

## APPENDIX A – Raw Data from stage 1

### Consultation

A range of methods of ongoing consultation have been used to seek out views of carers, service users and the general public since the last local strategy for carers was produced in 2007. These include:

1. Locality Focus Groups held by Care for the Carers during 2008: 5 focus groups across the county were held, attended by 54 carers. Results showed that carers value groups and courses but respite is an issue – Carers Respite Training Budget set up. *“We are only human beings, we can only run for so long”*. Carers also highlighted transport issues, and asked for more information generally, particularly via GP surgeries
2. Survey of ESCC staff in November 2007 received 190 replies. Key themes from the replies were:-
  - A need for information and support about carers’ services
  - Benefits advice
  - More flexible working, particularly working from home
  - More support for the person cared for to fit in with their working role.  
*“It affects my energy levels and mental well-being (stress, anxiety, emotional upset) - it's not always easy to hide this and it does affect my performance and productivity at times”*
3. Summer 2008 workshops and “road shows” held by East Sussex Downs & Weald PCT revealed that the participants felt preventing hospital admission is the number one priority for consideration when commissioning services, along with the promotion of safe, high quality care and the prevention of disease.
4. Furthering Long Term Independence Workshop in October 2008 attended by service users and carers. The health and support needs of carers were seen as a priority, in particular the identification of carers via GPs in order to initiate preventative measures.
5. “Closer to Home” stakeholder events were held jointly by the Primary Care Trust and Adult Social Care throughout East Sussex in October and November 2007, revealed the provision of information and access to services, as well as service user involvement and better joint working to improve service delivery as key priorities. Healthcare priorities included:-
  - better access for rural population and for people with disabilities
  - out of hours services
  - end of life care
  - specific health needs of carers.

### Formal consultation on the strategy: Phase One

In order to ensure that this strategy responds both to Government legislation and the needs of local carers, a questionnaire was sent out to 3,200 local carers in January 2009

via Care for the Carers and Rethink asking them for their views on the priorities highlighted by the Government in “Carers at the heart of 21<sup>st</sup> Century Families and Communities”. A 29% response rate (920 responses) was achieved (including many additional individual comments, indicating a high level of interest and strong views about support needs from carers themselves.

### Who responded?

Three-quarters (74%) of respondents were female, 97% described themselves as white British and 21% said they had a disability. Responses were from across East Sussex (see map below), with the biggest clusters from around Eastbourne, Bexhill, Seaford and Hastings. Half of respondents were aged 65 and over and only 3% were under 30, with 16% aged between 45 and 54, and 15% aged 60 to 64.

Analysis of the responses revealed that the demographics of the respondents did not necessarily reflect the county wide figures, and further efforts were planned to consult with under-represented groups in Phase Two.

	<b>% of respondents</b>	<b>% across county</b>
Aged over 65	50%	23%
From a BME community	1.3%	5.2%

Full demographic details from the survey are available online, here:  
<http://www.eastsussex.gov.uk/yourcouncil/consultation/2009/supportforcarers/default>

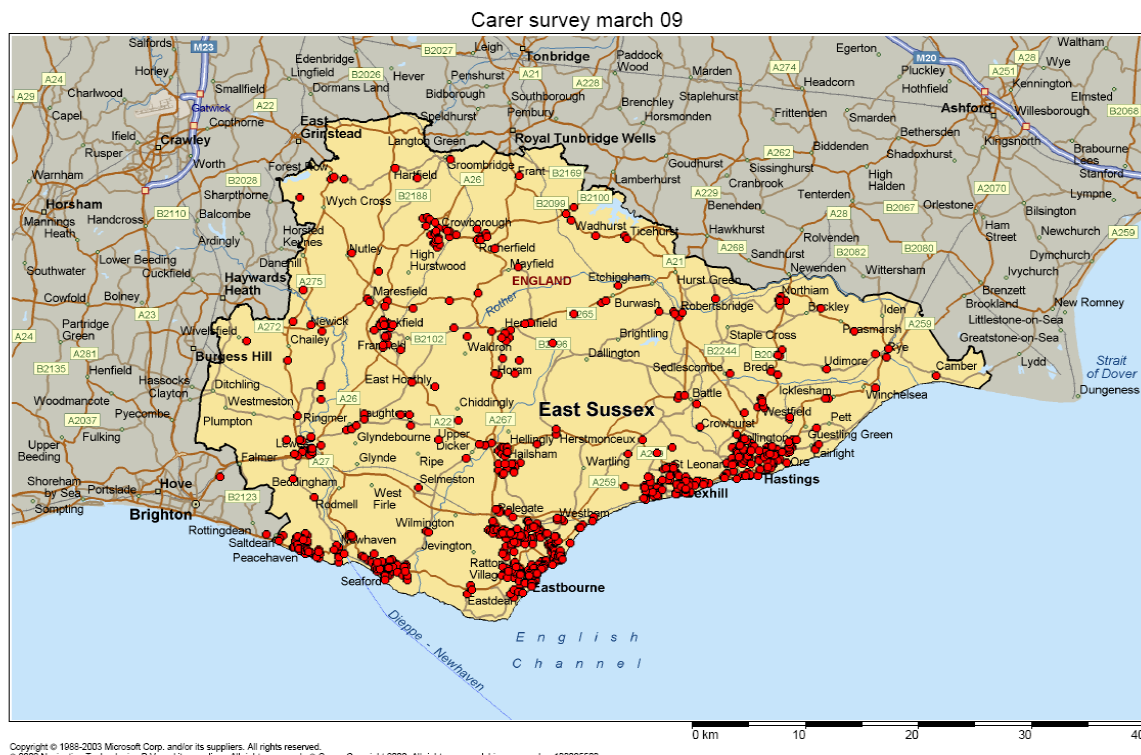


Chart 1: Location of people who responded to Phase 1 questionnaire

We also held two focus group meetings for carers who's views are seldom heard:

- older carers living in rural areas
- carers from minority communities living in deprived urban areas

and asked them the same questions.

### **What we learned**

Participants were asked to rank five possible areas of support in order of importance and add comments about how they could best be achieved. They were also asked what additional support they needed that might not have been covered in the questionnaire.

Clear support for the key priorities was evident from the responses to this and previous consultations. Carers told us:

#### **We want to be respected and listened to**

This included the need for carers to be respected and listened to by professionals, for professionals to be trained to recognise carers (particularly health professionals/GPs) and be aware of their needs, and for carers' views and expertise to be taken into account:

*"Not to be patronised by someone on a first visit who has never met the person I care for. In this instance I am the most experienced on care"*

#### **We want to stay mentally and physically well**

Emotional support from voluntary organisations and from other carers, and support to stay physically well and healthy is very much valued, but transport to enable carers to get to places is often an issue:

*"To have contact and know support is available + in the back ground - this helps keep stress levels down"*

#### **We want more breaks**

Namely, varied respite, individually tailored to need. A primary concern for carers is to know that the person they care for is well looked after, and people mentioned flexible and out of hours services, based at home:

*"I would like to have a break but I would NOT put my husband into a home"*

#### **We want easy access to information and training**

It is evident that information needs to be in a variety of media and available from a variety of places in order to be accessible for all, and that leaflets need to be simplified. Carers also expressed a desire for more training in how to look after their loved ones' specific needs (for instance, safe lifting techniques):

*"Most important would be information and easy access to speak to someone if there were any questions within the information that people would like to ask"*

### We want to be able to work if we choose

This was the lowest priority, probably because many carers who responded were above retirement age; however among younger carers this was important:

*“Flexible working hours and feeling secure that time off to care doesn’t jeopardize career achievement opportunities”*

The following graph shows how carers ranked the various types of support:

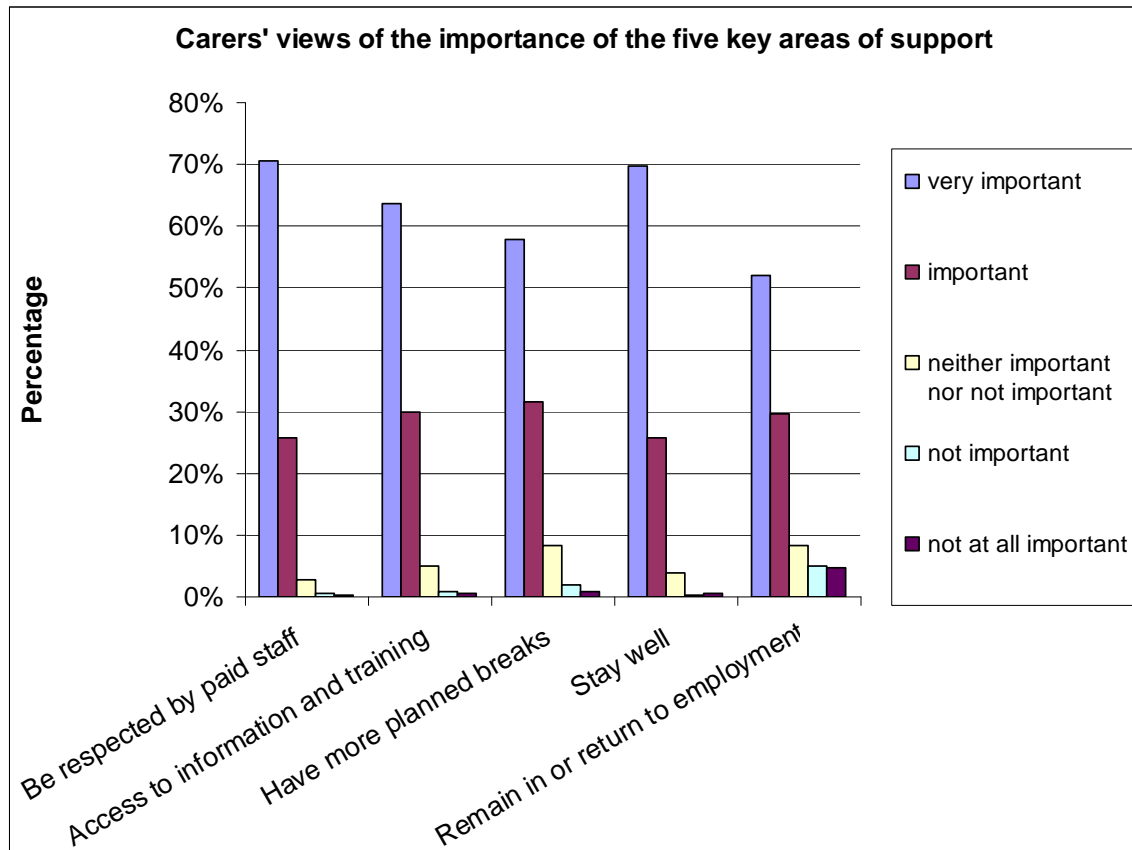


Chart 2: Carers’ views of the various types of support

Carers’ identified **financial pressures** as the biggest priority for them not covered in the questionnaire (16% of people who said something was missing thought financial support should be included). Carers felt they are not fairly rewarded for the work they do as carers. We have fed back to people that the issue of financial benefits is outside the remit of health and social-care services, however the Government will be reviewing Carers’ Allowance in 2011.

**Feedback for participants** was sent to the Care for the Carers and ReThink mailing lists in April/May 2009, and we put an article in CareLine, Your County and Brief Encounter (for staff). The ESCC website was updated with feedback documents including the raw quantitative data and a leaflet outlining key findings. WE also provided feedback directly to people who participated in events we ran.

You can find these documents here:

<http://www.eastsussex.gov.uk/yourcouncil/consultation/2009/supportforcarers/default>

A draft Joint Commissioning Strategy for Carers was drawn up based on the priorities identified in this phase of the consultation and the Government's priorities for support. To check we had understood carers' needs correctly, we tested the draft strategy in Phase Two of the consultation.

### **Consultation on the draft strategy: Phase Two**

We designed a simple questionnaire to test whether the elements of support we identified in the strategy were clear and useful for carers. We also asked again for comments about anything we were missing out. Instead of mailing this to the same carers we had already consulted with, we made the questionnaire available on the ESCC website, issued a press release, and mailed it to community and voluntary organisations, GPs, pharmacies, Community Matrons, and Citizens' Advice Bureaux . We also put articles in a range of community and interest-based newsletters and on local organisations' websites.

During a three month period (June-September 2009) we took the questionnaire to a number of events across the county in order to reach out to as many people as possible, with a particular attempt to focus on younger people, and people from BME communities.

These included: visits to three rural villages with a Carers' Consultation Bus, attendance at the St Leonards Festival, East Sussex Seniors Forum's Older People's Engagement Day, all the local Partnership Board meetings and sub-group meetings where appropriate and a variety of voluntary sector coffee mornings and rural network meetings. We also asked local voluntary organisations, directly and via the local CVS, to participate in the consultation themselves.

We asked Care for the Carers to host a conference for carers, which was themed around the consultation, as well as providing information. The conference, which was held in Eastbourne, was publicised very widely through the press with a view to attracting carers who were not necessarily already in touch with Care for the Carers, and it was attended by approximately 50 carers as well as key managers from local statutory services. Carers and managers discussed the key themes of the strategy as it affected them in terms of the care group of the person cared for.

Responses from these consultations are all included in the final analysis.

We received 185 completed questionnaires.

### **Who responded?**

Nearly two thirds (61%) of respondents were female (males were better represented than in Phase One). 48% of respondents were aged 65 and over and 3.5% were under 30.15% were aged between 45 and 54, and 15% aged 60 to 64. Comparing this to estimates of the ages of the population of East Sussex shows that we achieved a

broadly representative range of respondents in a number of age brackets (30-34, 45-49, 50-54 and 85-89 year olds).

92% of respondents described themselves as white British, meaning there was a broader representation from other communities compared to Phase One (notably from people identifying themselves as 'White: other', 'White: Irish' and 'Other') and 19% said they had a disability. Responses were clustered around Bexhill and Hastings.



Chart 3: Location of people who responded to Phase 2 questionnaire

### What we learned

The questionnaire set out the key elements of the draft strategy grouped under three headings for different areas of support:

- 'Improving access to respite and breaks',
- 'Helping carers stay mentally and physically well',
- and 'Respecting, involving and listening to carers'.

Respondents were asked whether they understood the plans (so we could make sure we were using language people found clear, and the responses we were getting about how helpful the plans were could be trusted) and whether they thought the plans would help carers.

95% of people felt that the plans would help carers (see Chart 4 below).

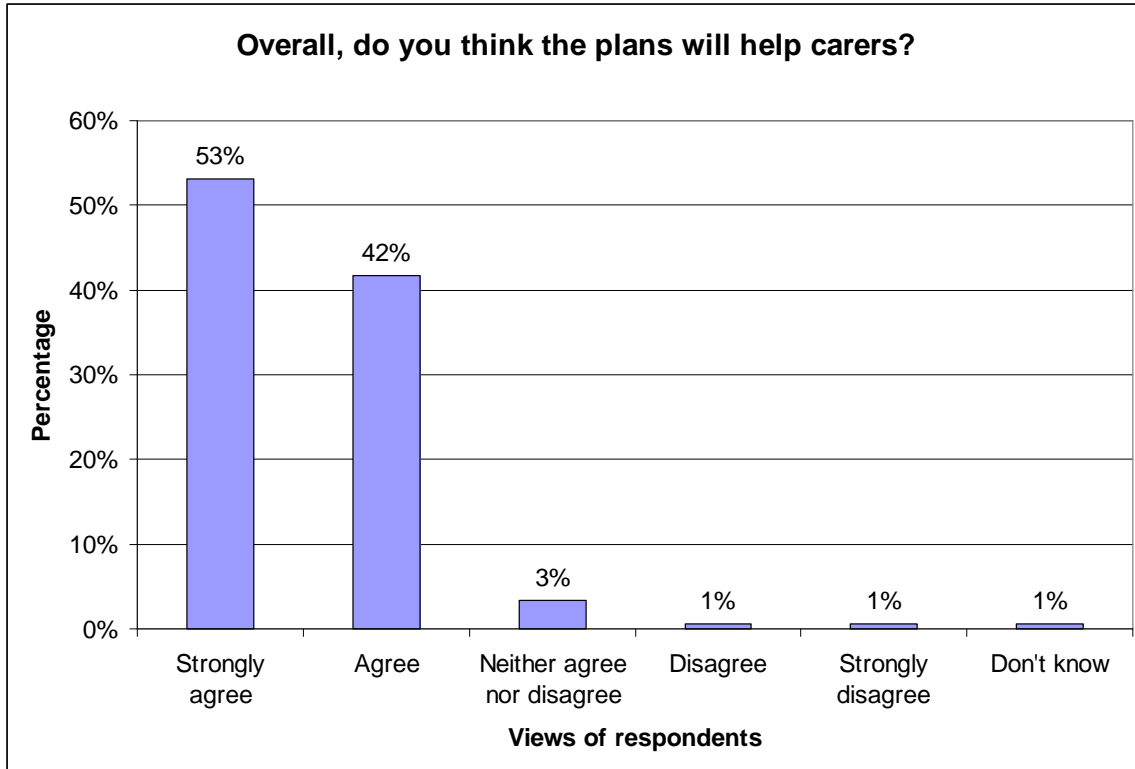


Chart 4: Overall, I think the plans will help carers (percentages have been rounded)

This is a strong endorsement of the draft strategy and is welcome. The following charts show the breakdown across the different areas of support, first in terms of how well people understood the plans, and then how far they thought they would help carers.

We looked at comments from the two people who disagreed and strongly disagreed to understand their reasons. In both cases, it seemed they were utterly disillusioned about Local Authority involvement in and provision of social care:

“Carer's need "hands on" help. Not mental mish mash. All carers are mentally able to carry out their duties "hands on people with dedication are what is needed for carer relief" No more GPs, social workers or support groups please.”

“The plans are good in principle but won't change the attitudes of social workers. So that won't help.”

It's worth noting that while more people 'strongly agree' with the plans than simply 'agree' with them, the proportions of these people who added comments on the proposals (as opposed to just ticking boxes) are similar (38% and 45% respectively). That is, it doesn't appear that people chose to just 'agree' rather than 'strongly agree' because they had significantly more comments to make about the plans than those who strongly agreed.

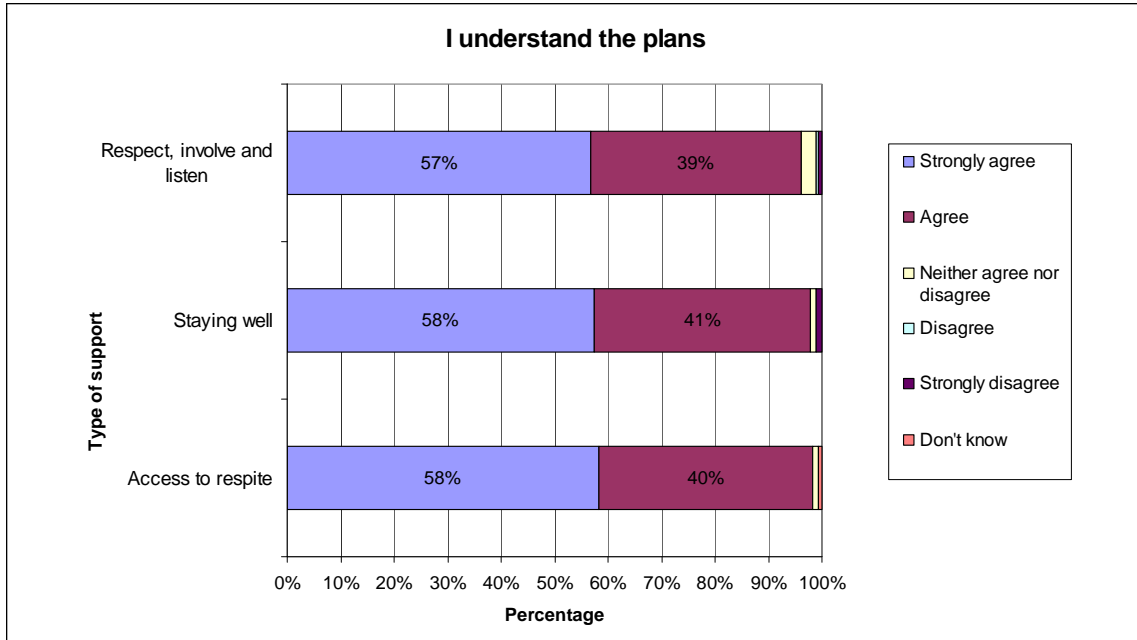


Chart 5: I understand the plans (percentages have been rounded)

Often, plans/strategies put out for consultation use jargon and language that makes it hard for people to understand (see, for instance, the Plain English campaign website). We went to efforts to ensure the questionnaire was in Plain English and would be easy to understand, so people could meaningfully comment on our plans. These responses mean that we can trust that people who say they agree with the plans probably do agree with the plans as we were trying to state them.

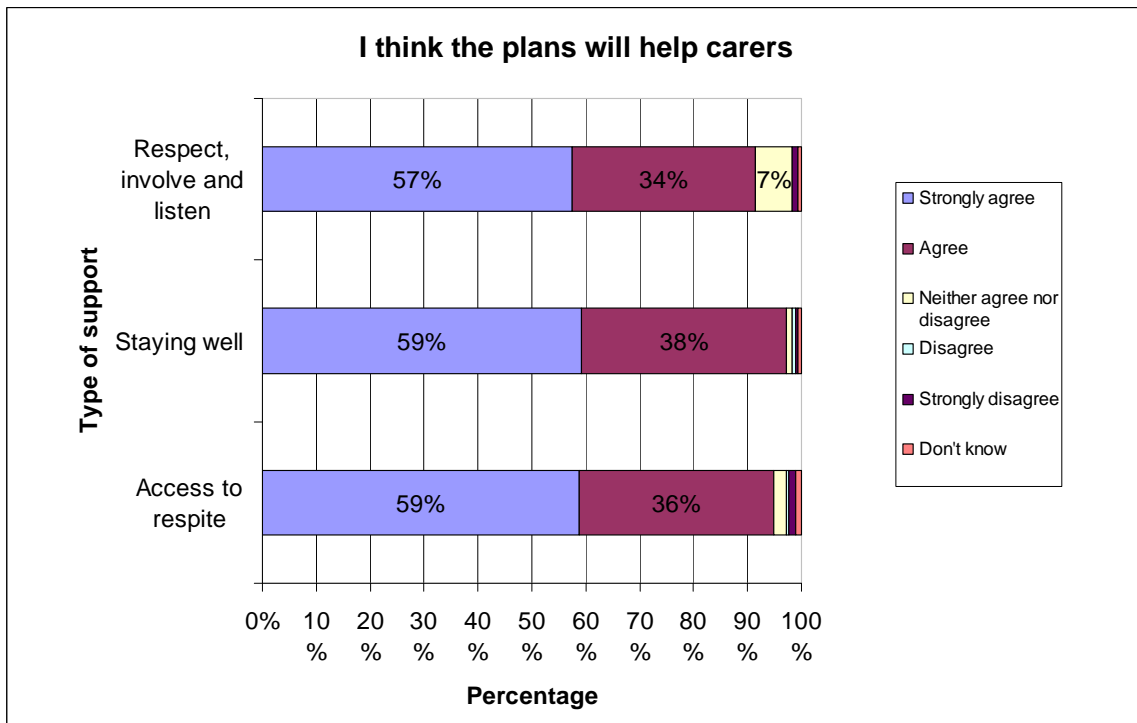


Chart 6: I think the plans will help carers (percentages have been rounded)

There is a very good level of support for each of the three types of support covered by the plans. People's comments on each area of the plans add further insight and are set out briefly below.

In addition, we refer to the responses from **Rethink** under these themes, and these quotes/comments are attributed. They have submitted an extensive response which will be taken into account in full, including at the implementation stage. **Care for the Carers** have also submitted a response which will be considered in full, which is very much focused on the structures for decision-making, planning and delivery rather than the thematic areas in the survey.

At the **conference** hosted by Care for the Carers we held four workshops with carers to look in detail at the draft plans. Two workshops were attended by carers of older people, one by people caring for someone with a learning disability, and one by people caring for someone with a long term illness(es). Their comments are included under each of the three themes below and labeled Carers' Workshop (OP, LD or LTC).

Finally, comments from the **ESCC/ESSA Older People's Engagement Day (OPED)** will be noted.

### **Access to respite/breaks**

The top five themes that emerged from survey respondents' comments about our plans to improve respite are as follows:

#### **1. Organising and implementation of plans (23 responses)**

How will these plans be implemented? There was some scepticism about the plans, because respondents were unsure of how they would be made a reality:

*"Plans need putting in force not stored as pipe dreams for the future. It is now today we need help or where 1 is ill there will be 2 soon"*

#### **2. Funding costs (16 responses)**

Affordability and fair pricing are crucial to service users if plans are to be implemented:

*"is not clear as to whether you are only going to make an annual charge if you need to use the service. Wouldn't it be more suitable to make a charge each time needed"*

#### **3. Cared for person's needs (15 responses)**

Considering the specific needs of the person who the carer cares for; when devising respite schemes for carers. Also looking at the impact of respite on the cared for individual:

*"Will substitute carers be able to deal properly with client who perhaps has MS or a stoma, Aspergers syndrome etc. It is of little use putting in a substitute carer who is out of their depth and can only deal with household chores etc"*

#### **4. Positive impact of respite services on carers (13 responses)**

Respondents recognise the impact of respite, not just on themselves, but also whoever they care for:

*“Carers certainly need breaks and respite care, it helps them doing their best”*

#### **5. Assessment processes (13 responses)**

Respondents are unhappy with current assessment process, especially in terms of how long it takes: It is perceived as lengthy and often with a negative outcome:

*“Quicker timescale of doing assessment”*

**ReThink** put forward a number of arguments about support for people with mental health conditions. In particular, they raise the issue of scant home-based respite provision for carers of people with mental health conditions. They say:

*“...there seems a reluctance to provide it, presumably because of the increased risk... This may take the form of aggression, of self-harm or suicide, or other risky behaviours...However clearly there is a link between the stress on the carer and the diminishing chances of a break for precisely these points”*

They highlight a number of ways that ASC should respond to this unmet need, which will be taken into account.

#### **Staying well**

The top six themes are included below (we cannot separate a top five due to similar numbers of comments):

##### **1. Scepticism over the implementation of the plans (20 responses)**

Concern over how the plans will be implemented and how likely they are to be carried out. People seem concerned that they have seen little change over the preceding years and are doubtful they'll see it now:

*“These plans will only help if they are carried through”*

##### **2. Role of the third sector and not-for-profit (organizations like Crossroads, Care for the Carers) (11 responses)**

Respondents valued the role of third sector organisations and felt that some of the support in the plans could be provided by them:

*“I would like to see the organisations like Care for the Carers and Crossroads doing these things. They already do them, are reliable, and carers, like me are already using them”*

##### **3. Training-both of carers and supplied care staff (11 responses)**

Carers would value training on how best to support their loved-ones as well as making sure care staff are well-trained to deal with specific, often complex, conditions:

*“I asked for training on my first assessment form. Carer's need to know how best to handle difficult situations”*

#### **4. Proactive support and action (11 responses)**

Approaching carers before issues arise, providing information about support services:

*“Is it possible to have a proactive health professional (much like a health advisor to a new mum) who contacts the carer regularly in the first months, then regularly throughout their time as a carer”*

In the **Carers Workshops**, each group placed the issue of general support for carers and recognition of carers' needs in their top three priorities (based on the number of times related issues were raised). For carers of people with a learning disability, recognition of carers' needs was the most important issue of all. People commented that carers need to be involved in planning, to be assessed, and get good support from their GP and hospitals.

#### **5. Different ways of communicating vital information (10 responses)**

Information should be clear and accessible in different formats to meet the needs of everyone:

*“More telephone, face to face and written communication. Not everyone is on the internet especially those in older age groups”*

Participants in the **Older People's Engagement Day (OPED)** prioritised measures to improve access to appropriate information, guidance and advice above all other concerns.

In the **Carers Workshops (OP and LTC)**, participants who care for people with long term illness(es) and older people identified the most issues around getting the right information and advice, in the right format, at the right time. Their comments ranged from wanting help to fill in forms to the importance of a 'one stop shop' for information and easier access to information through non-statutory bodies (eg Care for the Carers) as carers may feel more comfortable requesting help from voluntary organizations rather than the Council. This wasn't identified as a key issue by those who cared for someone with a learning disability.

#### **6. GPs (10 responses)**

GPs were seen as unhelpful. It was felt they didn't understand the caring role:

*“More support from GPs would be welcome, even an acknowledgement would help!”*

This feeling was echoed by the **OPED** participants, who felt GPs could play a bigger and better role in supporting carers' needs.

**Rethink** offer some important analysis of how carers of people with mental health problems feel. This also seems relevant for carers in general:

*“...the complexity of adhering to policy and having clinical priorities around 'patient care' often seem to work against staff in MH [mental health] being able to convey a real sense of carers feeling heard...Being caught 'in the middle' is often at the core of the carer experience and has significant impact on wellbeing. For this reason, it cannot be divided off as a separate issue.”*

Rethink also say:

*"It needs to be clear that directing a carer towards the Assessment process is insufficient in itself as a response and does not replace time spent with the team that are working with the cared-for person".*

Respondents in the **Carers' Workshops** echoed these views, saying that a good supportive GP is vital and this wasn't always their experience.

### **Respect, involve and listen to carers**

The top five themes emerging from respondents comments are listed below:

#### **1. Scepticism about plans and concerns over implementation of plans (20 responses)**

Respondents felt that they had heard parts of the plan before. They felt a sense of scepticism over the plans or that the plans would be difficult to implement:

*"I will believe when I see it. I have done everything on my own nearly"*

#### **2. Communication needs (information sharing, signposting for carers, direct pathways to talk to care management) (15 responses)**

Carers often feel isolated because of a lack of communication. It is not easy for them to find the information they need to make decisions. Carers also want direct contact with those responsible for providing care:

*"We need to know how we can speak directly to health and social care managers"*

As mentioned above, participants in the **Carers' Workshops** also identified the issue of access to advice and communication as extremely important to them. Communication between services (for example during transition or on discharge from hospital) was raised as an area for improvement as well.

#### **3. Inclusivity of carers' and cared-for's needs (11 responses)**

Considering the needs of carers in tandem with those who they care for:

*"It is very important to listen to carers as well as the one who is being cared for"*

#### **4. Carers as experts (11 responses)**

Carers should be treated as knowledgeable about their own needs and/or the person who they care for:

*"Getting medical staff to accept that the 'carer' is an expert in the person cared for would be a big step"*

#### **5. Concerns with Care passport (9 responses)**

Concerns with the care passport system; how it works and how useful they are:

*"Regarding care passports nobody takes any notice of them, and have twice not got them back from hospitals or been asked for them"*

In addition, the issue of choice was discussed at the **OPED** and the **Carers' Workshops**. Participants felt that carers have diverse needs, often depending on the needs of the person they care for, and so, for instance, some carers wanted access to respite through someone coming to their home. Others didn't. Individualised support with a range of options was felt to be important by those who care for people with learning disabilities, in particular. Day services were prized alongside traditional home-based respite.

**Rethink** were clear that (necessary) policy and procedure can sometimes mean carers get a raw deal (again, Rethink support people with mental health conditions but their comments may ring true for all carers). They cite examples of the way practitioners can take a very strict line and tell carers nothing or very little about the cared-for person's medication (for example). Other practitioners, they say, may try to avoid real engagement with carers (they mention CPNs and psychiatrists) and look to refer them on as quickly as possible.

Rethink suggest a number of ways forward, including:

*"...an identified carer liaison worker within each area to ensure that issues are considered and to help identify how the practical day to day obstacles that arise in the implementation of good carer support and involvement at a local level can be addressed rather than considering each case in isolation."*

Involving carers in developing services and having a say in service development, they say, has proved difficult for them but would be welcome:

*"This service has attempted to recruit new representatives over several years but it is rare to find a carer who is willing, has capacity to cope with the format of the meeting and feels able to take on this responsibility as a long term commitment."*

In conclusion, Rethink argue that:

*"Caring for someone with mental health problems involves complexities which do not align well with many generic policies."*

And they note, crucially (which our survey reinforces) that:

*"Carers' wellbeing is closely linked to being involved with the service their cared for person receives."*

**Care for the Carers** (CFTC) welcome the 'general tone and direction' of the plans, and note that CFTC have been very much involved in developing the plans to this stage in partnership with ESCC.

However, they highlight a number of issues they feel were not included in the draft Commissioning Strategy:

- The link between carers strategies and action plans and other key strategies and planning groups (such as Older People, Mental Health, Learning Disability).
- References to relevant legislative and policy drivers.
- How partners (e.g. PCTs) are involved in delivering the plans.
- References to other resources necessary to deliver an effective strategy, including Job Centre Plus and the Learning and Skills Council.

CFTC question the lack of role the existing Carers' Strategy Group played in developing this strategy. Indeed, the thrust of CFTC's input is about the way partnership and

decision-making structures operate, and their views will be carefully considered and ASC will discuss this further with them directly.

In addition, CFTC request more information about the suggestion that carers may be charged for respite care. They are also keen to see structures within the statutory sector strengthened to provide better support to carers.

## **Conclusion**

We believe that this has been a robust consultation over the past nine months. We have tried to reach out to carers and members of the public across the county and to take into account their views, both after the initial stage and the final stage of the consultation, and to provide feedback to those who took part.

We have amended and developed the final strategy document as a direct result of the consultations, both in terms of building on tentative plans, clarifying our intentions and rectifying omissions.

We appreciate that there is a high level of scepticism about whether strategies of this nature can ever be fully delivered, but we believe that the aims of this strategy are realistic and we intend to monitor our actions and publish achievements against all the key themes during each of the five years it is in place. We have made clear where outcomes are outside the remit of health and social care services and/or are subject to fluctuations in the future financial climate.

We are very grateful to everyone who has contributed to this process, in particular to the voluntary and community sector organisations who participated in and promoted the consultation on our behalf.

September 2009