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#### Introduction

### Information collected on the Carers Survey is split into 6 sections:

- Section 1: About the person you care for
- Section 2: About your needs and experiences of support
- Section 3: The impact of caring and your quality of life
- Section 4: Information and advice quality
- Section 5: Arrangement of support and services in the last 12 months
- Section 6: About yourself

2012/13 is the second time a survey of this nature has been run. In 2009-10 a pilot survey was run in which councils were asked to volunteer to take part; 90 councils including Nottinghamshire agreed to do this. Further consideration of the findings from the voluntary survey has taken place and the number of questions has been reduced from 58 to 27.

# Information from the survey is used to produce **Adult Social Care Outcomes Framework Indicators**:

- 1D Carer-reported quality of life
- 3B Overall satisfaction of carers with social services
- **3C** The proportion of carers who report that they have been included or consulted in discussion about the person they care for
- 3D\* The proportion of people who use services and carers who find it easy to find information about services

#### **Overview**

In most cases the level of positive results has dropped since the 2009/10 survey.

- + Nottinghamshire remain slightly above average for overall satisfaction with support or services
- + The percentage of carers who feel they are neglecting themselves has fallen in Nottinghamshire since 2009/10
- + More carers in Nottinghamshire have no worries about their personal safety since 2009/10. Results for the East Midlands dropped and England remained the same
- + Nottinghamshire have scored higher than the East Midlands and England average for carers saying they felt involved or consulted to some level
- Carers in Nottinghamshire feel they spend less time doing things they want or enjoy than in the East Midlands or England
- Nottinghamshire score for carers having enough control over their lives is below the East Midlands and England average
- Results for social contact remain fairly consistent between years however Nottinghamshire scored below the East Midlands and England average in this area
- There has been a drop in the percentage of carers who feel they have encouragement and support in their role and Nottinghamshire are below the East Midlands and England average

<sup>\*</sup>This indicator includes results for carers and service users combined

### Some comments from carers

We had some fantastic support as a family, working out strategies of how to cope. This came at a good time as the family was at breaking point and we needed to pull together.

If you have a problem you have to explain the problem too many times to too many different people, in different departments then it takes too long to put the remedy into practice...

Although most of the operational procedures that I have read say that the carer will be fully involved in discussions and decisions, this rarely happens. It is frustrating to me as a carer and generally is counterproductive to my wife's care.

Support for the person I am caring for very good, but felt I could do with someone to talk to.

If you are allocated a good social worker it can make all the difference to the help you receive..

My mother recently had a period of respite which she thoroughly enjoyed and benefitted both her but also me, my Husband and Mother in Law who I also care for.

I get fed up with life and having to organise my time around when people can be with my husband.

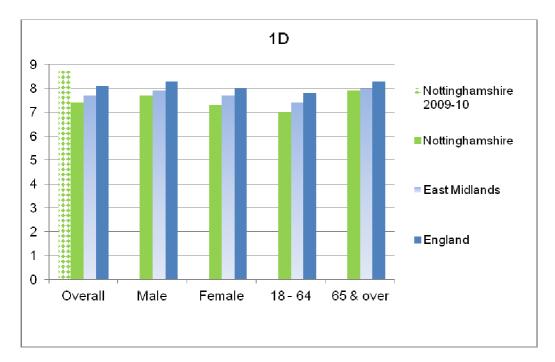
#### **ASCOF Indicator results**

The charts below compare Nottinghamshire's results to the East Midlands and England for 2012/13. Nottinghamshire's results for 2009/10 have also been added although it is not possible to recreate these results for the East Midlands or England using the information available.

In all cases the results have dropped since the 2009/10 survey.

### 1D Carer-reported quality of life

This is a composite measure which combines individual responses to seven questions measuring different outcomes related to overall quality of life which are mapped to 7 domains (occupation, time and space, control, personal care, safety, social participation and encouragement and support).

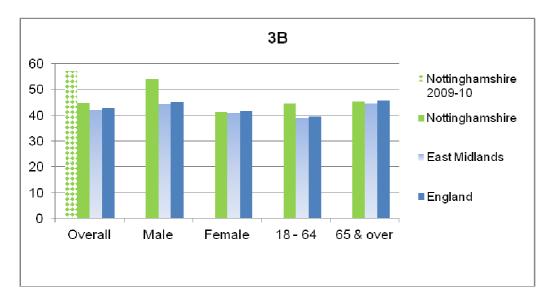


Overall for Nottinghamshire 7.4, East Midlands 7.7, England 8.1

Our overall score in this area is slightly below the average for the East Midlands and England. Males and those in the 65 and over age group report a slightly higher quality of life on average.

#### 3B Overall satisfaction of carers with social services

The measure is defined by determining the percentage of all those responding who identify strong satisfaction – i.e. by choosing the answer "I am extremely satisfied" or the answer "I am very satisfied".



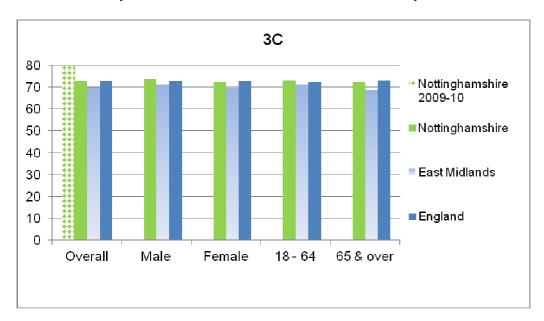
Overall for Nottinghamshire 44.8, East Midlands 42, England 42.7

Nottinghamshire have scored above average for overall satisfaction.

Males and those aged 18 – 64 show particularly high satisfaction levels. These spikes do not follow the pattern shown for these groups for the East Midlands or England.

### 3C The proportion of carers who report that they have been included or consulted in discussion about the person they care for

The measure is defined by determining the percentage of all those responding who choose the answer "I always felt involved or consulted" and "I usually felt involved or consulted".

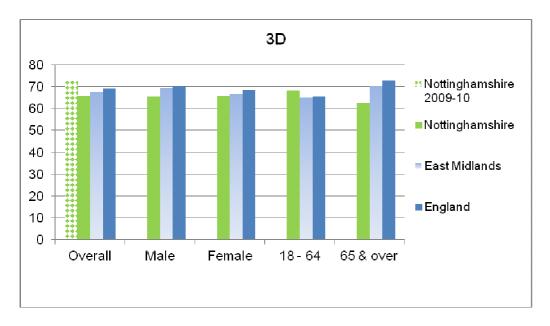


Overall for Nottinghamshire 72.7, East Midlands 70, England 72.8

Nottinghamshire have scored slightly above the East Midlands average and our scores are in line with the England average.

# 3D The proportion of people who use services and carers who find it easy to find information about services (Carers responses only)

This portion of the measure is defined by determining the average percentage across the two surveys of all those responding who select the response "Very easy to find" and "fairly easy to find".



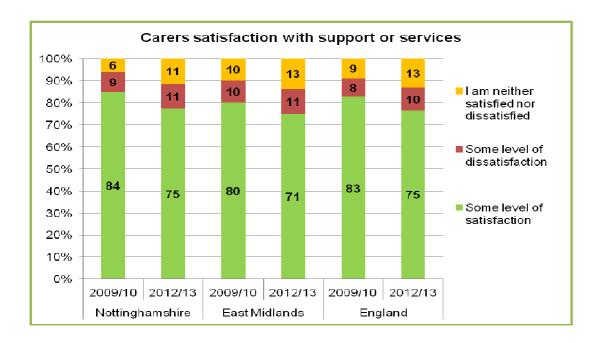
Overall for Nottinghamshire 65.8, East Midlands 67.6, England 69

Our overall score in this area is slightly below the average for the East Midlands and England. In Nottinghamshire the 18 – 64 age group found it easier to find information whilst the 65 and over age group found it more difficult. This does not follow the pattern shown for these age groups for the East Midlands or England.

### **Survey questions results**

### Overall how satisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?

	20	009/10		2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
Some level of satisfaction	84	80	83	75	71	75
Some level of dissatisfaction	9	10	8	11	11	10
Neither satisfied nor dissatisfied	6	10	9	11	13	13



The results of 2012/13 survey have been adjusted to allow comparison with the 2009/10 survey. This is because in the more recent survey an additional option was added for the carer to indicate they hadn't received any services.

The adjustment allows us to see that positive results have dropped since 2009/10 however Nottinghamshire's score has remained slightly above the average for the East Midlands.

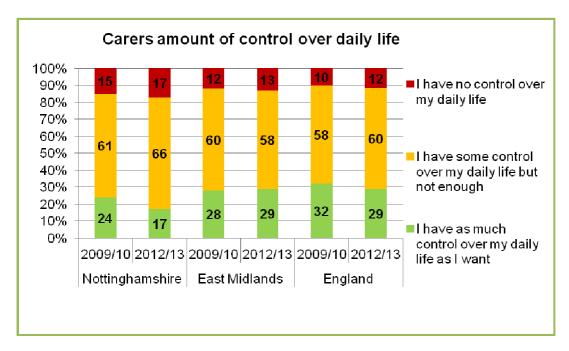
### Which of the following statements best describes how you spend your time?

	20	09/10		2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
I spend my time as I want	19	21	23	14	18	22
I spend some time but not enough	68	65	64	69	67	64
I don't do anything I value or enjoy with my time	13	13	13	18	15	14

Positive results for Nottinghamshire and the East Midlands have dropped since the 2009/10 survey. The England average has remained consistent.

# Which of the following statements best describes how much control you have over your daily life?

	20	009/10		2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
As much control as I want	24	28	32	17	29	29
Some control but not enough	61	60	58	66	58	60
No control over my daily life	15	12	10	17	13	12



The percentage of people saying they have as much control over their daily lives as possible had dropped since the 2009/10 survey in both Nottinghamshire and England. The East Midlands remains consistent.

# Thinking about how much time you have to look after yourself - in terms of getting enough sleep or eating well - which statement best describes your current situation?

	20	09/10		2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
I look after myself	52	58	62	55	52	60
Sometimes can't look after myself well enough	27	26	25	28	32	26
I feel I am neglecting myself	21	16	13	17	17	14

Nottinghamshire's results have improved slightly since the 2009/10 survey, with 17% of people saying they feel they are neglecting themselves compared to 21%.

### Thinking about your personal safety, which of the statements best describes your present situation?

	2009/10			2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
No worries	78	83	85	84	77	85
Some worries	21	16	14	15	19	14
Extremely worried	1	2	2	2	3	2



The percentage of people who have no worries about their personal safety has increased for Nottinghamshire and the East Midlands since the 2009/10 survey. The England average has remained consistent.

# Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?

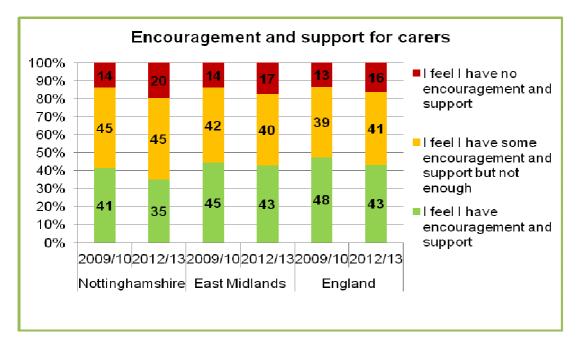
	2009/10			2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
As much social contact as I want	33	39	45	32	38	42
Some social contact but not enough	49	46	43	48	46	45

Little social						
contact and feel	18	15	13	20	17	14
socially isolated						

These results remain fairly consistent between years however Nottinghamshire is still below average for carers having as much social contact as they want.

# Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?

	20	09/10		2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
I have encouragement and support	41	45	48	35	43	43
I have some but not enough	45	42	39	45	40	41
No encouragement & support	14	14	13	20	17	16



There has been a drop in the percentage of people who feel they have encouragement and support in their role. Nottinghamshire has the biggest drop at 6% and our results are below the average for the East Midlands and England.

# In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?

	2	009/10	2012/13			
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
I have not tried to find information or advice in the last 12 months				27	27	28
Easy to find	72	68	74	48	50	50
Difficult to find	28	30	26	25	24	22

The results of the 2009/10 and the 2012/13 survey are not directly comparable as in the more recent survey an additional option was added for the carer to indicate they hadn't tried to find any information or advice.

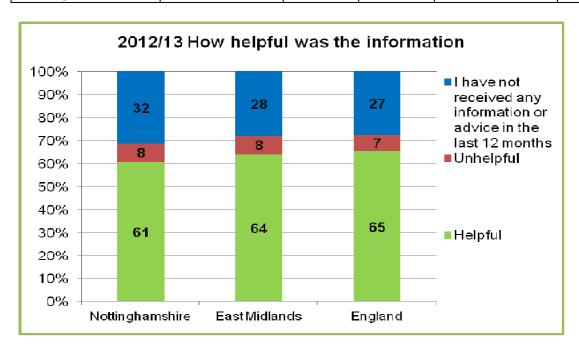
Our results are now slightly below the average for the East Midlands and England.

I have struggled in the past because it wasn't clear which source to contact but have found it easier after being given the "Golden Number".

All info easy to find when someone tells you where to look for it!! Hard to determine if you are entitled to the help and support or not.

### In the last 12 months, how helpful has the information and advice you have received been?

	2009/10			2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
Not received any info or advice				32	28	27
Helpful	93	93	92	61	64	65
Unhelpful	7	7	8	8	8	7



The results of the 2009/10 and the 2012/13 survey are not directly comparable as in the more recent survey an additional option was added for the carer to indicate they hadn't received any information or advice.

Our results are below the average for the East Midlands and England and we show a higher percentage of people saying they have not received any information or advice in the last 12

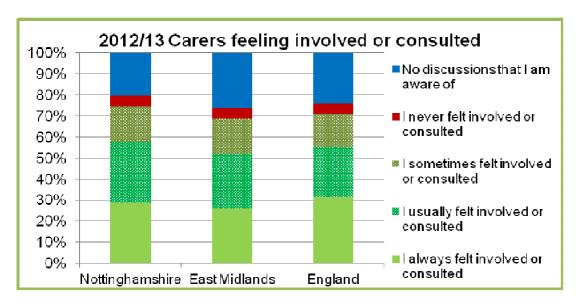
months.

Our G.P. Consultant, plus Social Services, have been very friendly, understanding and helpful.

Lack of awareness of local resources: time needs to be allowed within working hours, to allow workers to gather information which can be then passed on to carers about 'what's out there'.

In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

	20	009/10		2012/13		
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %
No discussions I am aware of				20	26	24
Always	45	50	50	29	26	32
Usually	34	28	28	29	26	24
Sometimes	15	16	15	17	17	16
Never	5	6	6	5	5	5

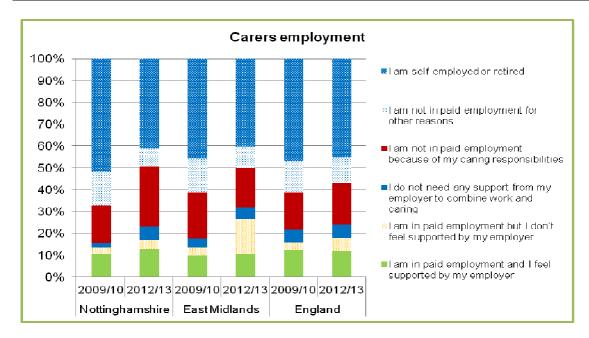


The results of the 2009/10 and the 2012/13 survey are not directly comparable as in the more recent survey an additional option was added for the carer to indicate there hadn't been any discussions.

Nottinghamshire have scored higher than the East Midlands and England average for carers saying they felt involved or consulted to some level (75% compared to 68% and 71%). We also show a lower percentage of people saying that there had not been any discussions in the last 12 months (20% compared to 26% and 24%).

# Thinking about combining paid work and caring, which of the following statements best describes your current situation?

	20	009/10		2012/13			
	Nottinghamshire %	East Midlands %	England %	Nottinghamshire %	East Midlands %	England %	
In paid employment and feel supported by employer	11	10	12	13	11	12	
In paid employment but don't feel supported by employer	3	3	4	4	16	6	
Do not need any support to combine work and caring	2	4	6	6	5	6	
Not in paid employment because of caring responsibilities	17	21	17	27	18	19	
Not in paid employment for other reasons	16	16	14	8	10	12	
Self-employed or retired	52	46	47	41	40	45	



The percentage of people that said they were retired or self employed has fallen across the board since 2009/10, with Nottinghamshire seeing the biggest reduction (52% down to 41%).

The percentage of people saying they do not work due to caring responsibilites has increased in Nottinghamshire by nearly the same percentage (17% to 27%).

Carers in employment regardless of the level of support they receive has increased across the board with Nottinghamshire showing a slight increase since 2009/10 in carers saying they felt supported by their employer.

The East Midlands average of carers in employment but not feeling supported has increased from 3% to 16% however Nottinghamshire do not follow this pattern, with an increase of only 1%.

If you have any comments or further questions about the information contained in this report please use the contact details below to get in touch.
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**Appendix 1: Comments Analysis by Laura Chambers** 

### **Carers Questionnaire Analysis**

June 2013

**Q13** In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?

Of the 77 respondents, 10 did not answer the question and so have not been used in the summary. So the data below is based on 67 responses.

87% (58) of the respondents felt that information and advice has been difficult to get hold of and on 13% (9) considered it to have been easy to access information or had never tried to. The table below breaks down the main reasons cited for considering information and advice gathering easy or difficult. The themes are ranked according to how often they were cited.

hard to access right people to	22	33%			
speak to/ fragmented system			given good support by		
			professionals	4	6%
poor sign posting- to and by					
staff/websites/general info	10	15%	not ever asked for any info	2	3%
Suitable support (from					
professionals and services)					
unavailable	10	15%	easy as work for the council	1	1%
poor information sharing with			Situation is improving - more		
carers e.g. about the person			diverse sources of advertising		
they care for or services they			info available e.g. GP surgery		
are eligible for	8	12%	electronic notice boards	1	1%
Financial problems are hard to					
get information on	3	4%	The 'golden number' is good	1	1%
no support given proactively to					
carers by NCC	2	3%			
poor communication between					
agencies	2	3%			
frail so cant source					
information and is hard to be a					
carer	2	3%			
System too bureaucratic	1	1%			
NCC policy messages are not					
clear	1	1%			

**Q14** Helpfulness of information and advice received in last 12 months (39 respondents inc. 3 voids):

Helpful	11	31%
Not helpful	22	61%
Moderately helpful	4	11%

Of the 31% (11) of respondents that found the information and advice they received helpful, 45% (5) was from statutory agencies and 55% (6) was from voluntary agencies.

The supplementary comments given to support why the information and advice given was helpful tended to relate to *how* it was presented in addition to the content. Satisfied respondents received a good all round service.

Staff were "very **friendly**, **understanding and helpful**", "...the one person who has always helped us with problems is...she is one fantastic lady" while also presenting a competent and **comprehensive service** as shown in the quotes "all the help given by the Carers Federation has proved most valuable" and "I can't praise Framework enough for this help, information and advice. Absolutely invaluable and took the need to use other services away".

Of those that said the service was unhelpful, the main themes for dissatisfaction were:

- Not being able to get information or advice =23% (5)
- Insufficient communication from/ access to professionals = 23% (5)
- The services offered were poorly matched to the individual =18% (4)
- Professionals don't know about services = 14% (3)
- Inaccurate or misleading information or services were offered =9% (2)
- Poor quality work delivered = 5% (1)
- Inflexible system that doesn't accommodate individual's desire for choice and control = 9% (2)

Of the 22 respondents who were dissatisfied only 5% (1) comment related to a voluntary sector agency. A further 2 (9%) comments related to both statutory public services and the voluntary sector and 19 (86%) related directly to public sector agencies within both ASCH and Health.

Q23 Any other comments or experiences you would like to tell us about?

Of the 160 responses to this question only 115 included comments or feedback that could be thematically clustered. Therefore 45 anecdotes have not been included in this summary data as these simply described respondents situations.

The themes identified have been ranked in order of their frequency of citation and are supplemented with some quotes to illustrate the theme more completely.

Deduced convice previous, the needs of the corer and cored for	26	240/
Reduced service provision –the needs of the carer and cared for	36	31%
"'Day' centre isn't for a day as he can be home by 3pm."		
"The services over the years have certainly depreciated."		
"(the day centre)due to the amalgamation with learning disabilities is really crowded,		
and not very enjoyable".		
"Nottinghamshire does not have a Care Home suitable for my daughter complex		
syndrome".		
"support on offer - unreasonably time limited".		
"With supported living tendered out to agencies standards are not reliable and care		
levels not guaranteed."		
"Multiple services with their own financial challenges do not work together - they merely		
pass the patient off to someone else".		
"but (it) would cost too much to have someone come in on my bad days".		
"I really thought may be useful but they were all between Mon and Fri and 9-5 so I was		
unable to attend any of them".		
"(Alzheimers) has completely destroyed our lives it is gradually ruining me financially		
and physically and will certainly kill me before it kills my wife."		
"Who helps the carer?"		
"Money allocated does not cover fees for respite places meaning I don't get a break"		
		2221
Good support from professionals	23	20%
"We had some fantastic support as a family, working out strategies of how to cope."		
"My family and myself have been very happy with the support/advice we have been		
given".		
"The quality of the service has been very good".		
"The care services offered have been efficiently organised by an excellent social worker		
and appropriately selected always with consultation".		
"I get good support twice a day from a Caring Agency. I do not resent my situation in		
any way."		
"she has attended since September for two days per week, she absolutely loves it, the		
staff are amazing, the faciliities second to none. The staff are very professional, very		
caring"		
"SW are very good - regular contact and support. As well as clinical PH".		
"Thank Social Services for the support they give us Long may it last!!".		
"Our case worker at Social Services (xx) has been very helpful when needed."		
"they were both very helpful, and a credit to Social Services".		
"We are extremely satisfied with the help and support we have received, every one we		
have been dealing with have been exceptional".		
"With regards to the help I have received it is second to none".		
There are insufficient comings available offering anothered available and	00	400/
There are insufficient services available offering emotional support	22	19%
"agring age by a very length and ignisting experience. Very get very little agestional		
"caringcan be a very lonely and isolating experience. You get very little emotional		
support"		
"Worst thing is everything being about them and 'the illness' and any time away leads to		
feelings of guilt." "Overall I feel very isolated".		

" It would be better if occasionally services staff rang me to offer encouragement."  "I was given no advice or support at any point in time."  "I just feel that I do not get the support I need".  "this situation is giving me constant cause for concern."		
"I could do with someone to talk to".		
Services are not joined up	11	10%
l've not able to spend the £150 awarded to me because I have no-one to look after him." "you have to explain the problem too many times to too many different people." "Uncoordinated services". "I would advocate more joined up working". "continuity is sometimes good!". "I rely on no one but it gets more and more difficult. More should be done."		
Bad service recommendations by inexperienced workers/poor service delivery	9	8%
"On occasion start and finish times are not fully consulted. Medication is sometimes found on the floor and probably not observed taking.  I am here every day and on certain days sandwiches are used from the day before if not been eaten previously".  "I still don't know if it has all been sorted out as no one has come back to me. This has woken me up to how our money is spent as rates and tax payer".  "I am especially concerned about how long it can sometimes take to get problems sorted out through the local authority".  "I am very dissapointed with the Start Team early on, they do not give support to the patient."  "We feel we don't get enough support from his doctor".  "I have never had any support. They have always worked against me. My worker is a waste of time."		
Carers are not involved in decisions relating to those they care for	4	3%
"It is frustrating to me as a carer and generally is counter-productive to my wife's care."  "Please get people to listen to the carer our life is hard enough".  "I have had to stamp my feet and get cross to make people hear".		
MH services fall short of required standards	4	3%
"We feel massive changes need to be made in Mental Health and the caring side to be highlighted in Graduated Post Graduate studies rather than evasion tactics used currently. (So as to avoid responsibility)."  "Experience of personal care when my husband was at home was terrible".  "Surely needs for Dementia sufferers should be classed by stage, not age."  "The normal husband / wife care person is not trained to deal with mental health problems and some doctors"		
NCC not responding to attempts at contact to access support	3	3%
"the main problem we as a family find is not being able to get any information on respite care or even a day centre".  "I'm sure it would help if we had a named Social Worker but at the moment we get an anonymous voice on the end of the phone. THAT IS IF THEY RETURN YOUR CALL!!"		
Respondents succeeded in coping due to family support and contacts in the system, not from going through the official route	2	2%
"Better access needed for people who don't have the family 'back up'". "Without my friend (whose husband had Alzheimers & has died) I would have been quite lost"		

#### **APPENDIX 1**

Carers breaks have been helpful	1	1%
"could these breaks be continued as they have been very helpful to me"		

The table above suggests that while many respondents (20%) feel they are receiving a service that they are very happy with from dedicated professionals, an additional 31% felt that for a range of reasons, the services on offer are not meeting the needs of the service user and/or carer, or were not joined up sufficiently well (10%). In addition to this there was a strong sense in the comments provided (22%) that there was a stark omission in terms services that are designed to meet the psychological or emotional needs of the carers and that this gap was aggravating carers' sense of isolation and of being trapped.