The Human Rights Commission

Older People in Long Stay Care

This is a preliminary interdisciplinary research project commissioned by the Human Rights Commission. Its aim is to gather and synthesise existing published material concerning the admission and treatment in general of older people in nursing homes at public and private expense having regard to standards of human rights law, constitutional and international. For purposes of completeness and comparison, some information on the position of older people living at home and their carers is included.

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Executive Summary

This is a preliminary interdisciplinary research project to gather and synthesise existing published material concerning the admission and treatment in general of older people in nursing homes at public and private expense having regard to standards of human rights law, constitutional and international. For purposes of completeness and comparison, some information on the position of older people living at home and their carers is included. The report includes an analysis of the human rights issues which may be relevant but does not include any legal conclusions regarding compliance with specific human rights norms.

The Main Findings of the Report

The report outlines the development of policy and provision of long stay care, the law on long stay and community care for older people and the current practice. It enumerates the relevant constitutional and human rights and makes a preliminary assessment of the human rights issues arising from Irish law and practice.

1. Community care is the preferred policy option for older people but is not adequate and is not being delivered as envisaged

Here we use "community care" to cover situations where an older person is living at home or with a relative and is receiving some public services from the health board or a voluntary organisation or from a carer who is receiving an income maintenance payment.

The stated policy on the provision of services for older people is based on the view that older people should be enabled to live in their own homes for as long as possible and that services should be in place to enable them to do so. This policy is not underpinned by appropriate legislation and is not being implemented in the intended manner.

The commitments given in various official policy documents - including *The Years Ahead* 1988 and the *Health Strategy 1994* to improved community care services have not been delivered. The *Health Strategy 2001* has further commitments to improved community care.

2. Long stay care – In practice, private provision is the favoured policy

While the policy of home based care accords with the wishes of older people themselves, it is recognised that the provision of long stay care facilities is an essential part of the continuum of care. There is no clearly stated policy on the public private mix of long stay care which is considered appropriate. However, in practice, most of the recent growth in long stay places is in the private sector and recent initiatives in relation to taxation and Public Private Partnership arrangements suggest that the official policy favours private provision.

3. The law and practice on entitlement to long stay care are unclear

The law on entitlement to health board long stay care is not clear. There is an absence of clarity in the admission procedures and the rules about the resident's liability to contribute to his/her care are also unclear. This lack of clarity means that there is an unacceptable risk of arbitrariness in decision making.

Commitments to clarify entitlement have been given in the *Health Strategy 1994* and again in the *Health Strategy 2001* but have not been implemented.

Dependent older people may qualify for a health board subvention towards the cost of a private nursing home place if they pass a means test. The rules in respect of dependency assessment are reasonably clear but there are a number of problems in the means test.

4. There is no legislation on quality of care. The health boards as provider are not subject to any external assessment while they are the inspector of the private sector providers.

There is no specific legislation dealing with the quality of health board long stay care places for older people and they are not subject to any external assessment of quality. Private nursing homes must be registered with the health boards, must meet specific standards and must be inspected at least twice a year to ensure that they adhere to the statutory standards.

Commitments to establish an independent inspectorate have been included in the policy documents *The Years Ahead* 1988 and the *Health Strategy 1994* but have not been implemented. The *Health Strategy 2001* includes a commitment to have the Irish Social Services Inspectorate (ISSI) put on a statutory basis and have its remit extended to long stay care facilities for older people.

5. **Entitlement to community care is not clear and there is no specific payment for caring.**

Entitlement to community care services is also unclear. Health boards are not legally obliged to provide certain services, notably a home help service. The level of service varies considerably throughout the country.

Carers of older people may be entitled to one of two specific social welfare payments for carers but each is contingent on specific conditions. There is no payment for caring per se.

The commitments given in various official policy documents - including *The Years Ahead* 1988 and the *Health Strategy 1994* to putting community care services on a statutory basis with consistent criteria for entitlement have not been delivered.

6. There are not enough long stay care beds available.

This is accepted in the *Health Strategy 2001*. The commitments given in previous policy documents *The Years Ahead* 1988 and the *Health Strategy 1994* to specific norms for

long stay beds as well as associated assessment and rehabilitation beds have not been implemented. There are further commitments in the *Health Strategy 2001*.

7. There is very little up to date published information available on the quality of care in either public or private long stay care.

The publicly available information on access and admission to public care is inadequate. There is virtually no published information available on the quality of care being provided. The report of inspections of private nursing homes give considerable information on private nursing homes but there has been no systematic analysis of these reports

8. The complaints and appeals procedures are inadequate

There is no statutory independent complaints and appeals procedure within the health services. There is no organised comprehensive advocacy service for vulnerable older people in care. There is no provision for third party complaints to be heard.

Commitments to establish a statutory independent appeals procedure have been included in the policy documents *The Years Ahead* 1988 and the *Health Strategy 1994* but have not been implemented. The commitment is repeated in the *Health Strategy 2001*.

9. A Human Rights Approach

The rights based approach to the provision of services can be applied to the issue of people in long stay care in the same way as it is applied to rights for people with disabilities and in other areas of social inclusion. Human rights language is mainly concerned with broad civil and political rights. However, economic, social and cultural rights are inextricably interconnected with civil and political rights. It is not possible to be an active citizen and enjoy civil and political rights without appropriate economic, social and cultural rights. This is recognised in the various UN covenants and conventions and in the National Anti-Poverty Strategy in Ireland.

The rights which are enshrined in the Irish Constitution, EU law and international conventions and covenants and which may be in issue in any assessment of the situation of people in long stay care are:

- the right to equality and non-discrimination
- the right to vindication of the person
- the right to personal liberty
- family rights
- the right to individual privacy
- the right to marital privacy
- the right to bodily integrity
- the right to respect for physical and moral integrity
- the right not to be tortured or ill treated
- the right to an effective remedy
- social and economic rights, including the right to health and social security services

- the right to participation in decision making

10. Human rights issues

From the analysis of existing provision and law and the enumeration of human rights, the following human rights issues need to be addressed:

- the adequacy of measures to ensure equality of treatment between older people in long term care and those being cared for at home and between those in public care and in private care
- the lack of clarity of entitlement
- the inadequate provision of public care, the level of reliance on private care
- the adequacy of measures to ensure equality and equity in the allocation of available places, in the assessment of need, in the manner in which the means test is applied.
- the adequacy of mechanisms for protection of vulnerable older people (this is not restricted to older people in long stay care)
- the incidence of inhuman or degrading treatment in care and/or the lack of respect for human dignity
- the right to an effective remedy, in the absence of adequate complaints and appeals procedures
- the right to participate in decision making.

Older People in Long Stay Care

Introduction and Background Information

1. The Human Rights Commission

1.1 The Human Rights Commission was established by the Human Rights Commission Acts, 2000 and 2001. Among its functions are:

- to keep under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights
- to promote understanding and awareness of the importance of human rights in the State and, for this purpose, to undertake, sponsor or commission, or provide financial or other assistance for research and educational activities

This report arises from the Commission's decision to undertake research on the situation of older people in public and private long stay care.

1.2 **The research objectives**

The research objectives set by the Human Rights Commission are as follows:

"I To draw together existing (in principle, already published) research and reliable factual information from a range of disciplines and interests, e.g. medical, economic, social science, psychology, public administration, carers' associations. The focus would be on identifying in relation to one or more (all if this facilitates the task) representative geographical area(s) under the responsibility of a regional/area health authority what safeguards exist in relation to the treatment (in the general sense, not confined to health care) of elderly residents. The emphasis would be on the existence or absence of set national standards and the enforcement of monitoring of them by means of unannounced or other independent inspections of nursing homes or otherwise. Relevant statistics of inspections and other monitoring mechanisms and relevant standards of quality (including training of personnel) and codes of practice as well, if appropriate, as illustrative case-histories might be included.

II To draw together such existing research and factual information on policy, practice and standards in one or more representative geographical area(s) under the responsibility of a regional/area health authority with a view to identifying avenues of access to and security of tenure in nursing homes. The Commission is interested in residence in both (a) private nursing homes by people who may have budgeted for their remaining years on the basis of, for example, the sale of their homes; and (b) public care nursing homes. It envisages greater emphasis in the case of publicly funded care on the transparency or otherwise of the procedure whereby a bed is found for a long-stay patient (e.g. existence or otherwise of application forms, means tests, published criteria for priorities and for the exercise of discretion when resources are scarce, channel of communication to and identity of decision-makers).

III To set out the text and where relevant brief summary of consequential case-law concerning the most important and relevant rights in the Constitution and in international law, such as the European Convention on Human Rights and instruments guaranteeing rights in the economic, social and cultural fields. At a secondary level, appropriate reference might be made to existing provisions of ordinary law that are applicable in Ireland or elsewhere. While regard should be had to such human rights guarantees as the prohibition of inhuman and degrading treatment (including the concept of human dignity) and the right to respect for private life (physical and moral integrity), no legal conclusions regarding compliance with specific human rights norms are required at this stage.

For the purposes of completeness or comparison it would be desirable to include rather than exclude material concerning the position of carers and elderly in their own or their family's homes (subsidised and supported or otherwise) without losing sight of the focus on general treatment in and access to nursing homes."

The Commission also asked that the report set out recommendations as to more refined terms of reference for further research/action.

1.3 Role of National Human Rights Institutions

The International Covenant on Economic, Social and Cultural Rights (see Chapter 4) sets out standards for economic and social rights. The UN Committee on Economic, Social and Cultural Rights (CESCR) has issued a number of general comments on articles of the Covenant. General Comment No 10 (1998) deals with the role of national human rights institutions in the protection of economic, social and cultural rights.

> "The Committee notes that national institutions have a potentially crucial role to play in promoting and ensuring the indivisibility and interdependence of all human rights. Unfortunately, this role has too often either not been accorded to the institution or has been neglected or given a low priority by it. It is therefore essential that full attention be given to economic, social and cultural rights in all of the relevant activities of these institutions."

It goes on to list the types of activities that can be undertaken by national institutions in relation to these rights. These include:

- The scrutinizing of existing laws and administrative acts …………….. to ensure that they are consistent with the requirements of the International Covenant on Economic, Social and Cultural Rights;
- Providing technical advice, or undertaking surveys in relation to economic, social and cultural rights,
- The identification of national-level benchmarks against which the realization of Covenant obligations can be measured;

- Conducting research and inquiries designed to ascertain the extent to which particular economic, social and cultural rights are being realized, either within the State as a whole or in areas or in relation to communities of particular vulnerability;
- Monitoring compliance with specific rights recognized under the Covenant and providing reports thereon to the public authorities and civil society; and
- Examining complaints alleging infringements of applicable economic, social and cultural rights standards within the State.

Older People in Ireland

3. The Central Statistics Office (CSO 1997 and 2002) and reports of the National Council on Ageing and Older People (Fahey, 1995, NCAOP 2001) provide information on the numbers of older people in Ireland and on their health and living conditions. There were approximately 430,000 people aged 65 and over living in Ireland in 2001. This is just over 11% of the total population. The majority of those aged 65+ were women – 56.7%.

Demographic projections suggest that there will be significant growth in the numbers of older people over the next ten years. The numbers have been projected to grow by nearly 108,000 in the period 1996 – 2011. It is expected that there will be approximately 840,000 people aged 65 and over in 2031 – that is more than twice as many as is 1996. By 2011, it has been projected that those aged 65 and over will constitute just over 14% of the total population and that proportion could be between 18% and 21% by 2031. However, these projections were based on the assumption that overall population growth would be static. Preliminary results from the 2002 Census shows that this is not the case – in fact, the overall population grew by 8% between 1996 and 2002. This does not invalidate the projections for the absolute numbers but it suggests that older people will not constitute such a high proportion of the total population.

Just over 21% of older people are aged 80 years or over. Projections suggest that this will have increased to almost 25% by 2011.

Nearly half of all older people live in rural areas. Projections suggest that the Eastern Regional Health Authority (ERHA) area will have the greatest growth in its older population in coming years. The North Western Health Board (NWHB) and the Western Health Board (WHB) areas continue to have the greatest proportion of older people. In terms of counties, in 1996, Leitrim (in the NWHB area) had the highest proportion of its population aged 65 and over. South Dublin (mainly in the East Coast Area Health Board) and Fingal (mainly in the Northern Area Health Board) had the lowest proportion.
In 1996, there were nearly 107,000 older people living alone (25.9%). Of these, almost 71,000 were women. Almost 30% of those aged 75 and over lived alone.

Only about 5% of older people are in long stay care. It is estimated that there may be approximately another 1% in acute hospitals at any one time. People aged 65 and over occupy 46% of acute hospital beds.

The National Council on Ageing and Older People (NCAOP) carried out a survey of the views of older people living in the community on the health and social services available to them. The survey was carried out in the Eastern Regional Health Authority (ERHA) area and the Western Heath Board (WHB) area and is published in *The Health and Social Services for Older People* – usually known as the HeSSOP report (Garavan et al., 2001)

Among the relevant findings of the study are:

- 30% of older people lived with one other person – usually a spouse
- 29% lived with more than one other person
- 28% lived alone, most of these were women and a quarter were aged over 80
- 83% owned the property they lived in; 12% lived in property owned or rented by another person, usually a relative; 5% lived in property rented by themselves
- 3% did not have basic facilities such as bath/shower, hot water supply, flush toilet or adequate heating. Those living in the WHB area were more likely to be without these facilities.
- 96% had a telephone.

Over 75% said they were self-sufficient in their abilities to perform tasks of daily living and 60% had no functional disability; 80% rated their quality of life as good or very good and over 75% scored high on morale. The majority said they were never or not very often bothered by loneliness and 85% 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% spending no time alone. Twelve per cent usually needed help with one or more tasks of daily living. 6% had major difficulties and a further 8% were severely impaired. 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.

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. 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%) received help from one or more people on a regular basis. Just over 20% received help either most of the day or continuously, including during the night.

What Older People want

4. The HeSSOP report clearly shows that older people want to be cared for in their own homes with minimal health service involvement. The vast majority - 87% - wanted to continue to live in their own homes. Over 50% hoped to be cared for by family and friends with 25% 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.

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. 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 was a separate dwelling space. The least acceptable option was boarding out - this was unacceptable to 77 per cent of older people.

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.

Human Rights, Laws and Values

5. This report includes a factual account of the laws and policies in relation to long stay care and an attempt to provide a human rights perspective for these laws and policies. The value of a rights based approach to services for older people is outlined in Chapter 4. Among other things, a rights based approach reduces the risk of lack of transparency and equity.

The vast majority of older people live independent lives, only 5% are in long stay care. However, this proportion is likely to increase as people live longer. Long stay care is almost never the first choice of any individual. It may be the best or the only option – or the least worst option - given the person's needs and circumstances. Older people in general are not in need of care but those who go into long stay care are almost invariably in need of care. They are, therefore, vulnerable. The enumeration, clarification and implementation of the rights of vulnerable people ought to be a priority in a civilised society.

The rights of older people ought to a priority for selfish reasons as well. We all hope to reach our third and fourth ages – not yet, but someday. As a society, we should celebrate rather than bemoan the fact that people are living longer and should make adequate arrangements for the increasing number of older people who will need care.

The Words We Use

6. The author of this paper does not consider that political correctness is necessarily a virtue. Nevertheless, the words we use often express an attitude, whether consciously or otherwise.

It seems that "elderly" people, like other groups such as "disabled" people consider that the use of the descriptive word as a noun is dehumanising. Terms such as "Seniors", "Senior Citizens", "Elders" have not entered into common use in Ireland in the way they have in the USA. Throughout this paper, the term "older people" is used as this seems to be the termed favoured by groups representing older people. In general, it means people aged 65 and over but the law and the practice applies to all adult residents of long stay care.

Official reports issued over the past forty years use words which reflect the then prevailing attitudes. For example, earlier reports talk about "institutional" care while more recent reports are more likely to use "residential" or "long term" or "long stay" care. The people in question are variously referred to as "patients", "residents", even "inmates" on some occasions. In this paper the term "residents" is used. Among other things, it makes no statement about health or other status. The term "long stay care" is used because it seems to be the most neutral description; long term care may be provided at home or in a long stay place.

"Community care" is generally taken to mean care in the person's own home or in the home of a relative. This should perhaps be more accurately described as family or domestic care. Community care is sometimes used to include, for example, day centre care, day hospital care and even community hospital care. Day centres themselves can be entirely social centres or can be providers of a significant level of health services. Here we use "community care" to cover situations where an older person is living at home or with a relative and is receiving some public services from the health board or a voluntary organisation or from a carer who is receiving an income maintenance payment.

The words used to describe the various kinds of care can be quite confusing even if they do not have any particular connotations of attitudes. The distinctions between welfare homes, community nursing units, community hospitals are not always obvious and the level of service provided by them may be broadly similar. The name used may not be significant in general but it could be relevant to whether or not a resident is obliged to pay for the services. The development of the different kinds of care is described in Chapter 1. Except in cases where the differences are an issue, we use the term "health board long stay care" to describe all the publicly funded care places provided by health boards. The term "private nursing homes" covers those nursing homes which are governed by the nursing homes legislation as described in Chapter 2.

In the UK, a distinction is made between residential homes and nursing homes and between health care and social care. This is because, in general, health care is free and

social care is not. (The Royal Commission on the Funding of Long Term Care for the Elderly which reported in 2000 made distinctions between personal care, living costs and accommodation costs. This Commission was established to consider the funding of long-term care for older people and specifically to address how the cost of that care should be apportioned between public funds and individuals. Broadly, it recommended that personal and nursing care should be publicly funded and that people should contribute to the costs of accommodation and living. The UK Government rejected this recommendation because of the costs involved.)

In the USA, the long stay care sector (almost exclusively private and mainly for profit businesses but with some residents getting Medicare funding) is known as the managed care industry. The Chairman and Chief Executive of the USA's largest nursing home chain was quoted in the New York Times as saying that "nursing care to the elderly is not all that different from selling tacos at a fast-food chain". (New York Times, 7 July 2002; he is a former senior manager at Taco Bell). The similarities quoted included operating multiple units and reliance on low paid employees. This company is facing criminal investigations for inadequate patient care at a number of its units but does appear to be improving the standards of care. It had also been involved in Medicare fraud.

National Council on Ageing and Older People

7. The National Council on Ageing and Older People (NCAOP) has published a large number of reports on older people in Ireland. These reports are the principal source of information for this paper. The NCAOP is a statutory advisory body to the Minister for Health and Children on all aspects of ageing and the welfare of older people. It was established in 1997 under its present title but a similar organisation has existed since 1981. It was previously known as the National Council for the Elderly (1990 to 1997) and the National Council for the Aged (1981 to January 1990).

Chapter 1: Development of Policy and Provision of Long Stay Care

1.1 Overview

1.1.1 The stated policy on the provision of services for older people is based on the view that older people should be enabled to live in their own homes for as long as possible and that services should be in place to enable them to do so. While this policy has been set out and restated a number of times in official policy documents, it has not been backed up by legislation. The policies have not been implemented in the manner set out.

1.1.2 While the policy of home based care accords with the wishes of older people themselves, it is recognised that the provision of long stay care facilities is an essential part of the continuum of care. There is no clearly stated policy on the public private mix of long stay care which is considered appropriate. However, in practice, most of the recent growth in long stay places is in the private sector and the Minister for Health and Children has recently announced that Public Private Partnership arrangements are to be used to provide further public facilities.

1.2 Care of the Aged Report 1968

1.2.1 The first detailed policy statement on services for older people was set out in the *Care of the Aged Report* which was published in 1968 (Working Party on Services for the Elderly, 1988). This set out the public policy that older people should be maintained in their own homes for as long as possible and that community care services should be developed to enable this to be achieved.

1.2.2 It also set out the policy on the provision of long stay care. It proposed that the County Homes (which were originally provided for under the Poor Law and were based mainly in former workhouses) should be replaced by two kinds of long term residential care:

- Geriatric hospitals which would cater for older people who need continuous nursing care and
- Welfare homes to cater for older people who "do not need care in a hospital setting but for whom institutional care is required". They were to be for people who were frail or who needed institutional care for social, rather than health reasons.

1.2.3 The report also recommended an extended role for residential care being provided by voluntary groups – mainly religious orders - but it did not address the question of private provision. Private provision was already officially recognised in that the Homes for Incapacitated Persons Act, 1964 provided for standards and inspections (it did not require registration).

1.2.4 The Health Act, 1970 provided for the payment of subventions by health boards for beds in approved private nursing homes. The subventions were based on beds occupied and not on the means or the needs of the residents. During the 1970's and 1980's, there was a dramatic increase in private long stay residential provision. During the 1970s, the number of welfare homes increased but this stopped in the 1980s. There was also a reduction in the number of public long stay beds and a reduction in the number of older people in acute hospitals and psychiatric institutions. (O'Shea et al, 1991).

1.3 The Years Ahead, 1988

1.3.1 *The Years Ahead: A Policy for the Elderly* was produced in 1988. (Working Party on Services for the Elderly, 1998). This document remains the official policy statement on services for older people. It has been complemented, but not supplanted, by the 1994 Health Strategy (Department of Health, 1994) and the 2001 Health Strategy (Department of Health and Children, 2001).

1.3.2 *The Years Ahead* restated the policy of favouring home/community care for older people. It set out the objectives of policy for older people as follows:

- to maintain older people in dignity and independence in their own home;
- to restore those older people who become ill or dependent to independence at home;
- to encourage and support the care of older people in their own community by family, neighbours and voluntary bodies in every way possible;
- to provide a high quality of hospital and residential care for older people when they can no longer be maintained in dignity and independence at home.

1.3.3 *The Years Ahead* included detailed goals for provision of services and a five year investment plan. That five year plan was to have been implemented by 1993. The desired development of community care services is set out as well as detailed proposals for long stay provision.

1.3.4 **Long Stay Policy**

1.3.4.1 *The Years Ahead* proposed a change in the policy in long stay provision. It proposed that "existing geriatric hospitals and homes, long-stay district hospitals and welfare homes, be developed as community hospitals, where appropriate, providing a wide range of acute and long stay services for older patients and their carers."

1.3.4.2 Purpose built facilities should be put in place where there were no existing facilities suitable for conversion. It recommended very specific norms for long stay beds and that those norms should be reviewed to ensure their adequacy.

1.3.4.3 The community hospitals were to provide a range of services including assessment, rehabilitation and convalescent care, terminal care facilities, information and support for carers.

1.3.4.4 The services of geriatricians should be available to the assessment and rehabilitation unit of the community hospital. The medical direction of the unit should be the responsibility of a GP who would be appointed as part time medical officer. The older person's own GP would provide medical care to the individual.

1.3.4.5 It recommended the introduction of a new system of registration of private nursing homes and subventions for residents.

1.3.5 Implementation of the Years Ahead policy

1.3.5.1 The Review of the Implementation of *The Years Ahead* was published by the NCAOP in 1997 (Ruddle et al, 1997) This provides a comprehensive, systematic analysis of the services for older people as they existed in 1997.

Community Care

1.3.5.2 This review shows that the community care services had not developed in the manner envisaged and the legislation to put them on a statutory basis had not been drafted.

Long Stay Care

1.3.5.3 Long stay care – in particular, private nursing home care had increased very considerably. The funding of private nursing home care had been put on a statutory basis and legislation had been introduced for the registration and inspection of private nursing homes – the Health (Nursing Homes) Act, 1990 and associated regulations (This legislation came into effect in 1993.)

Community hospitals

1.3.5.4 The Review concluded that community hospitals had not developed in the manner set out. Such development as occurred was slow and ad hoc because the money had not been made available. Community hospitals were unevenly spread throughout the country. Not all of them provided assessment and rehabilitation, there were different arrangements for assessment in the different health boards. Some health boards considered that assessment was best carried out in the geriatric departments of general hospitals.

1.3.5.5 The review shows that the arrangements for medical care varied between health boards. There were not enough geriatricans to provide the intended level of service.

1.3.5.6 The problems with providing paramedical services at community care level were also evident in community hospitals. "The level, extent and adequacy of provision differ across health boards, and across community care areas within health boards and are linked to the absence of adequate funding for the development of the community hospital service."

Long stay care beds

1.3.5.7 The review shows that the norms on long stay bed provision were not being met and that there had not been any review of the adequacy of those norms.

1.4 The 1994 Health Strategy

1.4.1 As already stated, this strategy complemented *The Years Ahead*. Among the relevant commitments in this strategy were:

- the aim would be to ensure that not less than 90% of those over 75 years of age continue to live at home
- to increase the number of specialist departments of medicine of old age and provide additional places for convalescent care
- to set out statutory rules for eligibility and charges for services such as community care, home help etc. to be applied on a uniform basis nationally.
- to establish a formal appeals system for medical cards and subventions towards private nursing care.

1.4.2 The statutory basis for community care services and the formal appeals system have not been put in place.

1.4.3 The Strategy accepts that the legislation governing long-stay public care "gives rise to anomalies and inequities as regards the charges which can be made and the basis on which they can be made. The legislation will be amended to provide a clearer and fairer basis for contributions towards the cost of long-term maintenance". No such legislation has been introduced.

1.5 The 2001 Health Strategy

1.5.1 The 2001 Health Strategy identifies a number of proposed actions on services for older people. The Strategy outlines the main gaps in service provision as being:

- community support services (e.g. paramedic services, community nursing services, health promotion, home help service, day care)
- acute hospitals (e.g. shortages in assessment and rehabilitation beds and day hospital facilities)
- long stay places (e.g. need for additional community nursing units).

1.5.2 The relevant proposals are as follows:

a) A co-ordinated action plan to meet the needs of ageing and older people will be developed by the Department of Health and Children in conjunction with the Departments of the Environment and Local Government; Social, Community and Family Affairs; and Public Enterprise (this plan is currently being drafted).
b) Community groups will be funded to facilitate volunteers in providing support services such as shopping, visiting and transport for older people.

c) An action plan for dementia, based on the recommendations of the National Council for Ageing and Older People, will be implemented.
d) A national palliative care service will be developed.
e) New legislation to provide for clear statutory provisions on entitlement will be introduced; this will include provision for entitlement to the core community care services, a clear framework for financing of long stay care for older people and an emphasis on implementing a standard approach to dependency assessment and the payment of subventions in each area of the country.
f) The Nursing Home Subvention Scheme will be amended to take account of the expenditure review of the scheme. The intention is to reform the operation of existing schemes, including the Carer's Allowance, in order to introduce an integrated care subvention scheme which maximises support for home care. In addition, subvention rates payable in private nursing homes will be reviewed. (The Department of Health and Children and the Department of Social and Family Affairs are working on the details of how this will work. It is not clear exactly what is involved but it seems that the Carer's Allowance, the nursing homes subvention and other supports will be taken into account in a scheme which may give greater choice between home and nursing home care.)
g) An integrated approach to care planning for individuals will be introduced. This will include the appointment of key workers for dependent older people such as those on the margins of home and residential care.
h) There are specific commitments to increase the range of community services and the number of long stay beds, including:

- 1,370 additional assessment and rehabilitation beds; associated development of acute geriatric medical services and appointment of additional geriatricians
- 600 additional day places with facilities encompassing specialist areas such as falls, osteoporosis treatment, fracture prevention, Parkinson´s Disease, stroke prevention, heart failure and continence promotion clinics.
- 800 additional extended care/community nursing unit places per annum over the next 7 years including provision for people with dementia
- Improved staffing levels in extended care units.

1.5.3 The Strategy also envisages integration and expansion of quality systems throughout the health and personal social services system and an independent Health Information and Quality Authority. National standards for community and long-term residential care of older people will be a priority

1.5.4 The Irish Social Services Inspectorate (ISSI) is to be established on a statutory basis and its remit extended to include long stay care for people with disabilities and older people. No action has been taken to implement this decision and there are no proposals for the necessary legislation nor a timetable for extension of the remit.

1.5.5 The Strategy also includes proposals for consulting older people about services – see Section 1.9 below.

1.6 Long Term Care Funding

1.6.1 The Department of Social and Family Affairs is conducting a study into long-term care funding, in both the private and public sectors, with a view to developing a strategy for future action. This study is looking at all aspects of the funding of long term care including the financing of personal long-term care needs in the community. The report has been completed but is not yet published.

1.7 Carers

1.7.1 It is estimated that there are 97,500 households in Ireland in which a carer is caring for an older person (O'Shea and Hughes, 1994). Only about one third are receiving a social welfare payment for caring – see Chapter 2.

1.7.2 The Department of Social, Community and Family Affairs published a review of the Carer's Allowance in 1998. A number of the recommendations in that review have been implemented including the introduction of a Carer's Benefit and various improvements in Carer's Allowance.

1.7.3 The review recommended that a new non-means tested 'continual care payment' should be introduced, following the introduction of a needs assessment, for all carers who are providing the highest levels of care, i.e. where the care recipient is highly dependent. This recommendation has been endorsed by Comhairle, the national agency for information and advice on social services (Comhairle 2002).

1.8 Public and Private Mix

1.8.1 The policy of favouring private provision over public provision of long stay care has never been articulated but it has been pursued, both by the provision of nursing homes subventions, by tax relief for the capital financing of private nursing homes and by extending the tax relief on fees paid to private nursing homes (all detailed in Chapter 2).

1.8.2 It is clear that the provision of nursing home subventions has led to a major increase in this sector. The introduction of capital allowances for the financing of new nursing homes was introduced recently (Finance Act, 2001) so its impact cannot yet be assessed but it is likely to increase supply.

Costs of private and public care

1.8.3 There is not enough information available on the relative costs of public and private long stay care. The information available does not allow for any reasonable comparison. For example, expenditure on public care includes the costs of medical care. medicines and appliances while such costs are not included in private nursing home care. It is very difficult to assess the real cost of community care especially if this involves a full time carer who is not receiving an income maintenance payment. (Clinch et al, 1998, Blackwell et al, 1992 and O'Shea E., 2000)

Private health insurance

1.8.4 The level of private health insurance is lower among older people so they have been particularly affected by the problems of access to public beds in acute hospitals. The major health insurers do not admit people aged 65 and over into their schemes (this is allowed under the relevant legislation). Private health insurance does not cover long stay care.

1.8.5 Tax relief for long stay care insurance was introduced in 2001. However, there do not appear to be any companies offering this sort of insurance.

1.8.6 Public Private Partnerships

1.8.6.1 In July 2002, the Minister for Health and Children announced that the Department intended to pilot a Public Private Partnership (PPP) initiative in the provision of long stay Community Nursing Units for older people (Department of Health and Children, 2002). The pilot projects will be in the Eastern Regional Health Authority (ERHA) and in the Southern Health Board (SHB) because the Department considers that these are the two areas in which the "need for additional long stay beds is most acute".

1.8.6.2 The services to be offered in these Community Nursing units will include assessment/ rehabilitation, respite, extended care, services for mentally infirm older people and convalescent facilities. Day Centres for older people will be combined with the Community Nursing Units (50 beds) in each site to "help promote the dignity and independence of older people and to support them in living at home."

1.8.6.3 It is anticipated that 17 new Community Nursing Units will be created when the PPP initial Pilot Programme is complete, providing up to a maximum of 850 new beds. The EHRA will provide 9 new Community Nursing Units (3 in each of the area health boards), giving a total of 450 new beds. The SHB will provide 8 new Community Nursing Units giving a total of 400 new beds.

1.8.6.4 The Department say that "the preferred model for PPPs is one where the private partner designs, builds, finances and operates the facility (DBOF)". It is not yet entirely clear, but it appears that these new units will differ from private nursing homes in that the health board will have the decision about who gets a long stay place.

1.9 A Voice for Older People in long stay care

1.9.1 The review of The Years Ahead noted that the question of consulting older people was rarely if ever mentioned in public policy documents. This has now changed somewhat. The 2001 Health Strategy includes the following relevant proposals:

- Regional Advisory Panels/Co-ordinating Committees (including service providers and consumers) will be established in all health board areas … for older consumers and their carers to provide them with a voice …… These committees will be modelled on similar developments in the area of disability services and

include representation of statutory and voluntary service providers as well as consumers.
- Randomly selected consumer panels will be convened at regular intervals in each health board area to allow the public to have their say in health matters that concern them locally.
- A National Consultative Forum will be established to meet on an annual basis to monitor the implementation of the Health Strategy.

1.9.2 There is no mechanism at present for the representation of older people in long stay care. Older people generally are not well organised and have yet to form an effective lobbying group. Older people in long stay care are particularly excluded from such organisations as exist. The Equality Authority has developed proposals on how this situation could be improved (Equality Authority, 2002). These include putting an onus on policy makers to adjust their consultative processes to allow for the participation of older people, age awareness training for policy makers, more support for networking among older peoples' organisations and the development of advocacy services.

Chapter 2: The law on long stay and community care for older people

2.1 Overview

2.1.1 The law on entitlement to health board long stay care is not clear. There is an absence of clarity in the admission procedures and the rules about the resident's liability to contribute to his/her care are also unclear. This problem has been recognised in both the 1994 *Health Strategy* (Department of Health 1994) and the 2001 *Health Strategy* (Department of Health and Children, 2001). It has been outlined in a number of publications but most thoroughly in the Ombudsman's Report on *Nursing Home Subventions*, (Office of the Ombudsman, 2001).

2.1.2 Dependent older people may qualify for a health board subvention towards the cost of a private nursing home place if they pass a means test. The rules in respect of dependency assessment are reasonably clear but there are a number of problems in the means test.

2.1.3 There is no specific legislation dealing with the quality of health board long stay care places for older people and they are not subject to any external assessment of quality. The providers or funders of public care – the health boards - are themselves the regulators of the private sector. Private nursing homes must be registered with the health boards, must meet specific standards and must be inspected at least twice a year to ensure that they adhere to the statutory standards.

2.1.4 Entitlement to community care services is also unclear. Health Boards are not legally obliged to provide certain services, notably a home help service. The level of service varies considerably throughout the country.

2.1.5 Carers of older people may be entitled to one of two specific social welfare payments for carers but each is contingent on specific conditions. There is no payment for caring per se.

2.2 Health Board Long Stay Care

2.2.1 There are two major interconnected issues in the law on health board long stay care – who exactly is entitled to avail of this care and who is obliged to contribute to the cost of the care provided.

2.2.2 Entitlement to In-Patient Services

2.2.2.1 Under the Health Acts (in particular, Section 52 of the Health Act, 1970) health boards are obliged to make in-patient services available to everyone who lives in Ireland. In-patient services are defined in the Health Acts as "institutional services provided for people while maintained in a hospital, convalescent home, or home for persons suffering from physical or mental disability or in accommodation ancillary

thereto". In a Supreme Court case in 1976, it was held that the services being provided to an old person who was a long stay patient in a health board home were in-patient services and not simply shelter and maintenance. (In the Matter of Maud McInerney, a Ward of Court, Supreme Court, 20 December 1976)

2.2.2.2 It would seem to be the case that this means that people are entitled to avail of in-patient services in a public bed in a public hospital or in a health board home. However, the Department of Health and Children take the view that the legislation does not confer a legally enforceable right on any person. This argument was first advanced in response to the Ombudsman's report and has since been restated in the 2001 Health Strategy. The argument is that the Health Acts distinguish between eligibility for services and entitlement to them and that being eligible does not mean that a person has an entitlement. The Ombudsman dismisses this argument - "the Ombudsman does not accept that there is any doubt as to the obligation on health boards to provide in-patient services". The writer strongly agrees with the Ombudsman.

2.2.2.3 In practice, it seems to be accepted by the Department and the health boards that people have an entitlement to avail of in-patient services in public hospitals but not in long stay care places.

2.2.2.4 Access to public beds in public hospitals is via GP referrals or Accident and Emergency units. Public hospitals include health board owned hospitals and the large voluntary hospitals. In public beds, medical treatment is free of charge for everyone. Maintenance is also free for medical card holders and a number of other groups. Those who are not entitled to free maintenance have to pay a daily charge of €33 (up to a maximum of €330 in a year).

("Medical card holders" is the usual term for people who have what the legislation describes as "full eligibility" for the health services. In legal terms, a person who is "unable without undue hardship to arrange general practitioner medical and surgical services for themselves and their dependants" (Section 45, Health Act, 1970) has full eligibility. Since July 2001, everyone aged 70 or over is entitled to a medical card under the Health (Miscellaneous Provisions) Act, 2001.)

Nursing Homes Providing In-patient services

2.2.2.5 Many of the residents of private nursing homes are receiving in-patient services. Others may be getting "institutional assistance" (the modern term would be "social care") .

2.2.2.6 Subsidiary legislation was introduced at the time the Health (Nursing Homes) Act, 1990 came into effect (1993) which says that if in-patient services under Section 52 of the Health Act are being provided to a person in a registered nursing home, the rules which apply are the Nursing Homes Act rules. It is doubtful if this is valid legislation (Statutory Instrument 224/93). The Ombudsman has questioned its validity.

2.2.3 Long term maintenance charges

2.2.3.1 In certain circumstances, long term maintenance charges may be payable by people who are in-patients in a public hospital. (The relevant legislation is the Health (Charges for In-Patient Services) Regulations, 1976.) These charges only apply to people who:

- do not have a medical card and
- have no dependants, and
- have been in receipt of in-patient services for 30 days or for periods amounting in total to 30 days in the previous 12 months.

2.2.3.2 The charge is based on income. There is no set charge. Instead, the patient must be allowed to have a certain amount of income left after paying the charge (usually called "pocket money"). Legally, at least €3.17 per week must be left but, in practice, more than this is usually left (between €15 and €20 a week is normal but it may be less if a person has some capital.)

2.2.3.3 Long stay charges may arise in cases where people are in acute hospital beds for the required length of time but they are most often applied in the case of people receiving in-patient services in geriatric beds in district and community hospitals, in geriatric hospitals and in psychiatric hospitals. Since everyone over 70 is now entitled (since July 2001) to a medical card, the numbers liable for long stay charges should be small.

2.2.3.4 Medical cards are sometimes withdrawn when people enter health board long stay care. This withdrawal is justified on the basis that the people concerned no longer meet the criterion for the award of a medical card set out in Section 45 of the Health Act, 1970. The rights of people over the age of 70 are not dependent on this criterion so their medical cards should not be withdrawn in any circumstances. There is evidence in recent complaints to the Ombudsman[1] that health boards are continuing to withdraw medical cards from people aged 70 and over and then charging long stay charges. This is clearly illegal.

2.2.4 Institutional Assistance charges

2.2.4.1 It would appear that the Health Acts give an entitlement to in-patient services in places other than public hospitals. People who are getting in-patient services in welfare homes and similar institutions should come under the same arrangements as those who are in public hospitals. However, the services being provided in institutions such as welfare homes are sometimes categorised as "institutional assistance" rather than in-patient services. Under the Institutional Assistance Regulations, 1954, as amended, a person availing of institutional assistance i.e. shelter and maintenance, is not getting 'in-patient' services and so may be charged for the shelter and maintenance service.

2.2.4.2 In practice, this frequently happens in welfare homes and similar institutions even though many of the residents may be getting in-patient services. There

[1] Discussions with Office of the Ombudsman staff, August 2002

may be problems in establishing where the dividing line between "in-patient services" and shelter and maintenance lies but if the care includes nursing care, it is likely to be classified as in-patient services.

2.2.4.3 The charge is based on income. There is no set charge. Allowance is made for items such as rent and insurance and a reasonable amount is left to the patient as "pocket money". The current practice is to leave pocket money of €18.16. Charges for institutional assistance apply from the time the person enters the institution and they apply to everyone including medical card holders and people with dependants.

2.2.5 Criteria for Admission to health board long stay places

2.2.5.1 There are no clear rules about access to health board long stay places. While, in theory, everyone who needs the service may have an entitlement, in practice, there are not enough places available. In general, people get health board long stay places after an assessment by the GP and possibly also the health board Director of Services for Older People and/or a referral from an acute hospital. There are no written guidelines on how this assessment of need is carried out.

2.2.5.2 There is no formal application process. There are no guidelines about what happens if there is similar need and not enough places to meet the need. In practice, some health boards may send the person to a contracted bed in a private nursing home – see section below. The fact that there are not enough health board long stay places to meet the need is accepted by the Department of Health and Children.

2.2.6 Freedom of Information

2.2.6.1 Under Section 16 of the Freedom of Information Act, 1997, public bodies which are subject to the Act are obliged to publish:

- the rules, procedures, practices, guidelines and interpretations used by the public body and the precedents kept by the public body for the purposes of decisions, determinations or recommendations in relation to schemes administered by the public body and
- information about the way such schemes are administered

2.2.6.2 Health Boards are subject to the FOI legislation. Their Section 16 Manuals should include detailed information on eligibility for health board long stay care and the guidelines which are used in making decisions on access to such care and on charges for such care.

2.2.6.3 The following description of eligibility is taken from the North Western Health Board *Freedom Of Information Act, Section 16 Manual*.

The description under the heading "Community Hospitals" is as follows:

> "Older people who are unable to live at home and who require a high level of nursing, paramedical and support care, in the short or

> longer term, are generally admitted to a Community Hospital. All persons referred are medically assessed prior to admission.
>
> In addition to high levels of nursing, paramedical and support staff the community Hospitals employ the facility of local G.Ps to provide medical care, and will arrange specialist appointments when required.
>
> Older people discharged from acute Hospital care may also be admitted to Community Hospitals for recuperation or rehabilitation prior to discharge home."

Under the heading "Community Nursing Units/Welfare Homes":

> "Older people who are unable to live at home but who do not require a high level of nursing, paramedical and support care in the short or longer term are generally accommodated in community Nursing Units or Welfare Homes.
>
> These facilities do not have the same high staff ratio as community hospitals, but medical, nursing and support services are available.
>
> Typically, the residents in the facilities would be frail older people who need some nursing and support care for short or longer periods.
>
> Older patients discharged from acute hospital care may be admitted to these facilities for recuperation prior to discharge home."

Under the heading "Eligibility Criteria":

> "Requests for Community Hospitals or Community Nursing Units/Welfare Home services are made by the local G.P., except in the case of acute hospital discharges which are arranged between the General Hospital and the appropriate community facility.
>
> All requests are subject to assessment in order to prioritise the urgency of referral.
>
> Persons admitted will be liable to a charge for non-acute and long term care even if they hold a medical card. These charges will be based on the individuals income and outgoings and are calculated in accordance with Institutional Assistance Regulations 1954/65."

2.2.6.4 Apart from the lack of precision about exactly who is entitled, this extract is notable for its statement about charges. This gives the impression that everyone admitted to a community hospital, community nursing home or welfare home is liable for charges under the Institutional Assistance Regulations. This is not so. Medical card holders who are receiving in-patient services are not legally liable for any charges.

2.2.7 Standards in Health Board Long Stay Care

2.2.7.1 The legislation on health board long stay care only deals with the obligation on health boards to provide it. There is no legislation on what form it should take – this is dealt with only in policy documents. There is no legislation on the quality of care which must be provided.

2.2.7.2 There are no statutory (or non-statutory) arrangements for the external inspection of health board long stay places. The Health Strategy 2001 repeats the proposal (already expressed in principle in *The Years Ahead,* 1998) to have the Irish Social Services Inspectorate (ISSI) put on a statutory basis and have its remit extended to long stay care facilities for older people. As already stated, there are no plans for immediate implementation of this proposal.

2.2.8 Complaints and Appeals Procedures

2.2.8.1 There is no statutory independent complaints and appeals system for health board services. Health boards and hospitals have internal systems. There are statutory independent appeals systems for many government services, including social welfare, tax and agricultural grants. Commitments to establish an appeals system specifically for medical card applicants and more generally for health services have been included in the 1994 and 2001 Health Strategies – see Chapter 1.

2.2.8.2 Complaints about health board actions or inactions may be made to the Ombudsman but his remit does not extend to public hospitals or to any private health services.

2.3 Private nursing homes

2.3.1 The Health (Nursing Homes) Act, 1990 and the various regulations made under it govern the private (and voluntary) nursing home sector. The legislation is described in detail in Appendix 1. The legislation provides for the registration of private nursing homes, standards of accommodation and care, the payment of a health board subvention to dependent older people who pass a means test and the contracting of beds to the health board.

2.3.2 Registration and Standards

2.3.2.1 Private nursing homes must be registered with the health board and are required to meet certain minimum standards. The register of nursing homes is available for public inspection.

2.3.2.2 Detailed requirements concerning minimum standards for nursing homes are set out in the legislation - these cover physical standards of accommodation as well as quality of care. Each resident must have a contract of care with the nursing home.

2.3.2.3 The health board is responsible for ensuring that the nursing homes comply with the legislation. They are obliged to inspect all nursing homes twice a year. The reports of these inspections are available under the Freedom of Information Act.

2.3.3 Code of Practice

2.3.3.1 There is also a Code of Practice for Nursing Homes which has been agreed by a group of people representing owners of nursing homes, health boards, the National Council on Ageing and Older People, carers and other people with experience in the care of older people. This Code is published by the Department of Health and Children. The Code is not legally binding and therefore its implementation is not monitored in a systematic way.

2.3.3.2 The purpose of the Code is to set out best standards of care to which all nursing home should operate. It covers a range of issues in relation to the provision of nursing home care including the philosophy of care; the involvement of residents in decision making; legal and financial issues; and the provision of services (including health services and medication). While the Code is not legally binding it does set standards for high quality care and encourages nursing homes to achieve these standards. The Department of the Environment and Local Government has produced a guide to fire safety in nursing homes.

2.3.4 Nursing Home Subventions

2.3.4.1 People who go into registered private nursing homes may get a subvention from the health board, if they are dependent and if they pass a means test. The rules about the award of the subvention are set out in the Nursing Home (Subvention) Regulations, 1993 as amended and are outlined in detail in Appendix 1.

2.3.4.2 The procedure for qualifying for a subvention initially involves an assessment of dependency. There are detailed rules about how this is assessment is made. If the person passes this test, then a detailed means test is carried out. Again, there are detailed rules. The means test does involve a degree of discretion about whether and how the family home is taken into account.

2.3.4.3 There are three maximum weekly rates of subvention which are related to the assessed level of dependency
Medium Dependency: €114.28 (£90)
High Dependency: €152.37 (£120)
Maximum Dependency €190.46 (£150)

These rates were set in April 2001.

2.3.4.4 The subvention is designed to help with nursing homes costs. It is unlikely that the maximum amount would fund the full cost in any nursing home. The maximum is the same throughout the country even though the costs of nursing home care are considerably greater in the greater Dublin area than, for example, in the North Western Health Board area.

2.3.5 Contracted Beds

2.3.5.1 In general, the subvention is not meant to meet the full costs. However, the health board has a discretion under the regulations to pay more than the stated maximum subvention. This may happen where the health board has what are called "contracted beds" in private nursing homes.

2.3.5.2 A person may be allocated a contracted bed if it is considered that he/she is entitled to a health board long stay place but none is available. The health board pays more than the maximum level of subvention – usually the full cost as agreed with the nursing home. The health board treats the resident as if he/she were in a health board long stay place. This means that the resident may be charged long stay charges or charges for institutional assistance as outlined above.

2.4 Community Care and Supports for Carers

2.4.1 Community care services are provided by health boards under the terms of the Health Acts. In this context, community care services are considered to include the Public Health Nursing Service (sometimes called Community nurses), Home Help service, meals on wheels, chiropody and other paramedical services.

2.4.2 Health Boards are obliged to provide public health nursing services but they may provide home help and other services. Services for house improvements are non statutory. (The local authorities also operate schemes of house improvements e.g. grants for adapting a house to facilitate a person with a disability.)

2.4.3 The Rights of Carers

2.4.3.1 There are virtually no rights arising as a result of caring per se. The social welfare Carer's Allowance is designed for low income carers who pass a means test. The Carer's Benefit which was introduced in October 2000 is for people who give up work to care, on a short term basis, and who have enough PRSI contributions. Neither is available to a person who is a carer but is entitled to another social welfare payment e.g. a widow's pension. In July 2002, there were 19,405 recipients of Carer's Allowance and 450 recipients of Carer's Benefit. (Comhairle, 2002). Both payments are provided for in the Social Welfare (Consolidation) Act, 1993 as amended.

Carer's Allowance

2.4.3.2 The Carer's Allowance is a means tested payment for people on low incomes who are providing full-time care and attention for a person who is so incapacitated as to require full time care and attention.

In order to be entitled to a carer's allowance, the carer

- must be living with or in a position to provide full-time care and attention to a person in need of care who is not living in long stay care.
- must be at least 18 years old and
- must not be engaged in employment or self-employment outside the home for more than 10 hours a week

If the carer is not actually living with the person being cared for, the carer's circumstances must allow you to provide full time care and attention and there must be a direct communication system between the two houses.

The means test for the Carer's Allowance is somewhat more generous than applies to other social welfare means tested payments. The first €191 of income for a single person or the first €382 of income for a couple is disregarded (from April 2002). The effect of this disregard is that the spouse of a person on average industrial earnings should pass the means test. A person who qualifies for a social welfare payment in his/her own right cannot qualify for a Carer's allowance. Carers who are married to social welfare recipients cease to be qualified adults if they start to receive Carer's allowance (This means that the spouse no longer qualifies for an extra payment)

Carer's benefit and Carer's leave

2.4.3.3 Carer's benefit is a social insurance payment payable to people who give up work in order to care for an incapacitated person. The conditions are broadly the same as for Carer's allowance but the carer must have an adequate PRSI record. The benefit may be paid for 15 months. Carers may be able to avail of carer's leave (The Carer's Leave Act, 2001) which allows them to retain their employment rights while they are caring and to return to their jobs or similar jobs when they finish caring.

Carers social welfare credits

2.4.3.4 Carers may be able to qualify for social welfare credits for periods spent caring. These may help the carer to qualify for long term social welfare benefits.

Respite Care

2.4.3.5 There is no legal right to respite care but recipients of Carer's Benefit or Allowance get an annual respite care grant - €635 (from June 2002) or double this if caring for more than one person. This is intended to help pay for respite care but it can be used any way the carer wishes.

Household benefits

2.4.3.6 Carers may also qualify for free travel and free electricity and related allowances (now being called Household benefits) if they meet various conditions.

Tax credits and allowances for carers

2.4.3.7 There is a number of tax credits and allowances for carers under the Taxes Consolidation Act, 1997 as amended. The tax credits and allowances which are available

do not have any single underlying policy objective. The Home Carer's Allowance was introduced to compensate stay at home spouses when individualisation of the standard rate income tax band was begun. Unlike the other credits and allowances, it is not confined to circumstances where an incapacitated person is in need of care. Some of the tax credits are very small and, in general, they are more relevant to a carer's spouse than to a carer.

The Home Carer's Tax credit
The Home Carer's tax credit was introduced in April 2000. The credit is worth €770 in the current tax year. The conditions attached are not as strict as the conditions for the social welfare payments.

Carers do not have to be full-time carers as the credit may be granted to carers who have a small income.

Dependent Relative Tax Credit
A tax credit of €60 is available to people who help to maintain certain relatives including:

- a relative of the person or spouse who is incapacitated by old age or infirmity
- the person's or the spouse's widowed father or mother whether incapacitated or not
- a child who lives with the person and on whose services the person is dependent because of old age or infirmity.

The relative's income must not be more than maximum of the over 80 rate of the Old Age Contributory Pension plus the Living Alone Allowance plus the island allowance plus €207.

This credit used to be important, not for its own worth, but because it was necessary to qualify for it in order to also qualify for tax relief on nursing home fees paid on behalf of the relative – see below. This is no longer the case.

There are just over 20,000 people claiming this allowance at present.

Employed Person taking care of an incapacitated family member
There is a tax free allowance of up to €30,000 for the employment of a person to care for a family member who is incapacitated. This is not a tax credit. The allowance is granted at the marginal tax rate. About 400 people get this allowance at present.

Tax Relief for Nursing Home Fees
2.4.3.8 Tax relief may be claimed on nursing home fees as part of medical expenses tax relief. (This is tax relief at the marginal rate and not a tax credit).

Effectively, whoever is actually paying the nursing home fees may claim the tax relief. Up to April 2001, a non resident of a nursing home could only get this tax relief in respect of a relative in a nursing home if the Dependent Relative Tax Credit was available. This was only available in the case of dependent relatives with low incomes.

This condition was removed in April 2001 so many more relatives should be able to claim this tax relief.

Chapter 3: The Current Practice

3.1 Overview

3.1.1 While older people clearly want to be cared for in their own homes, it is accepted that long stay provision is an essential element in the continuum of care. It is officially accepted that the current provision of services for older people at community level and in long stay provision is inadequate.

3.1.2 There is very little published material available on the quality of life in health board long stay facilities. There is no legislation on standards or quality of such care. They are not subject to any form of external inspection.

3.1.3 Private nursing homes are subject to inspection by health boards. There is no published analysis of the inspection reports. For the purposes of this paper, some of the inspections carried out in two health board areas have been examined.

3.1.4 The arrangements for assessing older peoples' needs and requirements are not consistent nor adequate.

3.1.5 Community care services are not widely used even by older people who clearly need them. There is broad agreement that the level of services is inadequate and the absence of a legislative basis is considered a major disadvantage.

3.1.6 The question of abuse, maltreatment or the exercise of undue influence on vulnerable older people is one that concerns many people. By its nature, it is very difficult to gather anything other than anecdotal evidence. There is some general research but there is no specific research on older people in long stay care.

3.2 Current provision of Long Stay Beds

3.2.1 The development of the different types of long stay care is described in Chapter 2. Long stay care facilities in Ireland now include

- health board geriatric homes/hospitals
- health board welfare homes
- health board district/community hospitals
- psychiatric hospital units
- private and voluntary nursing homes

3.2.2 It is difficult to get fully up to date accurate figures for the number of long stay beds available in each type of facility. The last official statistics were published in 1998 and relate to 1996 (Department of Health and Children, 1998). Further information

is available from the NCAOP (NCAOP, 2001), press releases and Dail and Seanad debates and questions[2] .

Some private nursing homes provide facilities for couples to stay together but there do not seem to be any public facilities where this is possible.

Health Board Geriatric Homes and Hospitals

3.2.3 This includes both geriatric hospitals and homes and long-stay geriatric units in general hospitals. In general, geriatric hospitals and homes are large institutions which are gradually being reduced and phased out in some cases. New facilities are being provided in geriatric units within general hospitals. The number of beds being provided had declined from about 7,000 in 1988 to less than 6,000 in 1996.

Health Board Welfare Homes

3.2.4 As outlined in Chapter 1, the policy is to phase out welfare homes in favour of community hospitals. The number of long stay beds in welfare homes fell from 1,589 beds in 1988 to 1,025 beds in 1996. Welfare homes are quite small with an average of 39.1 beds per home. This means that the provision of high levels of medical support is not practical. Thirty nine per cent of residents were in the 'high to maximum' level of dependency in 1996.

Health Board District and Community Hospitals/Community Nursing Units

3.2.5 District or community hospitals provide long-stay beds for older people at a local level. District hospitals are staffed by general practitioners and nurses. Community hospitals are designed to provide a broad range of services including long-stay care, assessment and rehabilitation, convalescent care, day hospital and/or day care services, respite care, and information, advice and support for those caring for older persons at home. The model for community hospitals was set out in the Years Ahead. The name community nursing unit is now used more often but the concept seems to be the same.

The number of district hospital long stay beds increased from 1,465 in 1988 to 2,200 in 1996. Each hospital had an average of 49.8 long-stay beds and 69.4% of residents were in the high or maximum dependency categories. Between 1997 and 2000, 400 additional beds were provided in 10 new community nursing units.

[2] A question about long stay care is included in the written questions virtually every day the Dail is in session. These questions frequently relate to a particular case (for example, why did a particular person not get a nursing home subvention) and are generally referred to the appropriate health board for reply directly to the TD. More general questions are also asked – for example, see Dail Debates, 9 October 2002 for questions on health boards' policies on contracted beds, an independent inspectorate and the issue of clarifying entitlement to health board long stay care. The Dail debated the Ombudsman's report on Nursing Home Subventions on 13 February 2001 and the Seanad held a general debate on care for older people which referred specifically to long stay care on 4 July 2001.

Psychiatric Hospitals and Hostels

3.2.6 There were approximately 1,600 people aged 65 or over resident in psychiatric hospitals and units in 2001 (Daly and Walsh, 2001). The rate of hospitalisation has been declining over the past 40 years for all age groups but people aged 75 and over have a higher rate than other age groups. In his most recent Annual Report, the Inspector of Mental Hospitals states:

> "Currently, close to forty per cent of persons resident in psychiatric units and hospitals are over sixty-five years and in some instances, particularly among the long-stay patients, this figure exceeds fifty per cent. Many, but not all, of these older persons now show little sign of behavioural disturbance related to psychiatric disorder and, among the more elderly of them in particular, their needs and disabilities relate to their age rather than to any psychiatric disorder. Their continued residence in long-stay psychiatric facilities is neither appropriate nor best suited to their needs. Their remaining on the psychiatric register is neither helpful clinically nor appropriate from a civil rights point of view. The Inspectorate has been urging the transfer of their care either to community residences where that is possible or to suitable in-patient continuing care facilities for older persons or, when they remain in psychiatric structures, their de-designation from the psychiatric register and the provision of their medical care by general practitioners." (Inspector of Mental Hospitals, 2002)

For those older people who do suffer from psychiatric illness, the Inspector accepted that "Considerable progress has been made in the last few years in providing specialised services for psychiatric illness in older persons, with the appointment of consultant psychiatrists for this sub-specialty". However, he goes on to point out that a shortage of nurses has delayed the opening of an acute psychiatric assessment unit for older people in Tallaght Hospital and that day hospital services adjoining in-patient facilities for older people are required and have not been put in place.

Private and Voluntary Nursing Homes

3.2.7 There are approximately 24,000 nursing home beds available in Ireland, 14,000 in private nursing homes.

Contracted beds in private nursing homes

3.2.8 There are considerable variations in the approach by health boards to contracted beds. Recent Dail questions show that some health boards do not use contracted beds at all even though they had an allocation for the purpose. Most health boards have increased their use of contract beds in recent years – for example, there was an increase of 19% in the year to August 2002 in the number of contract beds in the Eastern Regional Health Authority area.

Acute Hospitals

3.2.9 In theory, acute hospitals do not provide long stay places. In practice, they frequently do. As stated in the Introduction, it is estimated that approximately 1% of all older people may be in acute hospitals at any one time. People aged 65 and over occupy 46% of acute hospital beds[3]. Of course, many need acute care. Some geriatricians take the view that many of these people would be more appropriately cared for in long stay beds or in the community. One geriatrician is quoted[4] as saying that older people are

> " left languishing in acute hospitals because the services have not been developed that would allow them to return to their communities. They have been termed 'bed-blockers', but that is a disingenuous term because they are not blocking beds, they need to be in a hospital. They need to be looked after, it is just that they do not need to be looked after here. This is an acute hospital; it is not a nursing home. In terms of services, the biggest deficiency is in extended care, what used to be called 'long-term care beds'. There is not a sufficient amount, and the net effect of that is that acute hospitals fill up with patients who more appropriately should be placed in a nursing home-type setting or, ideally, the community services should be available to allow their discharge home."

3.3 Standards and Quality of Long Stay facilities

3.3.1 There is little published up to date information available on the standards and quality of long stay care facilities. The NCAOP reports on nursing homes were published in the 1980s and pre date the nursing homes legislation – indeed, they played a significant role in the development of that legislation (O'Connor and Thompsone, 1986; O'Connor and Walshe, 1986). They present a picture of the types of long stay care provided by private and voluntary nursing homes in the 1980s. They describe the buildings, facilities – care facilities, recreational facilities, the ages and physical and mental abilities of the residents, the degree of control which they have over their lives, staffing levels, admission and discharge procedures etc. There is no more recent similar survey so it is not possible to know whether the picture presented bears much resemblance to the current situation.

The NCAOP (then the National Council for the Aged) comments that "while the studies found a high level of care generally in the homes surveyed, they give evidence if a system that is custodial in orientation, having a philosophy of care that promotes dependence" . They found "symptoms of institutionalisation" among a significant number of nursing home residents.

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[3] 7th Annual Health Conference, Centre for Insurance Studies, Graduate School of Business, UCD; quoted in Irish Times, 1 November 2002.

[4] Irish Medical News, 29 April 2002; similar comments from other geriatricians, Irish Medical News, for example, 12 January 2001, 4 March 2002.

3.3.2 Framework for Quality

3.3.2.1 The NCAOP published *Framework for Quality in Long-Term Residential Care for Older People in Ireland* in 2000 (National Council on Ageing and Older People, 2000). This publication includes a study of the current situation regarding quality in long term residential care. The study consisted of

- a survey of public, private and voluntary providers of long term residential care and
- consultations with medical professionals and health board administrators

Questionnaires were sent to the managers of 580 long term care facilities. Approximately 30% took part. Of these, just over half had quality initiatives. These were grouped under into the following categories

- therapies
- individual assessment
- care practices
- Policies
- staffing
- recreational activities
- buildings/facilities.

3.3.2.2 Therapies were the most frequently mentioned quality initiatives across all facilities. Voluntary and private providers were more likely to report initiatives relating to recreational activities while health boards were more likely to be engaged in improving the standard of buildings. (Health Board facilities are often located in older buildings some of which were previously County Homes). Private and voluntary providers are required under the Health (Nursing Homes) Act, 1990 to have a certain standard in buildings.

(The report does not suggest that health board facilities are of a low standard)

3.3.2.3 The providers identified staffing as the most important factor contributing to overall quality of care. Recruitment and retention of staff was an issue for many. Buildings, facilities and care practices were also identified as important factors contributing to quality of care.

3.3.2.4 Over two thirds of the respondents were of the view that the introduction of a National Quality Monitoring Policy would be beneficial and this should apply to all providers.

3.3.2.5 The NCAOP proposed a Framework for Quality in Long-Term Residential Care. This proposed framework requires, among other things:

- An authoritative statement of policy on prevention, assessment, rehabilitation, standards of care, and the maintenance of independence and dignity in continuing care.
- uniform standards throughout the long stay sector, both public and private
- an independent inspectorate

- the development of quality assurance mechanisms

Social Gain

3.3.2 The voluntary organisation Age and Opportunity recently commissioned exploratory research into the concept of 'social gain' for older people in long stay care (OCS, 2002). The main objective was to develop a measurement tool for evaluating social gain. The research focused on the perceptions of older people themselves in exploring the dimensions of their quality of life as they experienced them prior and after entering long stay care. The research was conducted in two health board long stay care facilities and one voluntary nursing home. This is exploratory research and does not come to any definitive conclusions about the quality of care. It does present a picture of the lives of people in long stay care.

3.3.3 Health Board Long Stay Care

3.3.3.1 As stated in Chapter 2, the legislation on health board long stay care only deals with the obligation on health boards to provide it. There is no legislation on what form it should take – this is dealt with only in policy documents. The legislation does not deal with how need is to be assessed nor with how places are to be allocated when similar need exists. The promise to clarify entitlement to such care has not been implemented - the Department of Health and Children Business Plan for 2002 includes preparing the legislation on clarification of entitlements and on an appeals system. Neither piece of proposed legislation is included in the Government's legislative programme for the Dail session which started in October 2002.

Similarly, there are no statutory (or non statutory) arrangements for the external inspection of health board long stay places. The Health Strategy 2001 does repeat the proposal (already expressed in principle in The Years Ahead) to have the Irish Social Services Inspectorate (ISSI) put on a statutory basis and have its remit extended to long stay care facilities for older people**.**

(At present, the ISSI is an executive agency of the Department of Health and Children and is concerned exclusively with monitoring health board children's homes. It carries out extensive and comprehensive inspections. www.issi.ie.)

The legislation in relation to access to care is defective, as outlined in Chapter 2. Clear legislation with clear, enforceable rights is essential but, in itself, it will not guarantee high quality care. This requires that the ethos or philosophy of care be respectful of rights and have due regard to values such as dignity and equality

3.3.3.2 The Age and Opportunity exploratory study (OCS, 2002) examines two health board facilities. No general conclusions can be drawn from this small sample but the descriptions provided show that there are no written guidelines on admission policies and no written quality standards. However, they also show that residents are treated with kindness and efforts are made to provide a stimulating environment.

3.3.3.3 The absence of a formal admissions policy and the absence of a statutory basis for assessment of need means that the allocation of health board long stay places is, at least, non transparent. It is open to the charge of being arbitrary but this is impossible to prove or disprove without further information.

3.3.3.4 In the absence of any formal inspection and external evaluation of health board long stay places, it is not possible to make any definitive statement about quality. Various efforts have been made by individual facilities and sometimes at health board level to introduce advocacy services for vulnerable residents, general quality schemes and other measures to promote quality of life. These are not documented in any detail nor have they been evaluated. The absence of an advocacy system and of a statutory independent complaints and appeals system means that complains and problems may not be aired or, if they are, they may not be heard.

3.3.3.5 Complaints to the Ombudsman in relation to health board long stay care are mainly concerned with the arrangements for charging residents.

3.3.4 Private Nursing homes

Private nursing homes are subject to inspection by health boards as outlined in Chapter 2. There is no published analysis of the inspection reports. For the purposes of this paper, some of the recent inspections carried out by the East Coast Area Health Board and the North Western Health Board have been examined but this is not a comprehensive analysis. From the limited analysis, it is not possible to come to any conclusions about the quality of care but it is possible to say that there are shortcomings in the inspection system. Among other things, inspections are rarely, if ever, carried out at night; the inspection is largely concerned with the physical conditions and rarely addresses what might be termed broad quality of life or social gain issues; the health boards take very few prosecutions and almost never close down a nursing home. The sort of breaches of the law which were frequently mentioned in the reports included the absence of contracts of care, inadequate records of medication and the use of restraint, insufficient arrangements for privacy and the absence of safety equipment.

(The East Coast Area Health Board has 57 private nursing homes registered at present and there are over 300 contract beds. There are 118 registered in the total ERHA area. In general, they seem to fulfil the requirement to inspect nursing homes twice a year. One nursing home was visited 20 times in 2001. The NWHB has 18 registered nursing homes)

3.3.5 Complaints to the Ombudsman

3.3.5.1 Complaints to the Ombudsman are concerned mainly with the manner in which entitlement to a subvention is assessed – the Ombudsman's remit extends only to health board actions and not to those of private nursing homes. His remit does not include voluntary hospitals or homes even though they are almost entirely publicly

funded. He can investigate how the health board deals with private nursing homes but cannot investigate the private nursing homes themselves.

The Ombudsman frequently draws attention to the inadequate appeals machinery available within the health services generally and in relation to long stay services.

Report on Nursing Home Subventions

3.3.5.2 The Ombudsman's Report on Nursing Home Subventions (Office of the Ombudsman, 2001) is very critical of the actions and practices of the Department of Health and Children and the health boards. The report covers two major issues - the family assessment issue and the "pocket money" issue.

The family assessment issue is no longer relevant as the legislation has been changed. Of course, it is likely that families are still contributing to the costs of private nursing homes. the maximum level of the nursing home subvention at present is about one third of the cost of a nursing home place in the Dublin area – see below.

3.3.5.3 The practices of health boards in relation to pocket money has now also been changed and it appears that they are correctly applying the law. However, health boards were allocated money to repay those residents or their heirs from whom pocket money was wrongly withheld. The Comptroller and Auditor General's report found that a number of health boards had not used this allocation for its intended purpose (Comptroller and Auditor General, 2001). Recent Dail questions show that this issue has still not been fully resolved.

Annual reports of Ombudsman

3.3.5.4 The Annual Reports of the Ombudsman in recent years show that:

In 2001, there were a total of 555 complaints relating to Health Boards; of these, 213 were concerned with nursing home/long stay care. The Ombudsman's report does not give details of the kinds of complaints involved but it is clear from the Ombudsman's report on Nursing Home Subventions that complaints in respect of subventions figure prominently. Discussions with the Ombudsman's Office show that there are also a number of complaints into the charging arrangements for health board long stay places – the operation of the long term charges, institutional assistance charges and the withdrawal of medical cards from people who become residents in health board long stay places.

The number of complaints in relation to nursing home/long stay places in 2001 showed a considerable increase on previous years. This could be due to people experiencing more problems or it could be due to greater public awareness of the role of the Ombudsman resulting from publicity about his investigation into nursing home subventions.

In 2000, 44 of the 304 health board complaints related to nursing home/long stay and 29 of the 387 complaints in 1999.

3.3.5.5 The reports include a sample of the problems investigated by the Ombudsman each year and so they include an outline of some of the problems experienced by people in accessing community care facilities for older people.

Cases reported by the Ombudsman in his recent annual reports include:

- failure of a health board to tell an applicant for a nursing home subvention of a statutory discretion available to the Chief Executive Officer in assessing such applications. This arose when the applicant was already in the nursing home when the application was made. While the general rule is that such applications must be made before taking up residence (see Appendix 1), there are exceptions and the applicant was not told of these. In this case, the applicant had actually been discharged from a health board hospital on condition that he go to a nursing home.

- unfair and inadequate procedures in assessing an application for a subvention e.g. not accepting medical evidence that an admission to a nursing home was an emergency admission.

- inadequate care provided in a private nursing home – the Ombudsman could not investigate the complaint against the nursing home but he could, and did, investigate the complaint that the health board had not adequately investigated the nursing home. A woman had complained about the care provided by a nursing home for her mother immediately prior to her mother's death. She complained that some of the medical equipment was not functioning properly and that there was no basis for the nursing home's assessment that her mother suffered from Alzheimer's disease. The health board investigated the complaint and rejected it. The Ombudsman found that there was evidence that the investigation by the health board was "inadequate and thus contrary to fair or sound administration." The health board had a different team investigate the complaint and found that it was valid. The nursing home was obliged to draw up written policies and procedures in relation to a number of medical card issues. At the request of the Ombudsman, the complainant was given an ex gratia payment by the health board.

3.4 Nursing Home Subventions

3.4.1 It is clearly the case that the level of nursing home subvention is too low for people whose only income is a social welfare pension. Older people are very heavily reliant on social welfare payments (Layte et al, 1999). The combined total of a social welfare pension and the maximum subvention would not fund a place in a private nursing home in the Dublin area but it may do in some rural areas. The subvention level may also be too low for middle income older people. It can happen that if one spouse is in a nursing home, the other home spouse may have no income left. There are no provisions for ensuring that the other spouse is adequately provided for. The issue is known as "spousal impoverishment" in the USA.

3.4.2 The rules on the means test are not sufficiently clear. For example, the value of the older person's home may be taken into account in certain circumstances (see

Appendix 1). There seem to be different practices in different health board areas about how and when this is done. Sometimes a health board may require a person to let the house and use the income to help fund the nursing home place. This may not be practical if the house is in poor repair. While individual decisions may be made on a sensible and practical basis, there is not sufficient transparency.

(In the USA, the family home is taken into account. Usually a lien is placed on the house and the money is collected after the death of the recipient and spouse.

There is a constant legal battle raging about this assessment of the home. There is an entire industry in the USA dedicated to ensuring that the home is available for the heirs and not to pay for Medicaid. The Health Insurance Portability and Accountability Act of 1996 imposes a criminal sanction for knowing and wilful transfer of assets to gain Medicaid eligibility. The debate reached such a point that the Balanced Budget Act, 1997 made it a crime for lawyers to advise clients on how to transfer assets in order to qualify for Medicaid – it quickly became known as the "Granny's Advisor goes to Jail Act". Not surprisingly it was declared unconstitutional, on the grounds of freedom of speech.

In the UK, the value of the house may also be taken into account and a lien may also be placed. There does not seem to be quite such a well developed industry in asset protection there.)

3.5 Assessment of Need

3.5.1 There is no general arrangement for the assessment of the needs of older people. Older people who are going into health board long stay care are usually assessed but the rules governing this assessment are not set out in legislation or, indeed, in a policy document. This contrasts with the detailed legislative basis for the assessment of people who apply for nursing home subventions (see Appendix 1).

3.5.2 The review of the Carer's Allowance recommended that a needs assessment (covering all social and health services) of the needs of the care recipient and the carer should be introduced (Department of Social, Community and Family Affairs, 1998). A Working Group, chaired by the Minister of State at the Department of Health and Children (with responsibility for older people), was established in 1999 to set up a system of carers' needs assessment. This has not yet reported.

3.5.3 Needs are sometimes expressed in terms of demand for existing services. However, this may not be an adequate assessment as needs may sometimes be better met by new arrangements. In order to develop a care plan that will effectively address the needs of an older person, a structured assessment is necessary both to identify a person's difficulties or problem areas and to identify their strengths and supports.

3.5.4 The NCAOP have published *Care and Case Management for Older People in Ireland* (Delaney et al, 2001). Case management involves the development of

individually tailored care plans and care management involves a system for the planning, co-ordination and delivery of services. The whole process involves a process of consultation between older people themselves and their carers, general practitioners and other health and social service professionals.

3.5.5 The Council believes that research on effectiveness in long-term care is needed. Such research must include the following:

- an assessment of the effectiveness of long-term residential care in terms of the availability and admission waiting times for those who have an assessed need for such care;
- a review of existing assessment procedures used to determine need for long-term residential care and other alternative community provision in all health board regions.

The Eastern Regional Health Authority is currently considering the introduction of case management in its functional area.

3.5.6 Disability Bill

3.5.6.1 The Disability Bill, 2001 contains a number of provisions which, if enacted, could be relevant to older people. The Bill has been withdrawn because of strenuous opposition by groups representing people with disabilities to various aspects of it.

3.5.6.2 The Disability Bill in its present form has elements which, if enacted, would considerably improve the situation of older people. People with disabilities consider the Bill totally inadequate yet it would be a significant improvement for older people. In particular, the right to an assessment of need and the establishment of a statutory independent complaints and appeals mechanisms would be considerable improvements.

3.5.6.3 Disability is defined as meaning, in relation to a person, a substantial restriction in the capacity of the person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment. Clearly this definition would cover a number of dependent older people.

3.5.6.4 Among the provisions of the Bill which would be relevant are the statutory obligation on public bodies to provide integrated services for people with disabilities, assessment of need and advocacy provisions.

3.5.6.5 Health Boards would be obliged to provide an "assessment of need" when a person with a disability applies for a health service. There would be a statutory independent appeals system for people who were not satisfied with the assessment or with the action taken as a result of it. (There are no statutory appeals systems for health services generally – see Chapter 2.)

3.5.6.6 The health board would have to ensure that, as far as possible, the person with a disability is involved in the assessment, has access to relevant information about it, including information on possible treatment, therapy or other service to be provided.

Where the person is unable to be involved because of disability or age, a representative should be involved – this may be a personal advocate.

3.5.6.7 When this assessment of need shows that the person with a disability needs a health service, the health board will be obliged to "take such steps as are reasonable to provide the service as soon as practicable and to the greatest practicable extent". The health board may provide the service directly or by arrangement with a voluntary body. The service will come under the Ombudsman's remit regardless of who provides it.

3.5.6.8 The Bill provides for an advocacy service for people who need it. In this context advocacy is defined as including

- representing, supporting or training people with disabilities for the purpose of helping them to promote their best interests in relation to matters affecting their welfare and quality of life
- for that purpose, supporting or training their families, carers or other persons, or members of organisations or groups representing their interests, and
- representing, helping or supporting "qualifying people" to get access to a service provided by a statutory body or voluntary body,

but does not include representation in legal proceedings.

3.6 Need for More Information

3.6.1 In order to make an assessment of the human rights issues arising in long stay care, places, more information is needed. Among the issues on which more information is needed are:

- what happens to older people who need care but for whom it is not provided in the community, who cannot get a health board place and who cannot afford a private nursing home?
- what element of choice is exercised by the older person who goes into long stay care? Are decisions being made by families, medical professionals?
- was the entry into care the result of a planned decision or a response to an emergency?
- how was need assessed; was it assessed in terms of the services available or in terms of the wishes and capacity of the older person?
- was there a choice of type of long stay place available?
- are spouses involuntarily separated by one being in long stay care without facilities for the other?
- how are residents of private nursing homes paying for their care; to what degree is finance being provided by family members; are spouses impoverished by the costs involved?
- what control do residents have over their immediate environment; are there set meal times; access to kitchen facilities; set bedtime?
- is there an over protective environment or paternalistic practices?

- are there ways in which residents can influence the policies of the institution?
- is there genuine consent to medical treatment? are medicines administered to make patients less demanding
- is force being used to administer treatment?
- instances of restraint – are they properly documented? are they in the interests of the patient or of the institution?
- is there electronic monitoring and, if so, is it justified?
- who makes the personal care decisions in cases of residents who are unable to make them?
- what attempts are made to provide a stimulating environment, contact with the home place?
- are the staffing levels sufficient to provide, not just physical and medical care, but also kindness, companionship and some fun?
- is eccentricity (as judged by others) catered for?

3.6.2 In the case of private nursing homes, there is a need for a systematic study of the inspections carried out by Health Boards to see

- if the statutory requirement of 2 inspections per year is being met
- how many have been subjected to more than the statutory minimum inspections
- if inspections are carried out at night
- if inspections are carried out without notice
- what sort of problems are being identified
- what action is taken to address problems
- whether problems are more likely to be identified in specific complaints rather than in routine inspections
- if there are structured interviews with residents and relatives
- whether health boards have consistent standards
- whether inspections are sufficiently broad to provide information about the quality of life of residents
- if health boards are being sufficiently rigorous in the follow up when problems are identified; if they are reluctant to close down nursing homes because of a shortage of alternative places
- if there is evidence of residents being evicted because they are difficult to manage
- if the powers available to the inspectors are adequate
- if the reporting arrangements are adequate, for example, if all reports should automatically be made public and if there should be a facility for the inspectors to report directly to the Oireachtas or an Oireachtas Committee

3.7 Community Care Services

3.7.1 The inadequacy of community care service provision is outlined in the Review of the Implementation of the Years Ahead (Ruddle et al, 1997) and in other publications, especially the HeSSOP report (Garavan et al, 2001) and the report on the *Future Organisation of the Home Help Services*. (Haslett et al, 1998)

3.7.2 The situation is well illustrated in recent actions by the Western Health Board. In July 2002, the WHB sent a letter to recipients of the home help service saying that the maximum hours would be cut from 18 hours to 11 hours a week; this letter was rescinded after a public outcry. The Board then said it would be "carrying out a needs assessment on all recipients of the service on a case by case basis in the coming months to ensure that we can continue to respond both to existing and emerging needs". The implication is that either a needs assessment had not been carried out before the service was provided or, if it was, it did not get the right answer. The discretionary nature of the service means that it can be withdrawn without notice.

Legislative basis

3.7.3 The NCAOP considers that one of the major difficulties with the Years Ahead report is its non statutory status and the failure to implement its recommendations on putting in place a legislative framework for older peoples' services. In its comments on the review the NCAOP states that " it is noteworthy that the only significant legislation on services for older people since 1988 has lead to a growth in institutional rather than community based care".

The NCAOP consider that the situation in respect of community care services will not improve until there is a legislative basis for the core services, including home helps and until there is significantly greater investment. The designation on core services on a legislative basis 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." (Layte et al, 1999)

3.7.4 On community care services, the HeSSOP report shows that:

- 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
- 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.
- 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.
- 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.
- Less than 2 per cent had used respite services.
- One per cent had seen a social worker in the past twelve months with fewer using counselling or psychological services.

Stigma and cost were significant barriers 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 spoke similarly of 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.

Two thirds of these older people had medical cards and 38 per cent had private health insurance. (Since July 2001, everyone aged 70 and over should have a medical card) Almost one in ten had neither a medical card not private insurance. Many medical card holders reported making payments for health or social services in the past year even though, legally, these are free to medical card holders. Forty-three per cent of medical card holders who used the home help service paid either partially or in full for the service.

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.

3.8 Abuse, Neglect and Undue Influence

3.8.1 The question of abuse, maltreatment or the exercise of undue influence on vulnerable older people is one that concerns many people. By its nature, it is very difficult to gather anything other than anecdotal evidence. There is some general research but there is no specific research on older people in long stay care.

3.8.2 Service providers including solicitors and doctors provide anecdotal evidence of undue influence and fraud. Similar evidence is provided by family members and other visitors. This ranges from the collection (possibly legitimately) of pension money and its inappropriate retention to direct taking of money to undue influence on the making of wills. There have been a number of court cases on these issues but none involved a person in long stay care.

3.8.3 The Law Reform Commission is currently examining issues in relation to the protection of vulnerable older people. It is developing proposals for replacement of the Ward of Court system with a system of Public Guardianship which would enable protective measures to be put in place for vulnerable older people. This would include facilities for redress in cases of undue influence. A discussion document is due to be issued early in 2003.

3.8.4 The NCAOP exploratory study on abuse and neglect of older people includes accounts by service providers of abuse known to them (O'Loughlin and Duggan, 1998). The majority of the incidents described involved abuse in the home – quite often, long stay care was the solution.

The following issues were raised in this report in relation to long stay care:

- private nursing homes leaving the dirty washing for relatives
- generally poor standard of care in private nursing home

- inadequate hygiene, inadequate food supplies, residents' belongings missing, bed sores

3.8.5 The Code of Practice for Nursing Homes contains provisions for the protection of residents from abuse and undue influence. This is not legally enforceable and there is no mechanism for establishing whether or not its provisions are respected.

3.8.6 The Working Group on Elder Abuse is finalising its report. It will outline the services required to deal with abuse and it broadly supports the establishment of a Public Guardian to vindicate the rights of vulnerable older people.

Enduring Power of Attorney

3.8.7 There is a specific protection for nursing home residents executing an enduring power of attorney under the Powers of Attorney Act, 1996. This prevents the owner of a nursing home in which the donor is resident from being appointed the attorney except in very specific circumstances.

The attorney may not be the owner of a nursing home (whether or not it is a nursing home within the meaning of the Health (Nursing Homes) Act, 1990) in which the donor resides, or a person residing with or an employee or agent of the owner, unless the attorney is a spouse, parent, child or sibling of the donor.

Making Wills

3.8.8 It is the practice of most hospital and long stay place staff to refuse to witness wills being made by or for residents. This can cause difficulties but it is considered to be in the best interests of the residents.

Chapter 4: A Human Rights Approach

4.1 Overview

4.1.1 The rights based approach to the provision of services can be applied to the issue of people in long stay care in the same way as it is applied to rights for people with disabilities and in other areas of social inclusion. Social, economic and cultural rights are being recognised as fundamental rights of citizenship in the same way as political and civil rights.

4.1.2 The Irish Constitution and EU law provide for enforceable rights such as equality and non-discrimination. The European Convention on Human Rights should also be directly enforceable in the near future. Other international conventions and covenants, while not directly enforceable, promote a culture of rights recognition and protection and a benchmark for assessment of rights.

4.1.3 The objectives of this research include an enumeration of the relevant human rights instruments. Legal conclusions are not part of the brief for this research but, in any event there is not enough information available on which such conclusions could be based.

4.1.4 There is a range of human rights issues which arise from an examination of the laws and policies which apply to people in long stay care.

4.2 The Rights Based Approach to Services

4.2.1 The rights based approach to services has developed largely in the context of rights for people with disabilities. It is gradually being applied to poverty reduction strategies both in the Office of the UN High Commissioner for Human Rights documents and in the Irish National Anti-Poverty Strategy. It is equally applicable to rights for older people.

4.2.2 The rights based approach is based on the view that peoples' rights to services should be clearly set out in legislation, that rights to services should be consistent and fair and that those services should be delivered in a timely manner and in a manner which is respectful of the rights and dignity of all people. It can be contrasted with the "charity" or discretionary approach to services which inevitably runs the risk of not being transparent or equitable.

4.2.3 One of the main arguments in favour of a rights based approach is that it enables the empowerment of the people to whom services are being delivered. Older people in care have needs but they should also have rights. A recognition of legal rights involves legal obligations on others. The service providers are obliged to respect, protect and fulfil the rights of the service recipients. This obligation applies to the service providers in their capacity as providers and also in their relationship to private sector

providers – they must ensure that private sector providers also respect, protect and fulfil the rights of service recipients.

4.2.4 Empowerment of the service recipient requires that service providers are accountable in an accessible, transparent and effective manner, provide for equality of treatment and non-discrimination and facilitate the participation of service recipients in the decision making processes.

Enforcement of Rights

4.2.5 Irish constitutional rights and rights arising from EU legislation are directly enforceable in the Irish courts. Rights enumerated in other international instruments are usually not directly enforceable. Nevertheless, they have persuasive effects. Their existence contributes to a culture of rights protection. The legislative underpinning of rights is clearly desirable but, in the absence of such legislation, international human rights instruments provide benchmarks by which services can be measured.

Economic, Social and Cultural Rights

4.2.6 Human rights language is mainly concerned with broad civil and political rights. However, economic, social and cultural rights are inextricably interconnected with civil and political rights. It is not possible to be an active citizen and enjoy civil and political rights without appropriate economic, social and cultural rights. This is recognised in the various UN covenants and conventions. It is also recognised in the *Review of the National Anti-Poverty Strategy* (DSCFA 2002) when it states:

> "Citizenship rights encompass not only the core civil and political rights and obligations but also social, economic and cultural rights and obligations that underpin equality of opportunity and policies on access to education, employment, health, housing and social services"

According to the Strategy, the Government is committed to setting out detailed standards in relation to access to services. The Review refers to the need for

> "a move towards a more formal expression of entitlements across the range of public services and to setting standards and guidelines regarding the standard of service delivery which can be expected by the customer"

It also states that the

> "principles set out in the International Covenant on Economic, Social and Cultural Rights and other international human rights instruments adopted by Ireland will inform the future development of social inclusion policy."

4.3 The Constitution of Ireland

4.3.1 Article 45.4.1 contains the clearest statement on the rights of older people. This provides that

> "The State pledges itself to safeguard with special care the economic interests of the weaker sections of the community, and, where necessary, to contribute to the support of the infirm, the widow, the orphan, and the aged".

This article belongs to the Directive Principles of Social Policy section of the constitution and therefore does not have the same legal status as the other sections. The Directive Principles are intended for the general guidance of the legislators and are not absolutely binding in the way that other articles of the Constitution are.

4.3.2 The constitutional rights which may be relevant to older people in long stay care set out in the Constitution are:

Article 40.1

"All citizens shall, as human persons, be held equal before the law
This shall not be held to mean that the State shall not in its enactments have due regard to differences of capacity, physical and moral, and of social function."

It is generally considered that this guarantee of equality in Article 40.1 is narrowly worded and it has not been widely relied on to promote equality. Because of this, a majority of The Constitution Review Group (CRG) considered that the following wording should be substituted:

"All persons shall be held equal before the law. This shall not be taken to mean that the State may not have due regard to relevant differences.

No person shall be unfairly discriminated against, directly or indirectly, on any ground such as sex, race, age, disability, sexual orientation, colour, language, culture, religion, political or other opinion, national, social or ethnic origin, membership of the travelling community, property, birth or other status."

Article 40.3.2

"The State shall, in particular, by its laws protect as best it may from unjust attack and, in the case of injustice done, vindicate the life, person, good name, and property rights of every citizen"

It is not clear if vindication of the person of every citizen includes a right to protection.

Article 40.4.1

"No citizen shall be deprived of his personal liberty save in accordance with law".

Article 41.1.1
"The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law."

4.3.3 Unspecified personal rights
Article 40.3.1 provides that the State guarantees in its laws to respect and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen.

To date, a number of unspecified rights have been identified. The relevant ones are:
- right to bodily integrity - once this right was established it was broadened into a more general right not to have one's health endangered by the actions of the state – but this occurred in cases involving prisoners. It is not at all clear that this could be extended to a general obligation on the state to ensure the health of citizens.
- right not to be tortured or ill treated
- right to marital privacy
- right to individual privacy

There may be others yet to be identified but as the Constitution Review Group has pointed out - "there does not appear to be any objective method of ascertaining what these personal rights are".

4.4 European Union Law
4.4.1 Article 13 of the Consolidated Version of the Treaty establishing the European Community (inserted by the Treaty of Amsterdam) provides that the EU may take action to combat discrimination on a number of grounds including age. To date, a Directive on discrimination in employment has been agreed and is due to come into effect in 2003.

Charter of Fundamental Rights of the EU
4.4.2 This Charter is not legally enforceable. Its precise status is one of the issues being considered by the Convention on the Future of Europe. It has been suggested that it may form the basis for a Constitution for the EU.

Article 3 – right to respect for physical and moral integrity
Article 7 – respect for private and family life
Article 21 – non-discrimination

Article 25 – The Rights of the Elderly
"The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life"

Article 33 – the family shall enjoy legal, economic and social protection.

4.5 European Convention on Human Rights, 1950

4.5.1 Ireland is a party to the European Convention on Human Rights which was agreed by the Council of Europe. As a states party to the Convention, Ireland is bound to honour the obligations outlined there. The Convention has never been enacted into domestic law but its provisions are, nevertheless, deemed to be of persuasive (if not binding) authority before the Irish courts. A Bill to incorporate the Convention into Irish law was published in 2001 but has not been enacted. It has been put on the order paper for the Dail session which started in October 2002 but it is not clear when it will be debated and enacted.

4.5.1.1 Article 3 – Prohibition of torture

"No one shall be subjected to torture or to inhuman or degrading treatment or punishment."

The Convention protects an individual against torture, inhuman and degrading treatment. No definition of these terms is contained in the text. The Court has tended to distinguish between torture and other forms of degrading and inhuman treatment having regard to the intensity and severity of suffering. The suffering felt need not be purely physical but can be psychological. Factors like age and physical condition may be taken into account in determining whether or not a violation has occurred. Techniques which arouse fear, anguish and inferiority were found to constitute degrading treatment.

There have been no specific cases dealing with this article in relation to older people in long stay care but the Court has addressed the question of ill treatment by private individuals which may be relevant in this context.

In Z v UK (10 May 2001), the Court of Human Rights held that states were obliged to ensure that individuals were not subject to degrading treatment including such ill treatment administered by private individuals. States are required to ensure effective protection of children and other vulnerable people.

4.5.1.2 Article 5 – Right to liberty and security

"1 Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

………………………..

e the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants;"

A number of aspects of Irish mental health legislation are often criticised on the basis that they constitute a breach of the Convention. One area where the mental health legislation is often regarded as unsatisfactory is the perceived inadequacy of the review of detention – this is addressed in the Mental Health Act, 2001 (this Act is not yet fully in effect).

Care Orders for Older People

4.5.1.3 The European Court of Human Rights has delivered one judgement that is directly concerned with the rights of older people. Judgement in the case of H.M. v Switzerland was given on 26 February 2002.

The case addressed the issue of the involuntary admission of an older person to residential care. The Court found that there was no breach of Article 5 of the Convention as the applicant had been placed in care in her own interests in order to provide her with the necessary medical care, as well as satisfactory living conditions and hygiene.

There was some evidence that the applicant was suffering from a mental disorder but this was not a factor in the majority decision. A judge who concurred with the majority decision found that there was no breach because the applicant was a person of unsound mind.

(There is no corresponding law in Ireland. People may be involuntarily admitted to psychiatric hospitals or units if they are mentally ill. (The relevant law is the Mental Treatment Act, 1945. The Mental Health Act, 2001 is expected to be put into effect soon. The Mental Health Commission has been established). The White Paper on *a New Mental Health Act* included proposals for the introduction of adult care orders for mentally disordered people who are being abused, neglected or exploited. The Mental Health Act, 2001 does not include such a provision. It does change the criteria for admission to psychiatric hospitals or units – basically, people who are suffering from a mental disorder may be involuntarily admitted.

The Law Reform Commission and the Working Party on Elder Abuse are likely to advocate an arrangement along the lines of the one in issue in the Swiss case.)

4.5.1.4 Article 8 – Right to respect for private and family life

“1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2 There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.”

The right to respect for physical and moral integrity is an aspect of the right to privacy. In X and Y v the Netherlands, the Court of Human Rights held that Article 8 does not merely compel the state to refrain from interference but may require it to adopt measures to secure respect for private life even in the sphere of the relations of individuals between themselves.

4.5.1.5 Article 9 – Freedom of thought, conscience and religion

“Everyone has the right to freedom of thought, conscience and religion; ……”

4.5.1.6 Article 13 – Right to an effective remedy

"Everyone whose rights and freedoms as set forth in this Convention are violated shall have an effective remedy before a national authority notwithstanding that the violation has been committed by persons acting in an official capacity."

4.5.1.7 Article 14 – Prohibition of discrimination

"The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status."

Recommendation for the Legal Protection of Persons Suffering from Mental Disorders

4.5.2 In 1983 the Committee of Ministers of the Council of Europe issued a Recommendation for the Legal Protection of Persons Suffering from Mental Disorders Placed as Involuntary Patients. This Recommendation, which has no legal effect at domestic level, incorporates safeguards established in the case law under the European Convention. Ireland entered reservations (opt-out clause) in respect of the provisions of the Recommendation which relate to the giving of advice to patients as to whether or not to appeal against one's detention and the giving of notice to a patient that they have a right of appeal.

The European Social Charter, 1961

4.5.3 This is the Council of Europe Charter as distinct from the EU Charter. The Social Charter outlines states' obligations in relation to economic and social rights, particularly in the sphere of employment, health and social welfare benefits.

4.6 Other International Instruments

4.6.1 Universal Declaration of Human Rights

Article 8.

"Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law."

Article 12.

"No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks."

Article 22.

"Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality."

4.6.2 International Covenant on Civil and Political Rights

Many of the rights protected by this Covenant are also protected by the Irish Constitution. The Covenant goes further than the Constitution in the rights it guarantees to non-Irish citizens, its equality provisions and status afforded to minority groups.

4.6.3 International Covenant on Economic, Social and Cultural Rights

4.6.3.1 This Covenant does not set out rights as such but instead lists standards towards which parties to the Covenant are obliged to work.

The International Covenant on Economic, Social and Cultural Rights provides the most comprehensive article on the right to health in international human rights law. Article 12.1 of the Covenant provides for the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health". Article 12.2 lists a number of "steps to be taken by the States parties ... to achieve the full realization of this right".

4.6.3.2 The UN Committee on Economic, Social and Cultural Rights (CESCR) has issued a number of general comments on articles of the Covenant. These comments are imbued with the rights based approach to services. While the Covenant does not specifically deal with the rights of older people, the general comments apply the general approach of the Covenant to older peoples' rights.

4.6.3.3 CESCR General Comment No. 6, (1995) deals with the economic, social and cultural rights of older people. In this the CESCR expresses the view

> "that States parties to the Covenant are obligated to pay particular attention to promoting and protecting the economic, social and cultural rights of older persons. The Committee's own role in this regard is rendered all the more important by the fact that, unlike the case of other population groups such as women and children, no comprehensive international convention yet exists in relation to the rights of older persons and no binding supervisory arrangements attach to the various sets of United Nations principles in this area."

The comment goes on to state that

> "The methods that States parties use to fulfil the obligations they have assumed under the Covenant in respect of older persons ……………………. include the need to determine the nature and scope of problems within a State through regular monitoring, the need to adopt properly designed policies and programmes to meet requirements, the need to enact legislation when necessary and to eliminate any discriminatory legislation and the need to ensure the relevant budget support ………".

4.6.3.4 General Comment No. 14 (2000) deals with the right to the highest attainable standard of health. It states that health services have to be accessible to everyone without discrimination. Among other things, this means that they must be physically accessible and affordable. While this is applicable to everyone, it clearly has special resonance for older people in need of care.

4.6.4 UN Principles for Older People 1991

Under the UN Principles for Older People the General Assembly adopted 18 principles under the headings of Independence, Participation, Care, Self-fulfilment and Dignity.

Among other things, it provides that

- older people should be active participants in the formulation and implementation of policies which affect them.
- older people should benefit from family care, health care and be able to enjoy human rights and fundamental freedoms when residing in a shelter, care or treatment facility.
- older people should be able to live in dignity and security and be free of exploitation and physical or mental abuse, should be treated fairly, regardless of age, gender, racial or ethnic background, disability, financial situation or any other status, and be valued independently of their economic contribution.

4.6.5 International Plan of Action on Ageing, 2002

4.6.5.1 In 1982 the World Assembly on Ageing adopted the Vienna International Plan of Action on Ageing. At the United Nations Second World Assembly on Ageing held in Madrid in 2002, an International Plan of Action was agreed (United Nations, 2002). This involves a series of recommendations and an implementation plan. The United Nations Economic Commission for Europe is currently looking at ways of implementing the plan at European level.

4.6.5.2 The aim of the International Plan of Action is to ensure that people are able to age with security and dignity and to continue to participate in their societies as citizens with full rights. The objectives include:

- The full realisation of all human rights and fundamental freedoms of all older people
- Empowerment of older people to fully and effectively participate in the economic, political and social lives of their societies
- Ensuring the full enjoyment of economic, social and cultural rights

The plan recognises the rights based approach to service provision and the importance of participation in decision making. It specifically calls for participation by older people in the planning and implementation of social and health care programmes which affect them and for wider availability of community care. It addresses the need to "establish and apply standards and mechanisms to ensure quality care in formal care settings".

4.6.6 UN Convention on the Rights of the Child/UN Committee on the Rights of the Child

There is no corresponding mechanism for older people. This Committee held a one day session in September 2002 to address the issue of private sector provision for children and its role in implementing children's rights. The principle of the best interests of the child now well established

4.7 Human Rights Issues for People in Long Stay Care

4.7.1 From the analysis of existing provision and law and the enumeration of human rights, the following human rights issues need to be addressed:

- the adequacy of measures to ensure equality of treatment between older people in long term care and those being cared for at home and between those in public care and in private care
- the lack of clarity of entitlement
- the inadequate provision of public care, the level of reliance on private care
- the adequacy of measures to ensure equality and equity in the allocation of available places, in the assessment of need, in the manner in which the means test is applied.
- the adequacy of mechanisms for protection of vulnerable older people (this is not restricted to older people in long stay care)
- the incidence of inhuman or degrading treatment in care and/or the lack of respect for human dignity
- the right to an effective remedy, in the absence of adequate complaints and appeals procedures
- the right to participate in decision making

4.7.2 Equality of treatment

4.7.2.1 The right to equality and the principle of non-discrimination are enshrined in Irish and EU law and they are fundamental elements of international human rights law. The right to equality means that all people are equal before the law – the law should be drafted in general terms applicable to every person and be enforced in an equal manner. Everyone is entitled to equal protection of the law against arbitrary and discriminatory treatment by private parties.

4.7.2.2 This preliminary study provides some evidence that older people who need care may not be treated equally. The constitutional equality clause allows for discrimination which is based on differences of capacity but it would appear that even those of similar capacity are being treated unequally. The precise extent of the inequality is difficult to measure but it is clear that people being cared for by family members/in the community are not receiving similar resources as those in long term care. There are differences in treatment between people in public care and people receiving nursing home subventions but it is not possible, given the present level of information, to ascertain whether one group is more favourably treated than the other.

4.7.2.3 There are not enough long stay care beds available in the public sector. Even when the private subvented sector is added on, there are still not enough beds. This raises issues about equality and equity in the allocation of long stay places. There is not enough information available about how such places are allocated.

4.7.3 Lack of clarity of entitlements

The absence of clarity in entitlement to services must inevitably result in unequal treatment. It also offends the basic principles of administrative law.

4.7.4 The right to vindication of the person

There is no effective mechanism for the protection of vulnerable older people. This is relevant to all older people and not only to those in long term care. There is not enough information available to establish that vulnerable older people are being mistreated while in long stay care. The absence of a complaints procedure and the paucity of advocacy services means that allegations of mistreatment may not be voiced or heard.

4.7.5 Inhuman and Degrading treatment

Further research is needed to establish how older people in care are treated, what their quality of life is like and whether or not they are involved in decisions which affect their lives. This research must take into account the direct experiences of older people as expressed by themselves. It must also take into account the vulnerability of people in long stay care or their own perceived vulnerability and fear of reprisal in the event of complaints

4.7.6 Right to respect for physical and moral integrity

Conditions of care which do not warrant denunciation as inhuman or degrading may still fail to respect the dignity and integrity of the individual. Again, there is not enough information available to make any assessment.

4.7.7 The right to an effective remedy

Clear, precise and easily accessible information is an essential pre-requisite for the enforcement of rights. The quantity and quality of public information provided by health boards about long stay care is poor.

In the case of access to public long stay care, health boards either have no detailed guidelines or these guidelines are not made available, as is statutorily required, in their Freedom of Information Section 16 manuals.

There are no statutory independent complaints and appeals systems in the health services. This means that older people in care do not have access to effective remedies. While the nursing homes legislation (see Appendix) provides for complaints by residents, it does not specifically provide for complaints by third parties.

4.7.8 Absence of external inspection system for public long stay

The absence of an external inspection system for public long stay care means that there is no mechanism whereby the service providers can be held accountable. The provider of public facilities is the inspector of the private sector. As there is a shortage of facilities, the public provider has an interest in ensuring that the private facilities remain in place even if they do not accord with set standards.

4.7.9 The right to participate in decision making

There is no systematic way in which older people in care can be involved in decisions about their care. There are commitments in the Health Strategy 2001 to establish consultative procedures. There is not enough information available on whether or not older people are at all involved in the running of their long stay care homes.

Chapter 5: Recommendations for Further Research

Further information is needed before conclusions can be drawn on compliance with human rights norms. It is recommended that the following further research be carried out:

1. Quality of life studies

In order to make an assessment of the human rights issues arising in long stay care, places, more information is needed. Studies of the quality of life in public long stay care and in private nursing homes broadly along the lines of the studies conducted by the NCAOP in the 1980s are required.

Among the issues on which more information is needed are:

- what happens to older people who need care but for whom it is not provided in the community, who cannot get a health board place and who cannot afford a private nursing home?
- what element of choice is exercised by the older person who goes into long stay care? Are decisions being made by families, medical professionals?
- was the entry into care the result of a planned decision or a response to an emergency?
- how was need assessed; was it assessed in terms of the services available or in terms of the wishes and capacity of the older person?
- was there a choice of type of long stay place available?
- are spouses involuntarily separated by one being in long stay care without facilities for the other?
- how are residents of private nursing homes paying for their care; to what degree is finance being provided by family members; are spouses impoverished by the costs involved?
- what control do residents have over their immediate environment; are there set meal times; access to kitchen facilities; set bedtime?
- is there an over protective environment or paternalistic practices?
- are there ways in which residents can influence the policies of the institution?
- is there genuine consent to medical treatment? are medicines administered to make patients less demanding
- is force being used to administer treatment?
- instances of restraint – are they properly documented? are they in the interests of the patient or of the institution?
- is there electronic monitoring and, if so, is it justified?
- who makes the personal care decisions in cases of residents who are unable to make them?
- what attempts are made to provide a stimulating environment, contact with the home place?

- are the staffing levels sufficient to provide, not just physical and medical care, but also kindness, companionship and some fun?
- is eccentricity (as judged by others) catered for?

These studies should be conducted by or in conjunction with the National Council on Ageing and Older People.

2. Relative costs and benefits of public and private long stay care and of community care

There is not enough information available to judge whether or not older people with similar needs are being treated equally and equitably.

There is a need for an examination of the costs involved in the provision of public long stay and private nursing home subvented care, together with the level of benefits provided to ascertain the relative costs of such care. A similar examination of the costs of community care is needed.

This should examine, among other things,

- the level of services being provided in public and private long stay care
- the public cost, including tax expenditures, of each kind of care
- the cost benefit of the two kinds of care
- the costs to families of providing care, including the income foregone by carers
- the cost to the state of community care and the benefit accruing

This should be conducted by or in conjunction with the Health Research Board and/or the Economic and Social Research Institute.

3. Study of the Inspection reports on private nursing homes

There is a need for a systematic study of the inspections carried out by Health Boards to see

- if the statutory requirement of 2 inspections per year is being met
- how many have been subjected to more than the statutory minimum inspections
- if inspections are carried out at night
- if inspections are carried out without notice
- what sort of problems are being identified
- what action is taken to address problems
- whether problems are more likely to be identified in specific complaints rather than in routine inspections
- if there are structured interviews with residents and relatives

- whether health boards have consistent standards
- whether inspections are sufficiently broad to provide information about the quality of life of residents
- if health boards are being sufficiently rigorous in the follow up when problems are identified; if they are reluctant to close down nursing homes because of a shortage of alternative places
- if there is evidence of residents being evicted because they are difficult to manage
- if the powers available to the inspectors are adequate
- if the reporting arrangements are adequate, for example, if all reports should automatically be made public and if there should be a facility for the inspectors to report directly to the Oireachtas or an Oireachtas Committee

This should be carried out by the Health Research Board and/or National Council on Ageing and Older People.

Appendix: Private Nursing Homes – Standards and Subventions

The Health (Nursing Homes) Act, 1990 and the various regulations made under it govern the private (and voluntary) nursing home sector.

(The Health (Nursing Homes) Act, 1990.
The Nursing Homes (Care & Welfare) Regulations, 1993.
The Nursing Homes (Subvention) Regulations, 1993 as amended.
The Health (In-Patient Services) Regulations, 1993.)

This legislation provides for the registration of private nursing homes, standards of accommodation and care, the payment of a health board subvention to dependent older people who pass a means test and the contracting of beds to the health board.

Definition of nursing home
A 'nursing home' is an institution for the care and maintenance of more than two dependent people (i.e. people who need assistance with the activities of daily living by reason of physical or mental infirmity). Various institutions are excluded from this definition including 'mental institutions', maternity homes and institutions where the majority of patients are priests or members of religious orders. All nursing homes must be registered by the health board and the health board is obliged to keep a list of registered nursing homes. Any member of the public is entitled to inspect this register.

Registration
Private nursing homes must be registered with the health board and are required to meet certain minimum standards. These standards are set out in legislation and include rules about the standard of accommodation as well as of care.

Minimum standards
Detailed requirements concerning minimum standards for nursing homes are set out in legislation.

The main issues addressed in the legislation include the following :

Suitable and sufficient care - nursing homes must ensure that "suitable and sufficient care" is provided to maintain the welfare and well-being of the residents, having regard to the nature and extent of their dependency. There are detailed rules in relation to specific aspects of care for example, required staffing levels.

Nursing and medical care and treatment - a high standard of nursing care and appropriate medical care by a doctor of the resident's choice must be provided. There are detailed provisions in relation to medical treatment and physiotherapy, drugs and medicines, chiropody, occupational therapy and other health services.

Occupational and recreational facilities - the nursing home must provide facilities for the occupation and recreation of residents.

Accommodation and facilities - there are detailed rules about accommodation, facilities and minimum heating standards.

Safety and design - there are provisions in relation to the design of the nursing home so as to ensure maximum safety for residents. Nursing homes must also, of course, comply with the building regulations and with general fire and safety rules. Nursing home are required to ensure that residents are adequately insured against injury while being maintained in the home.

Kitchen facilities - each home must have a separate kitchen with suitable and sufficient facilities and equipment and must have provision for food storage in hygienic conditions.

Hygiene and sanitary facilities - there are detailed rules about hygiene and sanitary facilities.

Nutrition - nursing homes must ensure that suitable, sufficient, nutritious and varied food is provided. Dietary restrictions on medical or religious grounds must be respected. Meal time should be at the normal time of family meals and residents should be involved in menu planning and choice of food.

Privacy and Respect - residents must be able to undertake personal activities in private

Freedom of choice - residents should be able to exercise freedom of choice (to the extent that this does not infringe on the rights of other people)

Religious facilities - the nursing home must provide adequate arrangements to facilitate residents in the practice of their religion.

Safety of personal possessions - there are detailed provisions for the protection of the personal possessions of residents

Information on current affairs, - residents must be provided with information about current affairs and similar issues.

Visits - the nursing home should encourage residents to maintain contact with family and friends of their choice and allow visits at reasonable times.

Discharge - on discharge, the nursing home must tell the resident or his/her representatives of the date of the proposed discharge, the reasons for the discharge and give at least 14 days notice to make alternative arrangements.

Terminally ill patients and death - the nursing home must provide adequate arrangements for the care of the dying and provide for the special needs of terminally ill

residents. The nursing home must also ensure respect for the remains of the deceased, make arrangements for the removal of remains and notify the Medical Officer for Health of the death within 48 hours.

Records - each nursing home must keep a register of all residents setting out basic personal, medical and other details. All personal records must be treated with confidentiality and should be retained for not less than 5 years after the person ceases to live in the home. Residents should have access to personal records subject to certain restrictions in limited cases.

Information - each home must have a brochure setting out information about the home including the name and address of the proprietor, the admissions policy, accommodation provided and special facilities and services.

Contract of care

The regulations require that a contract of care be agreed between the resident and the nursing home. This contract must set out the terms that are to govern care and welfare and must include details of the services to be provided and the fees to be charged. It must be provided to every resident within two months of admission to the nursing home.

(The Code of Practice for Nursing Homes states that the contract should cover

- the services to be provided to the resident
- the level of fees, time and method of payment, whether in advance or in arrears
- extra services and appliances which are charged separately (this cannot include 'essential' services)
- a procedure for increasing fees when necessary
- provision for review of placement
- the personal items which a person may bring to the home and those which the home will provide
- arrangements for the care of pets (where allowed)
- terms under which the resident may vacate the accommodation temporarily (e.g. for holidays or admission to hospital)
- the circumstances in which a resident can be asked to leave
- procedure on either side for terminating the arrangement or giving notice of changes
- statement of insurance cover
- provision for the observance of religious beliefs
- procedure on the death of a resident
- arrangement for holidays)

A comprehensive nursing review of the care of each resident should be undertaken by the nursing home at least every six months.

The resident may not be charged any more than the amount as agreed in the contract of care. This means that there can be no further separate charges for bed and board, nursing care appropriate to the level of dependency, incontinence wear and bedding, laundry service and aids and appliances necessary to assist a dependent person with the activities

of daily living. A special service or item of equipment must be the subject of a separate agreement between the resident and the nursing home and must be set out in the contract of care.

Nursing Home Complaints
A resident or someone acting on his/her behalf may make a complaint to the health board in relation to any matter concerning the premises or the maintenance, or the care or welfare of the resident. The complaint should normally be in writing but the health board can accept an oral complaint if it is not possible to put it in writing. The board must investigate the complaint and the proprietor or the person in charge of the nursing home must be notified and given the opportunity to respond to the complaint. If the complaint is upheld, the health board can direct the nursing home to take specified action in relation to the complaint and the proprietor must comply with this. The health board must notify the complainant of the outcome of the complaint.

(The Code of Practice for Nursing Homes also recommends that each nursing home should have an in-house procedure to deal with complaints without prejudice to the formal procedure set out above).

Nursing Home Subventions
People who go into registered private nursing homes may get a subvention from the health board, if they are dependent and if they pass a means test. The rules about the award of the subvention are set out in the Nursing Home (Subvention) Regulations, 1993 as amended.

The amount of the subvention depends on the degree of dependence and means. There are set maximum rates for the different incapacity levels.

The subvention is designed to help with nursing homes costs. In general, it is not meant to meet the full costs. However, there are circumstances in which the health board may pay the full cost of a private nursing homes bed. This is the case where the health board has what are called "contracted beds" in private nursing homes.

A person must apply for a subvention <u>before</u> going into the nursing home unless there is an emergency. If this rule is broken, the person may not be allowed to apply for 2 years, unless the Chief Executive Officer of the Health Board decides otherwise.

Applicants must be told the result of the application within eight weeks and must be given reasons for a refusal or a reduced level of subvention.

Criteria for qualifying for a subvention
In order to qualify for a subvention a person must be
- sufficiently dependent to require maintenance in a nursing home and
- unable to pay any or part of the cost of maintenance in the home i.e. must pass a means test.

Dependency
An assessment of the level of dependency is carried out on behalf of the health board by a doctor, nurse, occupational therapist or physiotherapist. The assessment involves interviewing the applicant and his/her nearest relatives. Medical condition is taken into account and the assessment also includes an evaluation of the person's ability to carry out the tasks of daily living and of the level of social support available.

The assessment of ability to carry out the tasks of daily living takes into account
- degree of mobility,
- ability to dress unaided,
- ability to feed unaided,
- ability to communicate,
- extent of orientation,
- level of co-operation,
- ability to bathe unaided,
- quality of memory and
- degree of continence.

The assessment of social support takes into account
- housing conditions,
- the number of people in the household,
- the ability of the household members (if any) to care for the applicant
- the extent of support from the community and the services being received.

The person carrying put the assessment compiles a report on the level of dependency. There are three levels – medium, high and maximum. This report must make a recommendation on how the applicant's need for care should be met. For example, it may recommend that it could be best met by staying at home, by going into a welfare home or community hospital or by going into a nursing home.

The report is then considered by an assessment team which is appointed by the health board and includes people with professional experience in the care of dependent people. This team makes the decision on whether or not the applicant meets the dependency requirements for a nursing home subvention, what the level of dependency is and whether a health board long stay place should be offered.

The means test
The means test takes into account the income and the assets of the applicant and the spouse (and cohabiting partner in the case of income). The means test is usually carried out by the Community Welfare Officer.

The means test involves looking at the income which the applicant and spouse (or cohabiting partner) received in the previous 12 months. Income from all sources is taken into account including wages, salary, pension, allowances, payments for part-time and seasonal work, income from rentals, investments and savings and all contributions from all sources. Income is assessed net of PRSI, income tax and the health contribution.

The income of a married or cohabiting person is taken to be half the total income of the couple. A person may not deliberately try to reduce income in order to qualify for a subvention e.g. by diverting it to someone else. If this is done, the income is taken into account anyway, even if the person no longer has access to it.

The total income for the purposes of the means test is net income less one fifth of the weekly rate of the old age (non-contributory) pension payable at the time. (In effect, the person must be allowed retain this amount which is sometimes referred to as pocket money. This was the subject of much of the Ombudsman's report on Nursing Home Subventions (Office of the Ombudsman, 2001). The health boards were incorrectly not allowing nursing home residents to retain this money. This practice has now ceased.)

Farm or Business income

The income from a farm or business is calculated on the basis of the accounts if they are available. If they are not, a notional assessment is made – usually 5% of the capital value (but this is not a rule).

Assets

The following assets **may** be taken into account:

- house property (excluding household furniture and goods)
- stocks, shares or securities
- money on hand, in trust, lodged, deposited or invested
- interests in a company or business of any kind (including a farm)
- interest in land
- life assurance or endowment policies
- valuables held as investments
- current value of equipment of a business or machinery, excluding a car, not covered under a previous heading.

The first €7,618.43 of any assets is disregarded.

The house

The principal private residence is not taken into account if it is occupied immediately before the application and continues to be occupied by a spouse, or child aged under 21 or in full time education, or relative in receipt of disability allowance, blind pension, disability benefit, invalidity pension or old age (non-contributory) pension.

To assess the notional annual income of the assets, the health board takes five per cent of the estimated market value of the principal residence if it was not occupied before or at the time of the application by one of the people listed. This is calculated net of mortgage, loan rental or purchase repayments.

Selling the house
If the house is sold, the proceeds are taken into account in the assessment of means for a nursing home subvention. (There is a social welfare rule that allows the proceeds of a house sale (up to €190,461) to be disregarded in certain circumstances. This does not apply to the nursing homes subvention means test)

Children's income
When the nursing homes subvention scheme was introduced in 1993, the subvention could have been reduced if it was considered that the applicant's children could contribute to the nursing home costs. An assessment of the income of any children living in Ireland was carried out. This arrangement ended on 1 January 1999.

Refusal of subvention

A health board may refuse to pay any subvention if the assets, excluding the house, are greater than £20,000 or if the principal residence is valued at £75,000 or more (and is not occupied by any of the people outlined above) or if income is greater than £5,000 per year.

Level of Subvention
There are three maximum weekly rates of subvention which are related to the assessed level of dependency:

Medium Dependency: €114.28
High Dependency: €152.37
Maximum Dependency €190.46

These rates were set in April 2001.

If means as assessed by the health board are equal to or lower than the weekly rate of old age (non-contributory) pension payable at the time, the maximum rate appropriate to the level of dependency is paid.

If means are higher than the rate of old age (non-contributory) pension payable at the time, the subvention may be reduced by the amount of the excess.

For people who were in a nursing home when the present rules came into force (1 September 1993) or were admitted to a home without applying for a subvention (and therefore subject to disqualification from the subvention for 2 years), a health board may reduce the subvention by the actual payments which were being made by the person or on his/her behalf. This is additional to the amount by which means exceed the old age (non-

contributory) pension. So if €100 per week had been paid towards the cost of nursing home care, the board may reduce the subvention by a further €100.

These reductions in the level of subvention may be applied; the health board is not obliged to apply them.

Where a health board enters into an arrangement with a registered nursing home to provide in-patient services (contracted beds) the board may pay a subvention exceeding the relevant maximum rate and must pay at least the maximum.

Choice of Nursing Home

If a person is considered to be eligible for a subvention, the health board may offer a health board long stay place instead. The rules don't specifically say that a person may be refused a subvention if he/she refuses the health board offer of a place but the implication is that this may happen.

If a health board long stay place if not offered, the health board must pay the subvention to the nursing home chosen by the applicant or by someone on his/her behalf, provided it is a registered home. The nursing home may be anywhere on the island of Ireland.

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