raised by carers and the Voluntary sector on their behalf.

13.22 Confidentiality continues to be an issue. It is apparent that there is limited support for carers of people with mental health needs, as CPNs for example respond to the needs of the cared for person. Carers receive no effective support to play a meaningful role which co-ordinates with the care plan. Carers reported that their views are not listened to, that there is a lack of information due to privacy laws, which can create barriers for carers and that carers of people with mental health needs find it difficult to access the support they need. Difficulties can arise for carers of mental health patients where the patient doesn't agree to the family being involved. They may actively refuse to agree to the family being seen, or do not suggest to the

psychiatrist that the family would like to be seen as they are depressed and they are not actively involved. Carers/families are therefore left without support. A survey has shown that 66% of psychiatrists do not discuss cases in full in which carers have an interest due to lack of time (Rethink). Carers are reportedly not involved proactively by professionals in the therapeutic alliance and an associated lack of training available. Carers particularly expressed the need for support to help with coping strategies. The importance of improving communication for carers was emphasised, particularly around boundaries of confidentiality, and that it was important to find a way in which carers could be listened to, access their knowledge of the cared for person valued by the professionals.

13.23 Although it is widely acknowledged that the needs of both the carer and service user should be taken into account when care is being planned, the response of staff to Carers was inconsistent, and lack of information and access to support clearly leads to significant frustration. Carers and the Voluntary sector commented that the treatment of the service user is impacted upon by the carers lack of insight and support to them. If Carers were better supported they in turn could give better support in the community and their well being taken into account. There was a clearly expressed need for improved access to support for carers, and access to information about what is happening, and to prepare the carer for the service user coming home. It was noted that at discharge there was a lack of information on discharge to housing, carers were not informed, and that this was partly due to the privacy laws. Although support for Carers of people with mental health needs is limited, some carers commented on the excellent support they had received in particular from Local dementia outreach (Age Concern), and the Maidstone Carers Project and also to the support at Priority House (West Kent Social Care Trust).

13.24 Government and local policy is increasingly placing care into the community, and care of the Community Health Teams. The current Community Mental Health services redesign in East Kent has given rise to concerns of carers that no structures will have sufficient funds backing them to be able to deliver a 24/7 service, meaning that more will fall to carers. It is important the potential for carers to become ill themselves (through worry and amount of support they provide should not be underestimated).

13.25 Respite

Respite is a key issue, and is the one support service that stands out as having the potential to offer significant support to carers. The Committee are concerned at the reported limited availability of appropriate respite for people with mental health needs, especially those with early onset dementia or severely mentally ill and reduction in respite provision in the community by the NHS.

13.26 It was noted that other general issues for carers for mental health sufferers are

- Carers are often afraid to speak out for fear of retribution and are daunted by the stigma attached to their families
- reluctance to comment on service inadequacies due to life pressures, time consuming to make a complaint, lack of knowledge or lack of confidence, no real advocacy support, fear of offending staff that provide the care
- Lack of information regarding services and activities available, and need for better access to policy documents (e.g. CPA, CRHT, AO, carers assessments) and

Board and Management meeting minutes. Although there are forums and local implementation teams that are open to the public the view is that dates and venues are not publicised enough and that minutes should be more readily available.

- Carers assessments are not carried out to standards identified according to NHS guidelines, and there is no detail from the Trust on what carers should expect.
- The cost of setting up power of attorney was reported to be rising from £50 - @£650, would impact on carers financially.

13.27 Recommendations to improve outcomes for carers:

- KCC in partnership with Health and the VCO's need to **improve understanding and signposting from Health sector** to available help and support for carers in the county. (Multi Agency action).
- **KCC to pursue with Health the need to consider how carers of mental health patients (and service users) can be better supported, particularly at times of crisis and out of hours.** Access to response support service in crisis is a key issue for carers, and needed especially out of hours and for those not meeting CATT criteria, as timely support can prevent harm and further deterioration and increased pressure on the carer. Need to give consideration to response times, communication, and consider a service for Carers/families, to enable carers/families to cope more effectively with crises, psychotic episodes and emotional strain of caring.

NB: see also recommendation 7 on type and provision of respite services in the county (respite was discussed in section 10.0 and 13.25).

14:0 Partnership and Funding

14.1 Concerns of the Voluntary sector:

A major pressure affecting the delivery of services to carers is the lack of resources and the increasing numbers of people needing support, and levels of support needed. It was highlighted that not all support for carers has to cost a lot of money. One organisation reported that they support over 600 carers on a core grant of £61,000, which equates to 28p per carer per day. The early intervention and support of the Voluntary sector can reduce the need for (and associated costs) of statutory health and Social care and needs to be recognised.

14.2 The voluntary sector know there are additional services they could offer that would benefit clients, but lack of resources and funding limit what they can do. It was suggested by some that more partnership working and sharing of resources would make funds go further.

14.3 It was clear that the Voluntary sector wanted to work more closely with the statutory sector, with all carers being referred to carer support organisation if they wish, with support for joint visits or joint carers assessments.

14.4 It was also suggested that there could be potential for Voluntary organisations to work in partnership with each other, presenting different options for service provision through perhaps pooling resources with each other, and whether this may give opportunities for additional respite provision.

14.5 There was overall all round praise from carers about the Voluntary sector as crucial service, offering support, and highly regarded services. A small sample of some of the comments:

- Don't know what I would do without carers support project
- Maidstone Carers Project very helpful, keep well informed , go out of their way to help,
- Age concern excellent , very supportive in darkest hrs
- Carer support service, excellent at helping prevent crisis point and planning respite, keep carer well informed (Dover Carer support Service)
- Dementia outreach excellent

14.6 Health

It was highlighted that there is some historical conflict between health and social services and that there is still sometimes a 'pass the parcel' of responsibility and lack of co-ordination (despite good intentions) adding to carers stress in accessing the services.

"5 wks into caring for husband after severe stroke – all before and after discharge well meaning but still trying to sort out who is responsible for what and 'buck –passing' is used by all disciplines from top to bottom

.... Impression of a total lack of co-ordination between services despite good intentions.”

14.7 The lack of clearly identified PCT leads for carers has hindered partnership working for carers over the past year and hindered the development of a multi agency Adult carers strategy. It was noted that The Director for Kent Adult Social Services was engaging with the Chief Executives regarding this issue at the time of the review.

14.8 District and Borough Councils also have a role to play and need to be encouraged to find ways to actively engage and support carers, perhaps through opportunities to access leisure facilities.

14.9 Funding

Funding is fundamental to improving outcomes for all carers whether accessing support from the Voluntary sector, KCC or the health service. The continued investment and partnership with the Voluntary Sector is crucial to the support of carers. It is also clear that it will become increasingly difficult for the voluntary sector to develop or increase their support for carers without increases in financial support, especially in light of increasing levels of need, increasing numbers referring and length of waiting lists for some services. It is also a concern of the Voluntary sector that additional funds may target sign-posting and identifying hidden carers and that insufficient funds will be allocated to increase direct care. It is important that these two aspects are supported together as raising the profile without the back up of resources and services would add to demand and pressure on services, and subsequently the waiting lists.

14.10 Carers Grant

The national strategy ‘Caring for Carers’ (1999) included the launch of the Carers Grant. The aim of which was to enable local authorities to support carers in taking a break, initially ring fenced for 3 years. The Grant is due to end in March 2008.

14.11 To date Kent has used the grant to support carers mainly through grants to the voluntary sector organisations along with support to service users e.g. respite. 20% of the grant is allocated to children’s services, to support both young carers and carers of children with disabilities and the remaining 80% to adult services to support carers of older people, those with learning and physical disabilities and mental health difficulties.

14.12 There is considerable concern from the Voluntary sector regarding the ending of the grant. It was stated that Annual/Short term funding has limited the ability to plan services ahead and that the uncertainty around continued funding has created difficulties for the sector to plan services longer term. There was a need for earlier notification of funds as some organisations stated they were having to let people go as they could not guarantee them a post past March 08. It was stated that it was likely that the base budget would include a non-ringfenced allocation for carers. Concerns were expressed that if funds are allocated in the base budget due to the way formulae work KCC could lose out on funds previously received under the specific grant system. Despite the change to a three year budget settlement it was commented that longer term commitment was difficult as budgets are not set in

concrete over the mid-longer term. They are reviewed annually to reflect changing priorities, pressures and demands, and is in effect fluid over time therefore making it difficult to contract for the longer term on this basis. Carers emphasised the need to obtain higher funding from government to provide more support services for carers, increase flexibility and the need for KCC to continue to give grants to provide support through the Voluntary sector.

Appendix One: List of Witnesses

Members encouraged to discuss the issue in their divisions, meet with local carers and report to the review group.

Desktop research: Literature search, including information on

- Key legislation
- Independent academic research from various universities, institutions and charitable organisations
- The 2001 Census
- Information provided by various Charities such as Carers UK, Rethink, The Princess Royal Trust for Carers
- National and local policy documents
- Benchmarking against other Local authorities – summary of issues
- Briefing notes

Written and oral evidence

The Committee received through written and oral evidence the views of officers from Kent Adult Social Services, officers from Children, Families and Education, senior managers from voluntary organisations and carers. The following internal and external witnesses gave oral evidence to the Committee in a series of Hearings.

Hearing date	Witnesses who attended hearing sessions
25 July 2007	Alf Archer , General Manager, Maidstone and North West Kent, Crossroads
	Loraine Bond , Service Manager, East Kent, Crossroads
	Sharon McGeouch , Senior Manager, Maidstone MIND
7 Aug 2007	Ron Alexander , Chief Executive, Carers First , Tonbridge.
	Judy Ayris , Dementia Carer Support Service, Age Concern , Canterbury.
	Joy Butcher , Executive Director of Find a Voice and Chair of Ashford District Partnership Group for Learning Disabilities.
	Carol Smith , Alzheimer's & Dementia Support Group , Northfleet
	Jane Barnes , Head of Adult Services Provider Unit (ASS) (KCC)
8 Aug 2007	Andrew Hickmott , Head of Childrens Services , West Kent (C, F & E)
	Amanda Hornsby , Policy Officer (C, F & E)
	Barbara Bradley , Policy Manager, Carers (ASS) (KCC)
	Chris Lovelock , Manager, Swale Carers Centre , 2 x Young Carers

Hearing date	Witnesses who attended hearing sessions
9 Aug 2007	Jean Penney , Project Manager , Independent Living (KASS) (KCC)
	Barbara Hagan , Project Manager, Carers Project , Maidstone.
	Peter Axton and Alan Thomas , Carers
	Kate Gollop , Manager, Volcare
15 Aug2007	Des Sowerby , Joint Direct Learning Disabilities (KASS) (KCC)
	Sue Graham , District Manager with Lead for Carers (KASS) (KCC)
	Jo Crittall , Care Manager (KASS) (KCC)
	Clare Martin , Head of Supporting People (KASS) (KCC)
16 Aug 2007	Ferne Haxby , Carers Lead, West Kent PCT
	Chris Belton Head of Adult Social Services- West Kent (KASS) (KCC)
	Mike Powe , District Manager – Thanet (KASS) (KCC)
	Barbara Bradley , Policy Manager, Carers (KASS) (KCC)
	Some witnesses also provided supplementary evidence to their hearings

Appendix Two: National and Local Policy Context

National Support:

The Disabled Persons (services, consultation and Representation) Act 1986 states that when assessing a disabled persons needs consideration must be given as to whether the carer is able to care for the disabled person.

Caring for people: Community care in the next decade and beyond white paper 1989
One of the six primary objectives of community care policy is to make practical support for carers a high priority. Young carers are not specifically mentioned.

The NHS Community Care Act 1990 provides a framework of community care procedures and policies as well as establishing support for Carers as a national priority.

Carers (recognition and Services) Act 1995 recognises that the needs of carers may well be different to those of the cared for person and introduced the concept of a Carers assessment. It gives carers who provide *substantial care on a regular basis* of any age the right to an assessment of **their** needs in relation to their ability to provide and continue to provide care (but not to services or assistance). It requires local authorities to carry out a carer's assessment, (if requested) at the same time that they assess or reassess the person requiring care.

National Carers Strategy 'Caring about carers'1999, seeks to improve flexibility and choice for carers and highlights the need for legislation to enable local councils with Social services responsibilities to provide services direct to carers. It describes the needs of carers, which included:-

- time off from caring, freedom to have a life of their own
- well being of the person being cared for
- relief from isolation
- receipt of reliable and satisfactory services
- recognition of their role
- the need for health and social services to identify carers support services in their area
- a say in service provision

Its key elements are:

- Information – carers being seen as real partners in care and being given better sources of information about the help and services available to them.
- Support – from communities in which they live, in planning and provision of services and development of policies in the workplace which will help them combine employment with caring.
- Care – allowing them to make real choices about their lives and maintaining their own health.
- Young carers – recognition of their role, support with caring tasks, information about the support available to them and the importance of emotional support.

National Service Framework for mental health 1999 sets national standards, based on clinical evidence, and sets out best practice for promoting mental health and treating mental illness. Standard 6 “Caring for Carers” aims to ensure health and social services assess the needs of carers (including young carers) who provide regular or substantial care for those with severe mental illness and provide care to meet their needs. The framework recognises that family carers may have their own needs and specifically mentions young carers. It recognises needs of those caring for someone with mental health problems are especially high, and acknowledges that young carers should be offered services to ensure they have the same life chances as other children. It emphasises that all carers on the care programme approach should have an assessment at least annually and have their own written support plan.

Under the Carers and Disabled Children Act 2000 carers who provide a ‘substantial’ amount of care on a ‘regular’ basis are eligible for an assessment of their needs. It gives carers over the age of 16 a new right to request an assessment of their own needs even if the cared for person refuses an assessment or the provision of community care services. Enables Local authorities to provide services and payments directly to carers following assessment in their own right, receive vouchers for short-term breaks and receive direct payments in lieu of services for which they have been assessed. Carers under the age of 16 need to access assessment and services through the 1995 Carers Act or 1989 Childrens Act.

The National Service Framework for Older People 2001. The rationale behind Standard 2 “Person Centred Care” is that older people and their carers should receive person centred care along with services which respect them as individuals and arranged around their needs.

The Community Care (Delayed Discharges) Act 2003 specifically refers to carers in relation to hospital discharge arrangements. The Act gives carers the right to an assessment and support when the person they care for leaves hospital. It also ensures that the local authority must make sure any services the patient needs for safe discharge are provided.

Before 2004 carers had a right to an assessment that took into account their needs as a carer, and offered support to them in their caring role. Wider issues such as training, employment and leisure needs were not necessarily taken into account. The 2004 Act should ensure that a carer’s lifelong learning, work and leisure needs are considered when that carer is assessed and that carers are also ‘informed’ of their rights.

Carers Equal Opportunities Act 2004 extends the obligations in relation to assessments and introduces a statutory obligation on Social services to inform Carers of their rights. It builds on the 1995 Act by ensuring that care assessments also now consider whether the carer works or wishes to work, and /or is undertaking or wishes to undertake education, training or pursue any leisure activities. Social services departments have to consider how carers can be supported to enable them to be involved in those activities outside of their caring responsibilities.

“.. This Act makes three main changes to the law with the objective of providing further support for carers and helping to ensure that they are not placed at a disadvantage because of the care they provide.

First, the Act requires local authorities to inform carers, in certain circumstances, that they may be entitled to an assessment under the 1995 and 2000 Acts.

Second, when undertaking a carer's assessment, the local authority must consider whether the carer works, undertakes any form of education, training or leisure activity, or wishes to do any of those things.

Third, the Act provides for co-operation between local authorities and other bodies in relation to the planning and provision of services that are relevant to carers..."

Green Paper (Independence, Wellbeing and Choice: our vision for the future of social care for adults in England). This Green Paper sets out a vision for adult social care over the next 10 to 15 years and how this might be realised. It invites everyone to give their views on the vision and the ideas set out in the document, as well as to contribute new ideas to the debate. The key proposals to deliver this vision include:

- wider use of direct payments and the piloting of individual budgets to stimulate the development of modern services delivered in the way people want;

White paper 'Our health, Our care, Our say' Jan 2006, sets out a 'vision to provide people with good quality social care and NHS services in the communities where they live. Social care services are changing to give service users more independence, choice and control'. It confirms the vision set out in the Department of Health Green Paper, Independence, Well-being and Choice.

It sets out how health and social services will change in the future, with a strategic shift to more services in local communities closer to peoples homes that supports:-

- independence and wellbeing
- people exercising choice and giving them a say
- people with high levels of need
- and that sustains realignment of the health and social care systems

The paper proposes a New Deal for Carers to include

- updating and extending the 1999 Strategy for Carers
- Councils and PCTs to nominate lead for carer services
- Establishing an information service/helpline for carers (£3-5M for a new National Emergency helpline).
- Ensuring short term home-based respite is established for carers in crisis or emergency situations (£25M nationally). Kent allocation is £588,000 (20% of which is for CFE).
- Creation and funding for an Expert Carers programme
- Support to carers is seen as a priority if the cared for person is to remain in their own home.

The needs of young carers are recognised in current legislation:

The Children Act 1989. Requires LA's to provide support services for all children in need (which includes children with a disability). Also to promote inter-agency working and facilitate service provision by independent providers.

The Children Act 2004 highlights the importance of providing services to children and young people to prevent escalation of need and therefore there is a direct relationship to the preventative services young carers may require.

The legislation is supported by:

- Caring for carers. The National Strategy for carers 1999
- Framework for assessment of Children in need and their families 2001
- DFES Circular10/99 – Social inclusion and pupil support
- National Service Framework for Children, Young People and Maternity Services

National Service Framework for Children, Young People and Maternity Services is a ten year programme to stimulate long term and sustained improvement in children's health. Intended to lead to a shift in services designed and delivered around needs of children and families using those services not around needs of organisations. The Childrens National Service framework is aimed at everyone who comes into contact with or delivers services to children and young people

A new National Carers Strategy due summer 2007.

The Carers Special Grant was introduced alongside the 1st National Carers Strategy (1999) as a time limited fund, which is due to end in March 2008. Set up to stimulate diversity and flexibility of provision to enable carers to have a break from caring. The grant also established a special fund (CG15) to provide flexible carers services directly to the carer.

Kent Drivers:

Towards 2010

Target 53: to enable people to lead independent lives, we will strengthen the support provided to people caring for relatives and friends.

Kent's Children and Young Persons Plan

Priority 5: with partners ensure that services continue to be developed to improve and promote healthy lifestyles outcomes for children

Key action 23: extend and enhance support to enable Young carers to deal with the challenges they face in their caring role and to flourish outside their caring role.

Invisible People DRAFT, a multi agency strategy for young carers in Kent 2007-2010. Developed in recognition of the challenges that young carers face in their everyday lives, and aims to support them in achieving their full potential. The DRAFT strategy recognises the complex needs of young carers and responds to this by identifying key activities that need to be undertaken to improve the outcomes for this group of children and young people. (Implementation group appointed to start on agreement of draft strategy).

Carers performance Indicators. The DOH developed two indicators to assess the impact on carers support provided at a local level.

- The number of carers assessments and reviews completed through the reporting period, by age group of carer and by age and client of the group
- The services provided to the carer as a result of the assessment through the reporting period, by age group of the carer and by age group and client group of the client.

The Future: A new Outcomes Framework for Performance Assessment of Adult social care 2006-07 CSCI Consultation Document published in July 2006, proposes an outcomes driven assessment framework based on the 7 social care outcomes. The proposed scoring system includes carers at 15% along with older people 40%, people with learning difficulties 15%, mental health 15%, physical and sensory disability 15%.

Appendix 3: Carer Assessments

Carers who provide regular and substantial amount of care have a right to request an assessment of their needs under the Carers and Disabled Children's Act 2000, Carers (recognition and Services) Act 1995, Carers Equal Opportunities Act 2004. The 2004 Act enables much closer co-operation between KCC, the PCTs the Acute Trusts and others when planning and providing services for carers.

The Carers assessment should be taken into account when deciding the package of care for the cared for person. Since 2001 the carer can receive services or direct payments in their own right. The importance of offering a carers assessment was stressed in the National Service Framework for older people and Mental Health as well as the White Paper on learning disabilities *Valuing People*.

It should be noted that the carers assessments often act as a 'gateway' to services. Enabling carers to begin to access respite care and short breaks, sitting services, training and education etc. They are a vital tool to ensure that as many carers receive support as possible. The assessments are carried out by Social workers to assess the carers ability to provide and continue to provide care for the cared for person.

Number of carers assessed/reviewed

Carers Assessment is key to accessing services and support for carers, therefore it is important to explore how many carers have received a carers assessment and how progress is being made to improve performance in this area. The table below gives a summary of the number of carers assessed by Kent Adult Social Services.

Table 1: Summary of number of assessments

No. of Carers Assessed / Reviewed	2005-06	2006-07
No. of Carers Assessed Jointly	18311	19161
No. of Carers Assessed Separately	6840	6971
Total No. of Carers Assessed	25151	26132
No. of the Above that are New Carers		
No. of the Above that were Revised Assessments	Not known	Not known

It should be noted that the total number of assessments carried out is not known, as information is only collected by number of carers (as per RAPS return) (i.e. Carers are only counted once within any reporting period, in accordance with their most recent assessment /review). It is therefore not currently possible to ascertain the total number of assessments, how many carers assessments were reviews, frequency of reviews or identify the number of assessments of new carers.

The tables below give a breakdown of assessments by age group, joint or separate review and number of assessments by work area. All carers can request a separate assessment, and may be appropriate where difference of opinion between what service user desires and what their carer needs, also where carers needs are complex.

Table 2: Number of carers for whom assessments or reviews were completed during the period, by age group of carer

Age group of Carer	Number of carers assessed or reviewed separately	Number of carers assessed or reviewed jointly with the client	Number of carers declining an assessment
Period 01/04/05 to 31/03/06			
Under 18	42	60	0
18-64	2649	6545	679
65-74	1532	4648	397
75 and over	2617	7058	932
All ages	6840	18311	2008
Period: 01/04/06 to 31/03/07			
Under 18	43	61	0
18-64	2700	6670	692
65-74	1561	4987	405
75 and over	2667	7443	950
All ages	6971	19161	2047

Table 3: Number of carers assessed/reviewed by area

No. of Carers Assessed / Reviewed by area		
Area / District	2005-06	2006-07
East Kent	-	13726
EK OT Total	-	2084
Mental Health Total	-	1110
West Kent	-	8711
Total No. of Carers Assessed	-	26132

The table below gives details of services provided to the carer as a result of the assessment through the reporting period by age group.

Table 4: Number of carers receiving different types of services provided as an outcome of an assessment or review, by age group of carer

Age group of Carer	Services including breaks for the carer and/or other carers' specific services	Information and advice only
Period 01/04/05 to 31/03/06		
Under 18	18	74
18-64	4136	4528
65-74	2225	3545
75 and over	3965	5520
All ages	10344	13667
Period 01/04/06 to 31/03/07		
Under 18	18	75
18-64	4205	4585
65-74	2762	3590
75 and over	4031	5589
All ages	11016	13839

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