

Home from Home?

The Views of Residents on Social Gain and Quality of Life:

A Study in Three Care Centres for Older People

Age & Opportunity
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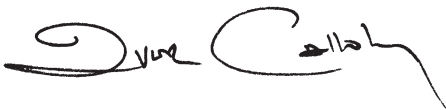
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Foreword by Ivor Callely, TD, Minister of State with Responsibility for Services for Older People

I am very pleased to be associated with the publication of this report – *'Home from Home? The Views of Residents on Social Gain and Quality of Life: A Study in Three Care Centres for Older People.'* I support the approach taken as the basis for the research, which is to interview residents of continuing care settings about how they perceive their own quality of life or 'social gain' within the care centre. I believe that this consultative approach should be at the heart of any attempt to improve standards in care services into the 21st century.

There is now general agreement as to the importance of social gain in the provision of residential care for older people, but, until now, very little had been done to attempt to measure, or indeed, to define it.

I welcome the report's documentation of certain domains that directly influence how quality of life is perceived by residents. The report's recommendations are straightforward enough to inform planning and implementing of residential care services. I look forward to working with health service providers and others in taking the learning from the research forward into improved environments for older people living in care.



Ivor Callely, TD

Preface

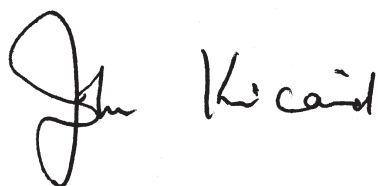
While most older people live independently in the community, and a minority do so with the assistance of others, a small but significant minority spend some time living in nursing homes, geriatric hospitals or other residential-care settings, where they receive continuing care – often until they die.

This study is concerned with such residents' perceptions of their quality of life. It is concerned not with medical and nursing care issues, but with the social dimension of the lives of such residents. The focus of the study is the concept of 'social gain', introduced by the 1994 Health Strategy, *Shaping a Healthier Future – A Strategy for Effective Healthcare in the 1990s*. There is no ready-made yardstick for social gain in these or other settings, and the present study was undertaken in this knowledge. Its aims include an exploration of the quality of life of residents in continuing-care homes and hospitals, in order to identify the main domains and dimensions of quality of life or 'social gain'.

The focus of the research is strictly on the situation as perceived by older people themselves, from pre-admission to everyday life in the home or hospital setting. While background is provided on the centres where the research was undertaken, this is intended only to provide a context, and the study is not an evaluation of the centres selected.

The study is meant to inform the development of good practice by highlighting the continuing importance of the social dimension of quality of life in the context of admission to and residence in continuing-care homes. It is hoped that the findings may contribute to the development of methods of reviewing and monitoring quality of life and social gain in ways that put the residents' perceptions and needs in the foreground. We present it as a small contribution towards a vision for residential care, which is people-centred and holistic, taking into account not only medical and physical needs, but also psychological, social and spiritual ones.

The results should be of interest to providers of residential care and those involved in the referral or admission process; to organisations concerned with promoting quality of life in residential settings; to older people generally and their organisations, and to all those concerned with the development of local communities.



John Kincaid
Chairperson
Age & Opportunity

Age & Opportunity is the Irish national agency working

- *to challenge negative attitudes to ageing and older people, and*
- *to promote greater participation by older people in society.*

Acknowledgements

Age & Opportunity wishes to thank the residents in the three centres for their time and co-operation. Without their co-operation, this study would have been impossible. We also wish to thank the Directors of Nursing and staff, in the homes concerned, for their assistance and support.

We are grateful to those who were directly involved in designing and executing the study. The research brief and research instruments were developed by Maura Boyle, as research advisor to the consultative committee, who also provided guidance to the research team. Hugh O'Connor and Ann Swift of OCS Consulting undertook the research and produced the final report.

The consultative committee that oversaw the study comprised people experienced in relevant policy and practice fields, as follows:

Sr Assumpta Burke, Director of Nursing, Holy Ghost Nursing Home, South Eastern Health Board, Waterford

Mairéad Campbell, Acting Director of Nursing, St Mary's Care Centre, Midland Health Board, Mullingar

Bob Carroll, Director, National Council on Ageing and Older People

James Conway, Assistant CEO, Mid-Western Health Board

Peter Dowling, Area Manager, Older People's Services, Mid-Western Health Board

Margaret Feeney, Project Specialist, Services for Older People, Midland Health Board

Dr John Gibbon, Physician in Geriatric Medicine

Des Keaney, Project Leader, North Western Health Board

Sr Stanislaus Kennedy, President, Focus Ireland

John Kincaid, Chairperson, Age & Opportunity

Joe Larragy, Lecturer in Social Policy, NUI Maynooth

Paul Maher, Education and Training Co-Ordinator, Age & Opportunity (Secretary)

Irene O'Connor, Director of Nursing, St Ita's Hospital, Newcastlewest, Co Limerick

Catherine Rose, Chief Executive, Age & Opportunity

Introduction by the National Council on Ageing and Older People

A continuum of health and social-care services is required to achieve the government policy objective of maintaining older people in dignity and independence in their own homes for as long as is possible or practicable (*The Years Ahead, 1988*). Though the aim is to enable older people to 'age in place' (and this is the self-expressed preference of older people themselves (HeSSOP, 2001)), it is acknowledged that long-term care continues to play an important role in the continuum of care services for older people. Older people who have a disability, who are frail or ill, or who are unable to live at home because of a lack of formal or informal care resources, will continue to need long-term residential care (NCAOP, 2000).

Approximately 5 per cent of those over 65 years of age are resident in long-term care facilities that comprise health board geriatric homes/hospitals; health board welfare homes; health board district/community hospitals; voluntary geriatric homes/hospitals; private nursing homes, and psychiatric hospitals/units. Older people living in long-term residential care may be regarded as being among the most vulnerable in our society by reason of the special supports and continuing care assistance they need. Therefore, particular attention must always be paid to their requirements and to 'providing a high quality of hospital and residential care for elderly people when they can no longer be maintained in dignity and independence at home' (*The Years Ahead, 1988*).

The issue of quality in long-term residential care is one that has always concerned the National Council on Ageing and Older People (NCAOP). The Council commissioned research into the quality of life in private and voluntary nursing homes in the mid-1980s (O'Connor and Walsh, 1986). The study highlighted two dimensions to quality in long-term residential care which were:

- Objective standards of care, encompassing the setting, buildings, facilities and staff arrangements, which were described as indicators of the possible quality of life that can be afforded to residents;
- The context of care: how residents experience life in that setting.

This report concluded that in the homes studied:

The environment of the homes entails living a passive life in public places. The quality of life needs to include the prevention of avoidable mental decline and the maintenance of physical and social function. The restoration of, or compensation for, loss of diminishing function is central to establishing the quality of life as the main theme of care.

(O'Connor and Walsh, 1986: 129)

Over the past number of years, there have been improvements in the provision of care for older people with a long-term dependency. The Health (Nursing Homes) Act 1990 which based its legislation on the recommendations of *The Years Ahead* (1988) was considered as being a milestone in the upgrading of standards of care delivered by nursing homes throughout the

country. However, this Act has been criticised for its provisions regarding quality control and standards of care. The first criticism was that the statutory sector is exempt from quality controls and inspections that apply to the voluntary and private sectors. The second criticism was that the standards are difficult to enforce because they are open to interpretation by inspection teams. This resulted in inconsistencies in the application of standards between health boards and between inspection teams within health boards.

In 1995, a voluntary Code of Practice for Nursing Homes was prepared and agreed by a group of people representing proprietors of nursing homes, health boards, carers and others with experience in the care of older people, and was published by the Department of Health. The Code aimed to generate a better understanding of what is involved in providing quality care to nursing-home residents. However, the Code has received little attention (NCAOP, 2000) and recent Council research (HeSSOP, 2001) has highlighted a low level of acceptability of residential care among older people, which appears to be related to the perceived poor quality of the services offered:

Nursing home equates with not being able to have a quality of life.

I wouldn't go near it again ... You see, they had no book for drawing my money, and they'd give me nothing back. And I had no cigarettes. I couldn't get the price of cigarettes out of them ... she [the matron] said the only way you'd get your book back is to go home ... you had no independence ... you were told to go here and to go there.

The private nursing homes are very expensive, and some of them are not up to much – I've experienced them – yes, I went in just for an experience – very average, you know. The cooking was good, but the accommodation is average...they squeeze too many into rooms if they can.

(HeSSOP, 2001: 206)

Images of long-term care homes as institutions where older people live passive lives without any autonomy or independence do not sit well with all our aspirations for a healthier old age for our relatives and friends, and for ourselves. Nursing homes are regulated because society takes the view that older people and/or their families are not in a position to exercise their usual consumer sovereignty in this area. The ultimate objective of regulation is that residents receive high-quality care with satisfactory outcomes. The real difficulty has been the absence of suitable measures of outcome – measures by which the quality of the service received can be judged; measures that have at their core the views of the consumer (O'Shea et al., 1991). With regard to outcomes of intervention, the Council has asserted that older people resident in long-term care settings should be cared for in such a way that they experience improvements in their physical and psychological health and that they feel that their quality of life is enhanced. In essence, the Council proposed that long-term residential care should be provided to those older people who can no longer be maintained in dignity and independence at home to such a standard that they experience both health gain and social gain from the service (NCAOP, 2000).

The National Health Strategy, *Quality and Fairness – A Health System for You* (2001) places a value on quality of life, and the achievement of social gain in addition to health gain as a central objective. This emphasis on quality of life is consistent with an attitudinal shift that has taken place in determining the effectiveness and quality of service provision in recent years. In the past, when

policy makers focused their attention on the measurement and consequences of care, this generally entailed measuring health outcomes only. However, there has been a movement away from a concentration on outcome indicators associated with the medical model of care, to a focus on indicators reflecting the views of the individual and the impact of interventions on their quality of life. The increased emphasis on ensuring that social gain in addition to health gain is an outcome of the Irish health and social-care system accords equal importance to the enhancement of the total individual and to the maintenance of function and the treatment of illness. In this way, interest is diverted away from illness and disability to wholeness and wellness.

The term 'social gain' first came to prominence when it appeared in the 1994 National Health Strategy, *Shaping a Healthier Future*. This document indicated that resource allocation must be made on the basis of outcomes measured by reference to the health gain and social gain anticipated from services. This Strategy stated that:

Health gain is concerned with health status, both in terms of increases in life expectancy and in terms of improvements in the quality of life through cure or alleviation of an illness or disability through any other general improvement in the health of the individual or the population at whom the service is directed.

Social gain is concerned with broader aspects of quality of life. It includes, for example, the quality added to the lives of dependent elderly people and their carers as a result of the provision of support services.

(Shaping a Healthier Future, 1994: 16)

Health gain is measurable. It comprises outcomes that are quantifiable. In contrast, social gain is much more difficult to define and to measure, and, despite a growing emphasis on the importance of social gain in residential care for older people, no clear definition of 'social gain' actually exists. In its absence, it is difficult to evaluate the quality of residential care and its performance in terms of enhancing social gain for residents.

Therefore, this pioneering research is to be welcomed by any individual/agency concerned with the promotion of quality in long-term residential care. Though the research was exploratory, the aims quite specific, and the results applicable in the Irish context for the particular demographic under scrutiny only, it has provided a deeper understanding of the dimensions of 'quality of life' which are important to older people, while living both in the community and in long-term residential care; it has informed input into the development of a clear definition of 'social gain' in the context of residential care for older people; and it has provided a clear qualitative picture of the views of older people in residential care, and, in doing so, has identified the likely factors and circumstances that contribute to social gain or loss among older persons in residential care. Consistent with the principle of person-centredness as espoused by *Quality and Fairness* (2001), this research took the approach of consulting with older people themselves in order to develop domains of social gain. Such an approach is conducive to ensuring appropriate and responsive care delivery, so that 'the right care will be given in the right place at the right time'. This methodology is also consistent with the democratic approach to consumer consultation that has been advocated in recent reports (HeSSOP, 2001), whereby older people are given a real and meaningful opportunity to influence how services are planned, delivered and evaluated.

The Council believes that this research is timely given the current shift of emphasis, as demonstrated in *Quality and Fairness* (2001), towards the need to establish high-quality services and national standards in residential and community settings, which will be inspected by a Social Services Inspectorate. It is proposed that in attempting to operationalise the term 'social gain', this research will be invaluable in assisting in the preparation of standards that will ensure that both the health and social-care needs of older people in residential settings will be fulfilled, that their quality of life will be enhanced, and that the overall quality of the service being delivered to them will be maximised.



Cllr. Eibhlin Byrne

Chairperson

National Council on Ageing and Older People

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1. INTRODUCTION

1.1 OBJECTIVES

The agreed objectives for the review were:

To develop a clear qualitative picture of the views of older people in long-term residential care on their perceptions of 'social gain' or loss, and to identify their views on the factors and circumstances which contribute to this gain or loss.

To provide informed suggestions for the development of a research instrument and for criteria by which 'social gain' may be measured in residential care settings.

1.2 APPROACH

The Terms of Reference stipulated that the focus of the research should be '*older persons' own definitions, feelings and opinions about the aspects of their lives which were socially and psychologically important to them, while living in the community, and their fears and worries about how these are affected by entering long-term residential care.*' It is important to emphasise at the outset, therefore, that the research relates to the subjective analysis of 'social gain' as offered by residents living in long-term residential care, as they themselves perceive and describe it. It is their voice that is heard in the findings. The researchers have sought not to impose their own views of the social gain of the residents as they (the researchers) may themselves have perceived it in their visits to the institutions. It is therefore worth emphasising that, in speaking only with the residents, and not their families, friends, doctors, nurses or other staff in the institutions, this study has a very specific focus, and the findings should be viewed in this context.

Before proceeding, it is also worth noting a number of other aspects of the approach to the study, for reasons of clarity.

- The role of the researchers was not to evaluate the institutions where the participating residents were living. Brief profiles of the institutions have been included simply as a backdrop to the views of the residents, as stipulated in the research brief.
- There are particular challenges inherent in assessing social gain from the point of view of the individuals themselves, as described earlier. The challenge of bias is particularly in evidence. This difficulty is further compounded when assessing the views of residents in long-term care. The older person is entirely dependent on the services provided by the institution, and may be anxious that criticism, or revealing sensitive information about themselves or their views, may impact on the provision of that service. The researchers made every effort to assure the residents that the information was collected entirely confidentially, and that its purpose was purely research based and would not impact on their place in the institution. In most cases, the researchers are confident that these assurances were taken in good faith. However, there was a tangible reluctance by some to criticise certain aspects of life in residential care, and the subjective findings should be understood with an element of this in mind.
- The consultants have approached the project from a research-based rather than medical perspective. As researchers and not medical professionals, they have concentrated on the 'social gain' aspects rather than specifically health-related aspects of long-term residential care.

- This study is exploratory. In developing the conclusions, the consultants have sought not only to draw on the findings of the research, but also to present some ideas and concepts which could usefully be worked through in future research in the area.

1.3 METHODOLOGY

To achieve the research objectives as outlined earlier, OCS Consulting undertook a number of stages of both primary and secondary research. The approach was informed by the detailed Terms of Reference, brief, and research tools received from Age & Opportunity (Terms of Reference and research tools are provided in the Appendices).

The core of the research was exploratory in-depth interviews with thirty-one older people residing in three Irish long-term residential-care institutions for older people. Since this was a piece of exploratory research, the institutions were selected by Age & Opportunity, not as a representative sample of all Irish long-term residential-care settings, but as offering variety in terms of geography and type, as well as supportive administrations with a genuine interest in the research and its findings.

The specific stages of the research were as follows:

Desk Research: In addition to the specific brief provided by Age & Opportunity, OCS Consulting recommended that generalised desk research be undertaken into the Irish and international contexts for 'social gain' and long-term care. The research, while by no means a formal literature review, was background information drawn on by the researchers to inform the conduct, analysis and conclusions of the study, drawing where possible on the latest findings in the area.

Profiling of Long-Term Residential-Care Institutions: Visits to each of the institutions in advance of the roll-out of the interviews with residents, interviews with the Directors of Nursing in the selected institutions, and a review of any available internal documentation, were all used to develop background profiles of the institutions. These profiles were not intended to be evaluations of the institutions, but sought to provide a context for the views and perspectives of the residents as they were collected. Age & Opportunity supplied a research tool to be used as the basis for developing these profiles. In the event, it was agreed by the consultative committee that the presentation of these profiles in the final report should be brief, focusing on key areas such as their care ethos and philosophy. It was further agreed that, as far as possible, their anonymity should be preserved.

Two Rounds of Interviews with Thirty-One Residents: Ten residents in two of the three institutions and eleven in the third were interviewed. The residents were selected by the Directors of Nursing, based on the following criteria provided by Age & Opportunity:

- That they should not be suffering from serious dementia;
- That, where possible, they should have entered the institution within the previous twelve months;
- That they should be largely representative of the general age profile within the institution;
- That both men and women would be selected.

Two rounds of in-depth interviews were conducted on a one-to-one basis with the thirty-one individuals in the three institutions. Over sixty interviews in all were conducted. The interviews took place in an environment where the resident felt comfortable – whether by their bed, in the day room, or outside when the weather permitted. Age & Opportunity supplied a questionnaire or topic guide for the interviews, which OCS separated into two. The first round of interviews consisted of largely exploratory and open-ended questions. The questions were kept deliberately open to give participants the opportunity to get to know the interviewers and to feel comfortable with them. The topic guide had a three-part structure:

- Life before entering residential care;
- The decision to enter residential care and the period of transition;
- Life in residential care.

The second round of interviews took place within a maximum of two weeks of the first. The topic guide for these interviews followed a similar basic structure, but the questions were more detailed, and covered some of the more personal and sensitive topics to be explored through the research. (Both topic guides are provided in the Appendices).

Analysis and Findings: The results of the interviews were analysed to develop a sense of the themes and factors denoted by the residents as contributing to their happiness and wellbeing, or as detracting from it. The findings were also analysed by the consultants in the context of the desk research, to develop conclusions on the area of ‘social gain’ in long-term care, and recommendations for how it might be measured.

1.4 TERMINOLOGY

The Terms of Reference emphasised that no clear definition of ‘social gain’ exists. The Terms of Reference nevertheless use both ‘social gain’ and ‘quality of life’ interchangeably. The starting point for the research, also established in the Terms of Reference, was that the concepts of ‘social gain’ or ‘quality of life’ both need to be understood in relation to the specific context in which they are being discussed – in this case, older people living in long-term residential care. Based on this idea, the study explores the make-up of these concepts for this specific demographic group in this particular setting. Given the level of uncertainty surrounding the concept of ‘social gain’, however, it is worth considering the more general background to its use, and its relationship to the term ‘quality of life’, as context for the research.

It would seem from our own brief overview of available literature that ‘social gain’ has a particularly Irish provenance. It is most frequently mentioned along with the concept of ‘health gain’. In other words, its key role seems to be to differentiate from the idea of ‘health gain’. Ireland’s Office for Health Gain provides the following definitions:

‘Health Gain’ is concerned with improvements in health status or life expectancy of individuals or populations. This can follow the cure or alleviation of illness or disability or from measures taken to prevent ill-health or to promote positive health.

‘Social Gain’ is concerned with the broader aspects of quality of life of groups such as the elderly or disabled and their carers, or vulnerable children.

‘Social gain,’ therefore, can be defined as relating to ‘the broader aspects of quality of life,’ and as such has a close relationship to the term ‘quality of life.’ A brief overview of the extremely wide-ranging and diverse literature on ‘quality of life’ reveals that there is a similar reluctance to define this concept in generic terms. In particular, there are two diverging ideas, of ‘health-related quality of life,’ which tends to focus on objectively observable outcomes of an illness or a medical intervention, and a broader concept of ‘quality of life’ which looks at life experiences and perceptions in a number of areas, not exclusively health related. For example, the World Health Organisation defines quality of life as:

An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

For the purposes of the research, the consultants have taken the concept of ‘social gain’ to be synonymous with this latter definition of quality of life, which includes, but does not exclusively focus on, healthcare issues. Through the research, we propose to interrogate the concept further, in the context of long-term residential care, to assess how residents describe and assess the positive and negative aspects of their lives, and to see what bearing this has on the understanding of the term ‘social gain’.

1.5 OVERVIEW AND STRUCTURE

The report begins with a brief profile of each of the three institutions which participated in the research. The demographic profile of the residents interviewed is also provided. Descriptive material relating to the lives of the respondents before and after entering long-term residential care follows as a context for the core of the review – the key findings relating to the constituent elements of social gain for individuals living in long-term care. Some observations arising from the background and findings are provided, followed by the conclusions and recommendations.

1.6 ACKNOWLEDGEMENTS

The consultants would like to thank Paul Maher of Age & Opportunity for his helpfulness and thoughtful input during the preparation of this report, and Maura Boyle for assisting in the development of the specific research brief. Special thanks should also go to the individuals, resident in the three institutions, who so generously and thoughtfully gave of their time and views over the course of the research. We are also extremely grateful to the Directors and their staff at the three institutions who facilitated us in every way. Finally, OCS would also like to thank the individuals who contributed their time to give feedback and their own general views on the area, including the consultative committee under its Chair, John Kincaid, and, in particular, Dr John Gibbon and Dr Helen McAvoy of the National Council on Ageing and Older People, both of whom agreed to be interviewed as part of the research.

Hugh O'Connor
 Ann Swift
 OCS Consulting

2. PROFILES OF THE INSTITUTIONS AND OF THE RESIDENTS INTERVIEWED

The profiling section is included to provide a brief overview of the residences involved, in terms of their size, rates of entry, admission policy, care ethos and philosophy, and to outline any social programmes which may already be in place. As specified in the research brief, the profiles are based on information reported during interviews with the Directors of Nursing in the selected institutions, and a review of any available internal documentation. It was also possible to obtain some additional information, at first hand, through observation when conducting a preparatory visit to each residential-care setting, as well as during the two additional visits to each centre when the residents were interviewed.

The research involved in this phase assisted in developing a contextual understanding of the environment in which the older people were resident, and assists in providing a 'support' for the reader. While this was viewed as an important phase, its purpose was not to evaluate the institutions, and the principal emphasis of the study centred on the interviews with the older people resident in each of the three centres. As a consequence, it was agreed with the consultative committee to keep the profiles brief.

2.1 Long-Term Residential-Care Setting One

Residential-Care Setting One is funded by and comes under the auspices of its Health Board. This centre's mission statement focuses on offering 'an equitable quality service on an individual basis for which we are accountable'. According to the Director of Nursing, this centre has a philosophy of care with which all staff and residents are familiar. It is based around '(w)holism. ... and is centred on the needs of the individual and is sensitive to the concerns of the family/carer.' Individualised care is seen 'as an interdisciplinary approach, acknowledging elders as unique persons and practised through consistent, professional, caring relationships.' The continuing-care service at this Residential-Care Setting provides nursing care to older people from the local community who are ill or highly dependent. The continuing-care service consists of 128 beds for 'long-stay' residents. These 128 beds are spread across four units or wards. More able and mobile residents are grouped together, while those residents who are terminally ill, highly dependent, or suffering from an advanced stage of dementia tend to be based in separate units where higher-level resources and facilities are more readily available. According to the Director of Nursing, the residents of the continuing-care units have access to medical and general nursing. Physiotherapy and speech-therapy services are available on an advisory basis.

At the time this research was undertaken, Long-Term Residential-Care Setting One provided 'long stay' care for 128 residents – seventy female and fifty-eight male. Approximately twenty-eight residents were suffering from varying forms of dementia, with ten of these residents diagnosed as suffering from Alzheimer's disease. Residents are housed in ward-type accommodation. Each resident has a bed and a small amount of storage space, usually in the form of a bedside locker, and a screen which can be pulled around the bed when there is a need for privacy. All of the units have a day room where residents can watch television, read or entertain visitors. The gardens attached to the centre are well maintained and include a number of flowerbeds, potted plants, trees and benches. A chapel, dining-room and library services are also provided by the centre.

According to the Director of Nursing, the care centre is visited by a geriatrician on a weekly basis

and by a general practitioner on a daily basis. In general, access to the various services is provided through referral from the acute services and by general practitioners operating within the centre's catchment area. Cases are assessed, and those considered to be in greatest need are given priority. Priority is given to those with high-dependency needs, such as those with multiple medical problems, including those requiring tube feeding, stroke victims and cancer sufferers.

Quality of life initiatives introduced by Residential-Care Setting One include the weekly running of group-based activities. Residents are invited to attend art and painting sessions, drama, storytelling and music sessions. The Director of Nursing states that social interaction and constant mental stimulation are actively encouraged by the care centre's management. Staff members are encouraged to take a little extra time from their daily duties in order to connect and converse with residents. In turn, residents are encouraged to sit in the day room and on the benches outside, in order to foster greater social interaction. The care centre also places value on the contribution made by friends, relatives and neighbours who visit residents in the centre. Visitors are therefore welcomed at any time from 9 a.m. to 9 p.m. Management 'would always like to do more' in terms of ensuring that a good quality of life is achieved by residents.

2.2 Long-Term Residential-Care Setting Two

Residential-Care Setting Two is also funded by and comes under the auspices of its Health Board (a different Board from that of Residential-Care Setting One). The centre serves the local community and it is estimated by the Director of Nursing that the catchment area comes within a radius of 'approximately 15 miles'. The main service provided by this care setting is that of continuing care for 'long-stay' residents who are ill or highly dependent. The continuing-care service consists of 118 beds for 'long-stay' residents. These beds are spread across five units or wards. The residents of the continuing-care service have access to medical, general nursing, physiotherapy, speech therapy, chiropody, activation and occupational therapy services when required. Residents whose health state is so complex that they require specialised medical/nursing care are usually referred to the County General Hospital. Approximately thirty residents are suffering from varying forms of dementia.

The gardens attached to the centre are well maintained and include potted plants, a number of flowerbeds, trees and benches. Many of the residents spend a lot of time sitting in the garden. An occupational-therapy room has also been set aside in one of the units of the centre. Residents are invited to attend occupational therapy on a weekly basis. Residents are housed in 'ward'-style accommodation. Each resident has a bed and some small storage space, which may come in the form of a bedside locker. Some small lockers for storing clothes and personal items are provided at the end of a number of the wards. All of the beds have a screen which can be drawn across when there is a need for privacy. All wards have a day room where residents can watch television, read or entertain visitors.

Access to the various services provided by the Centre is generally through referral by a general practitioner or public health nurse operating within the centre's catchment area. Residents are referred for individual therapies by the GP or, in some cases, nursing staff. Management is currently seeking to establish a committee which would assess referrals on an ongoing basis. Currently those applicants with the greatest need, in terms of illness and/or dependency, are given priority when space is available. Admissions are made not on the basis of a medical diagnosis alone. It was

suggested that the centre looks very favourably on applicants who are financially disadvantaged, and each applicant will be assessed in terms of all-round need, which includes both medical and personal circumstances. Many of the residents come to the centre following acute illness such as stroke, pneumonia or major surgery. The Clinical Nurse Manager or her deputy is responsible for the care of the patients in the ward. According to the Director of Nursing, 'a programme of care is developed for each resident based on their needs'. This programme tends to have greater weighting on health rather than on social-related issues. The care centre's management considers visits by family and friends to be very important to the older person while resident in the centre. Family encouragement and support are advocated and are considered to be of utmost importance during the transition from living in the community to living in long-stay care. Pastoral care was also considered by management to be very important.

Quality-of-life initiatives introduced by the centre include the frequent running of group-based activities. Residents are invited to attend an arts-based course, which is conducted by a local community artist and the clinical nurse specialist in activation therapy.

2.3 Long-Term Residential-Care Setting Three

Residential-Care Setting Three is an endowed institution which has existed since the 1500s and is administered by a Board of Trustees. The current centre was built in the early 1970s as a purpose-built care centre which would meet the needs of older people living in the local community. The centre consists of fifty-eight private rooms, a dining-room, a 'day room' and an oratory for residents. There is also a small garden within the grounds of the centre. As it does not come under the auspices of the local Health Board, the centre does not have a strictly enforced catchment area. It is estimated that the approximate catchment area is within a radius of 'about 30 to 40 miles'. The centre does not receive funding from the local Health Board and is managed by a Director of Nursing and a part-time administrator. Three religious sisters, including the Director of Nursing, provide care to the residents at the centre. There are also assistant staff at the centre.

The organisation's mission statement focuses on the reason for the existence of the centre, which is to ...

prolong the liberating healing mission of Jesus, through the ministry of health care by enabling the staff to achieve the highest standard of professional and spiritual development in order to provide total health care for the resident, support for the family and for each other within the home, realising and totally accepting the essential dignity of every human being and advancing the cause of Social Justice.

According to the Director of Nursing, Residential-Care Setting Three has an ethos which is centred both on the wellbeing of the individual resident and on protecting the best interests of the group at large. Currently, the primary service provided by the centre is that of 'long-stay' continuing care. This care service provides suitable accommodation and nursing care to older people from the local community who are no longer in a position to care for themselves comfortably. At the time this research was undertaken, the centre provided 'long-stay' care for fifty-eight residents – thirty female and twenty-eight male, in total. Those suffering from dementia, serious illness or incapacity tend not to be catered for at this centre, as the 'necessary support in the form of specialised nursing or medical care is not available.'

Residents are housed in individual rooms. Each room is furnished with a bed, a bedside locker, wardrobe space and a chair. Many of the rooms also have small tables and cupboards to hold personal possessions. According to the Director of Nursing, the residents and their families are encouraged to bring in a range of personal possessions, in order to 'put a personal stamp on the room'. Many residents have their own television, radio, photographs and other souvenirs from home. A day room / television room is provided, and residents are also free to entertain visitors in their rooms. Many have kettles and small refrigerators so that tea and biscuits can be offered to visitors. The garden attached to the centre is very well maintained and includes a number of flowerbeds, potted plants, trees and benches.

The Director of Nursing stated that a formal admission policy does not exist in this centre. Applications are assessed on their own merit and awarded to those deemed most suitable for life in the centre. Potential residents must be able to wash, dress and feed themselves, as the centre does not have the resources to provide the level of sophisticated care required by those with more dependent needs.

Table 1: A Comparison of the Three Residential-Care Settings

	Care Setting One		Care Setting Two		Care Setting Three	
Year Established	1841		1841		1971 (current building)	
Funding Organisation	Health Board		Health Board		Endowed institution	
Radius of Catchment Area (approx.)	30 miles		15 miles		35 miles	
Number of Beds	128		118		58	
Private Rooms/Ward Accommodation	Ward accommodation		Ward accommodation		Private rooms	
Numbers with Dementia	28		30		0	
Approximate Age Breakdown (over age 65)	Age	%	Age	%	Age	%
	65–69	7%	65–69	12%	65–69	4%
	70–79	29%	70–79	33%	70–79	25%
	80–89	56%	80–89	40%	80–89	66%
	90+	5%	90+	10%	90+	5%
Gender Breakdown	Male	Female	Male	Female	Male	Female
	45%	55%	40%	60%	48%	52%
Staff Number	35 nurses 40 attendant staff		64 nurses 58 attendant staff		6 nurses 8 attendant staff	
Approximate Nursing Staff to Resident Ratio	1 : 3.7		1 : 1.8		1 : 9.7	

Quality-of-life initiatives introduced by this centre include the weekly running of group-based activities. Residents are encouraged to attend storytelling and music sessions. Reminiscence therapy is also facilitated on a weekly basis. The management also seeks to provide a number of trips for residents during the year.

2.4 Profile of the Sample of Residents

In total, interviews were held with thirty-one residents, spread across the three long-term residential-care settings involved in the study. As this study was designed to be an exploratory research assignment, it was considered that a large representative sample would 'not have the same priority that it would have in a highly structured, quantitative study' (see the Terms of Reference in Appendix 1). Nevertheless, the composition of the interview group was developed with the twin objectives of reflecting the composition of older people living in full-time care and developing a sample of interviewees capable of providing the information which was sought. Consideration had to be given to the size of the available sample from which appropriate interviewees could be drawn. This was affected by the following factors:

- The number of residents who had moved to full-time care within the previous eighteen months;
- The number of residents not suffering from serious dementia;
- The gender split to reflect the male to female ratio in each of the three care centres.

Some compromises therefore had to be reached in identifying ten appropriate candidates in each of the three care centres.

The following tables outline the characteristics of the residents from each of the three care centres involved in the study.

Table 2: Age of the Residents Interviewed

Numbers Interviewed	Age				
	Under 65	65–69	70–79	80–89	90+
Care Centre One		1	3	5	1
Care Centre Two	1	2	2	3	2
Care Centre Three			1	10	
Total	1	3	6	18	3

Table 3: Gender of the Residents Interviewed

	Gender	
Numbers Interviewed	Male	Female
Care Centre One	5	5
Care Centre Two	4	6
Care Centre Three	3	8
Total	12	19

Table 4: Period of Residency of the Residents Interviewed

	Period of Residency		
Numbers Interviewed	Less than twelve months	Less than eighteen months	Less than twenty-four months
Care Centre One	5	4	1
Care Centre Two	9	1	
Care Centre Three	7		4
Total	21	5	5

In terms of age, the majority (58%) of residents interviewed were between 80 and 89 years of age. Those between 70 and 79 years of age were the second largest grouping (19%). Just one resident was under the age of 65, while three residents were over 90 years of age. Most (61%) of the residents interviewed were female.

As a range of criteria had to be met in terms of the target sample, the most important criterion being ability to provide the information sought, some flexibility had to be offered in terms of length of residency. As a result, 68 per cent of the interviewees had been resident for less than twelve months, while a further 16 per cent were resident for less than eighteen months. Of the thirty-one interviewees, yet another 16 per cent were resident for less than twenty-four months.

3. LIFE BEFORE AND AFTER ENTERING LONG-TERM RESIDENTIAL CARE

The consultative committee established to advise on and monitor the research, chose a research design whereby older people who had recently entered long-term residential care would be interviewed. As the consultants had selected people who had taken up residence in the care centres within the previous twenty-four months, the interviewees were in a position to describe the experience of moving from living in the community to living in long-term residential care. For many of these people, the memories of the life that they had led before, and the 'quality' of that life, were still vivid. Although the interview used a structured format, the questions were organised in such a way as to resemble a more informal conversation, but with a purpose. This conversation, therefore, focused on what the residents' lives were like before moving into residential care, the decision involved in making that move, and the residents' early experiences in long-term care. This section serves, therefore, to illustrate the attitudes, experiences and the quality of life experienced by those older people.

The range of issues identified highlights that, although many similarities exist, the older people interviewed are not an homogeneous group. Many had had very different life experiences. Some viewed their new life in long-term care as 'an opportunity for a new and positive phase' of their lives, while, for others, life in care was an inevitable destination which 'just has to be tolerated'. By examining the reasons why these people entered residential care, the decision-making process involved, and the experience of the resident in adjusting to life in long-term care, our purpose is to provide a contextual understanding as a background to the findings on quality of life and social gain in long-term care.

3.1 Life Before Entering Care

Although many of the residents had had very different life experiences, several common themes continued to arise in terms of lifestyle, favoured pastimes and elements of home life which were valued. Of the thirty-one residents who were interviewed, eighteen had lived on their own in the years preceding the move to residential care. Many of this group had at some point lived with other family members until the time of death of a partner, brother or sister or the move of children away from the family home. Although a small number of residents had experienced disagreements with family members, which had ultimately contributed to the decision to move to full-time care, the majority spoke very highly of their families and suggested that proximity to and interaction with the family unit was the factor they appreciated most when living in the community. In the case of those who had lived alone in recent years, many spoke very positively of the interaction and social contact they had with friends and neighbours from the local community. This social contact appeared to be of paramount importance to the majority of older people interviewed.

3.1.1 Occupation

A significant majority of residents would appear to have led very busy and full lives. The majority worked either 'outside' or 'inside' the home for most of their lives in the community. Much of this work, in the case of both males and females, tended to be labour-intensive, such as farming, gardening, construction-related activity, and childcare. Many residents appeared to take pride in the work ethic that they had displayed and the contribution that they had made to the family unit. A sense of satisfaction in keeping active all their lives was apparent among many residents. Most of

the older people described themselves as having enough money to provide for the immediate needs of themselves and their family. Although most were very happy with their own personal circumstances, few would have described themselves as being 'comfortable'. The following comment was very typical of many of the older people interviewed.

We worked hard all our lives and kept busy. We had enough to keep us but we were never rich. But we were happy.

3.1.2 Interests

Religion and observance of the sacraments was of significant interest to many of the residents interviewed. Many residents, especially those living on their own, passed considerable amounts of time praying and listening to or attending religious services. This activity appeared to offer many of those residents great peace and satisfaction. Attending religious services also appeared to be part of the older persons' social interaction, as they tended to meet with friends and neighbours after mass at the weekend.

In terms of other interests, watching television and listening to the radio featured highly among the majority of older people interviewed. Greater reliance appeared to be placed on these media as 'forms of companionship' as the residents advanced in years or became less mobile. The newspaper was read by most of the older people on a daily basis. In previous years, many of the older people would have attended local sporting occasions on a regular basis.

3.1.3 Health

Many of the residents had enjoyed good health throughout their lives and had managed to remain active until recent years. A small number of residents had experienced poor health for a considerable time, in some cases up to ten years, prior to moving into full-time residential care. The majority would, however, have experienced some health-related difficulties within the recent past. Many were cared for by a family member, such as a son or daughter, or, in their absence, a brother, sister, niece or nephew. In the absence of immediate family, many would have got assistance from a 'home-help' or from neighbours who would help with cooking, cleaning and shopping when required.

3.1.4 Perspective on Life in the Community

When speaking of their life in the community, the residents spoke favourably of the 'familiarity' of community life. Comfort was derived as a result of being familiar with the surrounding neighbourhood, the neighbours themselves, and their own homes. Interest in the local community appeared to be very strong for many of the residents. Many of the older people spoke of the strong link that they enjoyed with the local community. Unplanned visits to neighbours were very common in their daily lives. They enjoyed keeping up to date on community news, such as weddings, funerals, the sale of land, sporting events, local politics and other 'general bits of gossip'.

Home life was very important to the majority of those interviewed. Most looked back on it with fond memories. In recent years, however, several of the older people interviewed had begun to find elements of home life stressful. The fear of living alone and the risk of burglary or attack were often

commented upon. Many of the residents indicated that they had also started to experience difficulties in caring for themselves while living at home. Health-related issues made it difficult for some to perform basic duties of shopping, cooking and cleaning. It appeared that, in recent years, greater reliance had been placed on the involvement of the support network in caring for the older person. For many, a gradual increase in their dependency needs was evident in the recent years preceding their entry to full-time care.

3.2 Decision to Enter Long-Term Care

Among the thirty-one people interviewed, there was a diverse mix of individuals who had and who had not been involved in the decision to enter long-term care. A small number of individuals – approximately seven out of the thirty-one to whom the consultants spoke – had very much taken control of their own situation, and had requested a place in the particular institution. The majority – approximately seventeen of the thirty-one – had agreed on the advice of friends, family or local healthcare professionals. A small number of others – approximately six of the thirty-one, had taken no part in the decision or were resistant to it, and many were distressed and continued to be unsettled and angry as a result.

Many of the older people exhibited some reluctance to talk about this time of their lives. This was particularly the case for those who indicated unhappiness with the decision that had been reached or the way in which that decision had been reached.

I had a stroke earlier in the year and had to spend a month or so in the General Hospital. Although I had my own home, when the hospital was looking to release me, there was no one there to look after me. I had no say at all in moving here. They just sent me here. I could do nothing about it.

Several of the residents suggested that they had come to the home on the advice of others. In the case of those people who had been living alone prior to moving into long-term care, professionals such as the local district nurse and local GP were the most common source of advice or direction. In several cases, the 'home-help' also offered advice on the move.

The district nurse was worried that I wouldn't be able to look after myself for much longer and asked me where I would like to end up. I knew of this place and I said it would be great to get in here. It was great then that she recommended me for a place.

The home-help used to speak about this place quite a bit and how nice it was and how caring the staff were. I suppose that helped to make up my mind.

I had a chat with my local doctor about my situation. I knew that I wasn't really able to look after myself. He then put me on the list for here.

In the case of those older people who had lived with other family members, those family members, particularly sons and daughters, were involved in the decision to move to long-term care. When these immediate family members were absent, nieces and nephews often performed a similar role. Brothers and sisters were often consulted, or offered advice, to those residents who had never married.

Although some of the interviewees were very clear that they had had no involvement in the decision to move to long-term residential care, there was a general reluctance to talk about how

the decision had been made. It was not always possible to make a clear distinction between those individuals in their lives who had offered advice and those who had actually made the decision. The older persons were unclear, or unwilling, to share 'why' that particular centre had been chosen.

I came here in the ambulance in my night gown. I had no idea where I was going. I suppose the doctor in the hospital made the decision.

I just woke up here. I'm not sure if it was the doctor or my sister who decided that this was where I should go.

I would have liked to stay at home but my sons made the arrangements for me to move here. I didn't want to trouble them so I didn't say anything.

We had been talking about it quite a bit. The district nurse and the GP made all the necessary arrangements.

Some of the residents had personally taken charge of their move to residential care. Some of these fully embraced the idea, and were delighted with their new lifestyle. Others were less positive but felt that it had been the only option for them.

I decided to sell my house and I split the proceeds amongst my family to come here. I was happy to come here. The perceptions of the 'home' were changing and I knew that from the daycare it was OK.

At first it was the doctor who suggested it. I came down, saw the room and booked myself in. I have no regrets at all.

3.3 Reasons for Entering Residential Care

Many reasons were put forward by the older people for their entry into residential care. There were few examples, however, of older people who had engaged, or for whom others had engaged, in a lengthy or involved 'decision-making process' prior to entering long-term care. For the majority of interviewees, the decision was made in a response to an urgent situation, such as a stroke or death of a companion, which called for an urgent remedy. However, rather than suggesting one reason alone, many of the residents suggested a combination of reasons for their move, thereby indicating that their ability to live in the community had gradually been eroded over the years. The final decision was usually made on foot of a critical incident which made it too difficult or impossible for the older person to continue to live in the community.

The most common reasons put forward for the move to residential care were as follows:

Poor Health: A 'gradual' move to residential care was typical for many of the older people interviewed. Many had suffered from a stroke, heart attack or other serious medical condition and were therefore being cared for in the local or county general hospital prior to moving to the home. When the hospital wished to discharge them, many of the older people themselves were reluctant to return home as they knew that they would not be in a position to look after themselves.

There was no way, after the stroke that I would be able to look after myself. I wanted to go somewhere that I would be properly looked after.

In the case of some residents, the doctor caring for the patient in the hospital would recommend a certain residential-care setting. In some cases, this recommendation was seen as a very positive contribution:

The doctor said that I would be well looked after here and at that time I was quite worried as to where I would end up.

However, in the case of a few, it was viewed as an unwelcome intrusion:

If it weren't for that doctor in the hospital sending me here, I wouldn't be in this bloody place. I wanted to go home to my house.

Certainly, the doctor seemed to be a key decision-maker for many in relation to the move to the home. Some residents did not want their health-related problems to be a 'burden' to their family, and so they themselves decided to move to long-term care. For seventeen of the residents, poor health was a key factor in the decision to move.

Insecurity / Fear of Living Alone: Many of the residents were living alone and indicated that they were fearful that their house would be broken into or that they would be attacked. For several of the older people, both male and female, this was a constant fear.

I would be constantly checking the spy hole in the front door and would sit by the phone in case anything would happen. Noises during the night would really frighten me. I hardly slept at all for the fear.

The fear of a 'fall', stroke or heart attack was also mentioned by many who were living alone. Several suggested that they led very limited lives as they had been reluctant to venture any significant distance from the telephone or their 'panic button' in case of a medical emergency. For many, this fear of burglary, physical attack or medical emergency contributed to the decision to move to long-term care. Approximately ten of the thirty-one residents cited fear and insecurity as the key reason for the move.

Death of a 'Life Companion' / Lack of Companionship: With the exception of a small number who had lived independently for several years, the majority of older people interviewed had lived with some family members for the large part of their life. The death of a 'life companion', such as a husband or wife or in some cases brother, sister, son or daughter, was understandably traumatic and, in many cases, a key influencing factor on the decision to go into residential care. In many cases, the older people remained living on their own for some time after the death of such a close companion before moving to long-term care. The death, however, was identified as the first step in the older person's move to long-term care. Illness or loss of confidence on the part of the surviving older person often followed such a death. The death of a close companion left many without the necessary care or support which would enable them to continue living in the community.

When my wife died, my own health gradually got worse, and the district nurse suggested the move to long-term care. I suppose that I wasn't really able to look after myself properly.

Loneliness and boredom caused by living alone were also suggested by some as contributory factors to the decision to move to long-term care. Approximately five residents out of the thirty-one stated that the death of a companion had been the key factor in the decision to move into residential care.

Inability to Cope: A small number of the interviewees suggested that their ability, and in some cases interest, in looking after themselves had slipped to such an extent that they were not in a position to cope with living on their own.

I went off my food and went down to five stone. The doctor sent me to the general hospital and suggested that I think of long-term care.

I had no way of getting into town to do the shopping, and the home-help only came a couple of times a week. The house and garden was too big anyway and there was no way I could look after it on my own.

In the case of these residents, a third party – such as a family member, district nurse, general practitioner or neighbour – tended to be involved in the decision to move to residential care, or in encouraging the older person to move to long-term care.

Breakdown of Family Unit / Inability of Family to Cope: For a small number of those interviewed, a gap developed in their support network, which they were not able to fill. This could have been brought about by the death of a companion or a change in the life circumstances of the primary carers.

My son's marriage broke up so I couldn't really stay in the family home any more.

My son got a new job in Dublin. I tried living up there with him for a while...but sure I don't know Dublin and he was out all day working.

Some of those interviewed suggested that they preferred to retain a 'sense of independence' and did not 'want to be a burden on anyone', and so decided to move to long-term care.

I could see the kids were busy with their own children and families now. I wanted to come to a place where you can be looked after without being a burden on anyone.

Planning for the Future while it was Still Possible: Although few in number, there were some residents who had decided to move into long-term care at a point where there was not an immediate need for it. These residents appeared to be very proud of their own independence, and were unwilling to be a burden on their families. A very small minority also wanted to provide financially for their children while they could live to see them enjoy it.

I wanted to provide for my children while I still could, so I sold the house and split it between them. I didn't want to go and live with them. That would have been too much for me.

Although these residents would have been still able to live in the community if they so wished, they chose to remain independent of family and other potential carers.

I enjoyed living an independent life throughout my life and the last thing I want to be is a huge responsibility for my children.

I knew the house and bit of land was getting too much for me so I thought a move would be good before I got to a position where I couldn't cope. I would have hated that.

Homelessness: One or two of the residents had come to the home because their existing residence was no longer open to them. Some of these had come from sheltered accommodation or other rented accommodation. However, the majority had a home of their own, and material circumstances, at least in relation to a place to live, were not a key determinant for most.

3.4 Selecting a Home

Although many of the older people interviewed were not directly involved in the decision to move into long-term care, for those who were involved, the following factors were identified as contributing to the selection of a certain centre.

Close to Own Home and Neighbourhood / Convenience: Although many of these residents would never have visited the centre prior to making that decision, the fact that the care centre was close to their own neighbourhood appears to have been a very positive factor.

I had always known it [the care centre] was there for years, and sure home is only a few miles out the road. It's easy for the family and neighbours to come in and visit. It's nice as well to be among your own.

I can keep in touch with what's going on in the parish – the nurses and the other residents will always have a bit of news.

When asked to describe their own home life and the things that were important to them, 'family' and 'neighbours' featured very strongly in the replies. It appeared to be a significant comfort factor that the older people would remain in close contact with family and neighbours by living in a care centre that was close to home.

Being close to their own home and neighbourhood also appeared to assure residents that they would be able to retain a sense of personal identity:

I wanted to be able to shout for the parish or the county team with other locals when the championship is on.

I wanted to be able to talk and reminisce about local events, people and places with people who know the area.

A small number of residents also suggested that moving to a nearby care centre was the simplest option available to them:

Ah sure, I didn't want the bother of going to look at homes too far away – that would have been far too much trouble for me and my family.

Religious Ethos of the Centre: Religious observation was a very important part of the daily lives of the majority of those interviewed during the course of this research. In all three of the centres, religious services were held either daily or at least twice weekly. Many of those who were physically able availed of all the opportunities to attend the services offered. The availability of these services was perceived to be very important to those older people who were involved in the decision to move into long-term residential care.

I went to Mass every day of the week when I was living at home – I knew I would have liked to continue that when I came here.

Reputation: The majority of the older people interviewed lived within close proximity of the care centre. Many would have known someone who had been resident there, or a staff member working in the centre. As a result, people were able to develop opinions on the centre and the standard of care offered prior to moving there themselves. Many held positive opinions of the

centre prior to taking up residence, and so were more comfortable in taking the decision to move there themselves.

A neighbour down the road used to live here and I know their family spoke of it highly...that gave me a lot of comfort.

I used to come here to visit an aunt of mine. She seemed to be very happy here.

A nurse who worked here used to live in the same terrace as me. She was a wonderful, caring woman.

The Type of Accommodation and Facilities Offered: Although only one of the three care centres involved in this study, Long-Term Residential-Care Setting Three, offered private rooms, the type of accommodation and available facilities were highlighted by some of the interviewees as factors that they considered when making their decision. The privacy offered by the private rooms was considered by several of the residents in this care setting to be very attractive:

I knew that it would be far easier to settle into a place where I have my own bedroom. I think it would be very difficult to settle into a ward. (Resident in Care Setting Three)

I thought that your own room would offer you a fair bit of privacy. I could go for a nap or just be on my own when I want. That's what I liked about it the most. (Resident in Care Setting Three)

However, residents from all three centres suggested that they considered other facilities when making their decision:

When I used to come and visit my aunt here, it was always lovely and warm...very cosy.

I knew they had lovely gardens here and I always enjoyed the outdoors and doing a bit of gardening. I thought that would be nice.

I came here to the chapel for a service. I thought that was lovely. The building itself has a lot of character and history.

3.5 Initial Thoughts on Moving into a Home

The older people interviewed were asked to speak about their initial thoughts and emotions on moving into long-term care. Some of the key responses were as follows:

Positive Outlook: Slightly less than a third of the residents interviewed suggested that they were well prepared for their move to long-term residential care. These residents tended to have a very positive outlook and appeared to deal very well with the initial transition to long-term care. All of the residents who had been involved in the decision to move to the home continued to take the positive view.

It was my decision to move here. I wanted to make the most of it. I thought it was going to be a nice place to live...and it has turned out that way.

My family were well looked after and I was safe in the knowledge that they would be OK. That meant that I could settle in here really quickly. I just got on with it.

I didn't mind coming here. It's turned out much the same as I expected it to. I haven't changed the way I lead my life. I do much the same things as I always did.

Overcoming Initial Uncertainty and Unhappiness: A significant number of interviewees experienced a considerable amount of difficulty in settling into their new place of residence. Many found it quite upsetting and indicated how significant the change was in terms of comfort and lifestyle. Several of these residents suggested, however, that they had come to be more comfortable and to enjoy their new lifestyle once they had had a chance to settle in and become more familiar with the staff, other residents and surroundings.

It was really strange at first. I hated leaving my home. I didn't know anybody here. I found it hard to accept being here at first, but once I gave it a chance and got to know people and got involved in the activities I've been far happier.

It was upsetting leaving my home and coming to this new place but now that I've settled I think it's great. I haven't slept this well in years. I feel secure here. It's a bit like a home from home really.

It's just such a big change from living at home and all your familiar surroundings...but once you get the run of the place it's great. You really are well looked after and the staff are great. I've made some really good friends and we have a great bit of fun.

A Sense of Resignation: Other interviewees suggested that they had found the transition to living in long-term care to be very difficult, and that they had not yet come to terms with it. These interviewees, approximately a third of the residents, often underlined that there was 'no other option', and seemed to have resigned themselves to the idea. Some prided themselves on the way they put on a 'brave face' for the sake of relations, but accepted that they were not really happy and doubted that they ever would be while living in long-term residential care.

I suppose I'm lucky to have a bed here but I never wanted to give up my lovely home or my independence. It's important that the children don't worry about me so I try to be quite upbeat when they're around. I suppose it's quite nice here but nothing will really replace my home.

I never really thought I would end up in a place like this but now I think you just have to accept it.

I cried a lot when I got here first, but now I have just accepted my fate. I suppose I'd rather be here than a burden to my family.

Many of these residents suggested that, with the benefit of hindsight, they could see how difficult it was for the people responsible for caring for them in their own home, and that life in residential care was now a more suitable alternative.

A Sense of Having Been 'Let Down' by Family and Other Carers: For a small number of others, the experience of moving into residential care had been extremely traumatic and something about which they continue to be upset. Four of the thirty-one residents stated clearly that they were very unhappy living in a residential-care setting and that they would be anxious to return to their own home. For this group, while they experienced considerable limitations in their functioning and mobility, it was clear that returning home was a continuing aspiration.

I hated the idea of moving here. I miss my home terribly. I just wish I could go back home ... Maybe I will when I get a bit stronger.

Some of this small group felt let down or appeared to blame those who they thought were responsible for their move into long-term care.

If it weren't for that doctor, I would never have ended up here. All I want to do is go home to my house.

I thought my family would have been able to look after me but they're too busy with their own lives.

3.6 Life in Long-Term Residential Care

The way in which the average day is structured is similar in all three of the care centres involved in the study. The set routine of meals, personal care, prayer and organised activities tends to be highly structured. For many, the day starts early when the residents are woken by the staff on their rounds. Breakfast tends to be served between 7.30 and 8.00 a.m. Very few of the residents questioned the routine of the home, although waking times appeared early to some. Those residents who were reasonably fit, well and active were in a better position to superimpose their own routine on that of the care centre, while those who were incapacitated were able to create their own routine only around that provided directly by the care centre.

From the interviews it would seem that the most common pastimes were watching TV and reading the newspapers. The soap operas, sport and quizzes appeared to be the most popular television shows. Reading the newspaper, even just the headlines, also appeared to be part of the 'ritual' of daily life for many residents. All of those interviewed who regularly read the newspaper depended on the care centre to supply them with papers. Several residents expressed disappointment that they could no longer read the small print in the paper because of poor eyesight. Others also expressed frustration because of hearing difficulties. For some, it was upsetting that they had difficulty in listening to the radio or television, while for others it was frustrating that the television or radio was played at such a high volume.

A significant majority of the residents, both male and female, appeared to have a very strong interest in sport, both local and national. Both club and international soccer were extremely popular. Similarly, county football and hurling were of great interest to many of the residents. These interests appeared to be a significant source of enjoyment for many of the residents as they enjoyed the competitive aspect of the various games, and the opportunity they offered for discussion with other residents, staff and visitors. Many also liked to keep in touch with local teams and competitions, as they were seen to be a way of keeping in touch with residents' own neighbourhood or home town.

Religion and observance of the sacraments appeared to be of very significant interest to the majority of those residents interviewed. Most residents availed of every opportunity offered to attend the religious services. Mass was held frequently, in some cases daily, and at least weekly, in each of the three centres. Residents also had the opportunity to take Holy Communion on various days throughout the week. Some residents commented, though, that they would have appreciated the opportunity for their confession to be heard by a priest. Many suggested that the religious services were a comfort to them and something that gave them great peace and satisfaction.

Of those who were reasonably fit and active, many liked to go outside to the garden for a walk. This tended to be described as just a 'short stroll for a bit of fresh air' or a 'walk out to the door for a smoke'. Many of the active residents expressed a desire to spend some or all of their time away from the day room as it was suggested there was a need to break the monotony which this involved. Activities such as card-playing, knitting, crochet and bingo appeared to be favoured only by female residents.

Entertaining visitors seemed to give great enjoyment to those residents who spoke about it.

I look forward to the visit from my son every Saturday.

My daughter comes in every night and helps to dress me for bed.

Some of the neighbours call in now and again, and we will chat about the locality and what's happening. It's great to keep in touch and hear what's going on. I love to be able to chat to someone from outside.

Conversation with other residents and visitors was of huge importance to most of those interviewed.

Many of the residents also enjoyed being able to take a rest or a 'nap' whenever they liked. Many took the opportunity to go back for a nap after breakfast and in the mid-afternoon. The majority of residents suggested that they went to bed a lot earlier than they would have when they were living at home. Some suggested 'that that's what everyone else does' or 'that's what's encouraged'. Others suggested, 'that there is nothing else to do.'

The activities organised by the care centres, such as the art, music and drama sessions, received a considerable amount of very positive comment from residents.

I look forward to the music class on a Tuesday, It's great fun. We all have a good laugh and the instructor is excellent.

I never painted before I came here. I didn't think I would be able for it but it really is enjoyable and it's great to do something different. It was nice as well that we get to display the work.

The drama days are great. We do reminiscences and stories which can be very interesting. I like to prepare something ... a story maybe for each week. It's really important that you keep your mind active and stimulated.

The residents were asked whether, in long-term residential care, they gave any thought to the future. The majority of residents tended to focus on the short term instead of the long term – to a forthcoming trip, an activity, a relative's visit or a change in the season. Few were comfortable thinking in the longer term, and many stated specifically that they deliberately did not give the future, with all that implied, any thought.

I'm looking forward to maybe getting out around the grounds if the weather gets nice. I try not to think further ahead. Once you're in here you just take each day as it comes.

I just 'put that away' and don't really think about it.

I don't think about the future. When you get to my age, you just take each day.

I sometimes think about the future, but then I just push it away. I'm in here for good.

Many found the topic distressing, and most didn't wish to discuss it in any detail. Others expressed anxieties about the future, particularly in relation to the future of their property and also their families. Religion, in particular, was important to some in the context of the future:

The future? I leave that to the Lord.

I hope to go to heaven!

3.7 Factors Assisting a Positive Transition to Long-Term Care

From an analysis of the interviews and the comments made, there seem to be common themes associated with achieving a positive transition from home life to living long-term in residential care. The transition to long-term care tends to be upsetting for most, and indeed traumatic for many. As discussed previously, many of the residents the researchers spoke to had come to accept their new life after a period of time, and stated that they enjoyed life in a new environment. There appear to be common characteristics or circumstances associated with those who have coped with the transition:

Being Involved in the Decision: Residents who had been involved in the decision to move to the care centre tended to have a far more positive evaluation of their new life in residential care than those who had not been involved.

I had talked it over with my children and we all thought that it was the best idea. It was difficult at first but I settled in reasonably quickly.

Visiting the Home before Making a Decision: Those residents who had had the opportunity to visit the centre prior to taking up residency tended to be better prepared, and experienced a smoother transition. This visit could have been in direct relation to their own move to the centre or in connection with a visit to a relation or friend.

I knew a neighbour here and used to come to visit him fairly regularly. I was familiar with the grounds and the building. It wasn't much of a shock really.

Gradual Transition to Life in a New Home: Many of those interviewed had stayed in the care centre on a short-term basis or visited it regularly – for example, for respite care or day care – prior to living there on a long-term basis. The opportunity to develop a familiarity with the surroundings, the ethos and the orientation of the care centre appears to have been a valuable one. There tended to be considerably less anxiety experienced by these residents when taking up long-term residency than by other residents.

Well, I used to come here on respite care, one week in every five, and sure that was grand. I often thought it wouldn't be a bad place to end up.

I was in respite care on and off before coming here long-term. I didn't mind the idea of coming here long-term.

The matron told me that I could try it [the care centre] out for a month to see if I liked it. It was great that I didn't have to stay if I didn't want to.

Knowledge that Family at Home are Safe and Provided For: Family and especially children were extremely important to many of the residents. Although many had been cared for by family members for lengthy periods before moving to long-term care, it was clear that the older people still wanted to 'look after their children in some way'. Many worried about their children and their lives. Career and financial worries were most prevalent. Again, those who were confident that their children were safe and well provided for appeared to be more comfortable in living outside the family and wider community.

As long as I know the kids are safe, I'll be all-right.

I wanted to make sure that my children were provided for before I moved here. I'm happy that I did.

I used to worry about my two sons all the time. They've both got good jobs now. I'm very happy about that.

Knowledge that the Original Residence is Still Accessible: Many of the residents gave the impression that they accepted they would never return to living in the community. Many happy memories were contained in their own home. This place of residence, or the family home, therefore, continued to be an important asset and comfort to them while they were living in residential care. Many enjoyed and looked forward to visits to the home and drew great comfort from the fact that it was safe and being maintained by family or neighbours. This was still true for some who had not visited their home in several months.

It's great to know that the neighbours are looking after the house and the dogs. That's a huge weight off my mind.

My daughter lives nearby and drops into the house during the week to tidy it. The neighbours keep an eye on it as well for us.

Visits to Family and Friends: Some of the residents went to stay with family and friends on a reasonably regular basis. For some, this could be as often as every weekend or one weekend in every month. For others, it could be quite infrequent and as informal as 'now and again'. These trips appear to be a great source of satisfaction and happiness for these residents. Many of them looked forward to the scheduled visit and could 'base' the week or intervening period around that visit. The knowledge that such a visit was upcoming helped the resident to cope with their time more effectively. There was a sense that, were these visits to be terminated for any reason, a considerable void would be left in the lives of these residents.

I go home every weekend to stay with my niece. I love that trip and it helps me through the week.

I'd usually go and stay at home once a month. It's great to look forward to that and it's nice to see what's happening at home.

Receiving Visitors: Most of the residents experienced some degree of anxiety before moving to long-term residential care. Knowing that family and neighbours would visit on a regular basis appeared to be a significant comfort to many of these people. Fear of isolation and loneliness was common to many of the residents. It was quite clear that many drew significant comfort from the fact that friends and neighbours would visit frequently.

I knew my sons and daughters would visit me as often as they could. Knowing that was a huge blessing.

3.8 Summary

The lives of those in care can be very frustrating and limiting for some, while others experience a fuller and more open life. Physical ability is a contributing factor, but does not appear to be the sole determinant of participation in social activities. Those who enjoy reasonable physical and mental health do, of course, enjoy a greater degree of independence, when compared with those who are incapacitated. Many of these people are able to enjoy their own routine alongside that of the routine of the care centre. Social involvement with other residents and visitors through organised and ad-hoc activities, such as chatting, are of paramount importance to most capable residents. The lives of the residents are oriented by the ethos and orientation of the care centre.

4. THE DOMAINS OF 'SOCIAL GAIN'

The preceding findings relate to experiences before and after entering long-term residential care, as narrated by the residents themselves. These findings, as well as responses to specific open-ended questions asking the residents what did and did not make life good or bad in long-term residential care, were examined to develop a series of domains which would relate to quality of life or social gain in these settings. In the event, ten domains were established which drew together the comments of the respondents. In reality, there are close links between the domains, but they have been separated for clarity. It should be noted that the researchers considered all the elements contributing to or detracting from quality of life, not only those elements within the control of the staff of the home.

It is worth noting that the researchers found that the factors which detracted from quality of life and featured high on this list were not in all cases the same factors as those which added to quality of life. As a consequence, two separate lists have been developed – the first looking at the positive factors of quality of life, all of which had a negative 'flipside'; and the second exploring the factors which appeared only to have a negative side.

The factors on each list are presented in no particular order; however, companionship and security (positive) and loss of functional capacity and also of control and choice (negative) were particularly notable because of the frequency with which they were cited and the emphasis that they received.

4.1 Quality of Life – Factors with Positive and Negative Effects

Companionship and Loneliness: By far the most commonly cited factor contributing to quality of life for the residents was the availability of companionship. Many described the isolation and loneliness that they had experienced before coming to the home, and a large number perceived that the move to residential care had significantly improved their quality of life on this dimension. Nearly every resident with whom the researchers spoke mentioned having been lonely at some point. Companionship was seen as being a key element making up the criterion of 'home'.

I was the kind of man who would go in a pub and start talking to people. My father was the same. To be on your own is the worst thing.

When I lived on my own, I wouldn't go to bed as late as I do now – because of the company.

It feels like a home from home here. The company makes it feel like home.

The focus for the residents tended to be on the availability of company, rather than on the possibility of developing deep relationships with others. Most residents, when they spoke, associated company with being in the presence of a 'buzz' and 'life'. Some mentioned how much they enjoyed interacting with members of the other gender, although it seemed that this was not always possible. Few of the residents had developed very close friendships within the home, although for those who had, the friendships were very strong and an obvious source of wellbeing. For some, the loss of a close friend in the home had been upsetting, and there was a sense that perhaps it made people wary of forming further close relationships.

I want to go back to my original ward. My friends are there and they're here for good – just like me. They come up and see me here when they shouldn't! I used to go to bed about 9 p.m.; now it's 9.30 or even later if I'm with the girls.

I used to feel very alone. I thought it would just be little old me from now on and you lose your friends. I never thought I would have new friends but now I do.

I have somebody to talk to who is also hurling mad. I like to talk – I enjoy the company.

Having visitors was an important aspect of quality of life and related to the area of companionship. However, its main importance was in relation to maintaining personal identity and keeping in contact, and it has therefore been considered under a separate heading.

Despite being in the same homes as those who found the companionship to be positive, some still experienced loneliness, largely because they were unable to hear what their fellow residents were saying to them and therefore to take part in the conversations, or because they couldn't find people with whom they had shared interests. Others found the company occasionally to be a burden.

I am lonely. I just sit here. I can't talk to anyone as I can't hear them.

The people here are a bit 'rough'.

Some of the company I like – and some not.

I don't have a kindred spirit – people just seem to slow down here and aren't interested in anything.

Personal Identity and Privacy: Another factor which had both positive and negative aspects was that of personal identity, which the researchers have linked to the concept of privacy. Identity was expressed by the residents in a range of different ways. The most commonly cited was that of the physical space and the possibility of having your belongings around you, as well as privacy. It was notable that those who mentioned their personal space as a positive factor tended to be those with beds at the end of the ward, or, in Care-Setting Three, those who had their own rooms. For some, there was insufficient room in the home to have all their things around them, but they had retained their original residence with its furniture, and described this as being important to them. Others had family members living in their previous house or home, which they indicated contributed to the continued sense of identity for them. The 'flipside' of this dimension was that some worried about their house and how it was faring without them there. Some worried about its state of repair. For those residents who had neighbours looking after the house and, in some cases, their pets, there was a palpable sense of comfort and satisfaction that all was in order.

I would like more things around me but I don't want to cramp the space. I would feel sad if I didn't know that it was all in the house.

I have a lovely bed at the end – it's like being in a little room with the curtains.

I have my own space. I can come and go as I please. I can stay up late. I have my own bedside light. The radio is beside my bed and the TV down the hall.

It's nice that you have your own room and a sense of privacy. You can also make a cup of tea for a neighbour or relative who might drop in.

On the negative side, the physical layout and conditions did not arise frequently as a factor which undermined quality of life, and it seemed to be an area in which the residents felt a particular reluctance to be forthcoming. However, one or two did mention certain factors in this area which they felt undermined their quality of life:

I don't like the lack of privacy, although you can find a quiet corner if you want one. People are very curious and want to know all about you.

I don't like the lack of space. I think the bedroom here could be a bit bigger. That's what I don't like.

I don't have too many of my bits and pieces around me.

Everything is crammed. Also, I am by the door and it is too bright. The curtain is no good and lets in the light.

Home is where you are familiar with everything. At home you have your own things around you and can come and go as you please. You don't have that same choice here.

Pride in personal appearance was also a factor which contributed to quality of life for the residents, although it did not arise in its negative form. Residents described getting shaved, having their hair done and nails cut, as important to them in contributing to their quality of life.

Group Identity and Being Part of the Community: Identity constituted more, for the residents, than just the individual elements such as personal belongings and having privacy. Being part of the group and community were of very particular importance to almost all the individuals to whom the researchers spoke in the course of the research. This manifested itself in several ways. Many continued to read the local newspaper and were anxious to keep in touch with local events. Given that almost all of the residents were drawn from the same locality, there was a strong sense of the familiar and group identity as being a positive factor for life in the home. Some people's visitors knew other residents and dropped by while they were there. At the national level, there was also a strong sense of keeping up with current affairs, and of an identity. The recent election, GAA competitions and the World Cup were uppermost in many people's minds, and there was a sense that lively debate took place on these topics, and that the county identities lent themselves to healthy rivalry between residents, particularly on the men's wards.

When my wife died, my niece suggested that I come back to Ireland; I thought it was a great idea – it's good to be among your own.

I like to watch Nationwide, and keep an eye on what's going on around the country.

There's fellas here who played hurling for [county team] and I like to talk about sport with them.

My neighbours come in and tell me who has died in the town. They sometimes take me to the funeral if they can.

Being Active or Being Bored: Getting involved in activities within the institution was important to the residents. They tended to be positive about the options available to them, although for residents who had been active before moving in, there was a strong sense that these activities were not substitutes for areas in which they had previously been involved. Rather, they were a better option than inactivity.

I never thought about painting before but now I really enjoy it. I said yes to it – I would do anything to get out.

The activities helped a lot – they keep your mind active and are very stimulating.

I particularly like the three activity days which I find very stimulating and which I look forward to greatly.

I used to like being active – I was local president of [a national organisation with local branches] – but have to accept now that I can't do those things any more.

As discussed earlier, organised activities were not the only source of diversion for the residents. For those who were mobile and with good functional competence, a variety of activities organised by themselves, such as playing cards, knitting or reading were also taking place in the home.

A sense of the alternative was clear in the responses from some residents, for whom lack of meaningful activity impacted very negatively on their quality of life.

It's not home here. Everyone here is dead. You can't have people sitting around in a square all day just staring at each other. You need to keep our minds active – put us to work – challenge us – occupy our time – otherwise we are as good as dead.

We need more activities – keep us stimulated. Simple things like jigsaws and quizzes would be good.

I just sit and think all day about things I shouldn't.

I watch a huge amount of TV as I have extremely limited mobility – I am confined to the bed. The days are extremely long. I do love to watch current affairs and news programmes – but it is difficult to please everyone.

At the moment, everybody is suffocated here. They need to stop people being so isolated. Encourage people to keep up the things they have learned like painting or knitting or whatever.

Family and Friends: The dimension of companionship did not adequately express the importance of particular relationships to the residents that we spoke to. Companionship related to a general desire for company, whereas family and friends constituted important and lasting relationships for the residents, which were very important to them. The frequency of visits was something that was extremely important and cited often as a contributor to quality of life. Many of the residents were also in communication with their families via mobile telephones, or radio telephones in the case of Care-Setting Three, where many residents had their own phones in their rooms.

I really like it when my family visit.

I like having visitors. The priest comes, the gardaí, my old home-help, my nieces and nephews sometimes, and other people's visitors know me – people call out. I also have my mobile phone.

However, the absence of family and friends was a serious detractor from quality of life for many of the people to whom the consultants spoke. The visits were not a substitute, and many missed having their family around them, and admitted to 'living for' the regular visits, where these were made. Some residents were able to visit their relatives at weekends, or were frequently taken out of the home by friends and family. These breaks were said to contribute dramatically to their quality of life.

I really miss having my family around me – I used to hear all the troubles of my grandchildren.

I used to lead a quiet life – but it was great – having your friends and family around you, calling into neighbours, and relatives visiting.

I do get lonely sometimes and miss the neighbours – even though they visit often.

Safety and Security: For the majority of the residents, one of the key benefits of living in long-term residential care was the sense of safety and security which it brought. This contrasted fundamentally for them with their experiences before moving in, most of which had involved living alone. Safety and security had three aspects. The first related to having doctors, nurses and other

staff on hand in case of emergency. The fear of falling was particularly prevalent. Security also related to personal security, since many had been burgled at least once before coming to the home. Less frequent, but also cited by some, was the importance of the sense of the familiar, and of knowing where everything was and what to expect. Routine was a part of this comfort and familiarity, and these elements were important to some residents.

I feel safe and taken care of here.

Here you are safe. Otherwise you might walk too far and not know where you are. It's dangerous to be on your own.

The fact that there are people about. When I was on my own there weren't people about – now the nurses are here and the doctors are about if I need them.

The routine also had its down sides for some of the residents. Also, for some residents, the presence of the healthcare staff did not entirely remove the anxiety about falling.

It was a bit strange at first. You have to get up at a certain time. Everything has to be done to their time table.

They encourage me to walk here. But sometimes I am frightened in case I fall again.

Being Cared For: Many of the residents expressed the view that being cared for added to their sense of wellbeing. Again, in many cases, the sense of being looked after was contrasted with their situation before coming to the home, in which many felt that they had struggled with the everyday things of life. 'Being cared for' included having other people take an active interest in your health as well as your laundry, personal care and appearance, and meals. Food was a dominant feature of many of the conversations with the residents. For most, it was a source of pleasure, although some were critical because they felt they did not get enough, or because they felt that the timing of meals and the type of food served were not what they would prefer. The element of choice in relation to food was important to many residents.

I only have to ask for a glass of water and I get it.

You can have anything you want, whenever you want it.

Before, I never got a sweet in forty years. Now I am built up and feel so much better.

You don't get enough food here – only scraps.

I would prefer not to eat a big dinner so early in the day.

Food is good and if you don't like something, they'll swap it.

Relationships with particular nurses and other staff who took special interest in the residents were also part of quality of life in this domain. In Care-Setting Three, in particular, staff members were named and their contribution to quality of life was highlighted.

Sr X is always doing my laundry for me – it's better than a hotel here.

Sr X does everything for me. She takes special care of me and is very good to me.

I settled in here very quickly. People were so jolly and warm. They call you pet and love, and one nurse used to call us 'honey'. If they had been stiff or starchy, it would have been different – but they will always have a joke.

Some residents felt that the staff occasionally impacted negatively on their quality of life. It was felt that some of the staff weren't as nice as the others, and residents took notice of this.

Religion: For many residents, Mass had been part of the daily or weekly routine when living at home, and most were glad to have the opportunity to pursue this once in the home, although not all were sufficiently mobile to be able to avail of the option. Some residents emphasised how important religion was to them, and many read prayer pamphlets brought in by family and friends, and included among their few possessions religious pictures or ornaments.

I like religion and the fact that I can get all that here.

4.2 Quality of Life – Negative Domains

There were two domains which occurred almost solely in their negative form – those of the loss of control and choice, and also the loss of functional competence. These have been highlighted separately here in the report for this reason.

Control and Choice: Autonomy in terms of making choices and controlling aspects of their life, however trivial, was cited by many residents as impacting substantially on their quality of life. The residents wanted choice over simple things like the newspapers that they read, the time they got up and went to bed and ate, and the type of food and drink that they had. They also particularly wanted to be able to choose the television programmes that they got to watch.

When I lived at home, I liked the freedom. You could get up when you liked to and go to bed when you liked.

Home is where you have the freedom to do what you like.

Here we get up at 8 a.m. – it's too early.

I used to go to bed later – but I had my own TV then and could choose what I wanted to watch.

I like to read the paper, but they only get two here and my favourite is the Irish Sun, which we don't get.

I miss drinking stout. You're not allowed to do that here.

Functional Competence: The basic elements of physical functioning – walking, hearing and seeing – were frequently mentioned as impacting very negatively on quality of life. Essentially, problems in all these areas prevented residents from enjoying the other positive aspects of their lives from which they would otherwise be able to benefit.

I won't go to Mass – I'm scared I might have to cough, and I do go to the toilet a lot.

I would like to be able to read more – something I miss terribly – but I would need to get new glasses and there is no way that I will be able to make it to the optician's.

I would like to have a little more independence – to go out visiting more – but I know that's just not possible because I can't walk.

I'm lonely. I can't talk to anyone because I can't hear.

On the few occasions when these factors did arise in their positive form, it tended to be in the form of social comparisons with others in the home.

I count my lucky stars that I have all my faculties.

I am very happy – I am lucky that I have reasonably good health, my eyesight, literacy (unlike others here) and my faculties about me – it would be very difficult without them.

5. OBSERVATIONS

This research pursued the line that the only people adequately placed to define quality of life in long-term residential care are the individual residents themselves. The research is therefore positioned within current thinking in the area of quality of life, which places increasing emphasis on qualitative research that explores people's own subjective views, rather than the more traditional tools which measure objective factors. This presented particular challenges in the context of a care centre, where an individual's choice and autonomy can be limited and there is a tendency towards institutionalisation and low expectation, and also where the level of dependence can create anxiety about disclosing criticism. The researcher is faced with the ethical issue of being exactly true to the views of the resident as specifically expressed, or risking biasing the findings by 'reading between the lines'. For this research, the approach has related more to the former than the latter, and the domains of social gain outlined in Chapter 4 are a faithful reflection of the residents' views as they themselves provided them. However, in this chapter, the researchers have provided their own reflections on quality of life and social gain in long-term care, which draw on these views, but also reflect the researchers' perspective.

In her article, 'Long Term Care and a Good Quality of Life', leading American gerontologist Rosalie Kane makes an impassioned plea for a greater interest in the issue of long term care.

Long term care is a subject that should be capable of engaging the imagination positively. For many people, long term care decisions dictate the last chapters of their biographies — the chapter that should make sense of the story. Long term care shapes where people live, what they do, and the relationships transpiring within families and communities. How we choose to view long term care as a society, therefore, entails considering subjects as profound as the meaning of life. Long term care is intimate care, and how it is given, when it is given and by whom it is given shapes the biography of the long term care consumer and, by extension, the biography of family caregivers and the collective biography of the whole family.

(Kane, 2001)

Certainly, while there is an existing body of research in the Irish context which seeks to explore issues of quality of life in our long-term residential-care institutions, there is little general engagement at the wider level with the debate on long-term care. It is not a subject that receives the attention of our national media or that is frequently aired in public fora. It is therefore to be hoped that some of the broader ideas put forward in this section will contribute to a wider public debate about what we as a society would wish for our long-term care institutions.

5.1 'Health Gain' and 'Social Gain'

At the outset, an understanding of the term 'social gain' was established which was synonymous with the broader definitions of 'quality of life' currently in use. These broader definitions encompass issues relating to health, among a number of other determinants of an individual's wellbeing. Certainly, this research discovered that, for older people living in long-term care, health was only part of a diverse set of factors all of which were critical to providing a good quality of life. While it was important, it was not a dominating feature, and less important than, say, companionship, or keeping active.

This begs the question as to the utility of the term 'social gain'. Why introduce a second term when an existing and synonymous term 'quality of life' is already in use? The key would seem to lie in the rather confusing and wide range of understanding of the concept of 'quality of life', and the desire to differentiate between the tendency to focus on health, sometimes to the exclusion of a broader concern for 'quality of life' issues. For long-term residential care – the focus of this research – the study suggested that in the area of priorities, health and safety issues can tend to dominate at the expense of broader quality of life. As Kane again states:

Embedded in most of our rules and regulations is the idea that long term care should aspire to the best possible quality of life as is consistent with health and safety. But ordinary people may prefer the best health and safety outcomes possible that are consistent with quality of life.

(Kane, 2001)

This is not to undermine the importance of health in the context of the long-term care setting. The research showed that, in a great deal of cases, the management of health and functioning is a key enabler to the other important aspects of life identified by the residents. But in other cases, emphasising only health issues in designing routines and practices for long-term care residences can likewise impact negatively on broader aspects of life quality, and sometimes can prevent the broader benefits from being realised. Health gain is not an end in itself, but a means to an end. The challenge for the institutions is to identify the areas where life-quality issues are negatively impacted in this way, and identify, in co-operation with the residents as well as other stakeholders such as medical staff, where trade-offs could be made. The researchers would emphasise the research finding that no amount of health gain is sufficient, on its own, to generate quality of life for the individual resident; its role is only in enabling the other factors which residents highlighted, such as companionship, to be realised.

These findings further suggest that there is value in the continued use of the terms 'social gain' and 'health gain' in relation to the long-term care setting, in that they perform an important function of emphasising that 'health gain' on its own is only one outcome. However, in advocating their continued use, it is important to emphasise that the concept of 'health gain' is encompassed in the term 'social gain', in that broadly defined 'quality of life' or wellbeing cannot be achieved without a concern for health as part of the whole.

5.2 Do Older People Experience Social Gain in Long-Term Care?

The research poses the overall question: do older people entering long-term residential care experience social gain as well as health gain? It is important to note that life in long-term residential care is, first of all, very different from life in the community. Many residents described how 'strange' it had been during their first few days and weeks. Of the thirty-one residents with whom the consultants spoke, only one really continued their routine as it had originally been before moving into the home. This individual was sufficiently mobile to be able to travel independently outside the home, which essentially they used as their base. For all the others, moving to the home required significant adjustment to a new way of life.

Despite the difference in lifestyles, was a similar or even increased level of 'quality of life' maintained in long-term residential care? Approximately seven or eight individuals out of the thirty-one felt that their quality of life had actually improved, with a similar number strongly believing that it had not. The factors which influenced them in their views one way or the other

tended to be the same, and these have been captured in Chapter 4. However, their perspectives were very different on which factors were important, and in relation to each factor whether the experience of living in long-term care contributed to or took away from their quality of life on that measure. This idea underlines two important aspects of defining quality of life.

Firstly, 'quality of life' tends to be described as a 'static' concept. However, in the researchers' experience of talking to the residents, their views as to the level at which they experienced quality of life were based on a more 'dynamic' view of the concept. This dynamic view compared their present circumstances to their previous circumstances and indeed to their previous expectations of where they would be at this stage in life, and also to those of the situation, past and present, of their peer group. This is not to undermine the concept of 'domains' of quality of life, which were consistent in this research, but it does alter, for each individual, levels of expectation within each domain, and the level at which quality of life was therefore experienced. The residents who were neither strongly positive nor negative about their circumstances, but who had 'come to accept' their life in long-term care, seemed to be those who had, albeit reluctantly, revised their levels of expectation to match the reality of life in the institution. So the level at which 'quality of life' is experienced is predicated on each individual and their very particular experiences and expectations, and their situation in comparison with these. This finding would correlate with the current research which sees perceptions of quality of life as often based on processes of social comparison, and also the finding that expectation levels play a key role in defining quality of life.

5.3 Quality of Life as a Dynamic Concept

The importance of the dynamic nature of 'quality of life' was particularly in evidence in relation to the positive impact on perceptions of quality of life which being involved in the decision had on the residents. The research found that individuals who had been involved in making the decision were more likely to be content with their quality of life, and that those who had not were not. Many of these latter individuals could not come to terms with the imposition on them of the new lifestyle.

Secondly, the assessment within each domain as to whether quality of life is experienced or not, as well as the domains themselves, would appear to be strongly dependent on cultural factors and age group, such that particular groups of individuals adhering to certain demographics are likely to have different needs from others. The domains the researchers have developed in the study are relevant to a population of Irish, regionally based, men and women, mainly from the lower socio-economic groups and of a particular generation. Their views may not correlate with those of individuals of the same generation coming from very urban backgrounds, or from different groups altogether. Their views may also not correlate with those, from the same group, still living within the community.

This idea casts light on the importance of religion in the lives of the residents. A different generation entering long-term care may not place such emphasis on this aspect of their lives. However, there is a significant amount of research in the area of religion and spirituality and their impact on quality of life, particularly for older people. In the eyes of some it is

an aspect of quality of life which has been surprisingly neglected ... in contrast with the USA where the subject of religion and ageing is a popular theme in the annual conferences of the Gerontological Society of America.

(Coleman, 2001).

Setting aside cultural and political differences, it may be that this domain will continue to be an issue, but in a broader context, into the future.

5.4 Influencing Factors

The research has also led the consultants to conclude that, in general, the factors which impact positively on quality of life can also impact negatively. However, two domains – those of functional competence and also of control and choice – tended to have negative impacts, although they were not cited as contributing positively to quality of life in different circumstances. In other words, if these factors were not present, the residents commented on them and felt that they impeded quality of life, but they did not add positively to that same quality when they were present. This finding has echoes of the concept of self-actualisation in Maslow's hierarchy of needs. This theory, developed in 1970, focused attention on the role of human needs in explaining human behaviour. Maslow suggested that people had five different levels of needs: physiological, security, social, self-esteem, and self-actualisation. His theory was that each lower level need had to be satisfied, before the next level would become a concern. In his two-factor theory of motivation, Herzberg built on Maslow's theory to develop two types of factors which made individuals feel particularly satisfied in their work: satisfiers or motivators, which related to the desire for growth and to fulfil potential, and hygiene factors which would make a person dissatisfied, but of which no amount could actually elicit a feeling of wellbeing. In his context, Herzberg identified salary as one such hygiene factor. In this study, functional competence and control / autonomy have been identified as possible hygiene factors.

This idea would obviously have implications for the relative weights to be afforded to health gain as opposed to social gain in the long-term residential-care setting. It would suggest that no amount of improvement in health gain would be sufficient *on its own* to create a stronger sense of wellbeing – or improved quality of life – for the residents. Maslow's hierarchy of needs is certainly a useful idea when considering issues of self-actualisation. But the research would suggest that it is not the case that all the lower-level needs require fulfilling before the higher level needs can be considered. Older people make trade-offs in their own minds between these levels of needs, and may prefer to take a risk with some to be able to enjoy the others.

Finally, the most positive influencers on quality of life seemed to be the areas of companionship and social interaction, and also the possibility of keeping active. On the latter point, it is worth tentatively entering the debate on activities within long-term residential care, and their benefits. There has been some criticism of the level of activity taking place in some institutions. At a conference hosted by the American Society on Ageing, Bill Thomas of The Eden Alternative voiced his strong view that:

Everybody knows the problem is emptiness. I tour a lot of nursing homes and I'm really fascinated by how activity leaders cram as much into that calendar on the wall as they possibly can. It looks full. But it is not full ... And all of our time and energy gets drawn into this activity programme and frenzy and there is a mad dash to turn everything into therapy. Bibliotherapy, horticultural therapy, aromatherapy, music therapy, art therapy, pet therapy, reminiscence therapy ... An institution could double the amount of therapies in its facility and not really do much of anything to improve quality of life because lives will still be empty.

(Thomas, 1998)

This is a radical view, and in the Irish context there has been a significant amount of success with the use of art and music based activity programmes. However, in the light of this research, there may indeed be a point in relation to the role of activity. Many of the residents with whom the consultants spoke enjoyed and looked forward to the activities available to them. But for some there was a sense that the activities were a diversion from some of the inaction and boredom of being in the home. Perhaps Rosalie Kane has the answer when she indicates meaningful activity as a key domain, coming from her own research with older people in long-term care:

Long term care consumers need to perceive that their lives are replete with interesting and meaningful things to do and see. What is meaningful will differ according to the physical status of the individual. Some people can participate actively in a wide range of activities, others by choice or preference are in spectator roles. Still others ... can make meaningful contributions to their families, the nursing homes, or the community at large despite their physical dependency on care.

(Kane, 2001)

The conclusions and recommendations which follow have been developed to move this debate forward and to make some preliminary suggestions as to how the quality of life of residents in our long-term care institutions could be improved.

6. CONCLUSIONS AND RECOMMENDATIONS

The starting point for the research was the interest of Age & Opportunity in developing a measurement tool for evaluating social gain, which could be used to assess the performance of institutions in this area. The research developed a definition of social gain within long-term residential care, which incorporates the following eight domains with potentially positive or negative impacts:

- Companionship
- Personal identity and privacy
- Group identity and being part of the community
- Being involved in meaningful activity
- Contact with family and friends
- Being cared for
- Safety and security
- Religion.

The following domains with predominantly negative impacts should also be included in any definition:

- Functional competence
- Control and autonomy.

The consultants would emphasise that while this definition is apt for the Irish context for the particular demographic group under scrutiny, it does not necessarily constitute a general definition of social gain. While it will, of course, continue to be valid to assess objective aspects of life in long-term care, and where this is likely to contribute to an understanding of quality of life, it is the individuals themselves who are best placed to assess their quality of life, since this research has shown that it is an entirely individual concept, related to levels of expectation and personal circumstances before entering the home.

In relation to evaluating the performance of long-term-care institutions in the area of quality of life or social gain, the consultants would emphasise that there are several large-scale questions to be considered before a measurement tool for social gain can make a contribution in this area. As Rosalie Kane has stated:

The quality of life for long term care consumers is compromised by a societal reluctance to come to grips with their flaws. Without collective agreement on what is a good or even an acceptable quality of life for someone who needs long term care, the gerontological community cannot even cast relevant research questions or conduct programme evaluations in a way that gets to the heart of the matter. And until a realistic view of the goals of long term care and the range of what is possible for a long term care provider to produce is forged, there is a danger of unfairly scapegoating long term care providers for their inability to bring about universal happy endings.

(Kane, 2001)

The matter of quality of life within long-term residential care would seem to be the responsibility of a broader group than simply the individual institutions themselves. If we are to ensure that residents in long-term care experience a good quality of life, we may need, as a society, to establish a level of expectation in terms of what these institutions can do. This standard should draw on the

views of older people both within and outside residential care, but would also need to draw on the views of outside professionals, and indeed society itself, if it is to counterbalance the factors that inhibit disclosure detailed earlier. Such a standard is likely to include matters of health and autonomy, which can take away from the quality of life of the residents, but not to the exclusion of other matters relating to quality of life which can have a positive impact. Residents should be afforded more choice in relation to making the trade-offs between health and other issues, and between safety and quality of life.

With a more unified level of expectation, it is to be hoped that individuals entering long-term residential care would share, to a greater extent than at present, an understanding of their new lifestyle in advance of entering the institution. The consultants would also recommend that potential residents would be given the opportunity to visit the institution where possible before moving there on a long-term basis, for the same reason. Obviously, the individual's involvement in the decision-making process is to be advocated.

In relation to the measurement tool itself, the consultants have already outlined the domains which, in the Irish context and for this generation, such a tool should measure. However, there are also considerations in relation to the format and structure of such a tool. Given the highly individual nature of perceptions of quality of life, the researchers would recommend that the tool be structured in such a way that individuals themselves can weight the various elements and make an assessment based on those weightings. Such prioritisation does not need to be explicit, but can be drawn out using quantitative and statistical techniques, such as regression analysis, which will weight the factors for the individual based on their responses to particular questions. There are models of best practice in this area which could be drawn upon. The challenge with such an approach is that it can be highly complex to administer. The researchers would recommend that a detailed review of the literature in this specific area be conducted, with a view to assessing the least complex methodology for accomplishing this individualised measurement.

The researchers have emphasised that the issue of quality of life in residential care is a complex and far-reaching one, and one that should be dealt with through a debate drawing in not only professionals and researchers, but also the older people themselves, and the broader community. Indeed, the benefit of involving the broader community would also be in encouraging everybody to consider the ageing process, and to prepare themselves in some way for the idea that they themselves may need residential care in the future.

However, in the short term, the consultants would make the following recommendations for other small ways in which quality of life within long-term residential care could be improved:

- Involve older people in the decision to enter long-term residential care;
- Take the time to discuss the issue, and explore ways of making the transition that will enable the older person to become familiar with the institution before making the move;
- Continue with programmes of activities, which the residents enjoy, but consider ways of making them more meaningful and enabling older people to make a contribution through them, rather than seeing them as ways of 'passing the time'. Enable the older people to take part in planning and arranging these activities, and in selecting activities in which they would like to participate;
- Ensure that older people who need dentures, hearing aids or spectacles can get these appropriate to their needs, so that they can enjoy reading or interacting with others in comfort.

Establish 'quiet space' where people who find difficulty in hearing can interact on a one-to-one without the additional impediment of background noise from the television or other residents;

- Find ways to make even stronger the links, already strong in the Irish context, between the institution and local community. Some examples might be a local news notice board, or occasional trips out to the local GAA club games. Group activities could be linked to others in the community;
- Ensure that people with limited mobility can be put sitting with their fellow residents rather than having to stay in bed all day, every day;
- Search for areas where residents can exercise more choice over their day – for example, in terms of the newspapers that are bought, or, where possible, over the food that is served;
- Don't underestimate the benefit of a brief, one-to-one word between the staff and the resident. Where at all possible, try to build in time for brief conversations which do not involve giving personal or nursing care;
- Conduct further research into quality of life in long-term residential care, which draws on the views of friends and family as well as staff in the institutions. While these views may not correlate exactly with those of the residents, and should not supersede them, theirs is also an important contribution in this area. Many of the staff we met were interested and felt that they had a contribution to make in the area.

This is only a short list drawn from an array of options for long-term residential care institutions. They are in addition to the key conclusions on the bigger picture for the quality of life in long-term residential care. It is the consultants' view that there is enormous potential to improve the lives of many older people in the long-term care setting, if the concept of social gain and quality of life can be integrated with the concept of health gain.

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Appendix 1: Terms of Reference

The Terms of Reference for the study included the following:

Despite the growing emphasis on the importance of 'social gain' in residential care for older people, no clear definition of 'social gain' actually exists. In its absence, it is difficult to evaluate residential-care performance in terms of the 'social gain' of residents. Age & Opportunity, in its role of promoting the active participation of older people in society, believes that any such definition must begin with the experiences and perceptions of older persons themselves.

The project will examine, in an exploratory and mainly qualitative manner, the dimensions of 'quality of life' which individuals enjoyed prior to entering long-term residential care, and the degree to which they continue to enjoy these within long-term residential care homes, while having their dependency needs also met.

The objectives of this project are

- Primarily, to explore and highlight the perceptions of 'social gain' of a number of residents who have recently moved into a residential care setting, and from this
- To inform discussion on the development of an instrument for the measurement of quality of life and 'social gain' in residential-care settings.

This research project is very much a pilot one. Its focus will be older persons' own definitions, feelings and opinions about the aspects of their lives which were socially and psychologically important to them, while living in the community, and their fears and worries about how these are affected by entering long-term residential care. It further hopes to explore the degree to which such worries were realised upon entering long-term care, while also exploring perhaps unanticipated aspects of life in residential care which they find socially and psychologically rewarding or socially burdensome.

Consultative Committee

A consultative committee chaired by John Kincaid (Midland Health Board and Chairperson, Age & Opportunity) has been set up to advise on and monitor the research.

Research Venues

The research is to be carried out in three centres. These centres have been selected mainly because of the enthusiasm shown by their respective managements to be involved in a research study of this nature. However, the three centres also give a geographical spread to the research, and offer variety in terms of size and dependency levels.

Research Stages

Stage 1

The study will examine and describe in detail the residences involved, in terms of their size, age, history, catchment areas, rates of entry, care ethos and philosophy, social programmes already in

place, staff awareness and training in social gain, etc. Using the questionnaire attached (Format for Description of Continuing Care Residences), the researcher will interview a senior member of staff in each centre. Relevant policy documents by hospital management, especially those relating to social gain, should also be reviewed.

Stage 2

A number of options were open to the consultative committee in terms of the design of this study. After some deliberation, it was decided to go with a research design whereby older people who had recently entered long-term residential care (that is, one to twelve months earlier) would be interviewed. These people would be in a position to describe the experience of moving from living in the community to living in long-term residential care. Their memories of their previous quality of life should still be vivid, while they would have had time to assess what life in their new homes might have to offer them. This approach depends again on the older person not suffering from dementia. However, it has the advantage that, in each case, the researcher is comparing the life of one individual prior to and after entering long-stay care. The researchers will conduct detailed interviews with approximately thirty older people, using the questionnaire attached (Questionnaire on Social Gain for Residents). The questionnaire covers issues relevant to quality of life and social gain both outside and within a residential-care setting.

Since this is an exploratory research project, a large representative sample does not have the same priority that it would have in a highly structured, quantitative study. Nonetheless, it is important to consider the composition of the interviewee group based on the composition of the overall population of older people in long-stay care, as well as the practicalities of interviewing those who are able to provide the information sought. Therefore, a system of identifying potential interviewees will be devised based on:

- The size of the relevant group (those in care for between one and twelve months) in each care centre;
- The number of males to females to reflect the male to female ratio in the centres;
- The numbers not suffering from serious dementia.

Stage 3

The researchers will compile a report, which will:

- Describe the long-term care residences involved in the study;
- Describe the experiences of social gain or loss experienced by interviewees;
- Highlight the instances where social gain is achieved, and analyse the circumstances and factors which seem to be relevant to this gain;
- Highlight the instances where social loss is evident, and analyse the circumstances and factors which seem to be relevant to this loss;
- Include a summary of the main findings and conclusions of the fieldwork;
- Draw up a set of recommendations based on these findings.

Appendix 2: Research Tools

Format for Description of Continuing-Care Residences

1. Name of Centre
2. Address
3. Chief Informant (Position)
4. Other Informants (Positions)
5. Size (i.e. number of residents)
6. Rate of Admission
7. Turnover of Residents
8. Admission Policy
9. Number Suffering Psychiatric Illness
10. Staffing Ratio
11. Standard of Buildings
12. Interpersonal Relations between Staff
13. Care Ethos & Philosophy (Check for written policy statements & documents)
14. Range of Dependency Needs Met
15. Age Profile of Residents
16. Staffing Complement (Nurses, Care Assistants, Occupational Therapists, Social Workers, Geriatricians, etc.)
17. Catchment Area
18. Physical Description of Centre (Covering size, age, general appearance, facilities, grounds, etc.)
19. Profile of Typical Resident Accommodation
20. History of Centre (Note if old 'workhouse' / county home)
21. Social Gain Care Programmes in Place
22. Any Induction Programmes for new Residents
23. Staff Awareness-Training in Social Gain & Related Concepts.
24. Any Evaluations of Care Previously Undertaken or Ongoing?

Questionnaire on Social Gain for Residents

Decision to move into nursing home

1. What were the circumstances in which the decision was made for you to move in here? (Probe: onset of illness/bereavement/accident/disability/home circumstances)
2. Were there a number of residential-care places for you to choose from?
3. Were you involved in the decision to move in here?
4. Who talked to you about your options at that point? (Probe: Level of discussion, talking through options, interviewee's sense of being able to choose)
5. Would you have preferred to go home?
6. What would that have been like?
7. Do you feel going home is still an option for you?
8. Would you like to go home now/still?
9. Was the application system stressful for you? (Probe: means-testing, assessment of dependency level, application for subvention, etc.)
10. Were you happy with the decision to move in here?
11. And what was it like when you did move in? Did you feel welcomed? Did it take you a while to settle in?
12. Did you have any worries or fears about what life in residential care would be like? (Describe)
13. Would you say that it feels like home here? (Probe: What is home? What ingredients make up your idea of home? What could make this more like home?)

Could we talk for a while about what your life was like before you moved in here?

14. Were you living alone, or with other family members? (Describe)
15. Would you describe your life as happy before you moved in here? (Probe: depression, loneliness, fear of burglary, etc.)
16. Did you have a daily routine? (Probe: favourite daily rituals, television and radio programmes, hobbies, bingo, social activities, older persons' groups, pilgrimages, etc.)
17. How was your health at that stage – say, about a year ago?
18. Did you suffer from any illnesses a year ago?
19. Did you need help coping with this illness?
20. How was your sight, your hearing, your mobility, a year ago?
21. Did you have somebody who helped you out? Describe who and frequency. (Probe: Was there someone living with you who helped out in these areas? Who? Frequency? Hours per week? With meals? With housework? With personal care? With shopping? With nursing care?)
22. Were you able to go out and about? Shopping? Mass / Church? Visiting? Other Socialising? Visit GP?
23. What type of transport did you use?
24. Did you have relatives living nearby?

25. How frequently would you have seen your relatives?
26. Did you have friends living near you?
27. How frequently would you have seen them?
28. Did you have much contact with your neighbours?
29. Did you have pets at home? (If so, do you miss them? Worry about them?)

Life after moving in

30. What was moving in here like for you? (Describe)
31. Was it as you expected? (Note unexpected/expected aspects)
32. Do you have a room of your own, or do you share? (Probe number)
33. How do you feel about your accommodation? Do you feel that you have enough space/privacy?
34. Do staff members here knock on your door when they're coming into your room?
35. What is your daily routine now? (Describe)
36. Do you enjoy the daily routine here? (Probe aspects/activities)
37. Are there aspects of the routine that bother you, that you dislike or would like changed?
38. How do you like being with the other residents here? (Probe: lack of privacy, enjoyment of company, alleviation of loneliness, expectations and reality)
39. Do you get to watch your favourite TV programmes/listen to your favourite radio programmes/listen to favourite music?
40. Are you able to continue your hobbies, since you've moved in?
41. Have you taken up any new hobbies since moving in? (Probe recreational activities)
42. Do you get a chance to get out, now and again? (Probe: importance, frequency, etc.)
43. Do you get a break or holiday occasionally?
44. Do you have visitors? (Probe who and frequency, and if a decline in visiting)
45. When you have visitors, where do you entertain them? (Probe if they can give them tea/coffee, if privacy allowed)
46. How has your health been since you've moved in here? (Probe sense of wellbeing)
47. Can I ask you what is it you miss most about living at home?
48. And what do you most like about living here?
49. What aspects of living in a nursing home do you dislike most or would like to see changed?
50. Has life become easier since you've moved in?
51. Do you have worries about the future? (Probe financial security, increased dependency)
52. What are your hopes for the future?
53. Do you want to go home?
54. Do you think about dying? (Probe: Where would you like to die? Fear of death/being alone)
55. Do you have worries about the future?
56. What could be done to ease those worries?
57. All in all, would you describe yourself as happy here?
58. What would make you happier?