

Report to: **Adult Social Care Scrutiny Committee**  
Date: **9 June 2011**  
By: **Chairman of the Review Board**  
Title of report: **Scrutiny review of respite provision**  
Purpose of report: **To present the outcomes of the scrutiny review.**

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**RECOMMENDATION: that the Committee considers the report of the Review Board and makes recommendations to Cabinet for comment and County Council for approval.**

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## **1. Financial Appraisal**

1.1 There are no specific financial implications arising from the recommendations in the Review Board's report.

## **2. Summary**

2.1 Members of the Adult Social Care Scrutiny Committee had previously questioned whether there was enough respite provision across the county and how easy it was for carers to access it. The Committee therefore decided to set up a scrutiny review board in December 2010 to scrutinise this matter further.

2.2 The aim of the review was to assess the availability and accessibility of respite care provision in East Sussex to support adult carers in their role. During the course of the review the Review Board spoke to carers, ASC officers, voluntary and community organisations and independent providers through attending a range of established support network meetings, carers' events and meetings organised by ASC. In all Review Board members attended eight meetings and spoke to approximately 45 to 50 carers. A further nine carers provided written responses.

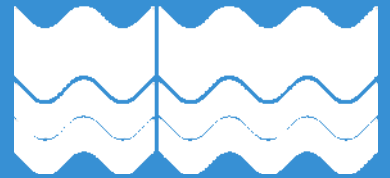
2.3 The report attached at appendix 1 contains a summary of work of the review, together with the findings and recommendations of the Review Board. The Committee is recommended to receive the Review Board's report for submission to Cabinet on 5 July 2011 and County Council on 19 July 2011

COUNCILLOR PAT OST  
Chairman of Review Board

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Local Members: All

Background Documents: None



# Scrutiny Review of Respite Provision

## Report by the Review Board:

Councillor Pat Ost (Chairman)

Councillor Colin Belsey

Councillor Beryl Healy

Councillor Phil Scott

Councillor Sylvia Tidy

Janet Colvert (LINK representative)

June 2011

Adult Social Care Scrutiny Committee – 9<sup>th</sup> June 2011

Cabinet – 5<sup>th</sup> July 2011

Full Council – 19<sup>th</sup> July 2011

**Final report of the Scrutiny Review of respite provision**

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## Recommendations

1	That Adult Social Care rationalise the entire range of terminology it uses in association with carers and respite provision to ensure that it is clear, concise and consistent across all teams in the department, Health professionals and voluntary and community organisations.
2	Updated guidance on the Carers Personal Budget to be provided to assessors, carers and voluntary and community organisations so that it is clear how the scheme operates.
3	That the Carers' Partnership Board works in conjunction with health, perhaps via the Clinical Executive Group, to ensure that hospitals, health workers, GPs and other professionals that have contact with carers are able to recognise the needs of carers and provide better signposting as to where support is available.
4	That a cross county sample of carers are surveyed in 12 months to assess whether there has been an improvement with the way in which their contact with ASC has been established and maintained.
5	Senior officers and appropriate Adult Social Care staff should attend carers' events to not only give formal presentations but also to have informal discussions with carers about their experiences.
6	That prior to a telephone assessment being carried out the person being assessed is sent a brief outline of what will be covered in the assessment so that they can give it some thought and get together any paperwork they may need to aid the discussion.
7	That the evaluation of the LEAN pilot is scrutinised by the Adult Social Care Scrutiny Committee, with particular focus on the way in which carers' assessments via the telephone have been carried out.
8	That Adult Social Care should continue to maintain funding for respite services such as the sitting service and the Carers Breaks Project.
9	That Adult Social Care continues to make improvements to the system for booking rolling residential respite to ensure that carers are able to book beds in advance and, where possible, at a location of their choice.
10	That funding to support carers should continue to be prioritised when Adult Social Care and Health are setting budgets.
11	That more support networks are developed across the county to empower carers to support themselves and others who carry out a similar caring role.

## Objectives and scope of the review

1. Members of the Adult Social Care Scrutiny Committee had previously questioned whether there was enough respite provision across the county and how easy it was for carers to access it. The Committee therefore decided to set up a scrutiny review board to scrutinise this matter further.
2. The aim of the review was to assess the availability and accessibility of respite care provision in East Sussex to support adult carers in their role. To achieve this, the Review Board:
  - Gained an understanding of the different types of respite provision available and who was eligible for it;
  - Assessed the current level and location of respite provision in East Sussex provided either in-house, by the independent sector or by the voluntary and community sector;
  - Gathered evidence and views on respite provision in East Sussex from carers, the voluntary and community sector and independent providers;
  - Considered the extent to which respite provision meets the needs and wishes of both the carer and the cared for person;
  - Considered the barriers that may prevent a carer or a cared for person accessing respite provision and how these could be overcome; and
  - Assessed the impact that Putting People First and direct payments has had on enabling carers to access respite services that best meet their needs.

### Exclusions

3. Carers can be any age, including children and young people, who often care for a parent. To ensure that the scope of the review remained manageable though the Review Board decided to exclude young carers from this review and concentrate just on adult carers who are caring for an adult.

## Background

4. A carer is someone who provides unpaid support to family or friends who would not be able to manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. Research in 2010 revealed that there were approximately five million carers in England, 12% of the adult population (aged 16 or over).<sup>1</sup>
5. Caring has a positive impact on the economy, saving social services and Health an estimated £87 billion a year in England.<sup>2</sup> However, providing care can have a negative impact on the health and well-being of carers, with those providing high levels of care twice as likely to end up sick or disabled.<sup>3</sup>
6. The proportion of the population with care needs is set to increase significantly over the next two decades as the size of the elderly population rises. This means that many more people are going to be taking on the role of a carer in the future.
7. The Review Board identified respite as being:

*A brief interval of rest or relief which is specially tailored to a carer's needs and aimed at supporting the carer to continue in their caring role.*

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<sup>1</sup> Survey of Carers in Households in England 2009/10, The Information Centre for health and social care, 2010, P7

<sup>2</sup> Carers UK: The Voice of Carers website, figures from 2009

<sup>3</sup> *ibid*

8. Respite covers a range of provision, including: residential, home based respite, sitting services and activities specifically aimed at providing a break for the carer. One off payments, provided through the Carers Personal Budget, also enable carers to purchase equipment or a service to support them in their caring roles. More details on the range of services available in East Sussex can be found at paragraphs 26 to 44.

9. Ensuring that a carer can continue in their caring role for as long as possible reduces the risk of the cared for person requiring a greater level of support, such as residential care. An additional benefit of the respite is that it can provide a positive experience for the cared for person. Either as an opportunity to spend time in a different environment away from home, take part in new activities or to be able to continue with a hobby they had previously enjoyed.

**Carers in East Sussex**

10. The most comprehensive data available on carers in East Sussex comes from the 2001 census. Given the age of this data and the fact that not all the people who care for someone classify themselves as a 'carer', it is doubtful that these figures reveal the true number of carers that there are in East Sussex.

11. In 2001, East Sussex was in line with the then national average for the percentage of the population who defined themselves as a carer, and roughly in line with the average for the South East. (see figure 1)

12. Whilst Wealden had the highest number of carers (due to the fact that it has the largest population of the five district and boroughs), the percentage of the population in each district and borough who defined themselves as a carer was also in line with the national average (ranging from 10 -11%). (see figure 1)

Fig 1: Breakdown of carers in East Sussex by District and Borough in 2001

<b>Area</b>	<b>Population</b>	<b>Number of carers</b>	<b>Carers as % of the population</b>
<b>Eastbourne</b>	89,667	8,767	10%
<b>Hastings</b>	85,029	8,635	10%
<b>Lewes</b>	92,177	9,695	11%
<b>Rother</b>	85,428	9,553	11%
<b>Wealden</b>	140,023	14,343	10%
<b>East Sussex</b>	<b>492,324</b>	<b>50,993</b>	<b>10%</b>
<b>South East</b>	<b>8,000,645</b>	<b>737,751</b>	<b>9%</b>
<b>England &amp; Wales</b>	<b>52,041,916</b>	<b>5,217,805</b>	<b>10%</b>

13. The majority of carers provided 1-19 hours of care per week (67-75% of carers in each district and borough). 17% to 23% of the carers in each district and borough provide over 50 hours of care per week. (see figure 2)

Fig 2: Breakdown of number of hours of care provided each week in 2001

District or Borough area	Number of carers providing 1-19 hrs care per week	Number of carers providing 20-49 hrs care per week	Number of carers providing 50+ hrs care per week
Eastbourne	6,019 (69%)	911 (10%)	1,837 (20%)
Hastings	5,752 (67%)	896 (10%)	1,987 (23%)
Lewes	7,151 (74%)	862 (9%)	1,682 (17%)
Rother	6,823 (71%)	861 (9%)	1,869 (20%)
Wealden	10,812 (75%)	1,103 (8%)	2,428 (17%)
<b>Total</b>	<b>36,557</b>	<b>4,633</b>	<b>9,803</b>

## National legislation

14. In recent years there have been several pieces of national legislation and key strategies aimed at supporting carers:

- The Carers and Disabled Children Act 2000  
Provided carers with the right to request an assessment of their needs and placed a requirement on local authorities to provide carers with services which help them to care.
- The Carers (Equal Opportunities) Act 2004  
Placed a duty on all Local Authorities to inform carers about their entitlement to an assessment, rather than wait for a carer to apply for one.
- Carers at the heart of 21st-century families and communities (2008)  
Set out a strategic vision that carers would be 'universally recognised and valued as being fundamental to strong families and stable communities'. With support tailored to meet individuals' needs that enabled carers to 'maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen'.
- Recognised, valued and supported: next steps for the Carers Strategy (2010)  
Identified the actions that the coalition Government would take over the next four years to ensure the best possible outcomes for carers and those they support. These included supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.

## East Sussex Joint Commissioning Strategy for Carers' Services 2010-15

15. This strategy was agreed between East Sussex County Council Adult Social Care Department, NHS Hastings and Rother Primary Care Trust and NHS East Sussex, Downs and Weald Primary Care Trust. Following consultation with carers it was decided that respite and carers breaks would be one of the three key areas that the strategy would focus on (the other two were support to stay mentally/physically well and respect and involvement).

16. The strategy highlighted the approach taken towards developing respite services via a *'menu of flexible, individually tailored home-based respite care services supplied by local, trusted providers from the third sector; to include out-of-hours and specialist support'*.

## Funding for respite services

### Adult Social Care funding

17. An annual Carers Grant is provided by the Government to East Sussex County Council. Originally this was ring fenced, which meant that it could only be spent on activities relating to supporting carers. This ring fence has now been removed, but ASC still uses the whole grant to support carers. In 2011/12 the sum was £2.2M.

18. Additional funding is also received from the PCTs (\*£245,000 in 2011/12) which is used to jointly commission Care for the Carers to provide support to carers, and the Association of Carers in Hastings to provide a sitting service for carers.

Fig 3: Breakdown of ASC expenditure for 2011/12

<b>Breakdown of expenditure</b>	<b>2011/12</b>
Grants to Voluntary Sector	£896,600
Home Based Respite (including CRESS)	£985,000
Carers Personal Budgets	£600,000
Other – Miscellaneous (eg salaries & publicity)	£113,000
<b>Total</b>	<b>£2,594,600*</b>

\*Figure includes contribution of £245,000 from the PCTs

19. Expenditure on residential respite and day services comes from the Community Care budget, rather than the Carers Grant. Cared for people accessing these services are subject to a financial assessment and if necessary are required to make a monetary contribution to the cost of these services. Services provided via the Carers Grant are free.

### Health funding

20. The PCTs receive additional funding from the Government to support carers, although this funding is not ring fenced. Nationally the funding in 2011/12 will be £100m, of which the Princess Royal Trust for carers estimates that the allocation for East Sussex will be just over £340,000.

21. The PCTs commission care packages for patients who meet the Continuing Health Care (CHC) criteria, which includes carers who have health issues. Some of these packages will include support to enable carers to have a break. In 2009/10 an analysis of the budget indicated that £826,000 of CHC spend related to carers' breaks.

Fig 4: Breakdown of PCT's expenditure for 2011/12

<b>Breakdown of expenditure</b>	<b>2011/12</b>
Care for Carers contribution	£245,000*
Grants to other Voluntary Sector organisations	£199,000
Estimated carers breaks costs included in CHC	£940,000
<b>Total</b>	<b>£1,384,000</b>

\*Figure provided to ASC to jointly fund some services



## **Carers' needs assessments**

22. To be able to access a service carers must undergo a carer's needs assessment. This is used to establish if a carer is providing regular and substantial support to the person they care for and the level of risk they face if support is not provided. This level of risk is established using the Fairer Access to Care Services (FACS) framework (as used for assessments for social care services). If it is established that there is a critical or substantial risk to the caring role breaking down in the immediate or foreseeable future then services are provided that contain or reduce this risk.

23. Assessments are carried out either at the carer's home, in the office or over the phone, depending on the preference of the carer. 'Party assessments' are also carried out, which is when both the carer and the cared for person are assessed at the same time. Financial assessments are carried out if the respite being provided is residential or day care. Home based respite services do not currently require a financial assessment.

24. From April 2010 until the end of February 2011 a total of 3,713 assessments or reviews of a previous assessment were offered to carers. Of these 2,737 were accepted. This only represented 7% of the carers in East Sussex (as calculated by the 2001 census).

## **Respite provision available in East Sussex**

25. Respite is often mistakenly seen as just a residential service, whereby the cared for person goes into a residential home for a period of time to enable the carer to have a break from their caring role. However, in recent years a range of different respite services have been developed across East Sussex to help support carers:

### **Home based respite**

26. A care worker supports the cared for person in their own home for a few hours each week to enable the carer to have a break on a regular basis. The care worker is qualified to provide personal care<sup>4</sup> to the cared for person.

27. The length of time for these sessions can vary depending on the needs or the situation of the carer. However, most carers usually have three hours per week, which can be taken in one sitting, split over the course of the week or hours can be built up to enable a longer break to be taken every couple of weeks.

28. Since June 2010 ASC has had in place a framework agreement with five private providers to offer this service. The carer can also take a direct payment and purchase the service from a different provider.

29. In 2010/11 funding for this service was £722,940, which supported a total of 466 carers to receive a regular home based service. With carers having, on average, three hours provision each week, this equated to approximately 72,500 hours of home based respite across the whole year.

### **Sitting service**

30. This service is very similar to the home based respite, but with this service it is a volunteer who sits with the cared for person whilst the carer has a break. The volunteer is not able to carry out any personal care for the cared for person.

31. For several years ASC has been funding sitting services through the Association of Carers (covering Rother and Hastings) and the Red Cross (covering North Wealden).

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<sup>4</sup> Personal care includes such things as Personal hygiene (e.g. bathing/showering, toileting) and the administering of medication

32. In 2010/11 the Association of Carers supported 185 carers for 2,857 hours and the Red Cross supported 70 carers for 789 hours.

### **Day service/opportunities**

33. Day services can be provided for a variety of reasons, including providing a carer with a break from their caring role. Traditional day services, where a centre provides activities for individuals either on a full day or half day basis, are still widely available. However, there is also a move towards providing 'day opportunities' whereby the cared for person is supported to take part in other activities, such as going out for lunch, attending a football match or continuing with a hobby. ASC has several day care centres available and services are also provided by both the private and the voluntary sector.

34. ASC does not record exactly how many of the day opportunities places are being used to provide carers with a break. However, recent reviews of two particular day centres suggests that approximately just under half of all service users (48.7%) using day opportunities do so to give their carer a break. Based on this, it is estimated that 763 carers received respite in 2010/11 by the person they care for attending day opportunities (an estimated total of 503,000 hours during the year).

35. Day opportunities are also available for carers. They can attend a range of courses such as photography, creative writing and IT. These not only give the carer a break from their caring role but also enable them to learn a new skill or take up a new hobby and to make new social contacts with other carers. Sound Architect is currently being funded by ASC to provide a range of courses for carers. From September 2009 until March 2011, six courses were run, each lasting seven or eight weeks. Each course supported between five and ten carers.

### **Carers Breaks Service**

36. Originally set up as a pilot with national government funding, this service is now jointly funded by ASC and Health until March 2012. This service purely offers support to cared for people who have complex mental health needs or dementia and their carers through the four Older People's Community Mental Health Teams. Following an assessment by a member of the Carers Breaks team a personalised support plan is developed to meet the particular needs of the carer and the cared for person. One to one support at home and/or day opportunities are provided in a range of locations across East Sussex, including St Leonards, Eastbourne, Peacehaven, Heathfield and Polegate. Support groups are also available for the carer, enabling them to meet with other carers who are in a similar situation.

37. Between October 2009 and March 2011 a total of 14,281 carers' breaks were provided. In March 2011 approximately 300 carers' breaks were provided each week.

### **Residential**

38. The cared for person stays in a residential home for a period of time (anything from just overnight to several weeks) to provide the carer with a break. This break can be used by the carer to spend some time at home by themselves, recuperate from an operation or to take a holiday. Where residential respite is provided on a regular basis this is known as 'rolling' respite.

39. ASC has several homes providing respite care for people with learning disabilities or mental health issues (eg dementia). Services are also provided by private care homes.

40. In 2010/11 approximately 500 carers received a respite break as a result of the person they cared for going into a residential setting. Depending on their level of need, these breaks will have ranged in length and frequency, including regular weekly or fortnightly overnight stays and annual two week breaks.

## **Additional support**

### **CRESS (Carers Respite Emergency Support Service)**

41. This is a service, accessed through a carer's assessment, that enables carers to develop a plan for how they would like the person they care for to be supported if there is an emergency (eg the carer is suddenly taken into hospital). The plan provides details about the cared for person and contact details for up to three relatives, friends or care providers that they would like to support the cared for person. In an emergency those people named in the emergency plan are contacted. If none of them are available then ASC will provide emergency cover.

42. By April 2011 2,857 carers were registered with CRESS.

### **Carers Personal Budgets**

43. This is a one-off payment to enable carers to buy services to support them in their caring role or enable them to have a life outside of caring. The money cannot be used to purchase personal care or go towards general household costs, like heating, food or paying bills. Carers use the money in a variety of ways, such as providing short breaks, gardening services, membership to a bowls club or a gym. The amount a carer receives varies according to their circumstances and the outcome of their carer's assessment.

44. Between 1<sup>st</sup> April and 31 December 2010 a total of 1,620 carers received a personal budget at a cost of £357,225 (an average of £220 per carer).

**Fig 5: Breakdown of how personal budgets were used (April – December 2010)**

<b>Outcome</b>	<b>Number</b>	<b>Amount</b>
Short break	574	£133,666
Support for caring role	464	£98,852
Leisure/social activities	309	£66,471
Health/wellbeing	227	£47,737
Education/training	44	£10,074
Help to remain in employment	2	£425
<b>Total</b>	<b>1,620</b>	<b>£357,225</b>

## **Consultation**

45. The Review Board made use of established support network meetings, carers' events and meetings organised by ASC as a means of speaking with carers, ASC officers, voluntary and community organisations and independent providers. In all, Review Board members attended eight such gatherings (see appendix 1 for more details) and spoke to approximately 45 to 50 carers. A further nine carers provided written responses. In the main the carers were caring for someone with dementia, which has led to a slight focus towards this in the findings of the report. However, the findings and recommendations will offer improvements for all carers in East Sussex.

## Findings and conclusions

46. The Review Board recognised the important role that carers play in supporting people in East Sussex to remain in their own home and lead, as far as possible, an independent life. Without the dedication and support that carers offer the people that they care for, many more people in East Sussex would need greater care packages or would have to move into a residential home much sooner than they would wish. This would also have financial implications for ASC, who would either have to fund more expensive services or would need to pick up the tab sooner for self-funders who have used up their funds quicker than expected.

### Information, advice and support

47. During the course of the review the Review Board realised that the issue of providing respite for carers is not simply about ensuring that the department has sufficient provision available. It is also about ensuring that procedures are in place so that carers are being identified and then supported to access the help and advice they need.

### Terminology and information

48. Evidence from ASC officers and carers revealed that some people, even though they are providing a regular level of care to someone, do not recognise themselves as a carer. Linked to this is the fact that some people, are still apprehensive about contacting ASC, viewing it as 'the state' which will interfere in their lives and may ultimately put the person they care for in a home<sup>5</sup>. All this can make it very difficult to encourage carers to come forward and ask for support.

49. The Review Board was surprised that such a small number of carers in East Sussex are known to ASC (see paragraph 24). Whilst the Review Board recognised that this is a national issue and not just local to East Sussex, it wants the department to aspire to reach greater numbers of carers in the future. Whilst the Review Board recognised that identifying more carers would put additional pressure on the funding of respite services, supporting more carers at an earlier stage, rather than when they reach crisis point, would enable more carers to remain in their role longer and reduce costs for the department in the long run. Also, many of the carers that the Review Board spoke with had sufficient funds to purchase services themselves and were simply looking for support and advice to enable them to do this in the most effective way.

50. Discussions with carers also revealed that some of the terminology used by ASC is a barrier. Because the word 'respite' has been used for many years by ASC to mean a short stay in a residential home, many carers do not recognise other services, such as a sitting service as being a form of respite. It was also very clear that carers do not necessarily use the same terms as the department. One carer did not recognise she was accessing the 'Carers Breaks Service'. She simply knew it as a weekly support group meeting.

51. Another issue related to Carers Personal Budget. This is a one off payment that carers can apply for each year, which should not to be confused with social carer personal budgets (the figure that each service user is allocated with from which services are provided). Furthermore, it was clear from discussions with carers that there was a great deal of confusion surrounding the Carers Personal Budget. Some carers believed they were entitled to an automatic payment of £300 each year, whilst others thought the provision was no longer available and had stopped applying for it.

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<sup>5</sup> This comment was made by several officers that the Review Board spoke to.

52. The Review Board had an opportunity to view a new document produced by ASC entitled 'Do you look after someone'. Whilst it contained the right type of information that a carer would want, the layout and terminology used did not lend itself to making it an easily accessible document and one that carers might readily use to find out information. Unfortunately it was too late for the Review Board to feed back its comments before the document went to print. Members felt that this was a missed opportunity.

**Recommendation 1**

**That Adult Social Care rationalise the entire range of terminology it uses in association with carers and respite provision to ensure that it is clear, concise and consistent across all teams in the department, Health professionals and voluntary and community organisations.**

**Recommendation 2**

**Updated guidance on the Carers Personal Budget to be provided to assessors, carers and voluntary and community organisations so that it is clear how the scheme operates.**

Signposting

***"I feel that I am in a wilderness and that I just stumble across things that can help me"***  
Carer looking after both her parents who have dementia

***"I feel like I am going backwards, having to find out things for myself rather than getting support or guidance from ASC"***  
Carer of someone with dementia

53. If carers are not recognising themselves as a 'carer' and not seeking advice and help when they need it, then the professionals that are in contact with them should be offering guidance. Hospitals, health workers and GPs are all obvious candidates for carrying out this role. A particular issue raised by carers of people with dementia was the lack of information available from GPs at the point of diagnosis of dementia. In several instances carers simply undertook a caring role for several years before becoming aware that there were organisations or services available that could support them and the person they cared for.

54. Few of the carers that the Review Board spoke to recognised Social Care Direct (SCD) as an obvious point of contact to access support or advice on respite services. The Review Board was informed that the support and advice given to carers was highlighted as an area of weakness in the 2010 inspection of SCD by the Care Quality Commission. Since then work has been ongoing on improving this service.

Accessing Adult Social Care

55. From discussions with carers it was very clear to the Review Board that the quality of support that they had received from ASC when they had initially made contact was mixed. Some carers full of praise for the level of support they had received, whilst others were struggling to even get ASC to return their call. In one case a carer stated that they had found it so difficult to contact ASC that they had given up trying.

56. A particular issue that several carers raised was how frustrated they became when they never managed to speak to the same person each time they contacted ASC and how they had to keep explaining their situation over and over again each time they called. For many, having a named contact in the department would make communication with ASC much easier.

57. The Review Board recognised that it might not be practical to provide each person contacting ASC with a named contact. However, it was important that people contacting ASC did not have to repeat their story each time they phoned. Likewise, everyone contacting ASC should receive the same professional and personalised service from all officers each time they contact the department.

58. The ASC department acknowledged that further improvements were needed to the way in which the department recorded information to ensure that it was captured quickly and accurately. This would ensure that when a person contacted ASC again the person they were speaking to would have a complete picture of their situation and would not require the caller to repeat details.

### **Recommendation 3**

**That the Carers' Partnership Board works in conjunction with health, perhaps via the Clinical Executive Group, to ensure that hospitals, health workers, GPs and other professionals that have contact with carers are able to recognise the needs of carers and provide better signposting as to where support is available.**

### **Recommendation 4**

**That a cross county sample of carers are surveyed in 12 months to assess whether there has been an improvement with the way in which their contact with ASC has been established and maintained.**

### **Feedback**

59. The Review Board found that the most valuable part of the review had been talking and listening to carers. This had given members a real insight into what life can be like for carers on a daily basis and the types of issues they have to deal with. These discussions also revealed that there were discrepancies between what they were hearing from senior officers and what carers were telling them. For example, mixed messages being received by carers about the Carers Personal Budget and issues with accessing rolling residential respite.

60. The Review Board was pleased to note the attendance of some ASC officers at events such as the Care for the Carers Forum. It wanted this to be increased though so that more officers from a range of departments attended events. This would provide an opportunity for officer to hear firsthand from carers about their life as a carer and the issues that they face. It would also enable officers to update carers with information on services and new developments, which would hopefully reduce some of the mixed messages that some carers seem to have been receiving.

### **Recommendation 5**

**Senior officers and appropriate Adult Social Care staff should attend carers' events to not only give formal presentations but also to have informal discussions with carers about their experiences.**

### Carers' assessments in the future

61. From May 2011 a new assessment process is being piloted by the assessment teams in Hastings as part of the LEAN<sup>6</sup> project. The aim is to streamline the assessment process and reduce the time taken from initial contact with ASC to an assessment taking place. One of the ways in which this will be done is by increasing the number of assessments that are carried out over the telephone.

62. The Review Board recognised the need to make improvements to the assessment process to ensure that they are handled more efficiently, which will improve the service for clients and make the best use of officer time. However, it had particular concerns about the use of telephone assessments for carers. Assessments carried out in the home offer the assessor an opportunity to see firsthand how a carer is coping. Whilst with telephone assessments there is a risk that vital details will be missed, particularly if a carer is reluctant to provide information, and this could lead to incorrect assessments being made.

63. Careful consideration must be given as to when telephone assessments should be used for carers and when they are used officers need to ensure that carers are fully prepared beforehand so that they can provide the relevant information required.

#### **Recommendation 6**

**That prior to a telephone assessment being carried out the person being assessed is sent a brief outline of what will be covered in the assessment so that they can give it some thought and get together any paperwork they may need to aid the discussion.**

#### **Recommendation 7**

**That the evaluation of the LEAN pilot is scrutinised by the Adult Social Care Scrutiny Committee, with particular focus on the way in which carers' assessments via the telephone have been carried out.**

### **Respite provision**

***"This group has been a life saver"***

Carer of someone with dementia who attends the support group at Marlborough House, St Leonards, provided through the Carers Breaks Project

***"Day care respite has been good for us and a much needed service to help me continue caring for a partner 24 hours a day, every day"***

Carer

64. The Review Board recognised that providing respite services that meet the needs of all carers and the people that they care for can be difficult and complex. As carers are caring for people who have very different needs, such as learning disability, mental health (including dementia) and physical disability, a range of services need to be available. From discussions with carers it was also apparent how varied their knowledge was about the support available to help them in their role.

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<sup>6</sup> LEAN is an improvement philosophy that focuses on activities to reduce waste and bring processes in line with customer value.

65. Respite services need to not only meet the needs of the carer but also provide a good experience for the cared for person. That way the carer is more likely to want to use these services again. A bad experience may put the carer and the cared for person off from accessing services, which would be detrimental to them both.

66. There is a wide range of different types of respite provision in East Sussex, as highlighted a paragraphs 26 to 44. Generally those services being accessed by carers were well received and provided them with valuable respite to enable them to continue in their caring role.

67. The Review Board was particularly impressed by the sitting service and the Carers Breaks Service. The sitting service offers a simple low level service that, from discussions with carers using it, is well received and provides much needed respite. The Carers Breaks Service is also well received by carers and clearly supported them and the person they care for through very stressful times. The Carers Breaks Service has also led to reduced admissions to hospital and nursing homes, as well as a financial saving of nearly £1m during the first nine months of the project for Health, ASC and service users<sup>7</sup>.

### **Recommendation 8**

**That Adult Social Care should continue to maintain funding for respite services such as the sitting service and the Carers Breaks Project.**

### **Rolling residential respite**

68. The Review Board identified that there still remains issues regarding the booking of rolling residential respite. It is not always possible for carers to be able to place the person they care for in the same residential home as they have previously used. Continuity is of particular importance to people who have a learning disability or dementia and not being able to access the same place each time can increase their levels of anxiety. Also some carers only receive a couple of weeks notice as to which homes have spaces. As carers often want to visit homes before making a choice, particularly if they have never used them before, this causes extra pressure for the carer, who is probably already feeling guilty about placing their loved one in a home.

69. The Review Board received assurances from ASC that the system for accessing rolling residential respite would improve in the future as more private homes set aside beds to use for this service. The Review Board was concerned though that whilst the system for booking rolling respite did seem to be improving it was developing very slowly. Access to rolling residential respite was so critical for many carers that it is important that they system was made as simple as possible, perhaps in time even mirroring the system for booking a hotel.

70. It was also an aspiration of the Review Board that, where a preference for accessing the same residential home for residential respite provision is made, ASC aims to meet this preference.

### **Recommendation 9**

**That Adult Social Care continues to make improvements to the system for booking rolling residential respite to ensure that carers are able to book beds in advance and, where possible, at a location of their choice.**

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<sup>7</sup> As evidenced in the Carers Breaks Demonstrate Site Project presentation given to the Review Board



### Meeting future demand

71. With the elderly population set to increase, more people being diagnosed with dementia and increasing number of learning disability adults reaching old age, the demands on carers will become greater and more will look to ASC for support to help them continue in their role.

72. The Review Board recognises that ASC does not have, and will never have, the necessary resources to provide respite support to all carers in the county who need it. It is therefore important that the resources available from both ASC and Health are used in the most effective way to provides services that best meet the needs of carers and that ways are found of developing support for as many carers as possible within the resources available.

#### **Recommendation 10**

**That funding to support carers should continue to be prioritised when Adult Social Care and Health are setting budgets.**

### Self help networks

***"I give my husband 300% and get 0% back. It is only other carers who are in the same situation as me that can really understand what this is like. The group is able to support each other on this journey".***

Carer of someone with dementia who attends the support group at Marlborough House, St Leonards, provided through the Carers Breaks Project

73. One way of tackling the issue of supporting greater numbers of carers in the future is for ASC to help more carers to support themselves through the development of their own support groups. The Review Board was impressed by the support group which meets at Marlborough House, St Leonards (part of the Carers Breaks Service). Here the carers offer each other support and share their own knowledge and experiences of dementia with each other. One group of carers had even got together and arranged a holiday for themselves and the people they cared for, something that the individual carers would not have done by themselves.

#### **Recommendation 11**

**That more support networks are developed across the county to empower carers to support themselves and others who carry out a similar caring role.**

### Review Board membership and support

Review Board Members: Councillor Pat Ost (Chairman), Councillor Colin Belsey, Councillor Beryl Healy, Councillor Phil Scott, Councillor Sylvia Tidy and Janet Colvert (LINK representative)

The Project Manager was Gillian Mauger (Scrutiny Lead Officer).

### Review Board meetings and consultation

Review Board meetings: 21<sup>st</sup> January, 9<sup>th</sup> February, 7<sup>th</sup> March, 28<sup>th</sup> March, 11<sup>th</sup> April, 26<sup>th</sup> April, 12<sup>th</sup> May and 24<sup>th</sup> May 2011

Consultation:

- 24<sup>th</sup> February – Carers Home Based Respite Framework – provider group meeting
- 10<sup>th</sup> March – Care for the Carers – Forum
- 17<sup>th</sup> March – Carers Service Network
- 17<sup>th</sup> March – Association of Carers – coffee morning
- 18<sup>th</sup> March – Respite Action Group
- 8<sup>th</sup> April – Alzheimer's Support Group (Lewes)
- 12<sup>th</sup> April – Carers receiving a service from the Carers Breaks Demonstrator Site Project
- 20<sup>th</sup> April – Alzheimer's Support Group (Bexhill)

### Sources of evidence

#### Local evidence

- Carers and services for carers in East Sussex, Brighton University's Health and Social Policy Research Centre, 2005
- East Sussex 3-Year Joint Commissioning Strategy for Carers' Services, 2007/08 to 2009/10
- East Sussex Joint Commissioning Strategy for Carers' Services, 2010-2015
- Review of Residential Respite Care for all Client Groups in East Sussex, ESCC, April 2007
- Reports to ASC Scrutiny Committee in June and November 2008 on the provision of short term residential respite care for older people
- What Carers Want (consultation with carers on what they want from ASC and Health services), ESCC, H&R PCT, ESD&W PCT, October 2009

#### National evidence

- Carers at the heart of 21<sup>st</sup> century families and communities, HM Government, 2008
- Hearts and Minds, The health effects of caring, The Social Policy Research Unit, 2004
- Our Health, Our Care, Our Say, Department of Health, January 2006
- Putting People First, HM Government, December 2007
- Recognised, valued and supported: next steps for the Carers Strategy, Department of Health, November 2010
- Survey of Carers in Households in England 2009/10, The Information Centre for health and social care, 2010

### Witnesses providing evidence

The Board would like to thank all the witnesses who provided evidence in person to the Review Board.

East Sussex County Council Officers:

- Barry Atkins, Head of Strategic Commissioning
- Peter Cattanach, Service Placement Team Manager
- Debbie Charman, Strategic Commissioning Manager – Carers
- Royston Collins, Service Placement Team Leader
- Andy Cunningham, Head of Assessment and Care Management
- Dr Rebekah Rees, Resource Officer
- Mark Stainton, Assistant Director, Adult Social Care, Operations
- Rita Stebbings, Assistant Director, Adult Social Care, Resources

Other witnesses:

- Liz Fenton, Chief Executive Care for the Carers

Written evidence was also received from:

- Alzheimer's Society
- Sound Architect
- The Association of Carers

*During the course of the review members had the opportunity to talk to many carers across East Sussex. All the carers were very open and frank about how caring for a loved one has impacted upon their lives and what life can be like day to day for a carer. The Review Board would like to thank carers for the wonderful job that they do and for taking the time to share their experiences with members.*

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An information pack containing the research carried out during the review obtained by contacting the Scrutiny Lead Officer