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**Health, Social Services
and Public Safety**

An Roinn

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SURVEY OF CARERS OF OLDER PEOPLE IN NORTHERN IRELAND

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About CIB

The purpose of Community Information Branch is to promote effective decision-making in children and adult social services by providing quality information and analysis. We collect, analyse, and disseminate a wide range of community information that is used to help monitor the delivery of personal social services policy. Information collected by CIB is used to assess HSS Trust performance, for corporate monitoring, policy evaluation, and to respond to parliamentary / assembly questions. Information is widely disseminated through a number of key statistical publications, most notably "Key Indicators of Personal Social Services for Northern Ireland" and "Community Statistics", both of which are National Statistics publications. The branch also produces a range of other statistical publications and reports, details of which are available by clicking on the link below.

http://www.dhsspsni.gov.uk/index/stats_research/stats-cib/stats-cib_pubs.htm

Our Vision and Values

Community Information Branch aims to:

- Provide up-to-date, quality information on children and adult social services and community health;
- to disseminate findings widely with a view to stimulating debate, promoting effective decision-making and improvement in service provision; and
- be an expert voice on social care information.

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Key Points

- Over three-quarters (77%) of the carers who responded to the survey were female. Almost two-thirds of carers were aged 55 or over.
- Three-quarters of people cared for were aged 75 or over, and almost two-thirds were female.
- Two-thirds of the people cared for lived in the same household as the carer.
- Over four-fifths of the people cared for had physical disabilities, and half had mental health problems.
- Over two-fifths (43%) of respondents said that, in a typical week, they provided care all the time, and a further 28% provided care for over 50 hours.
- About a quarter (26%) said that they never had breaks from caring, and over three-fifths had breaks only occasionally.
- 18% said that they always felt under stress because of caring responsibilities, 21% were under stress very often and 30% were under stress quite often.
- Respondents were asked to list which things would most support them in their caring role. The most common thing mentioned was respite care or breaks for the carer.
- 71% of those in contact with Social Services were provided with help in the home, 65% with disablement equipment, 52% with information, advice or counselling, and 46% were provided with respite breaks either at home or outside the home.
- Only 43% of respondents knew that they could have a separate assessment of their needs as a carer, and only 39% had been offered such an assessment.
- Less than one-third (30%) of respondents are always asked about the services they receive, 34% are always involved in deciding services for themselves and less than half (46%) are always involved in deciding the services for the person cared for.
- Almost half (45%) of carers were not given written care plans. Of those who received the plans, almost all (96%) said that the information was clear.
- Just over one-fifth of respondents had ever had to make a complaint, with two-thirds of them happy with the outcome of the complaint.
- When asked had their Trust or any other organisation asked for their opinion about services for carers in their community or area, 78% of respondents said that they had not been asked.

- After a decision was made to provide services, 55% of carers received help within a week.
- Almost two-thirds (64%) said that the services had always helped them.
- Almost three-quarters of respondents were satisfied with the **amount** of services they received and almost nine-tenths were satisfied with the **quality** of services provided.
- The services provided that respondents found most helpful were personal care and respite care.

SURVEY OF
CARERS OF OLDER PEOPLE
IN NORTHERN IRELAND

Introduction

Who Are Carers?

Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, people caring for ill or disabled children or young people under 18 who care for another family member (DHSSPS, 2002b). Carers, therefore, provide a valuable service, not only to the person being cared for, but also to the wider community.

In the 2001 Northern Ireland Census, just over 185,000 people or 11% of the population identified themselves as carers, that is:

“giving help or support to family members, friends, neighbours or others because of long-term physical or mental health or disability, or problems relating to old age”.

Almost two-fifths (59%) of these carers were female, with almost half (48%) aged under 45 and 40% aged 45-64. Three-fifths of carers provided care for 1-19 hours a week, 15% for 20-49 hours and one-quarter (25%) for 50 or more hours.

Surveys also provide an important source of information on the prevalence and characteristics of carers in Northern Ireland. The 1997 Health and Social Wellbeing Survey found that 18% of the respondents were carers (20% of females and 14% of males), and almost a quarter (24%) of those aged 45-64 provided care. Nine out of 10 cared for someone related to them – 46% of carers provided care for a parent and 22% for a partner or spouse. The majority of carers looking after someone outside their household cared for dependants aged 65 and over. Carers were more likely to suffer a great deal of stress than non-carers (DHSSPS, 2001).

In the 2001 Northern Ireland Household Panel Survey, 16% of respondents identified themselves as carers, with 38% of them caring for someone in the same household, 55% caring for someone in another household, and 7% caring for someone in their own household as well as someone in another household. Almost two-thirds (64%) of carers were female, 54% were aged 45 or over and 21% were aged 60 or over. Ten per cent provided care for 20-34 hours a week, 17% for 35 hours or more and 12% for 50 hours or more. Over three-fifths (61%) of the carers reported that they had some health problems (Evason, 2004).

The Northern Ireland Family Resources Survey has also collected information on carers. Respondents were asked if anyone in their household received care, or if anyone gave care to anyone living outside the household. The 2004-2005 survey found that 39% of carers provided 10 or more hours of care a week, with 23% providing care in excess of 35 hours a week. Although 26% of carers were caring for a partner or spouse, 40% of those caring for relatives were not members of the same household. Of those receiving care, 81% were attended to at least once a day, with 39% receiving care continuously (DSD, 2006).

Policies on Carers in Northern Ireland

The role of Northern Ireland carers was recognised in the 1990 policy document, *People First: Community Care for Northern Ireland in the 1990s* (DHSS, 1990), which recommended that appropriate packages of support be put in place for people who were able and willing to care for others. Among the six key objectives of the policy were:

- to promote the development of domiciliary care, day and respite services to enable people to live in their own homes wherever possible; and
- to ensure that service providers make practical support for carers a high priority.

The particular needs of carers of people with dementia in Northern Ireland was acknowledged by the Dementia Policy Scrutiny in 1994. A multidisciplinary team led by representatives of the Department of Health and Social Services carried out a detailed examination of service provision for people with dementia. It aimed to provide Health and Social Services Boards and Trusts with guidance that would contribute to a more co-ordinated and better targeted approach to meeting the needs of people with dementia and their carers. The report (DHSS, 1995) recommended that carers were given access to information, advice, counselling, appropriate training and services at an early stage and that their needs and abilities be taken into account when assessments were being conducted.

Based on experience since the introduction of *People First*, the *Review of Community Care* (DHSSPS, 2002a) gave a particular focus to services for older carers, stating that Trusts needed to make support for carers a high priority. It recommended that services such as respite and sitting services should be protected, regular respite should be built into care plans, and personal care services should involve as few changes as possible to enable carers to plan the rest of their lives outside of their caring role, as well as advocating support groups for carers. A carers' strategy should be implemented to ensure a range of practical support for carers, establish models of good practice and develop a set of key principles for carer support.

The carers' strategy for Northern Ireland was proposed in *Valuing Carers: Proposals for a Strategy for Carers in Northern Ireland* (DHSSPS, 2002b). The key principles, which formed the foundation of the strategy, were:

- carers are real and equal partners in the provision of care;
- carers need flexible and responsive support;
- carers have a right to a life outside caring;
- caring should be freely chosen; and
- government should invest in carers.

The strategy made 19 recommendations, notably in the areas of information and training, support services and breaks for carers. Health and Social Services Boards and Trusts needed to be particularly proactive in seeking out and supporting older carers. Trusts should also inform carers of their right to a separate assessment and should require that the results of such an assessment be separately recorded.

The *Carers and Direct Payments Act (Northern Ireland) 2002*, which came into effect in 2003, gave carers a statutory right to separate and independent assessment of their own needs and required Health and Social Services Trusts to inform carers of this right. It also allowed Health and Social Services Trusts to provide personal social services to support carers directly. In addition, it widened the availability of direct payments to enable clients to purchase their own services.

Following from *Valuing Carers*, the new carers' strategy was launched in 2006 as *Caring for Carers: Recognising, Valuing and Supporting the Caring Role* (DHSSPS, 2006). The strategy was developed round six areas of concern, which were identified during the original *Valuing Carers* consultation:

- the identification of those acting in a caring role;
- information for carers;
- support services;
- the special needs of young carers;
- training; and
- employment.

It set out a vision of what needs to be done to provide carers with the practical support they want and need to allow them to continue caring, as well as to recognise, value and provide practical support for the important contribution that carers make to our society.

Inspection of Social Services to Carers of Older People

Care may be provided to people of any age, but carers of older people have particular needs, especially as regards the services provided to them. The Social Services Inspectorate of the Department of Health, Social Services and Public Safety (DHSSPS) carried out an inspection of social care services for older people in 2005-2006. The aim of the inspection was to assess the extent to which such services meet the needs of carers of older people and comply with the policy objectives of *People First*, the recommendations of *Valuing Carers* and the requirements of the *Carers and Direct Payments Act*.

The main objectives of the inspection were to:

- establish the type, range and volume of current social care support services for older people;
- consider the structure, organisation and management of social care support services for carers of older people in relation to assuring quality and managing the performance of these services;
- determine the extent to which Boards and Trusts are complying with the requirements of *People First*, the *Carers and Direct Payments Act* in relation to the carer's right to a separate assessment of his/her need, and the recommendations of *Valuing Carers* in respect of various social care support services for carers of older people;
- consider how carers of older people are involved in decisions about the provision of services, and examining how services are organised and delivered;
- consider the resources currently allocated and identify any areas of unmet need;
- identify and promote good practice; and
- provide a report and make recommendations as necessary.

The inspection focused on the carer as a person in receipt of services designed to support them in their caring role, and as a key person to be consulted in relation to the needs of the cared for person and how services are designed and delivered to meet these needs.

Survey Methodology

The survey of carers of older people was conducted in 2005, to both inform the SSI inspection of social care services for older people and monitor the implementation of the *Carers and Direct Payments Act* for carers of older people. Each of the Health and Social Services Trusts providing a community service was given 50 self-completion questionnaires to distribute to carers who were in contact with Social Services in their Trust. In order to contact carers who may not have been in contact with Social Services, a further 420 questionnaires were distributed through contacts provided by Advice NI, an independent advice network which provides information on social issues affecting the community. A copy of the questionnaire is provided at Annex 1.

A total of 294 people completed the questionnaires distributed through the Health and Social Services Trusts and Advice NI – that is, 30% of the questionnaires distributed were completed. Response varied across Trusts, ranging from 40 completed questionnaires in Sperrin Lakeland Trust to 12 in the Ulster Community and Hospitals Trust. Only 29 responses were obtained from the questionnaires distributed through Advice NI. A breakdown of the numbers completing the questionnaire, according to Trust, is shown in Table 1 (Annex 2).

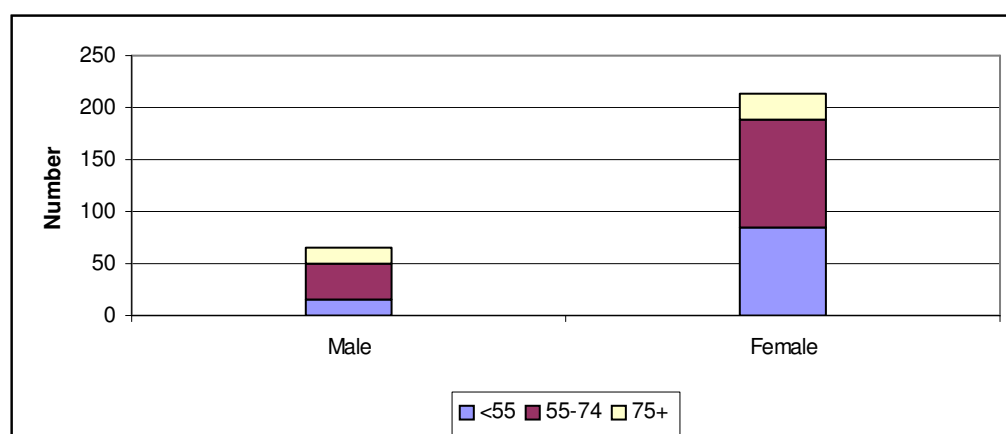
The survey was not based on a random sample of carers, and so it cannot be considered to be representative of all carers of older people in Northern Ireland. Nevertheless, it does reflect the experience of a significant number of individuals providing care services to those aged 65 and over.

Carers

Characteristics of Carers

A total of 294 individuals completed the questionnaire; over three-quarters (77%) were female and almost a quarter were male. Fifteen per cent were aged 75 or over, 48% were aged 55-74, 35% were aged 35-54 and only 2% were aged under 35. Just over three-quarters of the male carers (76%) were aged 55 or more, compared with three-fifths (60%) of female carers. Almost a quarter (24%) of the male carers and 12% of the female carers were aged 75 or more (Figure 1).

Figure 1 Gender and Age of Carers



Almost three-quarters (72%) of the carers were married, 14% were single, 7% were separated or divorced and 6% were widowed. Just under half (48%) of the respondents stated that they had a long-term illness, health problem or disability. Of these, the majority (63%) stated that this was a physical disability or illness, with 9% having a hearing disability and 7% a visual disability.

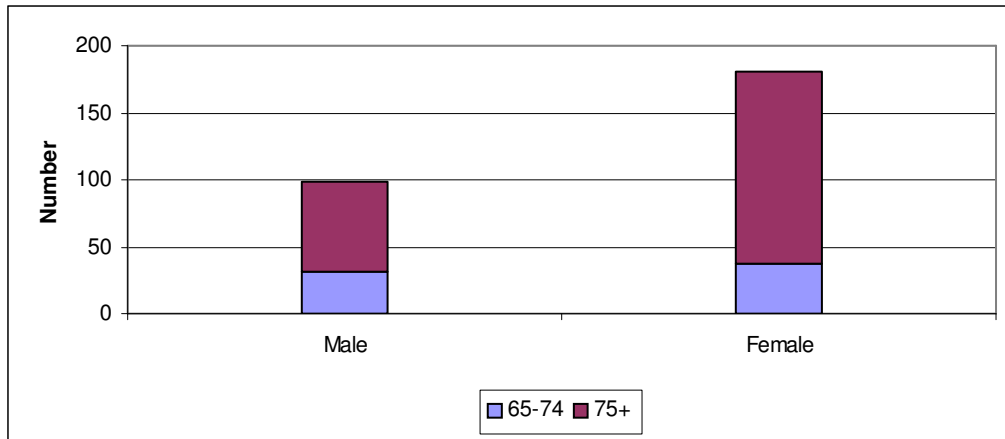
Almost all of the respondents (99%) recorded their ethnic category as white. Of those who stated their religion, 41% were Catholic, 56% were Protestant and 3% said that they were of another or no religion. Fifteen respondents did not state their religion.

Person Cared for

Most respondents (85%) cared for one person, and 15% for more than one. Respondents were asked to record the subsequent information in respect of only one of the people cared for – the one aged over 65, or the one aged over 65 for whom they spent the most time caring.

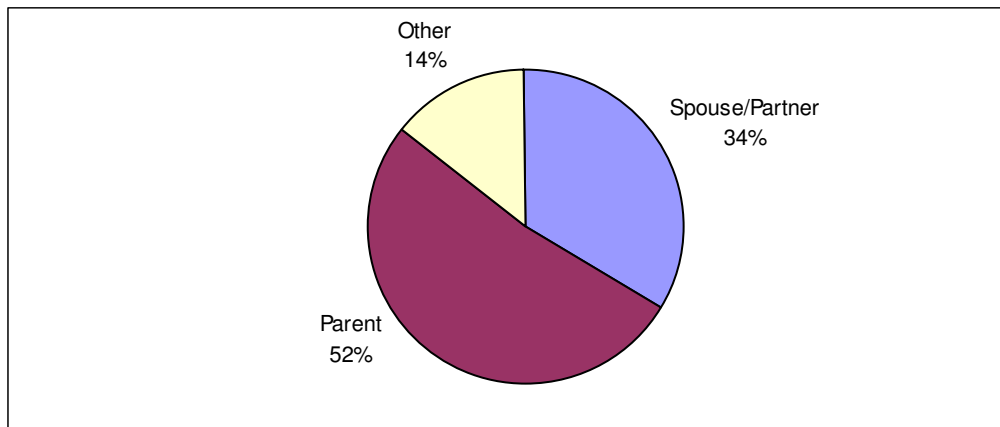
Three-quarters (75%) of people cared for were aged 75 or over, and 25% were aged 65-74. Sixty-five per cent were female and 35% were male (Figure 2).

Figure 2 Gender and Age of Person Cared for



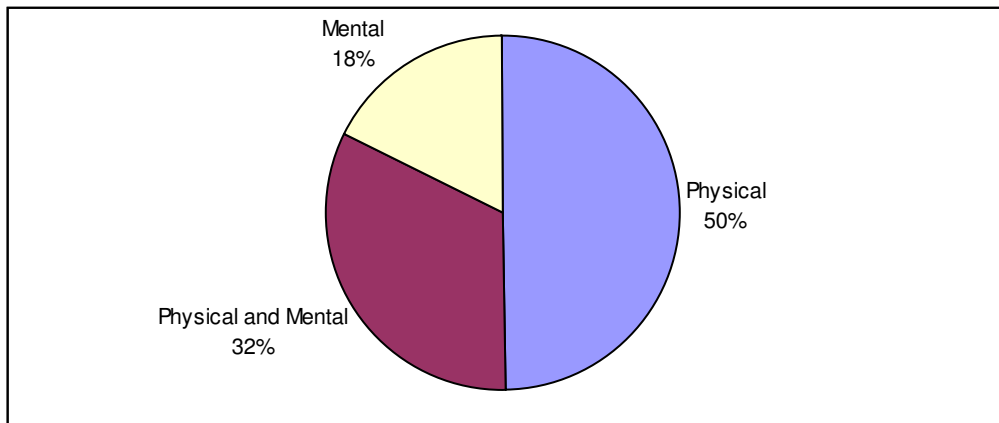
Just over half (52%) of people cared for were the carer's parent, with around one-third being a spouse or partner and 14% another type of relative or non-relative (Figure 3). Two-thirds (66%) lived in the same household as the carer.

Figure 3 Relationship to Person Cared for



Carers were asked to describe the disabilities or illnesses of the person cared for. Half of them (50%) had solely physical disabilities, such as heart disease, arthritis or mobility problems, 18% had solely mental health problems (e.g. dementia, Alzheimer’s disease, confusion or forgetfulness), and almost a third (32%) had both physical disabilities and mental health problems (Figure 4). Therefore over four-fifths (82%) of the people cared for had physical disabilities and half (50%) had mental health problems.

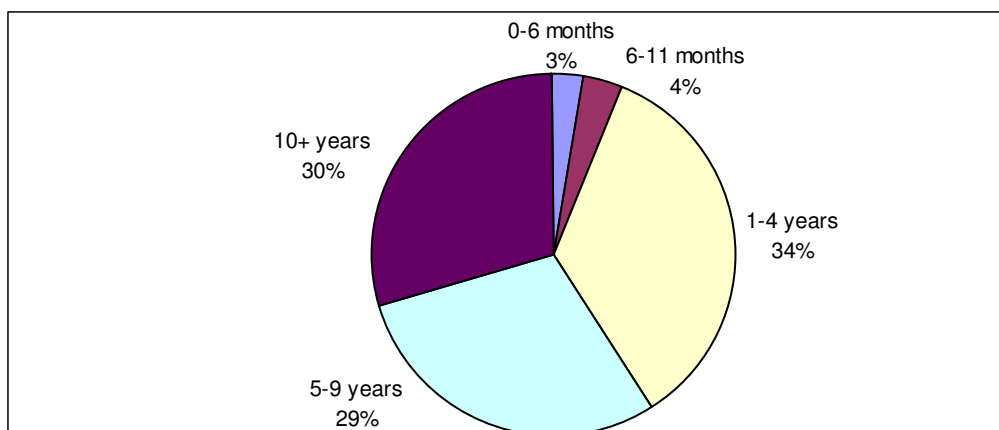
Figure 4 Type of Disability



Caring Responsibilities

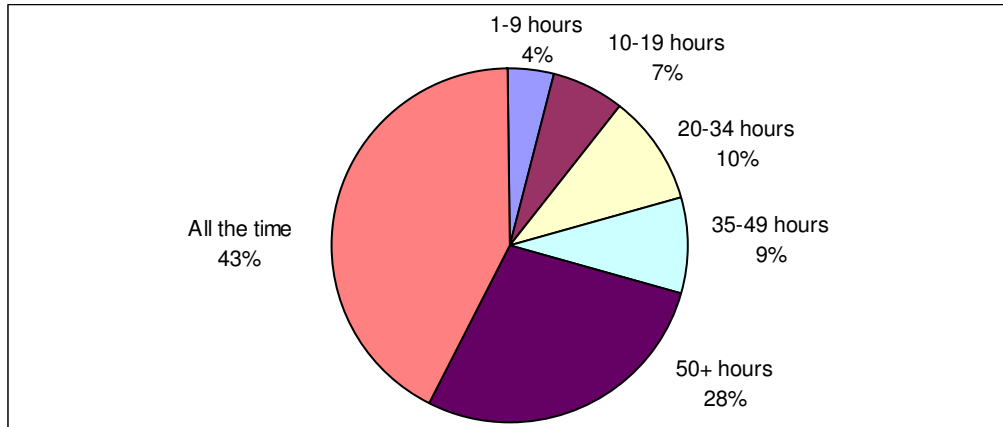
As noted above, 15% of respondents cared for more than one person. As regards the main person cared for, three in 10 (30%) of all carers had been caring for 10 years or more, the same proportion for 5-9 years and over a third (34%) for 1-4 years. Only 7% had been caring for less than one year (Figure 5).

Figure 5 Length of Time Caring



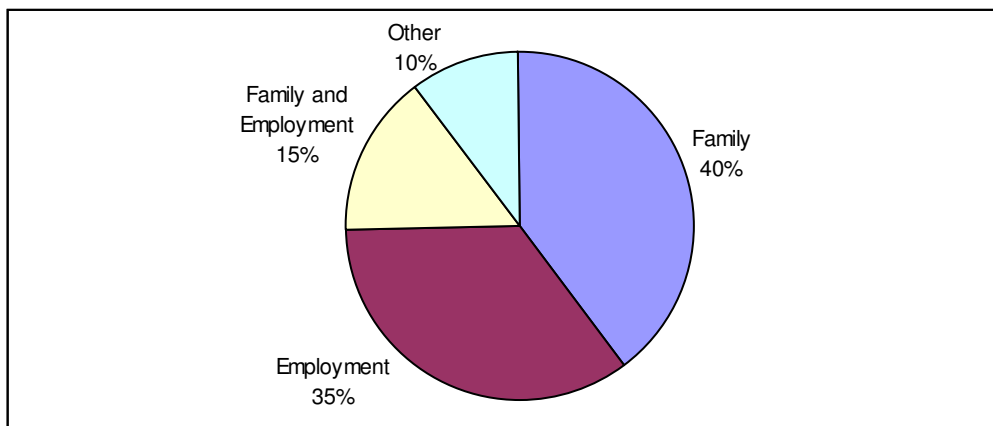
Over two-fifths (43%) of carers said that, in a typical week, they cared for the person all the time (Figure 6). Over a quarter (28%) said that they provided over 50 hours of care, 9% said that they cared for 35-49 hours and 10% said that they cared for 20-34 hours a week. Only 11% spent less than 20 hours in caring.

Figure 6 Hours Spent Caring



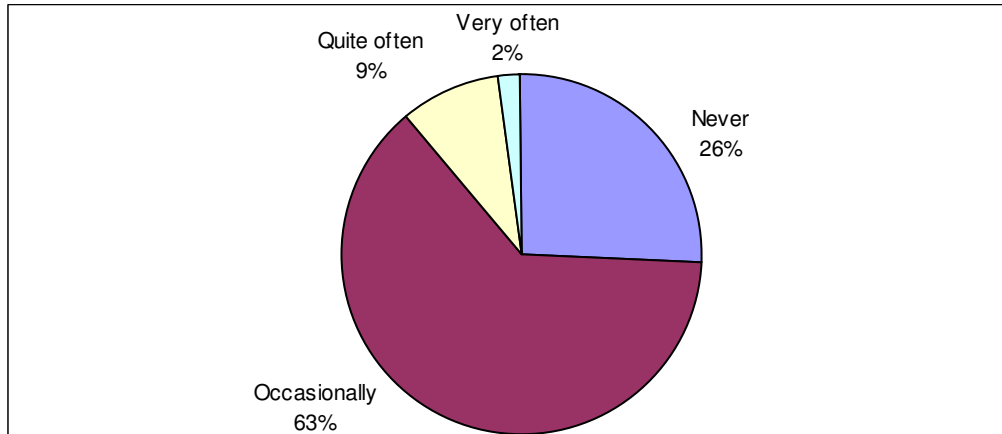
Around half (51%) of the carers stated that they had other responsibilities. Of these, 40% had family responsibilities, mostly involving looking after children, but were not in employment. Thirty-five per cent were in employment but did not have family responsibilities, and a further 15% had both employment and family responsibilities. One-tenth (10%) had other types of responsibility (Figure 7).

Figure 7 Other Responsibilities



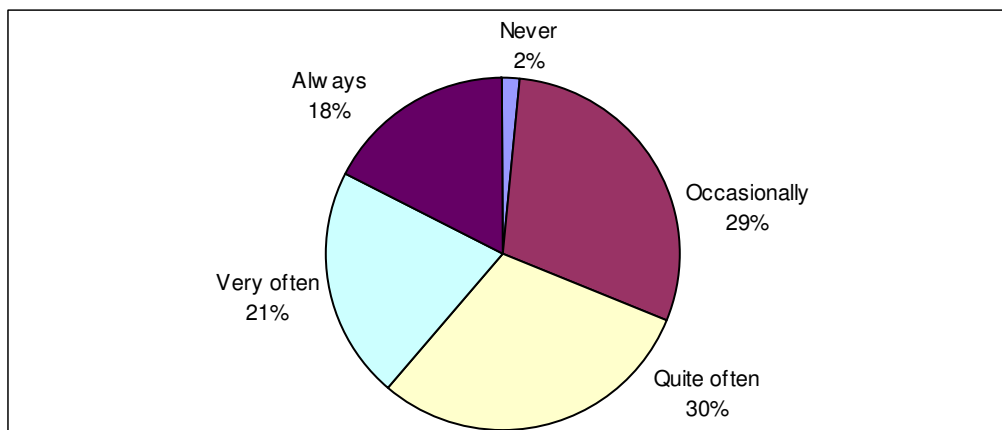
About a quarter (26%) said that they never had breaks from caring, and over three-fifths (63%) said that they had breaks from caring only occasionally (Figure 8). By contrast, only 11% said that they often had breaks from caring (9% quite often and 2% very often).

Figure 8 Breaks from Caring



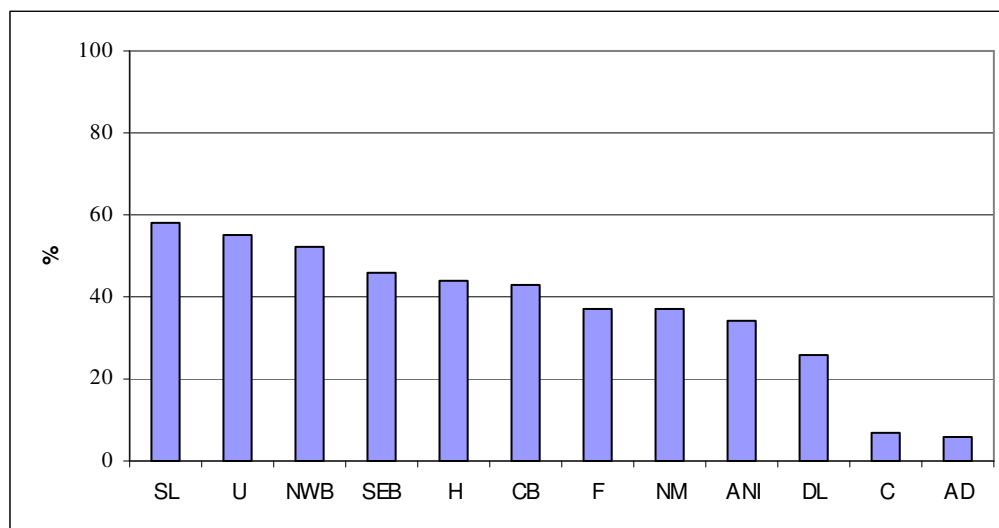
Eighteen per cent said that they always felt under stress because of their caring responsibilities, a further 21% were under stress very often, almost a third (30%) were under stress quite often and 29% were under stress occasionally. Only 2% said that they were never under stress (Figure 9).

Figure 9 Frequency under Stress



There was a wide variation across Trusts as regards the frequency that respondents felt under stress. In Armagh and Dungannon, only one of the 17 respondents (6%) said that they were always or very often under stress, whereas in Sperrin Lakeland 23 of the 40 respondents (58%) were under stress always or very often. The pattern is shown in Figure 10. The numbers of respondents in each of the Trusts are small and therefore analysis by Trust should be interpreted with caution.

Figure 10 Frequency under Stress, by Trust



Those people who said that they were always or very often under stress were more likely to have been caring for five years or more, to be caring all the time, and never have breaks from caring. They were also more likely to have a long term illness, and less likely to be satisfied with the amount of services provided. The differences in these proportions are all statistically significant. Table 2 (Annex 2) shows the comparisons and levels of significance.

Respondents were asked to list, in order of importance, the three things that they felt would be most helpful in supporting them in their caring role. The most common thing mentioned was respite care or breaks for the carer, enabling them to have more time to themselves. Typical comments included:

“getting breaks from caring”;

“opportunities for regular respite periods to prevent burn out”;

“someone to relieve the pressure of constant caring”;

“time to myself”;

“time to spend with my family”; and

“once a week I would like a day’s respite”.

Respondents also commented on specific types of service (home help, personal care, day care), that would most help them in their caring role. They included comments on an increase in the volume of services, including respite care:

- “extra home help”;*
- “2 carers instead of 1...”;*
- “more practical support in the home”;* and
- “an extra day at day centre”.*

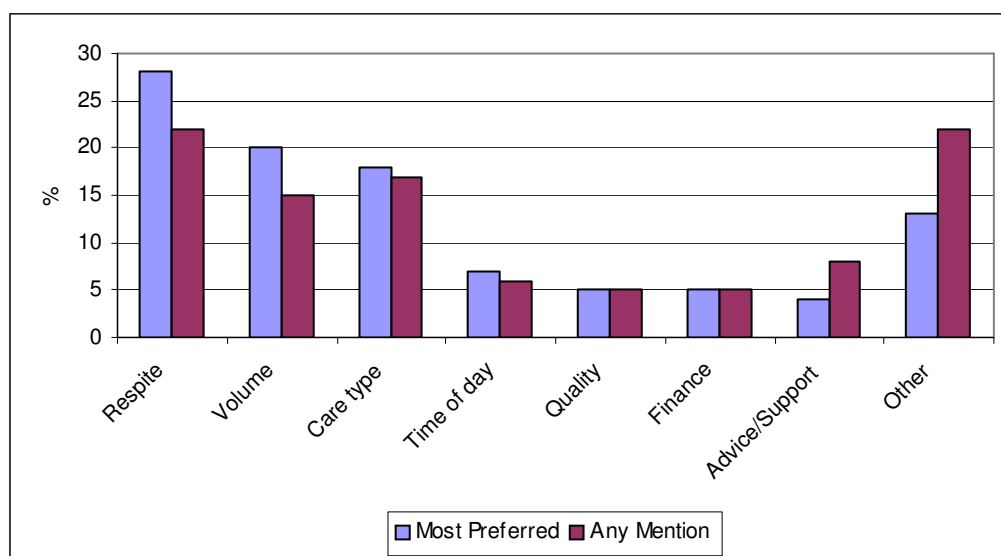
Other things carers felt would support them in their caring role were services provided at particular times, quality of service and advice or support:

- “morning and evening caring assistance”;*
- “overnight help”;*
- “someone who could stay ...from 7pm to 9pm...” ;*
- “more reliable carers”;*
- “easily accessed information on availability of different forms of help”;* and
- “someone to talk to at times who understands the problems”.*

Improvements in quality of equipment, care provided by medical professionals, and financial support were also mentioned.

Figure 11 shows the types of things stated to be most helpful, according to whether they were ranked as most preferred or mentioned as any one of the three preferences.

Figure 11 Most Helpful for Support



Summary

Three-quarters of people cared for were aged 75 or over, and almost two-thirds were female.

Two-thirds of the people cared for lived in the same household as the carer.

Over four-fifths of the people cared for had physical disabilities, and half had mental health problems.

Over two-fifths (43%) of respondents said that, in a typical week, they provided care all the time, and a further 28% provided care for over 50 hours.

About a quarter (26%) said that they never had breaks from caring, and over three-fifths had breaks only occasionally.

18% said that they always felt under stress because of caring responsibilities, 21% were under stress very often and 30% were under stress quite often.

Contact and Services

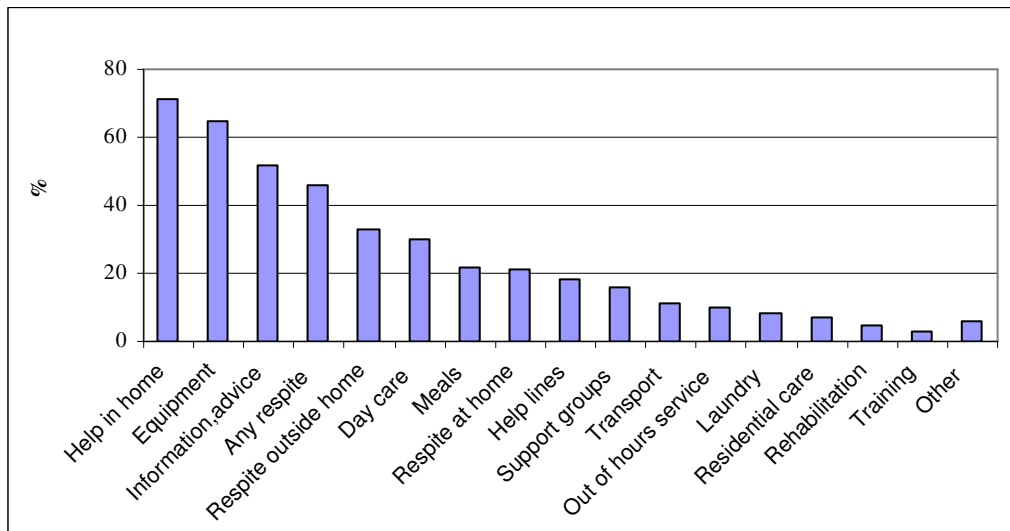
Contact with Social Services

Over nine-tenths (91%) of the carers who responded to the questionnaire said that they were currently in contact with Social Services. Given that the survey was administered to those in contact with Social Services or Advice NI this high figure is not surprising. The remainder did not know that Social Services provided services, did not think that the services would help, or did not want to become involved with Social Services. Of those in contact with Social Services, 98% said that they received a service.

As regards the types of services provided to support these carers in their role:

- 52% were provided with information, advice or counselling;
- 71% with help in the home;
- 21% with respite breaks at home;
- 33% with respite breaks outside the home;
- 46% with respite breaks either at home or outside the home;
- 65% with disablement equipment;
- 22% with a meals service;
- 8% with a laundry service;
- 30% with day care;
- 11% with help with transport;
- 16% with carer support groups or other support;
- 5% with rehabilitation;
- 10% with an out of hours service;
- 18% with help lines;
- 7% with residential care;
- 3% with training; and
- 6% with other services (e.g. nursing, shopping) (Figure 12).

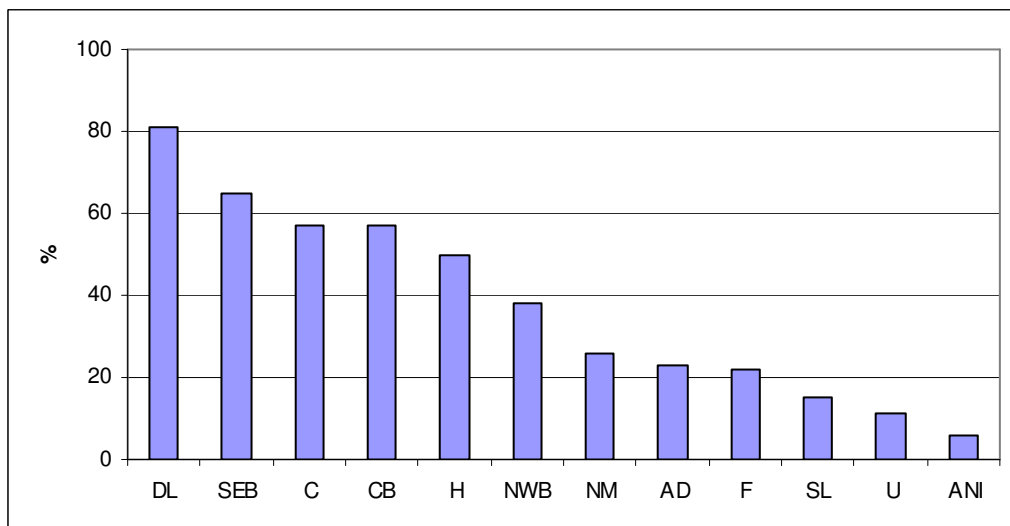
Figure 12 Services Provided



Carers' Assessments

Only 43% of the respondents in contact with Social Services knew that they could have a separate assessment of their needs as a carer, and only 39% had been offered a carer's assessment. Three-fifths of all carers in contact with Social Services had not therefore been offered an assessment, although they were entitled to one. Eighty-one per cent of carers in Down Lisburn Trust had been offered an assessment. By contrast, 15% of those in Sperrin Lakeland Trust, 11% of those in the Ulster Community and Hospitals Trust and only 6% of those contacted through Advice NI had been offered an assessment (Figure 13).

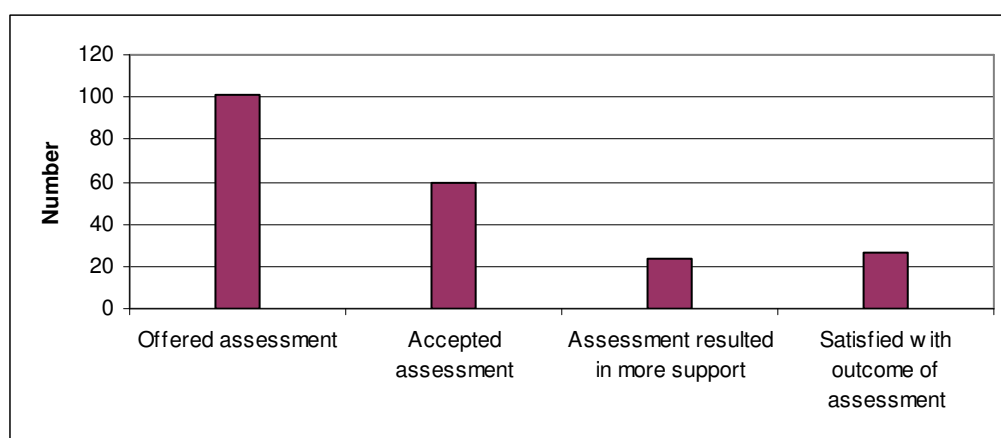
Figure 13 Offers of Carers' Assessments, by Trust



Of those who had been offered an assessment, over three-fifths (63%) had accepted the offer, and one-third (33%) declined the offer. (Four per cent said that they did not know whether they had accepted the offer.) Over half (51%) of those who accepted the offer said that the assessment had resulted in more support, but almost one-third (32%) said that the assessment had not resulted in more support. Seventeen per cent did not know whether the assessment had resulted in more support or not.

Almost three-fifths (59%) were satisfied with the outcome of the assessment, although 23% said that they were not satisfied. Eighteen per cent said that they did not know whether they were satisfied or not. Of those satisfied with the outcome of the assessment, 89% said that the assessment had resulted in more support. Figure 14 summarises the information on carers' assessments.

Figure 14 Carers' Assessments



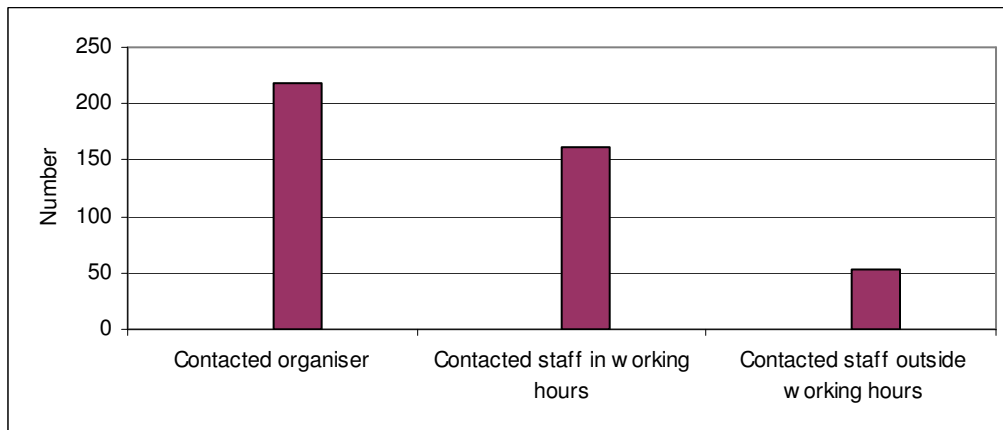
Making Contact with Services

Almost all (93%) of the carers had a single name contact for the person who organises their services, and 90% had to contact him/her. Of these people, 88% were able to make contact within 1-2 days, 9% made contact within 3-7 days and 3% had to wait more than 7 days.

The vast majority (87%) knew how to contact the staff who provide direct care services, such as home help, within working hours. Just over three-quarters (76%) had made contact. Over nine in 10 (92%) were able to make contact within 1-2 days, 6% within 3-7 days and for 2% this involved waiting for more than 7 days.

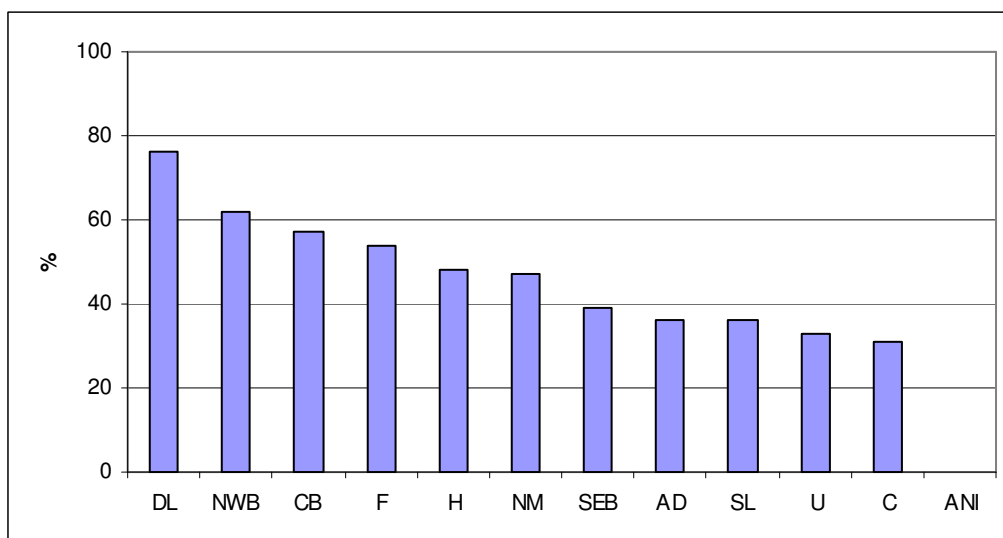
By contrast, only just over half (52%) knew how to contact the staff who provide direct care services outside working hours. Less than half (44%) of them had made contact outside working hours. Summary information on making contact with services is shown in Figure 15.

Figure 15 Contact with Social Services



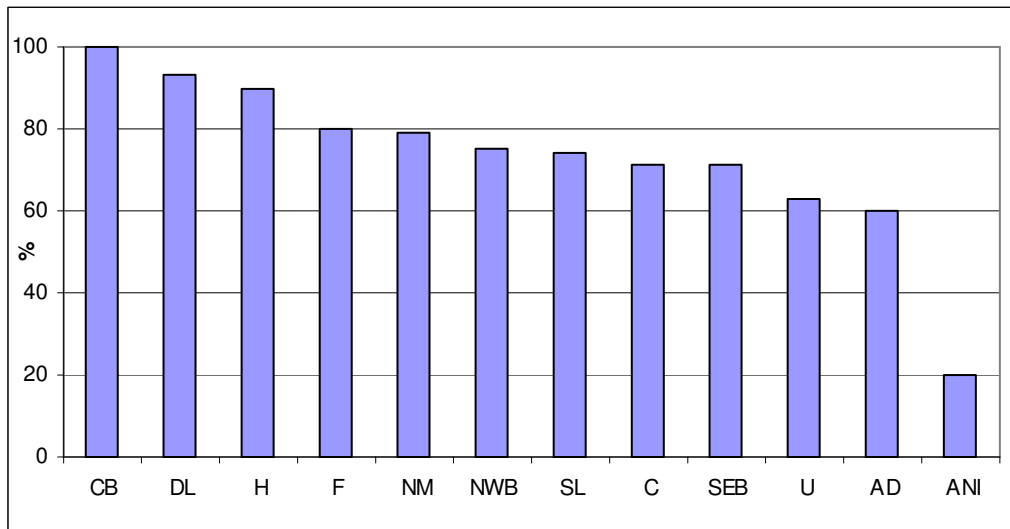
Less than one-third (30%) of the respondents are always asked what they think about the services they receive, with 46% usually or sometimes asked and 25% never asked. A slightly higher proportion (34%) are always involved in deciding services for themselves, 36% usually or sometimes involved, and almost a third (30%) never involved. Less than half (46%) are always involved in deciding on services for the person they care for, 41% usually or sometimes involved, and 13% never involved. The proportion of carers who said that they are always involved in deciding services for the person they cared for varied from 76% in Down Lisburn to none of those contacted through Advice NI. The pattern is shown in Figure 16. The small numbers of respondents involved in analysis by Trust must, however, be borne in mind.

Figure 16 Always Involved in Deciding Services for Cared for Person, by Trust



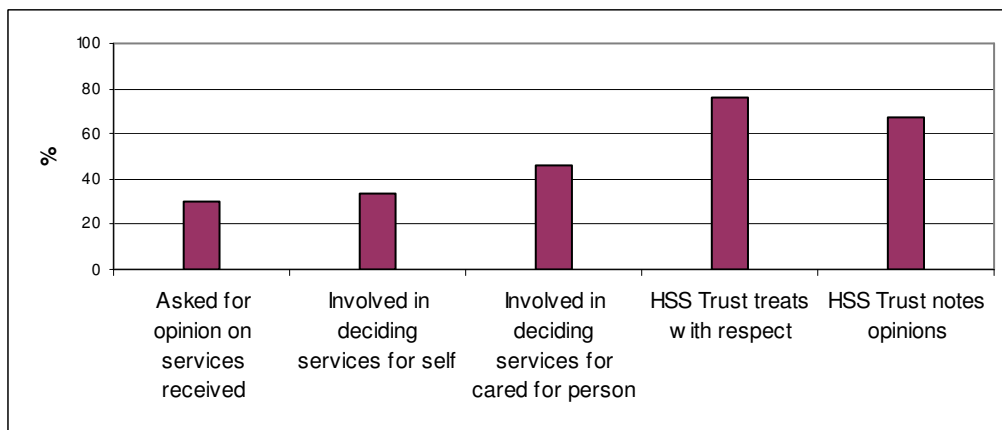
Just over three-quarters (76%) said that HSS Trust staff always treat them with respect, and 23% said that they are usually or sometimes treated with respect. Only 1% said that they are never treated with respect. Only 20% of respondents from Advice NI felt that HSS staff always treat them with respect, whereas all of the respondents from Craigavon & Banbridge Trust said that they are always treated with respect (Figure 17).

Figure 17 Always Treated with Respect, by Trust



As regards whether HSS staff take note of the carers' opinions, two-thirds (67%) said that staff always take note of their opinions, 30% that staff usually or sometimes take note of their opinions, and 3% said that their opinions are never noted. Information on carers' involvement with Social Services is summarised in Figure 18.

Figure 18 Involvement with Social Services (Percentage Stating 'Always')



Summary

Over nine-tenths of carers (91%) were currently in contact with Social Services. Of these, 98% received a service from them.

71% of those in contact with Social Services were provided with help in the home, 65% were provided with disablement equipment, 52% with information, advice or counselling, and 46% with respite breaks either at home or outside the home.

Only 43% of respondents knew that they could have a separate assessment of their needs as a carer, and only 39% had been offered such an assessment.

Of those who accepted the offer of an assessment, over half (51%) said that it resulted in more support, almost one-third (32%) said that it did not and 17% did not know whether it resulted in more support or not. Almost three-fifths were satisfied with the outcome of the assessment.

93% of carers had a single name contact for the organiser of their services, and 87% knew how to contact staff who provided direct care services within working hours, but only 52% knew how to contact staff outside working hours.

Less than one-third (30%) of respondents said that they are always asked about the services they receive, 34% are always involved in deciding services for themselves and less than half (46%) are always involved in deciding the services for the person they provide care for.

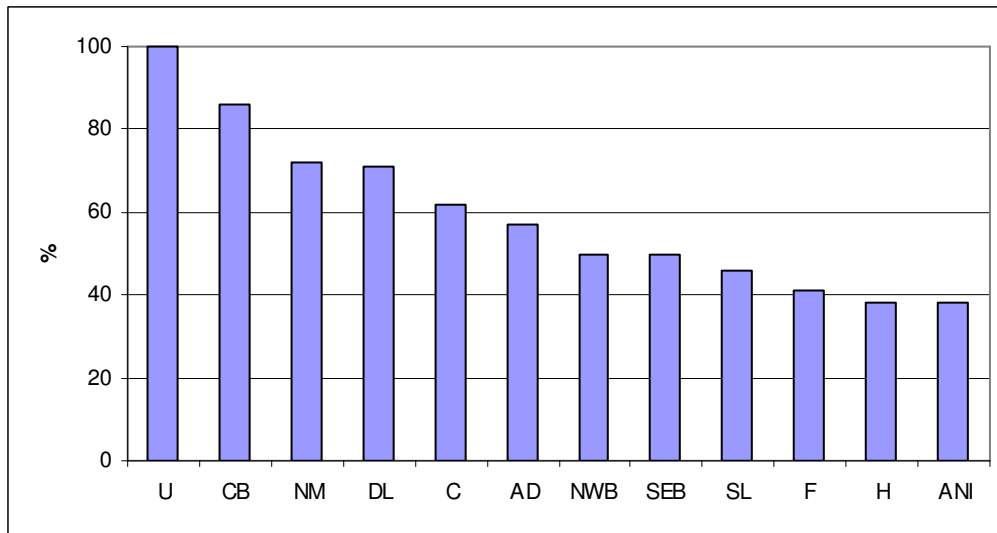
Just over three-quarters (76%) said that Trust staff treat them with respect, and 67% said that staff always take note of their opinions.

Information and Service Delivery

Information for Carers

Almost half (45%) of carers in contact with Social Services were not given written care plans, with the remaining 55% receiving these written care plans. The percentage receiving written care plans varied from 100% in the Ulster Trust to 38% in Homefirst Trust and among those contacted through Advice NI (Figure 19).

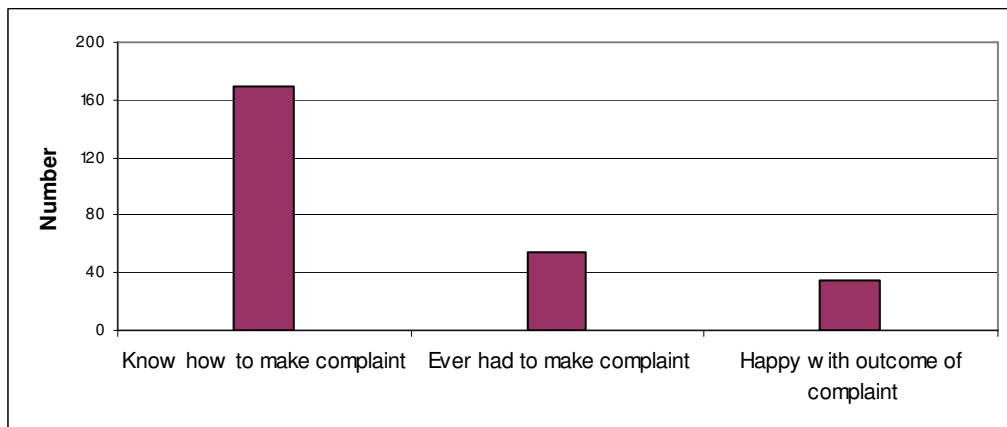
Figure 19 Given Written Care Plans, by Trust



Of those who received the plans, almost all (96%) said that the information was clear. Almost two-thirds (64%) who responded said that they felt they were made aware of the full range of services available (22 respondents did not answer the question). Three-quarters (75%) felt that they were kept informed of what was happening.

Almost two-thirds (65%) said that they knew how to make a complaint, and 35% said that they did not. Just over one-fifth (21%) of all respondents who were in contact with Social Services had ever had to make a complaint. Two-thirds (67%) of those who made a complaint were happy with the outcome (Figure 20).

Figure 20 Complaints



Over three-fifths (61%) did not know that they could see their own records if they wished, although 39% said that they did know. Sixteen per cent said that they knew they could have access to an interpreter/translator, 14% did not, and 70% said that this did not apply to them. Whilst almost one-third (31%) knew that they could have a friend, advisor or advocate to help them, 42% did not, and 27% said that this did not apply to them.

When asked had their Trust or any other organisation asked for their opinion about services for carers in their community or area, 78% of respondents said that they had not been asked. Of those who were asked for their opinion, 28% had been invited to participate in meetings to discuss these services and of these about a quarter (25%) were provided with help from Social Services to attend these meetings, 21% were not given help and 54% said that they did not need help.

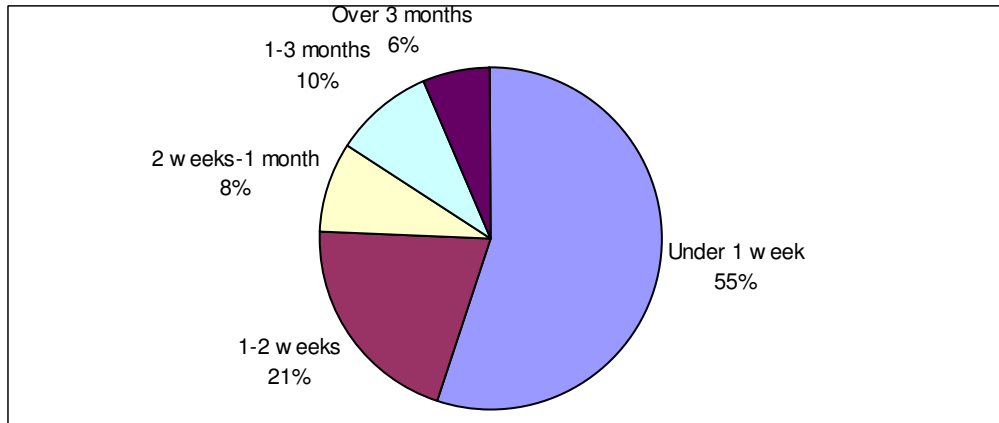
Paying for Services

Just over one-fifth of the carers (21%) said that they were charged for the social services they receive, and almost three-quarters (72%) said that they were not. Eight per cent of those who answered the question said that this question was not applicable to them. Eighteen per cent said that they knew how HSS Trusts worked out the charges for services, 56% did not, and a further 25% of respondents said that the question did not apply to them. Forty of the carers did not answer this question. A higher proportion (25%) said that they thought the charges were fair than those who did not (14%). Over three-fifths (61%) said that the question on fair charges was not applicable to them. Seventy-seven carers did not answer the question.

Quality of Services

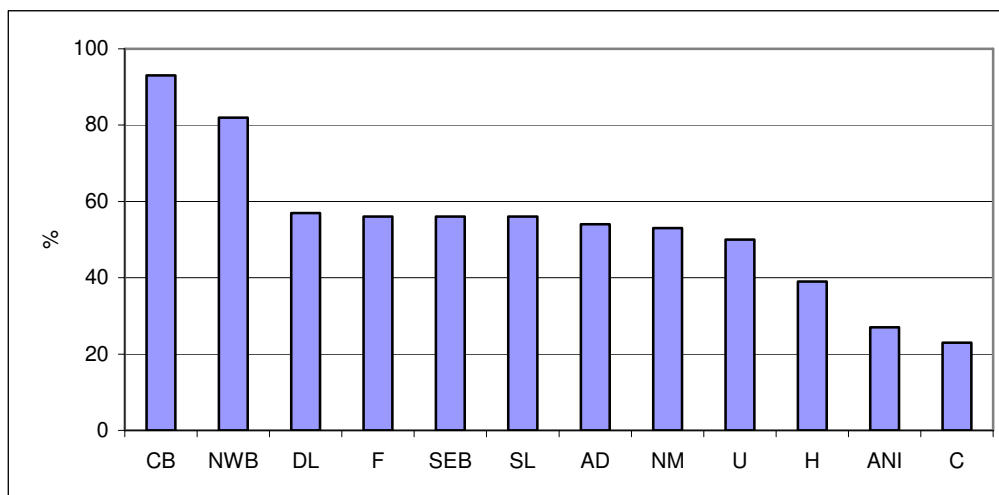
After a decision was made to provide services, 55% of carers got help within a week, and a further 21% got help within 1-2 weeks. Less than a quarter had to wait more than 2 weeks, with 8% waiting between 2 weeks and a month and 10% waiting 1-3 months. Three per cent had to wait for 3-6 months, the same proportion for 6 months to 1 year, and 1% waited more than a year (Figure 21). Twenty-six carers did not reply to this question.

Figure 21 How Soon Help Received



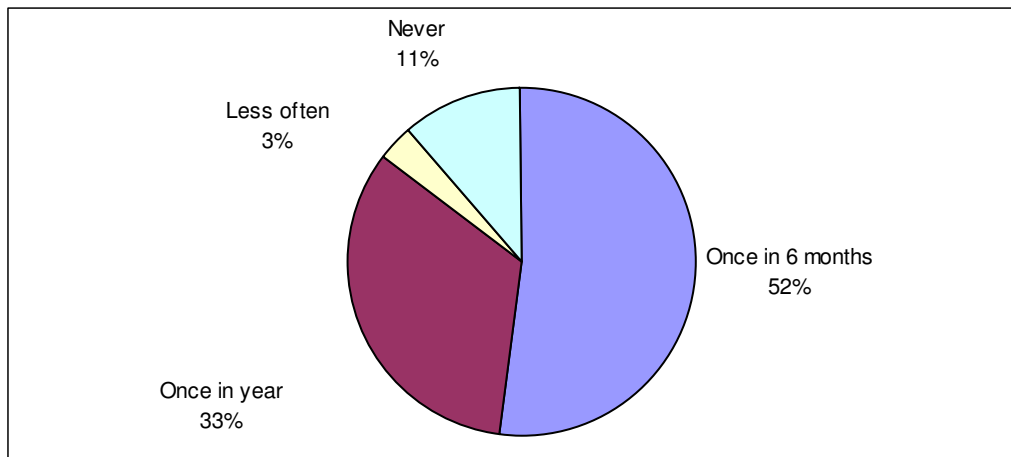
Regarding Trusts, 93% of respondents in Craigavon & Banbridge and 82% of respondents in North & West Belfast received help within a week. By contrast, a much smaller proportion (23%) of those in Causeway received help within a week. The pattern of Trust responses is shown in Figure 22.

Figure 22 Receiving Help within Week, by Trust



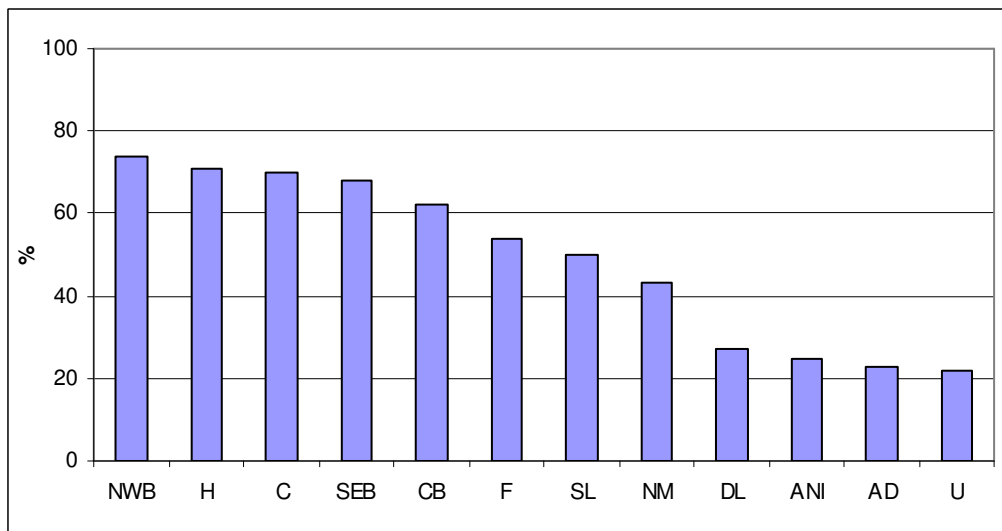
Over three-fifths (61%) were aware that they could request a review if they felt that they needed one, with 39% not being aware of this. Over half (52%) of carers said that their services were reviewed at least once every six months, with a further third (33%) having their services reviewed at least once every year (Figure 23). One per cent said that services were reviewed at least once every two years, and 3% said that they were reviewed less often than this. However, over one-tenth (11%) said that services were never reviewed.

Figure 23 How Often Services Reviewed



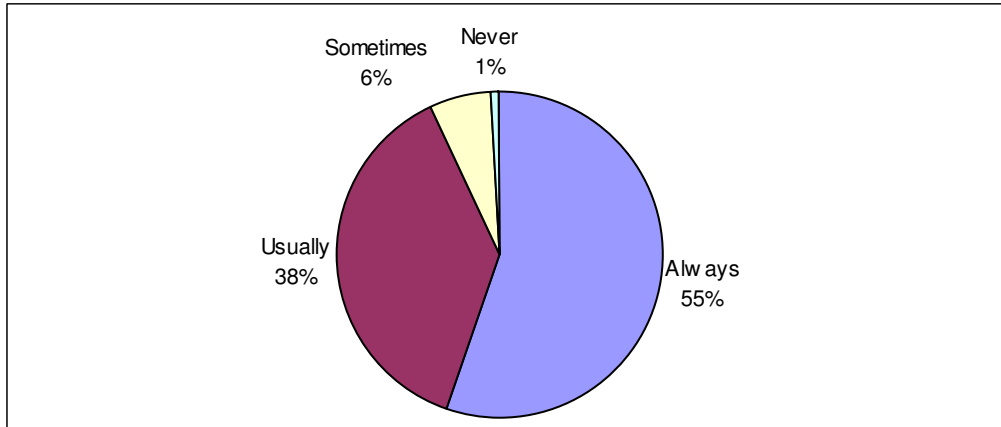
Across Trusts, the proportion who said that services were reviewed at least every six months varied from 74% in North & West Belfast to 22% in Ulster (Figure 24).

Figure 24 Services Reviewed Every Six Months, by Trust



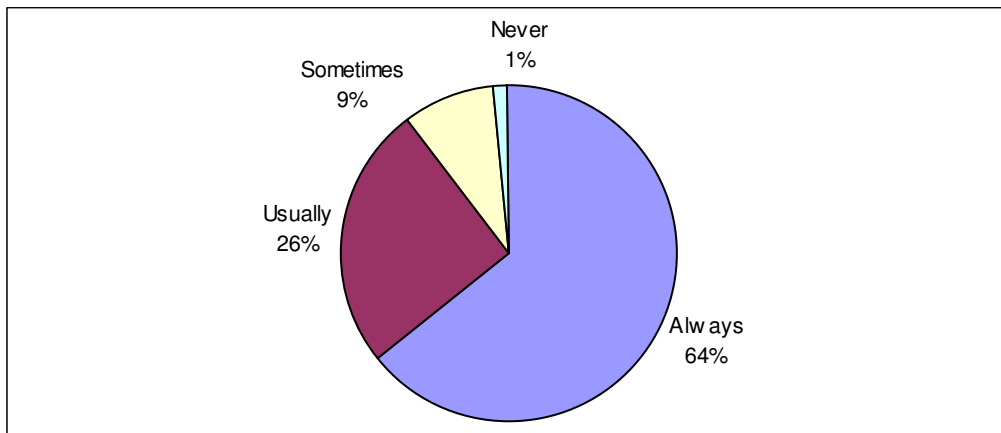
Over half (55%) said that any changes to services agreed are always carried out, with 38% saying that they are usually carried out and a further 6% that they are sometimes carried out. Only 1% said that changes are never carried out (Figure 25).

Figure 25 Changes Carried out



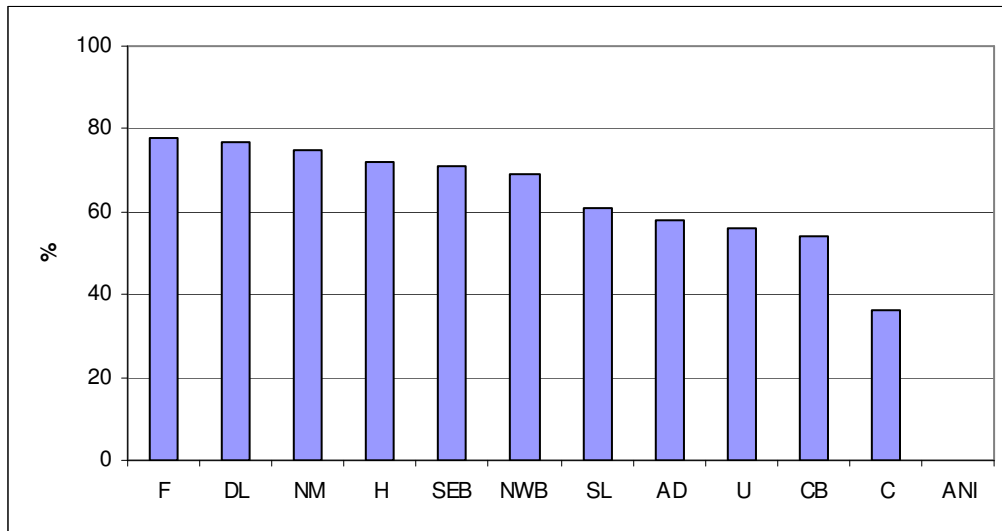
Almost two-thirds (64%) said that the services have always helped them, 26% that they have usually helped and 9% that they sometimes helped. Only 1% said that the services never helped (Figure 26). However, 43 carers did not answer the question.

Figure 26 Services Helped



Whilst some 78% of respondents in Foyle Trust and 77% in Down Lisburn Trust said that the services always helped, just 36% of respondents in Causeway and none of those who were in contact with Advice NI said that the services always helped (Figure 27). As the number of respondents within each Trust and those contacted through Advice NI is small these results need to be treated with some caution.

Figure 27 Services Always Helped, by Trust



When asked how satisfied they were with the amount of services they received, almost three-quarters said they were satisfied (31% 'very satisfied' and 42% 'quite satisfied'). Thirteen per cent were 'neither satisfied nor dissatisfied'. However, 14% were dissatisfied with the amount of services (11% 'quite dissatisfied' and 3% 'very dissatisfied') (Figure 28).

Figure 28 Satisfaction with Amount of Services

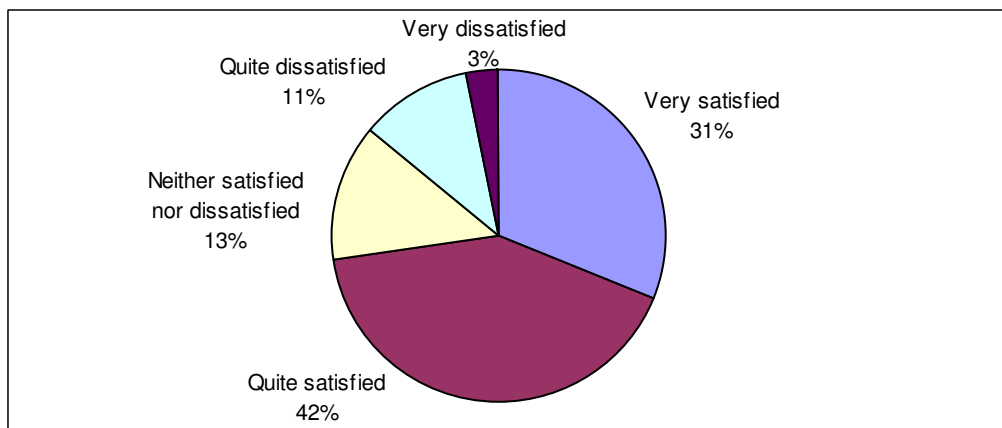
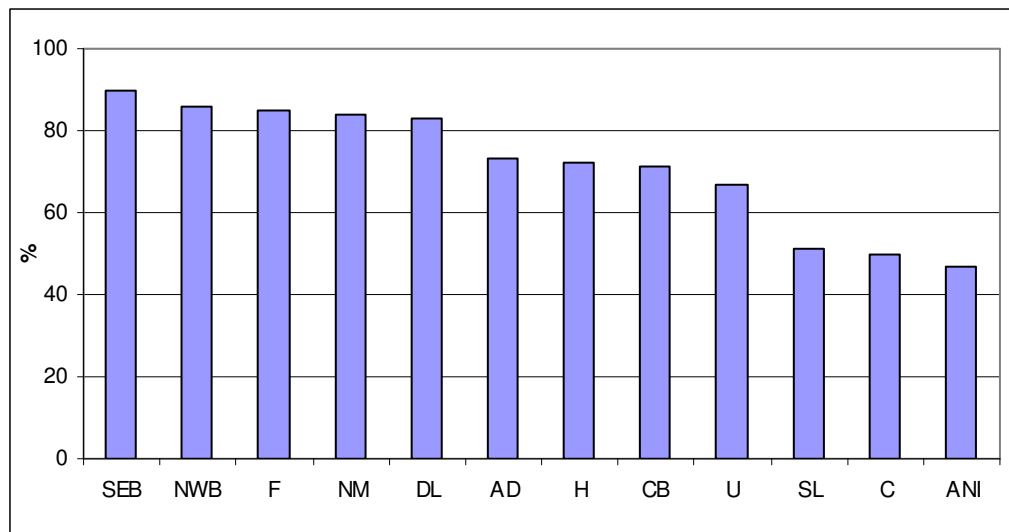


Figure 29 shows the pattern across Trusts for those who were 'very satisfied' or 'quite satisfied' with the amount of services provided.

Figure 29 Satisfaction with Amount of Services, by Trust



The responses from those individuals who were satisfied with the service they received ('very satisfied' or 'quite satisfied') were compared with those who indicated that they were not satisfied ('very dissatisfied', 'quite dissatisfied') or were 'neither satisfied nor dissatisfied' with the service they received. Those not satisfied with the amount of services received were more likely to be under stress 'always' or 'very often', and were less likely:

- to have had assessments that resulted in more support;
- to have been satisfied with the outcome of their assessment;
- to be asked about the services they receive;
- to have been involved in deciding on services for themselves or the person cared for;
- to be treated with respect or for their opinions to be noted;
- to be aware of the full range of services available to them or to be kept informed;
- to be happy with the outcome of any complaint made; and
- to think that charges for services were fair.

A smaller proportion of those who were not satisfied than those who were satisfied:

- received help within a week of request;
- were aware that they could request a review;
- had their services reviewed at least every six months;
- had changes carried out; and
- said that services always helped.

Those who were not satisfied with the amount of services were also likely not to be satisfied with the quality of the services. These differences were all found to be statistically significant (Table 3, Annex 2).

Almost nine-tenths of respondents were satisfied with the quality of services provided. This compares with almost three-quarters satisfied with the amount of services. Almost half (49%) were 'very satisfied' and 39% 'quite satisfied'. Six per cent were 'neither satisfied nor dissatisfied', 5% were 'quite dissatisfied' and only 1% were 'very dissatisfied' (Figure 30).

Figure 30 Satisfaction with Quality of Services

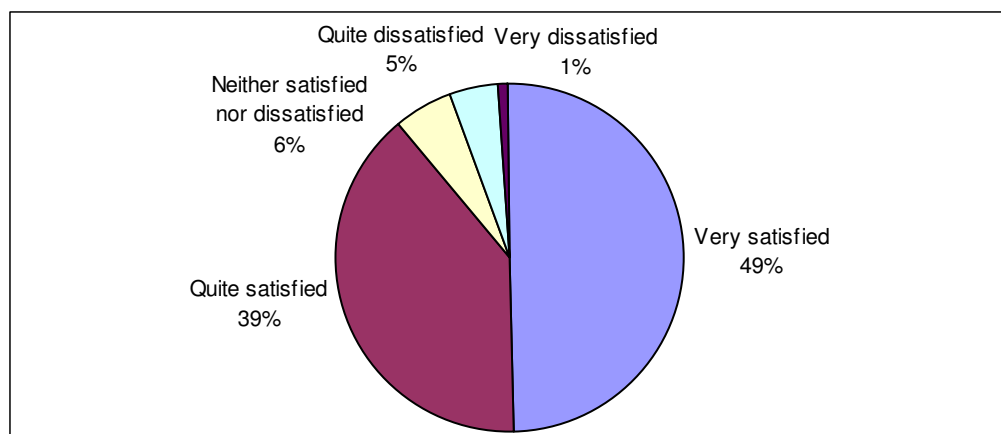
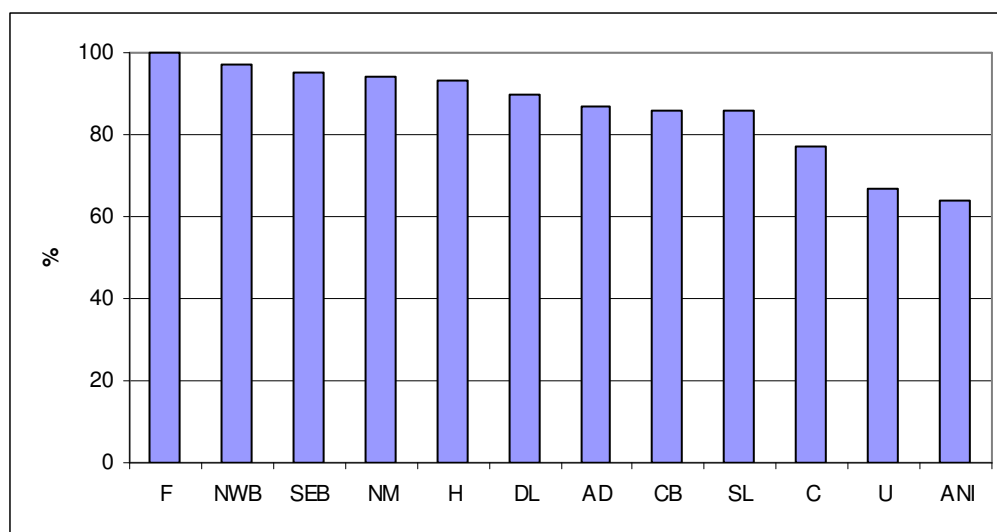


Figure 31 shows the pattern across Trusts for those who were ‘very satisfied’ or ‘quite satisfied’ with the quality of services provided.

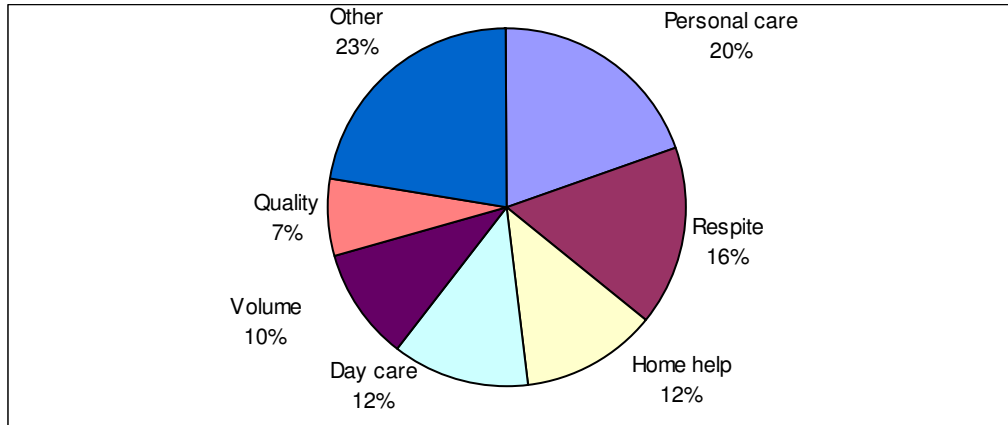
Figure 31 Satisfaction with Quality of Services, by Trust



Although the number of people who were not satisfied with the quality of services was quite small, when compared with those who were satisfied they were more likely never to have had breaks from caring, less likely to be asked about the services they receive, to decide on services for themselves or the person they cared for and to be treated with respect or for their opinions to be noted. They were less likely to be aware of the full range of services or to be kept informed and more likely to have made a complaint and not to be happy with the outcome of the complaint. These and other differences were found to be statistically significant (Table 4, Annex 2). Again as the numbers involved are small these findings should be interpreted with some caution.

Respondents were asked to describe which of the services provided they found most helpful. The most frequently mentioned was personal care (20%), followed by respite care (16%), home help and day care (each 12%), the volume of services (10%) and the quality of services (7%) (Figure 32).

Figure 32 Most Helpful Service



Regarding those found least helpful, only 74 respondents mentioned a service, and a total of 37 people responded with positive comments. Over a fifth of those services mentioned as least helpful related to care received from medical professionals.

Summary

Almost half (45%) of carers were not given written care plans. Of those who received the plans, almost all (96%) said that the information was clear.

Just over one-fifth of respondents had ever had to make a complaint, with two-thirds of them happy with the outcome of the complaint.

When asked had their Trust or any other organisation asked for their opinion about services for carers in their community or area, 78% of respondents said that they had not been asked.

After a decision was made to provide services, 55% of carers received help within a week; this ranged from 93% in one HSS Trust to 23% in another.

Whilst over half (52%) of respondents said that their services were reviewed at least once every six months, over one-tenth said that their services were never reviewed.

Almost two-thirds (64%) said that the services have always helped them.

Whilst almost three-quarters of respondents were satisfied with the amount of services they received (31% 'very satisfied' and 42% 'quite satisfied'), some 14% were dissatisfied.

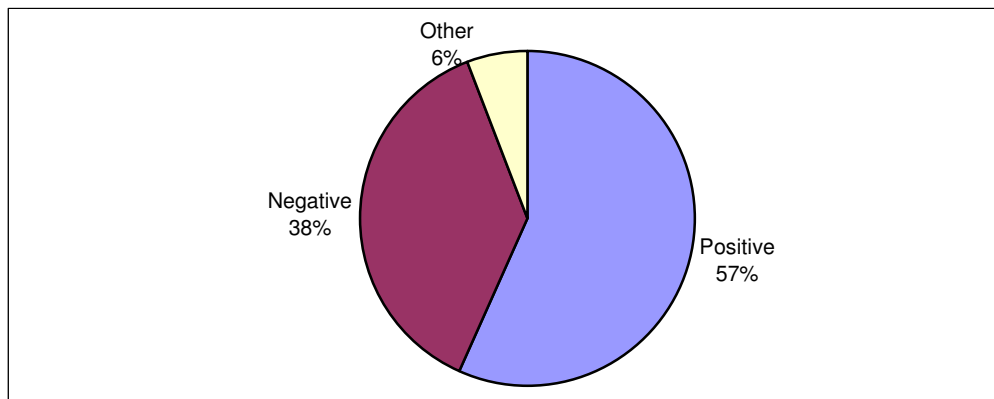
Almost nine-tenths were satisfied with the quality of services provided (49% 'very satisfied' and 39% 'quite satisfied'). Only 6% were dissatisfied with the quality of services.

The service provided which was stated to be most helpful was personal care (mentioned by 20% of respondents), followed by respite care (mentioned by 16%).

Further Comments

Respondents were invited to give any further comments about the services they received. Less than half (136 respondents) chose to do so (Figure 33). There were more 'positive' (57%) than 'negative' (38%) comments. A few comments (6%) were neither 'positive' nor 'negative', mainly giving suggestions for improvement of the service.

Figure 33 Further Comments



Many of the 'negative' comments centred on the fact that carers did not receive information about the range of services available to them, as well as a general lack of communication:

"No one ever asks how I am doing...";

"Social services should provide information to people's homes with useful telephone numbers...";

"Great lack of information on services";

"I cared for my mother for 6 years before I was made aware of care packages"; and

"As a carer I feel isolated. No communication and lack of information".

Other 'negative' comments related to the need for increase or improvement of the services:

"More care needed";

"Would like more day centres and respite";

"Would like better time keeping...";

"Not enough supervision of home help and carers"; and

"I would really like a better sitting service as I am tied to the house".

Despite the problems identified, many carers recognised the quality and value of the services provided:

“All the services I receive are very good”;

“Services are excellent”;

“Social worker is always pleasant and more than helpful”;

“Home help for personal care in the morning is very helpful as is the sitting service and respite”; and

“Respite is great because it gives me a break and the staff are good and helpful”,

and were appreciative of the help given:

“Very grateful for all the help I receive”;

“Very content with current care package”;

“Happy with everything and has made life a little easier for me and my family”; and

“Have been very grateful and appreciate the help I have been given”.

Most noteworthy was the importance to carers of the services provided:

“Can’t cope without the service received”;

“The services provided for me helped me to cope with what was becoming an intolerable burden”;

“All services provided are precious”; and

“The services I use are absolutely essential or I could not cope”.

Equality of Service Provision

Section 75 of the 1998 Northern Ireland Act placed a statutory obligation on public authorities, in carrying out their various functions, to have due regard to the need to promote equality of opportunity between persons of different religious belief, political opinion, racial group, age, marital status, or sexual orientation, between men and women, between persons with a disability and persons without, and between persons with dependants and persons without.

In the questionnaire, carers were asked to state their gender, age group, marital status, religion, ethnicity and whether they had a disability. Questions on political opinion and sexual orientation were not asked. All respondents, being carers, were considered to have dependants.

Analysis was confined to questions reflecting the service provided to the carer in order to assess whether there were any inequalities between particular groups. The questions used referred to whether the carer:

- was offered a carer's assessment;
- was asked about services provided;
- was allowed to decide about services for themselves;
- was allowed to decide about services for the cared for person;
- was treated with respect;
- had their opinions noted;
- was given written care plans;
- was aware of the full range of services provided;
- was kept informed of what was happening;
- had to make a complaint;
- was asked for their opinion on services;
- was aware that they could request a review;
- had their services reviewed at least every six months;
- had agreed changes to services carried out;
- was satisfied with the amount of services provided; and
- was satisfied with the quality of services provided.

Responses were compared according to:

- age (under 55 compared with 55 or over);
- gender (male compared with female);
- marital status (currently married compared with not currently married);
- disability (with a long-term illness or disability compared with without a long-term illness or disability); and
- religion (Catholic compared with Protestant).

Ethnicity was not included in the analysis as virtually all respondents (99%) recorded their ethnic group as white.

The differences in the responses were tested for statistical significance. Only those difference found to be statistically significant at or greater than the 95% level of significance are reported. Four differences were identified:

- carers aged under 55 were less likely to be treated with respect;
- male carers were less likely to be treated with respect;
- carers with a long-term illness or disability were more likely to be offered an assessment; and
- male carers were more likely to have services reviewed at least every six months.

Notes

Percentages do not necessarily add to 100% due to rounding of figures.

Except where indicated, the base number used for the calculation of percentages is the total number of persons who answered the relevant question, that is, excluding those to whom the question applied but who did not give an answer to the question.

The following Trust abbreviations have been used in the Figures:

AD – Armagh & Dungannon

C - Causeway

CB – Craigavon & Banbridge

DL – Down Lisburn

F - Foyle

H - Homefirst

NM – Newry & Mourne

NWB – North & West Belfast

SEB – South & East Belfast

SL – Sperrin Lakeland

U - Ulster

ANI – Advice NI

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Annex 1: Survey Questions

6. Please give a brief description of their disabilities/illnesses

7. How long have you cared for this person?

- 0-6 months
- 6-11 months
- 1-4 years
- 5-9 years
- 10 years or more

	1
	2
	3
	4
	5

8. In a typical week, how many hours do you spend caring for this person?

(Please include all the time you spend caring for this person, including any informal visits to check on them, sitting with them, keeping them company, helping with bills, housework, cooking and personal care, and so on)

- 1-9 hours
- 10-19 hours
- 20-34 hours
- 35-49 hours
- 50 or more hours, but not all the time
- All the time

	1
	2
	3
	4
	5
	6

9. Do you have any other responsibilities, such as looking after children or work commitments?

- Yes
- No

	1
	2

If yes, please specify below

10. How often do you have breaks from caring?

- Never
- Occasionally
- Quite often
- Very often

	1
	2
	3
	4

11. How often do you feel under stress because of your caring responsibilities?

- Never
- Occasionally
- Quite often
- Very often
- Always

	1
	2
	3
	4
	5

12. Please list, in order of importance, the three things which you feel are, or

would be, most helpful in supporting you in your caring role.

1. _____

2. _____

3. _____

13.

Are you currently in contact with Social Services in respect of either yourself or the person you care for?	Yes	<input type="checkbox"/>	1
	No	<input type="checkbox"/>	2

If yes, please proceed to Q15 overleaf

If you are not in contact with Social Services, please tell us why

14.

Didn't know they provided services for carers and/or the people they care for	<input type="checkbox"/>	1
Didn't think they provided services which might help us particularly and to which we would be entitled	<input type="checkbox"/>	2
Didn't wish to become involved with Social Services	<input type="checkbox"/>	3
The person I'm caring for did not want involvement of Social Services	<input type="checkbox"/>	4
Other (please specify below)	<input type="checkbox"/>	5
_____ _____		

If you are not currently in contact with Social Services either for yourself or the person you care for, please go to the questions on page 11.

If you are in contact with Social Services, please continue on the next page.

Q15 For those in contact with social services

What services do social services provide specifically to support you in your caring role?

(Please tick all that apply. Services provided to the person you care for should be included if you feel that these services are helpful to you and enable you to continue caring.)

Information, advice or counselling

Help in the home, for example, help with personal care or housework

Respite breaks at home

Respite breaks outside the home

Help with disablement equipment and home adaptations

Meals

Laundry

Day care

Help with transport

Carer support groups or other support

Rehabilitation

Out of hours service

Help lines

Residential care

Training

Other services (please specify below)

	1
	2
	3
	4
	5
	6
	7
	8
	9
	10
	11
	12
	13
	14
	15
	16

Carer assessments

16. Did you know that you can have a separate assessment of your needs as a carer? Yes 1
No 2

17. Have you been offered a carer's assessment? Yes 1
No 2

If no, please go to Q21

If yes,

18. Did you accept this offer of a carer's assessment? Yes 1
No 2
Don't know 3

If no or don't know, please go to Q21

If yes,

19. Has the carer's assessment resulted in more support for you? Yes 1
No 2
Don't know 3

20. Are you satisfied with the outcome of your assessment? Yes 1
No 2
Don't know 3

Making contact with services

21. Do you have a single name contact for the person who organises your services? Yes 1
No 2

22. Have you ever had to contact him/her? Yes 1
No 2

23. If yes, last time you did this, how long did it take to contact him/her?
1-2 days 1
3-7 days 2
More than 7 days 3

24. Do you know how to contact the staff who provide direct care services, (for example home help), within working hours? Yes 1
No 2
25. Have you ever had to contact him/her? Yes 1
No 2
26. If yes, last time you did this, how long did it take to contact him/her?
1-2 days 1
3-7 days 2
More than 7 days 3
27. Do you know how to contact the staff who provide direct care services (for example home help), outside working hours (before 9 a.m. or after 5 p.m.)? Yes 1
No 2
28. Have you ever had to contact him/her outside working hours? Yes 1
No 2
29. If yes, last time you did this, did you manage to contact Him/her outside working hours? Yes 1
No 2

Your involvement

	Always 1	Usually 2	Sometimes 3	Never 4
30. Are you asked what you think about the services you receive?				
31. Are you involved in deciding on services for yourself?				
32. Are you involved in deciding on services for the person you care for?				
33. Do HSS Trust staff treat you with respect?				
34. Do HSS Trust staff take note of your opinions about the person you care for?				

Informing you

35. Are you given written care plans outlining the services you and the person you care for receive? Yes 1
No 2

36. If yes, is this information clear? Yes 1
No 2

37. Do you feel you are made aware of the full range of services available when these decision are made? Yes 1
No 2

38. Do you feel you are kept informed of what is happening? Yes 1
No 2

39. Do you know how to make a complaint? Yes 1
No 2

40. Have you ever had to do this? Yes 1
No 2

41. If yes, were you happy with the outcome of your complaint? Yes 1
No 2

42. Did you know that you can see your own records if you wish? Yes 1
No 2

43. Did you know that if you wish you could have access to:

an interpreter/translator?

a friend/advisor/advocate to support you?

Yes	No	Not applicable
1	2	3
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

44. Has your Trust or any other organisation asked for your opinion about services for carers in your community or area? Yes 1
No 2

45. Have you been invited to participate in any meetings Yes 1

discussing these services?

No 2

46. If yes,

Did Social Services provide you with help so that you could attend these meetings?

Yes 1
No 2
Did not need help 3

Paying for services

47. Are you charged for any of the social services you receive?

48. Do you know how HSS Trusts work out the charges for services?

49. Do you think the charges are fair?

Yes 1	No 2	Not applicable 3
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Quality of services

50. How soon did you get help after a decision was made to provide services?

Within a week

More than a week, but less than 2 weeks

More than 2 weeks, but less than a month

More than a month, but less than 3 months

More than 3 months, but less than 6 months

More than 6 months, but less than a year

Longer than a year

<input type="checkbox"/>	1
<input type="checkbox"/>	2
<input type="checkbox"/>	3
<input type="checkbox"/>	4
<input type="checkbox"/>	5
<input type="checkbox"/>	6
<input type="checkbox"/>	7

51. Were you aware that you can request a review if you feel you need one?

Yes 1
No 2

52. How often are your services reviewed?

- At least once every 6 months 1
- At least once a year 2
- At least once every two years 3
- Less often than this 4
- Never 5

53. If changes are agreed are they carried out?

Always 1	Usually 2	Sometimes 3	Never 4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

54. Have the services helped you?

55. How satisfied are you with the amount of services you are receiving?

- Very satisfied 1
- Quite satisfied 2
- Neither satisfied nor dissatisfied 3
- Quite dissatisfied 4
- Very dissatisfied 5

56. How satisfied are you with the quality of services you are receiving?

- Very satisfied 1
- Quite satisfied 2
- Neither satisfied nor dissatisfied 3
- Quite dissatisfied 4
- Very dissatisfied 5

57. What service have you found most helpful?

58. What service have you found least helpful?

Overall Comments

Please use the space below to make any other comments about the services you have received.

Space for your comments

Information about you

Finally, it would be very helpful if you could answer these questions about yourself.

59. Age:

Under 16	1
16-19	2
20-34	3
35-54	4
55-74	5
75 or over	6

60. Sex:

Male	1
Female	2

61. Marital Status:

Single	1
Married	2
Separated/Divorced	3
Widowed	4

62. Please state your District Council area (if known)

63. Please give us the name of your Health and Social Services Trust (if known)

64. Do you have any long-term illness, health problem or disability which limits your daily activities or the work that you can do?

Yes	1
No	2

If yes, what is the nature of this disability? (please tick all that apply)

Visual	1
Hearing	2
Physical	3
Learning	4
Mental health	5
Other (please specify below)	6

65. What is your ethnic group?

White (excluding traveller)	1
Black	2
Asian	3
Chinese	4

Traveller	<input type="checkbox"/>	5
Mixed ethnic group	<input type="checkbox"/>	6
Other (please specify below)	<input type="checkbox"/>	7

66. What is your religion?

Catholic	<input type="checkbox"/>	1
Protestant	<input type="checkbox"/>	2
Other religion	<input type="checkbox"/>	3
None	<input type="checkbox"/>	4

Annex 2: Tables

Table 1 Response to Survey

	Number of Questionnaires Issued	Number of Questionnaires Completed
Armagh & Dungannon	50	17
Causeway	50	14
Craigavon & Banbridge	50	15
Down Lisburn	50	31
Foyle	50	30
Homefirst	50	33
Newry & Mourne	50	19
North & West Belfast	50	30
South & East Belfast	50	24
Sperrin Lakeland	50	40
Ulster	50	12
Advice NI	420	29
Northern Ireland Total	970	294

Note: A few of the questionnaires returned were void and are therefore not included as having been completed.

Table 2 Carers under Stress

Percentage of Respondents:	Under Stress Always or Very Often	Under Stress Less Frequently	Significance Level
Caring for 5 years or more	69%	55%	95%
Caring all the time	55%	37%	99%
Never having breaks	32%	20%	95%
Having long-term illness	57%	39%	99%
Satisfied with amount of services	66%	78%	95%

Note: Significance level refers to the level of statistical significance of the difference between the two percentages compared.

Table 3 Satisfaction with Amount of Services

Percentage of Respondents:	Not Satisfied with Amount of Services	Satisfied with Amount of Services	Significance Level
Under stress always/very often	51%	36%	95%
Whose assessment resulted in more support*	7%	55%	99%
Satisfied with outcome of assessment*	0%	74%	99.9%
Asked about services	9%	37%	99.9%
Deciding services for themselves	13%	41%	99.9%
Deciding services for cared for person	23%	55%	99.9%
Treated with respect	56%	83%	99.9%
With opinions noted	42%	75%	99.9%
Aware of full range of services	34%	77%	99.9%
Kept informed	54%	83%	99.9%
Happy with outcome of complaint*	43%	78%	95%
Thinking charges fair	12%	29%	95%
Who got help within week	36%	62%	99.9%
Aware can request review	47%	66%	99%
With services reviewed every 6 months	31%	59%	99.9%
With changes carried out*	26%	64%	99.9%
Whose services always helped	27%	76%	99.9%
Satisfied with quality of services	62%	98%	99.9%

Note: * Refers to questions that are not applicable to all respondents in contact with Social Services.

Significance level refers to the level of statistical significance of the difference between the two percentages compared.

Table 4 Satisfaction with Quality of Services

Percentage of Respondents:	Not Satisfied with Quality of Services	Satisfied with Quality of Services	Significance Level
Never having breaks	46%	23%	95%
Asked about services	11%	32%	95%
Deciding services for themselves	12%	36%	95%
Deciding services for cared for person	14%	50%	99.9%
Treated with respect	50%	80%	99.9%
With opinions noted	36%	72%	99.9%
Aware of full range of services	25%	71%	99.9%
Kept informed	36%	81%	99.9%
Having to make complaint	42%	19%	99%
Happy with outcome of complaint*	27%	77%	99%
Who got help within week	29%	59%	99%
Aware can request review	25%	65%	99.9%
With changes carried out*	29%	59%	99%
Whose services always helped	19%	71%	99.9%
Satisfied with amount of services	11%	82%	99.9%

Note: * Refers to questions that are not applicable to all respondents in contact with Social Services.

Significance level refers to the level of statistical significance of the difference between the two percentages compared.