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HeSSOP Health and Social Services for Older People Summary

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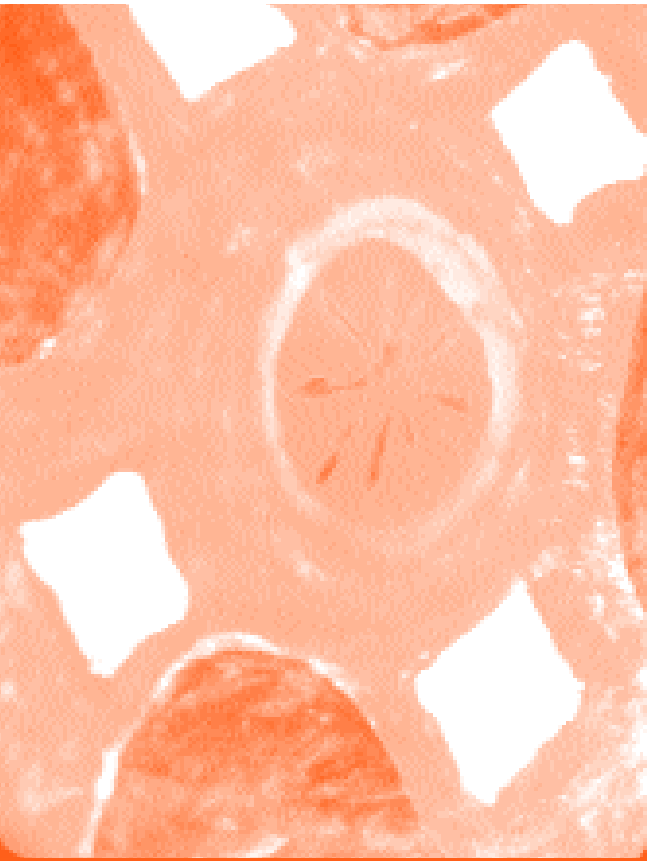
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Summary

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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

Health and Social Services for Older People

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 nor 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.

26

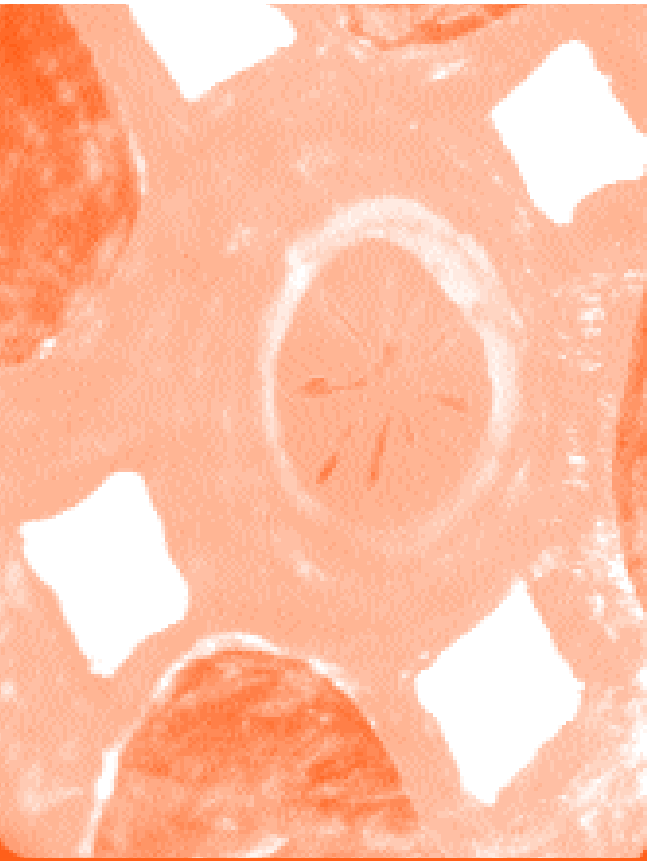
The HeSSOP study was the first such project to consult older people about health and social services on a large scale in Ireland. As such, it has achieved its objective to consult widely with older people. There needs, however, to be a model of consumer consultation if studies such as this are to be 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.

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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.

28

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

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

³Cited 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.**

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.

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