Patient and Client Council

Care at Home

Older people’s experiences of domiciliary care

June 2012

Your voice in health and social care

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Foreword

I am pleased to present this report which represents the views of older people and their carers from across Northern Ireland in relation to domiciliary care services. Domiciliary care is the term used in Northern Ireland to refer to the range of care services provided to people in their own home.

The timing of this project coincides with a major review of health and social care in Northern Ireland requested by the Minister for Health. Therefore the Patient and Client Council believes that there has never been a more important time for people to have a say in how domiciliary care services should be delivered.

The fact that so many people took time to give us their views is a clear sign that they really wish to have their voice heard about the care they receive in their home. From our many conversations it is clear to me and the staff of the Patient and Client Council that people really value domiciliary care services and the efforts of staff who deliver them.

There are important messages for the Minister for Health, the Department of Health, Social Services and Public Safety (the Department), the Health and Social Care Review Team and key decision makers in this report. It is evident from the report that many older people rely on the domiciliary care service they receive, however they are concerned about issues such as quality and continuity of care in their own home.

I would like to express my sincere thanks to everyone who took the time to complete a questionnaire, take part in an interview or participate in a focus group. Thank you for the generosity with which you gave of your time and shared your experiences.

The Patient and Client Council will strive to ensure that the voices captured in this report and resulting recommendations influence decision making in 2012 and beyond. I would also like to thank the staff of the Patient and Client Council who
worked so hard to help us engage with people in the community, in day centres and in their own homes.

During the next few years, we will see a significant change in the way our health and social care services are delivered. This report will help to ensure that the voice of people in Northern Ireland contributes to how domiciliary care services are provided in the future.

Maeve Hully
Chief Executive of the Patient and Client Council
Executive Summary

The purpose of this report is to record the experiences of older people receiving a domiciliary care service as well as the views of carers. The report provides a timely illustration of older people’s perspectives on domiciliary care, within the context of the review of health and social care currently being undertaken in Northern Ireland and the existing debate around care provision for a rapidly ageing population.

A total of 1161 people took part in this process; 700 people completed a questionnaire outlining their experiences of receiving domiciliary care, 38 people in receipt of an intensive home care service took part in an interview, 170 people participated in small discussion groups and 253 members of the public filled out a short questionnaire.

Through this combined approach of quantitative and qualitative methods, including one-to-one interviews with older people and their carers, this report expands on themes identified by service users in previous surveys, as well as providing fresh insight into home care services and a deeper understanding of older people’s experience of domiciliary care.

The findings of the questionnaire reveal that levels of satisfaction with the quality of home care are high, with 87% of people rating the quality of care as “good” or “very good”. Domiciliary care is clearly an invaluable service to many older people, both for the quality of care provided and the support and company of care workers. One of the most positive aspects of domiciliary care expressed by older people is that it enables them to remain in their own home and to maintain some sense of independence, rather than face the alternative of residential or nursing care.

However, a significant minority of people were unhappy with aspects of the service. 16% felt that the help they currently receive does not meet their needs. The most frequently voiced issues with home care in the questionnaires were: the short duration of calls, inconvenient call times, inconsistent quality of care staff, inflexibility and lack of continuity of care. As a result, 23% of people said that the care they
received only improved their quality of life “a little”. Whilst many felt that their care
did cover basic needs, a lot more support was needed in order to achieve a good
quality of life.

The 38 interviews with older people and their carers support the findings of the
questionnaire. All interviewees or their relative were in receipt of an intensive
domiciliary care service of 10 or more hours a week, as defined by the DHSSPS.
Most of the older people interviewed spoke highly of the service and the majority of
carers also valued the support provided by home care workers and the reassurance
they offered to carers, families and vulnerable older people living alone. The one-to-
one interviews provided a deeper understanding of the extent to which many people
depend on the domiciliary care service and the physical and emotional support
offered by their home care workers. The interviews also provided insight into the
frustrations that arise when the service is inconsistent, inflexible or, at times, of poor
quality.

Public perceptions of domiciliary care reflect these concerns; most people who took
part in a focus group or completed a short questionnaire said that older people
should be supported to remain in their own homes if this was their wish, but only if
the quality of home care was of an acceptable standard. It was felt that the service
should be wide-ranging and should encompass physical, social and psychological
needs. There was also much discussion amongst focus groups about the decrease
in assistance with less personal tasks such as cleaning, laundry and shopping.
Many people felt that help with these activities was just as essential in enabling older
people to remain at home as personal care.

It is evident from this report that people are genuinely concerned about the future of
domiciliary care provision. A key policy priority such as Homecare Reablement,
currently being implemented in the Southern Health and Social Care Trust, has been
welcomed by some as a meaningful way of supporting older people to regain the
skills and confidence needed to live independently. However, this is on the provision
that the focus remains on improving the quality of life of older people living at home,
rather than reducing the financial cost of social care.
1.0 Background and Purpose

1.1 The Patient and Client Council
The Patient and Client Council provides a powerful, independent voice for people.

The Patient and Client Council has four main duties. They are to:

- listen and act on people’s views;
- encourage people to get involved;
- help people make a complaint; and
- promote advice and information

1.2 What is the purpose of this report?
This report seeks to record the views of older people and their carers on domiciliary care, a service that is vital to many older people. The domiciliary care project comes as a result of the Patient and Client Council report ‘Priorities for Action’, in which members of the public identified social care for older people as one of their top three priorities for health and social care in Northern Ireland. Elderly care in the community is clearly an issue of concern. With the review of health and social care currently being undertaken in Northern Ireland and attempts to reduce government spending, it is even more important that services are run in a way which ensures that quality and dignity are core to the provision of domiciliary care services. It is intended that this report will provide a current picture of public, patient and client perspectives on domiciliary care services and will provide a platform for further discussion and debate about how this care should be delivered in the future.

1.3 Why is this report necessary?
The population of Northern Ireland, like that of the rest of the UK, is rapidly ageing. A demographic overview from the Office for National Statistics reveals that the number of people aged 65 and over in the UK increased by 20 per cent over the period 1985 - 2010. This trend looks set to continue. Those aged 65 and over accounted for 17 per cent of the UK population in 2010, however population trends predict that this demographic will account for 23 per cent of the population by 2035
(ONS 2010). Population projections for Northern Ireland follow a similar trajectory to that of the rest of the UK. Estimates from the Northern Ireland Statistics and Research Agency based on population figures for 2010 predict that the population aged 65 and over will see an increase of 7 per cent by 2030. The percentage of the population aged 80 and over is predicted to almost double over the same period (NISRA 2010).

In the context of an increasingly older population it is timely to reflect on the current provision of domiciliary care and to consider ways of making the service more effective and more efficient. While domiciliary care has long been a key part of the Health and Social Care Trusts’ work to deliver care in a community setting, increased demand and restricted budgets have resulted in a recent shift away from services such as housework and cleaning to a focus on personal care.

The Patient and Client Council has worked collaboratively with the Health and Social Care Trusts to explore older people’s views of the care they currently receive and to get their insight into developments in the service that will impact directly on them.

1.4 What are the aims and objectives of this project?

Aim
The aim of this project is to explore the experiences of older people and their carers receiving a domiciliary service throughout Northern Ireland in the context of pressure on services and the potential changing policy context for domiciliary care.

Objectives
- To outline current care provided to older people
- To gain older people’s perspectives on their own needs in relation to domiciliary care
- To examine older people’s and their carers’ views on how domiciliary care impacts on their lives
- To analyse older people’s and their carers’ views of how services might be delivered in the future
2.0 Our Approach

2.1 Background

The study was overseen by a Steering Group. As the Southern Trust was the first area in which the project was piloted, this particular group included representation from Age NI, the Patient and Client Council (staff and LAC members) and the Southern Health and Social Care Trust. A number of approaches were taken into consideration before the following methodology comprised of three distinct parts was agreed.

To begin with, groups working with people over age 65 and voluntary groups which support people with long-term conditions were targeted. They included Age NI and local groups specific to conditions such as Alzheimer’s disease, Parkinson’s disease and Multiple Sclerosis. Individuals attending these groups were asked to complete a questionnaire if they receive a domiciliary care package. Questionnaires were completed on an individual basis with support from Personal and Public Involvement officers from the Patient and Client Council. The questionnaires were distributed at a group meeting and, where possible, collected and returned on the same day. People were also given the opportunity to post their replies at a later date.

Secondly, a number of focus groups took place in order to explore general attitudes to domiciliary care, perceptions of domiciliary care amongst those not receiving the service and personal experience of and views on social care provision. The focus groups were limited to one carers’ group and one group of over 50s within each Trust area. Short questionnaires were also distributed at the Balmoral Show in order to gain public views on domiciliary care.

Finally, in order to ensure that people receiving an intensive domiciliary care package of more than 10 hours per week were represented, it was agreed that a maximum of 10-12 interviews would take place in each Trust area. Assistance was needed from the Trust to identify participants and to address any ethical issues raised by this process. Interviews were recorded or, if the interviewee preferred,
notes were taken instead. Each person was asked for their consent before the interviews and recordings took place.

All three elements were to be implemented in each Trust area in order to ensure geographic representativeness and to maintain consistency in data collection.

2.2 Implementation of the project

The project began in the Southern Trust. As stated in the methodology, the initial step was to network with voluntary and community groups to engage with people in receipt of domiciliary care. A number of locations and groups were targeted, but this provided only a small number of returns as people active in the community did not appear to be major recipients of domiciliary care packages. Other community settings such as post offices and shopping centres were also included, but again yielded few recipients of home care. It was then decided to obtain permission from the Trust to approach day centres. This proved to be a more fruitful means of obtaining older people’s views about domiciliary care. This process was followed in each Trust area, with the emphasis on day centres, but also including community-based work.

In addition, the opportunity arose in two Trust areas to distribute questionnaires through other means. In the Northern Trust questionnaires were sent out through the independent provider, Extra Care, while the Western Trust sought to supplement questionnaires completed in local day centres by distributing 360 questionnaires to those in receipt of a domiciliary care package across the Trust area. The numbers of questionnaires returned in each Trust area are given in Appendix 1.

Focus groups were then established in each Trust area. This process gave older people not receiving domiciliary care the opportunity to express their views on future services and to consider the question of paying for domiciliary care. Carers’ groups were asked for their perspective on the same questions. The locations of focus groups undertaken are given in Appendix 2.
Finally, a total of 38 interviews with both older people and carers were completed across the five Trusts. In addition, 10 interviews were held with older people in the Southern Trust about their experience of receiving a Reablement service. It should be noted that the Health and Social Care Trusts nominated people for interview. Patient and Client Council officers then interviewed willing participants in their own home, following a consent process.
3.0 Domiciliary Care Provision in Context

3.1 An Ageing Population

Much discussion has taken place about the ageing population of the UK and other countries. The rapid growth in the number of older people has considerable implications for the provision of health and social care services, particularly in the area of domiciliary care. The Department of Health, Social Services and Public Safety defines domiciliary care as follows:

“"The range of services put into place to support an individual in their home. Services may involve routine household tasks within or outside the home, personal care of the client and other associated domestic services necessary to maintain an individual in an acceptable level of health, hygiene, dignity, safety and ease in their home” (DHSSPS 2010: 8)

Older people are the largest single group of users of community health and social care services. The range of support required by an older person can vary, from assistance with basic tasks such as dressing or preparing meals, to intensive care in their home on a regular basis. A 2010 survey of domiciliary care services in Northern Ireland found that the majority of people (85%) receiving intensive domiciliary care was aged 65 and over. With this older population rapidly expanding, demands on care provision in Northern Ireland are only set to increase. As a result, Age NI has claimed that care of the elderly has now reached a critical point:

“Older people’s care is at crisis in Northern Ireland” (Age NI 2009: 46)

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1 Intensive domiciliary care is defined as 6 or more visits and more than 10 contact hours during the survey week (DHSSPS 2010: 1)
3.2 Current Policy

Current community care policy in Northern Ireland continues to be influenced by the 1990 DHSS policy document *People First: community care in Northern Ireland for the 1990s*. *People First* stated six central objectives in relation to community care, including the following intention:

“To promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever possible” (DHSS 1990: 6)

In 1990, *People First* recognised that domiciliary care services were generally inconsistent and that older people were being inappropriately admitted to hospital or care homes. In addition, older people who had been successfully rehabilitated were remaining in hospital. All of this was contrary to the fundamental characteristic of community care, the aim of which was to help people live as independently as possible in their own homes (DHSS 1990: 11).

Enabling people to live independently for as long as possible and a move away from over-reliance on residential and nursing care continues to be central to government policy on community care for the elderly. This reflects the aspirations of many older people who want to remain in their own homes for longer.

A 2008 survey of domiciliary care providers commissioned by the DHSSPS found that service users aged 65 and over accounted for almost 80% of all home care services provided in the week the survey was conducted (DHSSPS 2008: 9). Currently in Northern Ireland, Health and Social Care Trusts carry out care assessments to determine a person’s needs. If domiciliary care is recommended as the most suitable form of care, the Trust will either arrange the provision of this care through a statutory provider operated by the HSC Trusts or contract a voluntary or private independent provider. The NISRA statistical bulletin on domiciliary care services states that during one week in September 2010 the HSC Trusts provided domiciliary care services for 23,389 clients in Northern Ireland, of which 14,927 received services from the statutory sector and 11,482 from the independent sector (DHSSPS 2010: 14). It should be noted that about 13 per cent of people received...
part of their service from both the statutory and independent sector. Statutory sector provision of domiciliary care is steadily falling; from 2008 to 2010 the proportion of domiciliary care provided by the independent sector rose by 7 per cent (DHSSPS 2010: 14).

Twenty years on from *People First* the proportion of those receiving care in residential settings still exceeds those receiving a domiciliary care package (Northern Ireland Assembly 2009: 2). In 2007, a Northern Ireland Audit Office report on domiciliary care for older people stated that while the number of elderly people cared for in their own home had increased by 32 per cent since 1995/96, as a percentage of all care packages for older people, the number of people receiving domiciliary care only increased by 5 per cent. The report also found that since 2002 the balance between institutional care and domiciliary care has largely remained static (NIAO 2007: 13). Thus, while the provision of domiciliary care in Northern Ireland is improving, progress has been slow, and there continues to be people within institutional care settings who could be receiving care in the home.

The Northern Ireland Assembly Public Accounts Committee reported in 2008 that the DHSSPS still considered the aspirations of *People First* as central to policy on domiciliary care for older people, but accepted that some of its aims had yet to be achieved (PAC 2008). The challenge for the DHSSPS, the Committee concluded, was to continue to ensure that the balance of care for older people was shifted more emphatically towards the delivery of domiciliary care provision.

Concerns have also been voiced about the move away from low and moderate levels of care provision in recent years, with the focus shifting to those with more intensive care needs. In many ways this direction can actually be attributed to *People First*, which recommended that services should concentrate on those with the greatest need. The implementation of this principle has led some to argue that older people with a lower level of need are at risk of being overlooked. Age NI claims that recent efficiency savings have led to the withdrawal of less complex services like home help and meals-on-wheels, a trend it believes will only result in significant
health problems for those currently at the lower end of the care needs spectrum and thus higher costs in the future (Age NI 2009: 46-7).

The provision of less complex services has seen a decrease over recent years. The number of people aged 65 and over receiving a Meals Service fell from 5,148 to 4,209 between 2007-8 and 2009-10, a decrease of 18%. Figures for Home Help services were not included in the 2009-10 Adult Community Statistics publication, however between 2007-8 and 2008-9 the number of people aged 65 and over receiving a Home Help service reduced by 7% (DHSSPS 2007-10). As the 2007 NIAO report argues, the development of domiciliary care requires a more balanced approach if it is to deal with the challenges presented by an ageing population, one which incorporates low intensity services such as home-help, day care and meals-on-wheels, as well as intensive-care managed practices (NIAO 2007: 8, 17).

The provision of domiciliary care cannot be considered in isolation. Integrated care has been the aim of health and social services in recent years. As the name suggests integrated means the smooth transition from service to service, for example from hospital to community, with a team of professionals working together to meet the assessed needs of older people. Indeed Northern Ireland was thought to have an advantage in that health and social care were already integrated in contrast to the rest of the UK. However, a recent report carried out by Price Waterhouse Coopers on behalf of Independent Health and Care Providers argues that:

“It is probable that local authorities in England have been more advanced in seeking to take a “total place” approach to getting the maximum combined impact from all agency spend on older people” (PWC 2011: 41)

Integrated care remains key to developing policy and practice; both the current and previous Health Ministers have emphasised the importance of integrated care.² There is an argument, however, that other services need to be brought into the

² See www.northernireland.gov.uk. 5 December 2008 “McGimpsey welcomes Health Secretary to Northern Ireland” and 13 December 2011 “Oral Statement to the Assembly by Health Minister Edwin Poots”. Website last accessed 6 January 2012
integrated care mix. For example, Reed et al suggest that older people’s services should adopt a more collaborative approach;

“Integration across health, social care, housing and transport equally affect the way that older people live, yet these services tend to operate in parallel rather than in partnership with each other” (Reed et al 2005)

Age NI agree that if government policy on domiciliary care is to improve the quality of life experienced by an expanding elderly population, it must be considered together with a range of other services that impact on the daily lives of those receiving care within the home, such as accessible transport, secure housing and day centre facilities. If these external factors are not addressed alongside policy on domiciliary care, the growing emphasis on home care services could leave many older people feeling insecure and socially isolated (Age NI 2009: 50).

3.3 Reablement

The Department of Health identifies Homecare Reablement as a key policy priority for health and social care. Reablement is a short-term intervention that seeks to support people to develop or regain the skills and confidence necessary to live independently. It is a service that can be of benefit to people who have recently experienced a period of hospital or intermediate care, as well as those within the community who may require extra support to continue living at home. There has been no single approach to the Reablement services already in place across the United Kingdom, but central to the delivery of all services is the intention to maximise the individual’s ability to carry out the activities of daily living.

This central objective to maximise independence is reflected in the King’s Fund definition of Reablement, as stated in the North East Improvement and Efficiency Partnership best practice framework, ‘Reablement for All’:

“A process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients or service users and their family carers” (NEIEP 2010: 2)
‘Reablement for All’, states three essential elements to the most effective Reablement services: rehabilitation, motivation and social inclusion (NEIEP 2010: 2). The theory is that an intensive, short-term intervention by a Reablement team will not only help maintain independence but reduce the individual’s reliance on health and social care services in the long-term. ‘Reablement for All’ suggests that social inclusion is therefore just as integral to Reablement as physical rehabilitation and recommends that Reablement services should ensure they promote emotional well-being and community involvement. This approach, it argues, should have long-term benefits for health and social services more generally, as it is often an escalating sense of social isolation that can lead someone towards a state of dependency (NEIEP 2010: 16).

The ‘Reablement for All’ project consulted with service user groups about the characteristics they believed to be essential to an ‘ideal’ Reablement service. Their response endorsed this all-encompassing approach. They envisaged a multi-disciplinary service that brings together rehabilitation, social integration and emotional support within a culture that promotes independence and confidence.

A new Reablement service is fundamental to the Southern Health and Social Care Trusts ‘Living Your Life to the Full’ model of support for older people. Also integral to this model is a single, identifiable point of contact for older people seeking information and access to services and a Care Bureau that will streamline the coordination and commissioning of care packages.

The aim of the Southern Trust Reablement team is to provide care for people within their own homes for a defined period of up to six weeks in order to help them regain the skills necessary to live independently. An individual might be referred to the Reablement service in a number of circumstances, for example following a spell in hospital or after a period of declining health. One of the key principles of Reablement is to help older people “to do”, rather than “doing for”:
“The service will work with the individual to help them regain independence, recover skills and confidence for daily living. It will provide them with support and encouragement to re-learn skills and learn new skills so that they are able to undertake the daily tasks of living themselves, such as getting dressed and undressed, using the stairs, washing, preparing meals” (SHSCT 2010: 3)

Other Health and Social Care Trusts are also looking at and indeed implementing Reablement. The key role of this concept is now recognised in the establishment of a Regional Reablement Group, created by the DHSSPS.

### 3.4 Service User Experience

Previous surveys of domiciliary care users in Northern Ireland have found that satisfaction levels are generally high, but a significant number of people did express concern with the service. In 2007 a NIAO survey of 255 users of domiciliary care found that 63 per cent of interviewees were “very satisfied” with the home care service. However, many people did highlight issues with the service, most commonly around inflexibility, unreliable staff and the frequency and duration of visits by care workers. Improved communication and continuity of care were indicated as areas meriting specific attention.

A DHSSPS survey of care providers released the following year reported that 81 per cent of providers consulted with service users on a care plan in all cases prior to commencing care provision and 78 per cent provided a written guide containing information on their organisation. However, it remains that about a fifth of service users were not consulted about a care plan or provided with written information before their service commenced (DHSSPS 2008: 11-15).

Improved communication with users of domiciliary care emerges as a priority area in subsequent service user surveys. In 2009, the DHSSPS carried out an extensive survey of home care service users, the first of its kind in Northern Ireland. The survey received more than 4000 eligible responses. 86 per cent of respondents rated the domiciliary care service “good” or “very good”. More than 80 per cent said they were happy with the way care workers treated them and that they could not
manage without the help they receive (DHSSPS 2009: 1). However, a significant minority said they were unhappy with the way in which their care plan had been communicated to them; 38 per cent had not received a written guide outlining their care provision and 19 per cent had not been advised in advance of what the care worker was supposed to do for them. More than a quarter of respondents said they had not been consulted on suitable times for home care calls.

The survey also seemed to indicate a lack of correlation between the activities most users identified as those they were “not able” to perform, such as shopping and housework, and the activities most users indicated they receive help with, getting dressed/undressed and washing (DHSSPS 2009: 20-9). This response appears to suggest that the most basic needs of service users, such as personal care, are largely being met; however some concomitant activities of daily living, such as shopping or housework, are not regarded as an essential part of the domiciliary care package.

While this extensive survey reveals that most service users were satisfied with their home care service, it is important to note that a significant minority did not feel that their needs were being met by the care they received. Almost a third of service users said there were activities they would like their care worker to help them with that they did not receive assistance with at the time of the survey and more than a quarter believed that they needed more hours of domiciliary care each week.

This report seeks to add to these findings and expand on the themes identified by service users in previous surveys. However, by taking a combined approach of quantitative research, in the form of the questionnaire, and qualitative research, including one-to-one interviews with service users, this project is aimed at gaining fresh insight into and a deeper understanding of older people’s experiences of domiciliary care.
Domiciliary care is obviously a key service for older people and indeed user surveys indicate that there are high levels of satisfaction with the service. Older people value this service and underline the vital contribution it makes to their lives. Policy documents and statements from government and health and social care agencies clearly articulate their support for the integration of health and care services and are committed to helping people remain as independent for as long as possible. It remains to be seen however, in the current economic context, how such ideas will be overseen and implemented in order to ensure that older people receive the service they need at the right time, in the right place. The following section of this report details people’s experience and views of domiciliary care services and discusses results from the project which took place over an eighth month period.
4.0 Results / Findings

4.1 Questionnaires

A total of 700 people from across Northern Ireland completed a questionnaire describing their experiences of receiving a domiciliary care service. The following section outlines the findings of this survey. A summary of the findings from each of the five individuals Health and Social Care Trusts is available in a separate document on request.

All 700 respondents were aged 65 years or over. The age and gender profile of respondents was as follows:

Figure 1: Gender

![Pie chart showing gender distribution]

Figure 2: Age Group

![Bar chart showing age distribution]
4.1.1 Experience of the Domiciliary Care Service

The majority of people (61%) said they had been receiving a domiciliary care service for between 1 and 5 years. 16% had been in receipt of a service for more than 10 years. Most people said they received care 7 days a week.

Just over three quarters of those who responded were receiving less than 10 hours home care each week, with the remaining 24% in receipt of an intensive service of 10 hours a week or more. There were some notable variations between the Trust areas in terms of the number of people receiving an intensive service. People in the Belfast Trust were more likely than any other to receive less than 10 hours domiciliary care per week, 92% of all respondents. Two thirds of those were getting less than 4 hours home care each week and no-one said they got more than 14 hours assistance in the week. The area with the highest number of recipients of an intensive service of more than 10 weekly hours was the Western Trust (38%), although it is worth noting that the Western Trust also had the highest number of respondents aged 80 and over (66%).

Figure 3: Number of hours of domiciliary care received each week per Trust
Personal care was the most common kind of assistance people indicated that they receive help with. 73% of people were helped with washing, bathing or showering and 68% were assisted with dressing and undressing. The third most common kind of assistance given was meal preparation, with 63% of people helped to prepare, heat or serve food. A much smaller percentage of people said they receive less personal kinds of help such as housework and shopping, 10% and 5% of people respectively. Many individuals mentioned other activities their home care workers helped with that make a big difference to their experience of care, such as shaving, brushing hair, applying creams, short walks around the garden and checking personal safety.

Figure 4: What kind of activities do you get help with?

Again there were some notable differences in the kind of activities people said they received help within each Trust area. People in the Southern and Western Trust areas were more likely to receive assistance with personal care, such as washing and dressing, than in any other Trust area. In contrast, people in the Belfast Trust were least likely to indicate that they received help with personal care. For example, 88% of people in the Western Trust said they were assisted with washing or showering, as compared with just 44% of people in the Belfast Trust who indicated the same — exactly half the number of respondents. This disparity between the Western and Southern Trusts and the Belfast Trust extended to activities such as
getting dressed or undressed, help with toileting and assistance getting into or out of bed.

There was also a notable distinction between the two sets of response collected in the Northern Trust area. Two distribution methods were employed in the Northern Trust area; 91 people completed questionnaires in day centres and 170 people responded to questionnaires sent out by the provider Extra Care. The kinds of assistance most commonly indicated by people who completed questionnaires distributed by Extra Care were similar to those in the Western and Southern Trust areas - washing, dressing, getting in and out of bed and help with toileting. However, those who completed questionnaires in Northern Trust day centres were a lot less likely to say they were helped with such tasks, the response here being more similar to that of the Belfast Trust. For this reason, response from the Northern Trust and Extra Care in the Northern Trust are presented separately in Figure 5 below which outlines the kinds of activities people received help with per Trust area.

**Figure 5: Number of people assisted with activities per Trust area (%)**

![Graph showing the percentage of people assisted with various activities per Trust area](image-url)
While the number of people receiving help with meal preparation was generally consistent across the Trusts, a substantially higher number of people in the Belfast Trust said they got assistance with less personal tasks such as housework and shopping. For example, 28% of respondents in the Belfast Trust said they received help with housework and 13% with shopping, as compared to 4% of people in the Western Trust who said they received help with housework and just 2% with shopping.

4.1.2 Quality of Care

Levels of satisfaction with the quality of home care received are very high, with 87% of people rating the quality of care as “good” or “very good”. Only 3% of people felt that the quality of care they received was either “poor” or “very poor”.

4.1.3 Getting the Care You Need

Most people (88%) felt that their views were taken into consideration when the social worker came to talk to them about what help they might need and that they were subsequently informed about the help they would get. However, on average, 16% of people felt the help offered would not meet their needs. The most common explanation for this response was that not enough time was allocated to care workers in order to effectively attend to the older person receiving care. Individuals identified activities they struggled to get help with such as housework or getting into bed at night. A few people felt their needs were only being met because they paid for additional care.

“Social workers hands are tied, they would like to give more help but can’t. This is when you need help, when you grow old and aren’t fit to do anything for yourself. My home help is very good but hasn’t time to carry out her work.”

Some people said that they would like more regular contact with their social worker and to have their needs reassessed on a more regular basis. A few added that their health had deteriorated since they were last assessed for domiciliary care.
“I don’t think social workers should be doing this job until they have life skills, they just don’t understand older people”

4.1.4 Additional Support

Family support
80% of people said they receive help from someone other than their care worker. In most cases this was a family member; spouse, sibling, children, grandchildren, nieces and nephews. It is clear from comments that many people rely on the additional help provided by their relatives with tasks such as cooking, cleaning, shopping, taking medication, paperwork and transport. The company, conversation and emotional support of relatives, friends and neighbours were also considered by many as additional support. A few people said that they often felt guilty about relying on family for so much.

“I sometimes feel like [paying for private help], to take pressure off son. He does too much. My family remind me, what life does he have?”

Private Support
30% of people indicated that they pay privately for additional help. In most cases this was help with housework, such as cleaning, laundry or bed-making. Some people also paid for assistance with shopping, gardening or a respite or sitting service for their carers. However, of this 30%, a few people did have to pay for private personal care in order to make up for shortcomings in their domiciliary care package.

“Pay for private carer to cover gaps in care – toileting, washing, feeding, company, sometimes making meals, laundry on occasion, give medication”
4.1.5 Accessing Other Services

The majority of older people receiving domiciliary care said they used another service in their area. 62% of people access community transport, 15% use a grocery delivery or handyman service and 7% have access to a mobile library. Many people mentioned the day centre as another service they use in their local area. A few people said they attend local social or luncheon clubs for older people.

Almost half of all respondents said that they would contact their relatives if they needed information about local services. Some people identified day centre staff, their social worker or their home care worker as other sources of information. A few people would talk to friends and neighbours or a local community representative such as a councillor, priest or community worker.

67% of people said that their first point of contact in an emergency would be a family member. Some people added that they had a Lifeline panic button they could use in an emergency and a few said they would contact emergency services directly.

4.1.6 Staying Independent

Almost three quarters of people (74%) said the help they received from their domiciliary care worker improved their quality of life “a lot”. Only 3% of people felt that home care did not improve their quality of life at all. Many people described the care they receive as invaluable because without it they simply could not cope with the basic activities of daily living. Some people felt that the support provided by their home care worker and the reassurance gained from the daily visits enabled them to continue living independently in their own home.

“It means I can live as normal a life as possible in my own home”

3 Please note that these figures do not take into account the Western Trust as due to a printing error this question was omitted from the majority of questionnaires distributed in that area. As a result, only a small number of respondents in the Western Trust directly rated the extent to which domiciliary care improved their quality of life.
A few people added that the conversation and company provided by the care workers on a daily basis also improved their quality of life.

| “Depend on them physically but also depend on them emotionally” |

However, almost a fifth of people felt that the care they received only improved their quality of life “a little”. Some people commented on the limitations of their home care service, such as short duration of visits, little continuity as regards care staff and inconvenient or irregular call times. They felt that while the care they received did cover basic needs, a lot more support was needed in order to achieve a good quality of life.

| “It is basic care – all other care and support given by family and helper paid for by family” |

A third of all respondents identified other types of assistance that they felt would help them to live more independently. The three most commonly mentioned kinds of help were assistance with housework, more company within the home or help getting out to socialise and equipment, aids or adaptations to the home that would help people move about more freely or carry out activities more independently.

| “Would be great if someone could come out and speak to people in their own homes so that they see someone during the week – older people are left a lot on their own” |

A few people said that, rather than any new service, they could live more independently if their care workers simply had more time to do their job effectively.

4.1.7 Further Comments

A Valuable Service

Around half of those who commented further used this opportunity to say how much they valued domiciliary care, both for the quality of care and company provided by their care workers. Many praised the work of their regular home care workers, who
some felt went beyond their allocated duties to ensure they were well cared for, and took confidence from the knowledge they would be calling each day. One of the most positive aspects of domiciliary care for many older people was that it enabled them to continue living in their own home and to maintain some degree of independence.

“I am very pleased with my care package and without it I wouldn’t be able to live independently in my own home. They treat me with dignity and respect and are always polite and courteous to me”

Time Pressures
However, one of the most frequently occurring issues amongst respondents was the amount of time care workers spent in their homes. People felt that more time and care was needed. While some recognised that care workers struggled under heavy workloads, they felt that time pressures within the service meant essential needs were not being met and that care workers were often so rushed they did not take time to talk to or encourage the older person.

“Too rushed – they have too many people to see. They can’t wash you properly. They don’t have time to shower me so I only get washed with a cloth in the bedroom. It’s not good enough”

Poor continuity of care
Many people commented on the lack of continuity in their care. They felt that large teams of care workers operating within very tight time constraints impacted negatively on the service they receive. People were sometimes attended to by unfamiliar home care workers who were poorly informed about the individual’s needs. This lack of continuity could prove very unsettling for some vulnerable older people.

“There really needs to be more continuity of care with familiar faces. When services are needed, more staff should be trained to maintain this continuity”
Unreliable Staff
Some people suggested that the quality of care they received was very much dependent on the individual care worker. They were concerned that some care workers were not experienced, trained or even prepared for what to expect from the job. A need for better staff training was identified, especially in how to treat older people with dignity and respect.

“Carers require re-trained or up-skilled every 6 months. Carer to address person by NAME not PET. Use common sense to encourage patient to do simple tasks”

Inflexible
Many people said they would like to see more flexibility within the domiciliary care service. This was most commonly expressed in relation to inconvenient or irregular visiting times which could result in individuals not being helped out of bed until lunchtime or being put to bed much too early in the evening when they were not tired enough to sleep. Some people suggested that poor co-ordination and organisation from above was responsible for this lack of flexibility. Others felt that care workers were much too restricted in the tasks they could undertake, which made an already inflexible service even more limited.

“The girls don’t have time, they are always rushing. My times are terrible, I could wait til 10.30am before they come to take me out of bed and then it’s too early when they come to put me back into bed again”

Conclusion
The following comment from an older person living in the Western Trust area captures the many concerns expressed by people in receipt of domiciliary care across Northern Ireland, from time pressures and lack of training, to poor communication and little continuity of care:
“15 minutes in the morning is not enough time to shower, dress and get breakfast. I’m old now and it takes me time to do stuff. A lot of the time the girls don’t come. If the weather is bad I don’t see anybody and they don’t phone to say they are not coming. The morning visit is too late and the night visit is too early. I don’t want to go to bed at 8pm, the soaps aren’t even over. I don’t like it that all the carers change so much, I had to leave a key so they can get in to me in the morning and I’m not happy that I know who is coming through the door - a stranger. The young summer staff didn’t even know what bedroom I was in. Can these girls not be put on a rota so I know who I’m getting and when? Also, are the staff trained to do this work, because sometimes you wouldn’t think so”

However, a carer for an older person receiving domiciliary care suggested that older people were too anxious to speak out about failings in their care provision for fear that they might lose any services they currently receive.

“Older people DO NOT want to complain in case they lose the care that they get. I feel that there is no point in complaining as not a lot is done anyway. We have some lovely, kind carers who cannot do enough for my family but this is ruined by others who couldn’t care less about the clients”

Some people felt that while their physical needs were being met by home care, more emotional and social support was necessary to avoid loneliness and isolation amongst older people living at home. It was thought that a more wide-ranging service that encompassed the physical, emotional and psychological needs of the older person would be more beneficial in improving their quality of life.

“The focus is on the physical needs – more focus and attention to the emotional/psychological and social needs that help people be independent and retain their identity”
4.2 Interviews

38 people from across Northern Ireland were interviewed on a one to one basis about their experiences of domiciliary care. 29 of the interviewees were older people currently receiving a domiciliary care service and 9 were carers for a person in receipt of home care. 12 of the older people were interviewed along with their main carer.

All interviewees, or their relative, were in receipt of an intensive domiciliary care package of 10 or more hours per week, for a length of time that ranged between 4 months and 11 years. Each domiciliary care package consisted of 2 to 6 daily visits from home care workers, although the majority of people received 4 visits each day. The care workers assisted with a range of activities from personal care, such as washing, dressing and incontinence care, to other activities of daily living such as getting in and out of bed, administering medication and preparing meals. Some people also had a weekly sitting service to enable their carer to have some respite.

4.2.1 Experiencing Domiciliary Care

A Good Service

Most of the older people interviewed rated the service highly, both for the quality of care provided and the supportive and friendly approach of the care workers.

“Everything I need, I get ... excellent care, you couldn’t get better anywhere”

One lady described how her care workers often went beyond their set duties to help her; for example if she was feeling unwell they would phone during the day to check in and some came to visit when she spent time in hospital. Like many of the older people interviewed, she valued their company as much as the care they provided.

“I couldn’t rate it highly enough. The girls are very good, every last one of them. I’m glad of the company. If I hadn’t got them I wouldn’t be here, they do everything for me. The carers are the best anyone could wish for”
The majority of carers agreed that their relative’s home care workers were, for the most part, kind, reliable and willing to help. Some said they simply would not have coped without the support provided by the domiciliary care team. For example, one carer described how his wife had difficulties eating before she started to receive home care and consequently lost a lot of weight. He believed it was the input and encouragement of her care worker at meal times that helped her get back to a healthy weight.

A carer interviewed alongside her mother suggested that one of the main benefits of home care was the reassurance it offered carers and families that their relative was regularly monitored during the day. For her, domiciliary care was a vital safety net for vulnerable older people living on their own.

**An Inconsistent Service**

While most of the older people and carers said they were generally happy with their home care service, many did identify problems and inconsistencies with the service they received. The five most common issues raised were:

1. Care workers are not given enough time;
2. Poor continuity of care;
3. Inconsistent quality of staff;
4. Poor organisation at an administrative or managerial level;
5. Inflexible service.

These themes were reflected throughout the interviews from across Northern Ireland, even amongst those people who had a positive experience of domiciliary care, giving the overall impression of an inconsistent service.
1. Not enough time

The issue most interviewees raised with the domiciliary care service was that care workers are not given enough time with people. The majority of people suggested that calls were sometimes rushed, especially during holiday times or if their regular care worker was on leave. Too many clients on one rota could mean that care workers were often running late and under pressure to get to their next visit. This “clock-watching”, as one person referred to it, was upsetting for those who depended so much on the care provided.

Some people talked about how such time pressures impacted negatively on the quality of care provided. For example, one carer asked care workers if they could encourage her husband to carry out smaller tasks himself, in order to help build up confidence levels which were low since his stroke. Their response was that they were not allocated enough time to help him to help himself.

One older person felt that, while her care workers were very efficient, it was undignified that they did not even have time to talk to the people they were assisting.

“The girls themselves are very good, but they haven’t the time, you’re not going to do in twenty minutes what it would take an hour to do ... before you can say Jack Robinson they’re away. I understand they can’t talk to everybody, but if they would take one patient one day and take time to maybe give them ten minutes more”

2. Poor continuity of care

Many of those who were interviewed, both older people and carers, talked about how difficult it was to come to terms with certain aspects of domiciliary care, particularly coping with different people coming into their home on a daily basis. This was all the more difficult for those who said they had little continuity as regards care workers and irregular times of calls.

While most people praised their regular care workers, many said that some degree of their care was provided by large teams of unfamiliar care staff. The result, as one carer explained, was that some care workers formed close relationships with the family over time, while others made no effort to get to know the older people they
were attending to and appeared to work around what suited them rather than acting in the best interests of the client. Another carer agreed that it could at times feel like the person in need of care was being fitted into a service that already existed, rather than the service being fitted around each person’s individual needs.

“I had a team of seven that came and it was great, then they changed it and now you could have twenty different ones coming in. I’m not just as keen on that. You used to know who was coming but now the girls can’t tell you who is coming. Sometimes I feel they be a bit rushed, not through any fault of their own, through not having enough time and having to rush to the next person”

Two carers commented on some initial problems they had in achieving continuity in their relative’s care. In both cases it took more than a year to establish a regular team of care workers and until this time their relatives were attended to by large teams of different workers, which left them feeling nervous and unsettled. For one older person, these feelings of confusion were exacerbated by Alzheimer’s disease and their carer felt that a complaint the family made about the conduct of one particular care worker during this time went largely ignored by the care provider. Both carers said that their situation had improved since their relative was settled with a regular team of familiar carers.

3. Inconsistent quality of care staff

Some people felt that the quality of care provided could vary with the individual care worker, as some care staff appeared to be untrained, inexperienced or disinterested. A few of the carers interviewed were very concerned that new care workers were not informed about their relative’s needs, which were quite complex in some cases.

One carer was particularly vocal about the inconsistencies in quality of care staff. She said that while some care workers were “outstanding” others appeared to be poorly trained, unwilling to help and always in a hurry to leave. In their rush to get to the next call they often left items lying around for the carer to tidy up, which made her question how older people living on their own coped.
However, a few of the older people interviewed suggested that it was difficult to make a complaint about individual care workers. One person had recently enlisted the help of her son to report a care worker to management, but they found this difficult because the individual was part of a wider team.

“There was one lady, she didn’t care what she said to you ... they were all local girls that come to me and they got too familiar. My son reported it because the other girls wouldn’t report her, they said they had to work with her”

Another older person was currently in a similar situation. He felt that the behaviour of one of his home care workers was inappropriate, she was rude and used bad language, however as the staff worked in pairs he felt he could not report one without losing the other.

4. Poor organisation
More than half the carers interviewed identified problems with their relative’s care provider at an organisational level. They felt that the care providers did not communicate well with their clients. A common complaint was that clients were rarely informed if an existing care worker was leaving and someone new was starting, so they had no idea who was coming into their home. A few people suggested that new care staff seemed similarly ill-informed and often arrived at their house with little or no knowledge of the person they were there to assist.

“There biggest problem would be the office and the office staff because they don’t know where their left hand has gone or where their right hand is. We have to take pot luck on who is coming through that door and what time they are coming at. They could come at 8am but mightn’t come until 10am. I think the office should ring and tell you that you’re having so-and-so tomorrow, to put you in the picture more. There’s no organisation in the office, or maybe it’s a case of no communication between the client and the staff”

For some, ineffective communication and poor organisation was indicative of uncaring attitudes at management level, in that they failed to see the wider impact this could have on older people and their families. A few carers who had complained to providers about the standard of care their relative received felt that little action was taken to tackle these concerns. One carer suggested that it was the
hard work and positive attitude of care staff that sustained the care agency that provided his relative's care because the administrative side of the organisation was so ineffective.

5. Inflexible service
Some people felt that the service was too inflexible. For example, more than a fifth of people said that at least one of their calls was at an inconvenient time. This issue was particularly evident amongst interviewees in the Belfast and Southern Trusts; two thirds of people in both areas mentioned unsuitable call times. More often than not, the complaint was that the evening call came much too early and people were not ready to go to bed. For some, this meant missing out on social activities in the evening or long, restless nights trying to sleep. In other cases, people asked care workers to help them prepare for bed and they went themselves later, even though this was problematic for those who suffered from mobility problems.

“*They just get him into his pyjamas because at the time they come it’s too early to go to bed ... if he went to bed that early he would be up half the night*”

The issue here for some people was the inflexibility of the service and lack of personal choice.

“We never got a choice of times, always just whatever time they can fit you into a rota ... the main problem is there’s no flexibility at all”

One person reflected the views of many of the interviewees when she said that there was a lack of any common sense approach when it came to the provision of home care for older people. She felt that care workers were employed to assist people with the activities of daily living necessary to enable them to remain in their own home, and yet they were so restricted in the actual help they could give that it compromised their ability to meet that person’s needs. She believed that the domiciliary care service would benefit from a more balanced approach, in which care workers could use the remainder of their allocated time to assist the older person with smaller tasks such as putting the washing machine on, making a cup of tea, lighting the fire or even having a short conversation.
4.2.2 Independent Care Providers – some concerns

Some interviewees questioned the standard of care provided by private care agencies on behalf of the local Health and Social Care Trust. This concern was most commonly raised amongst interviewees in the Northern and South Eastern Trust areas. Four carers were particularly vocal on the issue and talked at length about their experiences. All agreed that it was difficult to achieve any continuity of care under their current provider because they tended to operate large teams of irregular care staff, rather than one core team of familiar care workers for each client.

One carer described how her husband’s weekly care package was covered by three different care agencies, which could lead to inconsistencies in his care. Her main concern was the high staff turnover at the agencies that meant there was little continuity in her husband’s care. The care team from one agency was particularly bad; they attempted to condense a 30 minute evening visit into 5 minutes. This was a severe knock to her husband’s confidence, as he liked to be given the time and the patience to try and carry out tasks as independently as possible. They stopped using this agency two years ago.

Two carers explained how responsibility for their relative’s care recently passed from the local Trust to an independent care provider. Both carers were distressed about the change as they were happy with the care they had been getting. From the outset they noticed discrepancies in the approach of the new care teams. Many of the care workers were poorly trained and uninformed about the needs of their client. They were untidy, disorganised and, at times, questionable in their hygiene practices.

Another carer had similar experiences of private care agencies in two different Trust areas. In both cases, she felt that her husband was not given the care and respect he deserved. These agencies, she believed, were poorly organised and staff were both inexperienced and disinterested. After discussions with their care manager and 3 months on a waiting list, her husband’s care provision was transferred directly under the local Trust. Since then they have seen a vast improvement in his care.
4.2.3 Additional Support

Family support
Almost all of the older people interviewed benefited from a lot of family support. Most relied on family members to do their shopping, laundry, housework, order prescriptions and provide transport to medical appointments. In most cases family members either prepared their meals or left food for the care workers to heat up and serve. People appeared to value the care and support provided by family and friends as much for its emotional and psychological benefits as for the more practical, physical assistance.

“If I didn’t have the family I had I might need more help, but I have a fantastic family. I’m very, very lucky”

While most people certainly depended on family to fill the gaps in their care, at least three interviewees with family said they relied mainly on the support provided by their domiciliary care workers. Like many of the older people interviewed, they were concerned that their relatives were busy with their own work and family commitments and did not like to ask for help too often or to become a burden. One interviewee who lived alone had, on more than one occasion, lain on the floor for hours after a fall waiting for her care worker to arrive rather than disturb her relative by using her emergency Lifeline button.

However, a few people suggested that finding an alternative source of support was not always easy. For example, one carer described how she used community transport to visit her husband when he spent a period in a nursing home. She really appreciated this service because she did not want to depend on her daughters for lifts. When her husband was back home and fit enough to go out, she contacted community transport again only to find that the service had been temporarily suspended due to a lack of volunteer drivers in their area. This left the couple feeling very frustrated; they believed that a rural transport service would make a huge difference to older people in their area. Instead, they were left again to depend on family members.
Private support
Two people said they had no family support whatsoever and both had to pay privately for additional services not covered by their domiciliary care package. One person was almost completely immobile as a result of severe osteoporosis but had to pay for a meals service and an extra weekly shower. The other person received a reduced service at weekends and, as a result, had to pay a care worker privately for incontinence care and to make tea. They both employed someone privately to do housework, laundry and shopping.

However, even those who had a lot of family support paid for additional services. Many people employed a private cleaner and some paid for a meals-on-wheels service to provide some of their meals. A few people paid for additional overnight or day time sitting services.

A carer talked about the financial strain of providing extra care for her relative that was not included in his care package. For example, her relative is very unsettled at night so she paid for a private overnight sitter twice a week so she can rest. Other hidden extras such as transport and specialised equipment also added to the cost.

Other medical support
Many people commented on the good support they received from their social worker and local GP. However, a few people did raise issues with accessing physiotherapy and occupational health services. This seemed to be particularly problematic in the Belfast and South Eastern Trust areas.

Two older people believed that they would benefit from physiotherapy but neither had been offered this service since they left hospital 1 and 3 years ago respectively. They both felt that they made good progress with their mobility with the aid of a physiotherapist in hospital, but since returning home both had been largely immobile and confined to either a chair or bed during the day. One suggested that getting back on her feet, even if it was only so she could move to the toilet and back unassisted, would be a huge boost to her confidence.
Two carers also said they had found it difficult to access physiotherapy for their relative. In one case, a carer recalled how medical staff in a specialist stroke unit advised that her husband would not benefit from physiotherapy and that he would be permanently bed bound and incontinent. She insisted on seeing a physiotherapist despite this advice and the intensive treatment he received as a result improved his quality of life immeasurably. Eight years later he can still get up, sit in the chair and use the toilet.

Five people identified difficulties accessing equipment from Occupational Therapy services. They had all been waiting at least 3 months, and in one case almost 2 years, for equipment that would help them to live more comfortably and more independently, such as a wheelchair, shower chair, support rails and safety ramp. One man, who had recently started receiving domiciliary care after an illness that left him confined to a wheelchair, spent 8 months in hospital but the OT service only arranged to have his house made suitable for a wheelchair on the day he was discharged. Consequently, his house was a building site for the first few days he was at home.

“The carers that come here are terrific ... but outside of that, for anything else I've tried to get, I've found it very difficult to get any help”

### 4.2.4 Maintaining Independence

Most of the older people interviewed felt that domiciliary care helped them to maintain their independence. Perhaps more importantly, it allowed them to stay in their own home. Many people said they would be reluctant to go into residential care. Even those who identified problems within the domiciliary care service said they would rather receive care at home than be in a hospital or residential setting.

“My one fear is having to go into a home”
One person believed that domiciliary care enabled her to maintain an active role in her local community and she was still chairing a fundraising group which she helped to establish more than 20 years earlier. Another person had recently moved from her own home into sheltered accommodation, a move that she believed helped her to sustain a sense of independence while getting that extra bit of support she needed. Her social life had also improved because the Fold organised activities and social events for residents. She felt that it was the older person’s responsibility to work towards retaining whatever independence they could.

“It’s up to you yourself you know, some people lap it up but I like to keep independent”

However, a few people expressed uncertainty that domiciliary care did help them remain independent. Some people said that long-term illness, mobility and sight problems had left them more or less confined to the house and, as a result, they had lost confidence and any sense of independence. Those with little or no family support added that, as a result, they could at times feel socially isolated.

Four people felt that issues with transport were preventing them from being as independent as they could be. Two of these people were recently informed that they could no longer attend their regular day centre and charity club because the voluntary transport provider was not able to safely assist them from their house to the bus. Another person said that they would benefit from financial assistance with travel costs to medical appointments so that they could arrange their own transport independently rather than always relying on friends and family for lifts.

One man who lived on his own felt that, while domiciliary care workers do help him to remain independent, his daughter’s help was more important in this regard. He was very proud, however, that he had continued to live alone for so long and never had to call on a member of family at night for assistance.
4.2.5 Impact on the Carer

Domiciliary care was also important to families who wanted to keep their elderly relative at home, rather than see them go into residential care. Almost all the carers interviewed expressed concerns about the standard of nursing home care. One carer was confident that the decision to take her husband home from hospital after a long, debilitating illness was instrumental in his recovery, despite being advised at the time that nursing care was the best option.

It was evident that most carers also appreciated the psychological benefits of home care for the family of the person being cared for. One carer described how difficult it was for the whole family when her mother spent a year in a nursing home. They felt their lives greatly improved when a domiciliary care package allowed their mother to move back home.

“My experience of keeping [husband] at home has been good for me psychologically”

However, where domiciliary care can enable an older person to remain at home, it can also divest the full-time carer of their independence. More than half the carers interviewed talked about the impact of their relative’s condition on their family and social life. In most cases it was the spouse of the person in receipt of care. One carer said that since her husband became dependent on an intensive home care package, she had lost the freedom to come and go as she pleases, to work part-time or to have friends call at the house. That the service her husband receives is unreliable only compounds this loss of independence.

“My privacy is totally gone now ... I don’t have any time for myself much”

Another carer was in a similar position. She felt she had lost a lot of friends through her husband’s illness. As a couple, they had an active social life, but now caring for her husband coupled with her own mobility problems meant she rarely left home.
One carer described how her husband’s physical and mental health was deteriorating; he had become increasingly aggressive and his personality had changed to such an extent that she no longer recognised him as the man she married. However, she did not feel they were getting the help necessary to enable them to cope with this change. She believed there should be a more holistic approach to domiciliary care; for example, she suggested that her local GP should work more closely with the domiciliary care team and treat her and her husband as one package, rather than as two individuals.

Other carers also said they found it difficult to get additional support for themselves, as full-time carers. One carer explained that while home care had enabled her husband, who was in the advanced stages of Alzheimer’s disease, to remain at home, it had restricted her independence. She felt that as her husband’s condition deteriorated she needed more hours of meaningful respite.

Another carer was similarly happy with the level of care her husband had received in the five years since he had a stroke, but she continued to find accessing a respite or sitting service problematic. On one occasion she had to pay a substantial amount for an overnight sitter while she was on holiday because her social worker said she had “no hope” of getting respite at home. She felt that the cost involved made a sitting service prohibitively expensive for many carers who needed the occasional afternoon or night away. She suggested a solution might be a specialised respite facility for older people, as her husband was reluctant to have respite in a nursing home because of negative associations with residential care.

“They should have somewhere people could go for respite that’s not institutionalised like a nursing home ... somewhere for people who don’t have dementia where there’s company you could chat to, that’s more relaxed”
4.2.6 Concerns about the Future

Most people interviewed about their experience of domiciliary care were generally happy with the level of care they received. However, it was evident throughout the interviewing process that people are very concerned that their services are under threat and that financial cutbacks could result in their current care package being either reduced or removed altogether. This sentiment was particularly strong amongst interviewees in the Western and Northern Trusts; at least one older person in each area had recently experienced a reduction in their domiciliary care service.

One older person and her carer had recently been informed that a new domiciliary care system was soon to be implemented in their area and they worried that this would mean less time and greater inconsistency. A few interviewees had already seen a recent reduction in their care package and they feared that more services would be taken away in the future. However, all were of the opinion that domiciliary care should increase with time, age and deteriorating health, rather than diminish.

“We’re happy the way it is, it’s working really well at the minute. The thing is she will always need this, she’s not going to get better, we need it in place and we need it to stay in place”

One person suggested that people had to be assertive in order to get a service that met their needs.

“There is a general drive to chip away at it ... you have to keep fighting for what you get”

A man in receipt of domiciliary care and his main carer, his wife, were asked if they had ever heard of the Reablement service in the Southern Trust. They both agreed they had not heard the term, but when the concept was explained to them they felt it was aimed at reducing people’s care package and cutting down on the number of care workers. They suggested that it was dangerous to cut corners when caring for the older population.

“[Elderly care] it’s not something you can save money at”
4.2.7 Six Case Studies on Domiciliary Care

The following six stories help to illustrate the issues and emotions experienced by older people in receipt of domiciliary care and the impact of home care on their families. These cases were selected from the 38 interviews carried out by the Patient and Client Council across the five Health and Social Care Trusts.

A Centenarian’s Experience of Domiciliary Care

A 100 year old lady explains why the help she receives from her domiciliary care workers is so important to her:

“\[The carers each have their own routines and it makes it different for me, it keeps it interesting. The most important thing is, when they come through the door they treat me with respect. I am not embarrassed, nor do they make me feel small. They come in to me and they are so willing and pleasant and that makes such a difference to my day\]

She has not one complaint to make about the care workers who have attended to her over the past seven years. She appreciates the respect and consideration they show her. For example, as she is blind the carers always knock and call out to tell her who is there before they come in. The support they lend means even more to her as she has little family left:

“I have nobody ... so these girls are my mainstay, do you understand?”

She remained quite active until she lost her sight about five years ago. Her blindness can leave her feeling isolated at times, especially as she cannot use the phone:

“When the girls leave me here I’m helpless in terms of outside contact”

However, she wishes to remain in her own home and the care she currently receives enables her to do so. Even after a recent stroke she refused to stay in hospital as she felt it would be “a sin” to take up a hospital bed when someone younger and more able could use it:

“I’m happy here at home ... every day is a bonus”
A Flawed Service

A lady with Parkinson’s disease expressed concern that inconsistent care and a lack of common sense in approach was resulting in a flawed domiciliary care service:

“Nine times out of ten it’s all right, but there’s a whole lot I don’t agree with. Some of the carers haven’t time, they rush in and out. I timed a girl one day, after 5 minutes she was away. She left my tea with my dinner, but by the time the dinner is eaten the tea is cold. Its wee things like that, they don’t realise”

She pointed out other inconsistencies in the care she receives, especially when members of her regular team are on leave:

“The carers, they never come in at the same time. One could come at one time and then maybe you’d have another one the next day at a different time. One regular carer was off sick for three months and my head was light at the many different faces. Some run in as quick as they can and away again and some would do all they can for you”

She felt that the quality of care was compromised because care workers are so restricted in the activities they can assist with:

“I’ve a big house and a big bathroom down there but there’s nobody to give me a shower, they’ll not let the carers shower me because there’s a wee step around the bottom of the shower, you have to get one of these wet rooms in. To me that’s stupid because I have to pay an outsider to give me a shower even though all those carers are coming in”

Her mobility is very poor as a result of Parkinson’s, but care workers are not allowed to help with household tasks like hanging out washing or lighting the fire. She suggested that their approach to meal preparation was also illogical:

“They say they’ll make your dinner when really you have to prepare meals for them to heat up. If you could make your dinner yourself you wouldn’t need them to heat it up. For instance, if you had nobody to prepare it for you or leave it for you and you couldn’t do it yourself, who’s going to make it for you? If you don’t have something there for them to warm, you don’t get anything nourishing, just bread and jam”

However, perhaps the biggest limit on her independence was a long wait for a ramp on her front door to allow safe access in and out of her home.

“I can’t get out, I’m a prisoner in my own house ... the days are desperately long, it’s really bad”
Independent Care Providers – one carer’s concerns

A carer spoke about the poor standard of care her husband received from independent care providers in two different Trust areas. After a debilitating stroke seven years ago, her husband’s initial care package was shared between by two private agencies. She felt that the agencies essentially competed for his custom and the care he received thereafter was extremely poor. The couple then moved to a different Trust area in order to be closer to relatives. Again, his initial care package was provided by a private agency:

“They were young girls who didn’t know how to care for someone, they were more interested in planning their weekend and when they were having their hair done, than caring for my husband. I found this company a complete disaster. The girls went to shower my husband on one occasion and I found them drying him with a bathmat. They would frequently turn up late and were claiming for times stating they were here when they were not”

She was alarmed at the number of care workers who attended to her husband:

“Over a period of 2 days I counted 16 different members of staff, I found this disturbing”

The carer explained her concerns to her husband’s care manager and stated that she wanted his care to be provided directly by the local Trust. Since this has been put in place, they have seen a vast improvement:

“They are very good, they do not put a time limit on his care, they stay as long as they are needed and are very caring towards myself and my husband. They are very accommodating and work round our needs and what we want”

The carer felt that the problem with private agencies was lack of training:

“A lot of these girls will never have worked in the caring profession and they receive little or no training, they shadow a person for 1 to 2 weeks and then they are on the job, then a few weeks later they have another new member of staff shadowing them”

She believed that tighter regulation for independent providers was essential:

“There really is something wrong with social care; they should start with better training and secondly do something about those private agencies, because they are getting away with murder”
Adapting to Home Care after Hospital

A man receiving domiciliary care for almost a year after a period of hospital care spoke along with his main carer, his wife, about their experience of the service. The carer described how the long hospital stay had left her husband very incapacitated, and when he initially came home they were both anxious and unsure about how home care would work. However, she felt that the input, advice and support provided by her husband’s domiciliary care workers were essential in helping them adapt to their new home situation.

“If I hadn’t had the care assistants ... because I didn’t know where to begin to look after him. The hospital wanted to send him to a nursing home, but he wasn’t doing very well in hospital so I wanted him home. Without their help I could not have got to the stage we are at today, because they could advise me, which they did, and the very fact that they were coming in shared my worry, that I could rely on them because they were experienced and I wasn’t. So without them my husband wouldn’t be walking, talking and sitting here today”

Due to the hard work and dedication of his carer, supported closely by the home care workers, his progress over the year has been slow but remarkable.

“It has been a long, slow process, you have to set your goals, but it’s worked”

His condition has improved so much since he started receiving domiciliary care that the original four daily visits from care workers have been reduced to two as the carer believes that, with the help of a weekly respite service, they can now manage on their own during the day. She describes respite as an invaluable aspect of home care because it improves the quality of the carer’s life.

Both agree that being at home has been essential to his recovery, and that this would have been a much more difficult journey without the input and support of the domiciliary care team.

“I am one person who could not cope without them and I will always be grateful for it. I would recommend it to anyone”
An Inconsistent Service

A lady in receipt of domiciliary care for almost ten years talked about her experiences along with her daughter, who is her main carer. Both women found it difficult to rate the quality of care as it was so variable:

“The quality of care varies with the worker ... it’s good and it’s bad, it just depends, depends on the carers”

She now has a regular team of care workers, but it took a long time to achieve this continuity of care. Before the current team was established many different care workers came to assist her at home, which made her feel nervous and unsettled - they all felt like “strangers”. Her daughter identified two main issues with the home care service her mother receives:

“The only problem with the carers is the communication and the rushing, sometimes they rush ... they could communicate more with you, talk to you more, that’s just it, they do what they have to do”.

The service is so rushed that the care workers do not always stay for the allocated 30 or 45 minutes:

“Usually when I’m here they don’t rush as much ... if I’m not here well they can have her in bed in 5 minutes, toilet and all, the whole lot”

Her mother agreed that this was the case:

“In fact I dread it when [daughter] is away, when she’s here they’re fine. It’s a race ... sometimes if I’m not washed enough [daughter] puts my finishing touches”

The home care does enable the lady to live at home with her daughter, and for that reason she is content despite these underlying issues. However, both mother and daughter are concerned about the future of the service. The social worker has informed them of a new system to be implemented in their area which they fear will make an already imperfect service even less reliable and that the older person will have even less choice over the care they receive.
A Carer’s Perspective on Domiciliary Care

A carer whose husband has been receiving home care for more than 5 years offered her perspective on the service. Six months before the interview took place, responsibility for her husband’s care passed from the local Trust to an independent provider. From the beginning she was unhappy with the new service:

“The girls are very pleasant and willing to help, I just felt they were not properly trained, they just didn’t have the information they needed”

In the first few weeks care workers repeatedly called her husband by the wrong name and it took more than a month for the care provider to issue an actual care plan. She felt that fault did not lie with the girls, but with the organisation:

“I don’t blame the girls. They didn’t have the information and I just don’t think they were well enough trained. I think that the girls should have had all that information before they went out to a new client, they should’ve even called to meet their client before they started coming”

Her husband’s care team consists of about 40 workers and with such large numbers, inconsistencies are difficult to manage. Many of the care workers lack training or are untidy in their work and appear to have little respect for the family home.

“I go in some mornings and there are wet trunks lying behind the door, a sheet lying over there. I’m here, I can pick them up, but somebody on their own?”

Not long after the new care team started, no-one turned up for a morning visit. After several hours and multiple phone calls to the provider, no one could offer an explanation as to why. Eventually she called on a family member to assist with her husband, who by this stage had been in bed for 15 hours, was wet through and extremely uncomfortable. The incident made her question how people living alone cope without a full-time carer to pick up where the home care providers fall short.

“I do feel that those issues need to be addressed, for [husband], but really for other people who maybe wouldn’t have that support system at home for them”

She is unsure if home care helps older people maintain independence. It enables her husband to stay at home, something he has always fought for. However, as a carer, home care has robbed her of independence and privacy.

“My privacy is totally gone … I don’t have any time for myself much”
4.3 Public Views on Domiciliary Care

This section explores perceptions of domiciliary care amongst the wider public. 16 small discussion groups were held with people not receiving a home care service and with carers’ groups to gain insight into attitudes towards domiciliary care and opinions on paying for health and social care. Short questionnaires on domiciliary care were also distributed to attendees of the Balmoral Show.

4.3.1 Focus Groups

A total of 170 people took part in 16 focus groups held across all Health and Social Care Trusts. They were asked for their thoughts on domiciliary care services for older people.

The majority of people had little or no direct experience of domiciliary care services for older people. However, just less than a fifth of people said they had experience of either receiving home care themselves or caring for someone in receipt of home care, although it is worth noting that not everyone was referring to a domiciliary care service for older people. Most of those said they had a positive experience of home care and valued the help provided by their care workers. Some people did comment on issues they had with the service such as time pressures, poor continuity of care, inconvenient or irregular call times and inflexibility.

There was a certain amount of confusion over the terminology “domiciliary care” amongst members of some groups who had no previous experience of home care. However, everyone understood what home care was once it was explained to them.

“Health Boards/Trusts need to use plain English – the ordinary person does not understand their terminology”

Two groups felt that home care was difficult to access and really only allocated to people who were not able to get out and about:

“If you can move you’re not entitled to home help”
If you needed help as you get older, what kind of services could be provided that would help you stay at home?

Many groups identified personal care, suitably equipped homes and help with meal preparation as services that would help them to remain at home as they get older. Some also added that social activities for older people, a reliable community transport service and help getting out and about would enable people to maintain their independence for longer. A respite or sitting service for carers was mentioned by a few groups as an essential service for full-time carers looking after an older person at home.

However, perhaps the most commonly mentioned service, and that which prompted the most discussion amongst groups, was assistance with the smaller tasks of daily living such as cleaning, laundry, changing beds, shopping, lighting the fire, putting out bins and making cups of tea. Many people felt that these less intensive tasks were just as fundamental in enabling older people to remain at home as personal care. One person reflected the thoughts of many others when they suggested that personal care could not be taken in isolation from the household and help with tasks such as cleaning, laundry and changing beds should be given if there was a need.

“Pensioners need help with things like cleaning, changing beds, cleaning windows – we shouldn’t have to pay for it”

In one focus group all ten members had recent experience of domiciliary care, and while everyone agreed that the standard of care was mostly good, many felt that the range of assistance given had diminished over the year and the old ‘Home Help’ system was better.

“Go back to the role of the old fashioned Home Help”

This discussion was also raised in other groups. People questioned why Home Helps were no longer allowed to carry out certain tasks such as housework or laundry. One lady who was 90 years old and registered blind made the following comment:
“I can wash and dress myself, I come to the luncheon club 5 days a week for a proper dinner and my family come at the weekends. What I can’t do is clean my house! So what good would domiciliary care be to me?”

However, a few groups, rather than listing activities they envisioned they might need help with in the future, suggested that if a domiciliary service was going to enable older people to stay at home it had to be flexible and able to be adapted to the needs of each individual. They felt that the current service was too restrictive to really enhance the lives of those who depended on the care provided. One group suggested that people needed more choice over the nature of the service they received and the kinds of assistance they felt were most essential to them.

**How would you find out about services or activities available in the community?**

Most groups identified family as their main source of information about services and activities that were available in their community. One group went further to suggest that, if most older people tend to talk to their families, then more focus should be put on advising families on how to access information and support.

Many people also said they would approach a community representative or charitable organisation for advice; examples given were a local community worker, library, church, women’s group, local council office or town hall, Age concern, Salvation Army or their regular social group or luncheon club. Some people said this was information they could research themselves through the internet, local newspapers or the notice board at the local pharmacy or GP surgery. This type of information was something people felt they heard about through word of mouth or chatting casually with friends and neighbours.

However, a few groups agreed that they found it difficult to access information about available services and individuals expressed concern that only those people who were well informed and knew how the system worked were able to access services, leaving those who struggled at a disadvantage.
Who do you think should pay for care?

The majority of people believed that older people should not have to pay for domiciliary care. They felt quite strongly that if people had worked all their lives, paid taxes and National Insurance, then they were entitled to be looked after in their older years. Some people added that many pensioners could simply not afford to pay for home care as they struggle to get by already.

“People who have paid national insurance all their lives should not be asked to pay – the older generation worked hard in jobs in linen mills/ship yards and lived without and who is going to look after us now?”

However, some groups had mixed feelings about this subject. Many people did feel that if people could afford to pay then they should at least contribute to the cost of their care.

“People who can afford to pay, should pay for it”

One group suggested that people today rely too much on government assistance, instead of looking at the more traditional sources of support such as family.

“Years ago your family just had to look after you and there was no talk of pension credits or anything. Now everybody wants something for nothing”

A few groups agreed that the question of who should pay for care was a very necessary debate, considering the ever-increasing older population. However, it is worth noting that some participants were reluctant to enter into a discussion about who should pay for care; it was evidently an uncomfortable subject for some.

Have you ever heard of Reablement?

Almost none of the focus group participants had ever heard of Reablement. A few people thought they had heard the term before, but were unsure about what it actually was.

However, when the concept of Reablement was explained to the groups, some people said they or someone they knew had received a similar service for a short
period after being discharged from hospital. Most people who commented further felt that Reablement sounded good in principal because it would help people to be more independent. However, a few groups expressed concern that it would be too expensive to implement such an intensive service at home, or that once the service was removed it would be difficult to access help again in the future if it was needed.

Other Comments
Some groups entered into a more general discussion about the domiciliary care service. Many were concerned that vulnerable people are not properly cared for in our society. They felt that a more joined up approach to services was necessary, in order to avoid duplication and ensure that older people received a wide-ranging service. It was suggested that more investment in training for domiciliary care workers was essential, because the quality of care provided was so inconsistent. Social isolation was also identified as an issue for older people who live alone and do not have the emotional support of family.

“Who is meant to change bedding of an elderly couple who have no family? Health Care, the clue is in the terminology. Are we caring for their health?”

4.3.2 Short Questionnaire

Members of the general public also had the opportunity to express their views on domiciliary care. A total of 253 people attending the Balmoral Show in May 2011 took the time to complete a short questionnaire on domiciliary care.

More than 80% of people who completed a questionnaire indicated that they were not in receipt of domiciliary care and that they did not care for someone who was in receipt of a home care service. Therefore, in the main, the response represents the opinions of those who currently have no experience of domiciliary care.
Who should provide domiciliary care?

Just over half of those who responded felt that the provision of domiciliary care should be shared between the health service and the family of the person who needs care. However, a substantial minority of 44% indicated that the health service or government should be solely responsible for providing this service.

Figure 6: Who do you think should provide domiciliary care services?

Some people added that the question of who provides domiciliary care depends on the individual case. For example, some suggested that if a person has paid National Insurance all their life then the health service should provide their care. For a few commentators, it was the medical condition of the individual that should dictate who provided their care.

“If not too bad then the family ... only when you really need lifting and laying, then the health service”

Only one person suggested that the public rely on the government too much and that people should be responsible for their own care in later life. However, a more common response was that a changing social landscape meant it was no longer realistic to expect families to take on the provision of home care:

“It was always the family at one time, but social change means that there is no-one to look after, people are further apart.”
Who should pay for domiciliary care?

Almost two thirds of people said that the health service or government should pay for domiciliary care.

Figure 7: Who do you think should pay for domiciliary care?

Some people explained this response by saying that they had paid for this service over the years through taxes and National Insurance and a few added that the health service should only pay for those who had also paid into the system.

“Anyone who has ‘contributed’ all their life shouldn’t have to pay”

Most of the remaining third of respondents felt that the cost should be shared between the health service and the person receiving the care.

“Everyone should pay their contribution ... Government shouldn’t pay for those who don’t”

However, more than half of the number of respondents who went on to explain their choice of answer added that the person receiving care should only contribute if their income allowed.

“Dependent on income of person(s) receiving the care”
Does geography affect your experience of domiciliary care?
People were asked to consider if the location of a person’s home might affect the likelihood of them receiving a domiciliary care service. Almost two thirds of people (62%) believed that it would.

The majority of those who commented felt that people living in rural areas were at a disadvantage. The most common issues raised were poor accessibility and lack of amenities in rural areas. Many people were of the opinion that people living in urban areas had better access to services:

“Less variety in rural areas, more expensive and less facilities”

Some people felt that staff working in rural areas faced additional pressures which could mean a less efficient service in the countryside. Examples given were longer travel times between calls and difficulty accessing isolated dwellings, which made organising a high volume of short calls more impractical. A few people added that, as a result, there was a problem of understaffing in rural areas.

“The 15 minutes allocated doesn’t make sense in a rural area”

Some people were of the opinion that, when it came to providing services, it was just easier to ignore those living in isolated parts of the countryside.

“Countryside – out of sight, out of mind!”

However, for a few commentators, access to domiciliary care services was not a question of rural or urban, but of geographical location in terms of Trust area.

“Depends what Trust you belong to - different criteria in different areas”
Do you think older people should always be supported to remain in their own home (if this is what they wish to do)?

Most people felt very strongly that if older people wished to remain in their own home then they should always be supported to do so. However, while only 1% of the 253 people who completed the questionnaire said that they disagreed with this statement, some people did add that older people should only be supported to remain in their own home under the right circumstances. In cases of very poor health or advanced age, helping people to remain at home was not always thought to be the best approach.

“Depends on the situation and how much care they need”

Some people were of the opinion that the home environment was much more beneficial to the health of the older person, but only if the quality of care provided was good. In order to achieve the necessary standard of care, individuals suggested that the domiciliary care service must be better funded, that care workers should be given more time to spend with each older person and that providing company should be just as integral to the service as providing practical care. Under these circumstances, staying at home would be the best option for the older person.

“Stay at home, you last longer”

Most people felt, however, that the decision should be left to the individual and if they wished to remain in their own home then they should be supported to do so.

“The individual’s wishes should be respected”
5.0 Conclusions

Domiciliary care is undoubtedly an invaluable service to many older people. Most of the older people who contributed to this report clearly appreciate the support of their home care workers, without whom many simply could not cope with the basic activities of daily living. Carers also acknowledged the benefits of domiciliary care; both for the assistance given and the reassurance it offers to families that their relative has regular contact during the day.

The findings of the questionnaire indicate that most people are satisfied with the service they receive and rate the quality of care highly. However, the nature of domiciliary care means that the service cannot simply be analysed as a range of tasks delivered to older people. The information collected in this study reveals that domiciliary care means more to older people than just physical help with everyday activities. For example, many older people valued the service because it helped alleviate their sense of social isolation. Domiciliary care workers are sometimes the only personal contact an older person has during the day and thus they provide much needed stimulus and conversation, especially to older people living alone.

The interviews in particular give insight into the extent to which many older people physically and emotionally depend on domiciliary care. Effective communication and continuity of care are central to ensuring that this experience is a positive one. It was clear from the interviews that many older people can find it difficult to come to terms with the domiciliary care service, especially coping with people coming into their home on a daily basis – a transition that is all the more difficult for those who have little continuity as regards care staff. This lack of continuity can prevent older people from building relationships with care workers who are often undertaking quite intimate tasks, as well as making it more difficult for care workers to identity poor health in the person receiving care. Familiar care workers who communicate effectively are crucial in helping older people feel like they are being treated with dignity and respect in their own homes.

Other inconsistencies with the domiciliary care service were identified, such as the short duration of care worker visits, inconsistent quality of staff and issues around
flexibility. These limitations on the service were voiced even by those who had a largely positive experience of domiciliary care. This is reflected in the fact that 87% of people who responded to the questionnaire rated the quality of care as ‘good’ or ‘very good’, and yet nearly a quarter of all respondents felt that home care only improved their quality of life ‘a little’. In many cases people felt the care provided only covered their most basic needs. The vast majority of older people continue to rely heavily on the support of relatives and almost a third pay privately for additional services.

One of the most valued aspects of domiciliary care is that it enables people to remain in their own home, rather than face the alternative of residential or nursing care. Even those older people who identified problems with the domiciliary care service said they would rather get care at home than in a residential setting and almost all the carers interviewed expressed concern with nursing home care. However, this perceived lack of appealing alternatives to home care also has implications for social isolation amongst older people who are reluctant to leave their home but struggling to cope both physically and psychologically.

This report reveals the very real concerns that people have about the future of the domiciliary care service, especially as many older people are only too aware of current discussions around budgetary constraints. People are anxious that the prospect of financial cutbacks and potential changes to the service will threaten the stability of current care packages and disrupt established routines which are of the utmost importance to older people. This fear over future reduction in services, and even fear of losing the service entirely, was especially evident during the interviewing process. While some interviewees expressed this fear openly, many were more reticent on this subject or reluctant to say anything which might be construed as critical of the service. These fears must be addressed before a more wide-ranging service which encompasses the physical, social and psychological needs of older people can be achieved.
6.0 Recommendations

This report has raised a number of issues in social care for older people. The recommendations have been divided into two sections – the first reflects the concerns raised by older people and the second section sets out the PCC’s view of the actions that could be taken in order to ensure the delivery and sustainability of domiciliary care services in the future. The recommendations are not in order of priority and are all, therefore, of equal importance.

Recommendations arising from issues raised by older people

- Care providers must ensure that their staff are aware of the need for maintaining dignity and respect both for the person receiving care and relatives caring for them.
- Health and Social Care Trusts and Independent/private providers should ensure that their staff receive consistent training so that the privacy, dignity and safety of the person receiving care not only meets minimum standards but is maintained at the highest possible level.
- Continuity of care (i.e. delivered by a designated team) must be ensured in order to make sure that any risk to or changes in the needs of vulnerable adults are identified quickly.
- Commissioners should look to provide emotional support within care packages that includes options such as a befriending service in order to address the social isolation of many older people.
- A clear patient care pathway should be established which ensures a smooth transition from hospital to care at home.
- Older people should be provided with a range of choices which both address their needs and are seen by them as desirable options for their future care.
Recommendations from the Patient and Client Council:

- A multi agency group should be established (to include transport and housing providers as well as health and social care) which is focused on practical outcomes for older people who need support.

- Stakeholders should facilitate opportunities for all to have discussions about how domiciliary care is assessed, planned and delivered in the future. This is to ensure that service users, carers and the public have the chance to contribute to the future of domiciliary care.

- Domiciliary care provision should link clearly into wider policy initiatives such as Ageing Well, Investing for Health and the Older People's Strategy in order to ensure that older people receive a joined up service.

- There should be an ongoing evaluation of the implementation of Reablement schemes. Reablement should be incorporated into the wider strategic framework for supporting the care needs of older people.
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Appendix 1

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## Appendix 2

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Appendix 3

DOMICILIARY CARE PROJECT

INFORMATION SHEET AND QUESTIONNAIRE

The Patient and Client Council wants to hear your views about domiciliary (home) care. For the purposes of this questionnaire domiciliary care is defined as:

“…personal care and domestic services that are necessary to ensure an acceptable level of health, hygiene, dignity, safety and ease of people in their home”. NISRA (Northern Ireland Statistics and Research Agency) 2009 Survey on Domiciliary Care.

Many older people receive home care and it is important that their opinions are recorded. We would very much like to hear your views about domiciliary care so that we can get a picture of what is being provided in the community. It would also be helpful to identify the positive and negative aspects of domiciliary care and what domiciliary care means to you.

We would, therefore, very much appreciate it, if you would complete the questionnaire on domiciliary care. Your views will help inform decisions made by your local Health and Social Care Trust. Your opinions will also be made available to the Department of Health, Social Services and Public Safety (DHSSPS).

If you decide to complete the questionnaire (which we hope you will), please be assured that all the information you give will be treated confidentially. No one will be able to identify you from the information you give us. All questionnaires will be stored safely in a locked cabinet.

If you have any queries about the questionnaire, please ask one of the staff who distributed it or telephone or write to Avril Craig, Research Officer, Patient and Client Council, 25-27 Wellington Place, Belfast BT1 6GD. Tel: 0800 917 0222 or e-mail avril.craig@hscni.net.
Domiciliary Care Questionnaire

1. How long have you been receiving home care (approximately)?
   Please specify
   ________________________________________________________

2. What kind of activities do you get help with?
   **Please tick all that apply**

   - Getting out of bed
   - Washing / Bathing / Showering
   - Getting dressed / Undressed
   - Assistance to take medication
   - Preparing and/or heating and serving food
   - Going to bed
   - Help with toileting
   - Other (please specify)  ___________________________________

3. How much help do you get per week (number of hours/minutes)? Please specify
   ________________________________________________________

4. How many days a week do you get help? Please specify?
   ________________________________________________________
5. Overall how would you rate the quality of care you receive?
   Please circle one
   
   Very good    Good    Satisfactory    Poor    Very Poor

6. Did you feel that your views were taken into consideration when the social worker came to talk to you about the help you might need?
   
   Yes   No

7. Were you told about what help you would get?
   
   Yes   No

8. Did you feel that this would meet your needs?
   
   Yes   No

   Please comment
   
   __________________________________________________
   __________________________________________________
   __________________________________________________

9. Do you receive any other help that your care worker does not provide (for example, from wife/husband/partner, friends, relatives, neighbours, or others)?
   
   Yes   No

   Please specify
   
   __________________________________________________

10. Do you pay anyone privately to help you?
    
    Yes   No

    If Yes, what tasks do they do for you
    
    __________________________________________________
11. **What other services do you access in your area? Please tick all that apply**

   Community transport [ ]  Mobile library [ ]  Handyman service [ ]

   Grocery delivery service (e.g. Tesco) [ ]

   Other [ ]  Please specify
   __________________________________________________________

12. **If you needed information about local services who would you contact first? Please tick one**

   Friends [ ]  Relatives [ ]  Neighbours [ ]  Other [ ]

   Please specify
   __________________________________________________________

13. **If you needed help in an emergency who would you contact first? Please tick one**

   Friends [ ]  Relatives [ ]  Neighbours [ ]  Other [ ]

   Please specify
   __________________________________________________________

14. **How much does the help you receive from your home care worker improve your quality of life? Please tick one**

   A lot [ ]  A little [ ]  Not at all [ ]

   Please explain?
   __________________________________________________________
15. Are there any other kinds of help which would help you live more independently?
   Yes ☐  No ☐

   Please specify.

   _________________________________________________________________

16. Any other comments.
   Please use this box to tell us more about your experience of domiciliary (home) care or to make any other comments about domiciliary care

   _________________________________________________________________

17. Age Group (please tick one box)

   65-69 ☐  70-74 ☐  75-79 ☐  80-85 ☐  85-89 ☐  90+ ☐

18. Are you? Male ☐  Female ☐
   Please tick one box

19. Nearest town or village  _______________
   OR first four digits/letters of postcode  _______________

Thank you for taking the time to complete this questionnaire. Please return to the Patient and Client Council in an envelope marked FREEPOST Patient and Client Council. This will ensure that it will be returned directly to us.
Appendix 4

Short Questionnaire for Domiciliary Care

The Patient and Client Council are seeking your views about domiciliary (home) care. Domiciliary care is when someone gets help with everyday tasks such as getting out of bed, washing and dressing, toileting and heating food. These are just examples. Answering the following questions will help us get a picture of what the public think about domiciliary care services

1. Do you receive domiciliary care? Yes □ No □

2. Are there any circumstances where people should pay for domiciliary care? Yes □ No □

3. Do you think that continuing to support older people at home is affordable? Yes □ No □

Please circle one answer to each of the following statements

4. Where you live influences your access to domiciliary care services

Strongly agree □ Agree □ Not sure □ Disagree □ Strongly disagree

5. Older people should be supported to remain in their own home (if this is what they wish to do so)

Strongly agree □ Agree □ Not sure □ Disagree □ Strongly disagree

6. Any other comments


Remember you can contact your local office on

**Telephone 0800 917 0222**

or email **info.pcc@hscni.net**

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**Belfast Area**
1st Floor, Lesley House
25-27 Wellington Place
Belfast BT1 6GD

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Houston’s Mill Site
10a Buckna Road
Broughshane
BT42 4NJ

**Southern Area**
Quaker Buildings
High Street
Lurgan BT66 8BB

**Western Area**
‘Hilltop’
Tyrone and Fermanagh Hospital
Omagh BT79 0NS

**South Eastern Area**
1st Floor, Lesley House
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Belfast BT1 6GD