Health and Social Services for Older People (HeSSOP)

Consulting older people on health and social services: A survey of service use, experiences and needs

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National Council on Ageing and Older People

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The HeSSOP report was prepared on behalf of:

National Council on Ageing and Older People

The Western Health Board

Northern, East Coast and South Western Area Health Boards
(Eastern Regional Health Authority Area)

Foreword

As Chairperson of the National Council on Ageing and Older People, it gives me great pleasure to present this study of older people's views on health and social services.

The study provides an evaluation of health and social services from the perspective of older people themselves and provides an opportunity for older people to express their lifelong care preferences. The National Council on Ageing and Older People strongly endorses the principle that older people should be involved in the development, planning and evaluation of their health and social services. This is underpinned by the principle that a health service fit for older people is a quality service that benefits everyone.

The research allows the voices of a large representative constituency of older people to be heard on their needs and aspirations for health and social services. Almost one thousand older people were randomly selected and invited to share their views and experiences on services they have used and their service needs. The approach taken by this study engaged older people in a consultative process at the outset to ensure the research design reflected their views and priorities and the Council is particularly pleased about this.

Through this study we hear older people strongly assert their preference to continue living at home within their own communities, being cared for by family or friends with complementary support from professional services. Overall the study provides us with a very comprehensive picture of the situation of older Irish people at the turn of the millennium.

The report illustrates the challenge for health and social service providers to develop systems for consulting directly with older people and their representatives in an appropriate and meaningful way. The report gives detailed consideration as to how such consultation can be implemented in practice. The publication of this report is very timely as the Department of Health and Children is now embarking on the formulation of a new health strategy. The National Council on Ageing and Older People hopes that the HeSSOP report will assist in this process, particularly with regard to furthering the commitment made in *Shaping a Healthier Future* to ensure that services are underpinned by consultation with users.

On behalf of the Council I would like to thank the authors of the report, Professor Hannah McGee, Ms Rebecca Garavan and Ms Rachel Winder, for all their hard work

and dedication which produced this very fine report. I would also like to thank Dr Mary Hynes who chaired the Council Consultative Committee that advised on the progress of the research and oversaw the preparation of the report. For their enthusiasm and commitment, thanks are also due to the members of the Committee: Ms Janet Convery, Mr Frank Goodwin, Mr Bernard Haddigan, Dr Siobhan Jennings, Mr Eddie Matthews, Ms Mary Mc Dermott, Ms Ann McKeon, Ms Niav O'Daly and Mr Michael O'Halloran. The Council also extends it thanks to the Eastern Regional Health Authority and the Western Health Board for the fruitful collaboration represented by this study.

Finally the Council would like to thank its Director Mr Bob Carroll, Research Officer Ms Catherine Conlon and former Research Officer Ms Nuala O'Donnell who steered the project on the Council's behalf. Thanks are also due to Mr Eamonn Quinn who prepared the report for publication and to the Council's administrative staff for their assistance throughout the course of the project.

Dr Michael Loftus
Chairperson, National Council on Ageing and Older People
May, 2001

Authors' Acknowledgements

The HeSSOP project study was jointly commissioned by the National Council on Ageing and Older People (NCAOP), the Western Health Board (WHB) and the Eastern Health Board (now the Northern, East Coast and South Western Area Health Boards in the Eastern Regional Health Authority (ERHA) Area). The Health Services Research Centre at the Department of Psychology, Royal College of Surgeons in Ireland conducted the study. The study team comprised health psychologists Ms Rebecca Garavan (study co-ordinator), Ms Rachel Winder (Researcher) and Professor Hannah McGee (centre director). The study aimed to consult with older people dwelling in the community to gain their perspectives on health and social services in order to assess and compare service use and need across boards. Further, the study examines, in the largest such study ever conducted in Ireland, the challenges to service delivery for older people.

This is the full report from the two separate population profiles - it combines and compares the findings from WHB to the three Area Health Boards in the ERHA Area survey. We acknowledge the support and assistance of many individuals in completing the report and particularly note the roles of the steering committee in the consultation process: Dr Mary Hynes (Director of Public Health) - committee chairman, Ms Mary Mc Dermott (Regional Co-ordinator of Services for Older People), Mr Bernard Haddigan (Regional Manager - Mental Health and Services for Older People) from the WHB; Mr Edward Matthews (Director of Services for Older People), Dr Siobhan Jennings (Department of Public Health), Ms Ann McKeon (Director of Customer Services and Appeals) from the ERHA Area; Ms Niav O'Daly (Irish Association of Older People), Mr Frank Goodwin (The Carers' Association), Mr Michael O'Halloran (Irish Citizen's National Parliament), Ms Janet Convery (NCAOP board member, lecturer in Department of Social Studies, Trinity College), Mr Bob Carroll (Chief Executive, NCAOP) and Ms Catherine Conlon (Research Officer, NCAOP).

Following wide consultation with key professionals and older people in each of the counties (i.e. Galway, Mayo, Roscommon, Wicklow, Kildare and Dublin), a survey questionnaire reflecting issues of most relevance for older people was developed. This was used as the basis for over 900 interviews with older people living in the community in the WHB and the ERHA area. We acknowledge the assistance of Mr James Williams and the Survey Unit of the Economic and Social Research Institute in completing the community interviews. We trust that this study will be of benefit in current planning for quality services for older people throughout Ireland.

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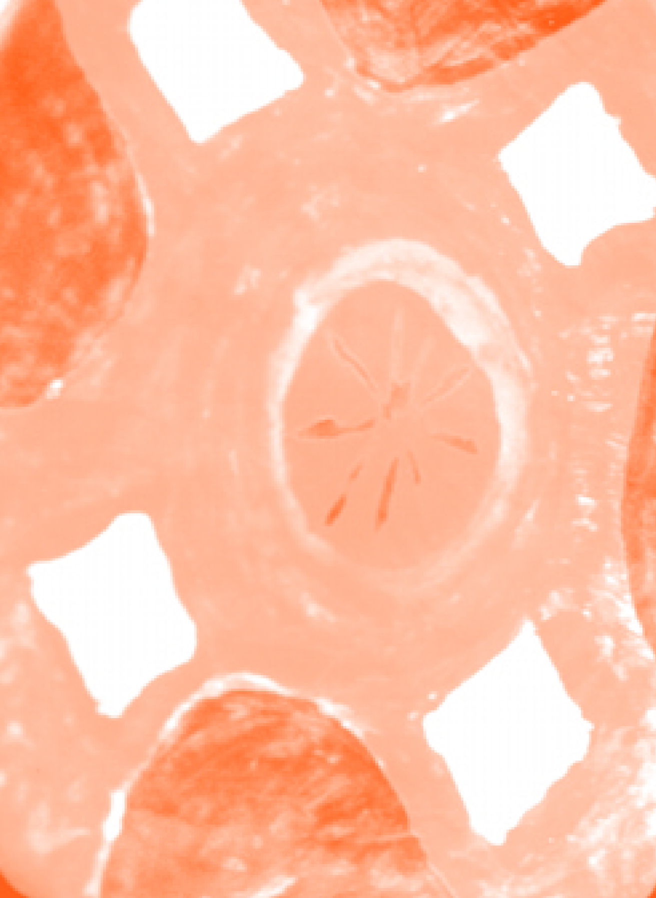


Summary

Summary

STUDY BACKGROUND

The views of older people living in the community on the health and social services available to them had not previously been assessed on a large scale in Ireland. The National Council on Ageing and Older People, in partnership with the Western Health Board (WHB) and the Eastern Regional Health Authority (ERHA) which was formerly the Eastern Health Board, has now carried out such an assessment. It is anticipated that this will assist in planning for services for older people.

A survey instrument was developed based on both literature review and focus group work. Groups of older people and key health and social service professionals in the two board areas were consulted to identify the most important concerns to be addressed in the study.

AIMS AND OBJECTIVES

The aim of the study was to provide a systematic evaluation of health and social service provision for older people from the perspective of older people living in the community needing and/or using these services.

The main objectives of the study were to:

- document older persons' experiences with a wide range of health and social services recently received or required
- determine preferences for long-term care
- compare findings across two health board areas
- develop recommendations for service provision based on these findings
- identify areas for further research
- identify methods of increasing the involvement of consumers of health services in policy and service development.

METHODS

A large, randomised survey of older people living in the community in the WHB and ERHA areas was conducted in spring 2000. The sample was identified from the

electoral register and home visits were conducted. People aged 65 years and older and living in private homes were invited to participate in an interview-based study. Where a person was unable to participate because of physical or cognitive impairment, a primary carer or next of kin living in the household was asked to participate as a 'proxy' respondent.

A separate focus group study was conducted on three of the islands in the WHB to ascertain older islanders' views of the services they needed and received. Key professionals were also consulted about their views on island services.

RESULTS

A total of 937 people completed the HeSSOP interview. This was a response rate of 67% with eighty-two respondents (9 per cent) providing a proxy report on an older adult too incapacitated to take part themselves.

Socio-Demographic Profile

More older women than men (54 and 46 per cent respectively) participated in the study. The proportion of women among the participants increased with age. This was similar to the general population profile of older people.

The group ranged in age from 65-99 years, with one third aged 65-69 years and less than 10 per cent aged 85 years or older. More older people lived in the WHB area: 26 per cent of the WHB group were aged 80 years and over in comparison to 16 per cent of ERHA respondents.

Most of the group were currently married (47 per cent) or widowed (41 per cent). Eleven per cent were single/never married.

The most common living arrangement for older people in the community was to live with one other person, usually a spouse (30 per cent). Twenty-nine per cent lived with more than one other person. Twenty-eight per cent lived alone. Most of those living alone were women and one in four were aged over 80 years.

Most older people (83 per cent) owned the property they lived in while 12 per cent lived in property owned or rented by someone else, usually a relative. A small number (5 per cent) lived in accommodation they themselves rented.

Three per cent of the group were without basic facilities such as bath or shower, hot water supply, flush toilet or adequate heating. Those living in the WHB area were

more likely to be without these facilities. Ninety-six per cent of older people had access to a telephone in their own homes.

Sixty per cent of the group surveyed were retired with another 30 per cent engaged in home duties. Most of the latter were women. Ten per cent of older people (65 years and older) were still in employment, 8 per cent were self-employed while 2 per cent were in paid employment. In addition, 8 per cent of people had been the main carer of someone else in the past year. A further 10 per cent of those not currently working were interested in obtaining employment, mostly on a part-time basis and mostly those in the ERHA area (16 versus 5 per cent).

Health And Well-Being Among Older People In The Community

The study provides a profile of the health and well-being of older people in the community based on their self-reported abilities and conditions.

Over 75 per cent reported being self-sufficient in their abilities to perform tasks of daily living and 60 per cent reported no functional disability. Eighty per cent rated their quality of life as good or very good and over 75 per cent scored high on morale.

The majority of older people said they were never or not very often bothered by loneliness and 85 per cent said they had a high level of emotional and social support. Most people spent part or all of the day with others with almost 40 per cent spending no time alone. About one third were alone for 1-4 hours daily but had company for the remainder of the day.

INDICATORS OF NEED

While the findings outlined above provide a positive impression of ageing and older people in present-day Ireland, the study also provides a profile of the level and type of need for help with activities of daily living as evaluated by older people themselves.

Twelve per cent of people surveyed usually needed help with one or more tasks of daily living. Six per cent had major difficulties and a further 8 per cent reported being severely impaired in their ability to undertake these daily living tasks. The activities people reported needing most help with were shopping, housework and foot care. Preparing a meal, managing one’s own affairs unaided, taking a bath, shampooing hair and reaching up to fetch objects were difficult for 7-10 per cent of older people living in the community.

The findings also give an understanding of the types of illnesses and conditions experienced by older people and how disruptive to their lives these can be. Even though the majority of older people reported being self-sufficient, a high number of health conditions were reported. Only 14 per cent had been free from all conditions in the previous year. For one in five people, the conditions they reported caused extreme disruption to their lives. Bone or joint conditions, foot problems, sleep problems, heart conditions, hearing difficulties and back problems were those most often associated with causing extreme disruption to older people's lives. In addition, over one third of the group had experienced pain in the past week. This pain was rated as severe for forty people (4 per cent) in this study.

Fifteen per cent of older people in the community reported borderline or clinical level scores for depression or anxiety. Clinical levels of anxiety were reported by 4 per cent and clinical levels of depression by 2 per cent of the group. This is similar to UK figures for equivalent groups.

Seven per cent reported they had had an accident resulting in 'serious injury' in the previous year. Almost half of these accidents happened in or about their homes.

Groups With Higher Levels Of Need

Some older people will experience more than one indicator of need for help from health or social services. For example, 3 per cent had at least one illness causing extreme disruption to their lives, had some level of difficulty carrying out activities of daily living independently and lived alone.

The likelihood of having a functional disability increased with age. The study found that people aged over 80:

- were significantly more likely to report having a functional disability and to find activities of daily living difficult to perform. Housework, shopping and foot care caused most difficulty
- rated their quality of life as lower than those aged less than 80 and were more pessimistic in their beliefs about their future health
- were more likely to report clinical or borderline scores for either anxiety or depression.

Women in the study reported poorer health status than men, even when matched for age:

- women, and in particular women aged over 80, had more difficulties carrying out activities of daily living
- women rated their quality of life as significantly lower than men
- women's beliefs about their own level of health were poorer than men's
- one in five (20 per cent) of women reported clinical or borderline scores for anxiety or depression compared with 15 per cent of men
- women were more likely to live alone.

There were differences in the profile of needs in the WHB and ERHA groups with generally higher levels of reported need in the WHB area and relatively lower use of services there. Formal assessment of need is necessary to fully understand these findings and their implications.

The needs of islanders in the WHB area, assessed separately, appeared broadly similar to those of other isolated older people in the study but they were compounded by the complexities of travel. A major cause for concern for those older people was having to leave their island permanently for health reasons.

CARING FOR OLDER PEOPLE IN THE COMMUNITY

While older people living in the community reported high levels of self-sufficiency, a significant proportion received help from other family members and members of the community which they considered necessary for them to maintain independence. Thus a high level of care was provided to older people in the community other than, or in addition to, the care received from health and social service professionals.

Almost half (44 per cent) received help from one or more people on a regular basis. Just over 20 per cent received help either most of the day or continuously, including during the night. Women and those aged over 80 received more help. This corresponded with findings regarding higher levels of dependency.

SOCIAL CONTACT

Older people's living arrangements were identified as important determinants of how much social contact they had. The average amount of time older people spent alone during the day was low but there were significant differences depending on whether they lived alone or not.

Almost 40 per cent of older people spent no time alone. This group comprised mainly those who were married. In contrast, almost half of those living alone spent 10-14 hours in the 'waking' day alone and another two thirds were alone for 5-9 hours daily. One quarter of those who spent most of the day alone had limited independence. When asked about their ability to attend events or visit family or friends outside the home, almost one in ten said they were unable to do so. A further 10 per cent could only do so with some or great difficulty. Many people in this position had difficulties carrying out activities of daily living.

Most older people were interested in maintaining social contact through contact with friends or relatives while over one in five was interested in becoming an active member of a club or group.

USE OF HEALTH AND SOCIAL SERVICES BY OLDER PEOPLE LIVING IN THE COMMUNITY

Hospital Services

Almost 25 per cent of older people in the survey had had an outpatient appointment in the previous year. Those in the ERHA area were more likely to have had this service (36 versus 15 per cent). Sixteen per cent of people had had a scheduled inpatient appointment in the previous year and 12 per cent had been seen in an Accident and Emergency Department. Four people (less than 1 per cent) had had hospital-based rehabilitation services in that year.

Primary Care Services

The General Practitioner

The general practitioner (GP) was a pivotal health professional contact for older people with 93 per cent having consulted their GP in the previous twelve months (an average of 5.3 visits). Most reported having 'their own GP' and having a long association with this doctor.

There was evidence of regular contact with the GP and preventative care in the high number of older people who had had a general health check (almost 75 per cent in the past three months) and their blood pressure checked (98 per cent in the past year).

Smoking

Nineteen per cent of the group were current smokers with most of these (72 per cent) not interested in advice on quitting.

Flu Vaccination

In the previous winter, 42 per cent (35 per cent in the ERHA and 48 per cent in the WHB) had obtained the flu vaccination. Somewhat more (59 per cent) intended to receive the vaccination for winter 2000. Again there were differences across boards (53 per cent in the ERHA and 64 per cent in the WHB).

Eye And Ear Conditions

One of the most commonly reported health conditions was eye or vision problems (22 per cent). Sixteen per cent had visited an optician during the past year with a further 7 per cent saying they would have liked to but had not done so. Similarly, 17 per cent of people surveyed reported hearing difficulties with 4 per cent having used aural services during the year. Eight per cent had used dental services with another 4 per cent saying they would have liked to have used these services.

Chiropody

Alongside optical services, chiropody was the service most used by older people with 16 per cent having availed of it during the previous year. In addition to being one of the two most used services, chiropody also had the highest additional demand - 12 per cent of those older people who had not used it would have liked to have done so.

The Public Health Nurse

The public health nurse (PHN) was the main home-based service used by older people in the community, 15 per cent having been visited by the PHN in the past year. Of these, almost half had seen the nurse once or twice in the year while over a quarter were visited regularly (i.e. on a weekly or monthly basis). Fourteen per cent of people visited would have liked to have used the service more and 3 per cent of those not visited said they would have liked to have received the service.

Other Community-Based Health And Social Services

There was a markedly low level of utilisation of other home and community-based health and social services with only 5 per cent or less of older people living in the community having used any one of these services in the past year.

Home Help, Meals-On-Wheels And Care Attendants

The home help service was used by 5 per cent, meals-on-wheels by 1 per cent and personal care attendants by less than 1 per cent.

Respite Care

Sixteen people (less than 2 per cent) had used respite services. Seven of these

were carers themselves with nine availing of the service to give respite to their usual carer.

Day Hospitals And Day Centres

Day hospitals or day care units, incorporating more medical services, were used by 5 per cent of people with visits ranging from once yearly to five days weekly. The more socially oriented day centres or clubs were used by 2 per cent of older people in the study with levels of use ranging from once to three times weekly.

Therapy Services

Three per cent of older people had received community-based physiotherapy in the past year with less than one per cent receiving occupational therapy or speech therapy. In each case, there were more older people who wanted to use the services but had not done so in comparison to the numbers of older people who had actually used them.

Aids And Devices

Apart from a walking stick (used by 17 per cent), the number of older people using other aids and devices was low - in most cases less than 5 per cent. A further 5 per cent expressed a need for a mobility aid (a walking stick, frame, wheelchair or crutches) and for a bath appliance, while 3 per cent felt they needed a raised toilet seat. In many cases, a similar percentage of people without such aids felt they needed them. Perceived need for aids corresponded well with reported difficulties in the activities of daily living.

Social Work And Counselling Services

One per cent of older people living in the community had seen a social worker in the past twelve months with fewer using counselling or psychological services. In both cases, twice as many people would have liked to have used the service than actually received it.

BARRIERS TO SERVICE USE

The study sought to identify what older people felt were the barriers to their using the services they needed. Barriers could be at the individual level such as:

- reluctance to avail of certain services at the interface between professionals and the public, such as lack of information about the availability of a service or the suitability of a service for particular health conditions

- access, such as transport, waiting time or cost.

Barriers to accessing services were identified across all the services.

Knowledge Of Services

While the percentages of people that reported specific barriers to using services were generally small, it is important to realise that they translate into large numbers of older people at community level. Furthermore, people can only decide they need and would like to use a service if they know it exists and what it entails.

Not knowing about the existence of a service was a barrier to almost one in ten people. When asked specifically about accessing information on services, 14 per cent said this was difficult or very difficult. The majority (79 per cent) identified their GP as their preferred source of information.

Stigma

Stigma was reported as a barrier to using services. Thirty per cent reported they would find using the meals-on-wheels services to be 'highly embarrassing' and 'would only use [it] with difficulty'. Almost 20 per cent gave the same rating to the home help service. Counselling, social work and personal care attendants were also described as highly embarrassing or stigmatising services by between 18-21 per cent of the overall population.

Cost

Cost was given as the reason for not using some services. Two thirds of these older people had medical cards and 38 per cent had private health insurance. Almost one in ten reported having neither a medical card not private insurance. Many medical card holders reported making payments for health or social services in the past year. Forty-three per cent of medical card holders who used the home help service paid either partially or in full for the service. Medical card holders also reported paying for the following services:

- care attendants (22 per cent)
- chiropody (29 per cent)
- physiotherapy (24 per cent)
- medical devices (26 per cent).

Transport

Transport was reported as a barrier to service use by less than 1 per cent of the population studied. However, 8 per cent of the group said that transportation services were more generally often or always a problem, with those in rural areas twice as likely to report such problems.

SERVICE DEVELOPMENT NEEDS IDENTIFIED

Throughout the study, older people indicated an additional need for services in a number of ways. One way to assess such need is to examine people's health status and circumstances to see if they might benefit from services were they to receive them.

A substantial proportion of those found to be severely impaired in carrying out activities of daily living (37 per cent) had not received any home-based services in the previous year.

When the numbers of people reporting a need for a service are compared with those actually receiving that service, it is clear that current health and social services are meeting the needs of only some older people. In addition, there may be service needs that professionals would recognise but which were not identified in this study by the older persons themselves. For seven of the fifteen home and community-based services examined in the study, there were more people who felt they needed the service than there were people who did receive it.

Preferences For Long-Term Care

When asked about their wishes were they to need long-term care in the future, there was a clear preference for being cared for in their own homes with minimal health service involvement. The majority (87 per cent) wanted to continue to live in their own homes. Over half of the group hoped to be cared for by family and friends with one quarter having no preference and a similar number preferring professional help. Professionals were preferred for the more intimate personal care tasks than for household tasks.

When asked to consider options that involved moving from their current residence to another residence but remaining in the community, their strongest preference was for an independent dwelling (a 'granny flat') attached to a relative's home. Forty per cent said they would opt for this while 25 per cent would accept living with a relative either with or without respite services. One in four would accept a move to sheltered housing as a community-based option.

Concerning options within the range of residential long-term care settings, those with nursing care services were preferred over those without. One third of those surveyed felt that moving to a private nursing home was acceptable to them, while a further 25 per cent indicated that public nursing homes were acceptable. Twenty per cent found the option of a residential home without nursing care acceptable.

In terms of unacceptable options, about half of all respondents said they would not accept either private or public nursing home or residential home options. Sheltered housing was unacceptable to 58 per cent of the group with almost half not willing to move into the home of a family member, even if there were a separate dwelling space. The least acceptable option was boarding out - this was unacceptable to 77 per cent of older people.

Expectations And Planning For Long-Term Care

Most older people expected that, in the event that they could no longer live independently, they would still continue to live in their own homes. This would be with no health board involvement or, at most, only respite care for 56 per cent of the group, with only 12 per cent expecting to have more extensive health board involvement. Others expected they would move to either 'granny flats' (8 per cent) or private (9 per cent) or public (6 per cent) nursing homes. Three per cent expected that they would move into another family member's home.

Although all of those surveyed had preferences for, and beliefs about, what would happen if they needed long-term care, over 75 per cent had never discussed their preferences with family members or other trusted persons. Eighty-six per cent believed their long-term care preferences would be honoured if they needed such care. This still leaves over 100 older people in this survey alone who were not convinced that their wishes would be met if they needed long-term care.

PRINCIPAL FINDINGS FROM CONSULTING WITH OLDER PEOPLE

An important outcome of this first major community consultation process is that older people themselves have confirmed that they want to continue living at home and being cared for there. This endorses the principles and objectives of services for the elderly as set out in *The Years Ahead* (1988) to enable older people to live in their own homes in dignity and independence for as long as possible. Older people have expressed clearly in this study that:

- they want to remain living in their own homes

- they want their family and friends to be their principal caregivers
- the role of health and social services should be to provide support to help them and their families to realise these aspirations.

Options such as boarding out and residential care remain unacceptable to significant numbers of older people. However, supported home care is presently the most underdeveloped component of care for older people in our health and social service system.

The study also reveals the extent of caring provided by family members or friends, including older people themselves. Almost half of those living in the community received some help on a regular basis. This complements the recent estimate of 97,500 households in Ireland having a carer looking after an older person (O'Shea, 2000). The challenge is to develop ways in which family caregivers can be facilitated, encouraged and supported to continue in their role of caring for older people at home.

The study shows that the role of health and social services in caring for older people in the community is underdeveloped. A significant number of people (37 per cent) found to be 'severely impaired' in carrying out activities of daily living had not received any home services in the past year. One in ten people who had an illness that caused extreme disruption to their life had not received any of the home or community-based services studied. When proportions of people who reported a need for a service are considered relative to the proportions in receipt of that service, it is clear that health and social services presently meet the needs of only some older people. For seven of fifteen home and community based-services examined, there were more people who wanted to receive the service but did not than people who did receive the service. In addition, significant proportions of those in receipt of services reported paying for some or all of the services although they may have been entitled to them without cost.

This study, from the perspective of older people themselves, confirms the conclusion of a *Review of the Recommendations of The Years Ahead* (Ruddle *et al,* 1997) that community health and social care services for older people remain very limited and fragmented.

The general practitioner (GP) remains the key health care provider for older people with almost all of those studied visiting a GP in the previous year. The majority of older people identified their GP as the preferred source of information about health

and social services. In combination, these findings highlight the importance of the GP in health promotion and anticipatory care for older people.

The study also demonstrates that many older people would feel stigmatised if they used some of the services available, in particular the more social care services. This new insight into the extent of stigma as a barrier to use of certain services by older Irish people presents a challenge for service providers. Similarly, different perceptions of the acceptability of public and private residential care illustrate the need to explore further what constitutes a quality service from older people's perspectives.

FUTURE WORK

The comparisons made throughout the HeSSOP study of the most urban and one of the most rural of the health board regions may be of benefit to other health boards with features comparable to either the WHB or the ERHA. It provides a service use and a consumer evaluation perspective to be used as a baseline to plan and assess developments in care for older people in the future.

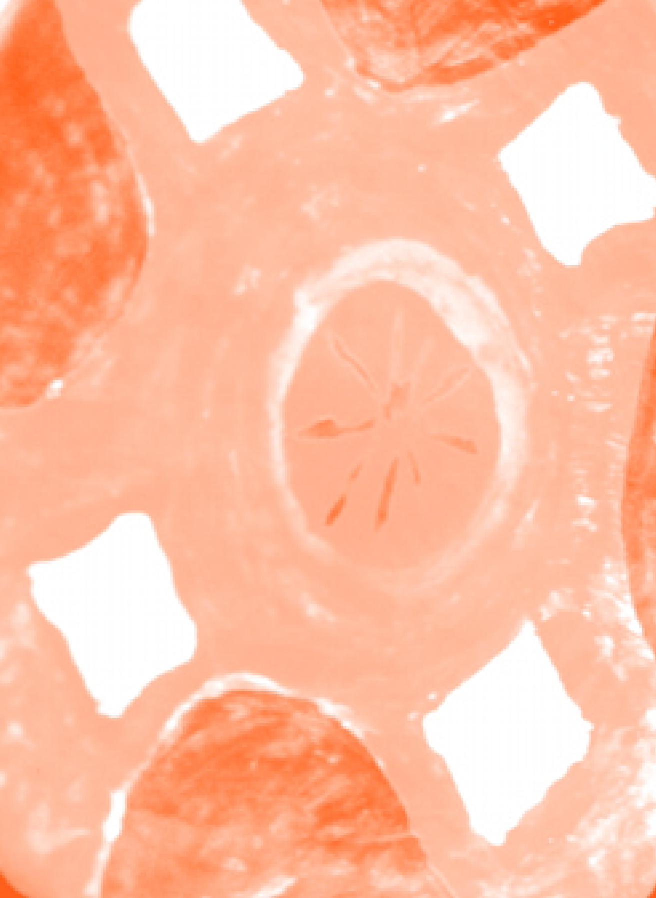
The HeSSOP study was the first such project to consult older people about health and social services on a large scale in Ireland. As such, it has achieved its objective to consult widely with older people. There needs, however, to be a model of consumer consultation if studies such as this are to be part of an ongoing process of policy and service development, evaluation and refinement. Some strategies to advance the process of consultation have been identified in this report.

REFERENCES

O'Shea, E., 2000. *The Costs of Caring for People with Dementia and Related Cognitive Impairments.* Dublin: National Council on Ageing and Older People.

Ruddle, H., Donoghue, F. and Mulvihill, R., 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendations.* Dublin: National Council on Ageing and Older People.

Working Party on Services for the Elderly, 1988. *The Years Ahead: A Policy for the Elderly.* Dublin: Stationery Office.



Council Comments and Recommendations

Council Comments and Recommendations

BACKGROUND TO THE STUDY

1. The health strategy document *Shaping a Healthier Future* published in 1994 signalled new directions in health policy, including adopting a consumer orientation in health care as a core principle. The aim of the HeSSOP study was to provide a broad-based assessment of health and social services from the perspective of older people living in the community. The value of this report is that it allows the views of a large, representative constituency of older people to be heard on their needs and aspirations for health and social services. The National Council on Ageing and Older People strongly endorses the principle that older people should be involved in the development, planning and evaluation of their health and social services.

   This study was undertaken collaboratively by the National Council on Ageing and Older People, the Western Health Board and the Eastern Regional Health Authority. There were two stages to the research design - a consultative stage and a survey stage. Older people and service providers were consulted through focus groups to inform the survey questionnaire. The main element of the study was a survey of 937 randomly selected older people who live in the community.

   The survey was undertaken in two health board areas. However, given that they represent the most urban area and one of the most rural of the country, incorporating island communities, we expect the findings will have value for other health boards. The age and gender profile of the sample of older people who took part in this study approximates to that of the general population of older people. To that extent it allows us to generate a picture of the situation of older Irish people living in the community and serves as a sound basis for service planning.

PRINCIPAL FINDINGS FROM CONSULTING WITH OLDER PEOPLE

2. An important outcome of this consultation process is that older people themselves have confirmed that they want to continue living at home and being

cared for there. **Older people have expressed clearly that they want to remain living in their own homes, that they wish their family or friends to be their principal caregivers and that the role of health and social services should be to provide support to help them and their families realise this aspiration.** Alternative options such as boarding out and residential care remain unacceptable to significant numbers of older people. This endorses the principles and objectives of services for the elderly as set out in *The Years Ahead* (Working Party on Services for the Elderly, 1988) which are to enable older people to live in their own homes in dignity and independence for as long as possible.

The study also reveals the extent of caring provided by family members or friends of older people. The findings indicate that almost half of older people living in the community receive some help on a regular basis. This has also been demonstrated in a recent report by O'Shea (2000) who estimates that 97,500 households in Ireland contain a carer looking after a person aged 65 or over who either lives with them or in another house. **The principal challenge posed by the research is to develop ways in which family caregivers can be facilitated, encouraged and supported to continue in their role of caring for older people at home.** Research has shown how caring often entails physical and mental strain and foregoing opportunities on the part of the carer (O'Shea, 2000). Meanwhile support services usually act as a substitute for the family when family care is absent or breaks down rather than offering support to ensure the continuation of family care on a complementary basis (O'Shea, 1993).

The findings from this study show that the role of health and social services in caring for older people in the community was limited. **A significant number of people (37 per cent) found to be 'severely impaired' in carrying out activities of daily living had not received any home services in the past year.** One in ten people experiencing extreme disruption to their lives through illness had not received any of the home or community-based services studied. The findings indicate that at present health and social services are only meeting the needs of some older people with many more reporting need for services than are in receipt of them. For seven of the fifteen home and community-based services studied, there were more people who did not receive the service but would have liked to than did receive it. In addition, significant proportions of those in receipt of services made top-up payments even though they held medical cards. **This study, from the perspective of older people themselves, confirms the conclusion of a 1997 review (Ruddle *et al,***

1997) of the implementation of the recommendations of *The Years Ahead* (Working Party on Services for Elderly Services, 1988) that community health and social care services in this country are extremely limited and fragmented.

The General Practitioner (GP) remains a key health provider for older people; they are much more likely to see their GP than any other health professional. This indicates the central position of the GP service in the care of older people and the opportunity for GPs to play a key role in health promotion and anticipatory care. In addition, a large majority of older people identified the GP as their preferred source of information about health and social services.

However, the study revealed that older people found some services stigmatising, in particular those providing domestic help or counselling services. This is a new insight into their views on services and presents a challenge for service providers. The finding that older people consider public residential care less acceptable than private residential care merits further investigation to determine the reason for this. It also illustrates a need to assess how both forms of provision can be brought up to a common standard in the interests of equity.

RECOMMENDATIONS BASED ON HeSSOP

3. The main reason for consulting with older people is to give them a voice to express what they want from their services and to evaluate the extent to which these needs and preferences are being met. As noted earlier, the older people consulted in this study were clear about their preferences to remain at home and be cared for principally by family members or friends. However, concern has been expressed about the capacity and propensity of family caregivers to carry out this role (O'Shea, 1993). In order to support and facilitate people assuming this role, health and social services need to develop ways for families to be partners in caring for older kin.

Develop Support Services for Carers

4. A policy of complementary support services for family carers of older people living in the community would meet a range of objectives. It would help ensure that older people are cared for at home in their communities by kin or friends, as is their preference. It would also safeguard the well-being of family caregivers and give proper recognition to the contribution carers make to society.

Pay Carers a Constant Care Attendance Allowance

5. The Council reiterates the following recommendations for supports to meet the needs of carers made in 1997:

> When asked carers would wish to receive three main types of support from the State (O'Shea and Hughes, 1994). Firstly, the vast majority of carers express a desire for direct payment for caring services. This would both recognise the value of the work performed by carers and allow them to purchase other forms of support (e.g. respite care) should they need to do so. Current payment rates, through the Carers Allowance Scheme, are restrictive (because of the means test) and low in comparison to the effort involved. As a result less than 9,000 carers received the allowance in 1996. A Constant Care Attendance Allowance for people caring full-time for dependent older relatives (e.g. those suffering from advanced dementia) would be a fairer alternative. The allowance would be similar to the Domiciliary Care Allowance which is provided for parents of severely disabled children, in that it would not be based on an assessment of the carer's means, but on the effort, and opportunity costs involved in providing full-time care at home. The allowance would be paid regardless of means, and should not be calculated in the means test for other social welfare payments.
> (Ruddle *et al, 1997*. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.29)

Following a review of the Carers Allowance, the Department of Social, Community and Family Affairs (1998) recommended the introduction of a new dependency-related 'continual care payment' for all carers who are providing the highest level of care. The Council recommends that this new payment should be introduced without delay.

Ensure Carers Receive the Information and Advice They Need

6. The second support most frequently sought by carers in Ireland is information and advice on health and social services, and on welfare entitlements. Carers also wish to know about the long-term prognosis and treatment options related

to the medical condition of the person they are caring for. Information is a relatively low cost method of providing support and it would diminish the burden of care for carers.
(Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.30)

Provide Comprehensive Respite Services

7. The third support most frequently sought by carers is relief care of various kinds. The fact that the carer must constantly remain in the home and is therefore confined on a daily basis is the most frequently cited stress of caring. Carers could benefit from the provision of a range of respite options, including day care places, short-term relief care (for instance through community residential services), night-sitting (freeing the carer for a number of hours in the late evening) and, most importantly, domiciliary relief provided by home helps during the day. Other options would be holiday beds (to enable carers to take a holiday) and 'floating beds' (accommodation with or without medical treatment for dependent older people for, say, two nights out of fourteen). There is also a need for secure night-time beds in community facilities for older people with dementia. People with dementia often have disturbed sleep patterns that can create intolerable burdens on the carer.
(Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.30)

While the Council welcomes the once-a-year payment to carers towards the cost of respite care provided for in the 1999 and 2000 budgets, this only goes part of the way to meeting carers needs. An infrastructure of flexible respite services is also necessary.

Challenge Assumptions About Women's Role As Carers And Generate Policies To Promote Balanced Gender Participation In Caring

8. The Council has also commented on prospective changes in the availability of family carers. Studies of carers in the community have found that carers are usually women and related to the person they are caring for (O'Connor *et al,* 1988; O'Shea, 2000). Factors influencing this include cultural stereotypes of women as 'carers' and social policies based on the assumption that men occupy the public sphere of work and women the private sphere of the home. Thus women are often perceived as being more available to care. Some analysts have indicated that the capacity and propensity of carers may be waning:

> The future supply of carers is open to a number of influences, most of which seem to be exerting a downward pressure on the number of carers available. A crude measure of caretaker potential is the ratio of women aged 45 to 69 years (given that the majority of carers are in this group) to the number of people aged 70 years or more (O'Shea 1993). In 1991 the ratio was 1.4 and is projected to rise to 1.6 by 2011. Thereafter it is expected to decline, reaching 1.3 by 2021. In the short-term, therefore, the supply of traditional carers is expected to rise slightly but declining numbers (in relative terms) are projected for the medium to long-term ... A further downward pressure is the increasing proportion of married women in the labour force.
> (Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.28)

In this context the implementation of measures to support family members taking time out of the workforce to care for older relatives is increasingly important. Recent developments such as the introduction of a Carers' Benefit scheme and the forthcoming Carers' Leave Bill are welcome in this regard. The Carers' Benefit scheme entitles anyone who has been in full-time employment for three months before becoming a full-time carer, and who gives up work in order to care, to a payment of £88.50 per week for a fifteen-month period. The Carers' Leave Bill will allow employees to leave their employment temporarily to provide full-time care for a fifteen-month period. These measures should be reviewed on an ongoing basis to assess if they are sufficient to meet the needs of people who would like to take time out of the workforce to care. More generally the cultural practices that assign the role of caring disproportionately to women need to be critically examined on the grounds of equity.

Develop Home And Community Care Services To Complement And Support Family Carers

9. Home and community-based health and social care services are essential to realising older people's aspirations to remain at home. They also play an important role as complementary supports for family caregivers. The low level of use of home and community care services evidenced in this study is indicative of their limited availability. This has been highlighted by Council research in the past (Ruddle *et al,* 1997) and now has been confirmed by older people themselves.

Establish Home And Community Care Services On A Statutory Basis In The Interests Of Equity

10. A central problem has been that home and community care services have never been established on an equitable basis. The 1994-1998 health strategy *Shaping A Healthier Future* (1994) acknowledged that this is because there are a number of services for which no eligibility criteria, or rules governing charges, are set down in legislation. It went on to say that this relates to services that play a very important role in providing appropriate care in the community to people who might otherwise need residential care; for example, community paramedical services, home helps, meals-on-wheels and day care centres. The strategy made the following commitment:

> National guidelines on eligibility and charges, which will be applied in a uniform manner in all areas, will be introduced in respect of all services where legislative provisions are at present absent. This development will form part of the reform of the basic framework of the health services and will be underpinned by the new legislation.
> (Department of Health, 1994. *Shaping a Healthier Future,* p.36)

To date this commitment has not been implemented. In the interim the Council identified the need for such legislation. The review of the implementation of the recommendations of *The Years Ahead* found that the discretionary nature of core services had led to a situation where older people in different areas of the country experienced considerable variations in the extent, scope and nature of services provided and in eligibility criteria (Ruddle *et al,* 1997). Based on these findings the Council made the following recommendation:

> The Council believes that a legislative framework governing the provision of essential services to older people is also required. The Council wishes to state at the outset that it believes the home help service, meals-on wheels, day care, respite care both inside and outside the home, paramedical services and sheltered housing are essential and should be designated as core services. These services have a proven record of providing social gain, and should be available to older people whenever required, throughout the country. These services should be designated as core services underpinned by legislation and appropriate statutory funding.

> (Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.9)

In 1998 the Department of Health commissioned a report to formulate recommendations on how a quality home help service might be made available to all who need it (Haslett *et al,* 1998). The report recommended a number of changes necessary for the provision of a quality service with designated funding and agreed national quality standards. Of the eight changes recommended, three related to the issue of equity: explicit and agreed criteria for assessment of need, standardised criteria for entitlement and national guidelines of service provision based on assessed needs. It concluded:

> If these changes are implemented the issue of the legal basis may become secondary. If these changes are not implemented the demand for legislation may become irresistible.
> (Haslett *et al,* 1998. *The Future Organisation of the Home Help Service in Ireland, 1998,* p.60)

To date these measures have not been introduced and so the recommendation to introduce legislation remains in force.

In 1999 the Council reiterated its recommendation that the provision of core services be underpinned by legislation and pointed out the need for an enabling legislative framework:

> The Council has previously called for community care services to be designated as a core service and expanded significantly (Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation*) and again reiterates this call. This designation would require the State to provide the services to all those who need them on the grounds of dependency or social circumstances. Clear and universal guidelines for the assessment of eligibility on the basis of need would be established at a national level. The discretionary service that currently exists would be replaced by a transparent and equitable system of service delivery. The services would be underpinned by legislation and appropriate funding. However, because legislation can often restrict the development of services (Mangan, 1997) appropriate legislation should allow scope for new services to be developed and delivered in an imaginative way

> and room for new initiatives to be taken.
> (Layte *et al,* 1999. *Income, Deprivation and Well-Being Among Older Irish People,* pp.11-12)

This study again highlights the need for home and community care services to be established on an equitable basis underpinned by legislation. The reasons identified in *Shaping a Healthier Future* (1994) as to why legislation is necessary remain, even though more resources are now available to the health services. A new health strategy is now anticipated and the Council expects that this will continue to honour those commitments made in *Shaping a Healthier Future* (1994) which would ensure the equitable provision of essential community services for older people by providing for the implementation of legislation as envisaged above.

Develop A National Framework For Multi-Disciplinary Assessment Of Older People

11. The findings of the HeSSOP study illustrate the need for a better system of identifying older people's needs to ensure services are delivered on an equitable basis. **The Council recommends that a national framework for multi-disciplinary assessment of older people in acute and community care settings should be developed.** In this context the Council reiterates its recommendation for the continued development of community and day hospitals:

> The Council recommends that the community hospital sector continue to grow in the manner envisaged by the Working Party, replacing geriatric hospitals and welfare homes where possible. It is essential that these hospitals are equipped with assessment and rehabilitation facilities for the disorders associated with old age and that they receive weekly visits from consultant geriatricians.
> (Ruddle *et al, 1997*. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* pp.24-5)

The striking findings in the report about the extent of pain experienced by older people raises a further issue related to the provision of day hospitals. The Council is anxious that older people should have access to pain management clinics. The Council considers that this would be addressed by the implementation of the above recommendation regarding the provision of day

hospitals from which they could be referred on to appropriate services including pain management clinics:

> The Council believes that all Departments of Medicine for the Elderly require on-campus day hospital facilities if they are to have meaningful contact with community residing older people living in the hospital's catchment area.
> (Ruddle *et al*, 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.23)

Expand Provision Of Multi-Disciplinary Care Teams To All Health Boards

12. This study shows that the provision of home or community-based rehabilitation is very limited. In 1997 the Council made the following recommendation:

> On the grounds of equity and quality the Council is concerned that many older people who require paramedical care at home are denied such services. The Council believes that such care is essential if ill and dependent older people are to continue living in the community and recommends that the health boards reconsider their opposition to the principle of domiciliary paramedical services.
> (Ruddle *et al*, 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.19)

Older people, in particular those in acute settings, should be assessed to identify their rehabilitative care needs. The objective should be to provide as much of this rehabilitation at home as possible in order to minimise the number of days older people spend in hospital or residential care. In a small number of cases health boards have established multi-disciplinary care teams who provide programmes of augmented care to people in their own homes either instead of hospitalisation or after discharge (e.g. District Care Units in the three health board areas of the Eastern Regional Health Authority). **The Council recommends that multi-disciplinary teams providing intensive domiciliary care for older people instead of hospitalisation or after discharge should be established in all health boards at district level.**

Introduce A Long-Term Care Allowance Scheme Applicable To Both Community Care And Residential Care

13. At present financial support to cover some of the costs of long-term care is

confined to subvention payments for residential care. This acts as a bias in favour of residential care and amounts to inequality of treatment between a dependent older person granted a subvention for nursing home care and an older person with a similar level of dependency cared for at home without financial support. There is, therefore, a need for a long-term care allowance scheme with a wider application. **The Council recommends that the nursing home subvention scheme be extended to a long-term care allowance scheme that includes provision for payments to a community-dwelling older person with an assessed level of dependency for the purpose of purchasing home and community care services.**

This raises the issue of financing long-term care. *The Review of the Carers' Allowance* (Department of Social, Community and Family Affairs, 1998) sets out a range of alternative financing arrangements for long-term care. The Council understands that the Department is conducting research on financing long-term care and hopes that this study will generate discussion and debate and lead to the establishment of an equitable, efficient and affordable system of long-term care financing. In this context, it recommends that the concept of social insurance be actively considered as the principal means of financing long-term care. In addition, provision must also be made for the significant number of older people who rely totally on the State for both income and support services.

The Council welcomes the tax relief on insurance products geared at providing for future care needs as part of the strategy of encouraging savings and providing for real future needs announced in Budget 2001. However, the Council is concerned that this signals a policy of supporting private financing of long-term care through private insurance schemes. A 1993 report published by the Council highlighted the shortcomings of such a policy:

> Pure private financing arrangements do not satisfy many of the conditions necessary for an equitable, efficient and affordable system of long-term care ... Evidence from other countries suggests that private insurance is unlikely to lead to comprehensive cover for old people. Private insurance schemes are also unlikely to bias the long-term care system towards home care solutions. Insurers, concerned about the potential for the substitution of paid for unpaid care, if home care is fully insured, are unlikely to restrict coverage to residential care. Screening programmes to avoid the problem of adverse selection is also likely to keep insurance out of the reach of many low income people,

> thereby undermining the principle of access on the basis of need rather than ability to pay. A pure private insurance model is, therefore, the least preferred option for the funding of long-term care in Ireland.
> (O'Shea, 1993. *The Impact of Social and Economic Policies on Older People in Ireland,* p. 217)

Commenting on the above cited report, the Council noted that such an approach could only provide for a section of the older population:

> The Council believes that the potential for long-term care insurance in the private sector should be actively considered and if possible developed. While it is unlikely to cover a majority of the population, it could provide a solution for a substantial minority.
> (O'Shea, E. and Hughes, J., 1994. *The Economics and Financing of Long-Term Care of the Elderly in Ireland.* Dublin: National Council on Ageing and Older People.)

Introduce Care Management As A Model To Co-ordinate Services For Older People

14. In the past the Council has advocated the concept of co-ordinated packages of care for older people and care management has been proposed as the basis for a co-ordinated delivery structure (Browne, 1992; Ruddle *et al,* 1997; O'Shea and O'Reilly, 1999). Care management involves developing packages of care for dependent older people, such as those on the margins of home and residential care, which are tailored to their individual needs. Consultation with the older person needing care and/or their relatives is incorporated into care management in recognition of the potential of people to come up with imaginative ways of meeting their own needs. Care managers also consult with local statutory and voluntary providers in developing care packages and, as a result, may stimulate service development to meet the needs of older people. In this sense care management has the potential to nurture and encourage new forms of provision and promote service efficiency and effectiveness.

    The Council recommends that Health Boards should implement care management as a model to co-ordinate services for older people. The model should be introduced on a pilot basis in two health boards as soon as possible (O'Shea, E. and O'Reilly, S., 1999).[1]

[1] To this end the Council is engaged in research to identify a model or models of care management suitable for implementation into the Irish health care setting.

The Standard of Housing for Older People

15. The standard of older people's accommodation is important to their health and quality of life. It is also a key factor in their capacity to take care of themselves at home or be cared for there should they become dependent. In recognition of this, the Working Party on Services for the Elderly recommended:

> The main emphasis in housing policy for the elderly should be to enable elderly people to choose between adapting their homes to the increasing disabilities of old age or to move to accommodation which is more suited to their needs.
> (Working Party on Services for the Elderly, 1988. *The Years Ahead,* p.74)

As a first step *The Years Ahead* recommended that:

> Priority should be given to improving the accommodation of the elderly lacking the basic amenities of an indoor toilet, hot and cold water and a bath or shower.
> (Working Party on Services for the Elderly, 1988. *The Years Ahead,* p.74)

The HeSSOP study found that a small group of older people (3 per cent) are still without basic facilities in their homes such as bath or shower, hot water supply, flush toilet or adequate heating. Those living in the Western Health Board were more likely to be without these facilities. Another Council report on *Income, Deprivation and Well-being Among Older Irish People* (Layte *et al,* 1999) concluded that older people experience housing deprivation more than any other group. The proportion of older people who live in housing with substantial physical defects, including dampness, wood rot, poor heating and leaking roofs, is larger than for the rest of the population. Certain subcategories of older people, especially those in private rented accommodation, are in a particularly vulnerable position (Layte *et al,* 1999, p.143). **The Council believes that all older people's homes should be equipped with basic facilities as a priority.**

Schemes To Repair, Upgrade And Adapt Older People's Homes

16. *The Years Ahead* (1988) envisaged that schemes to repair and upgrade older people's homes would be a central component of services for older people. The

report stated that older people's homes should be assessed to identify what repairs and adaptations were required to meet the accommodation needs of residents. A comprehensive and flexible scheme should be implemented to deliver this service under the auspices of the local authorities, with input from the health boards:

> Local authorities in consultation with health boards [should] carry out an immediate assessment of the need for housing repairs and adaptations among elderly households and together with health boards, they should plan a programme of repairs to meet those needs using existing schemes ... We recommend that the Department of Environment and Local Government should replace the existing *ad hoc* grant schemes with a comprehensive and flexible repairs and adaptations scheme for the elderly and disabled which local authorities could administer either by the provision of a grant or by organising the work on behalf of the elderly person.
> (Working Party on Services for the Elderly, 1988. *The Years Ahead,* pp.76, 77)

In 1997 the Council reviewed the implementation of these recommendations and concluded:

> The operation of the [housing repair] schemes remains reactive, as local authorities have not undertaken formal surveys of the need for repairs and adaptations to older people's homes. Neither have these schemes been integrated as recommended. Legislation has not been effected to oblige local authorities to repair and adapt the homes of older people, particularly those on low incomes as recommended.
> (Ruddle *et al,* 1997. *The Years Ahead: A Review of the Implementation of its Recommendations,* p.152)

The situation that applied in 1997 still applies in 2001. A number of schemes are operating to provide repairs or adaptations to the homes of older people, namely the Essential Repairs Grant Scheme, the House Improvement Grant for Disabled Persons (applicable to disabled elderly) and Special Housing Aid For The Elderly. The Department of Environment and Local Government allocated £8 million to Special Housing Aid For The Elderly during 2000. In 1999 the Essential Repairs Grant Scheme was allocated £2.1 million and the Disabled

Persons' Grant was allocated £3.7m.

A review of Special Housing Aid For The Elderly was completed by the Comptroller and Auditor General (Department of Environment and Local Government, 2000). The review concluded that the scheme represents value for money in contributing to the realisation of the objective of maintaining older people's capacity to remain at home and avoid moving into more expensive residential care. Therefore it was recommended that the scheme should be put on a more permanent footing:

> Formal terms of reference need to be drawn up for the Task Force, setting out its role and responsibilities and establishing a mandate and reporting arrangements for effective strategic management and co-ordination of the scheme ... The Department [of the Environment and Local Government] and the Task Force need to review the value of continuing the scheme on a temporary footing. (Comptroller and Auditor General, 2000. *Report on Value for Money Examination: Special Housing Aid for the Elderly,* p.22)

Given the findings cited earlier about housing deprivation among older people, there is still a clear need for the continuation of a scheme to repair and upgrade older people's homes. However, there are some difficulties prejudicing the effectiveness of the operation of the current schemes. The Comptroller and Auditor General's review (2000) showed that there is a significant backlog of work in all of the health boards, with waiting periods for applicants ranging from six months to four years. The Department of Environment and Local Government reviewed the Special Housing Aid For The Elderly in 2000 to assess the backlog and examine ways of increasing output under the scheme.[2]

The level of funding available to the scheme has been inadequate for two reasons - firstly to meet demand and secondly to enable more extensive work to be carried out under the scheme. The Department's review indicated that previously restricted funding for the Task Force has meant that heating systems could only be installed in a small minority of cases.[3]

Sourcing labour to undertake work under the Special Housing Aid For The Elderly is another difficulty impacting on the capacity of the scheme to meet the needs of older people. This was highlighted by both the Comptroller and Auditor

[2] Details of the review were announced in a press release from Minister Molloy dated 11 November 2000.

[3] Cited in press release from Minister Molloy dated 11 November 2000.

General's review and the review carried out by the Department of Environment and Local Government. The Department's review proposed the following measures to address labour shortage:

- previously the FÁS Youth Training Scheme had been relied on for labour. It was recommended that the Community Employment scheme should now be utilised as this has more participants
- in liaison with the Department of Social, Community and Family Affairs participants of the Back to Work scheme should be invited to tender for works under the scheme
- health boards should identify applicants for heating systems and link them up directly with heating and plumbing contractors known to the boards to speed up the processing of the work.

These measures are being piloted in the Western Health Board.

The Comptroller and Auditor General's review (2000) found that the implementation of the scheme varied between health boards and between community care areas within health boards. The review concluded:

> The effect of the diversity of approach is that the ability of elderly people to avail of the scheme and the manner in which they benefit from it depends on where they happen to live.
> (Comptroller and Auditor General, 2000. *Report on Value for Money Examination: Special Housing Aid for the Elderly,* p.ii)

The mechanisms used by the health boards, as revealed in the Comptroller and Auditor General review (2000), to carry out work under the scheme include:

- the health board paying the applicant a grant to engage a contractor themselves (38 per cent)
- using labour supplied by FÁS (31 per cent)
- the health board engaging a contractor directly (30 per cent)
- the health board supplying direct labour (1 per cent)

- joint ventures between health boards and voluntary organisations (<1 per cent).

The review noted concern about the heavy reliance on paying grants to applicants on the basis that this conflicts with the spirit of the scheme and may act as a barrier in taking up the scheme for people who are otherwise eligible to avail of it.

The Comptroller and Auditor General's review of the Special Housing Aid For The Elderly (2000, p.27) concluded the following:

- the Department, Task Force and health boards need to introduce strategic planning for the scheme at local and national level

- there is an urgent need to introduce a system of formal needs analysis in relation to the scheme

- expenditure under the scheme represents good value for money.

The review went on to say that a more comprehensive review of the scheme is needed and recommended that:

- the Department of Environment and Local Government and the health boards need to assess the value of local ways of implementing the scheme in order to apply the best approaches across all health boards

- the Department of Environment and Local Government and the Task Force need to review the value of continuing the scheme on a temporary footing

- the Department of Environment and Local Government, the Task Force and health boards should evaluate the effectiveness of the scheme in terms of improving the living conditions of older people who live in unsanitary or unfit accommodation but have neither the means nor capacity to undertake remedial work.

The Council concurs with the above conclusions and recommends that a comprehensive review of the Special Housing Aid For The Elderly should be undertaken by the Department of Environment and Local Government and the Task Force. The Council further recommends that the review should also examine the following:

- how the Special Housing Aid for the Elderly schemes relates to other schemes to repair and upgrade older people's homes

- whether the various schemes would be more effective if they were amalgamated into one scheme

- who should administer the scheme(s). This would address whether the scheme(s) should be under the auspices of local authorities or health boards or another designated agency

- the capacity of voluntary and community groups to be involved in the operation of the scheme, including an examination of provision through the social economy

- the option of establishing an agency with designated responsibility for administering (a) scheme(s) to repair, upgrade and adapt older people's homes.

Assess Older People's Housing Needs

17. As noted above an assessment of older residents' needs for repairs and adaptations to their homes is necessary. Comprehensive needs assessment would ensure adequate allocation of resources to the scheme(s) and provide a basis to benchmark progress in terms of work completed against need in the community.

    The issue of assessing housing circumstances in Ireland was addressed by Fahey and Watson (1995) in *An Analysis of Social Housing Need.* There are currently two systems of assessing need: assessments carried out by local authorities and a national survey of housing stock. Local authorities' assessments of housing need have been described as an administrative exercise based on the processing and analysis of applications for local authority rental accommodation (Fahey and Watson, 1995). A large-scale survey of housing stock was undertaken in 1990 (Finn, 1992) and the next national survey is planned for 2001. Fahey and Watson said of the 1990 Survey of Housing Stock:

    > The Survey of Housing Stock had some of the characteristics of the kind of [a] general assessment ... in that its coverage extended to all households rather than just those who had applied for housing assistance. However, it did not consider the social and economic

circumstances of households, and was administered by each local authority rather than on a centralised basis.

(Fahey and Watson, 1995. *An Analysis of Social Housing Need,* p. 208)

They went on to recommend the implementation of a national survey of housing standards for the purposes of comprehensively assessing housing circumstances and deficiencies. This would involve collecting data on households referring to social, economic and tenure circumstances as well as the physical characteristics of their accommodation. In Northern Ireland the Housing Executive carries out a House Condition Survey at five-year intervals, which includes an analysis of the association between dwelling conditions and the social and economic circumstances of households. The 1996 survey consisted of four main blocks of questions dealing with the physical attributes of the house; aspects of flats and common areas; aspects of the neighbourhood, and area and socio-economic questions. The design, administration, validation, analysis and general management of the survey are the responsibility of the Housing Executive's Research Unit. In the 1996 survey the data collection and preparation were subcontracted and the fieldwork was carried out by a range of professionals such as Environmental Health Officers, Chartered Surveyors and Chartered Architects.

The Council recommends that future Housing Surveys should undertake a comprehensive assessment of housing circumstances involving the collection of data at household level on social, economic and tenure circumstances as well as the physical characteristics of accommodation. The survey should be capable of assessing the housing circumstances of older people. It should also assess the needs of older people in relation to repairs and adaptations to underpin (a) scheme(s) for housing repairs and adaptations.

In making this recommendation the Council is aware that an assessment of older people's needs for repairs and adaptations to their homes could be carried out as a separate exercise for that cohort of the population alone, or could be undertaken as part of an assessment of the condition of the housing stock generally. While the former will satisfy the Council's recommendation, the latter approach would ultimately have the effect of ensuring that all accommodation is fit for older people. This could be achieved by incorporating such an assessment into the more general assessment of housing circumstances. A separate exercise could be undertaken by the inclusion of a separate schedule of items in the

housing survey which would be administered to households with a member over the age of 65 to identify older people's needs for repairs and adaptations. In general, any survey of housing conditions in the State should give a breakdown of its results by age of (eldest) resident(s).

Recommending the implementation of such a housing survey also raises the issue of an infrastructure for housing research. The National Economic and Social Forum published a report on *Social and Affordable Housing and Accommodation: Building the Future* in September 2000. That report recommended that a National Housing Authority should be established to provide strategic policy advice and support to the Minister for the Environment and Local Government, local authorities and other housing providers. The National Housing Authority proposed by the NESF is modelled on the Northern Ireland Housing Executive. It was further recommended that the Authority should include a dedicated Housing Research Unit which, *inter alia,* would:

- undertake a policy research and information needs assessment, in consultation with other housing interests

- adopt a programme for monitoring and evaluation purposes to better inform the future development of housing policy.

The Council endorses the establishment of a Housing Research Unit and believes that it could reside within the Housing Division of the Department of Environment and Local Government in the event of such an Authority as proposed by the NESF not being established.

Social Housing For Older People

18. In addition to schemes to upgrade older people's homes, *The Years Ahead* (1988) identified the need for local authorities to directly provide social housing for older people based on an assessment of need:

> The Minister for the Environment should monitor the implementation of the Housing [Act] 1988 and the position of the elderly requiring local authority accommodation to ensure that their needs are being met ... We recommend that local authorities give special attention to the elderly on low incomes in substandard private rented accommodation in planning and allocating accommodation for the elderly.

> (Working Party on Services for the Elderly, 1988. *The Years Ahead,* p.74)

Ruddle *et al* (1997) concluded that:

> Despite the continuing need for housing for older people as indicated by [a] 1996 assessment, there has been a considerable reduction in the volume of housing provided directly by local authorities for older people.
> (Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendations,* p.149)

Since then, overall social housing output by local authorities has increased and this expansion is expected to continue as housing was included for the first time in the 2000-2006 *National Development Plan* and reaffirmed in the *Programme for Prosperity and Fairness* (2000). The Programme for Prosperity and Fairness (2000) made specific commitments to increase output by Local Authorities and voluntary Housing Associations over the period of the programme. In June 2000 the Department of Environment and Local Government published *Action on Housing* (2000) which included a number of measures aimed at promoting more efficient utilisation of existing housing and to meeting the housing needs of the elderly more appropriately:

- local authorities, particularly in urban areas, will be encouraged to construct smaller dwellings in appropriate locations with a view to earmarking them for elderly people currently in accommodation inappropriate to their need

- the Minister for Health and Children will request the Chief Executive Officers of the health boards to consider the disincentive effect of loss of medical card eligibility on decisions made by the elderly to move to more appropriate accommodation. CEOs will be asked to consider the positions of persons in receipt of a medical card before selling their home but who could lose their entitlement, arising out of capital held following the sale of their home

- the Minister for Social, Community and Family Affairs will increase the amount of net proceeds from the sale of a home exempted during assessment of means for non-contributory pension purposes from £75,000 to £150,000 and will examine extension of the eligibility for the exemption to those taking up housing provided by local authorities and voluntary housing bodies.

However, social housing provision by local authorities for older people still falls short of demand. There was a 10 per cent increase in the number of households headed by an older person identified as in need of local authority housing between 1996 and 1999. Having regard to the measures cited above, **the Council recommends that provision of social housing by local authorities for older people should be expanded to ensure adequate supply to meet older people's needs. Measures should also be implemented to support social housing provision for older people by voluntary and co-operative housing associations. Referring back to the recommendation above regarding the implementation of a housing survey to carry out a comprehensive assessment of housing circumstances, the Council believes that such a survey is needed for the additional purposes of strategic planning in relation to the provision of social and sheltered housing for older people.**

Sheltered Housing For Older People

19. *The Years Ahead* (1988) envisaged that sheltered housing would form a central part of the continuum of care for older people:

> We recommend that where it is not feasible to maintain elderly persons in their own house or in ordinary local authority housing, sheltered housing should be considered as a first choice.
> (Working Party on Services for the Elderly, 1988. *The Years Ahead,* p.74)

To date voluntary housing organisations have been the largest provider of sheltered housing for older people. However, there is a very limited supply of fully developed sheltered housing as defined by the Irish Council for Social Housing.

Ruddle *et al* (1997) concluded that:

> Most of the purpose-built housing for older people does not address special needs or provide supportive communal facilities and services.
> (Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendations,* p.151)

In view of the increasing numbers of older people and their expressed wish to

remain living in their own communities, there is a clear need for the development of supported or sheltered housing for older people. **The Council recommends increased provision of sheltered housing by local authorities and voluntary housing associations.**

Given the important role played by voluntary providers of social and sheltered housing for older people in the past, it is imperative that they are given sufficient resources to have the capacity to continue and expand their provision of fully developed sheltered housing for older people. This entails making funding available to voluntary providers for on-site support services for dependent, elderly residents of sheltered housing schemes. The HeSSOP study has shown how limited community care services are at present and this supports the argument that additional funding is needed to provide adequate support services entailed in a fully developed sheltered housing development. **The Council recommends the implementation of a properly defined funding scheme for on-site support in voluntary sheltered housing schemes incorporating care costs and management costs. This scheme should cover the provision of services distinct from health board provided community care services.**

Finally, in relation to private provision of sheltered housing, the Council welcomes the announcement in *Action on Housing* (2000) that:

> The National Building Agency will pilot a home ownership sheltered housing development for elderly private homeowners wishing to purchase housing more suitable to their needs within their community and locale. The pilot will serve as a demonstration model that can be taken up by the private house building sector and local communities throughout the country.
> (Department of Environment and Local Government, 2000. *Action on Housing,* p.10)

The Transport Needs of Older People

20. Transport has long been identified as a difficulty for older people (O'Mahony, A., 1986) and Council recommendations since then for a co-ordinated policy for rural transport services under the auspices of local authorities have yet to be acted upon. Such a policy should include innovative use of existing services including school buses, health board vehicles and post vehicles as well as vouchers for private bus and taxi services. Partnerships should be forged

between statutory, voluntary and commercial providers at local level to maximise the range of transport options available. The transport initiatives undertaken by Area Development Management Partnership Companies and Community Groups described in the recent ADM report *Rural Transport: A National Study From A Community Perspective* (2000) are very impressive and informative. The ADM report highlighted the importance of partnership, local and county level co-ordination and co-ordination fora for the development of appropriate rural transport initiatives. **The Council suggests that County Development Boards should be considered as appropriate fora to examine and promote transport policy at county level particularly in light of their multi-agency and multi-sectoral representation.**

In addition, the Council has urged that the restriction of the free travel scheme to off-peak hours should be reviewed:

> Free travel is not available between 7 am and 9.45 am and between 4.30 pm and 6.30 pm. As many medical appointments are in the morning, older people may not be able to avail of the free travel scheme to carry out these essential journeys. The Council believes that older people should be able to use free travel for this purpose and suggests that presentation of a medical appointment card should allow the older person avail of free travel for the related journey.
> (Layte *et al,* 1999. *Income, Deprivation and Well-Being Among Older Irish People,* p.11)

Expand Provision of Chiropody Services as a Priority

21. In the HeSSOP study older people rated chiropody as one of the most important services for older people. It emerged as a critical service for older people given that foot conditions were one of the more common health problems reported and foot care was one of the activities of daily living older people were most likely to report finding difficult. Chiropody was the service most used by older people with 16 per cent having availed of it in the past year. It was also the service with the highest additional demand as 12 per cent of people who had not used it would have liked to. **Given the findings of the HeSSOP study, the Council recommends that chiropody services should be expanded significantly on both a community and domiciliary basis.**

Upgrade Public Long-term Residential Care

22. Steps should be taken to address aspects of public facilities older people find less acceptable. The principal difference between public and private residential care facilities is size, with public facilities having a larger number of beds. The policy of replacing older, larger facilities with smaller community hospitals or nursing units as recommended by *The Years Ahead* (1988) has begun to be implemented in recent years. The allocation of capital funding under the National Development Plan 2000-2006 to develop facilities for older people will mean that more progress will be made. Under the Health (Nursing Homes) Act 1990, private (and voluntary) nursing homes are subject to quality inspections but public facilities are not. **The Council reiterates a recent recommendation (*A Framework for Quality in Long-Term Residential Care for Older People in Ireland:* 2001) that regulations on quality in long-term residential care should be extended to public facilities to ensure common standards in all sectors.**

RECOMMENDATIONS ON CONSULTING OLDER PEOPLE

23. When the Council commissioned a review of the implementation of the recommendations of *The Years Ahead* (see Ruddle *et al,* 1997), it highlighted some shortcomings of that policy for older people including the absence of any reference to the need to consult with older people about services that most affect them. It stated:

> *Shaping a Healthier Future* stressed the importance of consumer participation in the planning of services and the accountability of service providers, principles largely ignored by *The Years Ahead* report. Given the number of changes that were recommended by the [*Years Ahead*] report, it is remarkable that no thought was given to asking older people about their value or to informing them about the changes proposed.
> (Ruddle *et al,* 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendation,* p.5)

The HeSSOP report notes that the principle of consumer oriented services was adopted in the 1994 health strategy document *Shaping a Healthier Future.* The strategy set out to reorientate the health system towards improving the effectiveness of health and personal social services by reshaping the way that services are planned and delivered. It identified three dimensions to this

reorientation - the services, the framework and the participants. Consumers and providers of health services constitute the participants and the following commitment was made in relation to them:

> There will be greater sensitivity to the right of the consumer to a service which responds to his or her needs in an equitable and quality-driven manner; and greater recognition will be given to the key role of those who provide the services and the importance of enabling them to do so to their full potential.
> (Department of Health, 1994. *Shaping a Healthier Future,* p.8)

The strategy envisaged a system that would be accountable to consumers:

> There must also be mechanisms to ensure that those with decision-making powers are adequately accountable to the consumers of the service.
> (Department of Health, 1994. *Shaping a Healthier Future,* p.11)

The strategy proposed some mechanisms to implement service quality measures:

- producing charters of rights including a specific commitment that a charter would be introduced to cover groups such as the elderly
- placing a requirement on health authorities to carry out evaluations such as consumer surveys and include their findings in the annual reports they make to the Minister
- encouraging each authority to identify and develop a quality initiative geared towards improving an aspect of service quality, with those initiatives which prove successful being adopted by other authorities.

In addition, a commitment was made to introduce legislation to reform the framework of the services which would include the following consumer related measures:

- the establishment of advisory groups in each health authority area to provide a voice for the users of the services
- the introduction of complaints procedures by all health authorities

- the introduction of a statutory requirement on health authorities to act as a channel to the Minister of the views and concerns of their populations.

Despite these detailed commitments, the HeSSOP report notes that while the principle of consumer oriented services was adopted in the 1994 health strategy document *Shaping a Healthier Future,* it has remained mostly aspirational since then.

CONSUMERISM AND OLDER PEOPLE

24. The HeSSOP study notes that the rhetoric of consumer consultation has found its way into the strategy and policy documents of the Irish health and social services system, but at this point, the aspiration is far from being realised. The study found that in Ireland efforts at consulting with consumers in the health and social system have been limited and can be viewed as primarily consumerist in orientation. It describes how under a consumerist approach to consultation, people are given only limited opportunities for involvement and participation by being asked to evaluate output without being given an explicit explanation of what happens to that evaluation or given an account of that evaluation. It also presents a democratic model of consultation as an alternative. In the democratic model, users take an active role in the decision-making process, including how services are developed, structured or provided. The report describes how democratic strategies for consultation are empowering and capable of strengthening people's commitment to a better health and social system while increasing their own sense of control over their lives. **The HeSSOP report considers that a democratic approach to consultation is the way forward and the Council endorses this view.**

Lynch *et al* (2001) argue that the focus on consumerism in public service provision has led to the concept of the 'market citizen' replacing the concept of the 'citizen with social rights'. A consumerist approach assumes that people are autonomous entities making individual choices without any constraints such as economic circumstances or caring obligations. Gilleard and Higgs (1998) examined the issue of adopting a consumerist approach to health services for older people and argued that while a consumerist orientated health care system may benefit people in their third age (characterised as a time when people are self-fulfilling agents free to pursue their own projects and plan their own lives and a time of physical and material well-being):

> The rhetoric of consumerism attributes to all older people a position

of agency, which as users of scarce and targeted resources, they cannot fill. Chronic illness and material impoverishment characterise the fourth age and turn older people into 'users'. (Gilleard and Higgs, 1998. 'Old People as Users and Consumers of Health Care: A Third Age Rhetoric for a Fourth Age Reality?' *Ageing and Society,* vol. 18, part 2, pp.234)

In light of the shortcomings of consumerist approaches highlighted above, the Council welcomes the distinction drawn in the report between democratic and consumerist approaches to consulting older people and concurs with the authors that a democratic approach to consultation is the way forward.

Mechanisms For Consulting With Users Of Health And Social Services

25. The challenge is to develop mechanisms for consulting with older people in a democratic way. The study refers to consultations taking place at micro and macro levels. There are various levels at which decisions are taken and policy is formulated that impact on the quality of older people's lives. The mechanisms proposed below are intended to ensure older people are consulted at each level.

The Forthcoming New Health Strategy Should Incorporate A Policy On Consulting Users Of Health And Social Services

26. The HeSSOP report recommends the development of a coherent and formalised strategy or policy for consumer involvement. The Council has in the past recommended that a strategy for the development of health and social care services for older people be developed. This strategy should have a firm commitment to the principle of consulting with and involving older people and carers in the planning and evaluation of services at all stages. The strategy should outline a model for planning and funding services for older people based on information collected across local areas feeding directly into the decision-making process. This process should have a strong consultative focus with older people asked to define health and social needs from their own perspective (Ruddle *et al,* 1997). The Council suggests that the forthcoming new health strategy provides an opportunity to develop a coherent and formalised policy and strategy for consulting users of health and social services. **The Council recommends that the purpose of consultation should be to ascertain how well a service is being delivered, based on the experiences and**

perceptions of users and the community. More generally, the strategy should include provision for the development of health and social care services for older people.

The Guidelines Set Out In HeSSOP Could Guide The Development Of Mechanisms For Consulting Consumers

27. The HeSSOP report proposes a six-step framework for consultation and identified the HeSSOP study as a Step 1 activity in the framework. This framework could be adopted by the new health strategy. The report also sets out guidelines for consulting with older people which could form a protocol for service providers to adhere to in developing ways of consulting older people:

- consumers should develop initiatives themselves
- the process should be accessible in terms of setting and format and should also have access to decision-making
- participants should be supported through measures such as facilitating skill-building
- qualitative methods should be used more in consultations
- all stakeholders should be involved
- the process should be accountable
- the process should be ongoing, dynamic and responsive.

PROPOSALS FOR CONSULTING OLDER PEOPLE

28. The Council proposes that the following mechanisms for consulting older people as users of health and social services should be considered by the strategy:

- establish advisory committees on services
- use research techniques to hear older people’s views on services
- develop service quality measures

- assess professional/patient interaction
- have older people represented in their own right as social partners at national level.

Establish Advisory Committees On Services

The Years Ahead (1988) recommended the establishment of an Advisory Committee on the Elderly comprised of health professionals and service providers from health boards and local authorities, representatives of voluntary organisations working on behalf of the elderly and nominated public representatives. In 1997 these had been established in only two of the eight health boards (Ruddle *et al,* 1997). Where these committees were established they were perceived by management as fulfilling a useful function in guiding policy-making and by Co-ordinators of Services for the Elderly as providing a forum for valuable exchanges of information, thereby leading to convergence on aims and priorities. Where they were not established it was because they were perceived as difficult to manage effectively and as adding another level of bureaucracy. It was suggested that there could be more effective ways of hearing the voice of older people than the committees proposed. (Ruddle *et al,* 1997). As noted, *Shaping a Healthier Future* (1994) proposed the establishment of advisory groups in each health authority area to provide an input to the authority from the users of the services as a mechanism for consultation. **The Council recommends that Advisory Committees recommended by *The Years Ahead* should be reviewed and given an extended remit to incorporate the function of consulting with older people. This would entail revising the composition of the Committees to include older people themselves. The revised committees could then act as Advisory Committees on Services for Older People. All user groups should be represented on such committees.**

Use Research Techniques To Hear Older People's Views On Services

The Council recommends that health boards ask consumers about services for the purposes of ascertaining how well a service is being delivered, based on the experiences and perceptions of users and the community. A range of research strategies such as surveys of users, focus groups and active work groups could be employed by health boards to do this.

Developing Service Quality Measures

The mechanisms for service quality proposed in *Shaping a Healthier Future* (1994) could also be developed including:

- a Charter of Rights for user groups, including older people, should be produced
- health authorities should include findings of evaluations such as consumer surveys that they carry out in their annual reports
- where health boards develop initiatives to improve an aspect of service quality these should be disseminated as good practice so they can be adopted by other boards
- complaints procedures should be implemented by all health authorities.

Assessing Professional/Patient Interaction

Traditionally professional/patient relationships have been dominated by the professionals who have not always listened to the patient creatively. **The Council recommends that health professionals should build an awareness of the individual patient into their care practices and try to involve people in their own care by informing them, listening to their point of view and involving them in decisions about their own care.** This may entail health boards implementing a programme of awareness building among staff.

Have Older People Represented In Their Own Right As Social Partners At National Level

Social Partnership at national level has been identified as the key site of policy and decision-making in contemporary Irish society. While social and community organisations representing a broad range of constituencies are recognised as social partners, older people as a constituency do not have recognition in their own right. **The Council recommends that older people should have recognition in their own right in the Social Partnership process.** A number of issues need to be addressed for such representation to occur:

- older people are not a homogenous group and if older people's participation in Social Partnership is to have any meaning it must be on the basis that the

interests of all older people are represented. In order to address this issue of accountability, the establishment of a Federation of older people's groups may be required. Another option may be to rotate representation among a number of representative organisations

- capacity building measures are required to support social and community groups participating in the partnership process on an equal basis with the other partners. This entails providing resources to groups both in terms of finances and personnel so they have access to supports such as a secretariat, research, childcare and respite for carers.

FURTHER RESEARCH BASED ON THE FINDINGS OF THE HeSSOP STUDY

29. The following areas for research recommended in the report have been incorporated into the Council's current work programme:

    - the implementation of care management as a model for delivering home care
    - developing a health and social care information strategy for older people
    - an investigation of older people's preferences for employment and retirement.

The Council endorses the recommendations to conduct research on strategies to promote older people's participation in planning for long-term care and to investigate further the stigma older people were found to associate with home and community care services.

The Council further recommends research with a multi-disciplinary input for the purposes of developing a national framework of assessment for older people that can be applied to assessing entitlement to services, community and nursing home subventions and care management on an equitable basis.

REFERENCES

Area Development Management Ltd, 2000. Rural Transport: *A national study from a community perspective.* Dublin: ADM, Dublin.

Browne, M., 1992. *Co-ordinating Services for the Elderly at Local Level: Swimming Against the Tide.* Dublin: National Council on Ageing and Older People.

Comptroller and Auditor General, 2000. *Report on Value for Money Examination: Special Housing Aid for the Elderly.* Report for Presentation to Dáil Éireann, Report No. 36, Government of Ireland.

Department of Health, 1994. *Shaping a Healthier Future: A Strategy for Effective Healthcare in the 1990s.* Dublin: Stationery Office.

Department of Social, Community and Family Affairs, 1998. *Review of the Carer's Allowance.* Dublin: Stationery Office.

Department of Environment and Local Government, 2000. *Action on Housing.* Dublin: Government of Ireland.

Fahey, T. and Watson, D., 1995. *An Analysis of Social Housing Need.* Dublin: The Economic and Social Research Institute.

Finn, M., 1992. *Survey of Housing Stock 1990.* Dublin: Environmental Research Unit.

Gilleard, C. and Higgs, P., 1998. 'Old People as Users and Consumers of Health Care: A Third Age Rhetoric for a Fourth Age Reality?' *Ageing and Society,* vol. 18, part 2, pp.233-49.

Haslett, D., Ruddle, H. and Hennessy, G., 1998. *The Future Organisation of the Home Help Service in Ireland.* Dublin: National Council on Ageing and Older People.

Layte, R., Fahey, T. and Whelan C., 1999. *Income, Deprivation and Well-Being Among Older Irish People.* Dublin: National Council on Ageing and Older People.

Lynch, K., Baker, J. and Cantillon, S., 2001. *Equality: Frameworks for Change.* Draft paper prepared for the National Economic and Social Forum (NESF) for the plenary meeting of the NESF on 30.1.2001.

Mangan, I., 1997. 'Equity, Consistency and Comprehensiveness: The Need for a Legislative Framework to Govern the Provision of Essential Services for Older People' in *Conference Proceedings: Review of the Implementation of The Years Ahead: A Policy for the Elderly and Implications for Future Policy on Older People in Ireland.* Dublin: National Council on Ageing and Older People.

National Council on Ageing and Older People, 2001. *A Framework for Quality in Long-Term Residential Care for Older People in Ireland.* Dublin: National Council on Ageing and Older People.

National Economic and Social Forum, 2000. *Social and Affordable Housing and Accommodation: Building the Future.* Dublin: NESF.

Northern Ireland Housing Executive, 1998. *Northern Ireland House Condition Survey: Summary Report.* Belfast: Housing Executive.

O'Connor, S., Ruddle, H., Gallagher, M. and Murphy, E., 1988. *Caring for the Elderly Part II. The Caring Process: A Study of Carers in the Home.* Dublin: National Council on Ageing and Older People.

O'Mahony, A., 1986. *The Elderly in the Community: Transport and Access to Services in Rural Areas.* Dublin: National Council on Ageing and Older People.

O'Shea, E., 1993. *The Impact of Social and Economic Policies on Older People in Ireland.* Dublin: National Council on Ageing and Older People.

O'Shea, E., 2000. *The Costs of Caring for People with Dementia and Related Cognitive Impairments.* Dublin: National Council on Ageing and Older People.

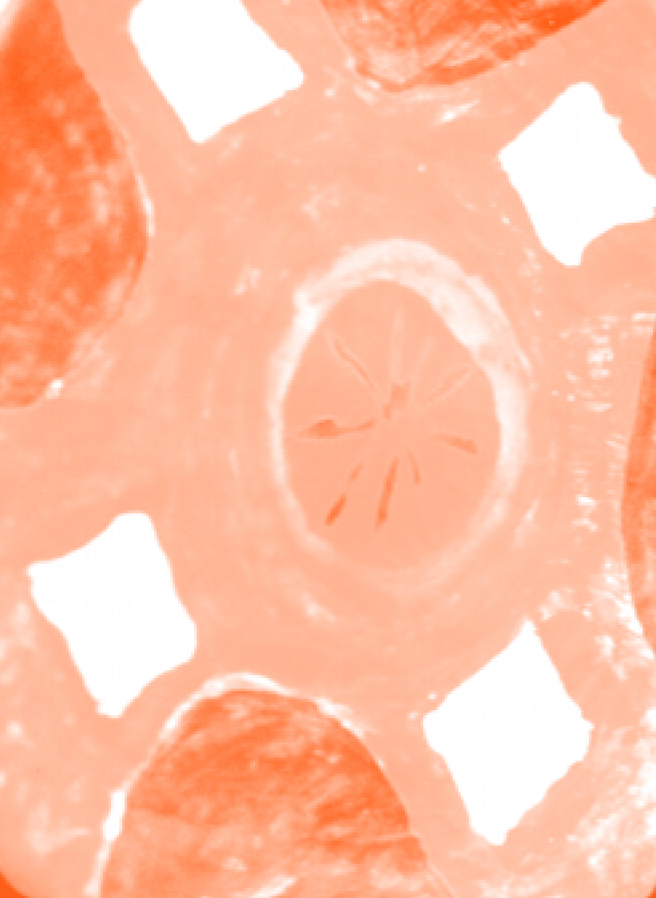
O'Shea, E. and Hughes, J., 1994. *The Economics and Financing of Long-Term Care of the Elderly in Ireland.* Dublin: National Council on Ageing and Older People.

O'Shea, E and O'Reilly, S., 1999. *An Action Plan For Dementia.* Dublin: National Council on Ageing and Older People.

Programme for Prosperity and Fairness, 2000. Dublin: Stationery Office.

Ruddle, H., Donoghue, F. and Mulvihill, R., 1997. *The Years Ahead Report: A Review of the Implementation of its Recommendations.* Dublin: National Council on Ageing and Older People.

Working Party on Services for the Elderly, 1988. *The Years Ahead: A Policy for the Elderly.* Dublin: Stationery Office.



Chapter 1

Consulting Older People

Chapter 1

Consulting Older People

If the [health] service could be made fit for older people, it would be fit for everyone.
(Tonks, 1999. *'Medicine Must Change To Serve An Ageing Society',* p.1451)

INTRODUCTION

Incorporating consumer consultation and participation in the health and social service arena has received increasing international attention since the 1980s. In Ireland, the 1994 health strategy *Shaping a Healthier Future* was a landmark Government document in that it directly recommended adopting 'consumer oriented' services as part of its future strategies (Department of Health, 1994).

In a recent review of the origins of 'consumerism' in health services in Ireland, Tim O'Sullivan (1998) outlined four benefits from utilising consumer input:

- it contributes to improved quality of care
- it helps professionals and patients - or those delivering and using the service - to come closer together
- user influence is a counter-balance to the strength of powerful interest groups, such as the State (seen as an interest group) and the professions
- it heightens awareness of patients' individual and collective needs.

While commitment to consumer participation and consultation regarding planning and evaluation in the health services was outlined in the Government's 1994 policy document, it has remained mostly aspirational across the 1994-1998 timeframe of the document and beyond. If the goals of consumer participation are accepted as legitimate, then the question of means must now be addressed - how to involve consumers in such a way as to maximise the potential benefits to themselves and to the system.

The new National Health Promotion Strategy (Department of Health and Children, 2000) specifically identifies older people as a target group and discusses partnership and consultation to achieve the strategic aim to 'enhance the quality of life and improve longevity for older people'. Traditionally, there has been a focus on services for younger people in Ireland, given the relatively young profile of our population (about 11.4 per cent of our population was aged 65+ in the 1996 census). Fahey (1995, 1998) outlines an anticipated relative stability in the proportion of older people in Ireland in the next twenty-five years at least. He proposes that influences on health spending internationally relate more to macroeconomic matters and to actual demands on services from various interests than to changes in demography *per se.* Services are seen as led by 'supply' rather than 'demand', with professionals acting as agents in informing patients of their needs and entitlements. In a rapidly developing Irish society, where traditional expectations and attitudes (e.g. regarding what can be expected from health and social services or from old age itself) combine with a range of health problems for older people (problems often distressing, frightening or embarrassing for individuals), there is a real challenge to health service providers to balance views of older people about service need and acceptability with benchmarks about best quality care. Moreover, while average health status decreases somewhat in older age, there is a larger variability in health care needs than at any other time in the lifecycle.

Improvement in our health services is necessary as indicated in widely diverse sources of information. While life expectancy is gradually increasing in Ireland, we are now in the unenviable position that life expectancy for an Irish woman or man at age 65 is the lowest in the European Union (Department of Health and Children, 1999). At the other end of a spectrum, we have relatively little data to determine the quality of services through outcome evaluation and auditing measures. The importance of improving the quality of health service delivery for Irish people cannot be overlooked.

Consultation with older people as major consumers of health care is now imperative as a core component of the evidence base from which policies and service plans for this group are developed across the Irish health boards. Such consultation is important, not just to reflect the views of older people in their own right, but also because the majority of structural, process and attitudinal challenges experienced by older people in availing of services are also challenges for other groups, for instance, people with disabilities in the population.

Consultation with older people is the focus of this report. However, as stated in the opening quotation to this report (taken from a recent *British Medical Journal* editorial), what benefits older people in terms of a quality service benefits everyone. Since our health service provision is mostly integrated across ages, changes in services for older people should also benefit other groups in society. Concerted efforts are required to ensure that this effort becomes a win-win approach for everyone, rather than an 'older versus other health service user' contest. As has been said about developing more enabling environments for people with disabilities, many of the modifications such as ramps in public places and easily managed water taps make autonomy and participation in community life possible for some and easier for all.

High quality health care is 'care that is desired by the *informed* patient or client (and family); is based on sound judgement of the professionals involved, from scientific study and/or experience; and is agreed upon and carried out in a relationship of mutual trust and respect' (Williams, 1996). One of the main challenges in developing some form of consultation with older people is to directly consult representatives of the largest constituency of older Irish people, i.e. those living in the community. This large group is typically under-researched because of the practical difficulty and costs associated with evaluation of adequate samples in their own homes. The aim of this project is to commence this consultation process.

THE HEALTH AND SOCIAL SERVICES FOR OLDER PEOPLE (HeSSOP) PROJECT

HeSSOP is a collaboration across the National Council on Ageing and Older People, the Western Health Board and the health boards in the Eastern Regional Health Authority Area.[4] Information on service use, service evaluation and perceptions of service need of a large group living in the community have been reported separately for each board in the first instance; this was to assist service planning for 2001. A combined report now follows to allow further analysis of patterns of use etc., including comparisons across boards to identify common and location-specific challenges to service delivery. While the project covers only two of the country's health boards as constituted at the time of the work, the particular boards involved

[4] On 1 March 2000, the Eastern Health Board was dissolved and replaced by the Eastern Regional Health Authority (ERHA) and three new Area Health Boards - the South Western Area Health Board, the Northern Health Board and the East Coast Area Health Board. The ERHA is responsible for the strategic planning of services, commissioning of services, funding services through service agreements with the three area health boards, voluntary hospitals and agencies and monitoring and evaluating the services provided. The area health boards will be responsible for service delivery, within their own area.

represent the most urban and one of the most rural of the boards. Thus findings are expected to have value for other health boards. The wider issue of consultation strategies to involve older people is addressed in this combined survey report.

Overall Aim Of Project

The aim is to provide a systematic evaluation of health and social service provision from the perspective of older people dwelling in the community needing and/or using these services.

Specific Objectives

The specific objectives of the project are as follows:

- to document health and social service experiences, use and needs by community-based groups of older individuals in two health board areas

- to provide a health and social profile of the over-65 age group in the two health board areas

- to assess preferences as to key care issues (home versus institutional care; home services by care professionals, and other concerns for future health needs)

- to establish policy recommendations for service improvements based on the above

- to compare information across the two health board areas to identify common and specific concerns and to consider issues of equity and access across the boards

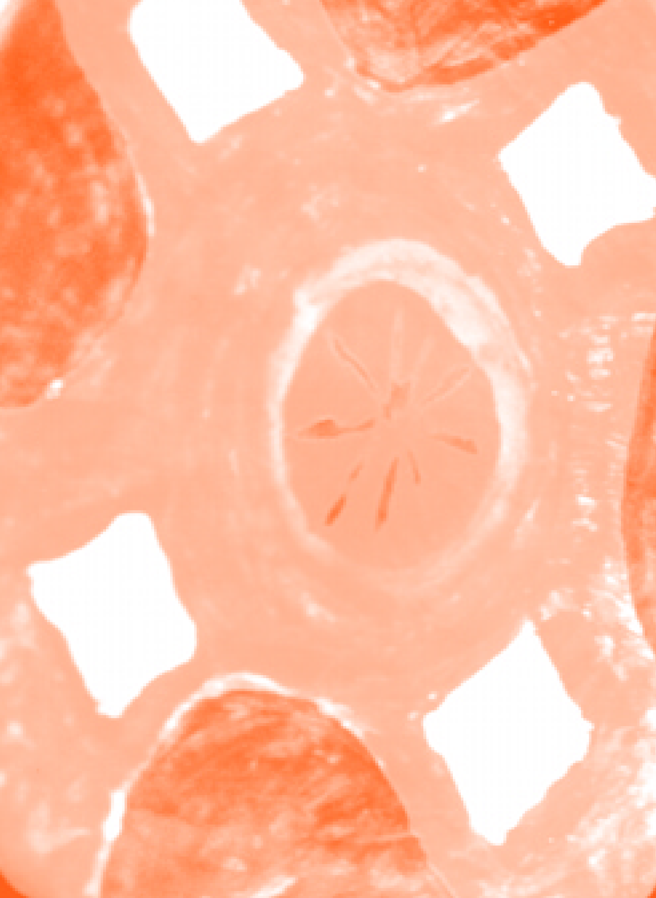
- to develop research protocols for the above issues, which can be used by other agencies when examining these issues for other locations

- to make recommendations about promoting consumer consultation for the future such that older and more marginalised groups can be consulted and their views incorporated into health and social service policy development.

This Report

The Western Health Board survey was reported in May 2000 (Garavan, Winder and McGee, 2000), and the Eastern Regional Health Authority Area survey in June 2000 (Garavan, Winder and McGee, 2000). These reports were for planning purposes in

the separate board areas. An outline of the methodology used and an analysis and discussion of the combined data from the two health board areas are reported here, as well as some detailed comparison of the major findings between the two boards. Findings from a smaller survey of islanders from the Western Health Board area are outlined too. The overall conclusions of the combined report, including service oriented conclusions, future directions based on this study and practical implications for how to involve older people in a wider process of consumer consultation are also considered.



Chapter 2

Methodology

Chapter 2
Methodology

DESIGN

The main research strategy for the HeSSOP project was to conduct a large randomised survey of older people living in the community in the Western Health Board (WHB) and the Eastern Regional Health Authority (ERHA) areas. The survey instrument was developed on the basis of three types of consultation. Firstly, an extensive literature review of research was completed on health and social service use and needs of older people, and on service user satisfaction more generally. Then consultations were conducted with two groups: local health and social service professionals, and older people, selected to represent various health and social service experiences. Professionals and older persons in the six WHB and ERHA area counties were included. The survey was then completed over a four-month period (March to June 2000). Further details of the methodology are outlined next.

SAMPLE

The survey targeted those living in the six WHB and ERHA area counties (Galway, Mayo Roscommon, Dublin, Kildare and Wicklow). Names were randomly selected from the electoral register. Eligible participants were those aged 65 years or older and living in a private household. Where the individual selected to take part in the survey was unable to do so (due to serious illness or cognitive impairment, for example), a primary carer or next of kin living in the same household was invited to participate as a ‘proxy’ participant. While there are weaknesses with proxy responding, it was very important to have some representations of service use and needs of those unable to respond as those potentially most needing health and social services in the community.

PROCEDURE

Consultation Process

Key Service Providers And Older Persons’ Interest Groups

A wide range of key health and social service providers were consulted to determine the content of the survey. These were primarily identified through the two Directors

of Services for Older People on the Boards (Ms Mary Mc Dermott for the WHB and Mr Edward Matthews for the ERHA area) and others as suggested through the conduct of the consultation exercise. The aim was to prioritise topics of interest to professionals and/or older people to initially use in the preparation for the focus groups with older people, and to later use in the development of the questionnaire. Views, experiences and perceived barriers to being the recipient of services were solicited. Service providers were consulted either in the form of focus groups or individual interviews. They included professional, administrative and older people's interest group representatives. Across the two boards the following were consulted:

- older people's service co-ordinators
- administrators
- geriatricians
- area medical officers
- GPs
- directors of nursing and psychiatric nursing services
- public health nurse superintendents
- matrons from community nursing unit
- nursing and care attendant staff from day hospitals, day centres and day care units
- acute services ward sisters
- long-stay hospital nursing staff
- carers' association members
- occupational therapists and physiotherapists
- social workers
- community welfare officers
- home help managers

- heads of ambulance service

- housing welfare officers.

A total of thirty-six personnel were interviewed in three focus groups, and many others were individually interviewed or contacted by phone.

Focus Groups With Older People

Participants for focus groups were contacted through community services managers and other key service providers (e.g. public health nurses, day centre managers, medical officers for elderly services, etc.) working in the health boards. Endeavours were made to obtain the experiences, views and needs from a broad range of participants from different backgrounds. Thus they represented those living in rural, village, town and city locations, those with assorted degrees of ability and those with varying levels of health and social care needs. They also ranged in terms of those with little or no experience of health and social services to those who required or received services on a regular basis. Some were members of active retirement groups or attended day centres, day care units or day hospitals; others had experience of community or hospital care. Six focus groups (three in each health board) comprising a total of sixty-two people, aged 65 years and older (twenty-three men, thirty-nine women) were conducted. Each group consisted of between eight and fourteen older people and lasted approximately two hours. Sessions were recorded with the participants' consent. The aim was to hear the views, experiences and preferences of older people themselves. Topic areas were kept broad so that information on a wide variety of topics could be covered. An honorarium was given to participants in appreciation of their contribution and to cover travel expenses.

Island Focus Groups

Older people living on the islands off the West of Ireland were not involved in the above process since, in some respects, their views, experiences and needs were hypothesised to be specific to their island lifestyle and thus different from those living on the mainland (e.g. access to hospital and home services, transport, access to information, etc.). Important differences would have been made invisible by random survey because of the much larger population on the mainland. Thus a series of separate focus groups were conducted following an initial consultation with key service providers on the islands. These findings are described in a separate section in the report so that strategies specific to the needs of older people living on the islands can be proposed.

Survey

Preparatory Work

A pilot of the survey was conducted, comprising six interviewers and thirty-one participants. The interview schedule was further amended as necessary over a period of ten days prior to commencing the full survey. Ethical approval for the survey was received from the Research Ethics Committee of the Royal College of Surgeons in Ireland (RCSI). Key service providers were made aware of the upcoming project by letter (Appendix B). Leaflets, explaining the study's purpose, were left as reminders with participating individuals. The leaflet provided contact telephone numbers to confirm the interviewer's identity if the participant wanted validation, or to discuss subsequent queries they had about the research or health board services.

Selection And Interview Process

The Economic and Social Research Institute's (ESRI) Survey Unit was engaged to conduct the interviews through local, experienced survey researchers. Names and addresses were randomly drawn from the Register of Electors for the health board counties. Interviewers called on the identified household and if a person of 65 years of age or older lived there, he or she was asked to take part in a study on health and social services for older people. Where there was more than one person of 65 years or over in the household, the person whose birthday was nearest to the interview date was asked to take part.

The survey contact outcomes are outlined in Table 2.1. Of 6,640 addresses identified, 8 per cent (512) could not be included for a variety of reasons (e.g. the household had been vacated or there was no reply following four separate house calls, complete refusal, etc.). Thirty-two addresses were excluded as they were of institutions rather than private households. Where contact was made, there was at least one person over 65 in 1,438 (23 per cent) of households. Eight per cent (113 people) were either too ill or impaired to participate in a survey with thirty-one (27 per cent) of these having no suitable proxy respondent. Of the others in this category, all did have a consenting proxy respondent. Of those contactable and without serious illness or impairment (1,325), 15 per cent directly declined. (Combining potential proxy and direct respondents, a total of 14 per cent refused participation.) A further 21 per cent of those able to participate directly did not participate because of unavailability, continuous non-contact with the individual concerned or other reasons. Thus 66.6 per cent of those eligible and capable of participating, or having a proxy represent them, did so. Of those consenting to be interviewed (861 and 82 proxy interviews), all but six people completed interviews. (For a further discussion of the response rates obtained in this study, please refer to

the section entitled 'Consulting with Older People: Lessons from this Survey'.)

Out of all 937 who completed the interview, 72.5 per cent (69.4 per cent in the WHB and 76.6 per cent in the ERHA area) said they were willing to be contacted again if a follow-up study were to be conducted (7.3 per cent of these have no telephone contact number).

Table 2.1: Response rates: outcomes of household survey invitation attempts

Response Outcome	Number of households		
area (N) (N)	**ERHA (N)**	**WHB**	**TOTAL**
Total interviews completed and usable for analysis:	**401**	**536**	**937**
person(s) aged 65+ and completed in person	377	478	855
person(s) aged 65+ and completed on a proxy basis	24	58	82
Household with person aged 65+ but who did not participate	**345**	**150**	**495**
person(s) aged 65+ and too physically ill or senile 18 and no proxy available	13	31	
person(s)age 65+ and refused to participate	145	51	196
person(s) 65+and permanently unavailable	123	47	170
other reason for non-participation	59	39	98
Interviews incomplete: insufficient data for inclusion in analysis	**3**	**3**	**6**
No one in household aged 65+	3,052	1,638	4,690
Complete refusal/household composition unknown	50	15	65
'Household' was institution (i.e. not a private residence)	29	3	32
Household vacated	17	7	24
Could not locate address	76	64	140
Other	202	49	251
TOTAL TARGET SAMPLE:	**4,175**	**2,465**	**6,640**

The finalised interview schedule was a 520-item questionnaire (although not all items were required to be answered by all respondents). Questions were broadly focused on:

- the respondent's health status and health and social service experiences over the past twelve months
- satisfaction with current health and social services
- level of demand for services not currently being used
- preferences for services that may be required in the future.

Where appropriate, questions were drawn from previously used and standardised tools, such as the measure of psychological distress, the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983), in order that useful comparisons could be made from the overall study. However, many questions included were constructed for this study on the basis of the consultation process with older people and service providers. The topics are outlined in brief below.

Demographic Characteristics
Data on age, gender, marital status, household composition (alone, spouse only, number of generations, etc.), occupation, education, geographic location (city, town, village) and living arrangements (head of household) were collected.

Finances
Information on household income, financial health coverage for care (medical card, private insurance or benefit schemes) and payment for services used were investigated.

Housing
Questions concerned the presence of a set of basic home facilities (such as hot water supply, bath or toilet), whether these were fully functional and if they could be used without assistance. Accommodation status (owner-occupied or rented) was evaluated.

General Health And Functional Independence
Occurrence of any physical or psychological conditions within the last twelve months

was recorded, including the extent to which the respondent felt that the condition had caused disruption to their life over the past month. Further questions focused on experience of pain in the past week. Functional independence was measured using the validated Stanford Health Assessment Questionnaire (HAQ) (Fries, Spitz and Young, 1982). Respondents were asked about their own functional abilities, taking into account the use of a device or aid if one was usually used, across a range of activities of daily living such as dressing or doing the shopping. The instrument was augmented to incorporate items that reflected activities with which older people may have difficulty. For purposes of comparison with other areas of the survey, however, the HAQ was generally used unamended to maintain its validity.

Regarding mental health, the Hospital Anxiety and Depression Scale (HADS), a validated fourteen item self-report measure, was completed to assess the prevalence of borderline and clinical levels of anxiety and depression requiring professional attention in this group of older people.

Health Behaviours And Health Promotion Activities
Exercise and smoking were selected as important health promotion targets for older people - levels of inactivity, smoking and barriers to more healthy behaviours were investigated, including the role of health professionals in encouraging smoking cessation. With regard to possible preventive and screening strategies recommended for use with older individuals, levels of uptake of the influenza vaccination ('flu injection'), frequency of blood pressure measurement and utilisation of general health check-ups were investigated.

Social Contact And Support
Social issues assessed included perceived emotional support, time spent alone in a typical waking day and level of interest in availing of visiting services/group membership.

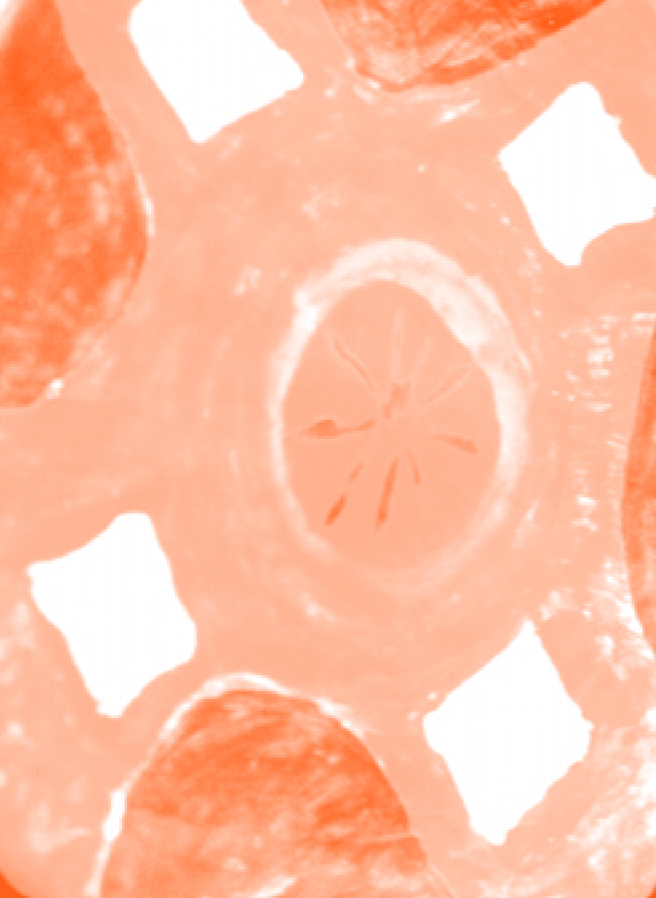
Utilisation Of Services
Service use, need, access and satisfaction were assessed across a wide spectrum of available services and professionals: GP and locum GP; A&E, hospital inpatient and outpatient experiences; day care/day hospital; day centre/club; respite care; public health nurse; care attendant; home help; social work; meals-on-wheels; chiropody; occupational, speech or physiotherapy, and dietary, optical, dental, audiological, psychological and rehabilitation services.

Factors Influencing Service Access And Acceptability
Views on the embarrassment (or stigma) associated with a variety of services were

assessed (e.g. meals-on-wheels, continence aids, chiropody services). Barriers to service use, such as the role of transport in service access, cost and lack of information were also examined.

Preferences For Long-Term Care

Views on preferences for long-term or high-intensity care, if required, were investigated. This involved comparisons between various combinations of home or family-based and health service-provided assistance.



Chapter 3

Profile of Participants

Chapter 3
Profile of Participants

DEMOGRAPHIC PROFILE OF GROUP

Age Distribution

A total of 937 respondents (46 per cent male, 54 per cent female) were interviewed and ranged in age from 65 to 99 years.[5] Twenty-two per cent were aged 80 years or older; almost twice as many women (27 per cent) as men (15 per cent) are in this category (Table 3.1). Age groups and gender within each health board are shown in more detail in Appendix A (Tables A1 and A2).

Table 3.1: Age and gender profile of respondents

Gender	Male (N=428)			Female (N=509)			
	ERHA area %	WHB %	TOTAL %	ERHA area %	WHB %	TOTAL %	TOTAL % (N=937)
Age group (years):							
65-69	45	38	41	32	21	26	32
70-74	27	24	25	29	24	26	26
75-79	17	19	18	17	25	21	20
80-84	7	13	10	11	16	14	13
85-89	3	6	4	7	11	9	7
90-94	1	<0.5	1	3	3	3	2
95+	0	<0.5	<0.5	1	<1	<1	<0.5
TOTAL %	100	100	100	100	100	100	100
(N)	(188)	(240)	(428)	(213)	(296)	(509)	(937)

[5] Male, mean age = 72.6, SD = 6.2; female, mean age = 75.4, SD = 7.2; t = 6.15, df = 1, 935, p<0.0001.

When examining the respondents by health board area, 57 per cent of the total sample were residing in the WHB, while 43 per cent were from the ERHA area. In general terms, respondents in the ERHA area were significantly younger[6] than in the WHB. Twenty six per cent of WHB respondents were in the 'old old' category (i.e., eighty years or more), compared to 16 per cent in the ERHA area, while in the ERHA, 38 per cent of respondents were aged 65-69 years, compared to 28 per cent in the WHB. The two health boards had similar percentages of men and women completing interviews (women: 55 per cent in the WHB and 53 per cent in the ERHA; men: 45 per cent in WHB and 47 per cent in the ERHA area).

In terms of the total number of people aged 65 years and over in these health board areas, the sample studied represented approximately 0.54 per cent of this age group within the health board areas studied (1.1 per cent of older people in the WHB and 0.32 per cent of older people in the three area health boards in the ERHA area: these statistics taken from *Health Statistics,* 1999).[7] Although there were variances between boards, the overall percentage of males to females within age groups (65-74, 75-84 and 85+) in the HeSSOP study were within at most 6 per cent of those figures for the whole of Ireland within those age groups. It appears, in so far as it can be determined, that the age and gender profile of the study sample approximates that of the general population of older people.

Proxy For Interviewees

The total sample incorporated 82 people (9 per cent) who were acting as proxy interviewees for the respondent, mainly due to the respondent being permanently (45 per cent) or temporarily (18 per cent) ill (Table 3.2). Fifty-seven per cent of those acting as proxies were either the son or daughter of the respondent. Spouses acted as proxies in a further 30 per cent of the cases. Grandchildren and non-relatives made up the remainder of those interviewed as proxies. Most proxies (76 per cent) lived with the respondent; the mean age for these was 53.8 years, with ages ranging from 20 to 82 years. Proxy interviewees were asked to answer survey questions from the *view of the respondent,* rather than putting forward their own

[6] ERHA area mean age = 73.0, SD = 6.6; WHB mean age = 75.0, SD = 7.0; $t = 4.32$; $df = 935, 1$, $p<0.0001$.

[7] The population of those aged 65 years or more in Ireland is 413,882 or 11.4 per cent of the total population (65-74 year old age group make up 57.8 per cent of older people, 33.8 per cent are 75-84 years, and 8.4 per cent are 85+). The population of those aged 65 years or more in the WHB is 49,188, or 13.96 per cent of the total population in the WHB (65-74 year old age group make up 54.2 per cent of older people, 36.6 per cent are 75-84 years, and 9.1 per cent are 85+). The ERHA area has 125,271 people aged 65 years or over or 9.67 per cent of the total population in the ERHA area (65-74 year old age group make up 59.8 per cent of older people, 31.8 per cent are 75-84 years and 8.4 per cent are 85+). (Health Statistics, 1999) In the HeSSOP study the 65-74 year old age group make up 58.4 per cent of older people, 32.1 per cent were 75-84 years, and 9.5 per cent were 85+).

views. For this reason, it was suggested that the HADS section, which requires a personal insight into the respondents' psychological feelings, should not be completed by proxy interviewees. However, in a significant number of proxy interviews, the section was in fact filled out. This data was therefore analysed and reported separately from the rest of the sample. In 42 per cent of cases, the person whose views were being represented by proxy was present for most or all of the interview. This may indicate that the views presented by the proxies were fairly reliable. In subsequent analyses, unless otherwise stated, proxy data are included.

Table 3.2: Profile of proxy respondents

	Proxy respondents (N=82)		
	Living with respondent % (N=62)	Living elsewhere % (N=20)	TOTAL % (N=82)
Gender:			
Male	30	-	-
Female	70	-	-
Relationship to respondent:			
Spouse	33	20	30
Child	43	25	39
Sibling	2	0	1
Son/daughter	15	25	18
Grandchild	2	0	1
Other relative	2	15	5
Non-relative	3	15	6
TOTAL	100	100	100
Reason for proxy response:			
Permanent illness	46	45	45
Temporary illness	15	25	18
'Other'	39	30	37
TOTAL	100	100	100
Respondents present for most or all of interview:	47	26	42

Marital Status

Out of the total sample, 102 (or 11 per cent) said they were single (i.e. never married), and 41 per cent were widowed, while the largest proportion were married (47 per cent). Very few were separated or divorced (1 per cent) (Table 3.3).

Table 3.3: Marital status by gender and health board

Gender (N=934)	Male (N=426)			Female (N=508)			
	ERHA area %	WHB %	TOTAL %	ERHA area %	WHB %	TOTAL %	TOTAL %
Marital status:							
Single	9	20	15	8	7	7	11
Widowed	14	15	15	56	68	63	41
Separated/divorced	2	2	2	2	0	1	1
Married	75	63	68	34	25	29	47
TOTAL %	100	100	100	100	100	100	100
(N)	(186)	(240)	(426)	(213)	(295)	(508)	(934)

Of the 438 respondents who reported being married, the majority (63 per cent) lived with their spouse only,[8] and 32 per cent lived with their children and/or grandchildren either with or without their spouse. Just over half (52 per cent) of all the respondents who were widowed, separated, divorced or single lived alone (no differences between WHB and ERHA area). A quarter (24 per cent) of the latter lived with one other person only, which in most cases tended to be a son or daughter (71 per cent) or a sibling (18 per cent). A further fifth (20 per cent) of those currently widowed, divorced or single lived with more than one other, either a member of the second generation (e.g. their children) and/or third generation (e.g. their grandchildren).

Of all those who were widowed (381 respondents), 6 per cent had been so for ten years or more. Men were over twice as likely to be married as women (68 per cent of male respondents versus 29 per cent of female respondents). Most women (63 per cent) were in fact widowed (more in the WHB than in the ERHA area - 68 per cent versus 56 per cent respectively). This may in some part be due to the greater longevity of the female compared to male respondents.

[8] Mean age of spouse if living alone with respondent = 69.5, SD = 8.2.

Education

In total, 535 respondents (57 per cent) had completed primary education only (67 per cent of respondents in the WHB versus 44 per cent of respondents in the ERHA area), while around a fifth (19 per cent) had reached Group or Junior Certificate level (Table 3.4). Leaving Certificate or an equivalent was completed by 14 per cent, and somewhat less (10 per cent) had gone on to third-level education (e.g. university, regional college or equivalent), although a few (1 per cent) had not finished the course.

Employment

The majority of older people reported being retired (60 per cent) or were involved in home duties (29 per cent) (Table 3.5). Very few men said that they were involved in home duties, whereas over half of the female respondents (53 per cent) reported that they were. Paid or self-employed respondents made up a further 10 per cent of the sample (19 per cent of men, 3 per cent of women).[9] While the numbers of those in 'paid' employment were very similar in both of the health boards (around 3 per cent), one fifth of those in the WHB reported being self-employed compared to only 3 per cent of those in the ERHA

Table 3.4: Education level achieved by gender and health board

Gender (N=932)	Male (N=424)			Female (N=508)			
	ERHA area %	WHB %	TOTAL %	ERHA area %	WHB %	TOTAL %	TOTAL %
Education level achieved:							
Primary	40	68	56	48	66	59	57
Group/Junior Certificate	19	12	15	26	19	22	19
Leaving/Matric	20	9	14	20	9	13	14
Third level	21	11	15	6	6	6	10
TOTAL %	100	100	100	100	100	100	100
(N)	(184)	(240)	(424)	(212)	(296)	(508)	(932)

[9] Mean age of employed respondents = 71.2 years, SD = 5.1.

Table 3.5: Employment and gender

Age group (N=932)	65-69 %		70-79 %		80+ %		TOTAL %		
Employment:	M	F	M	F	M	F	M	F	TOTAL
Paid employment	4	1	2	1	0	<0.5	3	1	2
Self-employed	19	2	16	2	10	4	16	2	8
Home duties	1	64	0	54	0	28	<0.5	53	29
Retired	75	33	81	42	90	66	80	43	60
Other	1	0	1	1	0	1	1	1	1
TOTAL % **(N)**	100 (173)	100 (128)	100 (185)	100 (240)	100 (68)	100 (138)	100 (426)	100 (506)	100 (932)

Desire To Work

Given the changing climate of employment in Ireland and an interest by employers and others in attracting back or retaining older workers, those not currently employed were asked whether they would like to return to work. More specifically, they were asked if they were interested in either full or part-time work given that there was a job that interested them. Of those who reported currently not working and who answered this question (799 respondents), 10 per cent said that they would like to work either part-time or full-time, with most indicating a preference for part-time (Table 3.6).[10] The desire to work was more evident in men than in women (15 per cent of men, versus 6 per cent of women). The picture was somewhat different in the two health board areas - around 16 per cent were keen to work in the ERHA area (23 per cent of men, 10 per cent of women), compared to 5 per cent in the WHB (7 per cent of men, 4 per cent of women).[11] There are a number of possible explanations for these differences, one being that the WHB respondents were older and also more disabled than those in the ERHA area. As has been noted by a recent National Council on Ageing and Older People (NCAOP) report

[10] Mean age of respondents with a desire to work = 71.4 years, SD = 5.6.

[11] Difference in desire to work in ERHA area and WHB: $X^2 = 32.6$, df = 2, $p<0.001$.

(Layte, Fahey and Whelan, 1999), it appears that there are still many older people who are not currently in work who would like to work. Thus flexible employment options for older people may be both of benefit to the older person as well as the employment market as a whole.

Table 3.6: Desire to work (if not currently in paid employment)

Gender (N=799)	Male (N=333)			Female (N=466)			
	ERHA area %	WHB %	TOTAL %	ERHA area %	WHB %	TOTAL %	TOTAL %
Age group:							
65-69	14	5	10	4	3	4	6
70-79	9	1	5	4	<0.5	2	3
80+	0	1	<0.5	2	1	1	1
No desire to work	77	93	85	90	96	93	90
TOTAL %	100	100	100	100	100	100	100
(N)	(172)	(161)	(333)	(200)	(266)	(466)	(799)

Household Income

Household income was measured in broad terms, in that respondents were asked about the approximate level of net household income (i.e. total income after tax, PRSI and other statutory deductions of all members of the household). It should be emphasised that unless a comparatively detailed study of socio-economic status is undertaken, such values discussed provide only a broad estimate of income and act as a guide when performing comparative analyses alongside other variables. The information obtained, if used in this form alone, would be of limited value, due to variation in household size and type.

For the purposes of this study, therefore, income was 'equivalised' across different sizes and types of households. For example, a net household income of £200 per week may be quite large if that person is living alone. However, if there are three adults and one child in the same household, £200 may be quite inadequate. Thus various equivalence scales are used in Ireland that try to accomplish a more comparative measure by assigning a 'weight' to each household member, which

takes into account the age category (e.g. adult or child) and the number of people within the household. The equivalence scale used here has been used in previous socio-economic studies (Layte, Fahey and Whelan, 1999; Callan *et al,* 1999) and was proposed as one that best reflects the rates of financial assistance for older people. The scale gives the first person in the household a weight of 1.00, with a weight of 0.66 attached to each subsequent adult and 0.33 to each child (up to the age of 14). Only one question addressed income in this study. Income per person was estimated and recategorised in low, medium or high levels, and is illustrated in Table 3.7.

In comparative terms, those in the lowest income category tended to be significantly older for both genders,[12] tended to be living in the WHB area (60 per cent)[13] or living alone (76 per cent.[14] Using the equivalised scale, Layte, Fahey and Whelan (1999) estimated that around 59 per cent of those aged 65 years or older in Ireland had £100 or less per week per person. This compares broadly to the current study, where overall 49 per cent fall into this low category (with minimal data collection on income). Layte, Fahey and Whelan (1999) found that elderly females living alone in rural areas had an increased risk of poverty (at the 50 per cent level). They contend that this may be due to the number who rely on the non-contributory or widows pensions as the sole income source for that household. For a more comprehensive study of social income and poverty see Layte, Fahey and Whelan (1999).

[12] Lower income for older females: $X^2 = 15.9$, df = 4, $p < 0.004$; males: $X^2 = 9.6$, df = 4, $p = 0.047$.

[13] Lower income in WHB: $X^2 = 82.8$, df = 2, $p < 0.001$.

[14] Living alone on lower income: $X^2 = 114.5$, df = 2, $p < 0.001$.

Table 3.7: Estimated equivalent income per person

	Estimated equivalent income per person							
	Low		Medium		High		TOTAL	
	%	(N)	%	(N)	%	(N)	%	(N)
Age group (years):								
65-69	37		56		6		100	(184)
70-79	51		43		6		100	(407)
80+	59		36		5		100	(193)
Health Board:								
ERHA area	32		58		10		100	(364)
WHB	60		38		2		100	(520)
Gender:								
Male	42		51		7		100	(402)
Female	54		41		5		100	(482)
Household composition:								
Living alone	76		19		5		100	(255)
Living with one other	25		66		9		100	(382)
Living with more than one other	57		43		<0.5		100	(247)
TOTAL % (N)	49	(429)	46	(406)	5	(49)	100	(884)

In response to an open-ended question asking what could be changed or provided which would make their life easier, some respondents focused on the inadequacy of old age pensions. A few others felt that older people should not be made to pay tax. As highlighted later in the report, financial concerns were a central issue for many people.

Socio-Economic Class

The sample was also classified in terms of socio-economic class (Table 3.8). About a quarter (24 per cent) were classified as professional, while over half (52 per cent) had worked or were working in skilled to unskilled manual occupations. While there were a number of small differences in percentages between the health board areas in terms of socio-economic status in most categories, the largest differences were in the categories of higher professionals (12 per cent in the ERHA area versus 6 per cent in the WHB) and skilled manual labour (19 per cent versus 29 per cent respectively).

Table 3.8: Socio-economic groups (CSO classification) in the two health board areas

	Health Board Area		
	ERHA area	WHB	TOTAL
	% (N)	% (N)	% (N)
Irish CSO socio-economic group:			
0 **Unclassified**	4	6	5
1 **Higher professional** (and managers and farmers with more than 200 acres)	12	7	9
2 **Lower professional** (and proprietors and farmers with 100-199 acres)	14	16	15
3 **Other non-manual** (and farmers with 50-99 acres)	21	17	19
4 **Skilled manual** (and farmers with 30-49 acres)	1	2	25
5 **Semi-skilled manual** (and farmers with <30 acres)	18	18	18
6 **Unskilled manual**	1	7	9
TOTAL % (N)	100 (401)	100 (536)	100 (937)

Household Composition

Table 3.9 shows the breakdown of household type and composition with variables such as gender, marital status, age group and health board.

Living Alone

Twenty-eight per cent of all the respondents lived alone and of these, almost three quarters (73 per cent) were widowed, while most of the remaining (24 per cent) were single (Appendix A, Tables A3 and A4 illustrate the breakdown of these variables between health boards.) In addition, over two thirds (70 per cent) of those living alone were female (69 per cent in the WHB, 73 per cent in the ERHA area), and just over a quarter (26 per cent) were aged 80 years or over. Widowed women in their seventies (36 per cent of all those living alone) or eighties (18 per cent of those living alone) were the most typical example of those who lived alone. Single men aged 65 to 79 years made up 10 per cent of all respondents living alone. Higher numbers of respondents lived alone in the WHB (30 per cent) than in the ERHA area (25 per cent) although this was difference was not significant. This compares to the 1996 census (Central Statistics Office, 1997) where it was estimated that 31.6 per cent of the population in Ireland, aged 70 and over, living in private households, live alone (and in the EHB 32.9 per cent of the group are estimated to live alone).

Living With Others

The majority of respondents in the overall sample (43 per cent) lived with one other person. Of these, 70 per cent lived with their spouse or partner only (41 per cent of men, 20 per cent of women). A further 22 per cent lived with a son or daughter and 6 per cent with a sibling. Of those (be it their spouse or another person) residing with the respondent, over 55 per cent were aged 65 years or over. Twenty-nine per cent of the overall sample lived with more than one other person. Over half (59 per cent) of these lived solely with one other generation (either a younger or older generation than the respondents themselves), while 29 per cent lived in a three-generation family household. Of those who lived with one or more others, the mean number of persons per household was 2.8[15] and this did not vary across health boards.

[15] Range = 2-8, SD = 1.2.

Table 3.9: Household type by gender, marital status and age group and in ERHA and WHB areas

	Household type: Respondent lives					
	Alone % (N)	(Two person household)		(More than two persons in household)		TOTAL % (N)
		With spouse only % (N)	With one other (no spouse) % (N)	With family: 2 or 3 generations % (N)	With other relatives and non-relatives % (N)	
Gender:						
Male	18	41	7	30	4	100 (428)
Female	36	20	20	21	3	100 (509)
Marital status:						
Single	61	1	24	0	14	100 (102)
Widowed	50	<0.5	24	24	2	100 (381)
Separated/divorced	39	15	31	15	0	100 (13)
Married	1	63	1	32	3	100 (438)
Age group (years):						
65-69	15	42	8	30	5	100 (304)
70-79	35	29	12	21	3	100 (427)
80+	33	14	22	27	4	100 (206)
ERHA area	25	33	12	25	5	100 (401)
WHB	30	28	14	25	3	100 (536)
TOTAL SAMPLE %(N)	28 (263)	30 (282)	13 (124)	25 (235)	4 (33)	100 (937)

To summarise these findings in terms of looking at the most common combination of variables for gender and age group, men were more likely to be married, aged 65 to 79 years and live alone with their spouse (35 per cent), or with a second generation (21 per cent). Women, on the other hand, were most likely to be widowed, aged 70 or over and live alone (28 per cent) or with a second and/or third generation (24 per cent). Women who were married, aged 65 to 79 years and lived with their spouse alone made up a further 20 per cent of female respondents.

Home Ownership

Generally, respondents (83 per cent) lived in property that they owned. Five per cent of respondents rented out their homes, while 12 per cent lived in property that was owned or rented by someone else. Nearly two thirds (64 per cent) of these properties were owned or rented by their own son or daughter, while others lived in homes owned or rented by their spouse (7 per cent), siblings (11 per cent), other relatives (3 per cent) or non-relatives (15 per cent). Most (71 per cent) of those relatives or non-relatives renting or owning the property lived in the home alongside the respondent.

Head Of Household

The 'head of household' has been used as a variable in some studies (e.g. Layte, Fahey and Whelan, 1999) as a useful marker for assessing those more likely to be at risk from a number of factors, including income poverty and basic or secondary deprivation. Older women (i.e. 75 years or over) who are head of their household, for example, tend to be associated with higher risk of basic deprivation and income poverty than older men (although older people are nevertheless at less risk of basic deprivation than 'non-elderly' households).

In an attempt to establish who was seen as 'the head of the household', respondents were asked who they saw as 'making most of the important decisions in the household'. Seventy-one per cent named themselves (with no differences between men and women), while 15 per cent named their spouse and a further 12 per cent put forward their son or daughter as the 'head of the household'. Two per cent of those designated as head of household comprised siblings, other relatives or non-relatives. Fifteen per cent of those respondents who named themselves also commented that they and another household member made joint decisions concerning household matters. Where joint decisions were made, spouses were reported most commonly, although children, siblings and non-relatives were also put forward. In total, 42 per cent of households had female heads over the age of 74 years.

BASIC HOME FACILITIES

Whilst conducting focus groups with older people, one of the areas which was identified as causing great concern for a small, but needy, group was the lack, or indeed the non-functioning, of facilities seen as basic to the larger population. As Layte, Fahey and Whelan (1999) point out, although older people appear to have similar mean scores for basic and secondary deprivation indices compared to the rest of the population, housing quality tends to be significantly poorer for them on some measures (damp walls and floor, rot in windows or floors, leaking roof, etc.). For the HeSSOP survey, basic facilities were defined as having a hot water supply, an indoor flush toilet, a bath or shower, adequate lighting and cooking facilities and the continuous use of a telephone.

Few respondents were found to be lacking these home facilities. Table 3.10 shows the range of facilities queried. Sixty-two people (i.e. 7 per cent of the sample) reported one or more basic facilities lacking in their home. Over half of these (4 per cent of all respondents) however, were lacking a telephone only, whilst another 3 per cent reported not having one or more of the other facilities such as a bath or shower or a hot water supply. Although these figures are small, it was clear that there were significantly more respondents lacking facilities in the WHB than in the ERHA area.[16] Eleven lacked a proper water supply, in that they had neither a hot water supply, an indoor flush toilet, nor a bath or shower (although most of the latter said that they had the continuous use of a telephone). Inadequate lighting and cooking facilities were reported even less commonly. Of those with these home facilities, only four respondents reported them to be non-functional and all of these respondents were in the WHB.

[16] $X^2 = 14.9$, df = 1, $p<0.001$.

Table 3.10: Respondents without basic household facilities in each health board area

	ERHA area % (N)	WHB % (N)	TOTAL % (N)
Facility:			
Use of a telephone	2 (8)	6 (32)	4 (40)
Bath or shower	1 (4)	3 (17)	2 (21)
Hot water supply	1 (3)	3 (16)	2 (19)
Indoor flush toilet	1 (4)	2 (9)	1 (13)
Adequate cooking facilities	0 (0)	1 (4)	<0.5 (4)
Adequate lighting	0 (0)	<0.5 (2)	<0.5 (2)
Absence of one or more of above facilities:	3 (12)	9 (50)	7 (62)
Inadequate/no heating system †	1 (4)	3 (17)	2 (21)
Damp/draughty home †	<0.5 (1)	2 (13)	1 (14)

† Asked only to those respondents who indicated that they were not always able to keep warm.

In comparing our deprivation data with that of Layte, Fahey and Whelan (1999), the overall figures of those lacking basic home facilities seem to be slightly lower in our sample compared to their data. For example, they found that possession of a toilet, which is not shared with other households, was lacking in 2 per cent of respondents (1.5 per cent stated this was due to lack of resources), while a bath or shower was lacking in 3.2 per cent of respondents. On the other hand, Layte, Fahey and Whelan's study found much higher numbers without a telephone (13.5 per cent did not have one). With the policy of free telephone rental allowance, some free call units for older people and the increased ease with which to obtain a mobile phone, this facility may now be much more accessible both in practical and economic terms for older people than it was some years ago (8 per cent of those with telephones

reported having a mobile phone in the HeSSOP survey). In addition, 82 per cent in Layte, Fahey and Whelan's study saw the possession of a telephone as a necessity and, with fast improving telecommunications, it could be hypothesised that this figure will rise.

Layte, Fahey and Whelan (1999) also found that 17.4 per cent lacked central heating and 6.1 per cent lacked adequate heating for their home. It appears then that many have other methods of heating (open fires, back boilers, oil-fired stoves, etc.) to maintain heat, as very few in the HeSSOP study were unable to keep themselves warm. When asked if over the past winter they had always been able to keep themselves warm, eight people (1 per cent) in total said that they were 'usually not warm', and thirty-eight (4 per cent) said that they were 'mostly warm, but sometimes cold'. Respondents were asked to indicate from a list of six reasons why they were unable 'always' to be warm. Twenty-one respondents (46 per cent) in this group said that their heating system was inadequate, while fourteen people (30 per cent) said that their home was damp or draughty and fourteen respondents also said that they could not afford enough fuel. Twelve respondents (26 per cent) said that they had a medical condition that affected their temperature, while 22 per cent could not manage their heating system. Others made specific comments such as that the fuel allowance was too little, that the roof was leaking or that they had no central heating. Whilst there is a fuel allowance provided for pensionable older people, at present this extends from mid-October to mid-April only. (For more information on entitlements for older people, please refer to the booklet *Entitlements for the Over Sixties* published by the National Social Service Board, 1999.) In response to an open-ended question on general needs, some respondents commented that the fuel allowance was not enough and in addition, that they felt it should be extended to all year round. Others made comments that they needed to have central heating installed. This was a particular concern of the respondents living in the WHB area for both fuel and central heating. Considering that many of the older people, especially those in rural areas, are more likely to live in older style homes which may be damper and less insulated than new accommodation, heating costs are likely to be high. In the UK, the government launched a major programme, the Home Energy Efficiency Scheme, to provide 'warmer, healthier homes for those most vulnerable to cold-related ill-health', and offered opportunities for comprehensive home improvements (Olsen, 2000). It is estimated to save older people £1,000 per year if both insulation and central heating are provided.

Of the sixty-two people reporting the absence of one or more basic facilities, 45 per cent lived alone, and a third lived with one other person. Twenty-seven per cent were aged 80 years or older, and while most (69 per cent) were fully independent,

18 per cent had some major limitations to independence when carrying out activities necessary for daily living. Most of those lacking facilities (71 per cent) appear also to have a low weekly income and 70 per cent of the 62 respondents were living in rural locations. Thirty-five per cent of those lacking facilities felt they 'definitely' or 'possibly' needed changes or adaptations made to their home to aid independent living. Of particular interest to many people (especially those in the West) was having a toilet downstairs or a shower installed. Getting into and out of a bath proved very difficult for some respondents.

Older people participating in focus group discussions on health and social services for older people voiced their views on the needs for adaptations in their own homes:

> There is another intermediate stage, that used to be looked after by the health board ... improving housing of the elderly ... you could do magnificent improvements to their houses so that they didn't have to leave them ... if that was sufficiently budgeted, we found it to be a marvellous scheme.

One man who came to the focus group was wheelchair bound, had no shower at home and currently showered and changed clothes in a nursing home twice a week. He was keen to obtain a shower and also had difficulty with wheelchair access in his own home:

> I applied and I never got it. I wanted ramps at the door: there's a step at the door.

Whilst the lack of basic home facilities is not common, for those that do not have them, the consequences go further than just hygiene and warmth. For one man, the social difficulties were clearly evident, as he explained during one focus group discussion his situation of having no toilet and bath facilities:

> I want to tell you something, now ... I have no sanitary [no toilet, no bathroom], terrible in two thousand and one - no sanitary - no fault of the [name of Health Board], but I still have to put up with it. And I'd say there wasn't many toilets around at that time fifty-six years ago, or even in this town, or even any other town. I worked on a big estate, I had the water laid in, at that time, but I still ended up with nothing. You're alright, when you're young, but when you're old, you need these things, and even if anybody comes to you; if anybody comes to the house ... very

> embarrassing ... not so much the men, but the ladies ... I don't think there's a house in the [board location] that hasn't got a toilet. I'm the odd one out.

Fahey and Murray (1994) reported that despite lacking such items as an indoor toilet, bath or shower or a dry, damp-free house, most (90 per cent) of respondents would not want to consider moving to a better equipped home. Even when lacking two or more of the above items or conditions, 78 per cent felt the same way. Thus they concluded that improving existing substandard housing, rather than building newer or purpose-built homes, seems to be what most older people without those basic facilities desire. Similarly, respondents in the present study more often described the need for home improvements or adaptations rather than the desire to move to better accommodations.

Although not specifically addressed in the survey, being a home owner adds more challenges than just having possession of adequate facilities. As one focus group member pointed out, the difficulties of maintaining a property may increase with age:

> Well there's things that have to be done so to speak, when you live in isolation ... you have to learn a lot about minding your own house and doing the necessary repairs, so you think you're going to have all the time in the world on your hands, but you find you don't ... you've got to know how to look after the gutters, and this doesn't work, and the sink chokes up and you plunge it ...

Chapter 4

Health Status and Behaviour

Chapter 4

Health Status and Behaviour

PROFILE OF HEALTH AND FUNCTIONAL ABILITY

Activities Of Daily Living

Functional ability was measured using the Stanford Health Assessment Questionnaire (HAQ) (Fries, Spitz and Young, 1982). The HAQ is normally used to measure levels of physical ability within the general population in terms of the activities that are performed on a daily basis. Respondents are asked to rate their ability to perform seventeen daily tasks within eight activity categories in the past week, on a four point scale - 'without any difficulty'; 'with some difficulty'; 'with much difficulty' or 'unable to do'. For each category of two to five activities, respondents are also asked 'Do you usually need help from another person in carrying out any of these tasks?' An overall measure of independence (ranging from 0-3) can be calculated from the eight categories, yielding four levels of ability to maintain independence in activities of daily living (ADL). Siegert, Vlemin, Van Den Broucke *et al* (1984) interpreted these scores as following:

- 0-0.5: the person is completely self-sufficient
- 0.51-1.25: the person is reasonably self-sufficient and experiences some minor and even major difficulties in performing ADL
- 1.26-2.0: the person is still self-sufficient but has many major difficulties in performing ADL
- 2.1-3.0: the person may be called 'severely disabled'.

The HAQ scores for the present HeSSOP study have been interpreted in the same manner.

Whilst the HAQ has been widely used in community settings, its primary purpose was for use in the hospital setting amongst rheumatoid arthritis patients. For the purposes of this study, therefore, some amendments were made to the tool to include activities that older people in particular may find difficulty with in their usual (home) surroundings. Additions were made to the questionnaire to incorporate eight

items, such as those requiring fine finger movement and sensation and physical flexibility (e.g. 'taking care of feet and toenails' or 'making a cup of tea'). An extra category was added to address difficulties with concentration, memory and reasoning skills (e.g. 'managing your own affairs', or 'remembering daily plans'). Respondents self-reported their abilities, taking into account the use of a device or aid if one was usually used. Thus the measure provided a guide to those activities that required extra help to overcome barriers to independence, as well as providing a measure of physical ability itself. While the amended areas were useful additions for this particular sample, it was felt that the original tool (with amended items omitted) would be more valid and appropriate to use when comparing physical ability with other variables or across studies.

Table 4.1 shows the prevalence of the four HAQ ability groups by age and gender. Tables 4.2a and 4.2b show the percentage of those reporting difficulty at four levels, and whether they usually needed help with one or more tasks in each category. Differences between health boards are also shown. Across all nine daily activity categories, on average, 12 per cent reported that they usually needed help with one or more of the tasks in each category.

Table 4.1: Distribution of HAQ scores by gender and mean age

	HAQ			
	0-0.5 (Self-sufficient)	**0.51-1.25 (Mostly minor difficulties with ADL)**	**1.26-2.0 (Major difficulties with ADL)**	**2.01-3.0 (Severely impaired)**
Male				
Percentage (N)	85 (362)	7 (31)	4 (17)	4 (18)
Mean age (SD)	72 (5.6)	76 (7.0)	76 (8.2)	80 (8.2)
Female				
Percentage (N)	71 (363)	11 (57)	7 (36)	11 (53)
Mean age (SD)	73 (6.0)	80 (7.4)	79 (4.5)	84 (6.8)
Total % (N)	77 (725)	9 (88)	6 (53)	8 (71)
Total Mean age	73 (5.8)	78 (7.5)	78 (6.1)	83 (7.3)

Table 4.2a: Functional ability (rated with device or aid if usually used) and percentage normally needing help, by health board

In the past week were you able to:		Functional ability: No difficulty %	Some difficulty %	Much difficulty %	Unable to do %	Usually need help for one or more tasks in category %: ERHA (N=401)	WHB (N=536)	TOTAL (N=937)
Personal care: Intimate	Wash and dry entire body	87	6	2	5	7	13	11
	Take a bath	83	6	3	8			
	Get on/off toilet	90	5	2	3			
Personal care: Dressing and grooming	Dress, including tying shoelaces and buttons	87	8	2	3	13	18	16
	Shampoo hair	84	6	2	8			
	Care of your feet and toe nails	78	9	3	10			
Arising ability	Stand up from an armless chair	87	7	2	4	5	8	7
	Get in and out of bed	90	6	2	2			
Eating and drinking	Prepare meals - including dinner	86	5	2	7	9	11	10
	Make a cup of tea	93	2	1	4			
	Cut meat	92	3	1	4			
	Lift a full cup or glass to mouth	96	2	<0.5	2			
	Open a new milk carton	88	5	3	4			

Table 4.2b: Functional ability (rated with device or aid if usually used) by health board (continued)

In the past week were you able to:		Functional ability				Usually need help for one or more tasks in category %		
		No difficulty %	Some difficulty %	Much difficulty %	Unable to do %	ERHA (N=401)	WHB (N=536)	TOTAL (N=937)
Walking Ability:	Walk outdoors on flat ground	88	6	2	4	7	12	10
	Climb up 5 stairs	82	9	4	5			
Reach ability:	Reach up and get down a 5 pound object	78	10	4	8	9	17	13
	Bend down and pick up clothing from floor	82	9	3	6			
Grip ability	Open car doors	90	5	1	4	6	10	8
	Open jars previously opened	89	6	2	3			
	Turn taps on/off	93	4	1	2			
Activity ability:	Do messages, shopping, etc	84	5	1	10	18	20	19
	Get into/out of car	86	7	4	3			
	Do housework e.g., vacuuming, cleaning.	75	9	5	11			
Cognitive ability	Manage own affairs (e.g., pay bills)	85	6	2	7	14	22	19
	Remember daily tasks (e.g., appointments)	85	8	2	5			
Mean scores		**89**	**6**	**2**	**5**	**10**	**13**	**12**

Four categories emerged as the main areas where help was usually needed. These areas were as follows:

- 1: ability for activities (e.g. shopping, getting into and out of the car, or doing housework) 19 per cent of the sample
- 2: cognitive ability (e.g. managing one's own affairs or remembering daily plans) 19 per cent
- 3: personal grooming (e.g. dressing, shampooing hair or care for feet and toenails) 16 per cent
- 4: reaching ability, 13 per cent.

The percentages given indicate the number of respondents who normally required help for one or more of the activities.

When comparing these findings with the Fahey and Murray 1994 study entitled *Health and Autonomy Among the Over-65s in Ireland,* where a seven-item functional capacity index was constructed from two previous surveys, figures for those reporting no functional disability were relatively similar (Table 4.3).

Table 4.3: Comparison of HeSSOP sample with Fahey and Murray study (1994) of respondents reporting no functional disabilities

	Age group						
	65-69		70-79		80+		TOTAL %
Functional ability measure:	Male	Female	Male	Female	Male	Female	
HeSSOP study: HAQ	78%	78%	68%	54%	31%	36%	58%
Fahey and Murray study: seven- item measure	81%	74%	68%	58%	37%	29%	61%

Each of the twenty-five tasks within the nine categories was also examined individually in order to gain more specific detail about the types of activities older people most often found difficult and indeed to ascertain what kind of help would be needed to remedy this. Housework (11 per cent) and caring for feet and toenails and shopping (both 10 per cent) were the activities that the highest number of

respondents reported being unable to do without help. Moderately high numbers were also unable to take a bath, shampoo their hair or reach to get down an object (each at 8 per cent), prepare meals or manage their own affairs unaided (both at 7 per cent).

Some daily tasks, such as getting into and out of the bath, are a major source of anxiety for those who have difficulty, as one woman commented on at a focus group:

> Or some gadget to help people get out of the bath, that's what I find hard ... it's when you get out - you might have to stay there if you couldn't get out, when you're living on your own.

Other apparently minor difficulties, such as opening a bottle of tablets, could have potential knock-on effects if the person is unable to do it. The following commentary took place between two people at a focus group:

> Oh the type you turn and twist - desperate.
> Oh they say, ' press the two sides', and I had to get this yoke, what d'you call it, like pliers - pincers. I could not if I died could I open it.

When level of independence (using the HAQ scale) was assessed by age group, people aged 80 years or older reported very significantly higher levels of difficulty carrying out these tasks than those younger than 80.[17] Housework, for example, is an area where many older people of all ages found difficulty, but for those aged 80 and over (the 'old-old'), the problem was much more widespread. Among those eighty or older, 43 per cent reported they had 'much difficulty' or were 'unable to' do housework without help, compared to just under 9 per cent of those aged less than 80. Thirty-eight per cent of those aged 80 or over had great difficulty or found it impossible to take care of their feet and toenails, compared to just 6 per cent of those aged under 80. Again, shopping was a task reported by 34 per cent of respondents aged 80 or older as very difficult or impossible without help, compared to only 5 per cent of those under 80 years. The preceding areas were those where the highest differences occurred, although a similar pattern was seen throughout all twenty-five tasks when comparing younger with older age groups.

[17] HAQ scores for those age under 80: mean = 0.25, SD = 0.54; age 80+: mean = 1.07, SD = 1.06; $t = 15.12$, $df = 1, 935$, $p < 0.0001$.

Gender differences were also quite marked. Overall, women had significantly higher HAQ scores, indicating less independence, than men.[18] These differences were evident when individual tasks were examined among all age groups, although the differences appeared much larger between women and men aged over 80,[19] and were found consistently throughout all tasks. Gender differences became much more striking when focusing specifically on people aged 80 or more (the 'old-old'). Comparing women aged 80 or older to men in the same age group, women were much more likely than men to report having 'much difficulty' or being 'unable to do' housework (49 per cent versus 28 per cent, respectively). Similarly, in this same age group, 32 per cent of women compared to 16 per cent of men found great difficulty managing their own affairs. Other areas where big differences were evident between men and women aged 80 and over were seen in taking a bath and reaching for an object (each 35 per cent versus 22 per cent), and climbing five steps (31 per cent versus 18 per cent). Taking care of their feet and toenails was a problem for 43 per cent of women over 80 versus 28 per cent of men. Similarly, shopping was a task reported by 38 per cent of women and 25 per cent of men as very difficult or impossible without help. Even after accounting for the larger numbers of women in the older age group in the sample, women in this 'old-old' category appear to find difficulty with these daily tasks more often than men do. Clearly the difficulty with these specific tasks for the 'old-old' has implications for targeting provision of services such as home help, meals-on-wheels, public health nurses and care attendants and chiropodists, to these older groups.

Lastly there are some differences in findings between the two health board areas in terms of respondents' functional independence. Generally, HAQ scores were significantly higher for respondents in the WHB compared to the ERHA area,[20] indicating that those in the WHB group were less independent overall. While there were minimal differences between the two health board areas in terms of age and ability, there were some interesting differences when gender was examined among the 'old-old'. For women aged 80 or older, 42 per cent of those in the WHB had major difficulties in daily activities compared to 35 per cent of women in the ERHA area. Of men aged 80 or over, on the other hand, those in the ERHA area tended to have more major difficulties than those in the WHB (30 per cent versus 23 per cent respectively).

[18] $t = 4.92$; $df = 1, 935$, $p<0.0001$.

[19] $t = 2.36$, $df = 1, 935$, $p = 0.019$.

[20] WHB: mean score = 0.48, SD = 0.82; ERHA area: mean score = 0.36, SD = 0.69; $t = -2.14$, $df = 1, 935$, $p = 0.016$

Use And Need Of Devices

Respondents were asked about a range of aids or devices (i.e. walking stick or frame, crutches, wheelchair, raised toilet seat, bath seat or handrail or other device) to help maintain their independence. More specifically, they were asked if they currently used these aids, or if not using them, whether or not they felt they were in need of any. The most common devices reported as currently being used were those to aid mobility. One hundred and sixty-one respondents (17 per cent) said that they usually used a walking stick and 4 per cent normally used a Zimmer frame. Three per cent used a wheelchair, while only four people reported using crutches. Two per cent in total used 'other' devices, which they specified as commodes, a chairlift for the stairs, a long shoehorn, handgrips for picking up objects and a side rail for a bed.

In terms of unmet needs, thirty-two respondents (5 per cent) said they needed but did not have a walking stick, frame, a wheelchair or crutches. For some aids, the percentages of those who needed the device were approaching the numbers of those who currently used the device. For example, forty-nine people (5 per cent) reported normally using a raised toilet seat, and a further 3 per cent said they needed the appliance. Similarly, bath appliances (i.e. bath seat or handrail) were used by 7 per cent of the respondents and a further 5 per cent felt in need of an appliance. Very few said they needed other appliances, but those that were mentioned tended to be home adaptations such as needing a bath, a shower or a stair rail.

Although provision of most aids requires a professional evaluation, it was useful to compare other respondent data from the survey with the respondents' perceived needs. (For more information on entitlements for aids and appliances for older people, please refer to the booklet *Entitlements for the Over Sixties* published by the National Social Service Board, 1999.) Some corroboration was found when comparing HAQ data to stated needs. For example, many respondents who reported the need for mobility aids also reported at least some degree of difficulty with activities that require adequate mobility (e.g. walking on flat ground, climbing steps, getting into and out of bed, standing up from an armless chair, housework or shopping). Similarly, most of those interested in obtaining bath appliances were people reporting at least some difficulty with bathing, and many of those reporting the need for a raised toilet seat were those also indicating that they had some difficulty getting on or off the toilet. However, there was a substantial number of respondents who, despite reporting no difficulty with these activities, felt that nevertheless, they needed a device to help them carry out the task (typically between a quarter and a third of those reporting the need for a device were in this category).

Further indications of possible needs for aids, devices or home adaptations were the numbers of respondents who were unable to use the basic facilities already in place in their homes (i.e. bath or shower, toilet, cooking facilities, lighting) without aid. Significant differences between the health board areas were found, with 7 per cent in the WHB needing assistance to use their facilities compared to 2 per cent in the ERHA area.[21] This is compatible with the finding of lower overall independence levels in the WHB than in the ERHA area. Facilities most commonly reported as being unable to be used without help were as follows:

- a bath or shower (7 per cent in the WHB versus 2 per cent in the ERHA area)
- cooking facilities (5 per cent versus 2 per cent respectively
- toilet (5 per cent and 1 per cent)
- lighting (4 per cent and <1 per cent).

Again, this points to a higher dependence on others in the WHB group compared to those in the ERHA area.

The importance of aids and devices for those who need and rely on them in maintaining independence around the home cannot be underestimated. Without them, vital tasks can become dangerous or impossible. The following comments, made at the focus groups of older people, illustrate their importance:

> My problem is that I had my hip done ten years ago, and ever since then I've never been able to pick any thing up - any thing that falls may stay there - there doesn't seem to be any remedy for it.

> We did all the normal things ... went along to see [name of person] at the resource centre. We waited so long [for a handrail in the bath] that there could have been an accident. It's getting things quickly that is important when you need them.

Severe Impairment: A Group Profile Of Service Use And Need

Being able to remain living at home, despite limited independence, is seen by many to be an important contribution to well-being. One of the aims of this study was to establish to what extent services were in place for those who needed them and

[21] X^2 = 0.66, d f= 1, p= 0.001.

whether they were being used by the most needy groups in older society. For those with very limited mobility, home services may be seen as vital to help maintain their independence and hence to stay in their own home. The following section looks at the small group of the most severely impaired respondents, the scope of their disabilities, their use of services and medical devices and their reported need of services and devices for those who currently are not receiving them. A comparison is made of this group combined with the remainder of the sample (i.e. those less disabled or without disability).

Eight per cent of the sample (seventy-one respondents) had HAQ scores of between 2.0 and 3.0, denoting severe impairment. Almost half (47 per cent) of these respondents were interviewed via a proxy on their behalf. Typically, this small subgroup of the sample was older (mean age = 83 years) and more often female (Table 3.13). Seventy per cent lived in the Western Health Board area. Over a third (37 per cent) lived with one other person, who was generally aged less than 65 years old. (Nine respondents, or 13 per cent of those severely impaired, lived with one other who was aged over 65 years.) Most (79 per cent) reported at least one illness that caused them extreme disruption, and the majority (70 per cent, compared to 34 per cent of those with less severe, or no impairment) had also experienced pain in the week before interview. Of those with severe impairment, 41 per cent (compared to 11 per cent of those with less severe, or no impairment) said their pain was moderate or severe and had lasted for between four days and the whole week.

In examining this area, it was found that 37 per cent of those with severe impairment had had no home services (i.e. public health nurse, personal care attendant, home help, social worker, meals-on-wheels, physiotherapy, occupational or respite care) at all in the last year. Looking at some of the individual daily activities, just over half (53 per cent) of those reporting being unable to either wash or dry their entire body, take a bath or get on or off the toilet have received care from a public health nurse, while only 6 per cent received a visit from a personal care attendant. Of those finding either shopping or housework (or both) very difficult or impossible when unaided, 17 per cent have received home help services and 4 per cent received meals-on-wheels.

Table 4.4 illustrates the pattern of use and need of services when comparing those with severe impairment (i.e. those with HAQ scores of more than 2) to others in the sample who have less severe, or no impairment (i.e. with HAQ scores of 0-2). From the table, it can be seen that, as expected, those with severe impairments use many of the services significantly more than those with less severe or no

impairments. However, when examining those who were currently not using the services, a significantly higher percentage of those severely impaired report a need for many of the services than the rest of the sample. Most often needed services amongst the severely impaired group were public health nurse (26 per cent), optical (15 per cent), home help (14 per cent), chiropody (14 per cent), care attendant (10 per cent) and physiotherapy services (10 per cent). On the other hand, the more able group reported less need of services in general and tended to be less in need of home and personal care services. Services most often reported as needed for this latter group were chiropody (12 per cent), optical (6 per cent), audiological (5 per cent), dental (4 per cent) physiotherapy services (4 per cent) and day centre use (4 per cent). On examining the use and need of medical aids and devices, 36 per cent of the severely impaired group usually used a wheelchair, 43 per cent used a raised toilet seat, and 37 per cent used bath appliances. In comparing severely disabled and less disabled groups (out of those who currently do not have these devices), there were significantly higher demands for these devices in the severely disabled group (need for a wheelchair 9 per cent versus 1 per cent; need for raised toilet seat 36 per cent versus 1 per cent; need for bath appliances 40 per cent versus 3 per cent respectively).

These results indicate that there is a comparatively high perceived need for services and medical devices amongst those with severe impairments. Further, the high correspondence between the respondents’ scores of impairment and their perceived needs indicates that they are most likely fairly accurate and justified in their perception of need.

Table 4.4: Use and need of services and medical devices: comparison of respondents with 'severe impairment' to all other respondents

Services	Currently using service/device		Currently not using service/device, but would like to use	
	Little/no impairment (N=866) %	Severe impairment (N=71) %	Little/no impairment % (N) %	Severe impairment % (N)
Public health nurse	12	56 ***	3 (21)	26 (7) ***
Care attendant	<0.5	7 ***	1 (11)	10 (6) ***
Home help	3	27 ***	2 (15)	14 (7) ***
Meals-on-wheels	1	3	2 (14)	0 (0)
Social worker	1	4 **	2 (12)	3 (2)
Chiropody	14	34 ***	12 (78)	14 (6)
Physiotherapy	3	10	4 (32)	10 (6) *
Occupational therapy	<1	4 ***	1 (8)	6 (4) **
Optical	15	23	6 (41)	15 (8) **
Dental	8	8	4 (31)	2 (1)
Hearing	4	6	5 (37)	8 (5)
Respite	<1	7 ***	1 (5)	7 (4) ***
Day centre	5	13 **	4 (35)	3 (2)
Wheelchair	1	36 ***	<1 (4)	9 (3) ***
Raised toilet seat	2	43 ***	1 (11)	36 (12) ***
Bath appliance	5	37 ***	3 (23)	40 (14) ***

*p<0.05 **p<0.01 ***p<0.001

Quality Of Life And Health

In general, most respondents (78 per cent) rated their quality of life as good or very good, when asked simply 'How do you rate your quality of life?'. On a five-point scale, only 8 per cent rated their quality of life as 'poor' or 'very poor'. A positive correlation was also found between how they rated their current health and quality of life,[22] although quality of life was significantly better for those who were less than 80 years old,[23] for men,[24] for those more independent in their daily activities[25] and for those living in rural locations.[26] Some of the positive aspects of ageing which were put forward during the focus groups included the following:

> Peace of mind.
>
> Time to yourself, and relax. Go where you like, when you like, answer to no one.
>
> Memories.
>
> It's nice to have a good memory, when you're old, and when you have the sight and the hearing, it's a benefit to have the two, a great benefit - thanks be to God I have!
>
> It's a good thing to keep a diary, and just record anything that you know happened during the day. Earlier I used to keep a lot of diaries, and I have them: it's interesting to go back on them, and read them ...
>
> I think reading, writing and listening to the radio help us to keep an active mind.

Respondents clearly differentiated between the quality of their life and the quality of their health. When asked 'Compared to one year ago, how would you rate your current health?', most people said it was the same (71 per cent), while 20 per cent believed it to be worse, and only 9 per cent thought it was better. A further question asked about beliefs about future health: 'How would you expect your health to be one year from now?'. Again, most people felt there would be no change (81 per cent), while 10 per cent thought it would be 'worse' or 'much worse' than

[22] $N = 870$, $r = 0.58$.
[23] $X^2 = 23.1$, $df = 4$, $p<0.001$.
[24] $X^2 = 18.7$, $df = 4$, $p<0.001$.
[25] $X^2 = 319.7$, $df = 12$, $p<0.001$.
[26] $X^2 = 14.4$, $df = 4$, $p<0.006$.

now, and another 9 per cent thought it would be 'better' or 'much better' than now. Beliefs about health were significantly poorer for those aged 80 or over, if they were female,[27] were experiencing extreme disruption from illness[28] or were less independent in activities of daily living.[29] Further analysis in this area is required to gauge the extent of correlation with other areas of life and health.

Provision Of Care By Others

For many older people, household companions, relatives, neighbours and friends provide an important role in maintaining an older person's independence. In most cases, this support is fulfilling for the helper and a comfort to the older person themselves. However, for some older people, this help can become a vital, daily (or in some cases, continuous) support line, without which they would be unable to continue to remain in the community. Responsibilities of those providing care can thus take up significant amounts of time and energy and may be unrelenting, especially where there are no back-up services in place. Even so, many carers persevere and are resolved to continue fulfilling that role. One woman in a focus group gave the example of her daughter who had multiple responsibilities to those living around her:

> I have just one daughter at home, and she has her mother, she has an aunt that lives in the house with us, and she has two aunts that live [near us], and we're all 60 or 70, and she'd have to set up a hospital to mind after the lot of us. She maintains that she'd be the one who would have to look after us.

In order to get a sense of the scope of care provided (but not by the health boards), respondents were asked about the provision of help by others that was necessary to maintain their independence on a regular basis. A list of potential helpers was provided from which they could choose one or more. Respondents were then asked how often they received this help, using categories from 'once weekly or less' to 'continuously, including the night'. While the majority of respondents (56 per cent) reported receiving no such help at all, many respondents (44 per cent) reported receiving help from one or more people on a regular basis (Table 4.5). On average, 21 per cent of the whole sample received a high level of assistance from one or more people (i.e. either most of the day, or continuously, including the night). Women received significantly higher levels of help than men[30] and those aged over 80 received significantly more help than younger respondents.[31] However,

[27] $X^2 = 13.3$, df = 4, $p<0.01$.
[28] $X^2 = 225.6$, df = 4, $p<0.001$.
[29] $X^2 = 288.0$, df = 12, $p<0.001$.
[30] $X^2 = 25.4$, df = 3, $p<0.001$.
[31] $X^2 = 79.7$, df = 3, $p<0.001$.

other than knowing the level and relationship of the 'carer' to the respondent and that the help was needed to maintain the respondents' independence on a regular basis, information on the type of help that was being received (e.g. personal care, physical, practical, emotional, spiritual, etc.) was not obtained.

On examining the sources of support and the amount of help provided more closely, spouses or partners and other relatives living in the household provided a great deal of help. Table 4.5 shows that 25 per cent and 26 per cent (respectively) of respondents who lived with spouses or other relatives reported that they were provided with care they felt was 'necessary to maintain independence'. Again, many of those helpers gave continuous support; 53 per cent and 40 per cent, respectively, of spouses and residing relatives provided help twenty-four hours a day, although it was not possible to examine in detail the type of help or care provided. Help was also reportedly supplied by relatives who lived elsewhere (24 per cent of all respondents) and neighbours (12 per cent), although help from these individuals tended to be one to two times a day or less often, rather than more continuously. Little help was availed of from voluntary organisations (1 per cent). Findings were similar for both health board areas, indicating few differences. The levels of provision of help clearly show that a sizeable number of older people are receiving critical assistance other than or on top of more formal services. There are also consequences to be considered regarding the numbers of helpers or carers involved in this process and the importance of provision of support and respite for these individuals. In response to an open-ended question to all respondents regarding their ideas of what could be changed or provided to make their lives easier, some spontaneously mentioned support for carers. More specifically, they felt that they should be receiving the carers' allowance, or the allowance should be increased. Others discussed the need for respite care.

Table 4.5: Percentage of respondents receiving regular help from relatives, friends and neighbours and frequency of help

Help Provided Regularly To Maintain Independence	% (N)	Frequency Of Help Provided				
		Continuous (including night) %	Most of the day %	1-2 times per day %	A few times a week %	Once weekly or less %
Help/care provider:						
Spouse/partner (where applicable, N=515)	25 (130)	53	19	12	12	4
Other relative in your household (where applicable, N=667)	26 (176)	40	16	16	16	12
Other relative living elsewhere (where applicable, N=884)	24 (209)	4	11	19	37	29
Neighbour (where applicable, N=895)	12 (105)	2	6	16	30	46
Voluntary organisation	1 (10)	20	0	30	10	40

During the focus groups, many who spoke up relayed their concerns about this high level of care from relatives and friends and the importance of getting a break from caregiving:

> The son that's with me, he goes out working for a few hours a day, that gets him out of the way from me, anyway, ... and it gives him a break, which is more important than me, because he needs it. .... If he comes back for dinner, he' s more inclined to joking or something - in better form anyway.

> There are many elderly people living in their own homes, but very disabled, and with the result that there's a daughter or son or somebody full time or a wife or a husband, and they want to get a break.

Focus group members also viewed formal respite care services as lacking:

> There are a lot more other people who require it, but they just don't look for it, because they feel it's not there.

> Respite care is ... limited, very limited. [Name of unit] provides some respite care, but it's not able to meet the demand.

Optimal care provision most likely involves a combination of care from relatives or friends, respite and formal service provision, tailored towards both those providing the care or help and the older person themselves. This area is discussed again later in the report, when carers, the level of independence and the level of service provision are examined together.

Older People As Carers

A substantial number of those interviewed (seventy-eight respondents, or 8 per cent of the sample) reported being the main person providing the necessary care for someone else in the past twelve months. Around two thirds (53) of these carers were women, and a few (13 per cent) were over 80 years old themselves. Most carers had no difficulties maintaining their own independence; however, fifteen respondents (or around a fifth of all carers) had HAQ scores indicating that they were experiencing minor or even major difficulties in performing activities of daily living. In addition, a significantly greater number of carers (20 per cent), compared to 11 per cent of respondents who were not carers, felt they currently 'definitely' or 'possibly' needed adaptations to their home to maintain their independence.[32] Thus,

[32] $X^2 = 14.6$, df = 4, $p<0.005$.

a small number of carers seemed to be at risk of becoming somewhat dependent themselves.

When asked about respite care, only five respondents out of the seventy-eight reporting to be carers said that they had been provided with respite from caring within the last year. Yet only a further nine respondents said that they would like to receive respite care. These findings may, however, reflect a lack of knowledge about the service. This perhaps points to the need for a more in-depth assessment of carers' needs and provision of more information about what is available if they are to take on what in some cases proves to be an extremely mentally, physically and time-consuming task. During the focus group discussion, one lady voiced her anxieties of caring for her disabled daughter and for her husband, who was debilitated by a stroke:

> I worry about my daughter ... she's a German measles case, so she gets bursitis, and I'd say about five times a year she falls flat in front of you, so she'll need a wheelchair in a short time ... I have two of them for the weekends ... if there's a pebble on the ground she'll fall ... She's full-time care.

Others focused on the importance of respite as a vital break for caregivers and clearly illustrate the need for respite care:

> My mother was always my responsibility, as the older child, and she lived to be almost 98. For about two years before it, she always felt that if she could be left in a hospital [for respite] ... so they took her in for the two weeks, and she never asked again, but it was great to get the rest. It took off all the responsibility off your shoulders ... no matter where you went, you had to get back.

> It's not a break unless you take charge of the person ... it was the best two weeks that ever I got.

It is important to note that even older persons who are not primary caregivers for someone else often give their time and help to others, and that helping others can be very rewarding. One woman gave this example during a focus group:

> Sometimes I help my neighbour, and go to social services centre every Thursday, and dance and sing and all the rest of it, but I must admit, sometimes I might feel that I'd prefer if I hadn't to go

today ... when you see what it meant to the others, may be to get out, you may be delighted with yourself that you made the effort ... I think it benefits the person who is giving his or her time as well.

Prevalence And Impact Of Health Conditions

In order to gain an understanding of the types of illnesses and medical conditions that affect the lives of older people, respondents were asked to indicate if they had suffered from any of thirty chronic illnesses or other health conditions in the past twelve months. Only 14 per cent of the entire sample reported that they were free from any underlying illness or condition in the past year. A further 21 per cent reported having only one condition, while 20 per cent reported two illness conditions. The total number of illnesses per respondent ranged from none to sixteen.[33] Table 4.6 shows the prevalence of the conditions for the whole study sample. There were no significant differences in findings between the two health boards on the number of conditions reported.[34]

The most commonly reported conditions were as follows:

- bone or joint conditions (46 per cent)
- hypertension (36 per cent)
- eye or vision problems (22 per cent)
- cardiac conditions (20 per cent)
- memory or concentration, hearing or ear and sleep problems (17 per cent each).

'Other illnesses' not listed but specified (by more than one respondent each) were hiatus hernias, circulatory disorders, vertigo, gall stone or gall bladder problems, tumours, gout and high cholesterol (reported by two to four respondents each). On comparing the two health board areas, the prevalences reported on each condition were, in the main, remarkably similar. With the exception of five conditions, all conditions were within 1-2 per cent of each other when compared across boards. In the WHB, for example, eye or vision problems were reported significantly more commonly (25 per cent versus 19 per cent in the ERHA area)[35] while in the ERHA

[33] Mean = 3.0, SD = 2.7.
[34] $t = -0.51$, df = 1, 935, NS.
[35] $X^2 = 4.1$, df = 1, $p = 0.043$.

area, diabetes mellitus was significantly more common than in the WHB (8 per cent versus 4 per cent, respectively).[36] The higher self-report of eye problems may, in part, be due to the older age group of the sample in the WHB.

For each condition that a respondent reported, they were then asked to rate the extent to which it had disrupted their life over the last month on a scale of disruption from 'extremely disrupted' to 'not at all disrupted'. These figures are also illustrated in Table 4.6. For example, hypertension (i.e. high blood pressure) was reported by 334 respondents (36 per cent), but only 1 per cent of those with high blood pressure said that it had caused extreme disruption in the past month.

[36] $X^2 = 5.6$, df = 1, $p = 0.018$.

Table 4.6: Prevalence of health conditions over past year and level of disruption caused in past month†

		Level of disruption %(N)			
	Prevalence	Extremely disruptive	Moderately disruptive	A little disruptive	Not at all disruptive
Condition:					
Bone or joint condition	46 (431)	18	31	8	13
Hypertension	36 (334)	1	19	29	51
Eye or vision problem	22 (206)	9	30	34	27
Cardiac condition	20 (183)	12	32	28	28
Memory/concentration problem	17 (162)	9	28	47	16
Ear or hearing problem	17 (160)	13	37	38	12
Sleep problems	17 (157)	16	34	43	7
Back problems or slipped disc	15 (135)	15	30	43	12
Respiratory condition	14 (125)	13	28	29	30
Foot problems	12 (114)	23	27	33	17
Depression/anxiety	12 (110)	12	33	41	14
Prostate/bladder problem	11 (99)	18	39	31	12
Bowel disorder	8 (70)	12	36	36	16
Dental/gum problem	6 (57)	3	24	40	33
Diabetes mellitus	6 (55)	11	28	30	31
Stomach or peptic ulcer	6 (55)	4	28	40	28
Migraine/chronic headache	5 (45)	7	44	28	21
Leg ulcer	4 (33)	18	30	37	15
Kidney disease	3 (31)	26	41	26	11
Serious skin disorder	3 (29)	0	22	56	22
Thyroid gland disorder	3 (25)	0	21	37	42
Cancer	3 (25)	20	24	24	32
Blood disorder	3 (24)	0	32	45	23
Other consequences of stroke	2 (20)	56	11	22	11
Speech difficulty	1 (8)	43	0	57	0
Parkinson's disease	1 (7)	42	29	29	0
Epilepsy	<0.5 (4)	50	25	25	0
Liver disorder	<0.5 (2)	0	0	0	100

† Condition prevalence ranked from most to least. Bold figures highlight the most disruptive conditions, regardless of prevalence.

Looking across all illness conditions, one hundred and eighty-four respondents (20 per cent) had at least one condition that they described as causing extreme disruption. In terms of a percentage of all nine hundred and thirty-seven respondents, the conditions most commonly reported as causing a life disruption that was extreme were bone or joint conditions (8 per cent of the whole sample); foot problems and sleep (3 per cent each); heart conditions, ear or hearing problems and back problems (causing extreme disruption to 2 per cent of the sample each). These areas have clear implication for provision of services such as chiropody, physiotherapy, occupational therapy, hearing services, etc.

When asked if there were any physical or mental problems that respondents had not sought care for, a few (twenty-two respondents, or 2 per cent) replied in the affirmative. Problems specified by the respondents were as follows:

- bone, joint or muscle problems (four respondents)
- foot problems, hearing difficulties, prostate or bladder problems, eye problems, mental or cognitive health problems (all put forward by two respondents each).

Although it is difficult to determine the seriousness of each of these due to their brief description, the medical problems mentioned ranged from 'in-growing toenails,' to 'a little Alzheimer's' to 'hip displacement'. Thus it appears that there is a small proportion of older people who are not seeking the necessary care to alleviate or perhaps further prevent a minor condition from turning into something more major.

Hearing

Two items on the questionnaire asked whether respondents had hearing difficulties and, if so, whether they wore a hearing aid. While 17 per cent said they had 'ear or hearing problems' (half of whom said it was moderately or extremely disruptive), eighty-three respondents (or 9 per cent) owned hearing aids. Almost a third (32 per cent) of these did not wear their hearing aid. Reasons for not wearing it were varied, including being uncomfortable (six people), 'could not hear with it in' (four), too noisy (three), that it was broken, difficult to manipulate, or that they wore it only occasionally. There is clearly a need to further investigate the need for, use, and barriers to use of hearing aids.

Pain

Pain had been experienced in the past week by over a third of the respondents interviewed (35 per cent). Fifty five (17 per cent) of those experiencing pain reported having mild pain for between four and seven days in the past week, and

26 per cent reported moderate pain over the same duration. A further 12 per cent had experienced severe pain for at least four days in the past week. It is clear that the management of chronic pain is something that needs to be addressed in the community.

PSYCHOLOGICAL HEALTH

Considering the possible stigma surrounding mental disorders, participants in focus groups were forthcoming when it came to discussions of their own feelings of depression, morale and loneliness. Therefore, it was important to gain some insight into the mental well-being of all the respondents. Psychological measures of general distress, such as the General Health Questionnaire (Goldberg, 1978), have been used in a number of other studies in Ireland. However, the measure provides only a general indicator of well-being and does not distinguish between various disorders. As anxiety and depression are among the most common disorders associated with older people, the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) was used here to gain some insight into the prevalence of each of these disorders in this older population. The HADS is particularly useful in differentiating between anxiety and depression and yields scores which indicate three levels (normal, borderline or clinical) of each. Scores in the borderline range may be interpreted as meaning that the person is at risk for developing the disorder, while scores that reach the clinical levels suggest that the person may meet the criteria for diagnosis of the disorder and require a professional level of intervention.[37]

For comparative purposes, Tables 4.7 and 4.8 display the percentages of respondents with borderline or clinical scores of depression and anxiety within groups by age, gender, health board area and rural versus urban location. Looking across both disorders, a borderline or clinical level of either anxiety or depression was found most commonly amongst women, (20 per cent of all women), amongst those living in rural locations (18 per cent), and amongst those aged 75 or older (18 per cent).

[37] It should be noted here that all respondents for whom a proxy was interviewed on their behalf have been analysed separately in this section, since in many cases a proxy interviewee would have had difficulty answering these questions from the point of view of the respondent. Interpretation of the results of those who did answer the section should nevertheless be treated with some caution.

Table 4.7: Prevalence of borderline and clinical anxiety and depression by gender, health board and location using Hospital Anxiety and Depression Scale (HADS)

	Gender		Board area		Location		
	Male (N=376) %	Female (N=447) %	ERHA (N=368) %	WHB (N=453) %	Rural (N=385) %	Urban (N=406) %	TOTAL (N=823) % (N)
ANXIETY:							
Borderline	3	8	7	5	6	6	6 (49)
Clinical disorder	3	6	4	4	4	4	4 (37)
DEPRESSION:							
Borderline	4	6	3	7	7	3	5 (42)
Clinical disorder	2	3	1	3	3	1	2 (19)
Clinical score for either disorder	4	6	5	7	7	5	6 (48)
Borderline or clinical scores for either disorder	10	20	14	16	18	12	15(121)

Anxiety

A total of thirty-seven respondents (4 per cent) had scores denoting clinical levels for anxiety and 6 per cent scored at borderline levels. When comparing women with men, in general, women reported greater levels of anxiety than men.[38] From Table 4.7, it can be seen that women had at least twice the prevalence of borderline and clinical scores combined (14 per cent of women versus 6 per cent of men in these categories),[39] although women of all ages appeared to be affected similarly (Tables 4.8 and 4.9). There appeared to be no differences in anxiety levels between those who lived in rural and urban areas.[40]

[38] $t = 5.33$; df = 821, 1; $p<0.001$.

[39] $X^2 = 12.23$, df = 1, $p<0.0001$.

[40] $t = 1.34$, df = 790, 1, $p = 0.18$.

Table 4.8: Prevalence of borderline and clinical anxiety and depression by age group, using HADS

	Age group		
	65-74 (N=500) %	75+ (N=324) %	TOTAL (N=824) % (N)
ANXIETY:			
Borderline	6	6	6 (49)
Clinical disorder	4	5	4 (37)
DEPRESSION:			
Borderline	3	8	5 (42)
Clinical disorder	1	4	2 (19)
Clinical score for either disorder	5	8	6 (48)
Borderline or clinical scores for either disorder	13	1	15 (121)

Table 4.9 shows percentages of those with either borderline or clinical levels of depression or anxiety by age and gender. For example, out of the 126 women aged 65-69, 13 per cent scored at levels denoting at least borderline depression. This compares to 7 per cent of men in this age group.

Depression

Only nineteen respondents (2 per cent) scored at levels suggesting clinical depression although a further forty-two (5 per cent) produced borderline scores for depression (Table 4.7). Again, in general, women scored reported greater levels of depression than men.[41] Indeed, women appeared to have a greater (but not significant) prevalence of either clinical or borderline depression (i.e. 6 per cent of men versus 9 per cent of women when borderline and clinical scores were combined);[42] however, this gender difference was less marked than with anxiety levels.

[41] $t = 2.30$; $df = 821, 1$, $p = 0.0216$.

[42] $X^2 = 3.4$, $df = 1$, $p = 0.067$.

Table 4.9: Prevalence of anxiety and depression (borderline or clinical scores) by gender and age group, using HADS

	Age group			
	65-69 %	70-79 %	80+ %	TOTAL % (N)
Anxiety disorder: Borderline/clinical:				
Male	7	7	4	6 (24)
Female	13	14	15	14 (61)
Depression disorder: Borderline/clinical:				
Male	3	7	5	6 (21)
Female	4	9	16	9 (41)

Examining these levels of depression by age groups (Tables 4.8 and 4.9) yields a slightly different picture. Men seemed to be more affected by depression in the 70-79 age group (although not significantly), while women were more likely to be depressed as they grew older.[43] Depression was also significantly more prevalent in the WHB (combined borderline and clinical scores - 10 per cent) than in the ERHA area (4 per cent).[44] However, this seems to be also linked to location (i.e. urban or rural), since those in rural locations score significantly higher on depression than those in urban locations (again, 10 and 4 per cent).[45] The fact that there were more respondents who are female, older or living alone in the WHB may also have contributed to this higher depression level.

Also of interest were the number of respondents who may be suffering from both depression and anxiety. Over a quarter of those with borderline or clinical levels of anxiety also scored highly for depression, and indeed, eight respondents had clinical levels of both.

[43] $X^2 = 10.2$, df = 2, p = 0.006.

[44] $X^2 = 7.8$, d f= 1, p = 0.005.

[45] t = 4.80, df = 789, 1, p$<$0.0001.

Other Factors Associated With Depression And Anxiety

Currently being married appeared to be associated with lower levels of depression,[46] but not anxiety.[47] While only 5 per cent of those who were married had borderline or clinical scores for depression, 10 and 11 per cent, respectively, of those who were widowed or single scored in these categories.

Functional independence was examined to see how it related to depression and anxiety. A moderately strong positive association between HADS depression scores and HAQ disability scores was found,[48] indicating that a greater level of depression was associated with a greater level of disability. This association was weaker for anxiety levels.[49] Although it is not surprising that depression is related to disability, Layte, Fahey and Whelan (1999) found the link between mobility and psychological distress to be higher amongst the older population than the rest of the population using the General Health Questionnaire.

Extreme disruption to life from chronic illness was also examined and was found to be strongly associated with both borderline and clinical depression scores[50] and anxiety scores.[51] Again, Layte, Fahey and Whelan (1999) reported that there was a strong link between levels of distress and chronic illness; they reported that presence of a chronic illness led to three times the risk of psychological distress. Further, chronic illness in combination with income poverty led to four and a half times the risk of distress than if neither of these factors were present (Layte, Fahey and Whelan, 1999). There is clearly a need for health professionals to be aware of the possibility of unrecognised depression or anxiety needing treatment.

If a proxy for the respondent completed the HADS, their data was analysed separately due to the fact that the validity of their responses may be questioned. However, respondents who required a proxy may be those who are most likely to have higher levels of mental distress due to mental or physical illnesses. Therefore the proxy data obtained is presented here for comparison purposes. For those proxies who completed the HADS, levels of anxiety and depression were markedly higher in their respondents compared to the rest of the population. In total, out of seventy proxy interviewees, 23 per cent produced high scores for anxiety for the respondent at either borderline (19 per cent) or clinical (4 per cent) levels, while 36 per cent produced high scores for depression (borderline, 10 per cent, clinical 26 per cent). Many of the respondents who had a proxy had limited independence and

[46] $X^2 = 9.7$, df = 3, p = 0.022.
[47] $X^2 = 3.2$, df = 3, p = 0.359.
[48] N = 823, r = 0.45.
[49] N = 823, r = 0.23.
[50] $X^2 = 63.4$, df = 1, p<0.001.
[51] $X^2 = 46.7$, df = 1, p<0.001.

indeed, a high correlation was found between the HAQ and levels of depression.[52] Again, while it is not entirely appropriate to administer the HADS to indirect observers, and these findings should be viewed with caution, it may suggest that a number of the respondents who were among the most psychologically distressed could not directly take part in this survey.

Morale

A more general measure of morale was also used to complement the HADS scores. The measure consisted of a selection of four statements, answered by means of a five-point scale, from which the scores were averaged for each person and recategorised into low, moderate and high morale (Table 4.10). Three of the statements were based on items taken from an eight-item ad hoc battery which were used in the 1993 study on Health and Autonomy in the Over 65s in Ireland (Fahey and Murray, 1994). One item, 'My age generally has not caused people to treat me with any less respect', was amended to remove the double negative as it was thought to be confusing. Table 4.10 depicts the three levels of morale by gender.

Table 4.10: Level of morale amongst older women and men

	Level of morale and gender					
	High:		Moderate		Low	
	Male %	Female %	Male %	Female %	Male %	Female %
	83	72	14	22	3	6
TOTAL % (N):	77 (719)		18 (171)		5 (42)	

Overall, morale was generally quite high, with only forty-two respondents (5 per cent) having scores suggestive of low morale. The majority (64 per cent) were able to agree with the statement 'I feel I still contribute to my community and society as much as I would like to', while around a fifth disagreed. The latter group are perhaps interesting, considering the numbers of respondents who would consider going back to full or part-time work. In support of this, almost a fifth also agreed that they were bored and had time on their hands that they did not know how to fill. Among the women, morale was somewhat lower than for men,[53] although on closer examination, this was evident in some items more than others. In particular, women were more likely to worry that that they were becoming a burden to other

[52] N = 70, r = 0.75.

[53] Female mean score = 3.79, SD = 0.72. Male mean score = 4.02, SD = 0.80 (t = 4.67; df = 930, 1, $p<0.0001$).

people. This may be due to the older age profile of women in general. Correlations between age and morale scores were generally low, indicating that being older or younger was not associated with higher or lower levels of morale.

Table 4.11 compares these results with those of Fahey and Murray's report (1994). One major difference between their findings and these is the statement regarding 'time on my hands'. However, this is most likely due to the more specific and negative connotations of the wording of this item in the current study (i.e. not knowing how to fill the time). Also of interest is the item about 'becoming a burden' as there is a smaller proportion of older people in the current study that agreed with feeling that way compared to those in the 1994 study.

SOCIAL CONTACT AND SUPPORT

Many respondents reported life situations that could indicate being at risk for problems such as isolation or lack of social support. Half the sample (51 per cent) lived in rural, possibly isolated settings, whilst the remainder were from urban areas. Many lived alone (28 per cent), or were widowed (41 per cent), and limitations on everyday independence due to mobility problems were fairly common (23 per cent). Twenty per cent had extremely disrupted lifestyles through illness. Some respondents suffered from a combination of these factors. For example, 3 percent of the sample (2 percent from rural areas and 1 per cent from urban areas) not only lived alone (either widowed, single or divorced) but also suffered from at least one illness causing extreme disruption and had some level of difficulty carrying out daily activities independently. Respondents were asked a number of questions in order to get a better sense of their level of social support and social inclusion.

Time Spent Alone

Spending time alone was seen as an important marker of social contact. In examining this area, a set of three questions was constructed to establish the average number of hours the respondent would usually spend alone on a typical weekday, Saturday and Sunday, from 8am to 10pm (i.e. a fourteen-hour period). Although the overall mean number of hours spent alone by respondents was relatively low, the number of hours spent alone varied considerably across respondents.[54] Table 4.12 shows respondents' age group and the mean number of hours spent each day, averaged over seven days, taking into account the differences which occur over weekends. Well over a third of respondents (38 per cent) spent no time at all alone during the day. Not unexpectedly, the majority of these respondents were younger, married or living with others.

[54] Weekday: mean = 4.0, SD = 4.5; Saturday mean = 3.2, SD = 4.2; Sunday: mean = 2.6, SD = 3.9.

Table 4.11: Percentage in agreement/disagreement with morale statements amongst older people: comparison of HeSSOP (2000) and Fahey and Murray (1994)

Statement:	Level of agreement/disagreement: Strongly agree/agree		Strongly disagree/disagree		Overall agreement (M&F) % (N)
	Male %	Female %	Male %	Female %	
HeSSOP (N=932): 'I am often bored and have time on my hands that I don't know how to fill'	15	21	78	71	19 (173)
Fahey/Murray (N=909): 'I often find I have time on my hands'	46	47	-	-	47
HeSSOP (N=927): 'Generally, people treat me with less respect due to my age'	7	10	88	86	8 (79)
Fahey/Murray (N=909): 'My age generally has not caused people to treat me with any less respect'	88	86	-	-	87
HeSSOP (N=929): 'I worry a great deal that I am becoming a burden to other people'	12	25	78	63	19 (180)
Fahey/Murray (N=909): 'I worry a good deal that I am becoming a burden to other people'	18	32	-	-	26
HeSSOP (N=927): 'I feel I still contribute to my community and society as much as I would like to'†	70	60	16	22	64 (599)

† No comparable statement in Murray and Fahey report.

The mean number of hours alone per day for those respondents spending no time alone was somewhat higher[55] throughout the whole week. This perhaps provides a more realistic view of those who live alone. Indeed, almost half (46 per cent) of all those living alone reported being alone for an average of 10-14 hours during the day, and another third (33 per cent) for 5-9 hours per day, throughout the week. Twenty four per cent of those spending 10-14 hours alone had limited independence when performing at least some activities of daily living without help.

Table 4.12: Mean number of hours spent alone during waking hours

	Average number of hours spent alone From 0800 to 2200 hrs, per day				
	0 %	**1-4 %**	**5-9 %**	**10-14 %**	**TOTAL % (N)**
Age group (years):					
65-69	42	34	16	8	100 (297)
70-79	35	29	20	16	100 (411)
80+	38	25	22	15	100 (197)
TOTAL % (N)	38 (340)	30 (271)	19 (172)	13 (122)	100 (905)

Acknowledging that time spent alone does not equate with being lonely, another question attempted to ascertain just how lonely respondents felt: 'How often in the last twelve months have you been bothered by loneliness?'. Answers were on a four-point scale from 'very often' to 'never'. The vast majority reported that they were 'never' or 'not very often' bothered. Only 10 per cent said that they were bothered by loneliness either 'very often' or 'fairly often'. However, many of the latter (40 per cent) spent 10-14 hours per day alone.

Although few reported being bothered by loneliness, some participants in the focus group discussions commented on aspects of loneliness and the importance of callers. Some clearly implied the need for a service that would specifically provide social contact:

> I had lots of callers ... I had a chair at the side of the bed, and ... seven people died that sat in that chair that kept me going - the

[55] Mean number of hours = 5.8 (SD 4.0).

whole lot [are since] dead - school mates, people I went to school with - not one alive. Now, you can sit the whole night - nobody: I'm really on my own now ... Yes, I do feel very depressed at times, and I'm not a great man for going out. I like a game of cards ... every Tuesday - that gives me a lift for the week ... But I'm not a fighter: I'd prefer to stay there and put up with it.

Someone should call in, you know, to see that they're all right, at night: there should be some sort of service.

It's a short period, 3 or 4 hours [to have a home help in the home] ... it [still] leaves a long period on their own.

The sad part about it is, that in this day of the Celtic Tiger, the actual traditional services that should be there for people, are not there on a total basis. So we're light years away from a system whereby there's somebody like the Samaritans who would just ring up somebody in the Health Board and [who] they'd go out to, just for a chat.

Social Support

Three items examined the respondents' level of social contact from a practical and emotional support viewpoint. The scores from all three items were averaged for each person and recategorised into low, moderate and high levels of social support. Overall, support appeared very high for the sample. No relationship was found between age and social support levels and no gender differences were identified. There was a weak negative correlation[56] between the number of hours spent alone per day and the level of social support, indicating that more hours spent alone were associated with less support. Not surprisingly, 45 per cent of those reporting very little social support spent 10-14 hours on their own daily. Table 4.13 shows the level of support categorised into high, moderate and low levels and Table 4.14 shows the results of individual items, comparing males to females.

[56] N = 901, r = -0.38.

Table 4.13: Level of social emotional support amongst older women and men

	Level of Social Support and Gender					
	High:		Moderate:		Low	
	Male %	Female %	Male %	Female %	Male %	Female %
	87	84	5	11	8	5
TOTAL % (N):	85 (795)		8 (76)		7 (61)	

On individual items, most respondents said that they had someone who made them 'feel loved and appreciated' (87 per cent) or someone they could 'confide in and would give advice and support' (89 per cent), either 'most of the time' or 'all of the time'. On the other hand, relatively few replied 'none of the time' or 'a little of the time' to these same items (6 and 5 per cent, respectively). More respondents (13 per cent) felt that they seldom had someone to 'help with practical tasks, such as preparing meals, household chores or shopping', although very few (6 per cent of these respondents) normally required help with any of these tasks.

The focus groups conducted with older people prior to commencing the survey uncovered many ideas from older people themselves that might provide social contact, such as the following:

> Supposing if there was somebody in the village that would be contacted - to contact the old people. That somebody could contact them during the day - they could be in bed for all you know but nobody knows.

> There's another service in rural [name of county] that you wouldn't be used to in urban centres, ... but it does break the day for some people, and that's the travelling shop. [It] calls to its customers and people and would give the news of the day.

Table 4.14: Percentage who have someone to provide social or emotional support

	Amount of Support				
	None/a little of the time		Most/all of the time		Most/all of the time
	Male %	Female %	Male %	Female %	Male/Female combined %
Do you have someone who:					
makes you feel loved and appreciated?	8	4	86	87	87
you can confide in and will give you advice and information?	6	5	89	89	89
will help you with practical tasks (e.g. preparing meals, household chores or shopping)?	11	14	85	80	82

These ideas were then developed into a set of items that explored the level of interest respondents had in a selection of social support or contact options. Table 4.15 shows these statements. Sixty-seven per cent were interested or very interested in one or more forms of contact, while 33 per cent were interested in at least two forms. Respondents appeared most interested in an informal visit from a friend or relative (60 per cent replied that they would be 'interested' or 'very interested'). Twenty-one per cent were interested in 'becoming an active member of a group' while 'a person whose job it is to visit older people', a 'volunteer who visits people' and 'a phone number to use for a chat' were interesting options for 17 per cent, 16 per cent and 15 per cent of the sample, respectively. Only a few were interested in 'a person whose job it is to accompany you outside the home'. However, over one third (34 per cent) of this respondent group had borderline or clinical scores for depression and/or anxiety, which may be why they valued that option more than others. One focus group participant was interested in this option for other reasons, as she explained why she had cancelled her CT scan because there was no one who could accompany her to it:

There wasn't any one to come with me. I have a problem with the vision in my left eye, so I would need to have someone with me.

Table 4.15: Personal interest in strategies to provide formal and informal social contact†

	Interested %	Not interested %	TOTAL % (N)
Interest in the following:			
An informal visitor (friend or relative)	60	34	100 (935)
A person whose job it is to visit older people	17	74	100 (934)
A volunteer who visits older people	16	76	100 (931)
A phone number to use for a chat or reassurance	15	78	100 (931)
A person whose job it is to accompany you outside	5	90	100 (929)
Becoming an active member of a group	21	73	100 (935)

† Percentages showing respondents who said 'unsure' to these statements are not shown.

Although the majority of older people may not be interested in these types of arrangements, nevertheless, for a small minority, there is a clear need and interest in some form of formal, socially-based contact. Indeed, when asked in an open-ended question about what could be changed or provided to make their life easier, a small number of people emphasised the need for informal social contact, such as clubs and outings, while others wanted a formal arrangement for someone to visit regularly.

The importance and added benefits of group participation were mentioned by more than a few at the focus groups. Below is an excerpt of a conversation between three people about active retirement and other groups:

> It's a very good way, actually [of meeting people].

> And it's companionship too, and it's fun.

> If only we had the transport.

> We have a game of bingo before we go home, we have tea and cake or biscuits, and we have a chat and ... we did yoga and painting before that.

Another comment during a focus group regarding the importance of group participation was:

> You do a lot of thinking when you're sitting on your own with none on your own ... If you get out there [for an outing], you don't be thinking at all you'd be meeting people, and you're twice as happy when you come back.

Attendance At Social Events

Many older people felt that getting out in the community and socialising was a critical component to maintaining their mental health, as illustrated by the following comment:

> It's great to get out and meet people, to save you being locked up in your own house, with nothing but the four walls - you do too much thinking.

Two items were designed to look at whether respondents were able to get out to social events if they so desired. Respondents rated how able they were over the last month to 'attend events outside your home (e.g. a community or social event)' and 'visit friends or family in your own home' on a four-point scale from 'without difficulty' to 'unable to do'. Most respondents were able to attend events and family gatherings without difficulty, nevertheless, 9 per cent said they were unable to attend events outside their home, and a further 10 per cent could attend, but only with some or great difficulty. Similarly, 7 per cent said that they were unable to visit friends' or family's homes, and 11 per cent found 'great difficulty' in visiting family and friends in the last month. Reasons for their difficulties are unknown, although it seems that many (72 per cent) who reported not being able or had much difficulty getting out had higher HAQ scores, indicating that they had major difficulties in carrying out daily activities independently. In addition, 25 per cent had found transport to be a regular problem for them. A handful of respondents made comments that they were 'housebound'. One man who had Parkinson's disease

himself commented on this at a focus group:

> I'd like there to be an association [for Parkinson's disease] like the one for Alzheimer's ... they've started one, but it's falling apart, because transport is a problem for everyone.

Transport certainly appears to be a common problem for many people wanting to attend events. This subject is discussed further under the heading 'Barriers to Care'.

HEALTH BEHAVIOURS AND PROMOTION

A selected range of activities were evaluated: two areas concerned people's own health-related behaviours (smoking and exercise), and three represented possible preventive and screening activities of health professionals for this group (the flu injection, blood pressure monitoring and general health check-ups).

Smoking

Current smoking was a habit reported by almost a fifth of respondents (19 per cent), with slightly more men than women smoking (22 per cent versus 18 per cent), although a quarter of the male smokers smoked a pipe rather than cigarettes. Thus the number of those who currently smoked cigarettes was about the same percentage across genders (Table 4.16). Just over half of the cigarette smokers said they smoked over ten cigarettes daily.[57] The vast majority had been smoking for over forty years.[58] Half of those who smoked had been spoken to about smoking by a medical doctor in the past year (55 per cent in the ERHA area versus 45 per cent in the WHB). Only twenty-one respondents (12 per cent) wanted help from their GP to stop smoking; most smokers (72 per cent) were not considering quitting at all.

Out of the whole sample, a significantly greater proportion of men than women had given up smoking at some point in their life (46 per cent of men versus 19 per cent of women; 32 per cent overall).[59] This statistic is somewhat deceptive as many more men than women had also taken up smoking at some point in their life. However, when examining just the smokers (either current or previous), fewer of the women (53 per cent) had given up the habit than the men (68 per cent). Of all the past smokers, most (46 per cent) had given up between age 50 and 65. The single most important reason given for giving up, from a choice of six reasons, was their own decision (72 per cent), while around one fifth had thought that medical advice had been the most important factor in giving up.

[57] Mean number of cigarettes per day: 14.6, SD: 8.9.

[58] Mean number of years smoking: 46 years; SD: 14.7.

[59] $X^2 = 96.7$, df = 1, $p<0.0001$.

Table 4.16: Levels of smoking and related medical advice

	Number of respondents %			Duration of smoking (years) Mean (SD)
	Male %	Female %	TOTAL%	
Smoking status:				
Never smoked (N=455)	32	63	49	NA
Ex-smoker (N=297)	46	19	32	28.8 (13.9)
Current smoker (N=183)	22	18	19	46.2 (14.7)
TOTAL % (N)	100 (428)	100 (509)	100 (937)	
Current smokers:				
Medical advice given in previous year?				
By GP only	37	43	40	
By hospital doctor only	3	3	3	
By both	6	8	7	
Total % (N)	46 (43)	54 (49)	50 (92)	
Would like GP assistance to quit	13	10	12	
Actively trying to quit	7	10	8	
Actively planning to quit	5	7	6	
Considering quitting	14	14	14	
Not considering quitting	74	69	72	
Ex-smokers:				
Age at quitting? < 50 years	40	40	40	
50-65 years	45	46	45	
66-74 years	15	14	14	
Most important reason for quitting?				
Own decision	73	70	72	
Specific medical advice	14	12	13	
General medical advice	7	9	7	
Advice from family/friends	4	6	5	
Media	2	2	2	
Other, professional advice	0	1	<0.5	

The Flu Injection As Primary Prevention

Inoculation against influenza (i.e. flu injection) was a topic which was assessed in the survey as an important preventive measure, particularly for older people. This study examined what the uptake rates are and what differences in uptake there are between and within groups based on gender, health board areas, age, disability and illness. Table 4.17 outlines levels of vaccination across a range of variables.

Just over two fifths (42 per cent) of the sample (35 per cent in the ERHA and 48 per cent in the WHB)[60] said that they had received the flu vaccine last winter. More women (46 per cent) than men (31 per cent),[61] especially in those age groups less than 80 years of age,[62] had had the inoculation. The idea to get vaccinated had most often been suggested by a doctor (54 per cent), although in over a third of cases (36 per cent) the respondent themselves suggested it to the doctor. Friends or relatives (6 per cent) had put forward the idea for some people. Only a very few (1 per cent) said they had been persuaded by media sources.

For those who did not receive a flu injection last year (58 per cent), respondents were given a list of six reasons why they had not (from which they could tick as many reasons as applied). Many (24 per cent) did not believe that it would reduce the risk of flu. One older person who attended a focus group put forward an example: 'He gave me the flu injection and I got the flu after it.' Another 15 per cent were concerned about the side effects; 8 per cent did not know they were entitled to it; 6 per cent of respondents reported a previous negative experience with flu' injections, and 5 per cent reported that their doctor said they did not need one.

In addition, more than half this number (235 respondents) chose to give their own reason for not getting the flu injection. Nineteen per cent gave reasons such as they had not bothered, they had 'put it on the long finger', that they forgot or that they did not think it important. Twelve per cent felt they did not need the injection (these were mainly those under 80 years old). Other comments included the following: they had not had the injection due to the cost (2 per cent); they did not usually get flu or were not normally sick (1 per cent), or conversely, they were already unwell (2 per cent). One per cent admitted that either they were afraid or they did not like injections.

[60] $X^2 = 15.3$, df = 1, $p < 0.0001$

[61] $X^2 = 8.4$ df = 1, $p = 0.004$.

[62] Women more than men, aged less than 80 years: $X^2 = 6.6$ df = 1, $p = 0.01$.

Table 4.17: Percentage of respondents who had 'flu injection comparing genders, HAQ scores and illness disruptions within health boards, age subgroups

		Gender		HAQ score		Illness disruption in past month		TOTAL
		Male %	Female %	0-0.5 %	>0.5 %	Not extreme %	Extreme %	% (N)
Age group:	**Health Board area:**							
	ERHA: TOTAL VACCINATED	32 (60)	38 (80)	32 (102)	48 (38)	32 (107)	52 (33)	35 (140)
	WHB: TOTAL VACCINATED	41 (95)	53 (155)	44 (174)	59 (76)	45 (180)	58 (70)	48 (250)
65-69	ERHA	19	34	25	40	23	40	26 (39)
	WHB	25	32	28	22	27	32	28(42)
	SUBTOTAL % (N)	22 (38)	33 (43)	26 (75)	32 (6)	25 (66)	36 (15)	27 (81)
70-79	ERHA	42	40	38	55	37	63	41 (75)
	WHB	45	52	47	58	48	57	49 (119)
	SUBTOTAL % (N)	31 (80)	47 (114)	43 (148)	57 (46)	43 (151)	59 (43)	46(194)
80+	ERHA	45	37	34	43	37	47	39 (26)
	WHB	65	68	69	65	64	71	67 (89)
	SUBTOTAL % (N)	54 (37)	57 (78)	58 (53)	57 (62)	54 (70)	65 (45)	58 (115)
TOTAL% (N)		**31 (155)**	**46 (235)**	**38 (276)**	**55(114)**	**39 (287)**	**56 (103)**	**42 (390)**

The level of uptake reported here represents winter 1999 (interviews commenced in March 2000), before a major 'flu epidemic developed in Ireland along with other European countries. Extensive media discussion took place shortly after Christmas (and in advance of these interviews) regarding the desirability of high levels of 'flu vaccination for winter 2000, in particular for older people. Intention to avail of these injections for the coming winter was of interest in this context. Of the overall study sample, 59 per cent intended to get the 'flu injection next year (64 per cent in the WHB, 53 per cent in the ERHA area); 21 per cent were not sure, and 20 per cent said they did not intend to. All but 2 per cent of those who were vaccinated last year were intending to do the same again in winter 2000. Around 30 per cent of the respondents who did not have the 'flu injection said they intended having it next year, although a slightly larger number (36 per cent) were not sure. Thus many people are still to be persuaded of the benefits of 'flu vaccination.

Blood Pressure Management

Three questions were aimed at blood pressure management, including when they last had it checked, what the level was and whether or not they are on regular medication for it. Recent blood pressure checks were the norm, with around two thirds of respondents (68 per cent) saying that they had had it measured within the past three months. A further 22 per cent had had blood pressure checked within the last year. Only 2 per cent of all respondents had not had it checked in the last five years. When asked about their blood pressure levels, all but 3 per cent reported they knew whether their blood pressure was high (16 per cent), normal (78 per cent) or low (3 per cent). Interestingly, 39 per cent said they were on regular medication for their blood pressure. This figure is higher than expected, most likely due to a number of respondents who indicated that they had normal pressure because of treatment.

General Health Check-Up

Nearly three quarters (72 per cent) of respondents said that they had had a general check-up with a GP within the last twelve months. Women were significantly more likely than men to have had a check-up,[63] and those who were older were significantly more likely to have been seen.[64] There was also a significant difference between health board areas in the proportion of respondents who had a check-up. More respondents in the WHB had had one than those in the ERHA area (76 per cent versus 67 per cent).[65] While the majority of respondents have had a check-up in the past year, there was a sizeable number who had not (237). In all, 66

[63] $X^2 = 6.24$, df = 2, p = 0.044.

[64] $X^2 = 10.85$, df = 4, p = 0.028.

[65] $X^2 = 9.85$, df = 2, p = 0.007.

respondents (28 per cent of this group) had had no visits to a GP at all in the last year. They were a group who were mainly independent and without severe disease disruption (and thus perhaps perceived themselves as in no need of a doctor).

Exercise

Respondents were asked a few questions about exercise: 'All things considered, do you think you exercise enough at present?'. If they responded 'no', they were asked 'Why not?' to get a sense of the barriers that people encountered. Respondents were given a range of reasons why they might not exercise enough, from which they could tick as many as they liked. Seventy-seven per cent of respondents reported in the affirmative that they exercised enough. Of those who reported that they did not get enough exercise, most respondents, and especially those aged 80 or more, cited their 'health' as the main reason. Nine per cent also said they were 'afraid of overdoing it'. Table 4.18 illustrates these reasons. Many older people put forward comments during focus groups discussions about the importance of keeping active (both physically and mentally) and how that relates to health:

> I keep active, too - walking. I don't walk that much now like I used to, but I walk from home as far as the church and back. Round in a circle, and that's a nice little walk. I keep active then by having joined three different organisations, Active Aged, ICA and I'm in the writers' group, and those keep me busy.

> One of the things that we pride ourselves is that the fact that being members of an active retirement association helps to keep you out of the doctor's surgery.

Table 4.18: Reasons given for being unable to take enough exercise

	Age group		
	65-79 % (N=129)	80+ % (N=81)	TOTAL % (N=210)
Health reasons	1	8	67
Areas for walking not safe/accessible/easy	6	5	6
Afraid of 'overdoing it'	12	5	9
Not interested	19	5	14
No time	10	0	6

In the interest of maintenance of health, regular free check-ups for all older people may be of benefit. The benefit may not necessarily be from the examination itself, but may promote a mindset that it is normal and routine to visit (or be visited by) a health practitioner despite apparent good health. This may also attract those who would not otherwise be seen and thus would provide an opportunity to discuss any anxieties over their own health. A new drive in the UK has just been launched this year which offers all people of pensionable age an annual free check-up, although further research is needed to prove that these interventions do indeed help older people keep healthier for longer.

ACCIDENTS AND FALLS

Accidents and falls in the older population are relatively common and can cause long-term difficulties; moreover, the risk of falling and sustaining an injury increases with age (ERHA Department of Public Health Report, 2000). Several questions attempted to examine the type and details of accidents in the HeSSOP study. First, respondents were asked 'In the last year have you had any accidents or mishaps which have caused sufficiently serious injuries that interfere with your daily activities?'. Those who had reported that they had were then asked where their most recent accident occurred. They were also asked to describe both the type of accident and the type of injury (see Table 4.19). A total of sixty-seven respondents (7 per cent) had had an accident resulting in 'serious injury' in the past year (no differences in rates between men and women or between those who lived alone or not). Respondents who had accidents were significantly more likely to be older.[66]

[66] Mean age: 76 years for those who reported accidents, versus 74 for those who were accident-free ($t = 2.37$, $df = 923, 1$, $p = 0.018$).

Table 4.19: Accidents and falls: type of accident, injury and location

Location of accident:	TOTAL no. of accidents in past year % (N)	Type of accident %		Type of injury	TOTAL number of injuries % (N)
Home:					
Kitchen	09 (6)	Falls	77	Bruising	19 (7)
Bathroom	02 (1)	Cuts	10	Muscle/ligament damage	16 (6)
Elsewhere -	28 (19)	Car	05	Other injury	19 (7)
Garden	19 (13)	Other	08	Fractures	13 (5)
				Back injury	11 (4)
				Lacerations	11 (4)
				Head/concussion	11 (4)
On the road:					
Car/bike accident	09 (6)	Car	67	Fractures	40 (4)
		Other	33	Bruising	30 (3)
				Head injury	10 (1)
				Muscle/ligament damage	10 (1)
				Shock	10 (1)
On foot:					
On road or pavement	14 (9)	Falls	67	Bruising	40 (4)
		Other	33	Fractures	30 (3)
				Head injury	10 (1)
				Lacerations	10 (1)
				Other injury	10 (1)
Elsewhere					
	19 (13)	Falls	78	Fractures	55 (6)
		Car	11	Bruising	09 (1)
		Other	11	Lacerations	09 (1)
				Knee injury	09 (1)
				Other injury	18 (2)
TOTAL% (N)	100 (67)				100 (67)

Fifty-eight per cent of all accidents happened at home, either inside the home (39 per cent) or in the garden (19 per cent). Of those in the home, 9 per cent were in the kitchen, 2 per cent in the bathroom and 28 per cent were elsewhere in the home. Other accidents occurred on a road and involved a car (9 per cent) or the respondent was a pedestrian (14 per cent). Many respondents (19 per cent) reported accidents happening elsewhere: falls in others' homes, in shops and involving vehicles (e.g. on farmland). Just under half of these respondents (48 per cent) visited an A&E department for an injury in the same year, and six respondents were admitted to hospital for an injury where hospitalisation lasted between two and sixty days.[67]

Whilst the figures for those having accidents are relatively small, it should be noted that only those who had survived, had returned or remained in their homes and were physically and psychologically well enough would be measured here. The SLÀN report (Kelleher and Fitzgerald, 1998) found decreasing levels of serious injury with age, with 13 per cent of those aged 55 or older having serious injury in the past year. Our figures are broadly comparable with the SLÁN report regarding locations of accidents: of those aged 55 years or over who had accidents, 49 per cent occurred in the home or garden, 20 per cent on foot, and 9 per cent involved a car or bicycle. The average length of stay in hospital after injury for the population of all age groups as a whole is considerably shorter (3.2 days) although it is clear that the very old tend to stay significantly longer in hospital (EHLASS - European Home and Leisure Accidents Surveillance System, 1998).

Safety

One question regarding public safety addressed the issue of fear of crime, and asked 'How safe do you feel alone in your home at night?'. While the vast majority (89 per cent) reported feeling 'safe' or 'very safe', 11 per cent reported that they felt 'unsafe' or 'very unsafe'. Women made up 71 per cent of those feeling unsafe, and most affected were those who lived with one other person and those who lived alone (39 per cent and 36 per cent respectively). Almost three quarters (72 per cent) of those feeling unsafe were residing in the WHB. Those living in rural areas were significantly more likely to feel unsafe than those in urban areas (13 per cent versus 8 per cent, respectively).[68] House alarms, locks, and security lights were seen as particular needs by participants when offered the opportunity to put forward their most pressing needs. A few felt the need for more Garda presence in their community, and one felt they would be more reassured by regular visits to their home.

[67] Mean = 20, SD = 25.

[68] $X^2 = 9.8$, df = 3, p = 0.021.

Discussions during focus groups with older people revealed that one of the items that many older people said had given them great peace of mind was the possession of a security pendant worn around the neck. In an emergency, they can press the button on the pendant in order to get help. A total of 177 people (19 per cent) owned a fully functioning personal alarm, although this seemed to have little bearing on how safe they felt; almost equal percentages of respondents felt unsafe or very unsafe, whether or not they possessed a personal alarm system (10 per cent and 11 per cent respectively). Looking at comments obtained from the focus groups, it seems that they perceived the pendant to be very useful and reassuring. Most described its usefulness in terms of obtaining help in the event of a medical emergency, rather than for the purposes of safety per se:

> They're very useful when you will have fallen down the stairs, and you don't want to get up, because you don't know what damage you'll have done to yourself; So you can press this little button, and this voice will say to you 'Margaret or Mary' or whatever, 'are you alright?'

> I pressed my alarm for an ambulance one night, I got it, from here, and I had a way of getting them into the house as well.

However, despite the security pendant providing some comfort, some people in the focus groups pointed out that they forgot to carry them or found them frustrating:

> I had the beeper ... I fell and I broke my arm, and I had to go from the back door, around the floor, on my bottom, to get to the beeper ... so they answered, and they called the ambulance.

> I have one, but I stopped wearing it because I was always hitting it, and they were ringing back to me ... they're a good idea.

For some older people, a security pendant may be viewed as an essential item, especially if they suffer from serious disabilities or live on their own. A few people, unprompted, mentioned security pendants as the one thing that would make their lives easier. For one man, a security pendant could have saved spending a night on the floor:

> ... you see I spent one night on the floor, I fell out of the chair ... all night [on the floor] ... it was a neighbour who came in the morning for a cigarette, and he was knocking on the door, and I

> shouted: I told him I couldn't get up off the floor ... and then I couldn't get to the phone, you see, because I have no legs.

Although the survey did not directly ask about environmental factors that were of concern to older people, a number of issues related to safety and security were brought up in response to an open-ended question about what could be changed or provided to make life easier. Examples of things that could be improved were street lighting, pedestrian crossings, the condition of the roads in rural areas and pollution.