



Consultation with Carers and Professionals 2007
Report from research April – June 2007

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1.0 EXECUTIVE SUMMARY

This report contains the findings of consultation with carers and professionals, which took place from April to June 2007. The report produced by Local Solutions Carers Project on behalf of Liverpool City Council will be used to inform 'The Liverpool Supporting Carers Strategy', which is currently being updated.

The aims of the consultation were to engage with carers, professionals and partner organisations to find out what carers needs are to ensure the best possible quality of service delivery.

Four specific areas were considered:

- Carers health
- Carers in employment
- An emergency care scheme for carers
- Advocacy services

The consultation incorporated a questionnaire distributed to over 500 carers by a number of organisations and three events, which were attended by carers, Young Carers and professionals. 180 completed questionnaires were returned by a broad cross section of carers, including 34 from carers in Black and Racial Minority communities.

The findings of the consultation are as follows:

Health

The majority of the carers who responded confirmed that caring had an unfavourable effect on their health with stress as the most common symptom. Half had an illness or disability, which affected their daily life.

Most carers who had seen their GP about their symptoms had found access to the surgery easy but a minority had found it to be difficult; over half stated that their GP knew they were a carer. A significant number had received information from someone in the Surgery but the majority had received information from other sources, in most cases the information received was either good or very good.

Most carers who had experience of hospital discharge (more than half of all respondents) had been consulted about discharge arrangements but services were not in place for all at the date of discharge, subsequently one third of carers were not satisfied with the discharge arrangements.

Employment

Two in ten of the carers who responded were either in full time or part time employment and most stated that someone at work knew about their caring role.

The majority were able to keep in contact with the person they care for by telephone and there were other support services provided by some employers. A carer network, which a significant number of carers felt would be of benefit, was the only service not provided. All of the suggestions given for employer support were felt to be of benefit.

Respondents also indicated that they would benefit from support services for the person they care for such as home care / day care.

More than one quarter felt that their career had been affected by their caring role, most in a negative way.

Carers Emergency Care Scheme

Most carers worry about what would happen to the person they care for if they were taken ill and unable to provide care. Over half had a plan for back up, which mostly depended upon family and friends; some had experienced situations when replacement care was needed but could not be provided.

Concerns were expressed by a considerable number of respondents about the arrangements for emergency / replacement care, including the quality and experience of the staff, the reliability of the service and the safety and wellbeing of the person they care for.

Advocacy

Almost half of all respondents confirmed there had been times when they had needed support in dealing with service providers and others. A similar number could also think of occasions when advocacy could help.

A significant number had experienced situations when their needs and wishes were different to the needs and wishes of the person they care for. Most felt that an independent person would have been of benefit in that situation.

Professionals Consultation Event

In considering carers' health and wellbeing the professionals felt that GPs could do more to support carers by identifying them sooner and ensuring that they were provided with information and advice.

The professionals felt that a better understanding by employers of the caring role and of the legislation and policies introduced to support working carers would overcome some of the difficulties they face. They also agreed that the Liverpool Carers Multi Agency Group should continue to push forward the Working Carers events.

Currently the professionals felt that carers would have to rely on family and friends due to a lack of professional response in an emergency situation. There were a number of suggestions for key features for an emergency care scheme and they agreed they would have an important part to play in the success of the service.

With regard to advocacy support the consensus of opinion was that an Advocacy Strategy and funding would be key to improving what they considered to be a service, which is currently found lacking.

Young Carers Consultation Event

The Young Carers at this event were asked about support in school; about their need for replacement care and about advocacy.

They felt that generally it would be helpful if someone in school knew they were a carer but at the same time they did not want special treatment or to be identified as different. They agreed that sometimes flexibility would be helpful.

In relation to emergency care generally Young Carers are less likely to have a network of family or friends they can rely on; it is also unlikely they would be able to make their own arrangements for replacement care in an emergency. If at all possible they would try to find a solution themselves.

Most of the group had not heard the word 'advocacy' and none knew what it meant. When it was explained they felt that generally they would prefer to speak for themselves. If they needed this type of support they would rather know the person speaking for them and they did not know where a Young Carer could go for advocacy other than Barnardo's.

Carers Consultation Event

This event gave carers the opportunity to come together to discuss the areas under consultation. It combined consultation with information and included an overview of the Emergency Response Scheme operating in Sefton, as well as information about the Steering Group charged with developing an Advocacy Strategy for Liverpool.

A discussion took place about the current arrangements for emergency / replacement care and the feeling generally was that professional support is lacking and carers therefore have to rely on family and friends. They agreed that it can be very frustrating for carers when systems do not work and subsequently the stress of caring can have an adverse effect on the carer's own health.

Further discussion took place about the type of emergency care scheme needed in Liverpool. It was agreed that emergencies can mean different things to different people and the scheme to provide replacement / emergency care would have to take account of different illnesses and care needs. The role of the professionals was seen as paramount in ensuring the scheme was successful.

Black and Racial Minority Carers

(For the purpose of this report the term Black and Racial Minority will be abbreviated to BRM).

In line with the findings overall carers from BRM communities indicated that caring had caused problems with their health; stress was again the most common symptom. Over half had found access to the GP Surgery easy or very easy but it had been difficult for a significant

minority. Whether carers had received information from the GP Surgery or other sources it was either good or very good.

Almost one third of carers who had experience of hospital discharge were either dissatisfied or very dissatisfied with the arrangements.

One third of carers who responded were in employment either full time or part time and access to carer support from other organisations was identified by them as the service of most benefit. More carers in this group stated that caring had affected their career than the sample overall.

Most carers worried about what would happen to the person they care for if they were taken ill; they had particular concerns relating to language and culture in relation to replacement care. Other concerns were very much in keeping with the findings overall.

Half of all carers in this sample had heard of advocacy and many had experienced situations when they had needed support in dealing with service providers and others. There had also been occasions for a significant number when their needs and wishes had been different to those of the person they care for and they felt that an independent person would have helped.

RECOMMENDATIONS

- More work is required by Health Care Professionals in Primary Care to develop and implement a uniform system for identifying and supporting carers.
- Carers to be consulted prior to hospital discharge to ensure that support services are in place.
- Leadership from the Primary Care and Hospital Trusts is required to drive forward improvement in service delivery.
- Further work is required to explore with carers the type of training they need to support them in their caring role and to improve their employment prospects.
- The Liverpool Carers Multi Agency Group to continue their work to highlight the recent legislation introduced to improve flexibility for carers in the workplace and to drive forward awareness and promotion of support services for carers.
- Consideration to be given to replacement care / child care to enable carers to participate in activities both at work and outside of work to reduce the feeling of exclusion and isolation.
- An emergency / replacement care service to be set up which is straightforward to arrange, prompt to respond and is reliable.
- The service must meet a wide range of needs and instill confidence in the carer and the person they care for.
- The service must be supported by professionals.
- In conjunction with Liverpool City Council's Advocacy Strategy there needs to be a greater awareness of what advocacy can mean for carers and how they can access this support.
- Further work is required to address the issues of cultural sensitivity and equity of service for carers within BRM communities.

Young Carers require:

- someone at school they can talk to
- flexibility in respect of homework
- the opportunity while at school to contact the person they care for
- support from professionals to identify sources of support in an emergency
- support services to accept referrals from an adult acting as advocate for them
- a different term than advocacy to be used, one that Young Carers understand

2.0 INTRODUCTION

This “**Consultation with Carers and Professionals 2007**” report contains the findings of a series of consultations with carers and professionals across Liverpool, which took place between April and June 2007 and has been produced by Local Solutions on behalf of Liverpool City Council.

2.1 Background and Objectives

Liverpool City Council is currently updating ‘**The Liverpool Supporting Carers Strategy**’, the overarching framework for developing and delivering carer support within the City, and the findings of the consultation contained in this report will be used to inform this strategy.

The Carers Project at Local Solutions has been consulting with carers over a number of years on behalf of City Council about what their needs are and the carer services and support they wish to see delivered.

The consultation undertaken during this period is an integral part of the continuous improvement process to ensure that the services delivered are best suited to the needs of carers. The consultation process has been designed to engage with professionals, partner organisations and carers with a view to informing and shaping the strategic planning process and ultimately to ensure the best possible quality of service delivery for carers.

This consultation looked at four specific areas relating to carers support as follows:

- **carers health**
- **carers in employment**
- **an emergency care scheme for carers**
- **advocacy services**

2.2 Methodology

Questionnaire

To involve as many carers as possible in the consultation process a questionnaire (see Appendix A) was developed in consultation with carers and was agreed with Liverpool City Council before being printed and distributed.

The questionnaire was developed to find out from carers about the impact of their caring role on their health; how their caring role affected their employment; what carers would like to see in an emergency care scheme and carers experience of advocacy services. The questionnaire used a combination of closed questions prompting a yes or no response and open questions allowing carers the opportunity to express their own personal experience. In addition consultation events were held at Liverpool Carers Centre for carers and professionals, and a consultation event with young carers took place at Barnardo’s Action with Young Carers.

The questionnaire was distributed by a number of organisations who come into contact with carers either directly or indirectly (see Appendix B); staff at Local Solutions Carers Project distributed the questionnaire to carers they support; carers support groups were visited and carers were also informed about the consultation process in the Spring edition of the 'Carers News' newsletter, and in newsletters and publications issued by other organisations. Information about the process was included on the Local Solutions and Liverpool City Council websites (www.localsolutions.org.uk and www.liv.gov.uk) and it was possible for the questionnaire to be completed electronically. In total over 500 carers received a hard copy of the questionnaire from the Carers Project.

The questionnaire was accompanied by a covering letter (see Appendix C), which explained the purpose of the consultation and the timescale; for those questionnaires sent by post or distributed by other organisations a reply paid envelope was enclosed.

The 'cut-off' date for returns was 30th June 2007, by this date 180 completed questionnaires had been returned, which represented a return rate in excess of 35%.

Consultation Events

Three consultation events were held; the first was attended by a broad cross section of professionals from a number of organisations, the second event was for Young Carers and the third for carers.

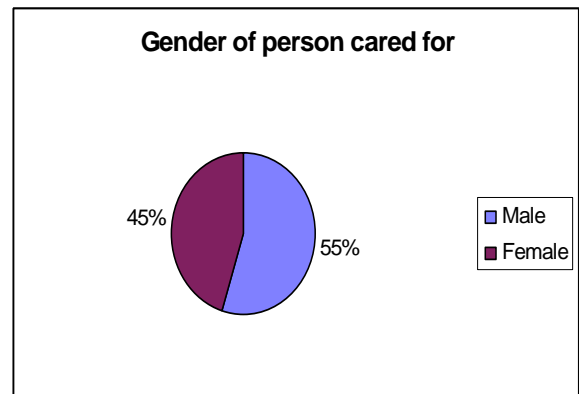
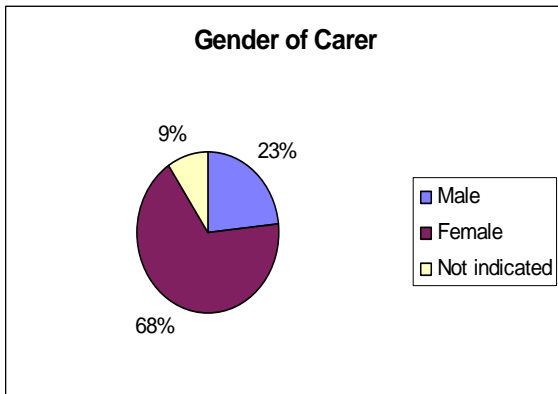
2.3 Sample

The following graphs show information about the carers who responded to the questionnaires, including gender, age, postcode, ethnic origin, the number of hours spent caring, the number of people who are cared for and the nature of the illness or disability of the person cared for:

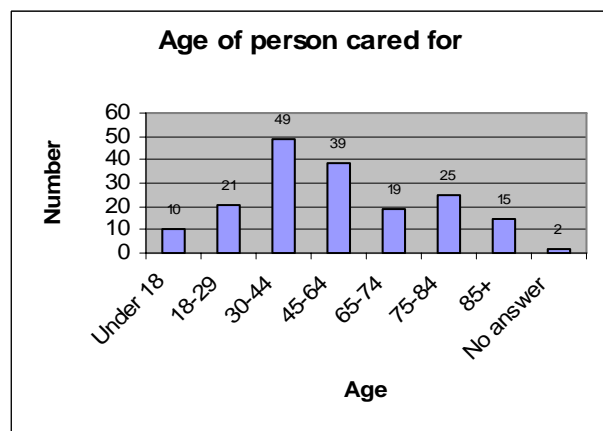
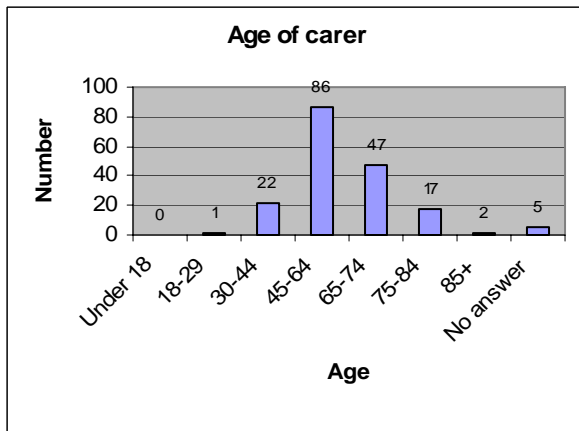
Some facts taken from these graphs are as follows:

- 68% of carers were women and 23% were men
- 55% of the people cared for were male
- The age group with the largest proportion of carers was from 45 – 64
- The postcode area with the highest number of carers was L8
- 73% of carers were caring for more than 50 hours per week, with 50% on call 24 hours a day
- 18% of all respondents (almost 2 in 10) were caring for two or more people
- Mental health was the most prevalent condition of the person cared for
- 20% of carers were from 10 minority ethnic groups

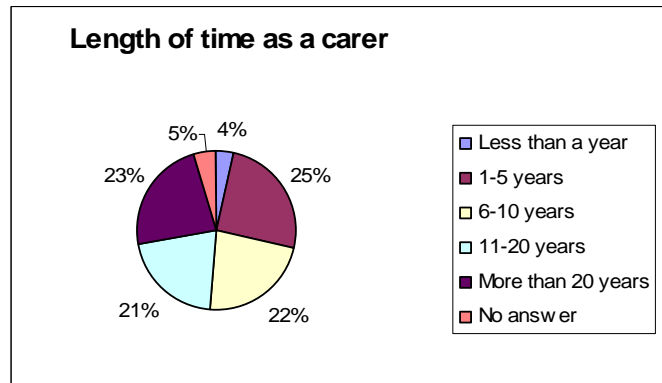
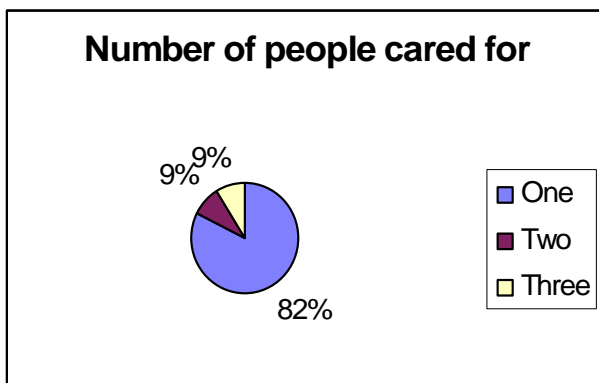
The following two graphs show the gender of the carer and the person cared for.



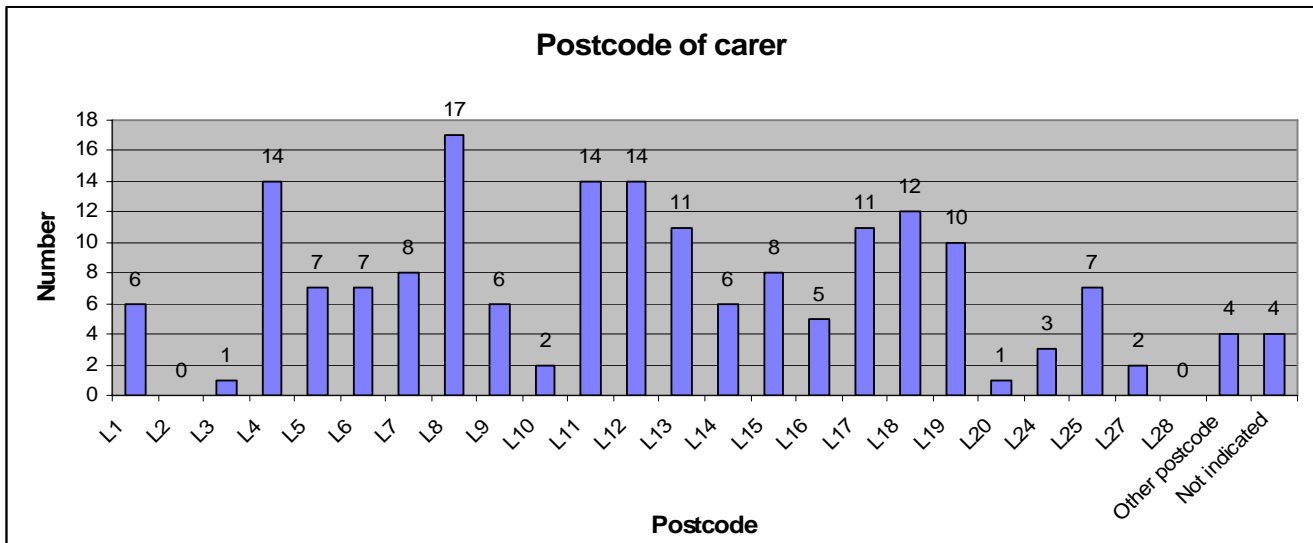
The next two graphs show the age of the carer and the person cared for respectively.



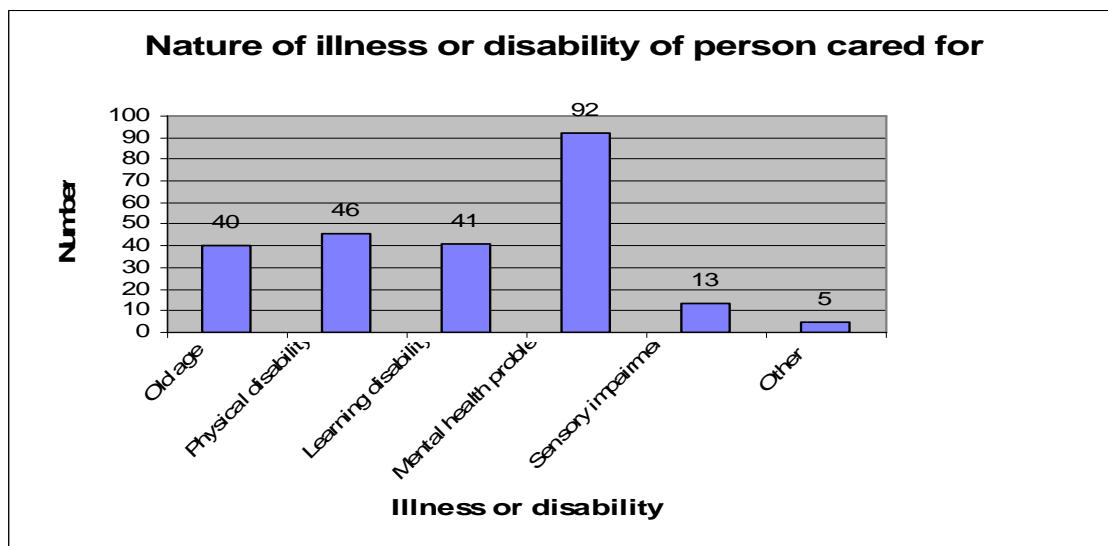
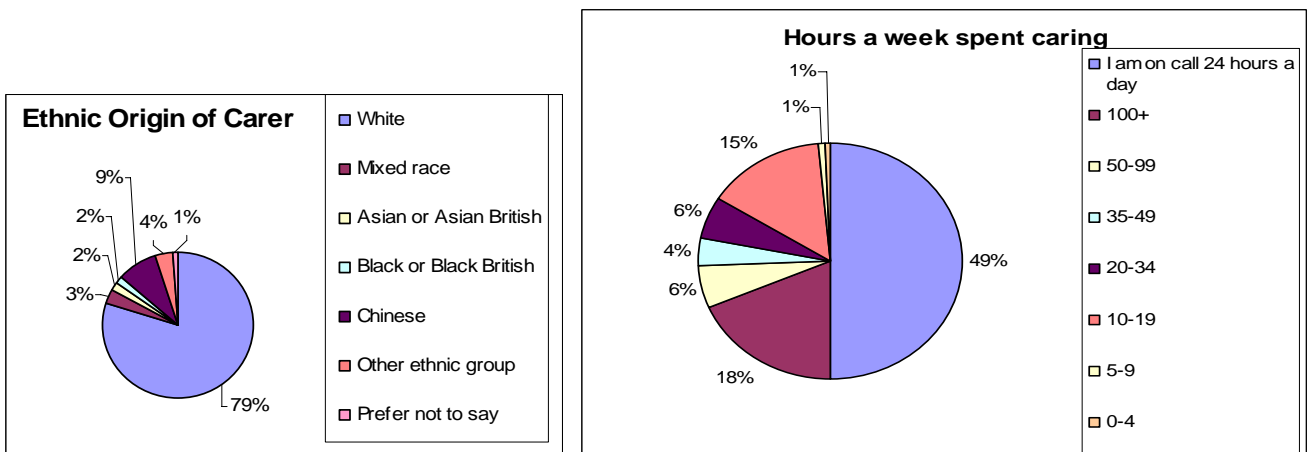
The following charts show the number of people cared for and the time spent caring.



The table below shows the geographic spread of the respondents across the City.



The following three graphs show carers by ethnic origin, the time spent caring and the nature of the illness or disability of the person cared for.



The report includes a section relating specifically to the findings from the questionnaires completed by carers from Black and Racial Minority communities in order to identify the similarities and the differences, if any, of the impact of caring and the support services subsequently required by carers in these communities. The findings have also been included in the overall analysis.

3.0 HEALTH

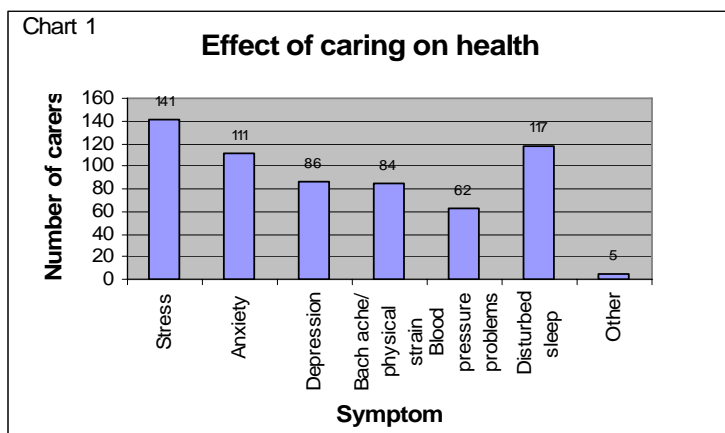
One of the priorities of the current Liverpool Supporting Carers Strategy is “**Maintaining the Health of Carers**” and this continues to be a priority for Liverpool City Council. Therefore it was appropriate that one of the areas for consultation with carers and professionals was carers’ health. The questionnaire subsequently included questions about carers own health; support from GP surgeries; carers involvement in hospital discharge and support that carers felt would be of benefit in maintaining their own health and wellbeing.

3.1 Carers Health

When carers were asked about their own health, 50% of respondents had a health check in the previous 12 months and 45% confirmed that they had a disability or an illness, which limited their daily activities. Examples given were:

- Heart condition and asthma
- Asthma / Diabetes
- Mental health problem - severe depression and anxiety
- Blood pressure and arthritis
- Joint and back pain

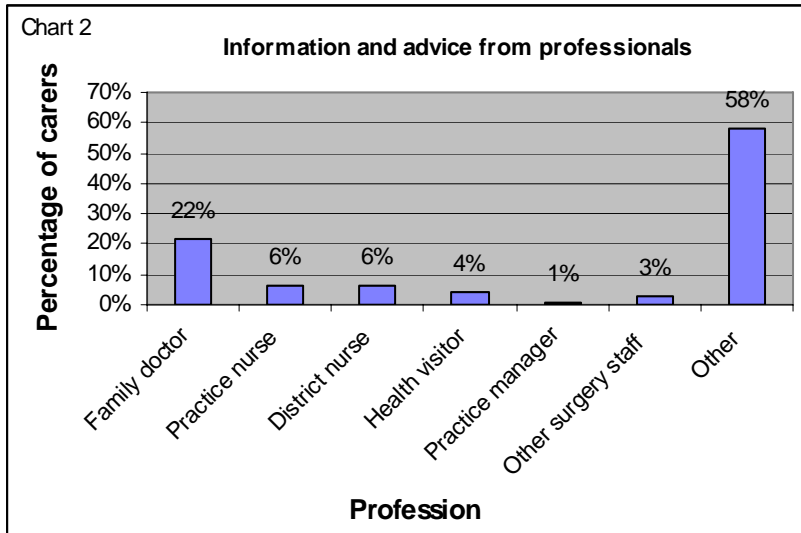
When asked whether their own health had been adversely affected by their caring role over three quarters (79%) felt that caring had an unfavourable effect, with many indicating more than one symptom. Chart 1 shows the pattern of responses; the two symptoms with the highest response were stress and disturbed sleep:



The figures indicate that a significant number of carers, who were experiencing problems with their own health, had not received a health check within the previous twelve months. This suggests that carers do not always recognise the link between caring and their own health.

3.2 GP Support

64% of respondents indicated that they had seen their GP about their symptoms and the majority stated that access to the surgery was easy (40%) or very easy (20%). 24% of carers stated that access was neutral but still a significant number (16%) stated that access was difficult or very difficult.



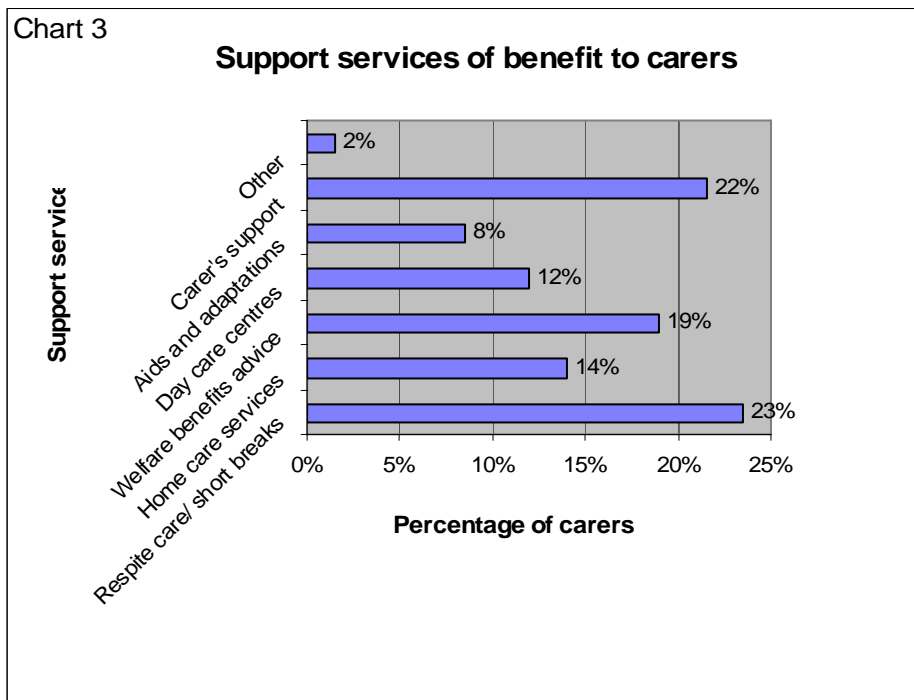
16% of respondents stated their GP did not know that they were a carer; 55% show that the GP did know and 23% were not sure. This is encouraging and perhaps shows that more GPs are following the recommendations made in the National Strategy for Carers that patients who are carers and patients who have carers should be identified by them. However Chart 2 shows that the majority (58%) of carers who responded are still receiving information from other sources, such as social workers, carers support workers, carers assessors and voluntary organisations; less than half (42%) indicated that they had received information about their caring role from staff in the GP surgery, whether this was the GP, practice nurse, district nurse or other surgery staff.

3.3 Information and Support

Overall the results show that the quality of information or support received was either good or very good; less than 5% of respondents indicated that the quality of information and support was poor.

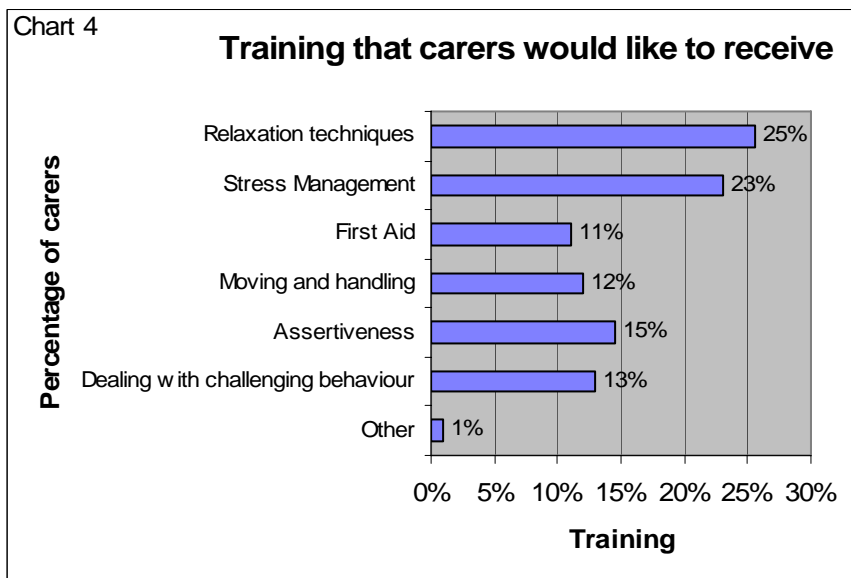
When asked what information would be of benefit 31% indicated a community care assessment for the person they care for, 26% carers assessments, 24% on the patient's illness or condition and only 19% about the patient's medication or side effects.

The support services that would be of benefit are shown in Chart 3 below, with respite care / short breaks and carers support coming top in the ratings.



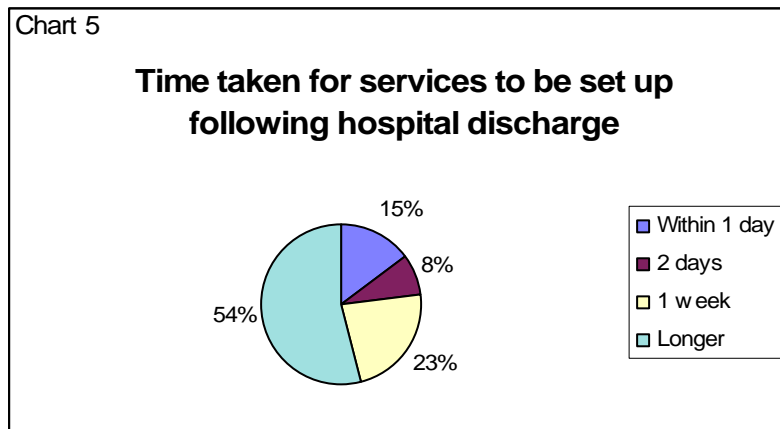
Carers were then asked about the training they had received or would like to receive. The results show that 33% had received training, the largest number had received training on dealing with challenging behaviour and the lowest number had received training in assertiveness.

The results of the training that carers would like to receive are shown in Chart 4; relaxation techniques and stress management were the most popular. Other suggestions made by carers included training for work, anger management and therapeutic respite courses.



3.4 Hospital Discharge

Over half of the respondents (57%) confirmed that the person they care for had been in hospital and of this number more than two thirds stated they were consulted when discharge arrangements were made. The results show that services were arranged prior to discharge in 59% of cases; however services were not place at the time of discharge for 18%. Chart 5 shows when services were delivered.



Although the figures show that the majority of carers were consulted and services were in place at the time of discharge for most patients who needed them, there were still a significant number who were not consulted and for whom services were not in place for some time after their hospital discharge.

Carers who had experience of hospital discharge gave the following ratings for overall satisfaction with the arrangements – over 50% stated that they were satisfied or very satisfied; 12% stated that they were dissatisfied and 12% stated that they were very dissatisfied. 21% did not answer this question. These figures indicate that there is still considerable work to be done to improve carers' experience of hospital discharge arrangements.

More than one in ten confirmed that the person they care for had been readmitted to hospital. For 75% it was more than one month before readmission, but for 17% it was within one month and for 8% it was within one week.

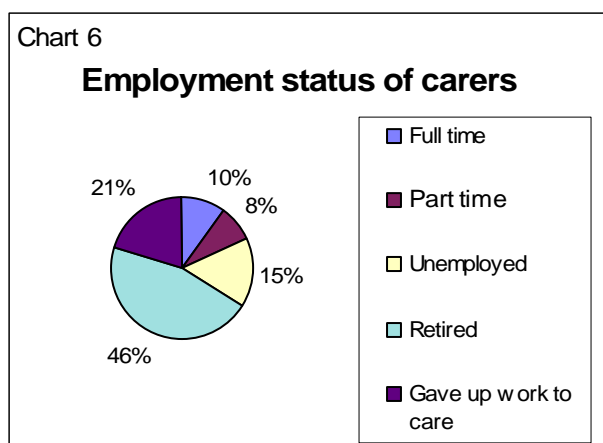
4.0 EMPLOYMENT

Government policy increasingly identifies carers as a group needing to be supported in the workplace. Following many years of campaigning The Work and Families Act 2006, introduced in April 2007, has given carers new rights at work. The new right to request flexible working could change carers' lives making the difference between giving up or staying in work; many carers give up work to care and this can lead to financial difficulties and isolation.

Priority 1 of the Liverpool Supporting Carers Strategy is 'Identifying Carers' and a key task to achieve this is to support Liverpool City Council employees enabling them to identify themselves as carers. Liverpool City Council is committed to supporting all working carers and is part of a Multi Agency Group in Liverpool who work in partnership to promote the rights of carers; the Multi Agency Group are currently working together to highlight the new rights of carers at work under the recent Act.

4.1 Carers employment status

Respondents were asked to state their employment status; Chart 6 below shows that 18% were either in full time or part time employment and that more than one in five carers, had given up work in order to care. The majority of carers who responded were retired (46%) this figure includes carers who indicated that they retired early due to their caring role. 15% of carers were unemployed, which means that they were actively looking for work.



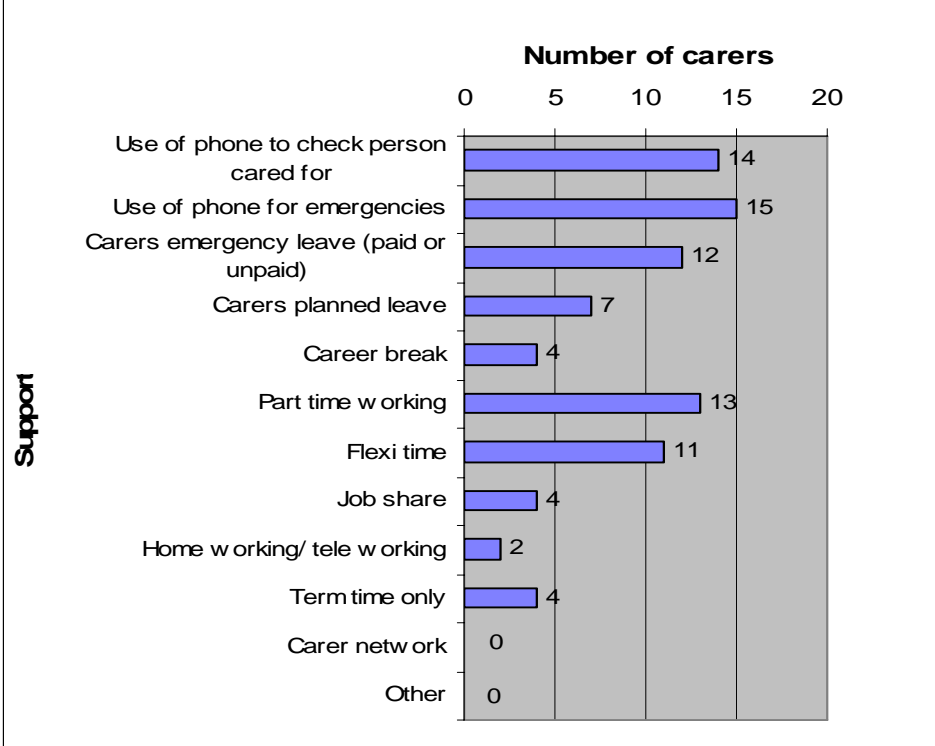
Of those carers in work two thirds confirmed that someone at work knew that they cared for someone; the responses do not show if this is a work colleague or their manager, and this includes carers who were self employed.

4.2 Carers support from employer

The table below, Chart 7, shows the support provided by employers. 47% of carers who responded were able to use a telephone for emergencies, which was the highest figure and 44% confirmed that they had the use of a telephone to check on the person they care for. Subsequently almost half of carers who were working were able to have contact with the person they care for, if only in an emergency, thereby providing some peace of mind in knowing they could be contacted if they were needed.

Chart 7

Support for carers from employers



When asked what support they felt they would benefit from a significant proportion selected a carers' network, which is not currently provided by any of the employers in the current sample. The highest proportion of respondents indicated that access to support from other organisations would be of benefit.

4.3 Support for the person cared for

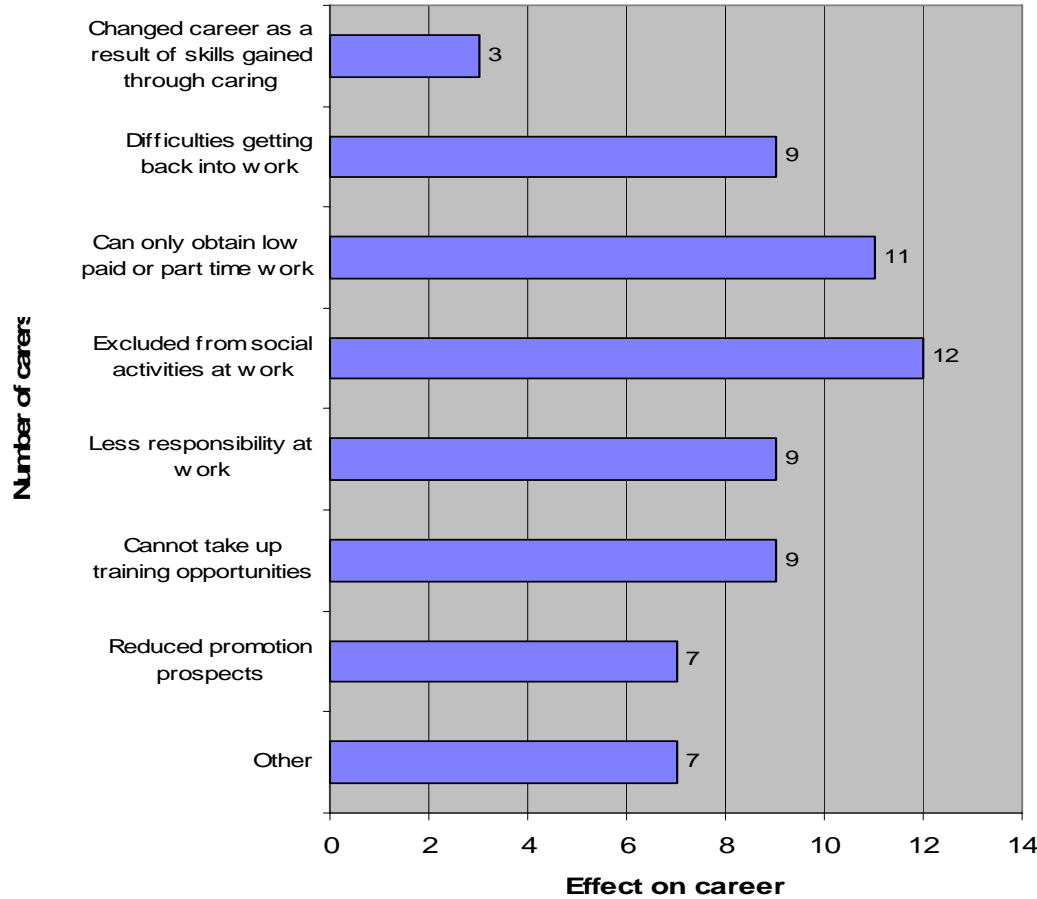
When asked if they would benefit from services for the person they cared for, the respondents indicated that each of the suggestions would be of almost equal benefit i.e. direct support e.g. home care or day care; direct payments to arrange their own support and information about registered or approved private care facilities. Carers who were not currently employed had also responded, perhaps with their opinion of what might have helped them to stay in work or what would help them to return to work.

4.4 Effect of caring role on career

Only 42% all respondents answered this question with 27% stating that their career had been affected by their caring role. The table below, Chart 9, shows that for many carers their career had been affected in a negative way, such as reduced promotion prospects, less responsibilities at work and exclusion from social activities at work. For a small number there was a positive effect as a result of the skills gained by caring.

Chart 9

Caring role and effect on career



Examples of ways in which carers careers have been affected are as follows:

- *“I have looked after my mother for over 40 years as she requires 24 hours a day care. I gave up my job 40+ years ago to look after her”*
- *“Sometimes I have to close the shop to accompany my sister and daughter to the hospital or other appointments”*
- *“The job I do now is much less pressurised and lower paid than my previous job. I could not deal with a high pressure job now due to my caring responsibilities”*
- *“Prospects of having to give up work as no after school / school holiday provision for age 16+. Also child tax credits cease at age 16”*

5.0 EMERGENCY CARE SCHEME

A survey was undertaken by Carers UK in 2004 to find out about carers' experiences of dealing with emergencies. The subsequent report, 'Back Me Up', published in January 2005 found that carers did not know who to contact to sort out replacement care when they had an emergency. Carers also stated that the response by emergency social services took too long and that replacement care services did not exist, sometimes with disturbing results.

Carers said they needed to know that if they were faced with an emergency replacement care would be sorted out competently and without delay, and if it was needed there would be back up from professionals. They needed a single point of contact with someone able to sort out replacement care so that they could deal with the emergency.

In February 2007 the Government launched the New Deal for Carers. This outlines a range of measures designed to recognise and support carers, including £25 million to be spent on providing short-term home based respite for carers in crisis or emergency situations in every local authority.

Liverpool City Council are eager to develop a service that meets local needs and is based upon what carers in Liverpool want. Therefore, the City Council were keen that this consultation ask key questions of carers that would direct the way in which emergency support for carers develops in Liverpool.

5.1 Current replacement / emergency care arrangements

More than three quarters of carers indicated that they worry about what will happen to the person they care for if they are taken ill and are unable to provide care. They worry about not knowing who to contact in an emergency (35%); that emergency services may take too long to respond (62%) and they did not know if replacement care was available or who would provide this care (65%). The figures show that carers are worried about more than one of these eventualities. The question specifically asked about carers concerns if they are taken ill but it must also be recognised that for different people an emergency will mean different things, subsequently an emergency or replacement care scheme should be developed in a way that addresses this.

It is perhaps of concern that only just over half of carers who responded, have a plan for back up in the event of an emergency; the vast majority of those who do have a plan rely on family and friends. Examples of the support that carers have are as follows:

- *"My family would have to organise"*
- *"My children (son or daughter)"*
- *"Brothers and sisters"*
- *"My sister will come and stay"*
- *"Maybe my husband will be able to help, depends on his job"*

Carers also gave examples of situations where they do not have family or friends to call on:

- *“I get Direct Payments and have a team of care assistants and nurses who come to help me. I rely on them heavily”*
- *“Very few family members in Liverpool”*
- *“My children live far away so it is inconvenient for me to ask for help*
- *“No family / friends able or willing to help me”*
- *“Cared for between ex-partner and myself – no-one else if anything happened to us”*

5.2 Care Needs

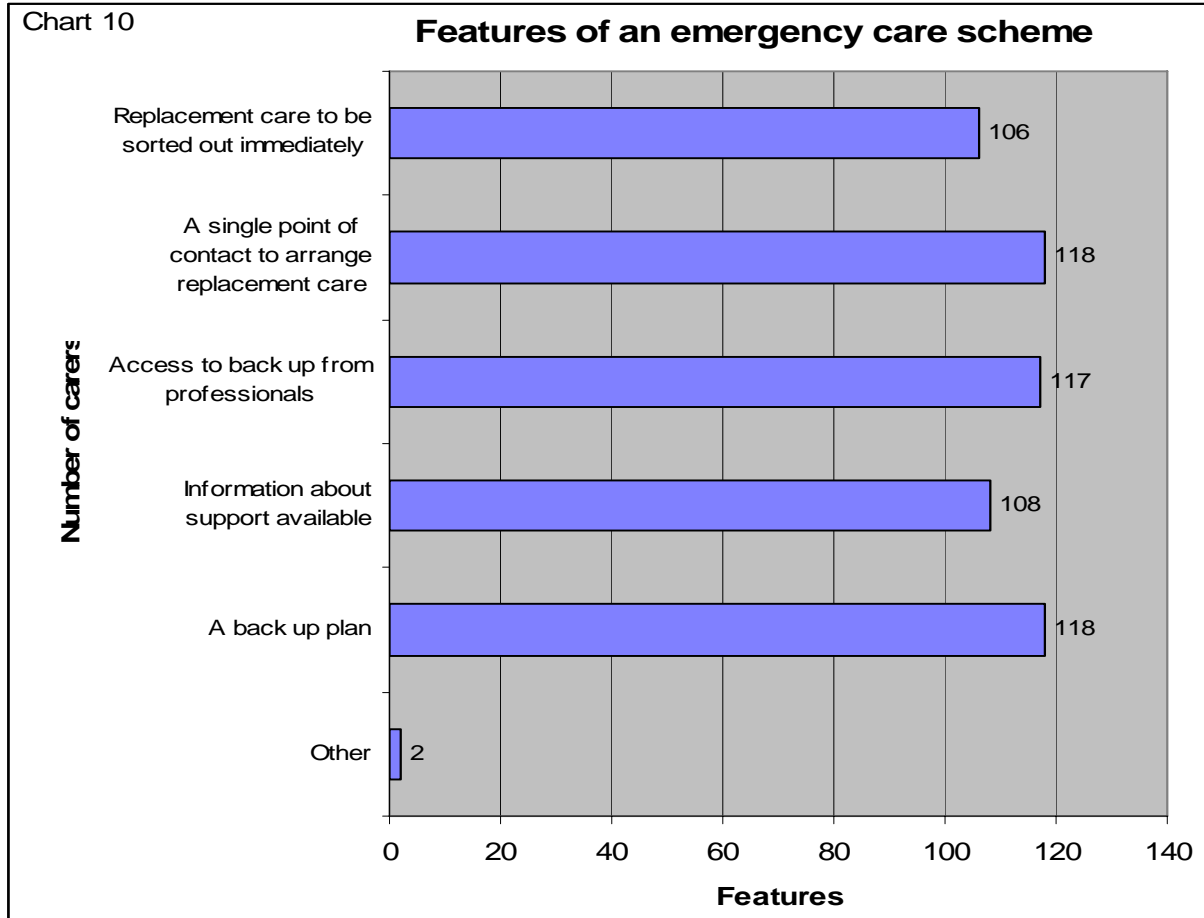
In order to deliver a service that meets the needs of carers in Liverpool it is necessary to have an understanding of the varying needs of the people who are cared for and examples of situations experienced by carers.

23% of carers who responded indicated that the person they cared for needed skilled care that their family could not provide and 14% confirmed that they had experienced difficulties in a situation when replacement care was needed but could not be provided, examples of some of the situations are given below:

- *“Doctor wanted me to go to hospital to be admitted but as there was no emergency care I could not go”*
- *“When I was ill I got a very poor response by social services”*
- *“Social services could not provide suitable / any respite support”*
- *“Contacted GP for carers as I had broken my ankle. He said I didn’t need his help to get carers even though I was told he needed to do the referral”*
- *“I had a stroke 3 days prior to my wife’s illness and no help was given to me or to check on how I was coping. I could not visit her as I was not mobile and I was never contacted after initial day of accident re my wife’s condition or how I / we would cope on her discharge”*

5.3 What Would Help?

Carers were presented with a list that might feature in an emergency care scheme and each of the suggestions was given more or less equal rating by over half of all respondents (see Chart 10). This shows that the majority of carers felt the need for a service from professionals to provide back up, which is straightforward to arrange, prompt and reliable.



In considering the features of an emergency / replacement care scheme it should be noted that almost half of all respondents (44%) indicated that they had particular concerns about arranging replacement or emergency care. Examples given were as follows:

- *“Would need to know daughter is safe and secure”*
- *“I would be concerned that the replacement / emergency care staff should be well trained”*
- *“If my children are not available I don’t know if I will be able to cope by myself”*
- *“I wouldn’t know who to contact”*
- *“Son’s delusions make it hard to deal with strangers”*
- *“I feel that emergency / replacement care would not be sorted out straight away”*

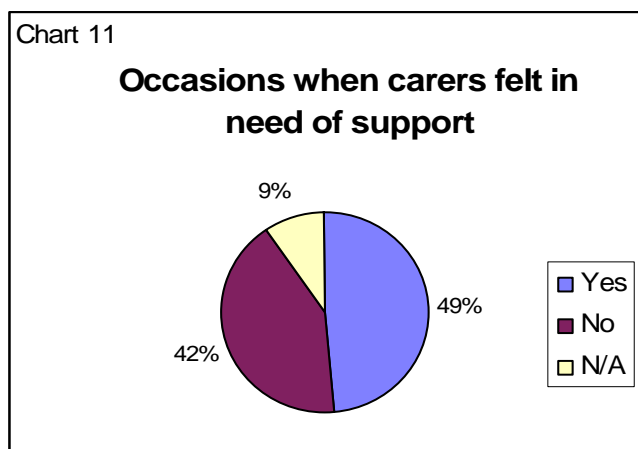
A number of carers had the same concern that the person providing the replacement care should be trained to meet the care needs of the person they were caring for and that the care would be equal to that which the carer would normally provide.

6.0 ADVOCACY

Liverpool City Council is currently working towards developing an Advocacy Strategy for the city, which will include the future commissioning intentions for advocacy services. An Advocacy Steering Group has been charged with developing the Strategy and they are keen that user and carer views are central to the process. As a result the consultation questionnaire included a section on advocacy to find out from carers whether they were aware that advocacy services exist; whether current services are beneficial and whether they are meeting their needs.

6.1 Has support been needed?

Almost half of all respondents indicated that there had been occasions when they had been in need of support in dealing with service providers and others, see Chart 11



A significant number indicated that both an independent person to listen to their views and wishes, as well as support to express them could have helped on those occasions when they needed support.

33% of respondents indicated that other types of support would have helped and examples given are as follows:

- *“Carer support when I first started caring”*
- *“More respite care and help of an evening through the week”*
- *“More intervention from services”*
- *“A single point of contact”*
- *“Useful to have carer support worker who is aware of cultural issues – illness affects whole family”*
- *“More information and more support from my GP”*

6.2 Differences in needs and wishes

Almost two thirds of carers stated that there had been occasions when there could have been a difference between their needs and wishes and those of the person they care for. The majority felt that an independent person to listen to the views and wishes of person cared for and help to express them would have helped. It is noted that a significant number of the carers who responded recognised that these conflicts will sometimes arise and that support from someone who is independent of them both is needed.

Almost one third of carers who responded stated that other types of support would have helped, they include:

- *“My mum would have benefited from someone from professionals to act on her behalf as some of the services she used to receive have been cut back. I feel hopeless and I have to do more caring when I myself have health problems”*
- *“Social services (Chinese)”*
- *“Someone to come to the house and not be afraid of her shouting”*
- *“Proper support from a social worker looking to the future”*
- *“Support worker turning up instead of letting her down”*

6.3 What is Advocacy?

When asked if they had heard of advocacy the results show that almost half of respondents had not. Those who had were asked what they would describe it as, below is a selection of the responses given:

- *“Liaison between both parties”*
- *“Someone who can speak up for you”*
- *“Support for person unable to speak for themselves”*
- *“Someone representing your views formally”*
- *“Mediator”*
- *“Solicitors advice”*
- *“A voice when I am no longer alive”*

The results show that the majority of carers who had heard of advocacy understood what it was and half indicated that there were situations when advocacy could help them or the person they care for.

7.0 Professionals Consultation Event

The first event was for professionals and was held at Liverpool Carers Centre on 30th May 2007; this was attended by twenty three professionals from a broad cross section of organisations. The event was planned to be a combination of consultation and information, with two presentations; the first by Dilwyn James, from Sefton Carers Centre on the Carers Emergency Response Scheme operating in Sefton and the second by George Sullivan, Equality and Human Rights Adviser at Mersey Care NHS Trust on the Human Rights Act and how this might affect carers.

The delegates were divided into four groups and each group discussed and answered questions relating to each of the four topics included in the questionnaire (a copy of the questions can be found in Appendix D). In addition the groups were asked to consider support services for carers.

7.1 Health

When asked about the health impact of caring on carers all four groups indicated stress along with physical symptoms. In addition the professionals referred to tiredness both physical and mental, tolerance levels and that the focus is on the health of the cared for rather than the carer.

With regard to strategies to overcome these issues it was agreed that there should be better links with GPs to identify hidden carers; that carers should have annual health checks; that health promotion should be a priority, with themes such as 'stress busting'; that intervention should be put in place early, not at times of crisis and that information should be up-to-date and available at the point of contact. Some of the professionals indicated that training should be available with links to the Expert Carer programme and all agreed that much more support was required such as:

- Financial
- Social
- Emergency
- Home support / respite
- Group support

The professionals responded that some of the ways that their organisations could implement the strategies would be with better communication; by promoting services; by identifying hidden carers and by ensuring that information was up-to-date.

They felt that their organisations could work together by forming stronger links; by sharing information about services available and respecting others expertise; by raising the profile of carers and promoting carers assessments, and by ensuring that the carer was at the centre of planning.

7.2 Employment

The professionals were also asked to discuss the major issues brought to their attention by carers in relation to employment.

Issues they identified included lack of support from services and from employers, this included time off to care and flexible working arrangements. They also highlighted carers having less opportunity to undertake education and training, and restrictions on the number of hours they are able to work thereby leaving them in a position of having to take low paid jobs. The professionals also referred to ignorance of policies, which might already be in place.

When asked about strategies that could be implemented to overcome these issues all of the groups highlighted the recent changes in legislation and how this should be used to accommodate the needs of carers. This would involve an understanding by employers of their responsibilities to employees with a caring role and policy within the organisation to support managers in making decisions. In addition one of the groups indicated that appropriate and timely support services for carers would be required.

The professionals felt that a dedicated 'carer champion' would be one of the ways that their organisation could implement the suggested strategies; also time in lieu, introduction of flexible working and carer awareness training.

They agreed that regular communication between organisations with a 'top tips' document to share methods of good practice would be one of the ways they could work together and that the Liverpool Carers Multi Agency Group should continue to push forward the Work and Family Act 2006 events.

7.3 Emergency Care

At their event professionals were asked to identify what currently happens if carers need replacement care in an emergency. The answers given included a lack of emergency response services; a reliance on family and friends; carer feeling isolated and alone; Careline – social services; Emergency Duty Team; Carers Emergency Card but this would depend on people being known.

When asked what an emergency was, the professionals mostly agreed that this would be different for different people but it would be unplanned and unexpected. Examples given were if the carer couldn't cope, or if the carer became ill and perhaps needed to go to hospital.

The following are some of the key features that the professionals would want to see in an emergency care scheme:

- 24hr emergency line
- Guaranteed support
- Quick response times
- Links with other organisations
- Follow up checks
- Easy to contact and access
- Skilled experienced well trained staff
- Flexibility
- Emergency interpreting service

The professionals felt that their role in making the service a success would be to promote the service; to register as many carers as possible; to monitor and review through feedback and to contribute to the evaluation of the service.

7.4 Advocacy

The professionals were asked who they felt carers would turn to if they needed advocacy support; they suggested a number of options including the Carers Centre; Carers Assessors; Carers Support workers; Professional advocates; GPs; Service Providers; family and friends. Some of the professionals felt there was a lack of advocacy provision in the City (particularly for carers) and that many services were not funded for the advocacy they undertake.

If there was a conflict between the wishes and needs of the carer and the person they care for the professionals showed that they would take various courses of action; they would find out if the person cared for had capacity to make decisions and if the carer was looking after their interests; they would facilitate the carer and the person they care for to compromise and listen to each other and if necessary they would also speak to external organisations for help. Others stated that they would support the carer but also ensure that the person who was cared for had adequate support from another organisation or service. There was agreement that the needs of both the carer and the person cared for should be separately assessed and that there would be situations when both would need support from someone independent of the other.

Regarding support carers are currently likely to get, two groups of professionals stated that there was no specific advocacy service for carers; others felt that overall there was a lack of advocacy services. As to the nature of the service this would depend on where they went; one group felt they would get a listening ear and empathy and that the service would be confidential and impartial, but it would not necessarily be consistent.

Finally the professionals were asked how they could improve the service. One group considered the funding and the strategy to be a priority. This was supported by other groups who also felt that raising awareness and an increase in advocacy services were necessary. Two of the groups suggested that it would be necessary to ensure that carers knew what advocacy was and perhaps a different term should be used e.g. "help to speak out".

7.5 SUPPORT SERVICES FOR CARERS

The following is an outline of the services that the professionals considered to be useful to carers:

7.5(1) Current Carers Services

- Carers Centre
- Respite / Short breaks
- Welfare Rights
- Support groups
- Information and advice
- A number they identify as initial contact
- Ongoing emotional support
- Pamper sessions

7.5(2) Services that would be of benefit

- More day centre places and open at the weekend
- Flexible transport arrangements
- Planning for the future
- Carers Emergency Response Team
- Further training
- Direct Payments
- Involve Young Carers in services

8.0 YOUNG CARERS CONSULTATION EVENT

The second event, which was for young carers, took place on 5th June 2007 at Barnardo's Action with Young Carers and involved staff from Local Solutions Carers Project and Barnardo's. The event was attended by eight young carers identified by Barnardo's and activities were devised to gather information relating to three of the four specific areas under consultation i.e. education (in place of employment), advocacy and emergency care. The young carers were all members of Healthy Lifestyles Groups, which Barnardo's were running, subsequently information regarding health was already being gathered and it was felt that requesting additional information at this event would result in duplication.

The aims of this consultation with Young Carers were to identify the impact of caring in relation to barriers for them being comfortable at school and to identify support needed there; to investigate the ways in which an emergency care service could meet their needs and to explore advocacy services and whether they are beneficial to Young Carers.

Information was collected using three activities over a two hour session. Each activity was designed to capture the views of young carers about each of the specific areas.

Young Carers in School

The group generally felt that it would be helpful if someone in school knew they were a Young Carer and for some their school's awareness of them being a Young Carer had been helpful, one example given is as follows:

- “My mum went into school and told the deputy that I’m a Young Carer and he said that I can phone home if I need to. It helps to know that I can go to the teacher.”

However most of the group stated that their school did not know anything about their caring responsibilities and some did not want anyone to know:

- “I keep it a secret.”
- My mobile phone was taken off me. I didn’t want to tell the teachers why I needed my phone in case someone heard them. I don’t want anyone to know because I don’t want to be different.”

When asked what Young Carers needed from school, they spoke about an open attitude and attention:

- Have signs saying ‘there are Young Carers in the school’. It would make them feel more calm about school.”

The Young Carers did not feel that they should be given special treatment in relation to homework but they did feel that flexibility would be helpful and they came up with solutions for situations where homework was not completed, the following are some examples:

- “Ask for homework deadline to be extended.”
- “If the situation is bad, homework doesn’t matter. Tell the teacher we are a carer, they should understand.”

The group agreed it was important that Young Carers felt able to ask for help. They felt that they could help other Young Carers who might feel isolated from their peers in the following ways:

- “I’d go up to them and say ‘do you wanna come to mine?’”
- “I’d say ‘come over to my house’.”

They could not think of an alternative to their help.

The results of this consultation show that Young Carers generally regard school as inflexible. They do not want to be given special treatment on account of their caring responsibilities and they do not want to be identified as different but they would feel more comfortable if there was an understanding within the school that Young Carers exist and are not unusual. Barriers to Young Carers feeling comfortable in school are being isolated from their peers, missing activities and being reprimanded for homework being late.

Young Carers and Emergencies

The group were asked to consider four situations in terms of whether they were emergencies or not, and what they would do in those situations.

They did not consider a surprise trip away from home for a birthday treat to be an emergency; they came up with some solutions to allow them to take part such as trying to arrange for someone they knew to provide replacement care but ultimately they felt that the Young Carer could decide not to go. Their solutions showed that for most Young Carers their lives would not accommodate a surprise.

The group also felt that a situation where the Young Carer had a follow up dental appointment for a painful abscess was not an emergency. They commented that the appointment could be rearranged and they felt the priority was the person they cared for. Unless the person they cared for could go with them or they could arrange replacement care with someone they knew they would cancel the appointment.

The only situation the group did regard as an emergency was where the Young Carer was traveling home from a school trip and the minibus had broken down. They felt that the person cared for would be very worried and also that something serious might happen to them. In this situation they would still try if possible to contact a family member first.

The Young Carers in this group saw emergencies as situations where there was no choice in terms of solutions. When they were presented with situations which may or may not be an emergency they had practical ways of addressing them and generally would not depend on other people to resolve them. What is evident is that Young Carers prioritise the needs of the person they care for over their own needs.

Emergency situations for Young Carers are compounded by the fact that they do not have tried and tested strategies for coping with crises and they are less likely than other children to have access to extended family. It is likely that if the person they care for was in need of care in an emergency, the Young Carer would need someone to make the arrangements for the replacement care and they would also need someone to care for them.

Young Carers and Advocacy

Most of the Young Carers in the group had not heard the word 'advocacy' and none knew what it meant. Once it was explained generally they did not want someone else to speak for them. They stated that they would prefer to express their own views but if there were circumstances where they needed someone to speak for them they would need to be confident that the person would know what they were doing. They also viewed their relationship with the person as important:

- "It depends on if you know them."
- "It's not always easy to talk to someone else about your personal feeling and views."

Most felt that despite already having a relationship with their teachers they would not be able to act as advocates:

- “It depends what it is.”
- It might sound better coming from me.”

As children and young people the Young Carers in this group found it difficult to fully understand the concept of advocacy, either you speak for yourself or someone speaks for you. To have someone say what you want them to say on your behalf is unusual. The confusion is highlighted by the fact that they felt that teachers could support them in school but they would not be able to act as their advocates.

What is clear from the consultation with this group of Young Carers is that they would not know where to go for support if they were not involved with Barnardo's.

A full report has been produced by Bridgit Carey from Barnardo's Action with Young Carers. This is available from Bridgit Carey at Barnardo's on 0151 708 7323 or Kathy Newton at Local Solutions on 0151 705 2390. A summary of the report can be found on page 6 of this report with recommendations on page 44.

9.0 CARERS CONSULTATION EVENT

This was held on 26th June 2007 at Liverpool Carers Centre and was attended by eight carers. The number of carers who attended was lower than at consultation events held in previous years however a significant number of carers had already participated in the consultation process by completing a questionnaire, which was available from a number of different sources; subsequently the overall response was higher. The event was held as it was felt that carers should still have the opportunity to come together to receive information and discuss the issues involved and it was arranged for the end of the consultation period to allow sufficient time for it to be promoted and also to inform the carers who attended about the process, which had been undertaken.

The event was planned to combine consultation with information but it transpired that it also provided carers with the opportunity to discuss their own caring role and difficulties that they experience, some were unique and related specifically to the condition of the person they care for and some were shared such as feeling frustrated about the lack of resources and lack of professional support in an emergency.

An overview of the Carers Emergency Response Scheme in Sefton was given at the start of the event and this led to discussion about the lack of similar support in Liverpool. Joe Monaghan then gave a presentation about advocacy. Mr. Monaghan is from the National Coalition of Citizen Advocacy and a member of a Steering Group charged with developing an Advocacy Strategy for the City. Finally the carers present were asked to consider the four areas under consultation, although the main part of the discussion was centred on the emergency care scheme.

Those carers who had not already completed a questionnaire were given the opportunity to do so.

Most of the carers agreed that currently in Liverpool they felt there was no help in an emergency and because of this they had to call on family, when possible, for support. One carer stated “I don’t have any back up in an emergency situation” another stated “basically nothing happens in an emergency, you cannot get hold of anyone”. They stated that even when systems are in place they don’t work and this results in carers feeling frustrated “going round in circles”. Some felt that carers themselves develop problems with their health because of the stress of caring, this was supported by the following comment “my health is deteriorating because of my care responsibilities because I don’t get anywhere when I ask for help from social services and the professionals”.

Carers looking after someone with a mental health condition felt that there could be difficulties arranging emergency / replacement care as the person they cared for would not always accept help from a family member let alone from someone they did not know. The group agreed that if the person cared for has challenging behaviour the person providing the replacement care would need to know them and understand their needs and that perhaps there should be different schemes for different conditions.

Another carer explained her own situation “My concern is when in an emergency situation they may send someone in who I don’t know and who doesn’t know how to help me or my mother; they don’t know how to handle my mum”.

The group observed that emergencies mean different things to different people; for some carers not being able to return home at the time expected by the person they cared for could constitute an emergency.

When asked what the professionals’ role would be in ensuring the success of an emergency care scheme the carers agreed that communication would be paramount; that carers would depend on professionals to direct them to the appropriate person / people or service to deal with the situation and that professionals should consult with carers over the person cared for; some carers felt that professionals do not listen to them and they try to separate the carer from the person they care for.

The event continued with the presentation by Joe Monaghan. This led to further discussion, which generally was about the lack of services and support for carers and the person who is cared for, and the lack of resources, which carers felt was common.

Some carers expressed negative opinions about carers assessments – that social workers do not go into enough detail and that carers should be given the form in advance; that there is no point in completing an assessment as there is no money to pay for what is wanted or needed and that completing carers self assessment form is a waste of time since the social workers do nothing about it when you send it in.

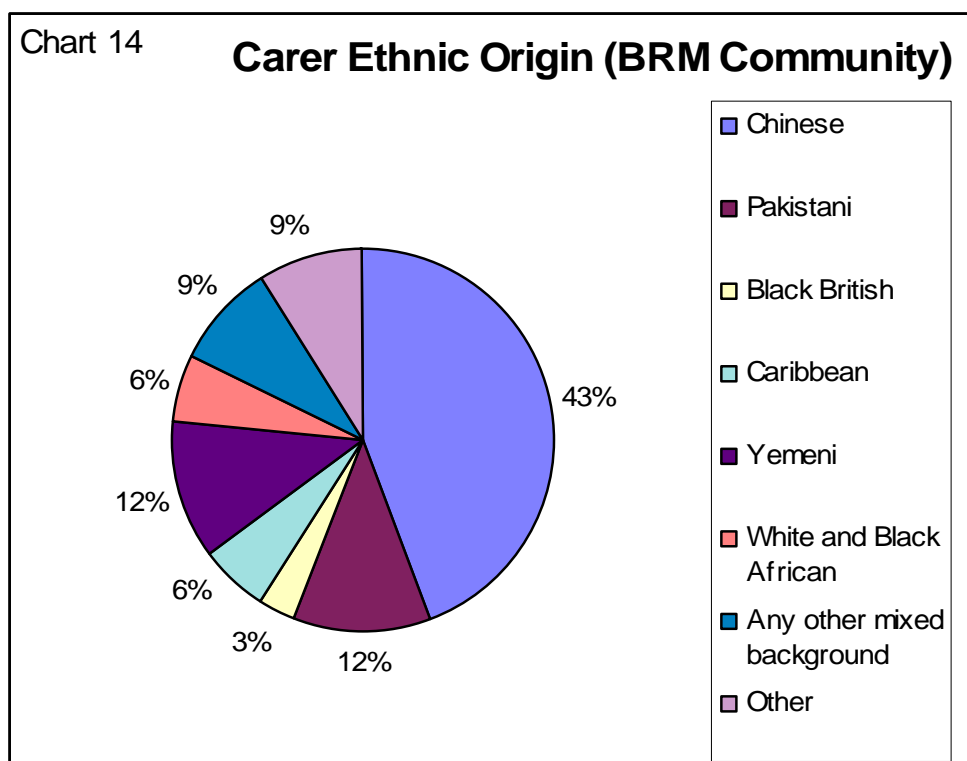
Ultimately carers at the event felt that an emergency / replacement care scheme in Liverpool was needed and perhaps was long overdue. There were concerns expressed about how this would be delivered given the wide range of conditions of the people who are cared for, and their current experience of lack of resources and negative response when their needs have been assessed but not delivered.

10.0 BLACK AND RACIAL MINORITY (BRM) COMMUNITIES

Historically consultation with carers from Black and Racial Minority communities has been difficult, with no-one from this group represented at the Carers Consultation events held in 2005. The consultation this year, has therefore taken a different approach by involving organisations working with carers within the BRM communities in an attempt to overcome some of the barriers such as language and culture, which may have contributed to the previous lack of participation. The consultation questionnaire was distributed by these organisations (see Appendix B) and in some cases staff were able to assist with completion.

The Carers Project at Local Solutions has had a BRM Carers Development Worker in post since March 2006. The post holder's hard work to publicise the service within the BRM communities has resulted in a significant number of referrals received from a variety of sources including 23 self referrals. The Development Worker subsequently used contacts with carers to overcome some of the barriers, particularly the language barrier, to encourage involvement and to assist with participation in the consultation process.

This increased involvement with BRM carers and the BRM communities has resulted in 34 completed questionnaires from carers from 10 ethnic groups; the table below (Chart 14) shows how this is broken down.



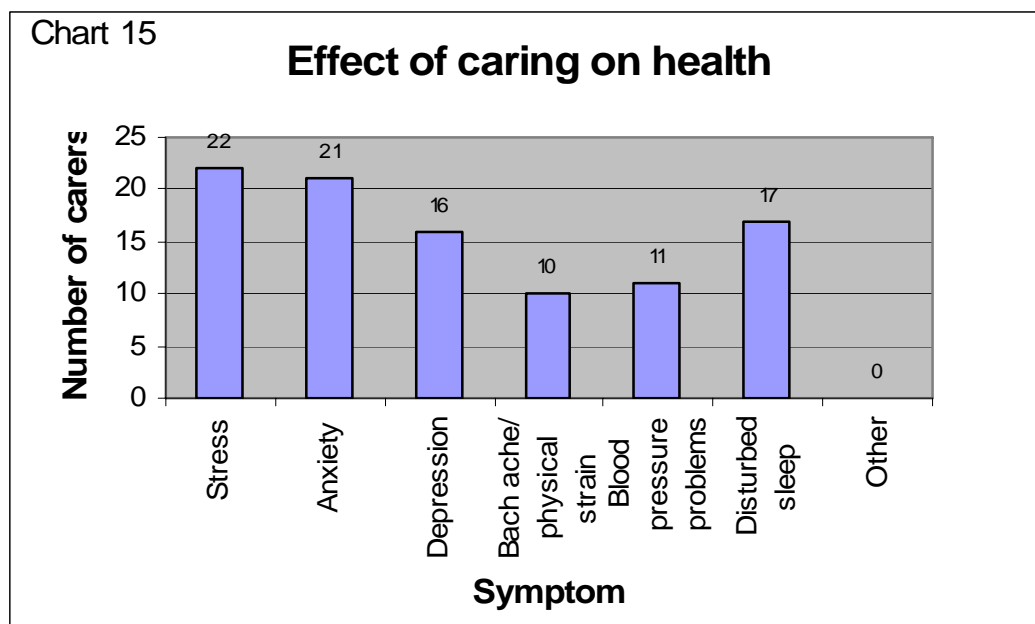
10.1 Health

10.1(1) Carers Health

The responses from BRM carers showed that over half had a health check in the previous 12 months with 59% indicating that they had a disability or illness, or sensory impairment which limited their daily activities. Examples given were:

- Mental health problem
- Arthritis
- Agoraphobia
- Depression / asthma
- High blood pressure / gout

Almost two thirds of carers responded that they felt that caring had an unfavourable effect on their health with a significant number experiencing more than one symptom. Chart 15 below shows the breakdown of responses given.



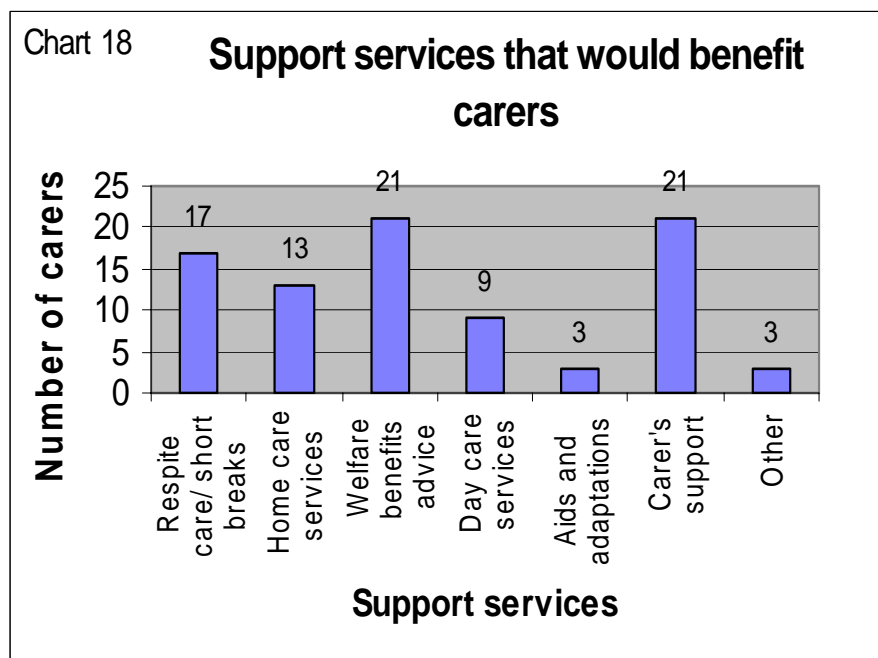
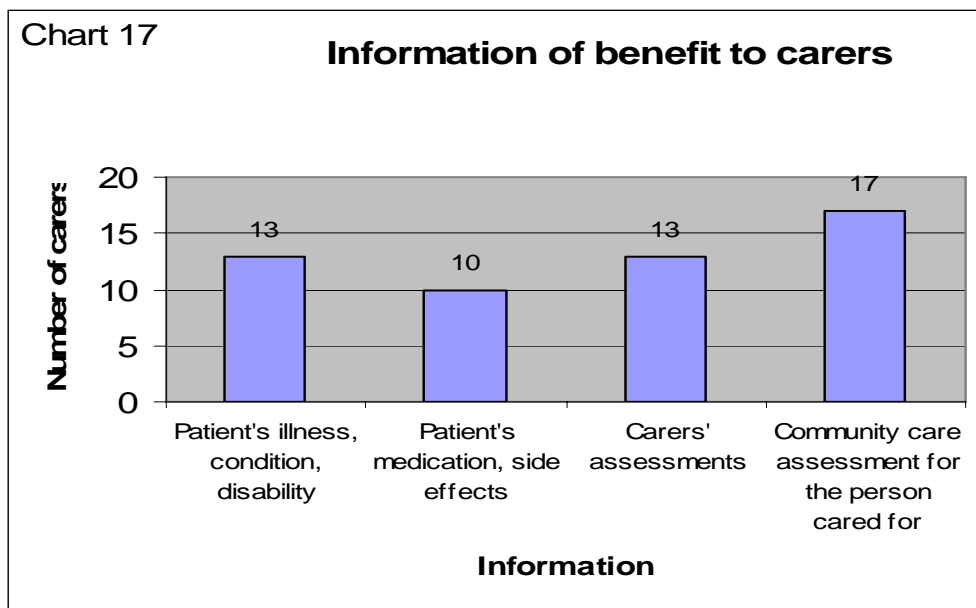
10.1(2) GP Support

56% of respondents had seen their GP about their symptoms and for 58% access to the GP surgery had been easy or very easy; for 16% access had been difficult. 44% indicated that their GP was aware of their needs and responsibilities as a carer.

It is noted that over three quarters of carers had received information or advice about their caring role; 61% had received this from sources other than the GP surgery staff but it is encouraging that 39% had received information from surgery staff, with more than two in ten receiving information from the GP. All respondents stated that the information was either good (74%) or very good (26%).

10.1(3) Information and Support

The tables below (Charts 17 and 18) show the range of information and services that carers would like to receive. A large number of carers have selected more than one of the options; the information that the highest number of carers wanted was about a community care assessment for the person who is cared for, while the most popular support services are welfare benefits advice and carer's support. One carer observed that information should be provided in Chinese.



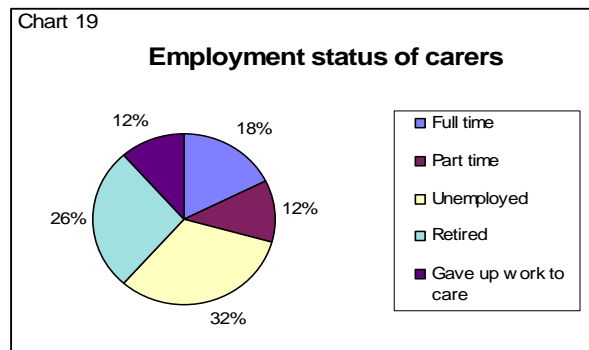
10.1(4) Hospital Discharge

44% of carers confirmed that the person they care for had been in hospital and of those 66% were consulted when the arrangements for discharge were made. Services were arranged prior to discharge for the majority, however they were only in place at the time of discharge for 62%. Subsequently while most carers were satisfied with the discharge arrangements, 30% were either dissatisfied or very dissatisfied. In two cases the person cared for was readmitted to hospital; one within one month and the other after more than one month.

10.2 Employment

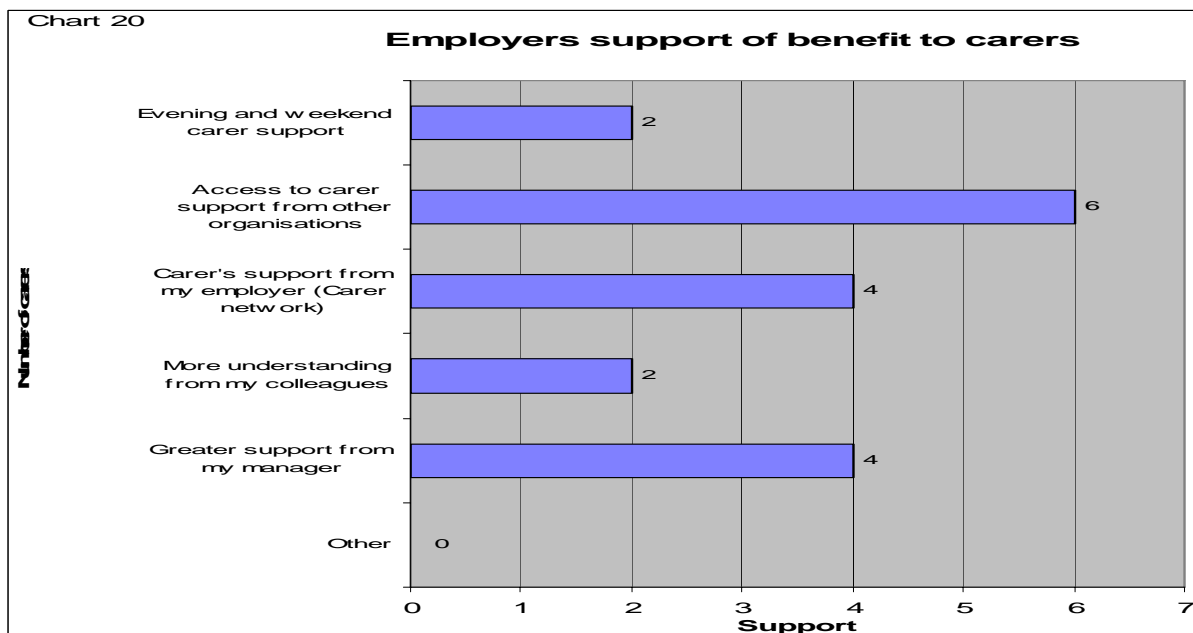
10.2(1) Carers employment status

The results of the questionnaire show that almost one third of carers from the BRM communities who responded were either in full time or part time employment and that an additional 12% gave up work to care (see Chart 19). One in four BRM carers in employment is self-employed.



10.2(2) Carers Support from employer

Chart 20 below shows the responses given when asked what would be of benefit to carers in Employment



10.2(3) Effect of caring role on career

Over two thirds of carers who responded indicated that their career had been affected as a direct result of their caring role. One of the responses given was “I used to work full time, due to my caring role I now only work part time”.

10.3 Emergency Care Scheme

10.3(1) Current replacement / emergency care arrangements

A significant number of carers confirmed that they worry about what would happen to the person they care for if they were taken ill but only 53% had a plan for back up. For the majority this plan relied on family and friends; for those carers who did not have family or friends to help the following are examples of the responses given:

- *“would utilise existing care agencies”*
- *“I have asked my sister from China to care for my father but she has only been granted to stay in the UK for 6 months. After that I don’t know what to do”*
- *“I get Direct Payments and I have a team of care assistants and nurses who come to help me. I rely on them heavily”*
- *“Scheme warden”*

10.3(2) Care Needs

24% of carers stated that the person they care for needed skilled care that family could not provide and half confirmed that they had experienced difficulties when replacement care was needed in an emergency. Examples given were as follows:

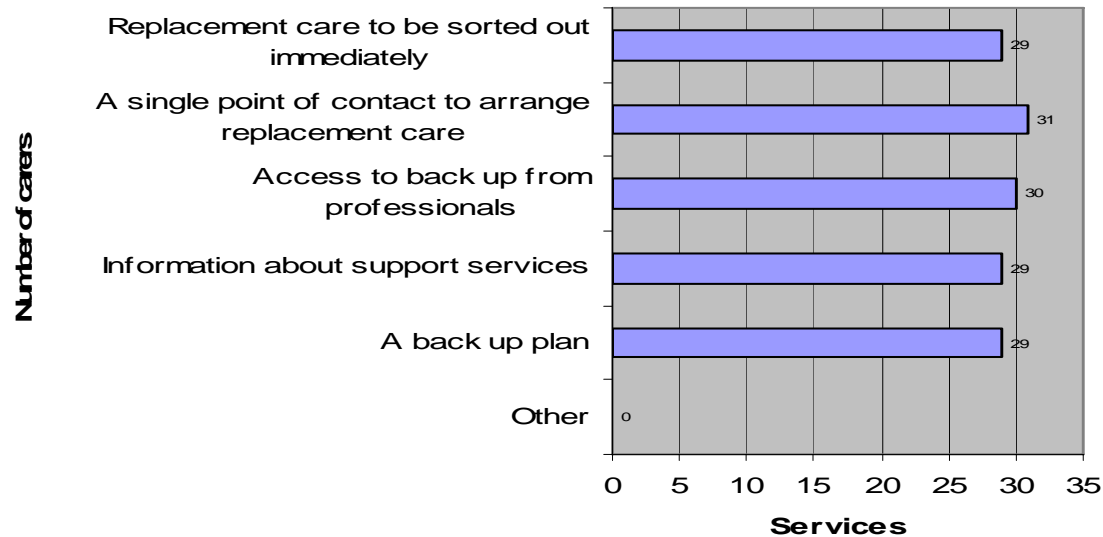
- *“When I have gone to Pakistan but there was no-one to check on my son”*
- *My father speaks only Shanhai dialect so no-one can communicate with him. He eats only specific food so it would be difficult for other people to care for him.*

10.3(3) What would help?

In line with the responses overall carers in the BRM community placed virtually equal importance on each of the possible features of an emergency care scheme. Chart 21 shows that only three carers were of the opinion that a single point of contact to arrange emergency was not needed; twenty nine out of the thirty four carers who responded considered that all of the suggested features were needed.

Chart 21

Services of benefit to carers in an emergency



Less carers in this sample from the BRM communities than from the sample overall, had particular concerns about arranging replacement / emergency care for the person they care for; 32% of carers in the sample responded that they would have particular concerns; 44% indicated that they would not; 21% did not know and 3% (1 person) did not answer the question.

When asked to give details about concerns the following comments were made:

- *“People not knowing her care plan and not dealing appropriately with her”*
- *“I worry about confidentiality – my community is very small and well linked so don’t want my private business becoming exposed to other”*
- *“Due to cultural and language barriers I find it difficult arranging replacement / emergency care for my father”*
- *“I am concerned that the replacement / emergency care staff should be well trained”*

10.4 Advocacy

10.4(1) Has support been needed?

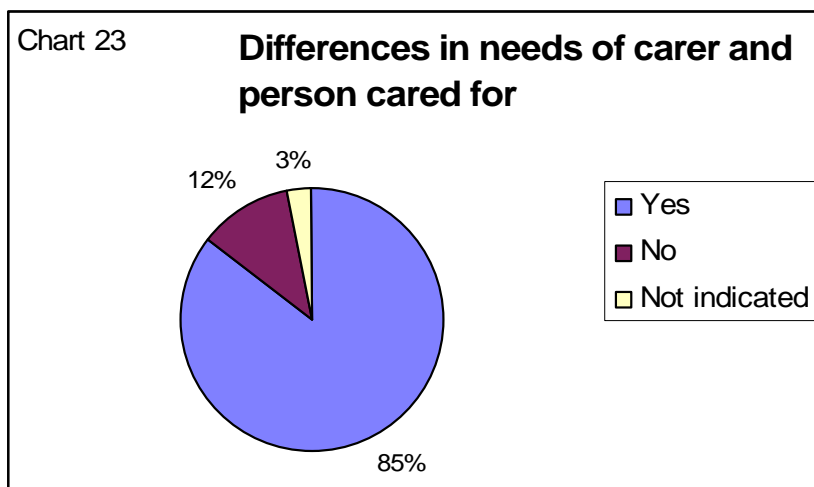
When asked if there had been occasions when support had been needed in dealing with service providers and others the response from the sample of carers from the BRM community was noticeably higher at 74%, than the overall sample (49%). Almost all of the carers who had experienced occasions when they needed support felt that an independent person would have been of benefit.

65% of carers indicated that other types of support would have helped; examples of the type of support are given below:

- *“An interpreter”*
- *“Useful to have support worker who is aware of cultural issues, illness affects whole family”*
- *“I need more information”*
- *“Family support / after school activities”*
- *“Not aware of other services available (I cannot read English)”*

10.4(2) Differences in needs and wishes

Chart 23 shows the number of carers (85%) from this group who confirmed there had been times when they felt there could be a difference between their needs and wishes and those of the person they care for; this is considerably higher than the overall sample, which was 60%. A similarity with the overall sample is that the highest number of carers indicated that having an independent person to listen to the views and wishes of the person they care for and help to express them would be of benefit.



The respondents gave the following examples of other types of support that would have helped the cared for person:

- *“A named worker he could rely on”*
- *“Social services (Chinese)”*
- *“Day centre for people with mental health problems”*
- *“Arrangements for helping my brother going to school or college”*
- *“After school and weekend activities”*

Other carers responded that other types of support might have helped but they didn't know what was available.

10.4(3) What is Advocacy?

Half of carers from the BRM communities who responded had heard of advocacy. Examples of what they would describe advocacy as are given below:

- *“Someone to speak up on your behalf”*
- *“A voice on my behalf”*
- *“Act on behalf of someone”*
- *“Acting on behalf of you, someone listens to you”*
- *“Support”*
- *“To help with legal matters”*

11.0 CONCLUSION AND RECOMMENDATIONS

It is positive that recommendations made following the 2005/2006 consultation have been taken forward and as a result significant developments in support and services for carers have been made. Perhaps most noteworthy is the opening of the Liverpool Carers Centre in November 2006, which provides a focal point in the City for carers accessing information, advice and support.

Training was also an issue raised by carers as an area for development in the 2005/2006 consultation. They requested that flexible training programmes be developed to meet their needs and be arranged to accommodate their caring role. Since that time a number of training courses have been developed including:

- Looking After Me – a free course for adults who care for someone living with a long-term health condition or disability; this was developed in partnership with Liverpool PCT, Liverpool City Council, Age Concern and Local Solutions Carers Project
- A range of training activities at the Liverpool Carers Centre that aim to support carers in their caring role and improve their own health and wellbeing
- Supporting the Dementia Journey – a free training course for carers developed by PSS in partnership with the Liverpool branch of the Alzheimer’s Society

The information from carers as a result of the consultation this year will undoubtedly lead to further development of training courses in accordance with the needs and wishes of carers.

The quality of support services was a further issue with promotion of work to reach 'hidden' carers as a priority. This issue has been addressed by the Liverpool Carers Multi Agency Group who work in partnership to raise awareness of carers and to promote their rights. The group recently focused on the rights of working carers under the Work and Families Act 2006; events were organised by the group for carers and employers to find out about the new rights of carers under this legislation and further work by the group is planned.

In addition the annual information day for carers and professionals, attracted a significant number of carers and professionals to the event held during Carers Week at St George's Hall. This event, which is growing in number each year, provides carers with the opportunity to find out about services and support from organisations across the City.

Additionally, the Carers Grant is being used innovatively by Liverpool City Council to create opportunities within the statutory, voluntary and community sector to provide carers with quality flexible services. Guided by criteria to ensure that resources are used fairly and effectively, they work with carers through the assessment process to identify what services will best meet their needs. The Carers Grant has enabled Liverpool City Council to provide carers in Liverpool with access to a range of support services including flexible short breaks that meet their individual needs and those of the person they care for.

The consultation with carers this year has once again shown that support is needed for carers to ensure that they can enjoy good physical and mental health; that they are not worse off financially by giving up work to provide care and that they have a good quality of life with access to leisure, and training and education.

The opening of Liverpool Carers Centre at Local Solutions in November 2006 has provided carers with the opportunity to access a number of training courses, including stress management and relaxation techniques and also to receive complementary therapies, which are aimed at encouraging carers to consider their own well being. The information gathered will enable further courses to be run, which are targeted at the areas of most importance and benefit to carers.

The Carers (Equal Opportunities) Act 2004 seeks to give carers more choice and better opportunities to lead a more fulfilling life, with the chance for those who wish to pursue leisure or training activities or to return to work. Carers Assessments are the gateway for carers to access support and services and it is important that when appropriate carers are aware of their right to such an assessment under the Carers and Disabled Children Act 2000. The assessment should take account of the impact of caring on the carer and services should be used in a flexible and innovative way, thereby not only helping the carer to care but also to have a life outside of caring.

Liverpool City Council is keen to provide carers with a choice of how their needs are assessed including the option of self assessment. The Carers Self Assessment document and process was initially developed in 2004 with the introduction of a hard copy document. The Carers Self Assessment E-Form was introduced in 2005 and this enabled carers to complete the form on-line. Through the Carers Self Assessment E-Form Liverpool City Council have been able to raise carers' awareness of their rights to assessment through partner agencies such as health and third sector organisations. It also provides carers with the opportunity to identify their own needs and how they want those needs to be met.

From the results of the consultation with carers this year the following recommendations are made:

HEALTH

Although there were some encouraging signs in the figures connected with GP support and Hospital Discharge, more work is required to ensure that a more uniform system for identifying and supporting carers is established in conjunction with Health Care professionals. The National Strategy for Carers sets out a check list for GPs and Primary Health Care Teams to enable them to better meet the health care needs of carers and while some GP surgeries are working towards satisfying this check list others are not.

Access to the GP surgery is an issue for carers and support to enable them to do so without difficulty is necessary, whether this is making arrangements for the person they care for to be looked after; appointment times or waiting room arrangements. For the carers who responded to this survey who found it difficult to access the GP surgery and for all carers who experience difficulties it is key that their particular needs are established and support put in place to overcome them.

In relation to hospital discharge the vast majority of carers were satisfied with the arrangements but a significant minority were not, which suggests that greater effort is needed to ensure that all the support services needed by the carer and the person they care for are put in place during the critical process of discharge.

There is still work to be done in encouraging hospital staff to involve the carer when discharge arrangements are being made and leadership from the PCT and from the Hospital Trusts is required to drive forward the commitment to improving the service delivery to carers and the person they care for.

EMPLOYMENT

Results from the survey show that carers are interested in receiving training to help them to deal with their role as carer as well as training, which may improve their employability prospects. Although the Liverpool Carers Centre at Local Solutions offers some provision tailored to the needs of carers more varied and flexible provision would be welcomed. Further work should therefore be done to explore with carers what type of training they feel would be of benefit as well as the arrangements that should be put in place to enable them to attend, such as location, time and whether replacement care, including childcare, would be needed.

For carers in employment it is apparent that support from their employer is already in place to some degree, with some offering more support than others. However what most carers wanted but none were receiving was access to a carer network offering information and advice. This suggests that the work started by the Liverpool Carers Multi Agency Group needs to be pushed forward with more emphasis on the importance of carer support within organisations or at least with the opportunity for signposting to other agencies or organisations offering support. Further promotion of support services from such organisations is also required.

Some carers felt excluded from activities both at work and outside of work, whether related to training or social activities and for some their caring responsibilities were compounded by the additional responsibility of childcare. To enable such carers to be able to participate in activities and events aimed at providing them with support, consideration should be given to replacement care not only for the person who is cared for but also for their child / children.

EMERGENCY / REPLACEMENT CARE

The results of the survey show that for a significant number of carers the issue of replacement care in an emergency is a major cause for concern, yet only half had a back up plan. The development of an emergency care scheme is therefore something that will be of great benefit to the majority of carers. The success of the service will depend upon it being flexible and one that meets the needs of carers in different situations. Many carers expressed concern about the quality of the service including the competence of the staff delivering the replacement care for people with a wide range of conditions and care needs, and the ease with which it could be accessed. For carers from the BRM communities language and cultural barriers were also an important issue.

Both carers and professionals felt that a key to the success of the service would be the role of the professionals; those delivering the service from the initial point of contact to the provision of care, and those who work with carers to ensure that they are given appropriate and timely information.

It is therefore recommended that a service is set up that is straightforward to arrange, is prompt to respond and is reliable. The service should also be able to meet a wide range of care needs and instill confidence in both the carer and the person who is being cared for. It is also vital that carers have the opportunity to access this service, which will depend upon hidden carers being identified and professionals informing carers of the support that is available for them.

ADVOCACY

Considerable work has been undertaken by the City Council in establishing an Advocacy Steering Group and developing a city wide Advocacy Strategy, and the results of the consultation indicate that such a policy is well advised with almost half of the respondents stating that they had needed this type of support. In conjunction with the City Council's policy there needs to be greater awareness of what advocacy can mean for carers and how they can best access such support.

It was encouraging to note from the research that carers recognise that conflicts will occasionally arise between them and the person they care for and that on such occasions an independent person may be able to provide support to help resolve the conflict. The majority of carers were in favour of the availability of this type of provision and it is therefore important that when it is needed the service is available and carers have the necessary information to access it.

BRM CARERS

Significant effort has been made by both Local Solutions and Liverpool City Council to raise the profile of caring within the BRM communities and this work is beginning to gain some recognition as nearly one in five of all respondents were from minority ethnic groups; Chinese being the largest group but also significant responses from Pakistani, Caribbean and African backgrounds.

On the whole the responses from the BRM carers were broadly similar to the responses provided by carers overall, however issues surrounding cultural sensitivity and equity of access do need to be examined in more detail. It is worth noting that more carers from BRM communities than the respondents overall felt that advocacy could help them or the person they care for in some situations.

YOUNG CARERS

A number of recommendations made for Young Carers following the consultation with a group of young carers supported by Barnardo's Action with Young Carers are contained in the report written by Bridgit Carey from Barnardo's. The following is a brief summary of some of the recommendations from the report.

In relation to support for young carers at school it was felt that there needed to be flexibility in respect of homework and being able to contact the person they care for without the young carer being identified as such. There should also be someone in school for them to talk to.

Regarding emergency care the main issues were the difference between an emergency for a young carer and for an adult carer, and how they would deal with it. It was felt that professionals would need to work with young carers to assist them to identify support and that services would need to accept requests from the person cared for or another adult acting as advocate for the young carer.

Professionals should also work with adults who might already be acting as advocates for young carers such as parents or other professionals. Finally young carers did not know what advocacy was therefore a different term needs to be used, one that young carers already understand.

Full details of the findings of the Young Carers Consultation event and the recommendations can be found in the report from Barnardo's.



Carers Consultation 2007
Questionnaire

Q1 Are you

Male		Female	
------	--	--------	--

Q2 What is your ethnic origin?

Asian or Asian British	Black or Black British	Chinese or other ethnic group
Asian British	African	Chinese
Bangladeshi	Black British	Gypsy
Indian	Caribbean	Irish Traveller*
Pakistani	Nigerian	Yemeni
Any other Asian background	Somali	Other (give details)
	Any other Black background	

Mixed	White
White and Asian	White British
White and Black African	White Irish
White and Black Caribbean	Any other white background
Any other mixed background	

Prefer not to say

--	--

*Irish Travellers are defined as a specific ethnic group who may also belong to a variety of racial backgrounds. For this reason, if you consider yourself to be a traveller, you may also tick another category which indicates your racial background.

Q3 What is your postcode?

L1		L7		L13		L19	
L2		L8		L14		L20	
L3		L9		L15		L24	
L4		L10		L16		L25	
L5		L11		L17		L27	
L6		L12		L18		L28	

Other postcode

--

Q4 How many people do you care for?

One		Two		Three	
-----	--	-----	--	-------	--

Q5 What is the nature of the illness or disability of the person you care for?

Old Age	
Physical disability	
Learning disability	
Mental Health Problem	
Sensory impairment (sight/ hearing/ speech)	
Other, please specify	

Q6 How old are you?

Under 18		18-29		30-44		45-64		65-74		75-84		85+	
----------	--	-------	--	-------	--	-------	--	-------	--	-------	--	-----	--

Q7 How old is the person you care for?

Under 18		18-29		30-44		45-64		65-74		75-84		85+	
----------	--	-------	--	-------	--	-------	--	-------	--	-------	--	-----	--

Q8 Who do you care for?

Mother/ Father		Husband/ Wife/ Partner		Son/ Daughter		Other, please specify
Other Relative		Friend		Neighbour		

Q9 Is the person you care for

Male		Female	
------	--	--------	--

Q10 Does the person live in the same house as you?

Yes		No	
-----	--	----	--

Q11 How many hours a week do you spend caring?

0-4		5-9		10-19		20-34		35-49		50-99		100+	
I am on call 24 hours a day													

Q12 How long have you been caring?

Less than a year		1-5 years		6-10 years		11-20 years		More than 20 years	
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Health

Q13 Have you had a health check in the last 12 months?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
-----	--------------------------	----	--------------------------

Q14 Do you have any disability/ illness or sensory impairment (sight/ hearing/ speech), which limits your daily activities?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
-----	--------------------------	----	--------------------------

Please give details

Q15 Do you feel that caring has had an unfavourable effect on your health?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
-----	--------------------------	----	--------------------------

Q16 Please tick all the symptoms that apply to you

Stress	<input type="checkbox"/>	Back ache/ physical strain	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	Blood pressure problems	<input type="checkbox"/>
Depression	<input type="checkbox"/>	Disturbed sleep	<input type="checkbox"/>
Other, please specify:	<input type="checkbox"/>		<input type="checkbox"/>

Q17 Have you had to see your GP about your symptoms?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
-----	--------------------------	----	--------------------------

Q18 If yes, was access to the GP surgery

Very easy	<input type="checkbox"/>	Easy	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Difficult	<input type="checkbox"/>	Very difficult	<input type="checkbox"/>
-----------	--------------------------	------	--------------------------	---------	--------------------------	-----------	--------------------------	----------------	--------------------------

Q19 Is your GP aware of your needs and responsibilities as a carer?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Don't know	<input type="checkbox"/>
-----	--------------------------	----	--------------------------	------------	--------------------------

Q20 Have you received information or advice about your caring role from any of the following? Please tick all that apply

Family doctor (GP)	<input type="checkbox"/>
Practice nurse	<input type="checkbox"/>
District nurse	<input type="checkbox"/>
Health Visitor	<input type="checkbox"/>
Practice manager	<input type="checkbox"/>
Other Surgery Staff	<input type="checkbox"/>
Other, please specify	<input type="checkbox"/>

Q21 If yes, would you describe the quality of the information/ support as

Very good		Good		Neutral		Poor	
-----------	--	------	--	---------	--	------	--

Q22 If you have not received information, advice or support, which if any, of the following would have been/ would still be of benefit to you?

Information about

Patient's illness, condition, disability		Carers' assessments	
Patient's medication or side effects		Community care assessment for the person you care for	

Support services

Respite care/ short breaks		Day Care services	
Home care services		Aids and adaptations	
Welfare benefits advice		Carer's support	
Other support, please specify			

Q23 What, if any training have you received or would you like to receive?

	Have received	Would like to receive
Dealing with challenging behaviour		
Assertiveness		
Moving and Handling		
First Aid		
Stress Management		
Relaxation techniques		
Other		

Q24 Has the person you care for been in hospital?

Yes		No	
-----	--	----	--

Q25 If yes, were you consulted when the arrangements for discharge were made?

Yes		No	
-----	--	----	--

Q26 Were services arranged prior to discharge?

Yes		No	
-----	--	----	--

Q27 If yes, were services in place at the time of discharge?

Yes		No	
-----	--	----	--

Q28 If not when were they delivered?

Within 1 day		2 days		1 week		Other (please specify	
--------------	--	--------	--	--------	--	-----------------------	--

Q29 How satisfied were you with the discharge arrangements?

Very satisfied		Satisfied		Dissatisfied		Very dissatisfied	
----------------	--	-----------	--	--------------	--	-------------------	--

Q30 Has the person you care for been readmitted to hospital?

Yes		No	
-----	--	----	--

Q31 If yes, please state whether within

1 day		2 days		1 week		1 month		More than a month	
Please give details:									

Employment

Q32 Do you work?

Yes full time	
Yes part time	
No I am unemployed	
No I am retired	
No I gave up work to care	

Q33 If yes, does anyone at work know that you care for someone?

Yes		No	
-----	--	----	--

Q34 Does your employer offer any of the following?

	Yes	No	Would help
Use of a telephone to check on the person you care for			
Use of a telephone for emergencies			
Carers emergency leave (paid or unpaid)			
Carers planned leave			
Career break			
Part time working			
Flexi time			
Job share			
Home working/ tele working			
Term time only			
Carer network			
Other, please specify			

Q35 Which, if any would be of benefit to you?

	Yes	No
Greater support from my manager		
More understanding from my colleagues		
Carers' support from my employer, such as a carer network or access to information and advice		
Access to carer support from other organisations		
Evening and weekend carer support		
Other, please specify		

Q36 Would you benefit from services for the person you care for? Please tick all that apply

Direct support e.g. home care or day care	
Direct payments to arrange your own support	
Information about registered and approved private care facilities	

Q37 Has your career been affected as a direct result of your caring role?

Yes		No	
-----	--	----	--

Q38 If yes, please tick all boxes that apply

Reduced promotion prospects	
Cannot take up training opportunities	
Less responsibility at work	
Excluded from social activities at work	
Can only obtain low paid or part time work	
Difficulties getting back into work	
Changed career as a result of skills gained by caring	
Other, please specify	

Emergency Care Scheme

Q39 Do you worry about what will happen to the person you care for if you are taken ill and are not able to provide care?

Yes		No	
-----	--	----	--

Q40 Please tick any of the following that apply:

I would not know who to contact in an emergency	
I worry that emergency support services may take too long to respond	
I do not know if replacement care is available or who would provide this care	

Q41 Do you have a plan for back up if you are not able to provide care due to an unplanned event?

Yes		No	
-----	--	----	--

Q42 If yes, does this rely on family and friends?

Yes		No	
-----	--	----	--

Q43 Does the person you care for need skilled care that your family cannot provide?

Yes		No	
-----	--	----	--

Q44 Have you ever experienced difficulties when replacement care was needed in an emergency but could not be provided?

Yes		No	
-----	--	----	--

Please give details

Q45 What would help in an emergency? Please tick all that apply

A back up plan	
Information about support available	
Access to back up from professionals	
A single point of contact to arrange replacement care	
Replacement care to be sorted out immediately	
Other, please specify	

Q46 Do you have any particular concerns about arranging replacement/ emergency care for the person you care for?

Yes		No	
-----	--	----	--

Please give details

Advocacy

Q47 Have there been occasions when you felt that you needed support in dealing with service providers and others?

Yes		No	
-----	--	----	--

Q48 If yes, which of the following do you feel could have helped you on those occasions? Please tick all that apply.

	Yes	No
An independent person to listen to your views and wishes	<input type="checkbox"/>	<input type="checkbox"/>
An independent person to support you in expressing your views and wishes	<input type="checkbox"/>	<input type="checkbox"/>
Both	<input type="checkbox"/>	<input type="checkbox"/>

Q49 Is there any other type of support that you feel would have helped you?

Yes		No	
-----	--	----	--

If yes, please provide more details

Q50 Have there been times when you have felt that there could be a difference between your needs and wishes and those of the person that you care for?

Yes		No	
-----	--	----	--

Q51 If yes, what do you feel could have helped the person that you care for in such a situation?

	Yes	No
An independent person to listen to her/ his views and wishes	<input type="checkbox"/>	<input type="checkbox"/>
An independent person to support her/ him in expressing her/ his views and wishes	<input type="checkbox"/>	<input type="checkbox"/>
Both	<input type="checkbox"/>	<input type="checkbox"/>

Q52 Is there any type of support that you feel would have helped her/ him?

Yes		No	
-----	--	----	--

Q53 Have you ever heard of advocacy?

Yes		No	
-----	--	----	--

Q54 If yes, what would you describe it as?

Q55 Do you think that advocacy could help you or the person that you care for in some situations?

Yes		No	
-----	--	----	--

Q56 Liverpool City Council and Primary Care Trust are currently looking at an Advocacy Policy and Strategy. Would you be interested in contributing to the consultation around these?

Yes		No	
-----	--	----	--

Please be assured that your feedback will be kept confidential and unless you choose to provide your details below, you will remain anonymous.

NAME:.....

ADDRESS:.....

.....

.....

POSTCODE:.....

E-MAIL:.....

PHONE:.....

Thank you for taking the time to complete this questionnaire. Please return to Kathy Newton, Senior Carers Development Officer, Carers Project, Local Solutions, Hall Lane, Liverpool L7 8TF. Tel: 0151 705 2390. E-mail: knewton@localsolutions.org.uk

All questionnaires should be returned by 30th June 2007

Appendix B – List of Organisations that helped to publicise consultation and distribute questionnaire

Aegis Choice in Care
Age Concern
Alzheimer's Society
Asperger's Carers Group
Barnardo's Action with Young Carers
Chinese Carers Network
Crossroads Carers Group
Joseph Gibbons Day Care Centre
Leighton Dene Resource Centre
Liverpool Carers Forum
Liverpool 8 Carers Scheme, Heal 8
Liverpool Carers Multi Agency Group
Liverpool Parent Partnership
Liverpool PCT
Liverpool Schizophrenia Association
Liverpool City Council
Liverpool DAAT
Local Solutions Homecare
Mary Seacole House
Mencap
Mental Health Consortium
Mental Health Carers Group at Liverpool Carers Centre
Mersey Care NHS Trust
Merseyside Stroke Network
Mossley Hill Hospital Carers Support Group
Natural Breaks
Neurosupport
Nugent Care
Oakfield Centre Carers Group
Parkinson's Disease Society
PSS
Rethink
Silk Road News
South Liverpool Epilepsy Support
Stroke Association

Many thanks to all of these organisations

Appendix C

Dear Carer

Your Chance to have Your Say – Carers Consultation 2007

The Carers Project at Local Solutions has been consulting with carers over a number of years on behalf of Liverpool City Council about what your needs are and the carer services and support you want.

The consultation this year will take place over a period of three months from 1st April to 30th June. This will give you the opportunity to have your say about what you would like to see in the next Liverpool Carers Strategy and about the services and support you would like to be developed.

Your involvement by completing this questionnaire will provide very important information about how well you feel you are supported in your caring role and about any gaps in services that you feel would help you as a carer.

This form, which should only take a few moments of your time to complete, is also available in electronic format or it can be completed by telephone interview. A consultation event is also being held at Liverpool Carers Centre on Tuesday 26th June; if you would like to attend this event or if you would like more details about alternative formats please contact me, **Kathy Newton on 0151 705 2390 or by e-mail knewton@localsolutions.org.uk**.

Please do not hesitate to contact me if you have any queries or if you require help to complete this form.

Many thanks for your assistance.

Yours sincerely

Kathy Newton
Senior Carers Development Officer

Appendix D

HEALTH

What do you think the health impact of caring is on carers?

What strategies could be implemented to overcome these issues?

How does or could your organisation implement these strategies?

How can your organisations work together to improve the health of carers?

EMPLOYMENT

What are the major issues that carers in employment bring to your attention as professionals?

What strategies could be implemented to overcome these issues?

How does or could your organisation implement these strategies?

How can your organisations work together to overcome these issues?

EMERGENCY CARE

What currently happens if carers experience an emergency when replacement care is needed?

What is an emergency?

What do you consider to be the key features of an emergency care service?

What do you think your role would be in ensuring that the service is successful?

ADVOCACY

Who would carers turn to if they need advocacy support?

What would/do you do if there is a conflict between the wishes and needs of the carer and the person they care for?

What support are they likely to get?

How could you improve the service?

SUPPORT SERVICES FOR CARERS

As professionals what services do you find are most useful to carers?

Do you find that carers are asking for services that are not available?

What service(s) would be of benefit?

